

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.

Additionally, many people are ‘sandwich carers’, looking after their own children or younger relatives while also caring for an older adult – often a parent or parent-in-law. Balancing these dual caring roles can present extra challenges.

However, it is vital that you take care of yourself otherwise your physical and mental health may suffer, which may impact your ability to continue in your caring role.

What is a carer?

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 care services, as well as financial benefits.

You are considered a carer if you regularly support the person with dementia with:

- washing and dressing
- getting out and about
- attending medical appointments
- taking medication
- household tasks like shopping, cleaning and laundry



- looking after their bills and finances
- providing company, or watching over them if they cannot be left alone

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, niggling 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

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- 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](https://www.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](https://www.nhs.uk/better-health/quit-smoking) for advice

Emotional support

Caring for someone with dementia can sometimes be exhausting, overwhelming and worrying, so it is important to have emotional support. This could come from:

- other family members
- friends
- your GP
- a professional counsellor or therapist: you can ask your GP for a referral to an NHS talking therapies service, refer yourself, or look for a private therapist – please see Sources of support on p13-14

Our dementia specialist Admiral Nurses are also here to offer expert, compassionate emotional support, whenever you need it. Please see Sources of support on p12 to find out how we can help.



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. For example, if you previously liked hiking and taking holidays together, consider why those activities appealed to you. Can you recreate them by going for short daytrips, walks in your local area or just sitting in the garden? Or if you enjoyed going to the theatre, could you watch plays on TV?

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
- working together to compile the person's life story – 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 p13 for more information
- taking part together in activities outside the home such as sport, pub quizzes, dance classes, a choir, bowling, or arts and crafts groups

Time to yourself and with others

Although it can be difficult, it is important to try to maintain a social 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 let them know how they can support you, as well as giving you a vital break from your caring role.

Let other family members and friends 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. Do not be afraid to ask them for 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.

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.



Try to continue with activities outside the home such as work, exercise, meeting friends, going to the theatre, supporting a sports team or volunteering.

Make an effort to keep in touch with family members and friends, for example by scheduling a phone or video call for a time when the person with dementia will be asleep, or meeting for coffee when they are at a day centre. Even a short conversation without interruptions could help you recharge your batteries.

Seek support and share experiences with other people who are caring for someone living with dementia, for example at a carers' group or dementia café. Your GP, social prescriber 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. You could also find out about befriending services – these are often run by charities, 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 p12 for our information on the carer's assessment
- Request a needs assessment for the person you care for – this looks at their care needs, and may result in support being put in place, for example from home carers
- 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 p12-14 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



Young carers

Children or young people who have a parent with young onset dementia (where symptoms develop before the age of 65) may end up taking on some caring tasks. They are entitled to a young carer's assessment to look at what support they need – please see Sources of support on p14 for information.

It is worth informing the child's school of the situation so they can offer support. You could also look into young carers' groups where they can meet other children and teenagers who have a caring role. Speak to the GP if you feel they need additional support.

Try to ensure that the young carer can maintain a life outside their caring role, for example by attending extracurricular clubs, playing for a sports team and spending time with friends. You could ask other family members or friends to help with this, for example by giving them lifts to activities if you cannot leave the person with dementia alone.

Our Consultant Admiral Nurse for Children and Young People supports children and teenagers who are living in families affected by dementia. If you would like to enquire about how they can support your child, please contact our Helpline – see Sources of support on p12.

Changes in caring roles

As the person's needs change, you may find it harder to provide their care, and might need to consider additional support, such as home carers or a move into a care home. This can be a difficult decision and it is natural to feel upset, worried and guilty. However, professional support can relieve some of the pressures on you and enable you and the person to spend quality time together, rather than your whole relationship being focused around caring. It can also avoid you reaching the point of burnout.

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 maintain a life outside caring, keeping up with your usual activities and relationships can help you cope with these times of transition.

If you need any support navigating changes in your caring role, please contact our Admiral Nurses – see Sources of support on p12.



Sources of support

If you are living with dementia or caring for someone with the condition, register for our free online sessions, ‘Dementia: what next?’ at [▶ dementiauk.org/dementia-what-next](https://dementiauk.org/dementia-what-next)

To speak to a dementia specialist Admiral Nurse, call our free Helpline on **0800 888 6678** (Monday–Friday 9am–9pm, Saturday and Sunday 9am–5pm, every day except 25th December) or email [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit [▶ dementiauk.org/book](https://dementiauk.org/book)

Dementia UK resources

Carer’s assessments

[▶ dementiauk.org/the-carers-assessment](https://dementiauk.org/the-carers-assessment)

Caring from a distance

[▶ dementiauk.org/caring-from-a-distance](https://dementiauk.org/caring-from-a-distance)

Changing relationships and roles

[▶ dementiauk.org/changing-relationships-and-roles](https://dementiauk.org/changing-relationships-and-roles)

Coping with feelings of guilt

[▶ dementiauk.org/coping-with-feelings-of-guilt](https://dementiauk.org/coping-with-feelings-of-guilt)

Financial and legal sources of support

[▶ dementiauk.org/financial-and-legal-sources-of-support](https://dementiauk.org/financial-and-legal-sources-of-support)

The emotional impact of a dementia diagnosis

[▶ dementiauk.org/emotional-impact](https://dementiauk.org/emotional-impact)

Grief, bereavement and loss

➤ dementiauk.org/bereavement

Keeping safe when you care for someone with dementia

➤ dementiauk.org/keeping-safe

Life story work

➤ dementiauk.org/life-story

Sandwich carers

➤ dementiauk.org/what-is-a-sandwich-carer

Supporting children and adolescents when a parent has young onset dementia

➤ dementiauk.org/supporting-children

Other resources

Befriending Networks

➤ befriending.co.uk

Benefits and financial support for carers

➤ gov.uk/browse/benefits/help-for-carers

British Association for Counselling and Psychotherapy (includes a directory of private therapists)

➤ bacp.co.uk

Carers Trust

➤ carers.org

Carers UK

➤ carersuk.org

Dementia Carers Count

➤ dementiacarers.org.uk

Government benefits calculator

➤ gov.uk/benefits-calculators

NHS Eatwell 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

NHS talking therapies for anxiety and depression (includes details of how to refer yourself)

➤ nhs.uk/nhs-services/mental-health-services/find-nhs-talking-therapies-for-anxiety-and-depression

NHS: young carers' rights

➤ nhs.uk/social-care-and-support/support-and-benefits-for-carers/being-a-young-carer-your-rights

tide: together in dementia everyday

➤ tide.uk.net



**To speak to a dementia specialist Admiral Nurse
about any aspect of dementia:**

Contact our Helpline:

0800 888 6678 or ➤ **helpline@dementiauk.org**

Book a virtual appointment:

➤ **dementiauk.org/book**

**Our charity relies entirely on donations to fund our
life-changing work. If you would like to donate to help us
support more families:**

- Call **0300 365 5500**
- Visit ➤ **dementiauk.org/donate**
- Scan the QR code



Thank you.



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Publication date: September 2025. Review date: September 2028. © Dementia UK 2025

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