

Carers: looking after yourself

Caring for a person with dementia can be rewarding, but it is also very challenging. You may not have the time to do all the things you need to do, and you may experience a range of difficult emotions. The needs of the person you care for will often come before your own, and this can mean that you don't look after yourself properly.

You might feel that it is not always possible to make time for yourself, but it is important for both you and the person with dementia. Looking after yourself – and learning to deal with challenges – means you will be in a better position to continue to care for the person with dementia. Keeping yourself healthy – physically, mentally and emotionally – can also help you to have a better relationship with them.

This factsheet is for carers. It explains some of the challenges that you may face when caring for a person with dementia and how best to cope with them. It offers tips and advice on how to look after yourself, and tells you what help and support is available.

Caring for a person with dementia

There are many positive things about caring. These include learning new skills, building on existing ones, strengthening relationships, having a sense of pride in what you are doing, and supporting someone who is important to you. And just because a person has dementia, it doesn't mean there won't still be good times for you to share.

However, caring can also be both physically and mentally exhausting. It affects every part of your life and can make you feel isolated, stressed and sometimes even depressed. You may also have your own physical and mental health needs, which you and others might overlook when you are caring for someone else.

Everyone will experience caring in their own way. There may be days when you feel like you can cope well, and others when you cannot. You may find that there are some aspects of caring you can manage easily, while others prove more difficult. This can change from day to day.

No matter how caring affects you, it is important that you learn to cope with some of the things you find difficult. In the following sections we look at some of the common challenges carers face and suggest ways of dealing with them.

Managing different priorities

You may often be faced with many different things you need to do at once. This can be difficult to manage and can leave you feeling exhausted – both physically and mentally.

Many carers feel torn between different responsibilities. You may be trying to care for children, look after someone who is unwell, or go to work, as well as caring for the person with dementia. As much as you may want to be able to manage everything, it is not always possible. It is important to remember that you are only one person and you cannot do everything. Try to focus on what is most important and don't be too hard on yourself about the things you can't manage.

Coping with changes

As the person's condition progresses, their needs and abilities will change. You'll need to learn to cope with this and adapt to these changes. It can often feel like you're having to start all over again.

It can be very difficult to see the person you care for struggling with things they used to be able to do. It is important to focus on what the

person can still do, and support them to do these things. Try not to focus on what they can't do.

Some of the changes you need to cope with will be small, but in time you may have to make bigger and more difficult decisions. This will include choices you have to make about where the person lives. For more information see 'Caring in the later stages' at the end of this factsheet.

Dealing with difficult emotions

One of the most difficult things about caring for a person with dementia is the range of emotions you experience. You may feel frustrated or burnt out. You may be angry and wonder 'Why me?' You may feel isolated and cut off from the world. Or you may feel guilty for thinking about yourself instead of the person you care for. There may be times when you feel that you no longer love, or even like, the person you are caring for. Maybe you worry that you are only caring for the person out of a sense of duty.

These are all very common reactions to caring for a person with dementia. Many other carers will be feeling the same as you do, and you shouldn't be ashamed about how you feel. But if you don't learn to deal with them, these feelings can have a negative impact on many parts of your life. They can affect your wellbeing and the wellbeing of the person you're caring for, so it is important to address them. See 'Getting help and support' below for more information.

Feeling guilty

Some of the emotions that you may experience, such as frustration, are normal responses to the situation. Other emotions can be more difficult to deal with, and can leave people feeling powerless or 'stuck'. One emotion that can be particularly hard to deal with is guilt. You might feel guilty for a number of reasons, such as:

- feeling that you are not living up to your own or other people's expectations

- feeling guilty about how you feel at times – eg angry or frustrated with the person you care for
- feeling that you're not coping as well as others, or that you should be 'doing better'
- feeling that you've had enough of your role as carer
- feeling resentful about the impact caring has on your life and that you never 'chose to do it'
- not having been more patient with the person when their symptoms were developing
- taking time for your own needs or being on your own
- having to make difficult decisions, such as moving the person with dementia into a care home.

You might feel guilty for one or many of these reasons. You can't help feeling this way, but you can help how you respond to these feelings. You should try to remember that you are managing a difficult situation and supporting someone who needs you. Nobody is perfect and everyone gets frustrated with people sometimes or makes mistakes. Try to remember that you are helping the person enormously by just being there and caring for them.

If it seems as though these feelings are reaching crisis point, it is important for you to seek support. See the 'Tips' section below for the kind of help and support that might be useful, as well as the 'Getting help and support' section later in this factsheet.

Tips: Caring for a person with dementia

- **Know your limits** – It is important to remember that you are only one person and there is only so much that you can do. Try to focus on what you can do and accept the things that you can't.

- **Prioritise** – When you have a lot of different things to do, it may help to prioritise. Work out which things you really need to do and which things are less important, and do the most important things first.
- **Don't compare yourself** – Try not to compare yourself or your situation to other carers. You may feel like they are coping much better than you, but everyone's situation will be different, and everyone has their own challenges to face. You may struggle with things that they find easy, but they may struggle with things that you cope with well.
- **Confront your feeling** – It is important to try to understand why you feel the way you do, and accept any negative feelings that you have. You are not alone in feeling this way – it is a normal reaction. Having negative feelings does not mean you are a bad person, and being aware of your feelings may make it easier to deal with them and move on.

If you are feeling frustrated, try to work out why. Are you trying to do too much? Are you not getting the help you need? Once you have understood why you feel the way you do, you will be able to make clearer decisions about what is right for you and for the person you are caring for.

- **Talk about things** – Talking is often the first step to dealing with your emotions. It may seem like a small thing, but it can make you feel less isolated and stressed, and it can help to put things in perspective. Bottling up your feelings, or not taking the time to address them, is likely to make things worse. This is bad for you as well as the person you care for.

You might want to talk to an understanding professional – such as the GP, social worker or counsellor – or a good friend or family member. You can also speak anonymously to someone on a helpline or discussion forum such as Alzheimer's Society's Talking Point ([alzheimers.org.uk/talkingpoint](https://www.alzheimers.org.uk/talkingpoint)). If you feel that you're really struggling, speak to someone as soon as possible.

- **Talk to other carers** – Talking about your experiences with other carers can also be hugely beneficial. You may be able to share advice

and discuss your experiences. It may also be easier to talk about your feelings with other carers because they understand what you are going through. Carers' support groups or discussion forums such as Talking Point are ideal. See 'Other useful organisations' for details.

- **Involve family and friends** – You may find involving family and friends helps to give you a break and reduce some of your stress. For some people they can provide a good range of support. Even if they can't offer day-to-day care, they may be able to look after the person while you have a break, or they might be able to assist in other ways, such as helping with finances.

It may help to talk about dementia to the people you know. Tell them what life is like for you, and for the person you care for. This may help them understand how much you do and what help and support you need. It may also help to suggest ways that people can help – sometimes they may not offer because they don't know what they can do. And if you say you can manage without help, people may not think to ask again. Remember to always let people know how valuable their support is.

- **Ask for help** – Don't be afraid to ask for help and support if you need it. If you don't have any friends or family who can help, or need types of support they can't provide, a voluntary organisation or your local authority might be able to help. Find out whether there are any services available for you or the person with dementia in your local area. Alzheimer's Society's National Dementia Helpline can help with this. Also see 'Getting help and support' later in this factsheet.

- **Think positively** – Pick out and focus on some of the positive aspects of caring and supporting someone, such as your commitment to the person you care for, and your fondness for them. Think about your relationship with them and the fact you are there for them and are helping them enormously.

- **Focus on the good things** – Sometimes it can be hard to see the positive things that you are achieving in your caring role. Writing things down – even small things, such as a shared joke – might be

useful. When you are having a difficult day, these things can remind you of the good you are doing and that there will be better times.

- **Take a break** – You will be able to cope better if you take breaks away from the person you care for and find time for yourself. Try to find time to reflect and relax, enjoy personal interests and hobbies, and socialise with friends and family. For more see ‘Taking a break’, below.

Looking after yourself

However caring makes you feel, it is important that you take the time to look after yourself. This will benefit you and the person you care for.

Your health and wellbeing

Caring can have a big impact on your mental and physical health and wellbeing. It is important to look after yourself well so that you can continue to care for the person with dementia.

- Try to eat a well-balanced diet, with at least five portions of fruit and vegetables every day. A healthy diet will be beneficial for the person you care for too.
- Taking regular exercise is good for your health – both physical and mental. You could try going for a walk or taking up an exercise class, or doing a crossword for example. Whatever you choose should be fun and something that you want to do.
- Spending time enjoying your hobbies and interests is good for your mental and physical health.
- Try to get enough sleep. Sleep is very important as it helps the brain and body recover from fatigue. It can be difficult if the person you care for has disturbed nights. You may find it easier to sleep when the person you care for is sleeping, and may be able to take advantage of daytime naps. If you are unable to get enough sleep, talk to your GP. They may be able to suggest services or techniques that can help.

- If you have a physical disability or a sensory impairment, these will affect your caring role. It is important to make sure you are getting all the support you are entitled to. Speak to your GP or social services department.
- If you have to help the person you care for to move around, be careful of your back. Speak to your GP for advice. They may be able to refer you to a physiotherapist or an occupational therapist. Some local carers' organisations provide training sessions on moving and handling. Contact your local carers' organisation, GP or social services to find out what is available in your area.
- See your GP on a regular basis to check up on your health. You may also want to be put on the Carers' Register. This is a list of patients who are carers – which GPs have been asked to keep – to help support them and the people they care for. Speak to your GP for more information or to register.
- If you are struggling to cope or feeling depressed, anxious or stressed, talk to your GP. There is help available, such as counselling or extra support services. These problems are easier to manage if you do something about them at an early stage.
- Consider using technology to help you in your caring role. This could include using the internet to help with online banking to pay bills, or shopping online to buy groceries. You may also want to think about electronic devices, known as 'assistive technology', such as gas monitors or locator devices. For more information see factsheet 437, **Assistive technology – devices to help with everyday living.**

Taking a break

It can be difficult to find time for yourself when you are caring for a person with dementia. You may feel guilty about wanting time alone, but it is important for your own wellbeing. When you do manage to get time to yourself, you may want to use it to catch up with other tasks such as housework or managing finances. However, taking breaks and continuing to do things that you enjoy can help you manage your

caring role. This could include having some 'time out' during the day to do a crossword or go for a coffee.

Many people find that taking the time to pursue things they enjoy helps them with their caring role. By taking regular breaks you may find yourself better able to support yourself and the person you care for. Time apart can also be good for both of you and can make you both feel better.

You don't have to take long breaks from caring, but a short time to enjoy yourself could make a lot of difference. Try to make time for something you enjoy every day, whether it is on your own or with the person you care for. By having a break, the person with dementia may also get to experience new things and have a change from their routine. Types of break might include:

- taking the time to sit down and have a cup of tea, read the paper, listen to music, or go for a walk
- going out for a coffee or drink
- meeting a friend or going shopping
- pursuing interests, hobbies and activities that you find enjoyable
- having a short holiday, whether it is a few days or a week.

Some of these activities may help you feel less isolated as well.

You may be able to take a break if someone you know, such as a friend or family member, can spend a few hours with the person you care for. If not, your local authority may be able to help. Alternatively you may have to find a local organisation or charity who offer this service. Providing care so that you can take a break is called 'respite care', or sometimes 'replacement care'. It could be for an hour or two, or for days or weeks.

A useful starting point may be your local Alzheimer's Society branch, Age UK or council social services department. They can tell you what is available in your area and how you can access it. You may find that you have to be persistent and push to get the help you need. This can be frustrating and you may feel you don't have the energy, but it is important to carry on and get the support you need.

For more information see factsheets 462, **Replacement care (respite care) in England**, W462, **Respite care in Wales**, or NI462, **Respite care in Northern Ireland**.

Getting help and support

If you are caring for someone with dementia, you may want or need support at some point. Carers who have less support are more likely to experience stress and depression. If you don't have friends or family who can help, or you are struggling to take a break, there are a number of organisations that help.

These include voluntary organisations, health and social care professionals and local authorities. You might need different types of help and support at different times. Not every type suits every carer and there may be an element of trial and error in finding the right services for you.

The types of help and support you might want to think about include:

- GPs, counsellors and other health professionals (eg dementia specialist nurse, occupational therapist) – these can offer support as well as advise on medical issues.
- Local support groups – these are available in many areas and are a good source of information. You will be able to talk to people in a similar situation and share ideas, tips and strategies about caring. For details of local support groups, contact Alzheimer's Society or Carers UK (see 'Other useful organisations').

- Online discussion forums – these can also be helpful and may offer practical suggestions, or simply a place where you can let off steam after a difficult day. You can access them at any time. You could try Alzheimer’s Society’s Talking Point at **alzheimers.org.uk/talkingpoint**. Carers UK also run a number of forums.
- Information – there is lots of information available on all aspects of caring. This can help if you are struggling with anything from financial issues and activities to depression or eating. See Alzheimer’s Society’s list of factsheets at **alzheimers.org.uk/factsheets**
- Adaptations to the home – you may be able to make improvements to your home that make life easier for the person you care for. This in turn could make things easier for you. These adaptations could improve a person’s mobility or help them to maintain their independence. For more see factsheet 429 – **Using equipment and making adaptations at home**.

Support from local authorities

Local authorities can provide help for people with dementia and their carers. Both the person with dementia and their carer are entitled to an assessment of their needs (called a ‘needs assessment’ or ‘community care assessment’). The local authority will use this to decide what support you are eligible to receive. They may be able to provide some or all of the following:

- information tailored to your needs
- day centres
- support groups
- support from professionals (such as a dementia specialist nurse)
- counselling
- adaptations to the home

- respite care (sometimes called replacement care).

There may be a charge for some of these services. Speak to your social services department for details.

As a carer, you can be assessed even if the person you care for chooses not to be. If you decide to ask for an assessment, there are some things you can do to prepare. Think about your role as a carer, how you are coping, and what support you need. Also consider the difficulties you have now, and those you may face in the long term if you continue caring at the same level. These may include:

- feeling stressed, depressed or anxious
- not getting enough sleep
- struggling to combine caring with work or other commitments
- coping with behaviours that challenge, such as walking about
- making time for the other interests in your life
- feeling tired or fatigued due to long hours spent caring and not getting enough breaks
- difficulty maintaining relationships with your family and friends
- having no plan for emergencies, such as if you become ill
- practical difficulties such as not being able to drive.

For more information see factsheets 418, **Assessment for care and support in England**, W418, **Assessment for care and support in Wales**, or NI418, **Community care assessment**, for those in Northern Ireland.

Legal and financial support

Your legal and financial situation may be affected if you are caring for a person with dementia. There are a number of areas to think about, such as those listed below.

- If you are planning to give up work, check whether flexible working, alongside help from the local authority, might allow you to stay in work. Carers have a right to request flexible working and employers have to give a good business reason for refusing the request.
- If you do have to give up work, you may be able to claim Carer's credit (a National Insurance credit for carers) so that your pension won't be affected. For more information contact the Carer's Allowance Unit (see 'Other useful organisations' at the end of this factsheet).
- Make sure you and the person you are caring for are receiving all the benefits you are entitled to. Age UK can advise on this, or you can visit an advice centre such as the Citizens Advice Bureau to get a full benefits check. For more information see factsheet 413, **Benefits**, and 'Other useful organisations' at the end of this factsheet.
- Think about ways to help manage your financial, health and welfare affairs in the future, and talk about it with the person you care for. This may be through a Lasting power of attorney. If the person with dementia receives benefits and is no longer able to manage this income, you can apply to be an appointee to manage this for them. For more see factsheets 472, **Lasting power of attorney**, and 467, **Financial and legal affairs**. For Northern Ireland, see NI472, **Enduring power of attorney**.
- Check your own position in terms of home and finances if the person you are caring for goes into long-term care or dies. See factsheet 467, **Financial and legal affairs**.

Caring in the later stages

Moving the person into a care home

When a person with dementia moves into a care home, it can have a big impact on the carer as well. You may worry about how the move will affect the person with dementia, and your relationship with them. You may also worry about the impact it will have on your own life, especially if you have been caring for the person for a long time. Some carers feel they have let the person with dementia down when they move into a care home, feeling that they should have been able to cope for longer. Some carers may also feel guilty that the person has gone into a care home, especially if they had promised the person they wouldn't be placed in one. This can be difficult to deal with, but you shouldn't be too hard on yourself. These decisions are often due to circumstances outside of your control, and you should remind yourself that you are doing what you think is best for the person you care for.

The move to a care home can also raise questions about your role and whether you are still needed. When the person you care for moves into a care home it will change your relationship. However, it doesn't mean the person with dementia no longer needs you, or that you won't be involved in their care (unless this is what you want).

Speak to the care home about ways you can help the person and, by doing so, help to maintain your relationship. Some carers find their relationship with the person improves when they move into a care home, because they can focus on their relationship and not on the day-to-day aspects and stresses of caring.

If you have any of these feelings, it is important for you to address them and seek support. This may be from family and friends, a support group, the care home or a professional (such as a dementia specialist nurse or support worker).

When your caring role ends

Dementia is a life-limiting illness and there will come a time when your caring role comes to an end. This can be a very difficult time, as you are grieving for the person who has died, as well as coping with the end to your caring role.

You may have lost contact with friends and family and find it hard to get back in touch with them. Or you may find it hard to adjust to not being a carer anymore, because you have thought of yourself as a carer for so long.

It may be worth spending some time thinking about the future, and what may happen when you are no longer caring. Try to find the details of carer's organisations – they can provide information and support to help you adjust when the time comes. For more see 'Other useful organisations' and factsheet 507, **Grief, loss and bereavement**.

Other useful organisations

Age UK

Tavis House
1–6 Tavistock Square
London WC1H 9NA

T 0800 169 6565 (advice line)
W www.ageuk.org.uk
www.ageuk.org.uk/contact-us (online contact form)

Wales – Age Cymru

Tŷ John Pathy
13/14 Neptune Court
Vanguard Way
Cardiff CF24 5PJ

T 08000 223 444 (advice line)
E enquiries@agecymru.org.uk
W www.agecymru.org.uk

Northern Ireland – Age NI

3 Lower Crescent
Belfast BT7 1NR
Northern Ireland

T 0808 808 7575 (Advice Service)
E info@ageni.org
W www.ageuk.org.uk/northern-ireland

Provides information and advice for older people in the UK.

Carer's Allowance Unit

Palatine House
Lancaster Road
Preston
Lancashire PR1 1HB

T 0345 608 4321 (8.30am–5pm Monday–Thursday, 8.30am–4.30pm Friday)
E cau.customer-services@dwp.gsi.gov.uk
W www.gov.uk/carers-allowance-unit

Provides information about eligibility for carer's allowance and carer's credits to protect your pension if you give up working to become a carer.

Carers Trust

32–36 Loman Street
London SE1 0EH

T 0844 800 4361
E info@carers.org
W www.carers.org

Works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

Carers UK

20 Great Dover Street
London SE1 4LX

T 0808 808 7777 (Advice line, Monday–Friday 10am–4pm)

E advice@carersuk.org

W www.carersuk.org

www.carersuk.org/forum (online discussion forum)

Provides information and advice to carers about their rights and how to access support. See in particular its factsheet about carers' assessments.

Citizens Advice Bureau (CAB)

Various locations

W www.citizensadvice.org.uk

www.adviceguide.org.uk

Your local CAB can provide information and advice in confidence or point you in the right direction. To find your nearest CAB look in the phone book, ask at your local library or look on the Citizens Advice website (above). Opening times vary.

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This factsheet has also been reviewed
by people affected by dementia.

A list of sources is available on
request.



Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland:
0300 222 11 22

9am–8pm Monday–Wednesday
9am–5pm Wednesday–Friday
10am–4pm Saturday–Sunday

alzheimers.org.uk

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leading support and research charity
for people with dementia, their
families and carers.



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