## **Advice for carers**





Practical and emotional help when you're looking after someone

# Information written with you in mind.

This information guide has been produced with the help of older people, carers and expert peer reviewers.

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## What this guide is about

Caring for a friend or relative can be hugely rewarding, but it can also be challenging. So it's good to know what support is available for you and the person you look after.

This guide looks at both the practical and emotional sides of caring. You'll find information about areas such as benefits and flexible working hours, as well as how your caring role could affect your wellbeing and social life. It also lets you know where to go if you need help – so you always know you're not alone.

"I care for my wife because I love her and she needs me. But that doesn't mean it isn't really hard sometimes."

Charles, 74



Where possible, the information given in this guide is applicable across the UK. When we refer to local council social services departments in England and Wales, we also mean local health and social care trusts in Northern Ireland.



Throughout the guide, this symbol indicates where information differs for Wales and Northern Ireland.

If the person you care for has dementia, you should also read our quide **Caring for someone with dementia**.

# Next steps

It's a good idea to find out the number for your local council. They'll be able to provide a lot of the support and information mentioned in this guide.

My local council phone number is:

## Getting the help you need

When you're looking after someone, it can be hard to look after yourself, too. But the right support can help to make life a bit easier.

#### Am I a carer?

The word 'carer' means different things to different people. That's because many of us don't necessarily see caring as a job – we help look after someone because we love them and we know they need our help.

This can be a positive thing, as you're always looking out for their best interests. But it can also mean that you feel a range of difficult emotions towards the person you're caring for. You may feel sadness or guilt – or even anger at times – as you do the best you can to help them.

However you see your role, if you're looking after a friend, relative or partner who needs support because they're ill or disabled, then you're a carer. It's important to acknowledge this because it means you could get extra support, such as financial benefits or flexible working arrangements.

There are many different ways you might care for someone. For instance, you may:

- be on hand to provide 24-hour care for your partner
- visit a relative who lives far away once a month to check how they're doing
- arrange hospital appointments by phone for a parent
- drop in to see a disabled friend each day to provide a meal and some company
- move in with a relative to help them recuperate after a major operation

Caring for someone can be a choice – one many of us decide we want to make despite the challenges. However, it's also common to become a carer without realising it. Either way, these may sound familiar:



Whether you feel you've chosen to be a carer or not, it can be overwhelming. But there is support available. Over the next few pages we'll explain what rights you have as a carer and what help is available to you.

# Next steps

The charity Carers UK is a good source of information, advice and support for carers (page 45). In England, the Government service Carers Direct can also offer information and advice (page 44).

### Help for carers

As a carer, you have certain basic rights that can help make your life that bit easier.

You may be entitled to:

- financial support through Carer's Allowance (see page 15)
- help looking after yourself, including the right to request flexible working from your employer (see page 31) or arrange respite care to give you a break (see page 35)
- assistance from social services like practical help at home, information about support groups near you, or, following a carer's assessment, counselling to help deal with stress (see pages 33-36)

You should also have your views taken into consideration by social services when they're deciding how best to meet the needs of the person you care for.

The best place to start is with a **carer's assessment** from your local council (see page 10), which will evaluate what support you might need as a carer and how they can help.

# Next steps

Contact your local Age UK, your local council or the Carers Trust (page 44) to find out what support is available for carers in your area. In Wales, contact Age Cymru Advice.

#### **Assessing your needs**

When you're so busy making sure someone else's needs are met, it's easy to overlook your own. But take a few minutes now to think about yourself – and the kind of help you need. For example, do you find yourself having any of these thoughts?

If you do, there's support available.

"I'm finding certain tasks difficult to carry out because of health or personal reasons."

> "I'm struggling to find enough time for myself, my family and friends."

"The person I'm looking after is getting worse, and I'm worried about how to cope."

#### What support could I get?

You're entitled to a free carer's assessment from the local council, which takes into account your support needs. After the assessment, the council decides whether you're eligible for help.

This could include help with caring, respite care to give you a break, or equipment to help you (see our guide **Adapting your home** for more information on this).

#### How do I arrange a carer's assessment?

Call your local council's social services department to ask for one. The council's contact number should be in your phone book or on their website. The person you care for is entitled to a separate needs assessment (see page 12), and this should also take into account your role as a carer.

If your council charges for carer support services, they must carry out a financial assessment to see if you're entitled to receive help with the cost. There should be a separate financial assessment for the person you care for if they receive charged-for services, such as a respite care home placement.



In Northern Ireland, home care services are not means-tested, but care provided in a residential or nursing care setting is.

"I had to call the council a couple of times to arrange an assessment - but I'm very glad I got it sorted."

Sean, 71



#### What will the council want to know?

Before your assessment, have a think about some of the following questions, and whether being a carer is affecting these or other parts of your life.

- Are you getting enough sleep?
- Can you get out and do things by yourself?
- Are you eating well?
- Is your physical or mental 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?



Contact your local council to request a carer's assessment.

# Assessing the needs of the person you care for

Regardless of income or savings, the person you care for is entitled to a needs assessment from their local council. You can ask for an assessment on their behalf, if needed.

#### What will happen?

When someone 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. The assessor will look at:

- the person's health and what they can and can't do
- their current living arrangements
- how they would like to be supported
- any feelings you have as their carer.

As well as the person's physical safety, the assessor should consider the emotional and social side of their life, and 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.

# Good to know



Even if someone isn't eligible for funding, necessary disability equipment and minor adaptions are free in England and don't depend on your finances. In Wales, there may be a charge for disability equipment depending on your circumstances. For more information, see Age Cymru's factsheet **Obtaining disability equipment and home adaptations in Wales**.

The assessor will consider the type of help the person needs, the care they're already receiving, and whether they're eligible for help from the council.

If the assessor finds that the person you care for is eligible for help, the council will produce a care and support plan setting out how it will meet their needs. You and the person you care for should be involved in drawing up the care plan. The care you provide should be recorded.



The council can usually charge for care services it arranges or provides. If it does so, it must carry out a financial assessment to see if the person you care for is entitled to help with the cost. In Northern Ireland, you won't have a financial assessment.

#### A financial assessment

This will look at the person's income and capital, and decide whether the council will fund all, some, or none of the person's care. If the council funds their care, the person can then choose between having the council arrange their care, or arranging some or all of it themselves through **direct payments**. In Wales, there is a maximum weekly charge for homecare and other non-residential social care services.

#### **Direct payments**

Direct payments are cash payments that can be used to pay for a carer. If a person decides to pay for a carer directly, they might take on the responsibilities of an employer, such as tax and pension contributions. Contact Skills for Care (page 48) for more information.

The person you look after 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 – for example, where it is necessary to meet the person's needs – the council may agree to this. This guidance is a bit more relaxed in Wales.

If you and the person you care for are considering this option, think carefully about how it could affect your family relationships, and whether becoming a paid carer will affect your eligibility for benefits. For more guidance, get in touch with your local Age UK.

If you care for someone who lacks **mental capacity**, you may be able to receive direct payments on their behalf. The person you care for may have dementia or another condition that might affect their ability to make their own decisions. You may also want to read our guide **Caring for someone with dementia**.



When we talk about 'mental capacity' we mean someone's ability to make decisions and understand their consequences.

# Next steps

See our factsheet Personal budgets and direct payments in adult social care to find out more. In Wales, see Age Cymru's factsheet Direct payments care services in Wales and Social care assessments for older people with care needs in Wales. In Northern Ireland, see Age NI's factsheet Care at home.

## Financial support

While it can seem like a hassle, getting some financial support in place can be a real help.

#### Carer's Allowance

The main welfare benefit for carers is called Carer's Allowance. It's worth £67.60 a week (this figure is usually reviewed in April) and you could be entitled to it if all of the following apply:

- You spend at least 35 hours a week caring for someone whether you live with them or not.
- The person you look after 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.
- You're not in full-time education or earning more than £128 a week (after tax and expenses).

If your State Pension is more than £67.60 a week, or if you get certain benefits at a higher amount, you will not be paid Carer's Allowance. This is because State Pension and Carer's Allowance are classed as 'overlapping' benefits. Instead, you may be awarded an 'underlying entitlement' to Carer's Allowance. This means you'll get extra money paid with any means-tested benefits you claim, like Pension Credit or Housing Benefit. If you decide to take a break from caring, your Carer's Allowance might be affected (see page 37). 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 if you get Carer's Allowance. Before making your claim, talk to your local Age UK.

#### **Carer's Credit**

If you give up work to care for someone, you might be worried that not paying National Insurance (NI) will lower your State Pension. Carer's Credit is a weekly benefit for carers, filling the gaps in your NI contributions.

The amount of State Pension you get usually depends on how many qualifying years of NI you have built up. But don't worry – if you care for someone for at least 20 hours a week, there's a system in place to protect your entitlement.

#### How do I claim?



If you're already claiming Carer's Allowance, you'll automatically get Carer's Credit. If not, you'll need to apply for it. Contact the Carer's Allowance Unit for more information (page 44). In Northern Ireland, contact the Disability and Carers Service (page 46).

# Next steps



For more information, see our guides Carer's Allowance and State Pension. To make a claim for Carer's Allowance, claim online at www.gov.uk/carers-allowance/how-to-claim. In Northern Ireland, contact the Disability and Carers Service (page 46). Carers UK produces a guide called Looking after someone: Information and support for carers (page 45).

### **Council Tax Support for carers**

#### Help if you have a low income

What you can claim depends on a number of things, including your age, your income, your savings, which benefits you receive, who you live with, and how much Council Tax you pay.



Local councils run their own Council Tax Support schemes (sometimes called Council Tax Reduction), so contact your local council to find out what they offer and whether you qualify. There is a national scheme for Council Tax Reduction in Wales.

#### Other discounts and exemptions

Depending on your council's scheme, you may be entitled to some discounts or even exemptions from your Council Tax if:

- you receive the Guarantee Credit part of Pension Credit this could entitle you to have your Council Tax paid in full
- you don't get the Guarantee Credit part of Pension Credit, but you have a low income and less than £16,000 in savings
- your property is empty if, for example, you have left it to care for someone else, then you could get a full exemption
- you live alone you can get 25% off your Council Tax bill, regardless of your financial circumstances
- you share your home with someone who is not jointly liable to pay Council Tax
- you're disabled and your home is adapted.



See our factsheet **Council Tax** for more information. In Wales, contact Age Cymru for their version of this factsheet. In Northern Ireland, contact Age NI for information on help with rates.

# Disability benefits for the person you're caring for

If the person you're looking after needs extra help getting around the house, or with personal care like dressing or washing, they may be able to claim Personal Independence Payment (PIP) if they are under State Pension age, or Attendance Allowance (AA) if they are over it.

You might need to help them make the claim – or make it on their behalf, if they don't have mental capacity and you have power of attorney (or if the Department of Work and Pensions (DWP) agrees). When filling in the forms, don't underplay their needs – ask them to think about all the things they can't do or have difficulty with.

#### Personal Independence Payment (PIP)

PIP has replaced Disability Living Allowance (DLA) for most people under State Pension age. If the person you care for currently claims DLA, they may be contacted and told how to apply for PIP instead.

PIP has two parts. They can claim either or both.

- **Daily living** if the person you look after has difficulty with daily activities like eating, washing or dressing.
- Mobility if they have difficulty moving around or going out.

#### How do they claim?

Most claims for PIP will involve a face-to-face assessment and a claim form. The person you care for may ask you for a hand filling out the form, or to go with them to the assessment to help them explain their needs.



To claim PIP, call the Department for Work and Pensions (page 46). 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 you to pick statements describing how difficult the person finds it to carry out ten daily living activities and two mobility activities.

It's important not to underplay their needs – don't say that they can do something without help unless they can do it safely and well, and can repeat it as many times as they need to.



For more information, see our 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**. In Wales, contact your local Age Cymru.

Your local Age UK or Citizens Advice (page 45) may be able to help you fill in the form. See our factsheet **Personal Independence Payment and Disability Living Allowance** to find out more.

"I'm now getting benefits I didn't know I couldn't claim. I couldn't believe I'd been missing out!"

Daphne, 68



#### **Attendance Allowance (AA)**

If the person you care for is over State Pension age and has difficulty with their personal care, or needs someone keeping an eye on them to stay safe, they can claim AA. There is no mobility component to AA, but there are different rates depending on how the person's health affects them.

# Next steps



See our factsheet **Attendance Allowance** for more information. Ask your local Age UK whether they can help you fill in the form to increase the chances of being awarded AA. In Wales, contact your local Age Cymru.

#### How do they claim?

You can apply online on the **GOV.UK** website or get a claim form by calling the Attendance Allowance helpline (page 44). Most claims for AA are decided solely on what you say in the claim form, so don't underplay the needs of the person you look after. Think about all the things they can't do, or have trouble with. For example:

- Describe any accidents or falls they've had.
- If they have good days and bad days, give details of one of the bad days, including how often they happen.
- List things they struggle to do without help, even if they've developed special ways to cope with certain activities.
- Emphasise what they can't do rather than what they can, and give examples of what happens if they don't receive the help they need.

Bear in mind that AA doesn't usually apply to problems with housework, shopping or gardening.



#### Common care needs to consider

Here are a few examples of things to consider when explaining the care needs of the person you're looking after. If they apply, give plenty of information in your own words about the person's circumstances. Remember to also include their mobility needs if they are applying for Personal Independence Payment (PIP).

#### Washing, bathing and looking after their appearance

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

#### Going to the toilet

Do they need help adjusting their clothes after using the toilet; using the toilet during the night; or changing clothes or bedding if they have an accident?

#### **Getting dressed or undressed**

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



#### **Mealtimes**

Do they need help or encouragement to plan and prepare a meal? 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, such as 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 keep an eye on 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 managing stairs; getting up from a chair; getting in and out of bed; or moving safely from room to room?



# What if the application is turned down?

Don't worry if an application for financial support is turned down – you still have options.

- Get in touch with Age UK to discuss challenging the decision and whether there are any time limits on doing so.
- Look at all the common needs on the last couple of pages of the form. Have you missed any out?
- Remember that the needs of the person you're caring for may change and increase so, even if they're not eligible for PIP or AA right now, they may be able to claim successfully in the future.

"Age UK were really helpful when my application was turned down. They helped me word things just right."

Alex, 70



## Good to know



If your application is turned down, seek advice from Age UK about challenging the decision.

## Practical tips and advice

Caring for someone can be tiring, physically and emotionally – but there are ways to ease some of the strain and give you both extra peace of mind.

### Helpful technology

There are two main kinds of technology that could help the person you're caring for stay safe and independent at home:

#### **Telecare**

Community alarms are an example of telecare. Having one could reassure the person you look after that they can call for help if you're not there. Other examples include devices that can tell if someone has fallen, had a seizure, left the gas on, or is leaving their house unaccompanied.

#### **Telehealth**

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

### Next steps



You may be able to explore telecare options through the local council following a needs assessment. Contact Living Made Easy to find out more about telecare and telehealth products (page 47). Our guide **Adapting your home** has more information on telecare, or visit **www.ageuk.org.uk/telecare**.

### Caring from a distance

If you live a long way from the person you care for, it's not always easy to stay actively involved in their care. This can make you feel guilty, anxious and overwhelmed. All of those emotions are completely normal and understandable.

There's nothing wrong with looking for help if you're finding things difficult – your health and wellbeing are important too. There are lots of things you could try that might make things easier for you and the person you're caring for.

Here are 10 questions to ask yourself:

- **1.** Caring from a distance can be time-consuming and expensive do you find yourself travelling for miles every weekend?
- **2.** Can anyone else share the responsibility? Could they contribute towards the costs, even if they're not able to be there very often?
- **3.** Travelling and looking after people are both tiring are they having an impact on your own health and wellbeing?
- **4.** You may be entitled to benefits have you applied for any you may be entitled to (see pages 15-21)?
- **5.** Have you checked what help is available? The person's local council can assess the needs of both of you, and may be able to offer you both some support. The person may be entitled to care at home, which could lighten the load for you.
- **6.** Did you know that the person you're looking after could get help from their local Age UK, such as home visits or handyperson services to help with minor home repairs? Other charities and home improvement agencies might also offer these services.

- 7. Would using a computer help with some tasks like online food shopping, or staying in touch when you can't be there? Contact your local Age UK or Online Centres Network (page 47) to find out about courses on using computers and the internet.
- **8.** Have you both considered other options, such as retirement housing, moving to a care home, or them moving closer to you or perhaps even moving in with you?
- **9.** As part of planning for the future, the person you care for may wish to create a power of attorney to allow you, or someone else, to make decisions on their behalf if they lose mental capacity.



In England and Wales, this is called a Lasting Power of Attorney. See our guide **Powers of attorney** to find out more. In Northern Ireland, you could set up an Enduring Power of Attorney, which will continue if the person you care for loses mental capacity.

**10.** It might seem obvious, but have you asked what the person you care for wants and needs? Having an open and honest conversation could really help you both.

## Good to know



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

### **Protecting yourself**

From hospital staff to paid carers, there may be many different people involved in helping you look after your loved one. It's important they always treat you – and the person you care for – with dignity and respect.

# What to do if you're not happy with how you're being treated

If you have any concerns about the service that you or the person who needs care is receiving, you can discuss it with the service provider or make a complaint. You can complain to your local council if it's providing or arranging the service, or the NHS if it is providing or arranging it. You can also contact the Care Quality Commission (CQC), but it's worth noting that it doesn't investigate "individual complaints" (page 44). The CQC regulates health and care services in England, ensuring they comply with agreed standards of care. It can take action if a provider falls short of these standards.



In Wales, contact the Care Inspectorate Wales about social care services (page 44), or the Healthcare Inspectorate Wales about health services (page 46). In Northern Ireland, contact the Regulation and Quality Improvement Authority (page 47).



"When Mum was being cared for, I just made sure I kept an eye on things because she has dementia and struggles to communicate if there's a problem."



Hannah, 51

#### **Abuse and neglect**

If you think abuse or neglect is taking place, you should raise this with the council, as it has a safeguarding duty. Under its safeguarding duty, the council must investigate concerns about abuse and neglect. The council's safeguarding duty applies regardless of how a person's care is arranged and funded.

If you think a crime has been committed, contact the police.

Abuse and neglect can come in many forms, from psychological to financial. It can also include self-neglect.

## **Next steps**



See our factsheet **Safeguarding older people from abuse and neglect** to find out more and for a more detailed explanation of what is meant by abuse and neglect. In Wales, see Age Cymru's version of this factsheet. Contact Hourglass for advice and support (page 46).

### Jane's story

#### Jane works full time and cares for her mum.

Jane shares caring responsibilities 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 eighties. 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 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 do her shopping, 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 too.

"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."

# Looking after yourself

When you care for someone, it can be easy to let your own needs slide. But it's vital that you look after yourself, too.

### **Caring and work**

If you're working as well as caring for someone, it can seem like there simply aren't enough hours in the day.

But there are lots of adjustments you can make to ensure that you find time to continue working and be a carer.

The first step is to think about how you'd like to balance working with your caring responsibilities. It's good to have a clear idea about this if you need to have a conversation with your employer about flexible working. Flexible working includes parttime, flexitime, compressed hours (working your agreed hours over fewer days), job-sharing or homeworking.

#### Flexible working

All employees have the right to request flexible working from their employer. You can make a request if you've been working for your employer for at least six months. Though they don't have to say yes, they need a sound business reason for saying no. If they do say no, you can make a new request next year.

# Good to know



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. Call Carers UK (page 45) for more information.

### Caring and your own time

It may sometimes feel like your life revolves around caring, with little room for anything else.

This may sound obvious, but doing things you enjoy will make you feel happier and more fulfilled – all things that can make you a better carer. So it's really important that you have your own interests and make time for them where possible.

If you can, try to find time for a hobby or regular activity. This could be something you go out for, 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 or meet new friends by going to an evening class.

Don't feel guilty for making time for yourself – you matter too.

# Next steps

Your local library is an excellent source of information about social activities, events, education and courses. You can also go online and see what's going on in your area. Check the U3A (University of the Third Age) website to learn about courses near you (page 48).

### Caring and your health

When you're caring for someone else, it's easy to let your own health take a back seat. But being a carer can put a strain on both your physical and emotional wellbeing, so it's important to make sure you look after yourself.

Sometimes it's the last thing you'll want to do, but try to eat healthily, stay active and make sure you get enough sleep. We know that can be easier said than done.

Don't forget about your emotional health. If you're struggling to manage, or feeling isolated or depressed, you should talk to your doctor. It may also help to let your family and friends know. Finding an online forum or joining a carers' support group may also help.

"Sometimes there just aren't enough hours in the day, but I always try and do a crossword with a cup of tea to have a bit of time to myself."



lan, 47

### **Next steps**



Our information guides **Healthy living** and **Your mind matters** have more suggestions to help you stay physically and mentally well.

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 (page 44).



#### Your doctor can help

It's a good idea to let your doctor know that you're a carer. They may be able to help by:

- suggesting ways to help you manage your own health needs if it's difficult for you to get to the doctor's 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 access some benefits
- involving you as much as possible in discussions about the person you care for.

## Good to know



If you care for someone with a serious or ongoing health condition, you may also qualify for a free annual flu jab.

### Having a break from caring

Caring can feel all-encompassing, but sometimes we need to do what's best for ourselves. That might mean taking a break from caring every now and then.

This doesn't mean you're letting down the person you look after. It's a sensible and realistic thing to do, and may help you care for them better, for longer. Some time off will help you pursue your own interests, catch up with friends, run errands, or simply recharge your batteries.

#### Respite care

If you need to take a break from caring, your local council may have a duty to arrange services for the person you care for. This is known as respite care. These services are means-tested, so the person you care for may have to contribute towards the cost of them. They 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 older people, 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 the person you care for is eligible for help with funding.



In some areas, respite care is provided as a result of your carer's assessment (see pages 10-11), while in others it's provided through a needs assessment for the person you look after (see pages 12-14), so it's best to make sure you're both assessed. In Northern Ireland, care services are free, but if you require care in a residential or nursing care setting it is means-tested.

#### Personal budget

You may also be entitled to a personal budget to cover any support needs identified in your assessment. You can take this as a direct payment to help you maintain interests beyond your caring responsibilities. For example, it could pay for membership of a club or for an internet connection. Contact your local council to see whether you qualify, and see our 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 factsheet Direct payments for social care services in Wales for more information. In Northern Ireland, contact Age NI for more information

# Next steps



Ask your local council's 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 factsheet Taking a break for more information (page 45).

### What happens if I take 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 (page 44) or an independent advice agency such as Age UK, Carers UK or Citizens Advice (pages 43-45).

#### These are the basic rules:

- You're allowed four weeks off from caring 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're 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 past 26 weeks. If you're receiving other benefits that include extra amounts for caring, these may also be affected by taking a break.

# Next steps



When you have a break from caring, make sure you tell the Carer's Allowance Unit where you made your claim, or the Disability and Carers Service in Northern Ireland (see pages 44 and 46). If your Carer's Allowance is suspended, contact them as soon as you go back to caring so that it can start being paid again.

## When caring becomes harder

Caring for someone is often unpredictable. Over time, you may find your caring role has got to the point where you can no longer cope. This could be because you simply can't devote the same amount of time and energy anymore. It could be because the person you're looking after needs more support than you can give them, or more specialist support.

Whatever your situation, there is no shame in asking for help. Be kind to yourself. Finding more support will make you a better carer. You should talk to your local council or explore options through private care providers.

#### **Get more support**

If the person you look after starts to need more support than you're able to give, they can ask their council to assess their needs or, if the council is already providing help, to review their care and support plan. They may be entitled to more services and support at home than before. You may also qualify for extra support, so it's worth getting a carer's assessment for yourself as well (see pages 10-11).

If the person you care for needs more care, they may have to think about moving into sheltered housing or a care home. This is a big decision and you should both take the time to look at all your options. Our quide **Housing options** is a good place to start.

# Next steps



For information on care homes, see our guide Care homes, which comes with a handy checklist. In Northern Ireland, contact Age NI for more information.

### When your caring role changes

You will always care about the person you're looking after. But in a practical sense, you may find your role and responsibilities as a carer do change – and it's good to be prepared for this.

#### If the person you care for is considering a care home

If the health of the person you care for is getting worse, or looking after them is taking its toll on you, a care home can be the best option for you both. This is a conversation you can have together, but ultimately it's up to the person you care for to decide whether it's right for them.

This might be a very difficult decision, and carers sometimes worry that they've let down the person they were looking after. But remember: you're only human, and no matter how much you may care about someone, you can't always keep caring for them at home.

Maybe the time's come to hand over some of your caring responsibilities to professionals so you can focus on the time you spend together? You can care for someone in many different ways.

You may still be entitled to a carer's assessment (see pages 10-11) and have the right to ask for flexible working (see page 31).

If the person you care for stops getting disability benefits (usually after 28 days), you'll no longer qualify for Carer's Allowance. If you received a carer premium or addition with means-tested benefits (see page 15), this will continue for an extra eight weeks after your Carer's Allowance stops.



You can use our helpful online benefits calculator at www.ageuk.org.uk/benefitscheck or visit your local Age UK. You can also read our 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

Losing the person you care for will always be hard.

You may experience different emotions. Many of us feel grief, emptiness and the loneliness of loss. But it's also common to feel a sense of guilt, especially if you're relieved at no longer facing the pressure of caring. This is totally understandable.

There is no right or wrong way to grieve. But you shouldn't try to cope with it all on your own.

You might find it helps to talk to family and friends who knew the person you cared for, to share memories and be there for one another. If the demands of your caring role made it difficult to stay in touch with family and friends, you could feel quite isolated. But it's important to ask for help.

You may prefer to speak to an organisation that offers support for people who have suffered a bereavement, such as Cruse Bereavement Care (see page 45). They are experts at supporting people just like you at this difficult and confusing time, and can offer counselling, advice and practical help. They can put you in touch with local bereavement groups, too.



You may find that grief affects you in some unexpected ways. For example, you might miss the relationships you've built up with the professionals who worked with you in a caring role. When you're no longer caring for someone physically, the sudden change in routine could leave you feeling confused and without a sense of purpose. This is completely normal, and it won't be like this forever.

However you grieve, it's important to be kind to yourself and recognise that you don't have to go through it alone. There is help out there.

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



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

# Carers support organisations

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

Carers Direct is a government-run helpline for people caring for someone in England. They can provide 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.

Call them on: 0300 123 1053 (0300 123 1004 for textphone).

**Carers Trust** is 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.

#### Call them on:

- 0300 772 9600 in England
- 0300 772 9702 in Wales
- 07826 930 508 in Northern Ireland

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

#### Call them on:

- 0800 144 8848 in England
- 0800 702 2020 in Wales

# Other useful organisations

#### **Age UK**

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

Age UK Advice: 0800 169 65 65

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

www.ageuk.org.uk

In Wales, contact Age Cymru Advice: 0300 303 44 98

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

#### **Attendance Allowance helpline**

Tel: 0800 731 0122

Textphone: **0800 731 0317** 

#### **Care Inspectorate Wales (CIW)**

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

Tel: 0300 7900 126

www.careinspectorate.wales

#### **Care Quality Commission (CQC)**

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

Tel: **03000 616161** www.cqc.org.uk

#### Carer's Allowance Unit

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

Tel: 0800 731 0297

Textphone: 0800 731 0317

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 9702** www.carers.org

In Wales, contact **0300 772 9702**In Northern Ireland, contact **07826 930 508** 

#### **Carers UK**

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

Tel: **0808 808 7777** www.carersuk.org

#### Citizens Advice

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

In England, tel: **0800 144 8848** www.citizensadvice.org.uk

In Wales, tel: **0800 702 2020** www.citizensadvice.org.uk/wales

Northern Ireland: www.citizensadvice.co.uk/about-us/northern-ireland

#### Crossroads

Offers respite care to carers in Northern Ireland.

Tel: 02891 814455

www.crossroadscare.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/get-help/local-services/northern-ireland/northern-ireland

#### **Department for Work and Pensions (DWP)**

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** 

www.gov.uk/government/organisations/department-for-

work-pensions

#### **Disability and Carers Service (Northern Ireland)**

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

Tel: 0800 587 0912

Textphone: 0800 012 1574

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

#### **GOV.UK**

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

www.gov.uk

In Wales, GOV.Wales www.gov.wales

In Northern Ireland, visit NI Direct www.nidirect.gov.uk

#### **Healthcare Inspectorate Wales (HIW)**

Independent inspector and regulator of all healthcare organisations in Wales.

Tel: **0300 062 8163** www.hiw.org.uk

#### **Hourglass**

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

Tel: 0808 808 8141

Textphone: **07860 052906 www.wearehourglass.org** 

#### **Independent Age**

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

Tel: 0800 319 6789

www.independentage.org

#### **Living Made Easy**

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

Tel: 0300 999 0004

www.livingmadeeasy.org.uk

#### **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

# Personal Independence Payment Centre (Northern Ireland)

For PIP claims in Northern Ireland.

Tel: 0800 012 1573

Textphone: 0800 587 0937

#### 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 9536 1111** www.rqia.org.uk

#### **Skills for Care**

Online toolkit to help people employ their own personal assistants.

Tel: **0113 241 1275** 

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



<sup>&</sup>lt;sup>†</sup> The Age UK network includes the charity, its trading companies and national partners (Cymru, Scotland and NI). We also work closely with local Age UKs. 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.

# Can you help Age UK?



If you would like to, please complete the donation form below with a gift and return to: Freepost Age UK REPLY. Alternatively, you can phone 0800 077 8751 or visit www.ageuk.org.uk/donate. If you prefer, you can donate directly to one of our national or local partners. Thank you.

Your details	AGUK0081 MXAQ21CA08C001
Title: Su	rname:
Home address:	
	Postcode:
Email address:	
We'd <sup>†</sup> like to keep in touch with you to tell you about the vital work we do for older people, our fundraising appeals and opportunities to support us, as well as the products and services you can buy.	
$\square$ <b>I do not wish</b> to receive communicati	ons by post.
We will never sell your data and we prom	ise to keep your details safe and secure.
Please tick the box to let us know all the ways you'd like to hear from us:	
☐ <b>I would</b> like to receive communication	ns by email.
If you change your mind about how we can contact you, please email <b>contact@ageuk.org.uk</b> or call <b>0800 169 8787</b> . For further details on how your data is used and stored by the Age UK network go to <b>www.ageuk.org.uk/help/privacy-policy.</b>	
Your gift	
I would like to make a gift of £:	
☐ I enclose a cheque/postal order made	payable to Age UK. <b>or</b>
I wish to make payment by (please tick):	,
☐ MasterCard ☐ Visa ☐ CAF CharityCar	d 🗆 Maestro
Card number	Expiry date
Signature	
<b>Gift Aid declaration</b> Yes, I want Age UK and its made for the four years prior to this year, and all donation you otherwise, as Gift Aid donations. I am a UK tax payer capital gains tax than the amount of Gift Aid claimed on a pay any difference. Today's date	s I make from the date of this declaration until I notify and understand that if I pay less income tax and/or

Age UK provides a range of services and your gift will go wherever the need is the greatest.

if you wish to cancel your declaration, or if your tax status, name or address changes.

# Help us be there for someone else

We hope you found this guide helpful. When times are tough, it's so important to get some support. Did you know you could help us reach someone else who needs a little help? Here's how:



#### Give your views on guides like this

Our Readers' Panel helps make sure the information we produce is right for older people and their families. We'd love you to join. Go to www.ageuk.org.uk/readers-panel.



#### Donate to us

Every donation we receive helps us be there for someone when they need us. To make a donation, call us on **0800 169 8787** or go to **www.ageuk.org/donate**.



#### Volunteer with us

Our volunteers make an incredible difference to people's lives. Get involved by contacting your local Age UK or at www.ageuk.org.uk/volunteer.



#### Campaign with us

We campaign to make life better for older people, and rely on the help of our strong network of campaigners. Add your voice to our latest campaigns at www.ageuk.org.uk/campaigns.



#### Remember us in your will

A gift to Age UK in your will is a very special way of helping older people get expert support in the years to come. Find out more by calling **020 3033 1421** or visit www.ageuk.org.uk/legacy.

#### What should I do now?

You may want to read some of our relevant information guides and factsheets, such as:

- Carer's allowance
- Caring for someone with dementia
- Your mind matters

You can order any of our guides or factsheets by giving our Advice Line a ring for free on **0800 169 65 65** (8am-7pm, 365 days a year).

Our friendly advisers are there to help answer any questions.

All of our publications are available in large print and audio formats.

There's plenty of really useful information on our website, too. Visit **www.ageuk.org.uk/care** to get started.

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



0800 169 65 65 www.ageuk.org.uk









Age UK is a charitable company limited by guarantee and registered in England and Wales (registered charity number 1128267 and registered company number 6825798). Registered address: Tavis House, 1–6 Tavistock Square, London WC1H 9NA. Age UK and its subsidiary companies and charities form the Age UK Group, dedicated to helping more people love later life. ID204668 08/21