

Coping with feelings of guilt



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 role. 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 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 – as 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 that 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, including your 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 time to access appointments and treatment, you may feel guilty 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 24-hour care without assistance, whether that is from family, friends or professionals. Try to accept that you did not 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 is natural to feel guilty, especially if you previously promised them

or yourself that you would care for them at home for the rest 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.

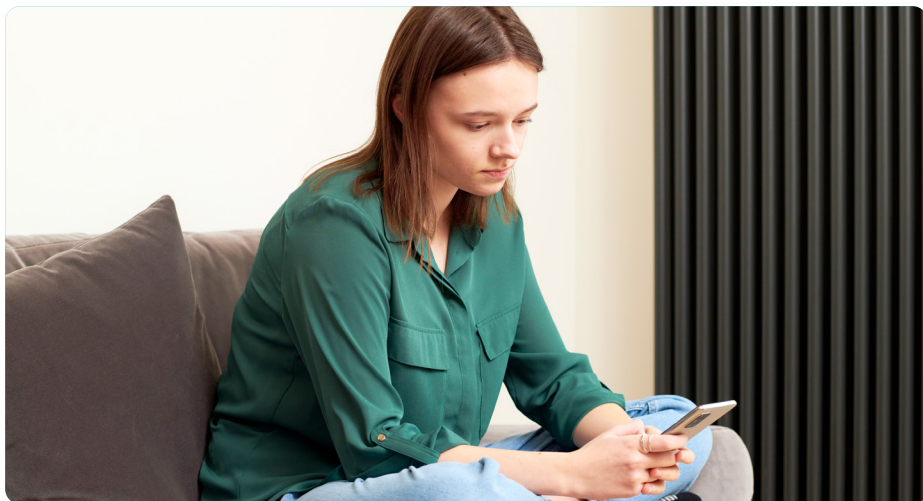
It may be helpful to discuss the issue with the person with dementia, if they are able to understand, and/or other family members so you are not making these decisions alone.

Rather than feeling you are letting the person down by hiring carers or moving them into residential care, you may find that it actually benefits you both – they 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 natural emotion when you support someone with dementia. However, you can only care for the person well if you are in good physical, mental and emotional health yourself, and that includes not being 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 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
- 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 p6 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 p6 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, eg 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
- Be aware that children and young people may also feel guilt – for

example, if they have a parent with young onset dementia (where symptoms develop before the age of 65), they may feel it is their fault their parent has dementia because they have been ‘naughty’. For our resources for children and teenagers, please see Sources of support on p6

Please do not struggle alone with feelings of guilt. There are many people and services that can offer advice and support, including our Dementia Helpline and virtual clinics – see Sources of support on p6 for contact details. If your feelings are overwhelming, speak to your GP, who may be able to refer you for specialist help.

Sources of support

To speak to a specialist dementia nurse about coping with guilt 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-a-clinic-appointment

Dementia UK resources

The Carer's Assessment
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

Considering a care home for a person with dementia
dementiauk.org/choosing-a-care-home

The emotional impact of a dementia diagnosis
dementiauk.org/emotional-impact-of-the-diagnosis

Financial and legal sources of support
dementiauk.org/sources-of-support-and-advice

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

Resources for parents
dementiauk.org/parents

Resources for children and young people
dementiauk.org/young-people



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/](https://nhs.uk/service-search/other-services/Local-Authority-Adult-Social-Care/LocationSearch/1918)

[other-services/Local-](https://nhs.uk/service-search/other-services/Local-Authority-Adult-Social-Care/LocationSearch/1918)

[Authority-Adult-Social-Care/](https://nhs.uk/service-search/other-services/Local-Authority-Adult-Social-Care/LocationSearch/1918)

[LocationSearch/1918](https://nhs.uk/service-search/other-services/Local-Authority-Adult-Social-Care/LocationSearch/1918)

NHS: carers' breaks and

respite care

nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carers-breaks-and-respite-care/

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

Publication date: February 2023

Review date: February 2025

© Dementia UK 2023

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-a-clinic-appointment



dementiauk.org • info@dementiauk.org

Dementia UK, 7th Floor, One Aldgate, London EC3N 1RE
Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC 047429).