

Coping with feelings of guilt



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People who care for someone with dementia often experience feelings of guilt. There are many reasons why this can occur.

- Looking after someone with dementia can be a 24-hour responsibility. You might feel guilty because you are tired and flagging, or because you are unable to be with the person every minute of the day and night
- You might feel you are not living up to your own expectations of what a carer should be, or to other people's expectations
- You may find it hard to relate to the person you are caring for
- At times, you may become frustrated or angry with the person with dementia, speak to them abruptly or lose your temper
- You may feel resentful if the person with dementia can no longer contribute in the way they once did financially or practically, eg helping around the house or with children
- You may feel guilty if you need help with your caring responsibilities – particularly if you decide to use a home carer or respite care – because you feel you should be able to cope with everything yourself
- You may need to rethink promises you made to yourself or the person with dementia as their condition progresses, eg, “I will never move them into a care home”
- You may feel guilty if other areas of your life, such as work, are suffering because of your caring duties – it is common to feel like you are not doing anything well
- You may feel guilty that you have less time to spend with other people, especially if you have young children, and resent the lack of free time for yourself



- If you have health issues of your own and struggle to provide care and/or need to take time out for appointments and treatment, you may experience guilt about having to put yourself first on occasion

Coping with guilt around changes in care

Caring for someone with dementia can be extremely hard. You may reach a point where it is simply not possible for you to provide care without assistance, whether that is from family, friends or professionals. Try to accept that you did not expect or ask to find yourself in a caring role, and that you are doing the best you can.

If you are considering using home carers, arranging respite care for the person with dementia or moving them into a care home, it

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is natural to feel guilty, especially if you previously promised them or yourself that you would care for them at home until the end of their life.

However, circumstances change over time. Back then, you did not know how the person's dementia would progress, so you could not make informed decisions about their future care. There is no shame in having to reconsider these decisions.

It may be helpful to discuss the issue with the person with dementia, if they are able to understand, and/or other family members so you are not making these decisions alone.

Instead of feeling you are letting the person down by bringing in additional support such as home carers or considering a move to a care home, you may find that it is a positive step for both of you. The person with dementia will benefit from professional support; you will be less tired and resentful; and the relationship between you will often improve when you are no longer having to carry out as many caring tasks and can focus on enjoying your time together.

Other ways to cope with feelings of guilt

Guilt is a common emotion when you support someone with dementia. However, caring well for the person also means caring for yourself by looking after your own physical, mental and emotional health. This includes taking steps to avoid becoming overwhelmed by feelings of stress or guilt.

- Try to consider what the person with dementia would do if the roles were reversed. If they were caring for you, what would you want them to do?
- See if someone can come in on a regular basis to sit with the person with dementia or take them out for a walk, a drive



or to a café. This will allow you to take a break. There may be community or faith groups in your area that provide volunteers or ‘befrienders’

- Do not be afraid to ask family and friends for help. They may not realise the extent of your caring responsibilities. People often like to feel useful and may be pleased they were asked
- Remind yourself that it is normal to feel a range of emotions, including guilt – but that these often ease as you adapt to changes in circumstances
- Talk to someone you trust about your thoughts and feelings. Simply being listened to can ease difficult emotions and help reframe your thoughts

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- Consider seeking talking therapy if you are finding feelings of guilt overwhelming. You can speak to your GP about being referred to a counsellor or refer yourself – see Sources of support on p10
- Contact Social Services to request a carer’s assessment. This will identify what support you might benefit from, such as home help or respite care. Please see Sources of support on p9 for information
- Look into what benefits and financial support you and the person with dementia may be eligible for. These may help with the cost of carers or care home fees. Please see Sources of support on p9 for information on financial and legal support
- If you work, speak to your employer about your caring responsibilities. This will help them understand what you are dealing with and put support in place, for example allowing you time off to attend appointments with the person with dementia
- If you also care for children or young people, explain in an age-appropriate way why you have less time to spend with them than you used to
- Consider asking another family member or friend if they could step in to look after the person with dementia so you can spend some time with your children or teenagers, either regularly or just for important occasions like parents’ evenings, school plays and sports days

Please do not struggle alone with feelings of guilt. There are many people and services that can offer advice and support, including our free Helpline – see Sources of support on p9 for contact details.



Guilt in children and young people

Children and young people may also feel guilt when someone close to them is living with dementia, especially if they have a parent with young onset dementia (where symptoms develop before the age of 65). They may feel it is their fault because they have been ‘naughty’. They may feel guilty about carrying on with their normal activities, like clubs and socialising, if things are difficult at home. Or they may find themselves in the role of young carer and experience guilt if they find this difficult or feel resentful of their responsibilities.

It is important to explain what is happening in a way that suits the child. Make sure they understand that their parent’s dementia is not their fault, and that they could not have done anything to prevent it. Keep conversations open and honest so the child knows they can talk about their feelings.



Try to ensure the child can carry on with their usual activities, for example by arranging for a friend to give them lifts if you cannot leave the person with dementia, and reassure them that they do not need to feel guilty for doing so.

Take the time to acknowledge that being a carer is a difficult role, and that it is natural to struggle with it – regardless of age. You can ask your GP about local groups for young carers so they can take time out and share their experiences with others.

For our resources for children and teenagers, please see Sources of support on p10.

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)

Considering a care home for a person with dementia

[▶ dementiauk.org/choosing-a-care-home](https://dementiauk.org/choosing-a-care-home)

The emotional impact of a dementia diagnosis

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

Financial and legal sources of support

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

Finding help and support at home

➤ dementiauk.org/finding-help-assistance

Looking after yourself as a carer

➤ dementiauk.org/looking-after-yourself-when-you-care

Supporting children and young people when a parent has young onset dementia

➤ dementiauk.org/supporting-children

Other resources

Befriending Networks

➤ befriending.co.uk

Carers Trust

➤ carers.org

Carers UK

➤ carersuk.org

Find local Adult Social Care Services

➤ nhs.uk/service-search/other-health-services/local-authority-adult-social-care

NHS: carers' breaks and respite care

➤ nhs.uk/social-care-and-support/support-and-benefits-for-carers/carer-breaks-and-respite-care

Refer yourself for NHS talking therapy

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



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

Contact our Helpline:

0800 888 6678 or [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Book a virtual appointment:

[▶ dementiauk.org/book](https://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](https://dementiauk.org/donate)
- Scan the QR code



Thank you.



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Helping families face dementia



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