



counsel + care 
for older people, their families and carers

guide

Guide 10:

Carers: what support is available?

As the age of the population increases, many people are taking on the role of carer to friends, neighbours and family. This can occur at any time but a large proportion of carers are over the age of 60, looking after older relatives. There are a number of entitlements and benefits that carers can receive. This guide will explain what these benefits and entitlements are and what services are available to help carers.

The Counsel and Care advice service works with older people, their families and carers to get the best care and support. All the guides and factsheets we produce are available from our website: www.counselandcare.org.uk or paper versions can be ordered by calling 020 7241 8522. You can call our advice line on 0845 300 7585 to arrange an appointment to speak to one of our experienced advisors.



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Your donations, legacies and payroll giving enable Counsel and Care to get the best care and support for older people, their families and carers

The Counsel and Care service is now part of Independent Age, a unique and growing charity providing information, advice and support for thousands of older people across the UK and the Republic of Ireland. Visit www.independentage.org for more information about Independent Age.

There are differences in the ways each country cares for and supports older people. The information in this guide applies essentially to England, although there may be similarities with countries in the rest of the UK.

For information about being a carer in Scotland or Wales, please see:

Assessment and Services from your local council in Scotland

(guide number 50); or

Assessment and Services from your local council in Wales (guide number 70).

All of the guides we publish may be downloaded from

www.counselandcare.org.uk/advice-and-information

or posted to you if you call our guide order line on **020 7241 8522**.

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1 Practical support

1.1 Who are carers?

A carer is defined by the government as 'a person who provides a substantial amount of care on a regular basis for a disabled person living at home'. This is in the 'Disabled Persons (Services, Consultation and Representation) Act 1986', section 8.

There are two types of carer. There are paid carers, known as 'care workers', 'home helps' or 'personal assistants, who can be employed privately or through a home care agency. The second type of carer is an unpaid carer, who may be a partner, relative, friend or a neighbour providing free care or supervision.

This guide explains the rights and entitlements of unpaid carers.

'The Carers (Equal Opportunities) Act 2004' gives unpaid carers a number of rights:

- Carers have a right to information. Local councils have a duty to inform carers of their right to a carer's assessment.
- In the carer's assessment, the wishes of the carer regarding their own training, education and leisure must be considered.
- Local councils have the power to enlist the support of other organisations when considering how to meet the needs of the carer, for example, through the housing department.

The 'Work and Families Act 2006' means that carers have the right to request flexible working. If you care for an older person, you are able to request flexible working so that you can more easily fit your employment around your caring responsibilities. The exact nature of your flexible working can be worked out on an individual basis with your employer,

but may include working from home on particular days each week, starting work later in the morning or finishing earlier in the afternoon so that you can visit the person you care for before/after work, and so on. It may also make things easier if you want to take time off work for emergencies, or to take the person you care for to a hospital appointment, for instance.

Your employer has a duty to seriously consider your request for flexible working, but they are under no obligation to grant it at this time. Your employer can refuse a request for flexible working if they have a business case for doing so, but they must put their reasons in writing.

1.2 Carers who are grandparents

In some families, grandparents may look after a dependent grandchild, either on a short or long-term basis. Under certain circumstances, the grandparent may be able to collect benefits, such as Child Benefit, on their behalf. This is a complex area. If you are in this situation, you should seek more information from an organisation such as The Grandparents' Association (tel.: 0845 434 9585; www.grandparents-association.org.uk).

1.3 National Carers Strategy

The Coalition Government published a revised Carers Strategy in November 2010 called 'Recognised, valued and supported: Next steps for the Carers Strategy'. The strategy identifies how the government intends to support carers over the next decade. The Department of Health has consulted with carers and carers' organisations and has identified four priority areas:

- Supporting carers to identify themselves as carers at an early stage, recognising the value of their contribution and involving

carers in designing local care services and in planning individual care packages;

- Enabling carers to fulfil their education and employment potential;
- Providing personalised support for carers and those they support, enabling them to have a family and community life;
- Supporting carers to remain mentally and physically well.

You can download a copy of the Carers Strategy from:

www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_122393.pdf

1.4 Care for a carer

If you are an unpaid carer, you may not necessarily have undertaken the role by choice, but because an older relative or friend needs your support. You may have undertaken this role so that the person you care for can stay in their own home. The support you provide may include: monitoring their health; ensuring that they are washed and dressed; making sure that they have eaten the right foods; or checking that they have taken any medication as prescribed.

As you have taken on these caring responsibilities, you may find your own life is affected. This may include:

- A need for practical support or regular respite breaks.
- Financial costs of caring and loss of income if you are unable to carry on working (or working on a full time basis) because you are a carer.
- Having a mixture of emotions, which may include feelings of inadequacy, frustration, resentment, being taken for granted or guilt for not doing enough.
- Restrictions on your lifestyle.

- A need for recognition as a carer, reassurance about what you are doing and information about what help is available to you.

1.5 How to find out about available support services

Your local council has a duty to provide you with information on support services for carers in your local area. This information may be obtained from your local council social services department, the council's information desk, your local library, your GP surgery or a hospital. It should also include face-to-face information, such as from a social worker who has a duty to tell you about your right to your own assessment of need. Please see the Carers Direct website:

www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx

for information about financial help, legal matters, keeping well, working, studying and other sources of support.

1.6 The carer's assessment

To decide whether you are entitled to a carer's assessment, and possibly eligible for council-provided services, a social worker or care manager should establish if you are providing, or intend to provide, 'a substantial amount of care on a regular basis'. A 'substantial amount of care' is not defined in law; therefore the interpretation is up to social services, having taken into account your individual circumstances. Social services can, at their discretion, assess all of a carer's needs even though the care provided by the carer may not be deemed 'substantial'.

The introduction of the 'Carers (Equal Opportunities) Act 2004' ensured that there are some aspects of a carer's life which must be taken into account during the carer's assessment. The assessment must consider:

1. The sustainability of the caring relationship - the carer's ability to continue to provide the caring role, whether this is sustainable and how great is the risk of the caring role becoming unsustainable.

2. The work, education and leisure needs of the carer - this includes whether the carer works or wishes to work, and is undertaking, or wishes to undertake, any education, training or leisure activity.

If these points are not addressed in your carer's assessment you should ask your social worker about them.

Each council can set their own eligibility criteria for the level of services they are able to provide related to the resources they have available. This means that there is variation in service provision between councils across the country. The eligibility criteria for carers' assessments are modelled on the guidance 'Prioritising need in the context of Putting People First: a whole system approach to eligibility for social care – guidance on eligibility criteria for adult social care, England 2010'. This guidance is used to assess the cared-for person's eligibility to services but local councils have discretion about whether to meet the carer's needs by providing services to the cared-for person.

The guidance suggests that the risk to the sustainability of the caring role can be categorised into one of four levels:

- Critical
- Substantial
- Moderate
- Low.

Local councils should prioritise the needs of the carer according to the immediate and longer-term risk if their needs were not met.

When assessing the risk, social services should focus on:

- The autonomy and freedom of the carer to make choices;
- Health and safety including freedom from harm, abuse and neglect;

- The ability to manage personal and other daily routines;
- The involvement in family and wider community life.

Your carer's assessment can be carried out at the same time as the assessment for the cared-for person. Alternatively, you may wish to have your assessment carried out separately, so that you can speak more openly to the social worker about your needs without fear of causing distress to the person you care for. Arrangements can be made for a carers assessment to take place in another setting, over the phone or whilst the cared-for person is not at home. Ask your social worker for a separate assessment in confidence.

Some councils offer a carer's self-assessment option on their website. Ask your local council or a social worker about this if you would prefer this to a face-to-face assessment.

For more information about assessments and eligibility to local council services, see our guide:

Assessment and Services from your local council in England (guide number 12).

Before the carer's assessment, it can be useful to think about how being a carer has affected you. You may want to consider things such as:

- Are you able to get enough sleep, or is it disturbed by your caring role?
- Is your health being affected? If so, how?
- Do you have any time for yourself?
- Are you able to go out without worrying about the safety of the person you care for?
- Are any of your other relationships being affected?
- Do you need information about benefits or other support available?

- Is your caring role having an impact on your job?
- How many hours per week are you caring, including night times and weekends?
- What equipment is needed by the cared-for person to enable you to care for them safely?
- Do you need any training, for example, in moving and handling the person you care for?

It may be helpful to record some of the above in a diary so that you can highlight this during the carer's assessment. During the assessment, try to provide as much information as you can about how caring has affected you, so that all of your needs are considered. Social services will use the assessment to decide what services and support, if any, can be provided for you.

The results of your carer's assessment should be recorded in a 'care plan' if services are being provided to you. A care plan is a written statement of your needs as a carer in your own right, detailing what support is necessary for you so that you can continue caring. These services should be in addition to any support services provided to the cared-for person by social services. You should be given a copy of your care plan.

If you do not feel that your carer's assessment was adequate, or your circumstances have changed since you had an assessment, you can ask for a re-assessment.

1.7 Caring for people with mental health issues

Carers who are looking after a person receiving care from specialist psychiatric services and assessed under a Care Programme Approach (CPA), should also have their physical and mental health needs assessed,

in addition to the basic assessment rights under the Carers Acts of 1995, 2000 and 2004.

1.8 Delays in assessment

There is no time limit for how quickly a carer's assessment should be carried out. How long you wait will depend on the urgency of your situation. However, social services should complete an assessment within a 'reasonable' time. Many social services departments will have their own internal targets for providing assessments. These may be included in their 'customer charter' or 'long-term care charter', which may be available on the council website.

If you feel your needs are urgent, for example, the person you care for has become acutely unwell and you feel you may need more help, an 'emergency' assessment by a duty social worker can be arranged for both you and the person you care for, if it is decided the person you care for does not need to go into hospital for treatment. Social services may then arrange a temporary care package until a full assessment and care plan can be arranged.

1.9 Receiving support services

Carers' services are not defined in law but can include anything that could help the carer care for the cared-for person. The sort of services you may be eligible to receive from social services could include:

- Respite care to give you a break from your caring role. For example, a sit-in service, day care for the cared-for person, or a short-term placement in a care home for the cared-for person;
- Respite vouchers for short breaks;
- Moving and handling training;

- Emotional support from other carers or people who understand your situation by way of attending a local carers' group (some groups also provide sit-in services);
- Welfare benefits advice;
- Activities for the person you care for;
- Trips such as holidays or special events;
- Driving lessons;
- A laundry or cleaning service;
- Gardening;
- Travel assistance (including help with taxi fares);
- Relaxation therapy.

The services you receive as a result of your carer's assessment may be provided directly by social services or by a private agency or voluntary organisation (paid for) by social services.

1.10 Direct payments and personal budgets

Carers can use a 'direct payment' or 'personal budget' to meet their needs as stated in their carer's assessment. This is where the local council gives you money to purchase the services you are assessed as needing, instead of them being provided directly by the council. For example, this could mean that you employ a care worker to visit you once a week, or someone to help you do the weekly food shopping.

Direct payments or personal budgets give you choice about how to meet your needs to enable you to continue in your caring role and to maintain your own health and wellbeing.

As a carer, you cannot use direct payments or a personal budget to purchase services to meet the assessed needs of the person you care for. The payment must only be used to meet your own needs. For example, it may be used to pay someone to sit with the cared-for person for three

hours a week so you can go shopping or meet up with friends. The cared-for person can apply for direct payments or a personal budget if they are assessed as needing support in their needs assessment. For more information about personal budgets and direct payments see our guide:

Home Care: using direct payments or a personal budget (guide number 23).

1.11 Community Care (Delayed Discharges etc) Act 2003

The Community Care (Delayed Discharges etc) Act 2003 introduced a system of cost reimbursement to the NHS if a patient is in hospital receiving acute care and their discharge is delayed. The council has to pay a fine if its social services department fails to assess the patient's needs and/or put the assessed services in place within the timescales set out in the Act.

The Act has increased carers' rights to carer's assessments and services. If the person you care for has to enter hospital, the Act ensures that the NHS body responsible for them has a duty to consult the patient and their carer about the discharge date, before giving notice to the council.

Services for the patient or for you (to assist you in your caring role) after the patient has been discharged from hospital may be available free-of-charge for the first 6 weeks after the discharge date. This support is known as 'intermediate care'. Any equipment the patient has been assessed as needing, up to the value of £1,000, will be provided free-of-charge.

Generally, the hospital social worker will be responsible for overseeing the patient's care package for a period of 6 weeks following discharge from hospital. However, following a review of the care package (within 2

weeks of the care package first being provided), it may be that the person's case will be transferred to the local council social services department if the person's care needs are being adequately met. If it is not, services should be adjusted accordingly.

1.12 Charges for support services

Only the cared-for person's financial circumstances can be taken into account in the financial assessment for care services for them. You cannot be charged for services provided to the cared-for person. You can only be charged for services if they are directly provided to you.

2 Financial support

If you are caring for someone, you may be entitled to claim the benefit, Carer's Allowance, as well as being provided with practical support. Carer's Allowance is worth up to £58.45 a week.

2.1 Qualifying for Carer's Allowance

Carer's Allowance is a benefit to help you look after someone with a disability. To qualify for Carer's Allowance, you must:

- Be aged 16 or over
- Be caring for someone for 35 hours or more a week
- Be caring for someone who receives Attendance Allowance, or the middle or higher rate care component of the Disability Living Allowance, or Constant Attendance Allowance (of £58.40 or more) paid with an industrial, war or service pension
- Be a resident in the UK
- Have lived in the UK for 26 weeks at least during the past 12 months
- Have no immigration conditions on your stay in the UK (subject to specified exceptions).

However, you do not qualify for Carer's Allowance if:

- You earn over £100 a week (after tax, National Insurance contributions, half of any contribution you make towards an occupational or personal pension and any allowable deductions such as income tax); or
- You are already receiving £58.45 a week or more from certain benefits or pensions, such as Incapacity Benefit, State Pension, Widows Pension, contribution-based Jobseekers Allowance and/or contribution-based Employment Support Allowance. This is known as the overlapping benefit rule. If you receive any of these benefits

at less than the rate of Carer's Allowance (£58.45), Carer's Allowance can only be paid to top up your income to the rate of Carer's Allowance. As these benefits tend to be higher in value than Carer's Allowance, it can be difficult to qualify for Carer's Allowance. If you would otherwise be entitled to Carer's Allowance but do not qualify due to the benefit overlapping rule described above, you may have 'underlying entitlement' to Carer's Allowance. This will be written in your decision letter following a claim.

2.2 Carer's Premium

If you receive Carer's Allowance or if you have an 'underlying entitlement' to Carer's Allowance but don't actually receive Carer's Allowance, due to the overlapping benefit rules described above, you may be eligible to receive a Carer's Premium of £32.60 a week. Receiving a Carer's Premium increases your 'appropriate amount' by £32.60 when you are assessed for means-tested benefits such as Pension Credit, Housing Benefit, or Council Tax Benefit. This may mean you receive a higher amount of a means-tested benefit than previously, or you suddenly become eligible for a means-tested benefit for the first time. For more information about these benefits, see our guides: **Council Tax Benefit and Housing Benefit** (guide number 22); and **Pension Credit** (guide number 2).

2.3 When Carer's Allowance or Carer's Premium will cease

The length of time Carer's Allowance can be paid after you stop caring for the cared-for person will depend on the individual circumstances of the situation. However, as a general rule, Carer's Allowance will cease immediately if:

- The cared-for person does not require your help anymore
- You choose not to be a carer anymore.

Carer's Allowance will cease after 28 days if:

- the cared-for person enters hospital for a period of longer than 4 weeks and loses their disability benefit
- the cared-for person enters a care home on a permanent basis, and loses their disability benefit after 4 weeks

If the person you care for dies, you may be entitled to continue receiving Carer's Allowance for up to 8 weeks after their death, depending on the circumstances of the situation.

If you lose your entitlement to Carer's Allowance, you may be eligible for other benefits. If you are under state pension age and out of work, you may be able to apply for Jobseeker's Allowance (JSA). Contact your local Jobcentre Plus (tel.: 0800 055 6688) for more information and help with applying. If you are over state pension age, you may be eligible for Pension Guarantee Credit, if you have an income below £142.70 per week as a single person or £217.90 as a couple. For more information about Pension Guarantee Credit, see our guide:

Pension Credit (guide number 2).

2.4 How to claim Carer's Allowance

You can apply for Carer's Allowance using form DS700. It is available from: www.dwp.gov.uk/advisers/claimforms/ds7001_print.pdf or you can get a copy by calling the Benefits Enquiry Line (tel.: 0800 88 22 00) or the Carer's Allowance Unit (tel.: 0845 608 4321). If you need help filling in the form, your local Age UK or Age Concern (tel.: 0800 169 65 65; www.ageuk.org.uk) may be able to help you.

If you were entitled to Carer's Allowance prior to claiming it, you can ask for your claim to be backdated for up to three months.

2.5 How Carer's Allowance affects other benefits:

Claiming Carer's Allowance can affect other benefits that you or the person you care for receive. You may want to consult an advice service before claiming Carer's Allowance to see how it will affect your benefits and the benefits of the person you care for. Carers UK (tel.: 0808 808 7777; www.carersuk.org) or Carers Direct (tel.: 0808 802 0202, www.nhs.uk/carersdirect) can advise you about the likely impact.

If the person you care for receives a Severe Disability Premium, they will lose this premium when you receive your first payment of Carer's Allowance. This means that although you will start to receive a Carer's Premium of £32.60 a week, the person you care for will lose their Severe Disability Premium worth £58.20 a week.

2.6 If your claim for Carer's Allowance is turned down

You will be sent a written decision in response to your claim for Carer's Allowance. If you disagree with the decision, you can ask for a written or spoken explanation of reasons for the decision, a revision, or you can lodge an appeal against the decision. You have one calendar month to challenge the decision, but this can be extended if there are special circumstances for the delay such as illness. You can lodge an appeal using a GL24 form. The form is available from:

www.dwp.gov.uk/docs/gl24dwp.pdf

If you wish to challenge the decision, it may be advisable to seek support from an organisation such as your local Age UK or Age Concern (tel.: 0800 169 6565; www.ageuk.org.uk) or Citizens Advice Bureau (tel.: 08444 111 444; www.citizensadvice.org.uk). They may be able to help you in deciding on how to proceed with your appeal and help you fill in the necessary forms and/or attend the tribunal with you.

3 Carers' organisations

The following organisations may be able to advise you about respite breaks, financial help and general support for carers:

- Carers UK (tel.: 0808 808 7777; www.carersuk.org) provides an advice service for carers and may be able to put you in touch with local support groups that can provide you with emotional and practical support.
- Carers Trust (tel.: 0844 800 4361; www.carers.org) provides information, home care and local support services for carers.
- Carers Direct (tel.: 0808 802 0202; www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx) is a comprehensive national information service for carers. The helpline and website is managed by the Department of Health and NHS Choices. The website contains information on support for carers, working and studying whilst caring, and financial and legal matters.

This guide is not a full explanation of the law and is aimed at people aged over 60.

The Counsel and Care service is now part of Independent Age. Independent Age is the operating name of the Royal United Kingdom Beneficent Association.

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