

Carers: looking after yourself

Caring for a person with dementia can be both rewarding and challenging. The needs of the person may often come before your own and this can mean that you struggle to manage everything. However, it can be easier to cope if you look after yourself properly. While you might feel that this is not always possible, it is important for both you and the person with dementia. This factsheet looks at why looking after yourself is important, the different types of needs that should be considered and where you can access support.

There are positive aspects of caring, such as learning new skills, building on existing ones, strengthening relationships and supporting someone who is important to you. However, it can also be both physically and mentally exhausting. It affects all aspects of your life and can lead to increased isolation, stress, conflicting emotions and sometimes depression. Carers also have their own physical and mental health needs, which can be overlooked when caring for a person with dementia.

It is important to look after yourself so that you do not become unwell and can continue to support the person you care for. Maintaining good health and emotional wellbeing will also help you in your caring role and in continuing your relationship with the person you care for. The type of support that carers need will vary depending on the individual circumstances. Different carers will also have different expectations of their role as a carer (eg a spouse or a young carer).

Emotional support

One of the most difficult things to overcome when caring for a person with dementia is the range of emotions you experience, such as anger, loneliness and guilt. Carers often say that they feel guilty for thinking about themselves when they are caring for a person with dementia. Being able to address these feelings is important, as they can affect your wellbeing. Many carers find that just talking about their situation with other people helps. This can be especially true if the people you talk to have experience of caring for a person with dementia. You can get different types of support from different places:

- Friends and family can provide a variety of support, both emotional and practical. Being able to talk to them about the situation and how you are feeling may help.
- GPs, counsellors and other professionals can offer support.
- Local support groups are available in many areas and are a great source of support and information. You will be able to talk to people experiencing a similar situation and be able to share ideas, tips and strategies about caring. For details of local support groups, contact Alzheimer's Society or Carers UK (see 'Other useful organisations' at the end of this factsheet).
- Online discussion forums can be a helpful source of support and practical suggestions, or simply a place to let off steam after a difficult day. They are available day and night. You could try Alzheimer's Society's Talking Point at alzheimers.org.uk/talkingpoint, or Carers UK run a number of forums.

Your relationship with the person with dementia may change and this can have an effect on how you feel towards them. It is important to be able to talk about these feelings with someone you trust. You should not be afraid to say how you feel – it is natural to be confused, upset or angry at times. You may find that there are some aspects of caring you can manage easily, while others prove more difficult. Everyone will experience caring in their own way.

Taking a break

It can be difficult to find time for yourself when you are caring for a person with dementia. 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, it is important to take breaks and continue to do things that you enjoy so that you don't become overwhelmed. This could include having some 'time out' during the day to do a crossword or go for a coffee, having a break (when someone else is looking after the person or they are at a day centre), or going on holiday.

By taking regular breaks you may find yourself better able to support yourself and the person you care for. It can be hard to take a break from caring and you may feel guilty, but all carers deserve a break and you will feel better for it.

You don't have to take long breaks from caring, but a short time to enjoy yourself could make a difference. Try to schedule in 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 break from their routine. Types of break might include:

- having a cup of tea, reading the paper, listening to music, or going for a walk
- looking at photos together
- going out for a coffee or drink
- meeting a friend or going shopping to get out of the house
- pursuing interests, hobbies and activities that you find enjoyable and give you a change from your caring role; this may help you to feel less isolated as well
- having a short holiday, whether it is a few days or a week.

Coming back to the relationship refreshed will be good for you and the person you care for. You could ask friends or family if they can help out – it may be for a couple of hours or they may be willing to look after the person for a few days. There may be local day services available, or you may be able to arrange for respite care (sometimes called replacement care). For more information see factsheet 462, **Respite care**. If you don't have friends or family who can help, or you are struggling to take a break, talk to your GP or local social services as they may be able to help.

Your health and wellbeing

Caring can have a significant impact on your mental and physical health and wellbeing. Therefore, it is important to look after your health to support you in your caring role.

- 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. Whatever you choose it should be fun and something that you want to do.
- Having hobbies and interests is also 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 because of the person you care for, 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 then these will affect your caring role. It is important to make sure you are receiving all the support you are entitled to. Speak to your GP or social services department.

- If you have to help the person 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 register on the Carers' Register. This is a register of patients who are also carers, which GPs have been asked to keep to help support carers and the people they care for. Speak to your GP for more information or to register.
- If you are struggling to cope and feel depressed, anxious or stressed, talk to your GP. There are options available such as counselling or extra support services, and these problems are easier to manage at an early stage.

Your financial wellbeing

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.

- If you are planning to give up work, check whether flexible working combined with additional support from the local authority might allow you to remain 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 a carer's credit 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 welfare 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 with dementia. 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. (See factsheet 472, **Lasting Powers of Attorney** and factsheet 467, **Financial and legal affairs**).
- 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**).

Getting support

If you are caring for someone with dementia, you may want or need support at some point. Carers who have less social support are more likely to experience stress and depression. You will benefit from different types of help and support, ranging from practical care to give you time off caring, to having someone to talk to about your feelings and concerns. Not every type of support suits every carer and there may be an element of trial and error in finding the right services for you.

Ask what is available in your area. Even if you don't need it at the time it may be useful in the future. You could ask your local Alzheimer's Society, GP, memory clinic or social services department.

Support from local services

Local authorities may 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, and the carer can be assessed even if the person with dementia chooses not to be.

If you decide to have a carer's assessment, there are some things you can do to help you 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 experience in the long term if you continue caring at the same level. These may include:

- stress, depression or anxiety
- lack of sleep
- struggling to combine caring with work and/or other commitments
- coping with behaviours that challenge, such as walking about
- making time for the other interests in your life
- fatigue due to long hours spent caring and lack of 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.

Some of the following may help you cope:

- information tailored to your needs
- day centres
- support groups
- talking to 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. Speak to your social services department for details. The memory clinic may have support programmes (such as a support group) in place for family carers, as well as people with dementia.

For more information see factsheet 418, **Assessment for care and support in England**.

Support from family and friends

Even though you may be coping well now, caring for a person with dementia may gradually become more demanding, both physically and emotionally. You may find involving family and friends helps to give you a break and reduce some of your stress.

- Try to involve other family members. 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.
- Try to accept help from friends or neighbours when they offer it. If you say you can manage without help, they may not think to ask again.
- It may help to suggest ways that people can help. Sometimes people may not offer because they don't know what they can do. You could ask them to stay with the person for an hour, or to go for a walk with them.
- Let people know how valuable their support is.
- It may help to talk to your family and close friends about dementia. Tell them what life is like for you, and for the person you care for. This may help explain what is happening for you and the person with dementia and will help them understand how much you do.
- Listen to others who may be able to share their own advice and discuss their own experiences.

Coping with conflicting demands

As a carer you may find that you are often faced with conflicting demands on your time. This can be difficult to manage and can leave you feeling exhausted – both physically and mentally.

- Recognise your own limits. You are only one person and there is only so much that you can do. Many carers feel torn between responsibilities – especially if they are 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.

- When you have a lot of conflicting demands it may help to prioritise the things that you must do and the things that are less important.
- Talk to others about what you are going through.
- Don't be afraid to ask for help and support if you need it. 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 you to find services in your area.

Don't be too hard on yourself

At times, caring may feel like a thankless task. The person with dementia may not seem to appreciate your efforts and may think they can do everything themselves. Others may be unaware of how much you do. You may feel guilty about your situation and wonder 'why me?' You may feel that you are not doing as well as you should be because you get angry and upset and often find yourself struggling with being a 'carer'. It might feel like other carers manage better than you do. Try to remember how well you are doing, managing a difficult situation and supporting someone who needs you. Nobody is perfect and there will be a variety of conflicting emotions when you are caring for a person with dementia.

The abilities of the person you care for will change as dementia progresses. It can be very difficult as a carer to see the person you care for struggling with things they used to be able to do. It is important to remember that while the person may not be able to do some things, there will be other things they can do. You may find that the person acts in what you consider strange ways, but these actions will mean something for the person with dementia. This can be very difficult to cope with but it can help to remember that the person with dementia is responding to their situation, not trying to be difficult.

Caring can be hard but there can also be positive experiences. Just because a person has dementia, it doesn't mean there won't still be good times for you to share. It may be these good times that help you manage the difficult side of caring and give you the strength to carry on. When you are experiencing difficult times, you don't have to go through them alone – there is help and support available.

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)

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 stop 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 (Adviceline, 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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Reviewed by: Dave Pulsford, Senior Lecturer, School of Health, University of Central Lancashire and Professor Gill Livingston, Professor of Psychiatry of Older People, Mental Health Sciences Unit, Faculty of Brain Science, University College London

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 1122

9am–8pm Monday–Wednesday

9am–5pm Thursday–Friday

10am–4pm Saturday–Sunday

alzheimers.org.uk

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers.

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