



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.

Age UK registered charity number (1128267)
Carers UK registered charity number (246329)
Carers Trust registered charity number (1145181)

To order the healthy caring guide (ref HC1) or the Healthy Ageing Guide (ref HA2) please order for free online via www.orderline.dh.gov.uk or call 0300123 1002. Publication date 11/4/16.



Contents

Who is this guide for?	2
What's it like caring for someone?	3
Getting help	5
Getting an assessment	7
Looking after your own health	9
Health and wellbeing	11
Taking a break	15
Making better use of technology	17
Multiple health conditions and caring	19
Preparing for the end of caring	21
Useful contacts	23
Notes	24
Action plan	25

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.

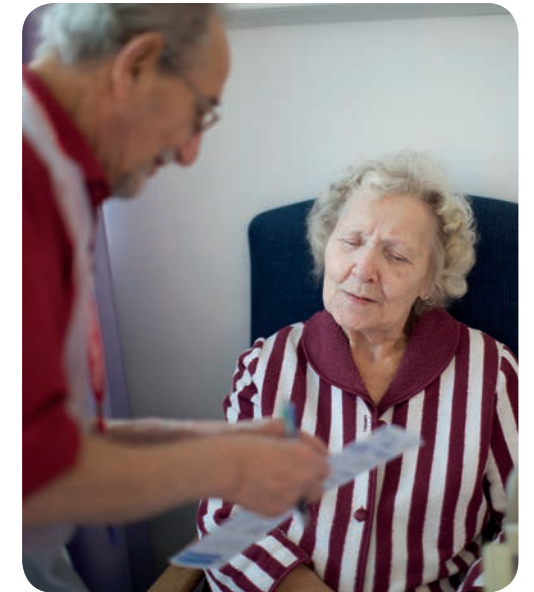
It can be difficult to find sources of support and navigate your way around your local health and care systems. But knowing about and using the support available, can help you feel more in control of your life and better able to cope with the ups and downs and stresses of caring.

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.

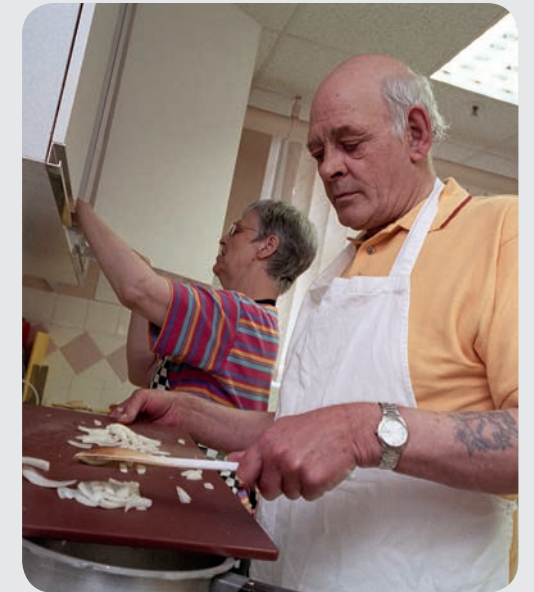
Whilst caring responsibilities can make it difficult, it is important that you try to keep up your social connections as these are good for maintaining your own wellbeing. This may include keeping in touch with family and friends – even if it's just a quick phone call, joining online carer networks or 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. "

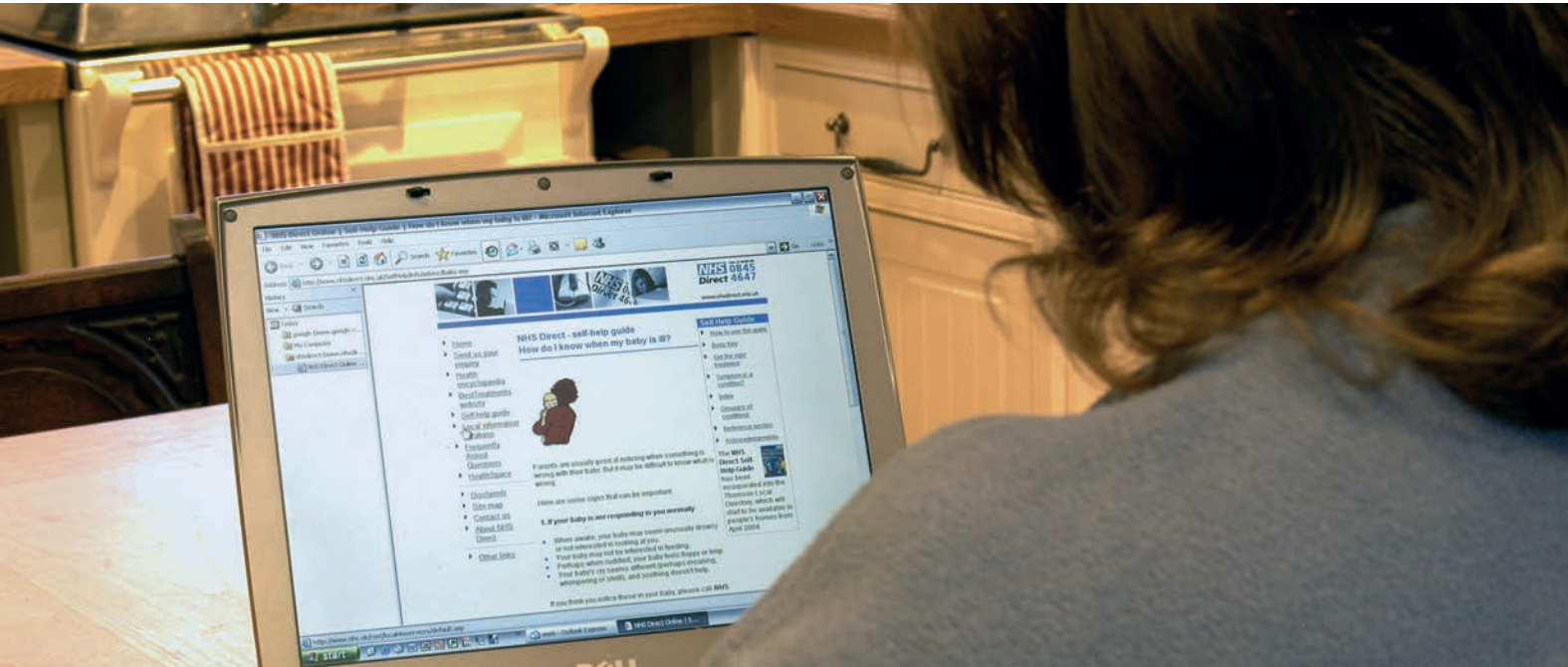


Contact your local carers service for information on breaks and carers support groups:

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.

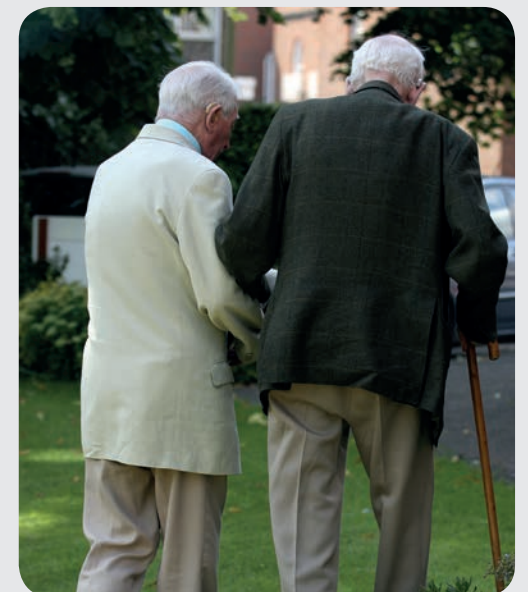
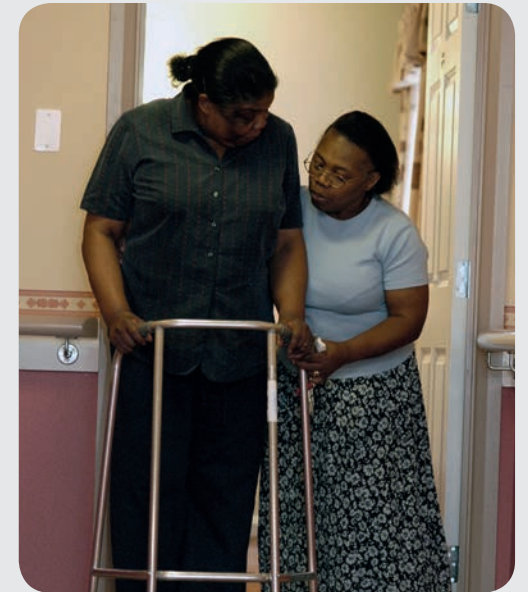
End of life and bereavement

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.