



DementiaUK
Helping families face dementia

Looking after yourself as a carer



Caring for someone with dementia can be a 24-hour a day role that is both physically and mentally demanding. It can be difficult to look after your own needs alongside those of the person with dementia, and balance your caring responsibilities with your home, family and work life.

However, it is vital that you take care of yourself, otherwise your physical and mental health may suffer and you may not be able to continue in your caring role.

Many people who support someone with dementia do not consider themselves to be carers. You may feel that you are simply doing what is expected of you as a family member, or your caring tasks may have become so routine that you rarely reflect on the impact they are having on your own life.

However, recognising yourself as a carer may entitle you to help from health and social services, as well as financial benefits.

Taking care of your health and wellbeing

It is important not to neglect your own health when caring for

someone with dementia. You may try to ignore physical or mental symptoms like headaches, nagging pain or feelings of depression, but you should visit your GP if you have any health concerns.

Try to:

- Keep up with your regular dentist, optician and hearing checks and any medical reviews
- Stay physically active: go for a walk, cycle, play sports if you enjoy them, swim, do yoga, or join local exercise classes
- Keep your mind active: read books or the newspaper, do puzzles and crosswords, play chess or card games, or learn a new skill or language
- Follow a healthy diet with regular mealtimes
- Keep to a good sleep routine. If the person with dementia tends to be unsettled at night, it may be useful for another family member or a paid carer to help on occasion so you can catch up on sleep
- Stay within recommended guidelines if you drink alcohol



– although it may seem to help you cope in the short-term, it can actually trigger feelings of anxiety and depression and affect your physical health.

Please visit drinkaware.co.uk for advice

- If you smoke, make every effort to stop to protect yourself from smoking-related illnesses. Please visit nhs.uk/better-health/quit-smoking for advice

Enjoying time with the person you care for

Because dementia is a progressive condition, the person with the diagnosis will change over time and you may begin to lose sight of

who they once were. It is normal to feel emotions such as grief, anger, and guilt. But there are things you can do to remain connected to the person so that your relationship, although different, still brings you both enjoyment.

You might need to be creative – if you previously liked hiking and taking holidays together, consider why those activities appealed to you. Can you recreate that sense of enjoyment by going for walks outside or sitting in the garden?

Any activity you can do together can be beneficial, so explore what the person living with dementia can still do, rather than what they cannot. You could try:

- listening to music together
- watching a favourite film
- going for a walk
- looking at photos
- physical touch, such as a hand massage
- compiling the person's life story together – a record of their past and present life that can help you reminisce and think about what matters to them as an individual. Please see Sources of support on p7 for more information
- taking part together in activities outside the home such as sport, pub quizzes, dance classes, choir, bowling, or arts and crafts groups
- Let other family members know what your caring responsibilities involve. Very often, people outside the home – and even inside it – do not realise just how much you are doing
- Ask other family members or friends to help. They may, for example, be able to sit with the person once a week so you can have a break
- Be specific about what you need – often, people are happy to help but do not know how
- Try to continue with activities outside the home such as exercise, meeting friends, going to the theatre, supporting a sports team, volunteering
- If possible, share jobs amongst the family. You could create a rota that includes general household tasks such as cooking and cleaning as well as looking after the person with dementia
- Schedule a phone or video call with a friend for a time when you know the person with dementia will be asleep, at a day centre etc. Even a short call without interruptions could help you

Time to yourself and with others

Although it can be difficult, try to maintain a social and family life outside of your caring responsibilities. Staying connected with family and friends gives you the opportunity to talk to other people about what you are going through and to get some vital support and respite from your caring role.

recharge your batteries

- Seek support and share experiences with other people who are caring for someone living with dementia, eg at a carers' group or dementia café. Your GP or social worker may have information on local groups
- Speak to your GP or social services about accessing local respite services so that you can arrange some time to yourself
- Find out about befriending services – these are often run by faith or community groups. Befrienders are usually volunteers and can sit with the person with dementia or take them out to give you a break
- If you have children or teenagers, try to make time to spend with them one to one or as a family, focusing on their needs rather than on the person with dementia. You could ask a family member, friend, volunteer befriender or paid carer to look after the person for a while so you can go to the cinema, go shopping, watch your child's school play or sports match, or simply go to the park



Support for carers

As a carer, you are entitled to support to help you in your role .

- Request a carer's assessment by contacting your local social services – this will help identify any support you need, such as respite care for the person with dementia. Please see Sources of support on p7 for our information on the carer's assessment
- Ensure you are claiming all the benefits you are entitled to, as these may help with some of the costs of caring – see Sources of support on p7 for information
- If you work, it is a good idea to tell your employer so they can put support in place such as allowing you time off to attend appointments for yourself or with the person you care for
- Children who have a parent with young onset dementia (where symptoms develop before the age of 65) may end up taking on some caring tasks. It is worth informing their school of the situation so they can offer support. You could also look into

young carers' groups where they can meet other young people who have a caring role

If the person you care for needs to move into a residential care home, goes into hospital or dies, your caring responsibilities may change or stop suddenly. It is important that you still have things to do and people to speak to – so while it might feel difficult to have a life outside caring, keeping up with your usual activities and relationships can help you cope with these times of transition further down the line.



Sources of support

To speak to a dementia specialist Admiral Nurse about looking after yourself as a carer or any other aspect of dementia, please call our Helpline on **0800 888 6678** (Monday to Friday 9am–9pm, Saturday and Sunday 9am–5pm) or email helpline@dementiauk.org

To book a phone or video call appointment with an Admiral Nurse, please visit dementiauk.org/book-an-appointment

Dementia UK resources

Carer's assessments
dementiauk.org/the-carers-assessment

Caring from a distance
dementiauk.org/caring-from-a-distance

Changing relationships and roles
dementiauk.org/changing-relationships-and-roles

Coping with feelings of guilt
dementiauk.org/coping-with-feelings-of-guilt

Emotional impact of a dementia diagnosis
dementiauk.org/emotional-impact

Grief, bereavement and loss
dementiauk.org/bereavement

Life story work
dementiauk.org/life-story

Other resources

Befriending Networks
befriending.co.uk

Carers Trust
carers.org

Carers UK
carersuk.org

Government benefits calculator
gov.uk/benefits-calculators

NHS eat well guide
nhs.uk/live-well/eat-well

NHS: benefits for carers
nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/benefits-for-carers

NHS: help for young carers
nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/help-for-young-carers

The information in this leaflet is written and reviewed by dementia specialist Admiral Nurses. We hope you find it useful. If you have feedback, please email feedback@dementiauk.org

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We want to ensure no one has to face dementia alone – and we can only do this because of our generous supporters. If you would like to help, please consider making a kind gift.



To donate: call **0300 365 5500**,
visit dementiauk.org/donate-to-support
or scan the QR code.
Thank you.



If you have questions or concerns about any aspect of dementia, please contact our Admiral Nurses.
Helpline: **0800 888 6678** or helpline@dementiauk.org
Virtual clinics: dementiauk.org/book-an-appointment



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