

Advice for carers

A practical guide



Information and advice you need to help you love later life.

We're Age UK and our goal is to enable older people to love later life.

We are passionate about affirming that your later years can be fulfilling years. Whether you're enjoying your later life or going through tough times, we're here to help you make the best of your life.

Our network includes Age Cymru, Age NI, Age Scotland, Age International and more than 160 local partners.

This information guide has been prepared by Age UK and contains general advice only, it should not be relied on as a basis for any decision or action and cannot be used as a substitute for professional medical advice.

Neither Age UK nor any of its subsidiary companies or charities accepts any liability arising from its use and it is the reader's sole responsibility to ensure any information is up to date and accurate.

Please note that the inclusion of named agencies, websites, companies, products, services or publications in this information guide does not constitute a recommendation or endorsement by Age UK or any of its subsidiary companies or charities.

Date of publication: March 2017. © Age UK 2017
Next review date: March 2019

Contents

What this guide is about	2
Are you a carer?	4
Your rights as a carer	5
Support with caring	6
Assessment for the person you care for	8
Caring from a distance	10
Helpful technology	12
Carer's Allowance	13
Council Tax Support for carers	14
Carer's Credit	15
Disability benefits for the person you're caring for	16
Making an application for Attendance Allowance	18
Common care needs to include	20
Making an application for Personal Independence Payment	22
What if the application is turned down?	23
Work and caring	24
Your health	26
Having a break from caring	27
What happens to my Carer's Allowance and other benefits when I take a break?	29
Caring and other activities	32
When your caring role changes	33
When caring ends	34
Safeguarding from abuse	36
Useful organisations	37

What this guide is about

Caring for a friend or relative can be a rewarding and fulfilling experience. It's also a big undertaking that, on occasion, can leave you feeling tired and stressed. But there is support available.

Whether you've been a carer for a long time, or have recently joined the millions of people across the UK who are caring for a relative or friend, you may wish to know more about the support available to you and the person you care for.

This guide looks at both the practical side of caring – the benefits you can claim, how to arrange flexible working hours, how to organise respite care – and the emotional side, such as the impact on your health and social life. It aims to let you know where to go for help, so you don't feel you have to manage on your own.

As far as possible, the information given in this guide is applicable across the UK.

In this guide, where we refer to a local council social services department in England and Wales, we intend this also to be a reference to a social work department in Scotland and a local health and social care trust in Northern Ireland.

Carers support organisations

Throughout this guide we refer to both national and local support services for carers. The three main organisations supporting carers in the UK are:

Carers Direct – a Government-run helpline for people living in or caring for someone in England. They can give information to help you make decisions about your personal support needs, including information about assessments, benefits, or work. They don't offer counselling or personal financial advice, but they can direct you to local and national specialist services for further help.

Carers Trust – a charity working with a local network of carers' centres. They offer support to carers, including information and advice, respite breaks, and training and employment opportunities.

Carers UK – provides advice and information to carers, as well as support through local carers' groups and their telephone listening service. They can offer practical advice on filling in forms and can carry out benefits checks.

For contact details of these and other useful organisations, see pages 37–42.

Key



This symbol indicates where information differs for Scotland, Wales and Northern Ireland.



This symbol indicates who to contact for the next steps you need to take.

Are you a carer?

If you look after your partner or a relative or friend who needs help because they are ill or disabled, then you are a carer. You may have looked after someone for a long time without ever thinking of yourself as a carer.

There are different ways in which you may care for someone else. For instance, you might:

- visit a relative who lives far away once a month to check on their wellbeing
- arrange hospital appointments by telephone for a parent
- live close enough to a disabled friend to be able to drop in every day to provide a meal and some company
- move in with a relative to help them recuperate after a major operation
- be on hand to provide 24-hour constant care for your partner.

Whether or not to take on a caring role is a decision that many of us will have to make at some point in our lives.

Becoming a carer can be rewarding but at times it may also feel overwhelming and demanding. Take time to review your options to ensure that you make the best decision for both you and the person who needs care. Getting help from friends and family can ease the stress, and your GP and social services should be able to provide support.

If the person you care for has dementia, you may want to read our free guide *Caring for someone with dementia*.

what next?

The charity Carers UK is a good source of information, advice and support for carers (see page 39). In England, the government service Carers Direct can also offer information and advice (see page 39).

Your rights as a carer

As a carer, you have certain basic rights. You have the right to:

- a carer's assessment (see pages 6–7)
- request flexible working from your employer (see page 24)
- receive financial support through Carer's Allowance, if you are eligible (see page 13)
- have your views taken into consideration by social services when they are deciding how best to meet the needs of the person you care for.

You may also have the right to:

- receive assistance from social services, such as practical help at home, counselling to deal with stress, and information about local support groups (see pages 6–7)
- arrange respite care to give you a break (see pages 27–28).

what next?

Contact your local Age UK or local council to find out more information on what support is available for carers in your area. Contact the Carers Trust (see page 39) or your local council to find out about carers' centres and other services for carers in your area.

Support with caring

Caring for someone can be difficult and there are lots of reasons why you might need support.

- You may find certain tasks difficult to carry out for health or personal reasons.
- It may be hard finding time for yourself, your family and friends.
- The condition of the person you care for may become worse.

You're entitled to a free carer's assessment. Call your local council's social services department to request one. The council's contact number should be in your phone book or on their website. The assessment is a chance to discuss what services or support you need as a carer. The person you care for is entitled to a separate needs assessment, and this should also take into account your role as a carer.

The kind of help and support you can get include: respite care to give you a break (see pages 27–28); information on local carers support groups; help with caring; and equipment to help you (our free guide *Adapting your home* has more information on this).



Your council may charge you for these services. They will have to carry out a financial assessment first. There is currently no charge for these services in Northern Ireland.

Before you have an assessment, think about the following questions and whether being a carer is having a significant impact on these or other things in your life.

- Are you getting enough sleep?
- Can you get out and do things by yourself?
- Are you eating well?
- Is your health being affected by caring?
- Can you cope with other family commitments?
- Is juggling work and caring difficult?
- Are you able to pursue your work or educational goals?
- Can you socialise and enjoy your hobbies in the way that you used to?
- Are there any other issues that may affect your ability to continue caring?

**what
next?**

Contact your local council to request an assessment, or see our free guide *Getting help at home* to find out more.

Becoming a carer can be **rewarding** but at times it may also feel **overwhelming** and **demanding**.

Assessment for the person you care for

The person you care for can have a needs assessment from the social services department of their local council. They can ask for one regardless of their income or savings, and no matter what their needs are. You can request a needs assessment for the person, if they are not able to ask for one themselves.

When the person has a needs assessment, the assessor will usually come to their home and talk to them about how they manage everyday tasks and what they want to achieve in their daily life.

The assessor will look at:

- the person's health and disabilities, and what they can and can't do
- their current living arrangements
- what help they're currently getting and whether this can continue
- how they would like to be supported
- any concerns that you have as their carer.

The assessor should consider the person's physical safety and the emotional and social side of their life, as well as any support that would prevent them needing more significant help in the future. Your thoughts and feelings as a carer should also be taken into account. After the assessment, a care plan should be agreed on, written down and a copy given to the person.

The assessor will consider the type of help the person needs, and whether their needs are great enough for the council to help them. If so, the person will have a financial assessment to decide whether the council will fund all, some or none of their care. Even if the assessment finds that the person is not eligible for funding, the council still has a duty to give information and advice about services or equipment that could help.

If the council agrees to fund their care, the person can then choose between having the council arrange their care, or arranging care themselves through direct payments.



This is a cash payment they can use to pay for a carer, or anything else that helps them meet their needs. See our free factsheet *Personal budgets and direct payments in adult social care* to find out more. In Wales, see Age Cymru's factsheet *Direct payments for community care services in Wales* and *Social care assessments for older people with care needs in Wales*. In Scotland, see factsheet *Care and support at home: assessment and funding*. If a person decides to pay for a carer directly, they may need to take on the responsibilities of an employer, such as tax and pension contributions. Skills for Care (see page 42) has more information.

The person may want to use their direct payments to employ you as their carer. You can't normally receive direct payments from a partner or relative you live with but in certain circumstances – such as a language barrier – the council may agree to this. If you and the person you care for are considering this, think carefully about how this could affect your family relationships and whether becoming a paid carer will affect your eligibility for benefits.

If you care for someone who lacks mental capacity to make their own decisions, for example if they have dementia, you may be able to receive direct payments on their behalf.

Caring from a distance

If you live a long way from your relative, being actively involved in their care as they get older can be a challenge. However, a planned, organised approach will help make your life easier. Think carefully about the following points and don't over-commit yourself.

- Have you asked what the person you care for wants and needs?
- Being a distance-carer can be time-consuming and expensive: you may find yourself travelling miles every weekend. Can you afford the time and the money to pay for fuel or fares?
- Can anyone else share the responsibility? Could they contribute towards the costs, even if they're not able to be there very often?
- Travelling and looking after people are both tiring – have you got the health and energy you need?
- Carers may be entitled to benefits – make sure you've applied for any you may be eligible for (see pages 13–15).
- The local social services department can assess the practical and emotional needs of both you and your relative and may provide services to support you both.
- Could your relative's local Age UK provide services to help them, such as home visits or handyperson services, which can help with minor home repairs? Other charities and home improvement agencies might also offer these services.

- Would using a computer help with some tasks? For example, you could show the person you care for how to order food shopping online and get it delivered. Being online is also a good way to stay in touch when you can't be there. Contact your local Age UK (see page 37) or Online Centres Network (see page 42) to find out about courses on using computers and the internet.
- Have you and your relative considered other options – perhaps retirement housing, moving to a care home, moving your relative closer to you or perhaps in with you?
-  In England, Wales or Scotland, if the person you care for is likely to lose their capacity to make decisions, talk to them about setting up a Lasting Power of Attorney to let you make decisions on their behalf. See our free guide *Powers of attorney* to find out more. In Scotland, see Age Scotland's guide on powers of attorney. In Northern Ireland, you could set up an Enduring Power of Attorney, which will continue if the person you care for loses mental capacity.
- Make sure the person you care for has had a needs assessment by the local authority. They may be entitled to care at home, which will ease the burden on you.

what next?

For more information about retirement housing, read our free guide *Housing options*.

Helpful technology

Technology known as telecare and telehealth can support someone's safety and independence at home. Community alarms are the best-known example of telecare. Having one could reassure the person you care for that they can call for help if you're not there. Other examples of telecare include devices that can detect if someone has fallen, had a seizure, left the gas on, or is trying to leave their house unsupervised.

Some areas run telehealth schemes to help people keep track of health problems at home with support from a health professional. For example, if your relative has high blood pressure, they can monitor it at home and electronically send the results back to their GP. This may help with looking after the health of the person you care for when you're not there.

Contact the Disabled Living Foundation to find out more about telecare and telehealth products (see page 41), or ask your GP. Our free guides *Adapting your home* and *At home with dementia* also have more information on telecare, or visit www.ageuk.org.uk/telecare.

what next?

Contact your council or search www.gov.uk/apply-for-community-alarm. Aid-call Limited, a subsidiary of AXA PPP healthcare Group Limited also provides Age UK branded personal alarms, including within Northern Ireland.* For more information about the service and the likely costs, call 0800 011 3846.

* Personal Alarms are provided by Aid-Call Limited, a subsidiary of AXA PPP healthcare, which is authorised and regulated by the Financial Conduct Authority for Consumer Credit. Financial Services Register number 707455. Aid-Call Limited is registered in England number 01488490.

Registered address: 5 Old Broad Street, London EC2N 1AD. VAT number 243 6741 60.

Aid-Call Limited works in association with Age UK Trading CIC, a commercial arm of Age UK (registered charity no. 1128267). Age UK Trading CIC donates its net profits to Age UK. Age UK Trading CIC is registered in England and Wales no. 01102972. Registered office: Tavis House, 1-6 Tavistock Square, London WC1H 9NA. Aid-Call Limited uses Age UK's trademarks under licence.

Carer's Allowance

The main welfare benefit specifically for carers is called Carer's Allowance.

To qualify you must spend at least 35 hours a week caring for a disabled person who receives Attendance Allowance, Disability Living Allowance care component (at the higher or middle rate), Personal Independence Payment daily living component (at either rate), Armed Forces Independence Payment or Constant Attendance Allowance.

If your State Pension is more than Carer's Allowance, or if you get certain benefits at a higher amount than Carer's Allowance, then you will not be paid Carer's Allowance. This is because State Pension and Carer's Allowance are classed as 'overlapping' benefits. They are both payments you can get if you're not working but you can only claim one at a time. Instead if you meet all the criteria you will be awarded an 'underlying entitlement' to Carer's Allowance. The good news is that this entitles you to get extra money paid with any means-tested benefits you claim, such as Pension Credit and Housing Benefit. This extra money is known as a carer premium, or carer addition when it's paid with Pension Credit.

If you receive Universal Credit, ask your local Age UK for advice.

Some means-tested benefits that the person you care for receives, such as Pension Credit or Income Support, may be reduced as a result of you getting Carer's Allowance. Check whether this is the case before making a claim.

what next?



For more information, read our free guide *Carer's Allowance*. Contact the Carer's Allowance Unit (see page 38) to get a claim form or make a claim online at www.gov.uk/carers-allowance/how-to-claim. In Northern Ireland, contact the Disability and Carers Service (see page 41).

Council Tax Support for carers

You may be entitled to support with your Council Tax bill if you're a carer.

Help if you have a low income



Councils run their own Council Tax Support schemes (sometimes called Council Tax Reduction) so you will need to contact your local council to find out about their scheme and whether you qualify. There are national schemes for Council Tax Reduction in Scotland and Wales. Contact your local council, Age Scotland or Age Cymru to find out more.

The support you get depends on factors including which benefits you receive, your age, your income, savings, how much Council Tax you pay, and who you live with. You may get more Council Tax Support if you receive a carer's benefit.

Other discounts and exemptions

If you live alone, you're entitled to a 25 per cent reduction in your Council Tax regardless of your financial circumstances.

If you have left your usual home empty to go somewhere else to care for someone, you should be able to get an exemption from Council Tax on your usual home.

Depending on your local council's scheme, you may be able to get a reduction or rebate in certain other circumstances, for example, if you share your home with someone who is not jointly liable to pay Council Tax, if you're disabled and your home is adapted, or if you're a carer.

**what
next?**



See our free factsheet *Council Tax* for more information. In Wales and Scotland, contact Age Cymru or Age Scotland for similar factsheets. In Northern Ireland, contact Age NI for information on help with rates.

Carer's Credit

If you give up work to care for someone, you may worry that not paying National Insurance will mean you're losing out on your entitlement to a State Pension. The amount of State Pension you get usually depends on how many qualifying years of National Insurance you have built up. However, if you care for someone for at least 20 hours per week, there is a system in place to protect your entitlement to basic and additional State Pension.

Carer's Credit is a weekly National Insurance credit for carers. It replaces the old system of Home Responsibilities Protection (HRP), which worked by reducing the number of qualifying years needed for a full basic State Pension to as few as 20. Past years of HRP will be recalculated into years of Carer's Credit, which will count towards your basic State Pension. You will automatically get Carer's Credit if you are already claiming Carer's Allowance. If not, you will need to apply for it. Contact the Carer's Allowance Unit for more information (see page 38).

what next?



See our free guide *More money in your pocket* for more information about State Pension. Age Cymru and Age NI have their own versions of this guide. Carers UK produces a free guide called *Looking after someone: Information and support for carers* (see page 39).

Disability benefits for the person you're caring for

If the person you care for needs extra help with mobility, or with personal care such as dressing or washing, they may be eligible to claim Personal Independence Payment (PIP) if they are under 65, or Attendance Allowance (AA) if they are 65 or over.

You may need to help the person you care for to claim a disability benefit (and if they are mentally incapacitated or terminally ill, you can claim it on their behalf if you have power of attorney or if the Department for Work and Pensions agrees). When filling in the forms, do not underestimate the person's needs. Ask them to think about all the things they can't do or have difficulty with.

Personal Independence Payment (PIP)

If the person you care for is under 65 and needs help with either personal care or walking around, they can claim PIP which has replaced Disability Living Allowance (DLA). If the person you care for currently claims DLA, they may be contacted and told how to apply for PIP instead.

PIP has two components:

- daily living: if the person has difficulty with certain activities considered essential to daily living
- mobility: if they have difficulty getting around outdoors.

They can claim one component or both. Each component will be paid at two different rates depending on their level of difficulty. See our free factsheet *Personal Independence Payment and Disability Living Allowance* to find out more.

Attendance Allowance (AA)

If the person you care for is over 65 and has difficulty with their personal care or needs supervision to keep them safe, they can claim AA. There is no mobility component to AA but there are different rates depending on how their disability affects them. See our free guide *Attendance Allowance* to learn more.

what next?



For more information, see our free guide *More money in your pocket* (Age Cymru and Age NI have their own versions of this guide). Visit your local Age UK for a benefits check, or use our online benefits calculator at www.ageuk.org.uk/benefitscheck.

You may need to **help the person** you care for to claim a disability benefit.

Making an application for Attendance Allowance

Most claims for Attendance Allowance are decided solely on the information on the claim form, so don't underestimate the needs of the person you care for. Think about all the things they can't do, or have trouble with because of their condition.

- Describe any accidents or falls they've had.
- If they have good days and bad days, complete the form with details of one of the bad days, including how often it happens.
- List things that the person struggles to do unaided, even if they've developed special ways to cope with certain activities.
- Emphasise what they can't do rather than what they can. What happens if they don't receive the help they need? Give examples if this has happened in the past.

Bear in mind that Attendance Allowance doesn't usually take into account problems with housework, cooking, shopping and gardening.

You can apply online for Attendance Allowance on the Gov.uk website or get a claim form by calling the Attendance Allowance helpline (see page 38).

Ask your local Age UK whether they can help you fill in the form to increase the person's chances of being awarded Attendance Allowance. See our free factsheet *Attendance Allowance* for more information.



Most claims for Attendance Allowance are decided solely on the **information on the claim form**, so **don't underestimate** the needs of the person you care for.

Common care needs to include

This section looks only at the care needs of the person you look after. Remember to include their mobility needs if they are applying for Personal Independence Payment (PIP).

Listed below are some examples of what to include. Use these suggestions as a guide, but give plenty of information in your own words about their personal circumstances.

Washing, bathing and looking after their appearance

Do they need help getting in and out of the bath or shower; adjusting shower controls; shaving; putting on skin cream; washing or drying their hair?

Going to the toilet

Do they need help adjusting their clothes after using the toilet, for example because they're partially sighted; using the toilet during the night; changing clothes or bedding if they have an accident?

Getting dressed or undressed

Do they need help with fastenings, shoelaces and buttons, for example because of arthritis, or with recognising when their clothes are on inside out?

Mealtimes

Do they need help or encouragement to plan and prepare a meal? For example, if they have sight loss, do they need someone to tell them where the food is on the plate, or read out menus?

Help with medical treatment

Do they need help identifying their tablets; reading and understanding instructions about taking medication; managing a condition like diabetes; recognising whether their condition deteriorates; or adjusting their hearing aid?

Communicating

Do they need help understanding or hearing people, or being understood by them; answering the phone; or reading and writing letters?

Supervision

Do they need someone to watch over them in case they have a seizure or pass out; in case they lack awareness of danger, or could be a danger to themselves or others; or in case they get confused, forgetful or disorientated? Do they need someone to give them medication; or to help calm them down during a panic attack?

Getting around safely

Do they need help navigating stairs; getting up from a chair; getting in and out of bed; or moving safely from room to room?

Making an application for Personal Independence Payment

Most claims for Personal Independence Payment will require a face-to-face assessment as well as a claim form. The person you care for may ask you for help with filling out the claim form and for you to go with them to the assessment to help explain their needs.



To claim, call the Department for Work and Pensions (DWP) (see page 40). In Northern Ireland, call the Personal Independence Payment Centre on 0800 012 1573. They will ask you for basic information and then send you a paper claim form.

The form will ask about the person's ability to carry out 10 daily living activities and two mobility activities. You'll need to choose from a list of statements on the form that describe levels of difficulty. Don't say that the person can perform an activity without help unless they can do it safely and well, and can repeat it as many times as they need to.

**what
next?**

Your local Age UK or Citizens Advice (see pages 37 and 39) may be able to help you fill in the form.

What if the application is turned down?

If the application is turned down, ask an advice agency such as Age UK whether you should challenge the decision and whether there are any time limits to do so. For AA, look at the common needs on pages 20–21. Have you missed any out? For PIP, did the assessment and claim form provide an accurate picture of the person's difficulties?

Remember that needs may change and increase, so even if the person you care for isn't eligible for AA or PIP now, they may be able to claim successfully in the future.



If your application is **turned down**, ask an advice agency whether you should **challenge the decision**.

Work and caring

If you're working as well as caring for someone, you may need flexible working arrangements. Being a carer doesn't necessarily mean giving up your job – you may just need to work in a way that fits in with your caring responsibilities. Common types of flexible working include part-time, flexitime, compressed hours (working your agreed hours over fewer days), job-sharing or homeworking.

All employees, not just carers, have the right to request flexible working from their employer. Your employer does not have to agree to it but they must have a sound business reason for refusing. You can make a request if you've been working for your employer for at least six months.

You can make one request for flexible working per year but if your circumstances change, your employer may be understanding of your needs and you may find they are willing to consider another request.

You also have the right to take a 'reasonable' amount of time off to deal with an emergency involving the person you care for. Your employer can decide whether this is paid or unpaid.

**what
next?**

For more information about work and caring, call Carers UK (see page 39).



Being a carer doesn't necessarily mean **giving up your job** – you may just need to work in a way that fits in with your **caring responsibilities**.

Your health

Caring can have a significant impact on both your physical and emotional health. It's easy to overlook your own health needs but it's important to stay as healthy as possible. Tell your GP that you're a carer and how this affects your ability to care for your own health. They may be able to help by:

- discussing ways to help you manage your own health needs if your caring responsibilities make it difficult to get to the GP surgery
- arranging appointments for you and the person you care for at the same time
- arranging for repeat prescriptions to be delivered to your local pharmacy
- providing supporting letters and information to help you and the person you care for to access some benefits
- involving you, where appropriate, in discussions about the person you care for.

Carers of people with serious or ongoing health conditions may also qualify for a free annual flu jab.

Try to eat healthily, stay active and get enough sleep. This can be difficult when you're a carer. Our free guides *Healthy living* and *Healthy eating* have suggestions.

Don't forget about your emotional health. If you're struggling to manage or feeling isolated or depressed, let your family and friends know. Joining a carers' support group or finding an online forum may help. Ask your GP about local groups. Our free information guide *Your mind matters* has more suggestions to help you look after your emotional health.

**what
next?**

Check your local council's website or contact the Carers Trust to find your local Carers' Centre. The Carers Trust offers practical and emotional support to carers (see page 39).

Having a break from caring

When you're taking care of someone, you need to remember to take care of yourself, too. Having a break doesn't mean you're letting down the person you look after, or saying you don't care – it's a sensible and realistic thing to do. A break will help you pursue your own interests, catch up with friends, run errands, or simply recharge your batteries.

If you need to take a break from caring, your local council has a responsibility to arrange services that help you. This is known as respite care. These services are means-tested so you or the person you care for may have to contribute towards the cost of them. Services include:

- Services at home – sitting and talking with the person you care for, cooking for them, helping them get dressed or taking them on outings.
- Day care – day centres offer social activities and outings for disabled adults, and sometimes workshops and training. Most can arrange transport to and from the centre.
- Residential care – care homes can provide short-term care for the person you look after. Care homes are expensive, so ask social services or your health authority if you're eligible for help with funding.

 In Northern Ireland, only respite in a residential care setting is means-tested. In Scotland, contact Age Scotland for information about funding.

In some areas, respite care is provided as a result of your carer's assessment, while in others it's provided through a needs assessment for the person you look after. It's best, therefore, to make sure you are both assessed.

In England, you may also be entitled to a personal budget depending on your support needs identified in the assessment. A personal budget is the amount of money that the council has calculated will cover those needs. You can take this as a direct payment, which is a sum of money paid directly to you to help you maintain interests beyond your caring responsibilities. For example, it could be payment for membership to a club or for an internet connection. Contact your local council to see whether you are eligible. See our free factsheet *Personal budgets and direct payments in adult social care* to find out more.

-  In Wales and Northern Ireland, you can't get a personal budget but direct payments are available. See Age Cymru's free factsheet *Direct payments for community care services in Wales* for more information. In Northern Ireland, contact Age NI for more information.
-  In Scotland, contact Age Scotland to find out about self-directed support and to request the free guide *Care and support at home: assessment and funding*.

what next?

Ask your social services department about what services are available in your area. Services may be provided by voluntary organisations, social services, health authorities or private agencies. See Carers UK's free factsheet *Taking a break* for more information (see page 39).

What happens to my Carer's Allowance when I have a break?

If you have time off from caring, there are special rules to decide whether you'll continue to receive Carer's Allowance (or an underlying entitlement to Carer's Allowance) or whether the payment will be suspended. The rules are complicated, so get specialist advice from the Carer's Allowance Unit (see page 38) or an independent advice agency such as Age UK, Carers UK or Citizens Advice (see pages 37-39). However, the basic rules are:

- you're allowed four weeks off from caring, for any reason, in any 26-week period without your Carer's Allowance being affected
- your Carer's Allowance will stop if the disability benefits of the person you're caring for stop. This might happen if they go into a hospital or care home for more than 28 days (unless they are paying the hospital or care home fees themselves)
- if you go into hospital, your Carer's Allowance may continue for up to 12 weeks. This may be less if you've had any other breaks within the last 26 weeks. If you're receiving other benefits which include extra amounts for caring, these may also be affected if you have a break from caring.

what next?



When you have a break from caring, always inform the Carer's Allowance Unit where you made your claim (or the Disability and Carers Service in Northern Ireland) – see pages 38 and 41 for contact details. If your Carer's Allowance is suspended, contact them as soon as you resume caring so that it can start being paid again.

Jane works full-time and is her mum's primary carer.

Jane shares caring for her mum with her two brothers, although she is the primary carer. They all live a long way from their mum, but Jane visits as often as she can and calls frequently, as well as relying on other support networks.

'My mum is in her late 80s. She lives in a flat on her own about 300 miles away and is about 200 miles from my two brothers. Her health has deteriorated over the past three years and she doesn't go out alone any more. I phone several times a week and try to visit every month so I can take her out, help with paperwork and be there for hospital appointments. It's difficult to fit everything in as I work full-time, but she so looks forward to my visits.

'There's always the worry that something will go wrong and none of us is near enough to get there quickly. But we're somewhat reassured because she always wears her community alarm pendant and we have confidence in her support network. She has a good GP practice and a lady who comes to clean and shop but is more like a friend. I approached social services about some concerns I had and she now has carers who come in the morning.

'Several years ago a neighbour suggested we contact Age UK for help with an Attendance Allowance claim which was successful. Mum now goes to their day centre once a week and really looks forward to it. They helped us in the past to find out what was available locally, so I know where to go for help if things change.'



'Mum now goes to
their day centre
once a week and
really looks
forward to it.'

Caring and other activities

You may feel that your life revolves around caring and you have little opportunity to do other things. If you're able to, you may find it helps to take part in a hobby or activity. This could be something you go out to do, like an exercise group, or something you enjoy doing at home by yourself or with online friends. You may want to learn a new skill by going to an evening class. This could also be a good way of meeting new friends.

Taking part in an activity or hobby you enjoy will give you the opportunity to do something for yourself – it's important that, as a carer, you have your own interests and make time where you can to pursue them.

what next?

Your local library is an excellent source of information about social activities, events, education and courses. Contact U3A (University of the Third Age) to learn about courses in your area (see page 42).



It's important that
as a carer, you have
your own interests.

When your caring role changes

If the condition of the person you've been caring for deteriorates and, for whatever reason, you're no longer able to provide the care they need, then it's time to think about arranging a different system of care.

The person you look after may require more support than you have the time or energy to give. Ask their local social services department to assess or reassess their care needs. Their changing health needs may entitle them to more services and support at home than before. Get a carer's assessment for yourself too, as you may be entitled to extra support (see pages 6-7).

If, however, the person you care for needs more intensive care, they may need to consider the possibility of moving into sheltered housing or a care home. This is a big decision and you should both take the time to look at all the options open to you. Think about other types of housing that may be suitable, such as extra-care sheltered housing. See our free guide *Housing options* for more information.

You may continue to provide some care for the person you look after, or you may find that your caring role has come to an end. If this is the case, read the next section, 'When caring ends'.

**what
next?**



For information on care homes, see our free guide *Care homes* and our *Care home checklist*. In Northern Ireland, contact Age NI or in Scotland, contact Age Scotland for more information.

When caring ends

Caring may come to an end when the person you're looking after moves into a care home, or when they die. Whatever the reason for your role as a carer ending, you may experience mixed emotions. You may feel guilty about being relieved that you no longer have the stress of caring, but you may also experience grief, emptiness and loneliness.

If the person you cared for has moved into a care home

This might have been a difficult decision, and perhaps you feel you've let down the person you were looking after. Remember, you're only human and there are limits to the care you can provide at home. If you're becoming exhausted or the health of the person you care for is getting worse, a care home can be the best option for you both. If you find you're still spending a lot of time caring for the person, you may still be entitled to a carer's assessment (see pages 6-7). You also still have the right to request flexible working (see page 24).

If the person you care for stops getting disability benefits (usually after four weeks), you'll no longer be entitled to Carer's Allowance. If you received a carer premium or addition with means-tested benefits (see page 13), this will continue for an extra eight weeks after your Carer's Allowance stops.

This could be a good opportunity to get a benefits check. Contact your local Age UK to see if they can give you a benefits check, or use our online benefits calculator at www.ageuk.org.uk/benefitscheck. You can also read our free guide *More money in your pocket*. Age Cymru and Age NI have their own versions of this guide.



If the person you cared for has died

As well as the loss of the person you cared for, you may also face the loss of the relationships you built up with the professionals involved in their care. Being a carer can be demanding and you may have lost touch with family and friends; getting back in contact with them or meeting new people may be the last thing you feel like doing while coping with a bereavement. As a result, you may feel very alone or isolated.

It may help to talk to family and friends who knew the person you cared for, to share memories and support each other. Or you might prefer to contact an organisation that offers support for people who have suffered a bereavement. Specialist organisations such as Cruse Bereavement Care (see page 40) can offer counselling, advice and practical help, and put you in touch with local bereavement groups.

-  In Scotland, contact Cruse Bereavement Scotland and in Northern Ireland, contact Cruse Bereavement Care Northern Ireland (see page 40). Whatever you do, remember that you do not have to cope alone. There is help out there for you from people who understand what you are going through.

You can continue to get Carer's Allowance for up to eight weeks after the death.

what next?

For more information about managing after a death, see our free guides *When someone dies* and *Bereavement*.

Safeguarding from abuse

All the health and social care professionals working with you and the person you care for should treat you with dignity and respect. If you have any concerns about the service that either of you receive, discuss it with the service provider or make a complaint. You can complain to your local council if they are providing a service, or contact the Care Quality

 Commission (see page 38). In Wales, contact the Care and Social Services Inspectorate Wales about social care services (see page 38), or the Healthcare Inspectorate Wales with regards to health services (see page 41). In Scotland, contact the Care Inspectorate (see page 38). In Northern Ireland, contact the Regulation and Quality Improvement Authority (see page 42).

If you think that abuse is taking place, it's important to take action to deal with it. Start by talking to the person you care for to find out what they want to do.

If you care for someone who lacks capacity to express their views, then you should act in their best interests. In extreme cases you may need to raise a safeguarding alert with the local council or, if a crime has been committed, to contact the police.

**what
next?**

See our free guide *Protecting yourself to find out more*.
Contact Action on Elder Abuse for help (see page 38).

Useful organisations

Age UK

We provide advice and information for people in later life through our Age UK Advice line, publications and online.

Age UK Advice: 0800 169 65 65

Lines are open seven days a week from 8am to 7pm.

www.ageuk.org.uk

Call Age UK Advice to find out whether there is a local Age UK near you, and to order free copies of our information guides and factsheets.

In Wales, contact

Age Cymru: 0800 022 3444

www.agecymru.org.uk

In Northern Ireland, contact

Age NI: 0808 808 7575

www.ageni.org

In Scotland, contact

Age Scotland: 0800 124 4222

www.agescotland.org.uk

The evidence sources used to create this guide are available on request. Contact resources@ageuk.org.uk

Action on Elder Abuse

Works to protect and prevent the abuse of vulnerable older adults.

Tel: 0808 808 8141

www.elderabuse.org.uk

Attendance Allowance helpline

Tel: 0345 605 6055

Textphone: 0345 604 5312

Care and Social Services Inspectorate Wales (CSSIW)

Oversees the inspection and regulation of care and social services in Wales.

Tel: 0300 790 0126

www.cssiw.org.uk

Care Inspectorate

National independent regulator of social care and social work services in Scotland.

Tel: 0345 600 9527

www.careinspectorate.com

Care Quality Commission (CQC)

National independent regulator of all health and social care services in England.

Tel: 03000 61 61 61

www.cqc.org.uk

Carer's Allowance Unit

For information on Carer's Allowance and how to make a claim.

Tel: 0345 608 4321

Textphone: 0345 604 5312

www.gov.uk/carers-allowance-unit

Carers Direct

Help and support if you want to talk to someone about your caring role and the options available to you.

Tel: 0300 123 1053 (England only)

Textphone: 0300 123 1004

Carers Trust

Offers practical help and assistance to carers. You can search on their website for local carers services in your area.

Tel: 0300 772 9600

www.carers.org

In Scotland, contact 0300 123 2008

In Wales, contact 029 2009 0087

Carers UK

Provides information and support for carers, including information about benefits.

Tel: 0808 808 7777

www.carersuk.org

Citizens Advice

National network of free advice centres offering free, confidential and independent advice, face to face or by telephone.

In Wales there is a national phone advice service on 0344 477 2020. It is available in some parts of England on 0344 411 1444. In Scotland, there is a national phone advice service on 0808 800 9060.

For online information and to find details of your nearest Citizens Advice in:

England or Wales: www.citizensadvice.org.uk

Northern Ireland: www.citizensadvice.co.uk

Scotland: www.cas.org.uk

Crossroads Caring for Carers

Offers respite care to carers in Northern Ireland.

Tel: 028 9181 4455

www.crossroadscare.co.uk

Crossroads Caring Scotland

Offers respite care to carers in Scotland.

Tel: 0141 226 3793

www.crossroads-scotland.co.uk

Cruse Bereavement Care

Provides emotional support and information to bereaved people across England, Wales and Northern Ireland.

Tel: 0808 808 1677

www.cruse.org.uk

In Wales, visit www.cruse.org.uk/wales

In Northern Ireland, visit www.cruse.org.uk/northern-ireland

In Scotland, visit www.crusescotland.org.uk

Department for Work and Pensions (DWP) - Personal Independence Payment claims

Call the DWP for more information about personal independence payments, to request a form to be sent to you by post, or to make a claim.

Tel: 0800 917 2222

Textphone: 0800 917 7777

Disability and Carers Service (Northern Ireland)

Administers Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit.

Tel: 0300 123 3356

Textphone: 028 9031 1092

www.nidirect.gov.uk/disability-and-carers-service

Disabled Living Foundation

Helps older and disabled people live independently at home with equipment.

Tel: 0300 999 0004

www.dlf.org.uk

www.livingmadeeasy.org.uk (for advice on daily living equipment)

Gov.uk

Provides information on public services such as benefits, jobs, pensions and health services.

www.gov.uk

In Northern Ireland, visit **NI Direct**

www.nidirect.gov.uk

Healthcare Inspectorate Wales

Independent inspector and regulator of all healthcare organisations in Wales.

Tel: 0300 062 8163

www.hiw.org.uk

Independent Age

Provides advice and information for older people, their families and carers.

Tel: 0800 319 6789

www.independentage.org

Northern Ireland Social Care Council

Regulatory body for social care in Northern Ireland.

Tel: 028 9536 2600

www.niscc.info

Online Centres Network

Can help you learn about computers and the internet at a local centre.

Tel: 0114 349 1666

www.onlinecentresnetwork.org

Regulation and Quality Improvement Authority (RQIA)

Independent body responsible for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland.

Tel: 028 9051 7500

www.rqia.org.uk

Skills for care

Online toolkit to help people employ their own personal assistants.

Tel: 0113 245 1716

www.employingpersonalassistants.co.uk

U3A (University of the Third Age)

Provides a chance for older people to study a wide variety of subjects in local groups. The emphasis is on learning for pleasure, so there are no accreditations or qualifications.

Tel: 020 8466 6139

www.u3a.org.uk

Can you help Age UK?

Please complete the donation form below with a gift of whatever you can afford and return to: **Freepost Age UK Supporter Services**. Alternatively, you can phone 0800 169 87 87 or visit www.ageuk.org.uk/donate If you prefer, you can donate directly to one of our national or local partners. Thank you.

We'd[†] like to let you know about the vital work we do for older people, our fundraising appeals and opportunities to support us, as well as the Age UK products and services you can buy.

Personal details

Title:	Initials:	Surname:
Address:		
Postcode:		

We will never sell your data and we promise to keep your details safe and secure.

☐ Please tick here if you **do not** wish to receive communications by post.

You can change your mind at any time by telephoning us on 0800 169 8787 or by writing to Supporter Services at the registered address below.

Your gift

I would like to make a gift of: £

☐ I enclose a cheque/postal order made payable to Age UK

Card payment

☐ MasterCard ☐ Visa ☐ CAF CharityCard

I wish to pay by (please tick) ☐ Maestro ☐ American Express

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Signature **X**

Expiry date /

Gift aid declaration

☐ Yes, I want Age UK and its partner organisations* to treat all donations I have made for the four years prior to this year, and all donations I make from the date of this declaration until I notify you otherwise, as Gift Aid donations. I am a UK tax payer and understand that if I pay less income tax and/or capital gains tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.
Date __/__/__ * Age Cymru, Age Scotland and Age NI



[†] We, includes the charity, its charitable and trading subsidiaries, and national charities (Age Cymru, Age Scotland and Age NI). Age UK is a charitable company limited by guarantee and registered in England (registered charity number 1128267 and registered company number 6825798). The registered address is Tavis House, 1-6 Tavistock Square, London WC1H 9NA. **Age UK provides a range of services and your gift will go wherever the need is the greatest.**

Supporting the work of Age UK

Age UK aims to enable all older people to love later life. We provide vital services, support, information and advice to thousands of older people across the UK.

In order to offer free information guides like this one, Age UK relies on the generosity of its supporters. If you would like to help us, here are a few ways you could get involved:

1 Make a donation
To make a donation to Age UK, simply complete the enclosed donation form, call us on **0800 169 8787** or visit **www.ageuk.org.uk/get-involved**

2 Donate items to our shops
By donating an unwanted item to one of our shops, you can help generate vital funds to support our work. To find your nearest Age UK shop, visit **www.ageuk.org.uk** and enter your postcode into the ‘What does Age UK do in your area?’ search function. Alternatively, call us on **0800 169 8787**

3 Leave a gift in your will
Nearly half the money we receive from supporters come from gifts left in wills. To find out more about how you could help in this way, please call the Age UK legacy team on **020 3033 1421** or email **legacies@ageuk.org.uk**



**Thank
you!**

What should I do now?

For more information on the issues covered in this guide, or to order any of our publications, please call Age UK Advice free on **0800 169 65 65** or visit www.ageuk.org.uk/homeandcare

Our publications are also available in large print and audio formats.



The Age UK Group offers a wide range of products and services specially designed for people in later life. For more information, please call **0800 169 18 19**.

If contact details for your local Age UK are not in the box below, call Age UK Advice free on **0800 169 65 65**.

