

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 expert peer reviewers as well as older people and carers.

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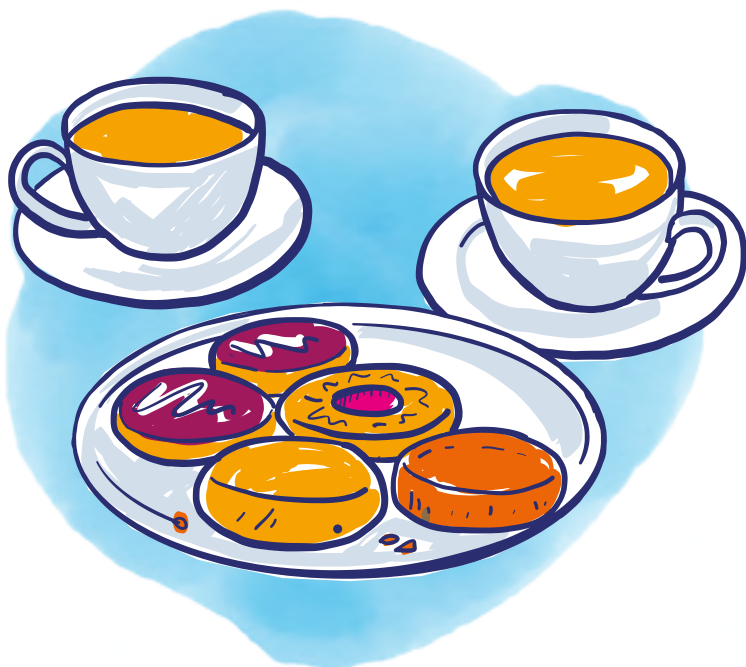
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What this guide is about

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 a local council social services department in England and Wales, we also mean local health and social care trust in Northern Ireland.

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



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

Next steps



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

My local council number is:

Getting the help you need

Am I a carer?

The word ‘carer’ means different things to different people. That’s because many of us don’t necessarily see our caring as a job or career choice. More often, we help look after someone because we love them, and we know they need our help. In other words, it’s personal not professional.

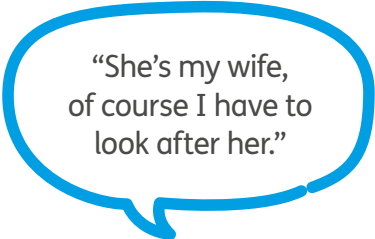
This can be a very positive thing – as you’re always looking out for their best interests. But it also means that you may feel lots of emotions towards the person you’re caring for. These could include sadness, guilt and even anger at times as you do the best you can to help them.

However you see your role, if you’re looking after a friend or relative who needs help because they’re ill or disabled, then you **are** a carer. And it’s important to acknowledge this because it means you could get extra help and support, like financial benefits or flexible working arrangements.

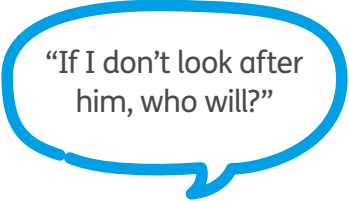
There are many different ways you might care for someone. For instance, you may:

- 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
- live close enough to a disabled friend 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.


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




"She's my wife,
of course I have to
look after her."



"If I don't look after
him, who will?"



"Mum looked after
me, now it's my turn
to look after her."



"I'm just doing what
anyone would do in
my situation."

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 (see page 45). In England, the Government service Carers Direct can also offer information and advice (see page 43).

Your rights as a carer

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

You may have the right to receive:

- **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 32) or arrange respite care to give you a break (see pages 36-37)
- **assistance from social services** like practical help at home, information about support groups near you, or counselling to help deal with stress following a carer's assessment (see pages 9-10).

You're also entitled to 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.

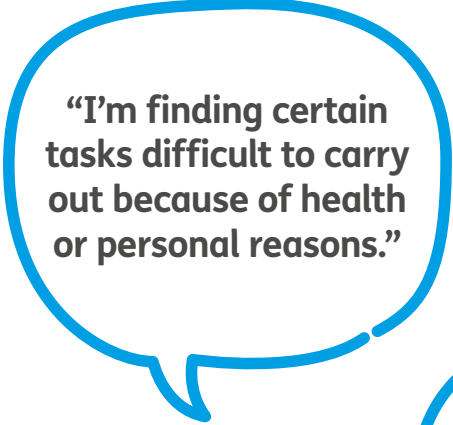
The best place to start is with a **carer's assessment** from your local council, which will evaluate what support you might need as a carer and how they can help.

Next steps


Contact your local Age UK, your local council or the Carers Trust (see page 43) to find out more information on what support is available for carers in your area. In Wales, contact Age Cymru.

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?



“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.”

Don't worry, if you are having any of these thoughts there's support available.

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.



Your council may charge you for these services and if it involves the person you care for (such as respite care), it will be means tested. They will have to carry out a financial assessment first. There is currently no charge for these services in Northern Ireland.

“Sometimes it felt a bit like pulling teeth trying to get the local council to arrange an assessment. But I'm glad I didn't give up, because it's been really helpful.”

Sean, 71



What will the council want to know?

Before your assessment, have a think about 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 and 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?

Next steps

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

Assessing the needs of the person you care for

Regardless of income or savings, everyone is entitled to a needs assessment from their local council. You can ask for an assessment for them if they can't do it themselves.

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 adaptations are free and don't depend on your finances.



After the assessment, everyone involved should agree on a care plan, which will be written down and given to the person whose needs have been assessed. 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 so, they'll have a financial assessment. 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 agrees to fund their care, the person can then choose between having the council arrange their care, or arranging it themselves through direct payments.



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

Direct payments

Direct payments are cash payments that can be used to pay for a carer, or anything else that helps you meet your needs. If a person decides to pay for a carer directly, they might take on the responsibilities of an employer, like tax and pension contributions. Contact Skills for Care (see page 48) for 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 – like if there's a language barrier – 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 to make their own decisions, 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**.

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 for community 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

Carer's Allowance

The main welfare benefit specifically for carers is called Carer's Allowance. It's worth £66.15 a week 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 £123 a week (after tax and expenses).

If your State Pension is more than £66.15 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, if you meet all the criteria you will be awarded an 'underlying entitlement' to Carer's Allowance. The good news is that 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 38).

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. Before making your claim, talk to your local Age UK to find out what your best option would be.

Carer's Credit

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

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 (see page 45). In Northern Ireland, contact the Disability and Carers Service (see page 47).

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 (see page 47). Carers UK produces a guide called **Looking after someone: Information and support for carers** (see page 45).

Council Tax Support for carers

Help if you have a low income



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 are national schemes for Council Tax Reduction in Wales.

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.

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 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, 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 similar factsheets. 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.

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 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** – paid if the person you look after has difficulty with daily activities like eating, washing or dressing.
- **Mobility** – paid 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, call the Department for Work and Pensions (DWP) (see page 47). 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 10 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.

“I'm now getting benefits I didn't know I could claim. I couldn't believe I'd been missing out!”
Daphne, 62



Next steps



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.

Your local Age UK or Citizens Advice (see pages 44 and 46) may be able to help you fill in the form. See our factsheet **Personal Independence Payment and Disability Living Allowance** to find out more.

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. See our guide **Attendance Allowance** to learn more.

How do they claim?

Most claims for AA are decided solely on what you say in the claim form, so don't underplay their needs. 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. What happens if they don't receive the help they need? Give examples if this has happened in the past.

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

You can apply online for AA on the GOV.UK website or get a claim form by calling the Attendance Allowance helpline (see page 44).

Next steps



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

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; putting on skin cream; 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; 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 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, you still have options.

- Get in touch with Age UK and we can 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. Have you missed any out?
- Remember that your needs may change and increase so, even if you're not eligible for PIP or AA right now, you may be able to claim successfully in the future.

“Age UK were really helpful when my application got turned down. They helped me work 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

Helpful technology

Caring can be tiring, physically and emotionally – but there are tools available that could help take some of the strain and give you both extra peace of mind. In particular, two kinds of technology could help the person you're caring for stay safe and independent at home:

Telecare

Community alarms are a well-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 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



Contact the Disabled Living Foundation to find out more about telecare and telehealth products (see page 47), or ask your doctor. Our guides **Adapting your home** and **At home with dementia** also have more information on telecare, or visit www.ageuk.org.uk/telecare.

Contact your council or search www.gov.uk/apply-for-community-alarm.

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 struggling – 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: you may find yourself travelling 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 eligible for (see pages 15-17)?
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. They may be entitled to care at home, which will 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 handyman 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 (see page 44) or Online Centres Network (see page 48) to find out about courses on using computers and the internet.

8. Have you both considered other options – perhaps retirement housing, moving to a care home, or them moving closer to you or perhaps even moving in with you?

9. In England and Wales, if the person you care for is likely to lose their capacity to make decisions, why not talk to them about setting up a Lasting Power of Attorney to let you make decisions on their behalf?



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 seems 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, read our guide **Housing options**.

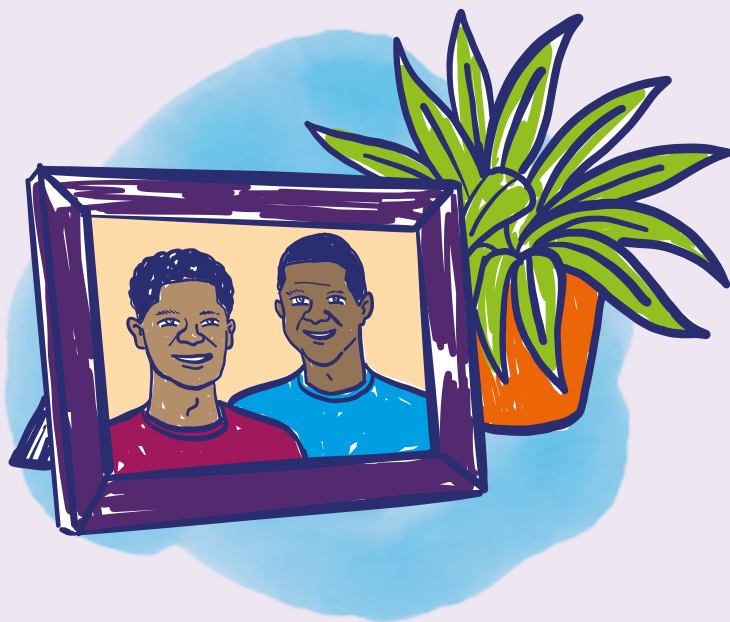
Jane's story

Jane works full-time and cares for her mum.

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.”

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 they are providing the service, or the NHS if they've arranged it. You can also contact the Care Quality Commission, but they don't investigate individuals case (see page 45).



In Wales, contact the Care and Social Services Inspectorate Wales about social care services (see page 44), or the Healthcare Inspectorate Wales with regards to health services (see page 47).

In Northern Ireland, contact the Regulation and Quality Improvement Authority (see page 48).



“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



Preventing abuse

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

If you care for someone who lacks mental capacity, you should act in their best interests.

Local councils must investigate concerns of abuse and neglect so raise any concerns with them. If you think a crime has been committed, contact the police.

Abuse 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’. Contact Action on Elder Abuse for help (see page 44).

Looking after yourself

Caring and work

Caring for someone is tiring and often unpredictable. If you're also trying to keep down a job, it may seem like there simply aren't enough hours in the day.

Finding the right balance can be a challenge, but help is available. There are lots of adjustments you can make to ensure that you find time to keep 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 a good idea to have a clear idea about this if you need to have this conversation with your employer. Common types of flexible working include part-time, 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 – and carers are no different. 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. Don't worry if they do say no – you can make a new request each 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 (see 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 are likely to 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. Self-care is a vital part of being a carer.



Make 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 in near you (see 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. 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, let your family and friends know. Finding an online forum or joining a carers' support group may also help. You can ask your doctor about local groups.

"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."

Ian, 47



Next steps



Our information guide **Healthy living** has 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 (see page 45).



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 to 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 be incredibly challenging 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, or saying you don't care. 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 has a responsibility to arrange services to help you. 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 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 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 9-10), while in others it's provided through a needs assessment for the person you look after (see page 12). So, it's best to make sure you are both assessed. In Northern Ireland, only respite in a residential care setting is means-tested.

Personal budget

You may also be entitled to a personal budget to cover any support needs identified in your assessment (see pages 9-10). You can take this as a direct payment 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 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 community 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 (see 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 (see page 45) or an independent advice agency such as Age UK, Carers UK or Citizens Advice (see pages 44-46).

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 which 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 45 and 47 for contact details. 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.

Whatever your situation, there is no shame in asking for help. Be kind to yourself. Finding more support will make you a better carer.

Get more support

If the person you look after starts to need more support than you're able to give, they can ask their local social services department to reassess their needs. If their condition has changed, 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 9-11).

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 guide **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. That's something which will never change. 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 cared for has moved into 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. 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 9-10) and have the right to ask for flexible working (see page 32).

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 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 when this happens. 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 46). They are experts at helping people just like you at this difficult and confusing time.



You may also 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 choose to 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.



Specialist organisations such as Cruse Bereavement Care (see page 46) can offer counselling, advice and practical help, and put you in touch with local bereavement groups.

Whatever you do, remember you don't have to cope with your loss alone. There is help available for you from people who understand what you're going through.

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

Next steps



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 both 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
- **029 2009 0087** 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 their telephone listening service. They can offer practical advice on filling in forms and can carry out benefits checks.

Call them on: **0808 808 7777**

For contact details of other useful organisations, see pages 44-48.

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

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

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: **0800 731 0122**

Textphone: **0800 731 0317**

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 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: **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 9600**

www.carers.org

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 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**.

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**

Crossroads Caring for Carers

Offers respite care to carers in Northern Ireland.

Tel: **028 9181 4455**

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/northern-ireland**

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: **0800 587 0912**

Textphone: **0800 012 1574**

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](http://www.nidirect.gov.uk)**

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 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

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 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.

Your details

AGUK0081 MXAQ-19CA05-C009

Title: Forename: Surname:

Home address:

Postcode:

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

☐ **I do not wish** to receive communications by post.

You can change your mind at any time by phoning **0800 169 87 87**

or writing to Supporter Services at the registered address below.

For further details on how your data is used and stored:

www.ageuk.org.uk/help/privacy-policy

Your gift

I would like to make a gift of £:

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

Card payment I wish to pay by (please tick):

☐ MasterCard ☐ Visa ☐ CAF CharityCard ☐ Maestro

Card number Expiry date

Signature

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. Today's date * Age Cymru, Age Scotland and Age NI. **Please ensure you provide your full name and address**, and let us know if you wish to cancel your declaration, or if your tax status, name or address changes.

[†] 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.**

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:

1

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/publications/readers-panel.

2

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.uk/donate.

3

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.

4

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.

5

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 other relevant guides, such as:

- **Caring for someone with dementia**
- **Your hospital stay**
- **Housing options**

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 will also be able to help answer any questions you have about anything you've read.

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



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