

The information in this pack will help to guide you to the information, support and advice available in Newcastle. If you live in another area, please contact the Carers Trust (www.carers.org) or one of the regional contacts below.

Newcastle Carers:	0191 275 5060 info@newcastlecarers.org.uk
Gateshead Carers Centre:	0191 490 0121 enquiries@gatesheadcarers.com
Carers Northumberland:	01670 320025 info@carersnorthumberland.org.uk
North Tyneside Carers' Centre:	0191 643 2298 enquiries@ntcarers.co.uk
Carers Direct Helpline:	0300 123 1053 Text phone user prefix with 18001 or download the Relay UK App to use text relay on other electronic devices.

Carers Assessment

If you have a need for support in relation to your caring role, you are entitled to a Carers Assessment from your local Council. If you live in Newcastle, you can request a Carers Assessment by contacting Community Health and Social Care Direct: **0191 278 8377**, SMS: **0191 278 8359**

Emergency Contact Scheme

This scheme is run by the British Red Cross. It helps carers think ahead and make an emergency contact plan for what would happen if they cannot be there to give care because of an emergency. If you would like more information, call the British Red Cross on **0191 273 7961** or email Carerscard_NorthEast@redcross.org

School Nursing and Health Visiting Service

The 0-19 years School Nursing and Health Visiting Service can provide support to young carers around their health needs. For further information, please contact the 0-19 years service on **0191 282 3319**.

District Nursing Service

If you have a District Nurse, they can signpost you to other support services in the community, including respite care.



Do you look after someone?



Carers and Young Carers are Welcome Here

Information produced by NUTH in collaboration with Newcastle Carers Newcastle City Council



A carer/young carer is someone who provides unpaid care and support to a family member, friend, partner or neighbour who has a disability, has an illness, is frail, has mental health difficulties or has alcohol or drug related problems. This includes people who receive Carers Allowance.

You may not see yourself as a carer/young carer, but if the description above applies to you, you probably are one.

The care we provide in hospital and in the community is a partnership between patients, carers, families and the healthcare staff. We are committed to working with you, as a Carer/Young Carer to meet the needs of the patient. We will:

- Talk to you about the person you care for, the care you provide and whether you and the patient would like to continue this care whilst they are in hospital
- Help you to care for the person in hospital, if you wish, by being flexible about visiting times
- Share information about care and treatment with the consent of the person you care for, to help you in your caring role
- Act in the best interest of the person you care for if they are unable to discuss their care or give consent
- Discuss and agree arrangements for admission/discharge with you in a timely manner.

If you have any questions we will be happy to talk to you.

If the person you care for has dementia, whilst they are in hospital, the **Dementia Nurse Specialist Team** can help you by providing information, support and guidance. If you would like to speak to a member of the team, call on **0191 213 9605** or email **nuth.dementiacareteam@nhs.net**.


The Newcastle upon Tyne Hospitals
NHS Foundation Trust

I am a carer

I am the carer for.....

This card enables flexible visiting as agreed with the Nurse-in-Charge



Healthcare at its best
with people at our heart

Do you look after someone?

Support and services for **Carers** in Newcastle

If you provide unpaid care and support to a family member, friend, partner or neighbour who has a disability, an illness, is frail, has mental health problems, alcohol or drug related problems, then this information is for **you**.



Local information, help and support

Newcastle Carers are a local, independent charity who work with us to support adults, children and young people caring for someone living in Newcastle upon Tyne.

Their free, confidential and impartial service provides dedicated support and information to carers of all ages.

They offer a range of services to suit adult carers needs including one to one information and support, groups and training and, for young carers, individual and group support and advice for their families.

More information about their services can be found on their website www.newcastlecarers.org.uk

Their Carers Information Line is open Monday to Friday, 9am to 5pm

Telephone: **0191 275 5060**

SMS: **0787 410 0043**

Email: info@newcastlecarers.org.uk

Website: www.newcastlecarers.org.uk

You can drop in to see a worker Monday to Friday between 1pm and 5pm at their office 135-139 Shields Road, Byker, Newcastle upon Tyne NE6 1DN. No appointment is needed.

Newcastle Carers work in other locations across the city.

Out of hours appointments are available on request.

Planning for emergencies

We work in partnership with the British Red Cross to provide the **Carers Emergency Contact Scheme**. This offers free emergency support to an adult whose carer suddenly becomes unable to offer them care in the usual way.

The scheme supports carers to draw up an emergency contact plan and provides a rapid response service 24 hours a day, 7 days a week including Bank Holidays.

The scheme also offers additional planned support to allow carers to attend personal appointments by accessing other Red Cross support at home activities including services or equipment.

For more information or to register for a card,

Tel: **0191 273 7961**

Email: **Carerscard_Northeast@redcross.org.uk**

Carers Assessment

We will always offer information and advice to support you in your caring role but recognise that this is not always enough to meet your needs. In this case, a carers assessment from the council may help.

A Carers Assessment offers you the opportunity to explain what your caring role is, what impact caring for someone is having on you and whether you are willing and able to carry on caring. It focuses on your needs and covers a number of areas such as your own health and wellbeing, looking after others, having time to yourself and the things you want to achieve on a day to day basis.

A Carers Assessment is usually carried out by a social worker.

Most carer's needs are assessed jointly with the adult they provide care and support to because that helps us to understand the whole situation and identify ways in which we can support both of you. However, you can ask for a separate assessment, even if the person you provide care to does not want or has not had an assessment from us.

**For more information contact
Community Health and Social Care
Direct on 0191 278 8377**



Useful Information

Newcastle City Council Services

Care and support for adults

Community Health and Social Care Direct (CHSCD) staff can talk to you and answer any questions you may have about adult social care in Newcastle. They can give you information and advice, advise you on local services, or may refer you for further assessment.

Opening times: Monday to Friday 8am to 5pm

Email: scd@newcastle.gov.uk

Phone: 0191 278 83 77

Textphone: 0191 278 83 59

Children

Initial Response Service (IRS) are the first point of contact for anyone worried about a child's safety or welfare. They work with families to identify support needed and who can help. They have a legal duty to safeguard children and will be the first to respond to any concerns.

Opening times: Monday to Friday 8am to 5pm

Email: IRSADMIN@newcastle.gov.uk

Telephone: 0191 277 2500

For adult or children's social work emergencies outside office hours, you should phone the Emergency Duty Team on **0191 278 78 78**

Benefits

The Welfare Rights service support carers in Newcastle with their benefits.

Opening times: Monday to Friday 9:30am to 12pm

Telephone: 0191 277 2627

Debt

Money Matters offer debt and budgeting advice to people who live in Newcastle.

Opening times: Monday to Friday between 8.30am and 4.30pm

Telephone: 0191 277 1050

Website: <https://www.newcastle.gov.uk/benefits-and-council-tax/welfarerightsand-money-advice/debt-and-money-advice>

Your Equipment Newcastle

If you or the person you're caring for are having problems carrying out day to day activities, Your Equipment Newcastle can help you to find and buy equipment to make daily living easier.

Visit: www.YourEquipmentNewcastle.org.uk

InformationNOW

Newcastle's information website where you can find local services, support and events.

Visit: www.informationnow.org.uk

Support for carers of people with drug and alcohol problems

PROPS North East supports families and friends affected by a loved one's drug or alcohol misuse across Newcastle and North Tyneside.

PROPS offer:

- one to one support
- peer support groups
- training around substance misuse and family training
- respite breaks
- an emergency out of hours telephone helpline.

Telephone: 0191 226 3440

Email: office@newcastleprops.org.uk

Telephone helplines

Carers UK is a national charity who give advice, information and support to carers. They connect carers so no-one has to care alone and campaign for and on behalf of carers.

Opening times: Monday and Tuesday, 10am to 4pm

Telephone helpline: 0808 808 777

Website: www.carersuk.org

Carers Direct (NHS) can give information and advice on your caring role. You can talk to them about what options are available to you.

Opening times: Helpline and webchat open Monday to Friday, 9am to 8pm and weekends, 11am to 4pm.

Telephone: 0300 123 1053

Website: <https://www.nhs.uk/conditions/social-care-and-supportguide/help-from-social-services-and-charities/helplines-andforums/>

GOV.UK

The best place to find government services and information, including lots of useful information for carers.

<https://www.gov.uk/browse/disabilities/carers>

As far as we know, the information in this booklet is accurate at the time of going to press. First edition, published February 2019.

Newcastle
City Council 

PALS



North of Tyne
Patient Advice and Liaison Service (PALS)

Freephone:

0800 0320202

The Patient Advice and Liaison Service

**Do you have questions or need
advice about NHS services?**

We're here to help with:

- **information**
- **advice and support**
- **help to sort out problems**

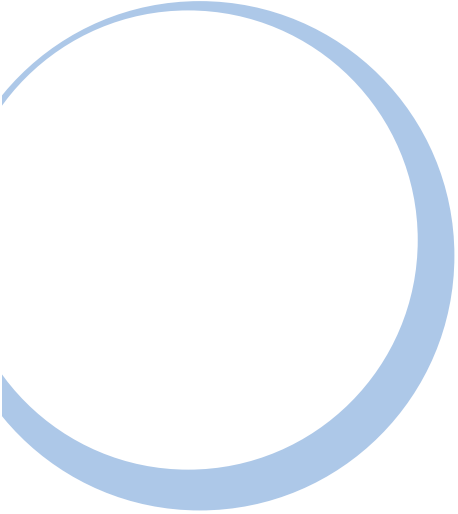
North of Tyne PALS for all NHS services in Newcastle, North Tyneside,
Northumberland and the North East Ambulance Service

PALS is a free, confidential NHS service for patients, their relatives and carers of all ages.

PALS will:

- help you to find answers to your questions about:
 - services
 - appointments
 - information about what will happen during appointments and treatment
 - where to get more information
 - who to talk to and where to get help
 - when you need an interpreter
 - coming out of hospital
 - information and support when someone dies
- help to sort out any problems quickly and informally
- help guide you through the different services available from the NHS including:
 - hospitals
 - doctors
 - dentists
 - ambulance
 - chemists
 - opticians
 - clinics

- pass on your compliments and suggestions
- provide you with information about social care services
- refer you to local and national support and advice agencies
- explain how you can make a complaint
- help you to improve your experience of NHS services



We act independently and can liaise with staff, managers and other organisations to find answers to your questions.

Your comments and questions will help to make changes and improve services for the future.



To contact PALS

Telephone:



0800 032 02 02

9.00-4.30 Monday to Friday – answer-phone at all other times

Write to:



FREEPOST PALS

Email:



northoftynepals@nhct.nhs.uk

Text:



07815 500015

This information is available in another format or language on request. Please contact PALS, details as above.

Reviewed February 2020

What others have said

"I felt safe coming home with someone. It was nice to have someone do my shopping and check things at home."

"It was a service that I didn't know I needed - but I was glad when you arrived on my doorstep."

"It was good to have some help as I could not have managed with the shopping myself."

Contact Us

📞 07534 043 578

🌐 bit.ly/hfhreferral

✉️ matthew.brindley@volunteeringmatters.org.uk



Newcastle

Home from Hospital

AND COMMUNITY SUPPORT

We are here to help you get back home safely, and stay there.



Our support is ideal for you if you are:

- 55+ years old
- a resident of Newcastle upon Tyne
- soon to be discharged from hospital, or recently returned home

Ways we can support you:



Shopping on your behalf



Collecting medicine, pensions or gas/electric meters



Links to community befriending services



Making sure your home is safe and comfortable



Supporting you to fill in forms, make phone calls or pay bills



Helping you to find empowering local community support



Arranging cleaning or other urgent home repairs



Carers Emergency Contact Scheme Newcastle



Do you look after someone who couldn't manage without your help and support?

Do they live in Newcastle?

Do you have an emergency plan?

What is the Carers Emergency Contact Scheme?

The Carers Emergency Contact Scheme is for adults, caring for adults.

It's

- Funded by Newcastle City Council
- A FREE service that means the person you care for can be looked after quickly if you have a personal crisis
- 24 hours a day, 7 days a week, including Bank Holidays

How does it work?

When you register, we help you to write your emergency contact plan. This means we know what support the person you care for needs. Your plan is stored safely so it's available in an emergency.

You are given a Carers Emergency Contact Scheme card to carry with you so that other people, including the emergency services know you are a carer and someone relies on you. In an emergency, your plan can be put into action.

What is a carers emergency?

A carers emergency is a personal crisis that stops you from being able to look after the person you care for. Such as, an illness, accident or emergency.

Why should I register?

This scheme makes sure that your plan is written down, kept safe and available in an emergency.

Even if you already have an emergency plan with a friend, relative or neighbour, it's a good idea to register with the Carers Emergency Card Scheme.

How do I register?

Contact: Sarah Wood, the Service Coordinator

Telephone: 0191 273 7961

Email: Carerscard_Northeast@redcross.org.uk

[Online registration form Carers Emergency Card Plan](#)

The British Red Cross Society, incorporated by Royal Charter 1908, is a charity registered in England and Wales (220949), Scotland SC037738), Isle of Man (0752) and Jersey (430).

You are not alone

props

FAMILY RECOVERY SERVICE

A specialist service
for people whose lives are
affected by someone else's
alcohol or drug use

Contact us today
0191 226 3440 or 07791246049
www.props.org.uk

Our Services



1-2-1 Support

Face to face, online or via telephone.



Group Support

Face to face & online.



Young Person Project

A specialist service for young people living in Newcastle aged 11yrs to 18yrs.



Training

We can offer a range of health, education and training packages.



Helpline

Telephone 9am-9pm, 7 days week.



Volunteering Help

Your time makes the difference.

The Linskill Centre,
Linskill Terrace,
North Shields,
Tyne & Wear,
NE30 2AY

Fenham Library &
Community Hub,
Fenham Hall Drive,
Newcastle Upon Tyne,
NE4 9XD

Registered Charity No.
1146582
0191 226 3440
<https://props.org.uk/>



Looking after someone

Information and support for carers in **England**



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About this guide

Every day 6,000 people in the UK become carers, looking after family or friends who are older, disabled or seriously ill.

COVID-19 support

For the latest updates, please see our **A-Z of changes to benefits, assessments and support – COVID-19**.

You can find our guidance at:
carersuk.org/coronavirus



At times, caring can bring many positives and rewards. There's nothing more natural and human than helping our loved ones get the most out of life.

There's also nothing more difficult than focusing on someone else's needs without neglecting our own. Whether we're caring around the clock or balancing caring with work and family life, it can be exhausting.

The 'system' can be bewildering. The emotions can be shattering.

This guide is designed to outline your rights as a carer and the support available to you.

We have produced separate versions of this guide for carers living in Scotland, Wales and Northern Ireland because there are some differences in legislation, health and social care.

However caring affects you, we're here.



This icon means there is a Carers UK factsheet available to download for free from our website or you can purchase a copy from our online shop: shopcarersuk.org

Call 020 7378 4999 for more details.

A carer's guide

Looking after someone can be tough. Here are 10 of the key challenges that caring can throw your way...

1 Getting the right advice and information... quickly!



Caring can be extremely complicated, whether we're grappling with the benefits system or considering how to pay for care. Each strand is confusing but when all the strands are tangled, it can feel bewildering. Turning to an expert can help to unravel the most complex situation.

"I was on the verge of a breakdown, and my family life was almost in crisis. I contacted the Carers UK Helpline and you gave me vital information that empowered me to challenge and win my case with my council."

2 Coping with feelings of guilt

When we're looking after someone, it's important to accept that guilt is normal and that we only feel it because we care. Being able to talk to people who understand what we're going through and how we feel can help us handle our feelings of guilt better.

"After the diagnosis, I was consumed with the thought that I could have done more. Why didn't I recognise the signs? I now accept that what has happened isn't anyone's fault.

So now I don't say I feel guilty, I say I feel sad – an easier emotion to cope with."



3 Being assertive with professionals

Looking after someone will often involve dealing with several different professionals. When we feel a professional has not explained things clearly, does not see the whole picture or perhaps is not doing what they should do, it can be hard to speak up. However, that is exactly what we need to do. And this starts with valuing ourselves and our caring role.



"The doctors discussed his condition with me and agreed that we should implement a care plan to give Dad a dignified and pain-free death. They asked if I wanted to talk to Dad about it, and I did."

4

Handling difficult conversations

Even a tricky conversation with professionals can be a breeze compared to having to deal with family and friends. We may have to ask a sibling to be more supportive, remind a friend that we still exist or talk gently to a parent who doesn't accept that they can't live independently any longer. This takes courage, bags of patience and tact. Talking it through with people outside the situation can make a world of difference.

"We put off talking about mental capacity with my grandmother. Having these difficult conversations early is far preferable to leaving it too late and having other people make decisions about the future."



6

5

Looking after our own health and wellbeing

As carers, we may have immediate needs such as taking breaks, getting sleep, eating properly or exercising. We may have longer-term needs such as building fulfilling relationships, pursuing hobbies or developing careers. Caring always involves an element of putting our own needs aside. However it's important that we look after ourselves too, so we can keep going as carers, and because we are individuals whose needs are just as valid as those of our loved ones.



"I never took a break – I look back now and wish I had been stronger to let others help care for Mum. After years of hardly any sleep and no break, I seem to be constantly poorly and my immune system is at a low."

6 Noticing when we're too stressed

Stress can alert us to potential dangers and spur us on to achieve a goal.

However, sometimes the balance tips too far and the pressure becomes so intense or persistent that we feel unable to cope.

As soon as we notice it getting too much, it's helpful to talk about how we feel rather than hoping the stress will go away.

“Sometimes stress and tiredness take their toll. One night we had a fight about nothing. At the time I didn't know what to do or where I could go for help. That's how it feels when we're under stress.”



7 Making difficult decisions

There will be points when we are faced with a particularly emotional or difficult decision.

Sometimes it's a decision we have planned for, or at least held at the back of our minds. Sometimes it's completely unexpected and leaves us feeling out of control. Where we can, thinking about decisions in advance can help us keep a cool head when it comes to the crunch.

“It's better to be prepared and to do some research about different options, even if you're not sure what route you'll go down. I couldn't have selected the right care home whilst mum was in hospital, in the middle of that stressful time.”



8

Keeping relationships fulfilling



“I was suddenly juggling hospital visits, a full-time job and trying not to scream. I remember feeling I had lost all control over my life: that stroke had happened not just to Peter, but to both of us.”

Caring for our loved ones can express the best of who we are, and can take a relationship to a profound new level. It can also push us to the brink through financial, emotional and practical strain. Illness can cast aside the best-laid plans and make relationships feel utterly different. What matters most is that there’s a way for us to talk honestly and find help when we need it.

8

9

Adapting to changing circumstances

Whether we’re looking after someone who’s recovering or whose condition is deteriorating over time, caring inevitably involves adapting to circumstances.

Sometimes it’s easy to focus on the practical details – the administration of care workers or move to the care home. Being able to stay attentive to our relationship with the person we’re caring for in the midst of all that change is far from easy.

“There were times when it seemed that Dad was at death’s door. But a couple of days later he was sitting up in bed, bright as a button. That really made the emotions difficult, constantly living on the edge.”



10 Keeping a sense of humour

Nothing relieves stress and tension better than a good laugh.

Sometimes caring can feel a bit like starring in our own sitcom, and there's no shortage of comedy material. Other times we may need a bit of help finding something to laugh about. Either way, sharing experiences with other carers is often great not just for feeling listened to and understood but for finding the humour that can keep us going.

“Dementia is no laughing matter, but humour is my way of coping.


I treat most of Dad's outbursts as comedy gold for the book or the sitcom I'll never get round to writing!”

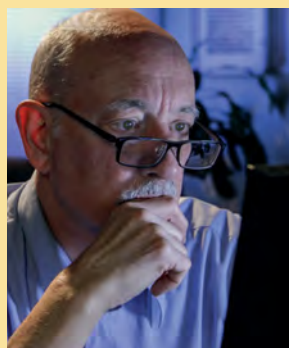


Join Carers UK for support, understanding and lasting change

However caring affects you and your family, we're here for you. By joining Carers UK, you can be part of a supportive community and a movement for change.

It's free to join us. Just visit carersuk.org/join or call 020 7378 4997.

 @carersuk  /carersuk



Getting help and support



Where to start

Caring can be hard work – physically and emotionally. It's important to find out about the different ways you can get help and support with caring.

One way to get help and support is through an assessment by the local authority social services department. Both you and the person you care for can get assessments. This may result in help and support being provided to you as a carer and/or to the person you are looking after. For further information see pages 13-14.

You could decide to buy in additional help and support for the person you are looking after. One option would be to employ an individual or use a care provider such as a care agency.

If you are looking for care providers you could:

- ask the local authority if they have a list of approved care providers
- search on the Care Quality Commission website:
cqc.org.uk

- search on the Which? Later Life Care services directory:
which.co.uk/later-life-care/care-services-directory

You could also find out about equipment and technology that could help. Even minor aids and adjustments could make the home safer and help someone you care for to feel more independent – see page 21.

Caring inevitably means adapting to changing circumstances, so it's important to think about the future. You may need to look into different ways of managing someone's affairs, either now or for the future – see page 16.

You could find out what support is available locally. For example, there may be a carers' organisation offering services nearby. To find out what's available in your area, use our directory:
carersuk.org/localsupport

Upfront is a free online tool that can help you get straight to the information you need.

Visit carersuk.org/upfront to give it a go!

Upfront



Online meetups for carers

Care for a Cuppa

Our Care for a Cuppa online chats offer the opportunity for carers to take a little break and spend some time talking to people who understand what you're going through.

Care for a Cuppa takes place online every week through Zoom. Visit carersuk.org/cuppa

Share and Learn

We're running a series of fun and relaxed online sessions for carers where visiting speakers share tips and skills on a range of topics.

From yoga to singing, and first aid to photography, there's something for everyone.

Find out more at carersuk.org/share-and-learn



Carer's assessment

If you are a carer and have a need for support, you should be offered a carer's assessment by the local authority of the person you are looking after.

If you are not offered a carer's assessment, you should contact the local authority and ask for one. You can have an assessment no matter what your level of need, the amount of care you provide or your financial means. Your carer's assessment should cover:

- your caring role and how it affects your life and wellbeing
- your feelings and choices about caring
- your health
- work, study, training, leisure
- relationships, social activities and your goals
- housing
- planning for emergencies (such as carer emergency card schemes).

Following the assessment, the local authority will decide if you are eligible for support. This can be provided either to you, or to the person you are looking after to reduce the impact of caring on you.

Support could be provided by the local authority, or in the form of a direct payment.

Some examples of the kind of support you could get include: driving lessons, taxi fares, a laptop, help with housework or gardening or a gym membership.

Whether the local authority will pay for any support will depend on your financial situation (if the local authority is one that does charge for carer support – not all do), or the financial situation of the person you are looking after (if services are provided to them).

Even if you are not considered to be eligible for support, the local authority must provide you with information and advice on local services to prevent your needs from escalating.



Read more at:
carersuk.org/carersassessment

For COVID-19 related updates, see our A-Z of changes here:
carersuk.org/covid-19-a-z

Note: Carers' assessments are for adults (18+) caring for adults (18+)

If you are looking after a child under 18 or are a carer who is under 18 visit carersuk.org/assessments-under-18 to find out more.

Assessment for the person you care for

If the person you are looking after is an adult and appears to have a need for support, they should be offered a needs assessment by their local authority.

The person you are looking after can have an assessment no matter what their level of need or their financial means. If they are not offered a needs assessment, they (or you) should contact the local authority and ask for one.

The assessment will look at their physical, mental and emotional needs. You can be involved in the assessment as their carer (with their consent).

Following the assessment, the local authority will decide whether the person you are looking after is eligible for support. Support could be provided by the local authority, or in the form of a direct payment.

Some examples of the kind of support the person you are looking after could get include: changes to their home to make it more suitable, a care worker, a place at a day centre or a temporary stay in residential care.

Whether the local authority will pay for any support provided will depend on the financial situation of the person you are looking after. The exception is if the support is of a type that must be provided free of charge, such as aids or minor adaptations (which means adaptations up to the value of £1,000).

Even if the person you are looking after is not considered to be eligible for support, the local authority must still provide information and advice.



Find out more at carersuk.org/needs-assessment

For COVID-19 guidance, see: carersuk.org/covid-19-a-z

Note: Needs assessments are for adults (18+)

If you are looking after a child under 18 who is a 'child in need', they can have a Children Act assessment from the local authority. A Children Act assessment will consider all the help that your child needs, the needs of any other children in the family and the help that you may need to care for the child.

Visit carersuk.org/assessments-under-18 for more detailed guidance.

Coming out of hospital

Deciding to care, or continue caring, for someone who is coming out of hospital can be very difficult. For COVID-19 related updates, see carersuk.org/covid-19-a-z


It is important to remember that it is your choice whether or not to take on a caring role.

Before the person you are looking after comes home from hospital, a discharge assessment should be carried out to see whether they need any support once they are discharged.

This discharge assessment should look at whether the person you are looking after is eligible for: any intermediate or reablement care, NHS continuing healthcare or NHS-funded nursing care, other NHS services and/or community care services from the local authority.

You should also be offered a carer's assessment to see whether you, as a carer, need support once the person you are looking after is discharged.

If you are not offered a carer's assessment, you could contact the local authority of the person you are looking after and ask for one.

 Find out more at carersuk.org/hospital

Our self-advocacy guide also offers tips on working with professionals. See carersuk.org/self-advocacy



The Care Quality Commission (CQC) regulates health and care services in England. This is to ensure that they are providing people with safe, effective, compassionate and high-quality care, as required by law.

By hearing about your recent experience of care, the CQC can help make care better for everyone – this is particularly important given the impact COVID-19 has had on services carers rely on.

If you have a recent experience – good or bad – please share it with them by visiting: cqc.org.uk/give-feedback-on-care



Managing someone's affairs

You may want to help manage the affairs of the person you are looking after, or you may want to know how to plan for doing this in the future.

There are different ways of managing someone's affairs. Much depends on whether the person you are looking after can currently make decisions for themselves (which is called having mental capacity) or whether they are unable to make decisions for themselves (which is called lacking mental capacity).

If the person you are looking after has mental capacity but wants some help with managing their bank or building society account, they could make a **third party mandate**. This gives a specific person, such as you as their carer, authority to manage their account.

If the person you are looking after can make decisions for themselves at the moment but wants to appoint a specific person, such as you as their carer, to make certain decisions on their behalf, should the need arise in the future, they could make a **lasting power of attorney** while they are still able to do so. The person you are looking after can only make a lasting power of attorney while they have mental capacity.

There are two main types:

Power of attorney for property and financial affairs – bank accounts, paying bills, collecting benefits/pensions and selling a home for example. It can be used before the person is unable to make their own decisions, if they so wish.

Power of attorney for health and welfare. It can only be used when the person is unable to make their own decisions.



Find out more at carersuk.org/managing-someones-affairs

MyBackUp

Our new contingency planning tool could help you prepare for the unexpected. Go to: carersdigital.org/mybackup



Taking a break

Caring for someone can be a full-time job so breaks are vital for your own wellbeing and quality of life.

With the added demands of caring during the COVID-19 pandemic, you may feel particularly run down and in need of a break, especially if the respite services you formerly used are no longer operating as before.

Think about the kind of break that you need and what kind of alternative care the person you are looking after needs.

There are different options for getting alternative care (often called respite care) for the person you are looking after whilst you take a break:

- getting help from the local authority social services department via assessments (see pages 13–14)

- arranging care yourself (see page 11)
- support from friends or family
- some organisations provide break services for carers or for the person being looked after (or both).

If you want to go on holiday, either alone or with the person you are looking after, there may be some help you could get towards the cost. You could see if there are any local grants or schemes to help carers with the cost of a holiday and you could have a look through the list of organisations in our Taking a break factsheet.



Find out more at carersuk.org/break-factsheet

“Catch up on sleep and give yourself time to think. There is no right way to use your time, just be gentle on yourself.”

“It took years before I was able to consider respite for my daughter. Years on, I now know I need that complete break each year. I come back recharged and more able to cope.”

Jocelyn's story

Jocelyn has been caring for her daughter, Amy, and her husband, Darran, for over 30 years. They believe breaks are essential.

“ When my daughter was four, she was diagnosed with a rare genetic condition called Trichothiodystrophy. This means that she has complex needs both physically and mentally. Several years later, my husband had an accident whilst working at the steelworks which resulted in him losing an arm and leg. This was life-changing for everyone. When I look back, I just think how did we get through that? Caring is not something you plan for. Truthfully, it was tough.

Having a break away allows you to be yourself for a while and enjoy the simple pleasures in life others can take for granted, such as going for a coffee or going to the cinema. It allows you to be free. You always feel lifted afterwards and it's important to just let go.

My idea of a break is to find a quiet place where I can be on my own for a couple of hours. It might involve taking the dogs for a walk or losing myself in a book. I like to visit art galleries and maintain hobbies I had before Amy's diagnosis and



Darran's accident, such as painting and drawing. I think it's important to retain some kind of identity because you can get lost in your caring role.

It's important to take time to recharge your body and mind. If you try to give without looking after yourself, you can run on empty. I've done that in the past and became very ill.

I got to a crisis-point where I was struggling and so I contacted Carers Wales – Beth's guidance made all the difference. It paid off as I was able to have a carer's assessment which helped me tremendously. Despite her limitations, Amy's enjoying her life to the full thanks to the direct payments we've received, which makes me happy.

My advice is don't be afraid, and really try to think of it as an investment for your own mental welfare. You have rights, and you can ask for help, and how to go about getting that help.

”



See carersuk.org/break-factsheet for more information.
Or watch our film series: carersuk.org/breaks

Jennie's story

Jennie cares for her three children who have complex needs. As an Enteral Nurse Specialist, she also looks after adults and children who are tube fed and provides training for their families.

Inspiringly, she's also a parent ambassador for Wellchild and runs a local rainbow unit.

“ I'm a carer for three children. We face challenges every day which has only been made harder by the COVID-19 situation.

We have Jack who's 18 and has ADHD and Tourette's. He was also tube fed for 15 years.

My daughter, Olivia, is 16. She has Narcolepsy and Cataplexy and collapses 30+ times a day. This means that she can't go out alone. She is currently tube fed and needs full support with this.

Finley, our 10 year old, has autism and gut dysmotility so has a jejunostomy tube connected to a pump 21 hours a day and a drainage bag from a gastrostomy tube to keep his tummy empty.

These are not designed for an active child who has no fear. His pump has been in the sea; it's been on a lake when he fell out of a canoe; it's been down the stairs. He has gone down a slide and left his whole tube at the top and pulled it right out. If you turn your back, he is causing problems somewhere.



This isn't just daytime care we provide for them all. At night, we have pumps alarming or sleep paralysis to deal with. As you can imagine, we are always chasing hospital appointments or prescriptions, trying to get assessments for equipment and then playing 'Jenga' trying to fit it all in the car or house.

It's a full-time job some days, and this is then on top of our full-time jobs. I try to book time out for appointments when I need to but I do struggle sometimes; I'm sometimes tired and emotional and don't get as much sleep as I should do. Our health always seems to take a back seat to the children which I think will become a problem in years to come.

I've been lucky enough to work for Nutricia who have been supportive of my role as a carer. I have had to be off work at a moment's notice when one of my children has been admitted to hospital and my team has always stepped up and covered my visits.

An important tip I have as a carer is to find your people: people in similar situations to you. Carers UK, WellChild, and Swan UK all have parents who get it and have helped me a lot.

The biggest frustration is that professionals often assume that everyone gets Carer's Allowance for caring. They also assume we get respite. It's a surprise to learn that everything is a fight. Every other carer in the same boat as us is a hero.



Carers UK is working in partnership with Nutricia to help improve understanding about nutrition and care.



Nutricia specialises in the delivery of medical nutrition for the very young, the old and the sick. They supply high quality feeds, systems and support services to patients and healthcare professionals.

Mike's story

“ In 2012, I discovered Carers UK after being a carer for my father for more than five years. It was during this time that I was looking for organisations I could volunteer for to use my experience.

I am forever grateful to Carers UK for involving me. Being a voice for carers since then, I have never looked back because there are so many unidentified carers out there who are desperately seeking guidance and practical help. The thought of many unfound carers who are missing out on support simply because they don't consider themselves as carers, fills me up with the dedication, passion and drive to reach out, especially to those belonging to BAME and other marginalised and silent groups, such as the very young or



elderly carers, as well as working 'sandwich' carers.

I have been involved as a user representative and a voice of carers with CCG, NHS Trusts, local authority, GP practices, CQC, GM Cancer, GM Mental Health and other platforms events.



Interested in volunteering?

Contact volunteering@carersuk.org for more details.

Equipment and technology

Different types of equipment, adaptations and technology could help make your home safer, your life easier and provide independence for the person you are looking after.

Equipment could be purchased privately or you might be able to get help with the cost through the NHS or through assessments from the local authority, if they decide that such equipment is necessary.

Minor adaptations (which means adaptations up to the value of £1,000) should be provided free of charge through assessments from the local authority, if they consider that the person you are looking after needs such adaptations. Adaptations that cost more than £1,000 could be paid for privately, or you could see if the person you are looking after can apply for a disabled facilities grant.

Assistive technology can help people live independently in their own homes and give you, the carer, peace of mind.

Unobtrusive monitoring devices such as sensors can be positioned throughout the home. They can detect if there is a problem, such as a gas leak or fire, and the person you look after needs assistance. Wearable technology can detect falls or locate a person if they have wandered.

There are also ways of using technology to monitor a person's health remotely through equipment they have in their home. Conditions such as asthma, heart failure, diabetes, chronic obstructive pulmonary disease (COPD), stroke and hypertension can be monitored.

Everyday technology, such as the internet or your mobile phone, can take the stress out of a whole host of tasks such as shopping and coordinating care for the person you look after, and can help them manage their own condition.

Find out more at carersuk.org/tech



Olga's story



22

“ When I first heard about Carers UK's Jointly app, I was juggling full-time work with caring for my parents. I was living in London – 170 miles away from their home in Staffordshire.

It was a complicated and stressful situation. My mum has a range of conditions, including osteoporosis and arthritis. My dad had been caring for her, until 2015 when he was diagnosed with lymphoma and needed care himself.

My siblings and I tried to coordinate it between us, taking turns to travel to their home to help around the house, cook meals and take them to appointments.

Jointly was an excellent way of making sure we had all the information we needed in one place. We only had to enter the

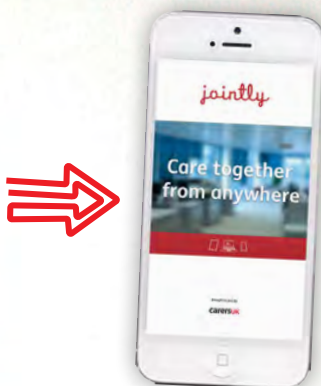
information once and all of us had access to it. Up until then we'd been trying to coordinate everything through email, phone calls and trying to share calendars.

Each time one of us took Mum or Dad to an appointment we would make notes in Jointly. The medication list meant we all had up-to-date information to share with the GP – which was essential when Dad was prescribed aspirin, which he wasn't allowed to have whilst on his cancer drugs.

Being able to look after my parents has been really important to me. I wanted to return the care and love they gave me during my childhood. After Dad passed away in 2016, my siblings and I have continued to share the care for Mum, and Jointly helps us do that. ”

Looking after someone?

Our *jointly* app can make your life easier



Looking after someone can be complicated. Jointly helps me stay on top of things and share information easily with everyone involved in sharing the care.

Jointly makes caring less stressful and a lot more organised.

Jointly is a mobile and online app designed to keep people connected as they share care.

It includes:

- Group messaging
- Task management
- Shared calendar
- Profile and contacts pages
- Medication manager.

Caring is easier when you do it *jointly*

jointlyapp.com

Developed by Carers UK



 **carersUK**
making life better for carers

Your finances



Getting information on benefits

Since the COVID-19 outbreak, there have been a number of changes to benefits, assessments and support. Find out more at carersuk.org/covid-19-a-z

It is a good idea to get a benefits check to make sure you and the person you are looking after are claiming all the benefits you are entitled to. In addition, it is a good idea to get benefits advice if you or the person you are looking after have a change of circumstances. The change might affect your benefits, so it's important to make sure you make the right decision for your situation.

Although benefits can be complicated, they can increase your household income and can sometimes help protect your State Pension entitlement in the future.

The Carers UK website describes the main conditions for each benefit and we have produced factsheets which provide more detailed explanations. Find out more at carersuk.org/benefits

The Carers UK Helpline can also help with questions that you have about benefits – email advice@carersuk.org or call **0808 808 7777**.

Check here for opening hours: carersuk.org/help-and-advice/talk-to-us

You can get a personalised benefits check online. It will take about 20 minutes to complete. Visit carersuk.org/benefits-calculator

These online benefits check tools are not suitable for everyone. Special rules apply to some groups of people, for example: students, people under 18, people in permanent residential care, UK nationals who live abroad and people who are not British or Irish citizens.

“Thank you so much for taking the time to do some research for me. I have calmed down somewhat now and can look at things more objectively having read your reply.”

Carer's Allowance

If you're looking after a family member or friend, you may be entitled to Carer's Allowance. For COVID-19 updates, see our A-Z of changes at: carersuk.org/covid-19-a-z

You may be eligible for Carer's Allowance if you meet all of the following conditions:

- you look after someone who gets a qualifying disability benefit – this includes the middle or the higher rate of the care component of Disability Living Allowance (DLA), either rate of the daily living component of Personal Independence Payment (PIP), either rate of Attendance Allowance, Constant Attendance Allowance (at a certain level) and Armed Forces Independence Payment (AFIP)
- you look after that person for at least 35 hours a week
- you are aged 16 or over
- you are not in full-time education
- you don't earn over £128 a week (after deductions)
- you satisfy UK presence and residence conditions.

If you are getting certain other benefits, including a State Pension, then you might not be able to be paid Carer's Allowance at the same time.

However, it might still be useful to make a claim and receive what is called the 'underlying entitlement' to Carer's Allowance, even though you won't be paid the benefit itself. This is because this 'underlying entitlement' to Carer's Allowance can help to increase any means-tested benefits you might be getting (such as Pension Credit, Housing Benefit and Council Tax Reduction), or it could mean that you become entitled to means-tested benefits for the first time.

Claiming Carer's Allowance can sometimes have an impact on other benefits you receive, but this shouldn't put you off thinking about making a claim, as it can often increase your household income overall.

Claiming Carer's Allowance never reduces the amount of Disability Living Allowance (DLA), Personal Independence Payment (PIP), Attendance Allowance or State Pension that the person you are looking after gets. However it can sometimes affect any means-tested benefits they get.



Find out more at carersuk.org/carersallowance

Top tip: When claiming, if your circumstances change, you must always notify the Carer's Allowance Unit: gov.uk/carers-allowance-report-change

Carer's Credit

Carer's Credit is a way of protecting your State Pension rights. It applies if you are looking after someone, but are not paying National Insurance contributions through paid work and are unable to claim Carer's Allowance.

You do not get paid any money if you claim Carer's Credit. However you get a National Insurance contribution credit to help protect your record (which helps to protect your entitlement to a State Pension).

If you already get Carer's Allowance, then you do not need to claim Carer's Credit as your record is already protected.

To claim Carer's Credit you need to be looking after someone for a total of 20 hours or more a week. Normally, the person you are looking after must be getting one of the following:

- the middle or the higher rate of the care component of Disability Living Allowance (DLA)
- either rate of the daily living component of Personal Independence Payment (PIP)
- either rate of Attendance Allowance
- Constant Attendance Allowance
- Armed Forces Independence Payment (AFIP).

However, if the person you are looking after doesn't get one of these benefits, you may still be able to claim Carer's Credit. When you apply, fill in the Care Certificate part of the application form and ask a health or social care professional to sign it.

Carer's Credit can also help with breaks in your caring role. You can claim Carer's Credit for any week within 12 weeks before the date you become entitled to Carer's Allowance or following the week you stop being entitled to Carer's Allowance. This is without meeting the 20-hour condition. This means you could have a break in caring for up to 12 weeks without losing your National Insurance contribution credit.



Find out more at carersuk.org/carerscredit



Disability benefits for the person you are looking after

The person you are looking after may be entitled to disability benefits to help pay for the extra costs of long-term illness or disability. For COVID-19 related updates, see our A-Z of changes at: carersuk.org/covid-19-a-z

Disability benefits are not dependent on how much money the person you are looking after has, and they are not based on their National Insurance record. However, there are conditions they would have to meet in order to receive one of these.

Disability Living Allowance (DLA)

If you are looking after a child under 16 then you could claim DLA for them. DLA has a care component which may be awarded if the child needs help with personal care (such as dressing, washing or using the toilet) or supervision to make sure they are safe, because of their illness or disability. The help the child needs must be substantially more than the help needed by a child of the same age without the illness or disability. DLA also has a mobility component which may be awarded if the child needs help getting around.



Find out more at carersuk.org/dla

Personal Independence Payment (PIP)

If you are looking after someone aged between 16 and State Pension age, then they could claim PIP. PIP has a daily living component which may be awarded if they need help with daily living activities, such as dressing, washing or using the toilet. PIP also has a mobility component which may be awarded if they need help getting around.



Find out more at carersuk.org/pip

Attendance Allowance

If you are looking after someone of State Pension age, they could claim Attendance Allowance.

Attendance Allowance may be awarded if they need help with personal care (such as dressing, washing or using the toilet), or supervision to make sure they are safe. If you are of State Pension age and feel you have such needs, you may also be eligible.



Find out more at carersuk.org/attendanceallowance

Help with Council Tax

If you're caring for someone, you may be able to get help with your Council Tax bill.

Council Tax Reduction (sometimes called Council Tax Support) is a scheme run by local authorities to help those on a low income with their Council Tax bill.

There are a number of circumstances in which **properties can be exempt from Council Tax**. These are the ones that may be particularly relevant to you as a carer:

- if you have left the property empty and it is no longer your main residence because you are providing personal care to someone
- if the only person(s) living in the property is severely mentally impaired and no one else could be liable to pay the Council Tax
- if the property has been left empty by someone who is now resident in a hospital, a care home or a hostel where personal care is provided.

There are sometimes **discounts you can get on the Council Tax bill**. If only one person lives in the property a 25% discount can be applied to the bill, and if no one lives in the property a 50% discount can be applied to the bill. Certain people, including some carers and people with a severe mental impairment, are not counted when the council works out how many people live in a property.

You may be able to pay less Council Tax under the **disability reduction scheme** if your home has had work carried out on it to help you or someone else living with a disability.



Find out more at carersuk.org/counciltax



Other financial help

There are other ways you may be able to reduce your household expenses – from getting help with fuel and health costs, to applying for certain loans or grants.

Help with fuel costs

There are a number of ways you can get help with fuel costs:

- You could contact your supplier to see if they have any discounted tariffs you are eligible for. You may also want to shop around to see if you can find a better deal from another supplier, by using a price comparison website.
- If you have reached the qualifying age, you may be entitled to a Winter Fuel Payment to help pay winter bills – this can be between £100 and £300 depending on your circumstances.
- If you're receiving certain benefits, you may be able to get a Cold Weather Payment of £25 for each week between 1 November and 31 March in which the average temperature in your local area is at or below freezing over seven consecutive days.
- If you meet certain conditions, you could get a Warm Home Discount on your electricity bill – this can be around £140.

Find out more at carersuk.org/fuel

Help with NHS health costs

If you are getting certain benefits, you may qualify for help with NHS health costs. This includes free prescriptions, free dental treatment, free NHS eye tests and vouchers to help pay for glasses/contact lenses, as well as reimbursement of fares to hospital for treatment for you or your child. You can also claim for the fares of a companion who needs to travel with you for medical reasons.

If you are aged 60 or over, you can get free prescriptions and NHS eye tests regardless of your income.

If you aren't getting benefits that entitle you to help with NHS health costs, but you have a low income, you may be able to get help with health costs through the NHS Low Income Scheme.

Prepayment certificates for prescriptions can also reduce costs if you regularly pay for medication.

Find out more at carersuk.org/healthcosts

COVID-19 financial support

In our A-Z listing, look up 'Debt worries' for guidance on what support is available in relation to the pandemic:

carersuk.org/covid-19-a-z

Budgeting Loan

If you are getting certain benefits, you may be able to get a Budgeting Loan to help pay for essential things like rent, furniture, clothes or funeral expenses.

The smallest amount you can borrow is £100. Budgeting Loans are interest free so you only pay back what you borrow. You normally have to repay the loan within 104 weeks.

Find out more at gov.uk/budgeting-help-benefits

Help from your local authority

Your local authority may have a welfare assistance scheme to help people in a crisis and/or those who cannot afford to buy household goods like fridges, freezers, beds etc.

You could get in touch with your local authority to see what help they can offer.

Using our local directory might be a helpful starting point: carersuk.org/localsupport

Grants

There are sometimes grants that you may be able to apply for. You could ask a local advice centre if there are any local grants.

Turn2us is a charity that has a grants search tool. Find out more at turn2us.org.uk



Your work



Working carers

If you are juggling work with caring for family or friends, you are not alone – there are up to five million working carers in the UK.

There are rights you have in the workplace that might help you to juggle work and care (see pages 34–35). As well as these statutory rights, you may also have additional contractual rights.

In addition to your rights at work, there might be other ways to strike a better balance, such as accessing relevant support at work (see page 36), or outside of your employment.

If you are struggling to manage work and care and are thinking of leaving work, it is important to consider the full implications this could have on your income, quality of life and future pension entitlements.

You could get a benefits check to find out what your financial situation would look like if you were to leave work or reduce your hours (see page 25).

Before deciding to give up work, it's worth seeing if you can improve your situation. See if there are any rights you have at work that could support you with your caring commitments (see pages 34–35), and check what other sources of help are available (see page 36).



Watch our film series for useful tips on flexible working: carersuk.org/flexibleworking

You can also download the guide, 'Let's talk about flexible working': carersuk.org/flex-working-guide

Your rights in work

Without the right support, the stress and pressure of juggling work and care could lead people to leave their jobs. It's important, therefore, to find out about your rights and about any support that is available.

Your rights at work come from two sources:

- The law gives you 'statutory rights' which everyone has.
- Your contract of employment gives you 'contractual rights', which can be more generous than statutory rights.

The following information is about statutory rights. However it is always worth checking your contract of employment, staff handbook or letter of appointment to see if you have any contractual rights on top of your statutory rights.

All employees have a **right to request flexible working** after they have worked for the same employer for 26 weeks (six months), as long as they haven't already made a flexible working request within the last 12 months.

Employers can only refuse requests for certain specified reasons.

Examples of flexible working include:

- home working
- part-time working
- term-time working
- flexitime
- working compressed hours
- job sharing
- shift work.

The Equality Act 2010 provides carers with **protection from some forms of discrimination**. For example, employers and providers of goods and services must not treat carers less favourably than those without caring responsibilities.

All employees have the **right to take a 'reasonable' amount of time off work to deal with an emergency or an unforeseen matter** involving a dependant. This could include your partner, child or parent, or someone living with you as part of your family – others who rely on you for help in an emergency may also qualify.

The time off is unpaid unless your employer is willing to give paid time off as a contractual right.

Examples of emergency situations:

- a disruption or breakdown in care arrangements
- the death of a dependant
- if a dependant falls ill, has been assaulted or is in an accident
- to make longer-term arrangements for a dependant who is ill or injured (but not to provide long-term care yourself)
- to deal with an incident involving a child during school hours.

If you have worked for the same employer for 12 months and you are responsible for a child aged under 18, you are entitled to 18 weeks' **parental leave** per child, which must be taken by the child's 18th birthday.

This time off is unpaid unless your employer is willing to give paid time off as a contractual right.

Visit [carersuk.org/work](https://www.carersuk.org/work) to read our online information.

"I applied to reduce my working hours from five to four days a week, on flexible working grounds. It's hard work, but does mean I can fit in appointments and care meetings on my day off."

"My employer supports me with a great deal of flexibility. When an emergency does happen, they tell me not to worry about work."

Getting support

Telling your employer that you are a carer may not always feel like an easy step.

Ask your employer if they have a carers policy or other support that could help you as a carer, such as special leave.

Some organisations provide support such as counselling services and information for carers such as advice packs. Trade unions can also be a good source of support. You may find that your colleagues are supportive, or even in similar caring situations themselves.

As well as seeing if there is any support available to carers through your employment, you could explore the support available outside of your employment.

This could include getting a carer's assessment to see if there is any support the local authority can offer to help you juggle work and care – see page 13.

This could also include speaking to others who know what you are going through.

Visit carersuk.org/localsupport to find carers' organisations and support services available for carers in your local area.

Our online Forum may be a good place to speak to other carers about how you are feeling – visit carersuk.org/forum

To become part of this online community – join us as a member: carersuk.org/join



Carers UK runs Employers for Carers, providing practical advice and resources to help employers support the carers in their workforce. You could talk to your employer about joining Employers for Carers – find out more at employersforcarers.org

Scott's story

Working carer Scott Corley's daughter, Amber, has cystic fibrosis. He shares his experience of the importance of having an employer who is supportive of carers.



“ When Amber was born I saw myself as a father, but after her cystic fibrosis diagnosis a thought jumped into my head, ‘I’ll have to give up work.’ That thought petrified me and that was when I realised I was a carer as well as a father. Now Amber’s 11 years old and my wife, Louise, and I care for her together.

I work as a service improvement partner for the Financial Ombudsman Service. My wife also works part-time for the same organisation.

It’s a balancing act. At work we try to help our managers understand our situation when we think Amber’s health is deteriorating. If I say to my manager, ‘Amber has a cough’ they need to understand that’s not just a normal cough and might be the start of something

more serious, which might involve me being away from the office.

My employers are really supportive of us. We have a dedicated carers’ group in the office and I am now its co-chair. The visibility of carers in our organisation has helped other colleagues better understand the role of carers.

Being transparent about my situation with my employers has worked for me, but I know not all employers are as receptive. The support my organisation has given me as a carer makes me more committed to them.

There have been some dark moments with Amber and just knowing that I can take a paid day’s leave to be with her makes all the difference. It feels like a bit of good luck in a sea of bad luck.

”

The Financial Ombudsman Service has been a member of Employers for Carers since 2012.

Managed by Carers UK, Employers for Carers helps employers in the UK to support employees with caring responsibilities. This includes training, raising awareness of caring and caring issues, reviewing and ‘carer proofing’ policies and helping organisations set up staff carer networks.

Directory

There are a range of national organisations that can provide help. We've listed some of these below.

Age UK

Information and advice for the over 60s.

T 0800 678 1602

ageuk.org.uk

Alzheimer's Society

Information and advice for people with dementia and their carers.

T 0333 150 3456

alzheimers.org.uk

Care Quality Commission

The independent regulator of health and social care in England.

T 03000 61 61 61

cqc.org.uk

Carers Trust

A network of local centres providing advice, information and support to carers.

T 0300 772 9600

carers.org

Citizens Advice

Local offices for advice/representation on benefits, debt and housing.

T 03444 111 444

citizensadvice.org.uk

Contact

Information and advice for families who care for children with a disability or special need.

T 0808 808 3555

contact.org.uk

Disabled Living Foundation

Information and advice on equipment for independent living.

T 0300 999 0004

dlf.org.uk

Independent Age

Information and advice for older people, their families and carers.

T 0800 319 6789

independentage.org

Macmillan Cancer Support

Information and advice for people with cancer, their families and carers.

T 0808 808 00 00

macmillan.org.uk

Marie Curie

Support for people living with any terminal illness, and their families.

T 0800 090 2309

mariecurie.org.uk

Carers UK Helpline

We're here for you with information, guidance and practical support every step of the way.

E advice@carersuk.org **T** 0808 808 7777



Mencap

Information and advice for people with a learning disability, their families and carers.

T 0808 808 1111

mencap.org.uk

Mind

Information and advice for people affected by mental illness and their carers.

T 0300 123 3393

mind.org.uk

Relate

Counselling and support services for couples, families and young people.

T 0300 003 0396

relate.org.uk

Rethink Mental Illness

Information, advice and community services for people affected by severe mental illness and their carers.

T 0808 801 0525

rethink.org

Samaritans

Samaritans are open 24 hours a day, 365 days a year.

T 116 123 E jo@samaritans.org

samaritans.org

Shelter

Information and advice on housing issues.

T 0808 800 4444

shelter.org.uk

Stroke Association

Information, support and advice to help those affected by stroke.

T 0303 3033 100

stroke.org.uk

Turn2us

Information and advice on benefits and grants.

T 0808 802 2000

turn2us.org.uk

There are also many support groups and organisations locally that can provide help.

Visit carersuk.org/localsupport to see what is available locally.



Every day 6,000 people become carers, looking after family or friends who are older, disabled or seriously ill.

However caring affects you, we're here.

For information and tailored support, contact the Carers UK Helpline:

E advice@carersuk.org

T 0808 808 7777

This guide was proudly supported by



We would welcome your feedback on this guide – please email comms@carersuk.org

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[carersuk.org](https://www.carersuk.org)



Public Health
England



A practical guide to healthy caring



This guide can be downloaded online at the following location:
www.england.nhs.uk/publication/a-practical-guide-to-healthy-caring/

This guide has been prepared by NHS England, Age UK, Carers Trust, Carers UK, Public Health England and older people themselves and contains general information which we hope will be of use to you.

Your individual case may well have specific circumstances that apply to it and so this guide should not be read as specific advice given to you, it should not be relied on as a basis for any decision or action you take in respect of the matters it covers and it should definitely not be used as a substitute for seeking specific advice from an appropriately qualified and experienced professional (generally, your GP).

Neither NHS England nor Age UK, PHE, Carers UK and Carers Trust nor any of their respective subsidiary companies or charities accept any liability arising from this guide or its use by you, except where the law states otherwise. We aim to ensure the information contained in the guide is as up to date and accurate as possible as at the time of publication, but it is inevitable that certain areas will be subject to change from time to time. Please see our website or contact us for more up to date information.

Please note, some of the people seen in the images in this guide are models.

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Who is this guide for?

The advice in this booklet will help you if you look after a friend or family member or have any form of caring responsibilities, but it is written to be particularly relevant for those who are about 65 years or older and are new to caring.

A carer is anybody who looks after someone who needs help because of their illness, frailty or disability. There are 5.4 million carers in England who make a critical and often underappreciated contribution not only to loved ones, neighbours and friends, but to the very sustainability of the NHS itself.

Caring for someone who is ill or disabled can help people live well at home and be part of their local community, but you also have to make sure you look after your own health and wellbeing too. The advice given here will provide hints and tips on how you can look after your own health as well as support the person you care for.

Case Study: Jeanette

"I think the time I love the best is when she frequently comes over and gives me a big hug! I know she loves me and I love her too."

Jeanette is 73 and cares for her daughter, Cathrine, who is 48 and has Down's syndrome, epilepsy and is profoundly deaf. Ten years ago Cathrine was also diagnosed with dementia.

Jeanette has cared for her daughter at home all her life. Although things can be difficult, caring for Cathrine is a pleasure she has a wonderful sense of humour, and is everyone's friend.

Jeanette's typical day starts early helping her daughter up and to the toilet, she then prepares her breakfast, medication and drink. Jeanette then continues to care for Cathrine's needs throughout the day, keeping her physically and mentally stimulated. Cathrine's behaviour is very changeable and has become more challenging with the development of dementia. After a day of caring, Jeanette may be disturbed at night to tend to her daughter.

Jeanette has developed her own health problems, she had major heart surgery followed by a stroke and also has age related arthritis plus deafness too. Over time, Jeanette has learned about the **importance of taking regular breaks for her own wellbeing and that these are important for her and Cathrine.**

What's it like caring for someone?



© Carers Trust

Most of us will care for someone at some point in our lives when someone close to us becomes ill, frail or disabled – it might be your husband, wife or partner, son or daughter, parent, close friend or neighbour.

Most people see caring as part and parcel of life. Caring brings rewards but it can bring challenges as well that we're not always prepared for.

Caring for someone can help to give them the fullest life possible. This guide is designed to help get the best out of life for yourself and the person you care for.

Caring for someone can start gradually and creep up on you, or it can happen overnight. Some people have a lifetime of experience of caring. Over time, carers often become experts in the health conditions of the person being cared for and can understand needs of the person very well.

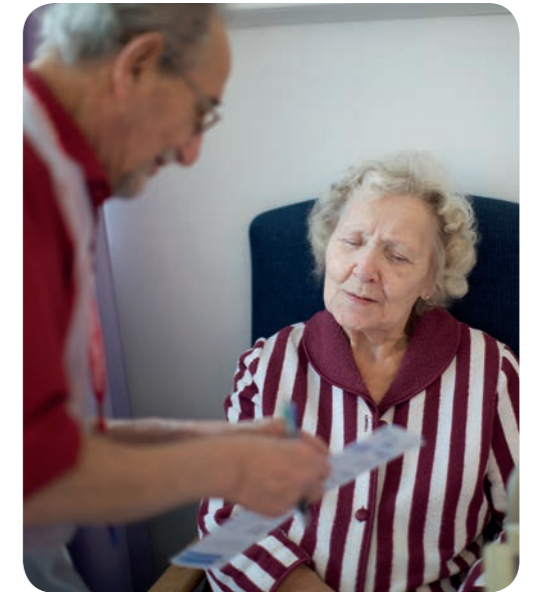
It can be difficult to find sources of support and navigate your way around your local health and care systems. But knowing about and using the support available, can help you feel more in control of your life and better able to cope with the ups and downs and stresses of caring.

This guide can help you get the right support and information and make the most out of life.

As a first step it's important that you recognise that you are a carer. Even though you might see yourself as a wife, husband, brother or daughter, you are still caring for someone.

You are not alone. 1.2 million people aged over 65 in England are caring for relatives and friends right now.

Carers play a valuable role in society, however it is important to remember it is choice. If you are not able to manage, talk to your GP, social services or local carers organisation.



Getting help



It is important to recognise you are a carer as there is information, support and advice that can help. Caring for someone can affect your own health and wellbeing, so getting help early is vital.

Common health issues associated with caring can be:

- back and neck injuries
- anxiety and depression
- stress which can affect you physically with aches and pains, stomach complaints, as well as emotionally with headaches or feeling unable to cope.
- increased pressure on any existing health conditions you may have



Do not put off going to the GP about your own health, as getting advice and information early is vital. It will help you to keep yourself well and manage your caring situation. It may also help to prevent a crisis.

Carers organisations

Can be enormously helpful, offering a variety of emotional and practical support. They will know what is available locally to support you and the person you care for to continue to take part in social activities or even take up something new. Keeping active and continuing with hobbies and friendships is not only enjoyable but good for your health.



Carers services are run by a variety of organisations and what they offer varies. They will all offer information, advice and guidance. They can help you to consider your own needs and inform you of your rights and entitlements as a carer.

Carers organisations may also provide:

- support groups or information programmes
- advocacy (helping you to get your voice heard)
- respite and leisure opportunities (see page 15)
- help to plan for emergencies as well as the future
- advice and support when someone is in hospital / ready to go home
- small grants for equipment or to take a break

It is important to look after yourself and getting in touch with a carers organisation early on in your caring role can help you receive the right support and information.

Other areas of support

If you are still at work and caring, talk to your HR department or manager and let them know you are a carer. Carers have certain rights at work. Contact Carers UK for more information.

Caring for someone with a long-term condition or disability can be expensive. Speak to your local carers or disability support service to ensure you are receiving everything you are entitled to.

Local and national condition-specific organisations such as the Alzheimer's Society, Stroke Association and MIND will be able to offer more expert advice on managing things like toilet problems, challenging behaviour or depression and anxiety (see page 23).



You can find out more about help and support for carers from:

NHS Choices: www.nhs.uk/Service-Search

Carers Trust: www.carers.org

Carers UK: Call their helpline on **0808 808 7777** or visit: www.carersuk.org

Age UK: call their advice line on **0800 169 65 65** or visit www.ageuk.org.uk for details of your local Age UK.

Getting an assessment



Carers and those they care for have a right to an assessment of their needs. This is usually carried out by the local social services department.

- for the carer it is known as a carer's assessment
- for the person needing care it is known as a needs assessment
- these assessments can be carried out either together or separately, whichever is most appropriate
- it should also include any other family members who are involved in or affected by the situation

Examples of the kind of help that could be available directly to you as a carer:

- help towards taking break
- help to relieve stress, improve health and promote wellbeing such as a gym membership, pamper session or having your hair or nails done
- technology to support you such as a mobile phone or computer where it is not possible to access computer services from a local library
- help with housework or gardening

Your local social services department may or may not charge you for the support provided to you as a carer. However if they do decide to charge carers for services they must carry out a financial assessment to determine how much you would need to contribute (if anything).

If the person you care for does not want any help and support, you as a carer are still able to receive support, advice and information. Speak to your local carers service for more information about what is available in your local area.

If the person you care for needs more support, you may have concerns about the costs involved in getting care at home. As the carer you are not responsible for the cost of their care. If they have been assessed as needing care, they will also be assessed to see how much they can afford to pay towards the cost of services, while still having enough money to live on.

If things change

It is important to ask for your situation to be looked at again to see what further help or support may be available. This can be done through a review of the carer's assessment and the care and support needs assessment.

The change may be:

- related to the person you care for, for example their health or mobility may have deteriorated or their housing situation may have changed

OR

- related to you directly. For example, you may have concerns about your own health, employment, finances or other family members

For more information about carer's assessments, care support needs and financial assessments:

Call Carers UK 0808 808 7777 or visit **www.carersuk.org**

Looking after your own health



Staying well while managing the demands of caring can be a real challenge but is important to you and for the person you care for.

It's tempting to put your own health and wellbeing last, but that can have an impact on your own health and it's important that you look after yourself.

These are a few suggestions that you might find helpful:

- tell your GP that you are caring for someone and ask them to mark it on your patient records. By understanding your circumstances, your GP will find it easier to offer the help and support you need. Don't avoid speaking to your GP about any new symptoms or changes you've noticed
- ask your GP about health checks, immunisation and screening programmes that are available to carers and older people. They can help you protect and improve your health
- sharing experiences and getting advice from other carers can be a lifeline. Local carers support groups or online forums can help
- make sure you try to get a break from caring even if it is only 10 minutes (see page 15)
- try to get a better night's sleep. Ask your GP for advice or read 'Getting enough sleep' on the Carers UK website

There are things that can help to save time and improve your health and wellbeing:

- you can do some things online such as access your GP records or make a GP or hospital appointment (see page 17)
- check with the local pharmacy for services that might help: home deliveries, medication reviews and advice on medication can make life easier
- does the person you are caring for consent to having health information shared with you? Make sure this is clearly recorded in their GP and hospital records so that doctors can involve you in decisions about their care
- don't be afraid to ask questions. The GP, consultant or specialist nurse will be able to give you information about the illness or disability the person you care for has. The more information you have the more confident you will feel in your caring role. If there are aspects of the condition you find difficult to manage or cope with, such as incontinence, difficulties with eating or challenging behaviour, make sure you ask for help as soon as you need it
- you can ask your GP or local carer group for information about getting help with transport to and from the GP practice or hospital

Health and wellbeing



When you are taking care of someone, it can be easy to forget to take care of yourself too.

There are things you can do to reduce the impact that caring can have on your physical and mental wellbeing. The following pages provide some advice on how you might do this. More information can be found in the Healthy Ageing Guide, details of which are on the back page of this leaflet.

Keeping healthy

There are simple steps you can take to ensure that your body and brain remain as healthy as possible as you age. They can also help manage existing health conditions you may have, and help you cope with the pressures caring can sometimes bring.

- **keeping active.** It's never too late to get active. Any physical activity for ten or more minutes that is of at least moderate intensity (i.e. raises your breathing rate) is beneficial to health. Think about activities you could coordinate with your caring role, or do with the person you care for to help keep you both active. For example: walking, cycling and swimming. The ideal is at least 150 minutes (2 ½ hours) of physical activity each week, muscle strengthening and balance activities (such as yoga) twice a week, and breaking up time spent sitting
- **eating well and maintaining a healthy weight.** Choose a variety of foods high in fibre, vitamins and minerals, like fruit, vegetables and wholegrains. Try to have fewer foods and drinks that are high in fat, salt and sugars. It's also important to keep hydrated – you should aim to drink 6-8 glasses of fluid a day
- **keeping alcohol consumption low.** Regularly drinking more than the recommended guidelines can damage your health. Men and women should not regularly drink more than 14 units of alcohol a week. This is equivalent to 6 pints of 4% beer, or 6 medium (175ml) glasses of 13% wine, spread over several days. One good way to cut down the amount you drink is to have several alcohol-free days each week
- **stopping smoking.** Even after many years, it's still worth stopping smoking. Whatever your age, you can expect to see a range of benefits when you stop smoking. If you do smoke, it's important to protect the person you care for and those around you from second-hand smoke by never smoking indoors or in the car

To quit, visit www.nhs.uk/smokefree, or call the smokefree helpline on 0300 123 1044.



Coping with stress

Stress, anxiety and depression can affect anyone, but the pressure and expectations of caring can make carers particularly vulnerable. In turn this can make caring more difficult to cope with.

Stress can affect your sleep and you can become more exhausted, tense, irritable and low. You can also feel as though you are losing control of your life and you have little way of regaining this control.

One of the first steps in dealing with stress is to acknowledge that it is happening and to think about the reasons. Starting to deal with the causes, even by taking very small steps, helps you feel more in control. The earlier you do this the better. Just talking about how you feel with someone can help you find a way to deal with it.

Joining a carers group could offer you the opportunity to share your experiences with other carers. Or you may prefer to use carers online forums such as those offered by Carers Trust and Carers UK.

Dealing with depression

Depression is when you feel persistently low or sad and can't find any pleasure in life for weeks and months rather than just a few days. Many of us feel like this sometimes, but depression is when these feelings last longer than a few days.

Depression is an illness, with real and sometimes frightening symptoms. It's not a sign of weakness or something you can 'snap out of' or deal with by 'pulling yourself together'. If you think you may be suffering from depression you should see your GP as soon as possible. Many people wait a long time before seeking help for depression from their GP. The treatment and support options for depression are very effective and the sooner you get help the sooner you can be on the way to recovery.



Keeping in touch and meeting people

Carers can sometimes feel lonely or socially isolated as a result of their caring responsibilities, which in turn impacts on their health. You may have found that caring has affected the relationship you have with the person you care for, as well as relationships you have with others.

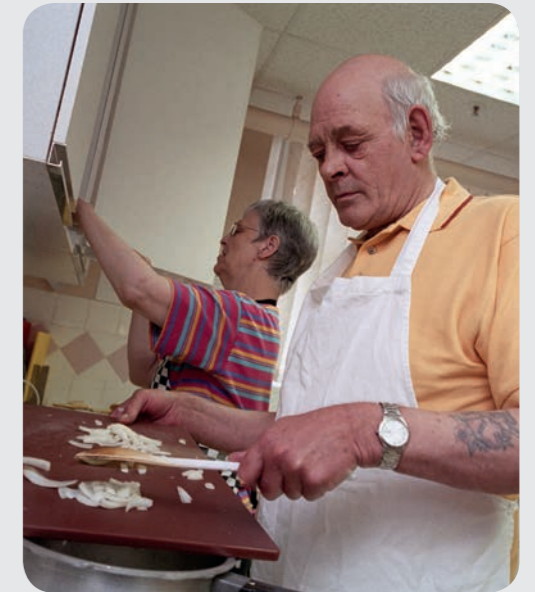
Whilst caring responsibilities can make it difficult, it is important that you try to keep up your social connections as these are good for maintaining your own wellbeing. This may include keeping in touch with family and friends – even if it's just a quick phone call, joining online carer networks or visiting your local carers' service. It may also include taking a little time out to engage in any hobbies you have and doing the things that make you happy.

If you find that you don't have any time to do the things you enjoy, then it is important to find ways to take a break from your caring role (see page 8).

Acknowledging resentment and guilt

Like many carers, you may find yourself caught up in a cycle of resentment and guilt. You may no longer feel like your life is your own and may feel guilty for feeling that way. At the same time, you may feel that you should be doing more for the person you care for, or feel as though you aren't doing a good job.

It's important that you allow yourself to feel these perfectly normal feelings and not get overwhelmed by guilt. It is also important to try to find time to take care of your health and wellbeing, rest and re-energise, which may help you cope with some of these feelings.



Taking a break



When was the last time you took a break? Taking a break from caring is important to give you a chance to recharge your batteries.

A break can be taken:

- informally with help and support from family and friends
- by trying to make time for yourself at home
- with the help of technology like telecare, giving you peace of mind (see page 17)
- formally through a carer's and/or a needs assessment (see page 7). Having a carer's assessment would help identify the type of break which will be helpful to you

If you are concerned about support available for a break contact your local care services for financial funding.

You can take a break and have emotional support together or separately. A break away from the demands of caring is as important as a rest from the physical demands of the role. Talk to the person you care for and plan regular breaks.

You may be able to get support with arranging a break from your caring role through an assessment of your needs and those of the person you care for. Or you may decide to arrange the extra care and support for you as the carer. Sometimes breaks are called respite care. This is usually replacement care and support for you, which can also give you a break from caring.

As the aim is to give the carer a break from caring to enable them to do something for themselves, this is called a 'carers break'. These are usually tailored to a carer's needs which are identified in a carer's assessment.

Here are some examples of breaks that carers have said they value:

" We use a holiday company specialising in people with disabilities so we can have a break away from everyday life and meet other people. "

" Fortnightly I visit the local carers group to meet other people. "

" We go to the gym or for a swim together, my husband has dementia but is still quite active. Most local pools have sessions for older and disabled people. "

" A week away once a year when my daughter goes into respite, she loves the break too. "

" My local church is opposite my house so I feel confident enough to pop over and leave my husband for an hour. "

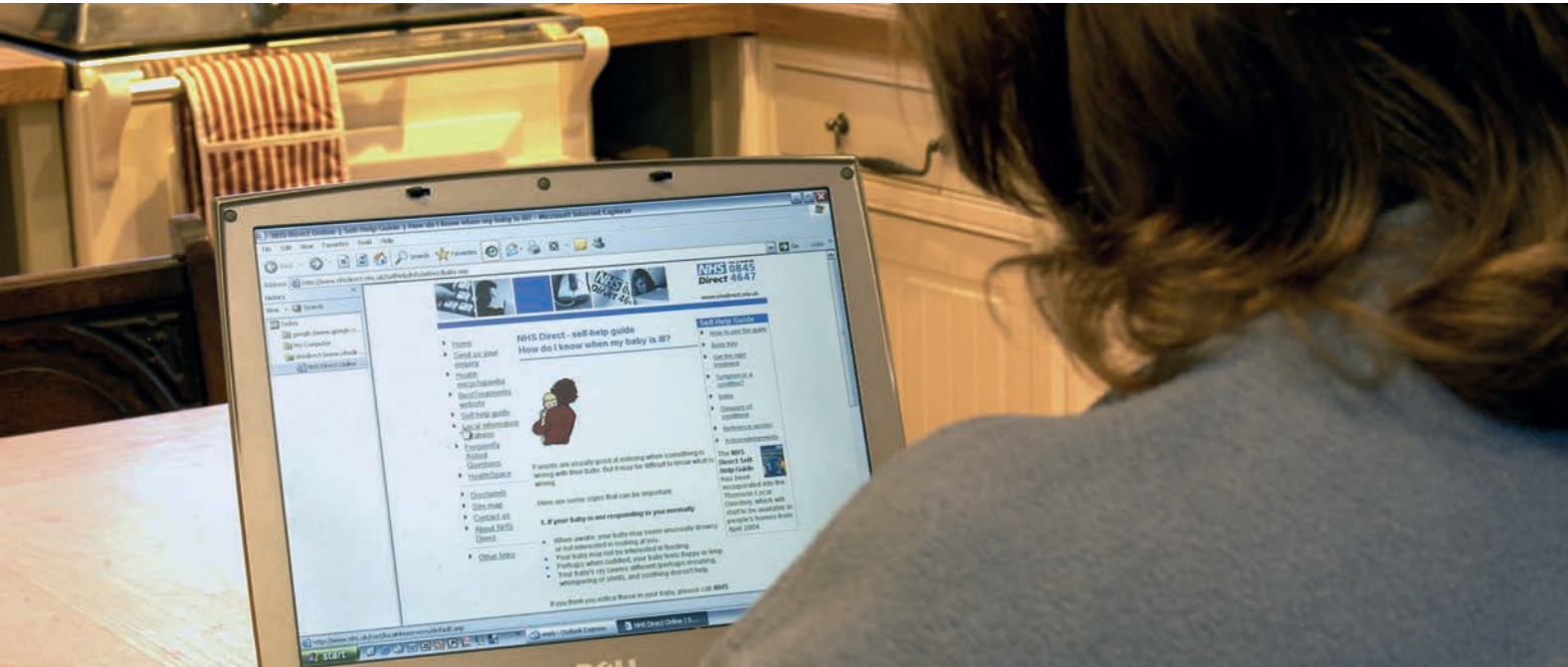


Contact your local carers service for information on breaks and carers support groups:

Carers Trust: www.carers.org

Carers UK: www.carersuk.org

Making better use of technology



Technology has become an important part of everyday life and can make life easier for carers in many ways.

As a carer you can use the internet to help manage your health and that of the person you care for by booking GP appointments and ordering repeat prescriptions online. Ask the practice receptionist how to do this.

If your GP wants to keep an eye on your blood pressure they can now give you equipment that automatically sends the results back to the surgery.

For more information you can access:

www.nhs.uk/choiceintheNHS/Yourchoices/appointment-booking/Pages/about-the-referral-system.aspx

It can be helpful to know what technology is available to help you, where you can find it, and how you can access it.

There are technological devices that can give you peace of mind to leave the house or get a good night's sleep, confident that you will be informed if an emergency occurs. These devices can also give the person you care for greater independence. This type of support is known as telecare.

Some examples of telecare devices which are being used to transform the lives of carers and those they look after are:

- sensors that can detect if the gas has been left on or if someone has got out of bed
- wearable technology such as a wrist alarm that allows you (the carer) to be alerted if a fall is detected

If you think this type of support would be helpful, raise it when the person you care for has their needs assessment or during your carer's assessment. You could also contact your local social services department and ask for information about their telecare services. If you are interested in purchasing technological devices and equipment, talk first to your local carers service to find out if there is any financial support available to assist you.

For more information and examples of technology support visit the Carers UK website at www.carersuk.org/help-and-advice/equipment-and-technology.

You can also use the internet to save time and connect with others:

- shopping for food (and other things) for home delivery
- online banking
- joining an online carers forum
- keeping in touch with family and friends by email, Skype, Facebook or WhatsApp
- sharing photos with family and friends
- using websites to find information and even research your family history
- keep your mind active by playing games online like Scrabble or Patience

For further information about getting online and making the best use of the internet, you can go to Age UK website: www.ageuk.org.uk/work-and-learning/technology-and-the-internet. You can also get information at your local library about getting online.

Why not find out if there is a local Age UK offering computer training courses in your area by calling **Age UK Advice on 0800 169 65 65** for the number of your local Age UK or visiting the Age UK website.

Multiple health conditions and caring



When we get older, we often develop several long-term conditions. People over 75 may have more than one health condition.

This, combined with the fact that our personalities and wishes are all different, makes every caring situation different.

As time goes on, people can often become experts in their conditions and say this helps them feel more in control and manage them better.

Step 1:

Find out more about your health conditions and those of the person you care for. The NHS Choices website is a good place to start as it provides information on lots of conditions. Your GP will be able to tell you more too, especially if you don't have access to the internet. You should also talk to your GP about making and regularly reviewing a care and support plan for both yourself and the person you care for. This helps ensure you both get the care and support you need.



Step 2:

If you or the person you care for take several different types of medication, it is useful to get a medications review and see what other services your pharmacy has to help with medication.



Step 3:

There are specialist support groups where you can meet and talk to carers who are likely to have similar experiences to you. Local Alzheimer's Society groups and some local Age UKs run dementia cafes for people living with dementia and their carers. There are clubs for people living with multiple sclerosis and their carers. Carers organisations run support groups open to anyone who has taken on a caring role. Ask your local Age UK about their services for older people.



Step 4:

You can start finding out about different health conditions and the organisations that support people living with those conditions on the **NHS Choices website: www.nhs.uk**

Preparing for the end of caring



Everyone's caring journey is different. For some, the person they care for will make a full recovery. In other cases, carers find that eventually they are unable to provide the care that's needed or are caring for someone they know only has a short time to live.

Whatever your experience of caring, thinking about what happens if you are no longer able to care anymore, or what will happen when the person you care for dies, can help you be ready for the future.

More care and support

If the person you look after is no longer able to look after themselves, even with further support for you and the person you care for, then residential or nursing care is a sensible and realistic option to consider.

Residential care

It's really important to get good advice about how to choose a care home, what to look for and, importantly, how much it might cost. Speak to social services or contact Age UK. Age UK has guides and information that can help you (see page 23). Care homes welcome residents' spouses, partners, relatives and friends and encourage them to continue to enjoy activities together.

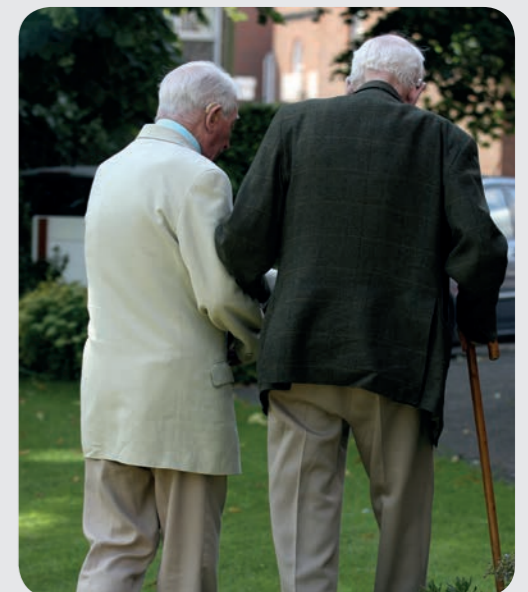
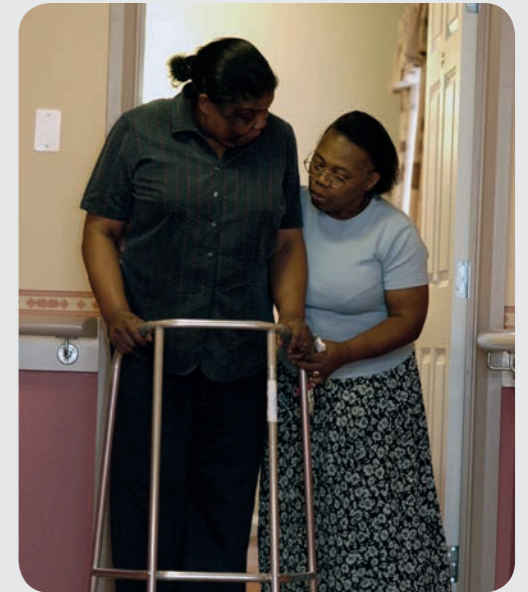
End of life and bereavement

It may be that your caring role is coming to an end because the person you care for is at the end of their life. Many people want to die at home. Your GP can tell you what support could be available locally to enable this to happen. Marie Curie has useful information to help families appreciate what to expect and about making plans for caring for a loved one at home. It's important that you get good information and support.

Grieving is a very personal thing and each person experiences this in their own way and within their own time frame. If you feel you are not coping, you may find it helpful to contact a specialist organisation like Cruise Bereavement Care (see page 23).

Rebuilding your life

There will come a time when you need to start thinking about rebuilding your life. Community groups are often a good place to start, or you may want to think about exploring the opportunities volunteering can offer.



Action plan



Five things we recommend you do:

1. Tell your friends, family and GP that you are a carer.
2. Find out more about your health condition(s) and those of the person you care for, their treatment and medication.
3. Find out what practical, financial and emotional support is available.
4. Speak to your local carers service to make a plan in case of emergency.
5. Make time for yourself today, even if it's only ten minutes.

Five things I am going to do:

1.

2.

3.

4.

5.