



DementiaUK

Helping families face dementia

Coping with feelings of guilt

Caring for someone with dementia



Feeling guilty when caring for someone with dementia

People who care for someone with dementia can often feel guilty. There are many reasons why these feelings of guilt can occur.

Looking after someone with dementia can be a 24-hour a day job, and you might feel guilty because you are tired and flagging, or simply not able to be with the person every minute, day and night. It is important to realise you cannot care for someone 24-hours a day.

You might feel guilty because you are not living up to your expectations of what a care giver should be, or to other people's expectations. Remember, you are only human, and it is a natural response to feel angry, distressed or resentful, at times.

Sometimes we make promises to loved ones about what we will do when they become unwell, for instance, "I will never put you into a care home".

However, circumstances change over time; back then, you did not have all the information about how things would affect you both. You might need to reconsider that promise or decision. It could 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 making these decisions together.

How can you cope with feelings of guilt

Practically speaking, you can only care for someone well if you are in good health yourself, and that includes not being overwhelmed by feelings of stress or guilt.

Caring for someone with dementia can be extremely hard. Try to be kind to yourself: you did not ask for this job and you are doing the best you can. Guilt, unfortunately, is natural, and it might not be possible to stop guilt altogether – yet you do not have to be consumed by it.

Firstly, consider what the person with dementia would do if the roles were reversed. If your loved one

was caring for you, what would you want them to do? When our circumstances change, the way we respond to them needs to change too. There is no shame in that.

Secondly, find out what help there is available in your area. You don't have to carry the entire responsibility alone; no one does. You could consider:

- Having a carer coming in on a regular basis to sit and talk with the person with dementia or to take them out for a walk, drive or to a cafe. This could enable you to recharge your batteries and have a break
- Asking for help from family and friends. Some people might think you are coping well and so might not offer help. People like to feel useful and may be pleased they were asked
- Requesting a carer's assessment from social services, as you may be entitled to respite
- Looking into what financial support you are entitled to. People diagnosed with dementia, and in some instances

their carers, may be entitled to Council Tax discounts, disregards and exemptions, Attendance Allowance (or Personal Independence Payment if dementia was diagnosed under 65 years of age) and you may be entitled to Carer's Allowance. This can all help with the cost of arranging some respite care

Please don't struggle on alone. There are people and services available who you can contact for advice and support. Sometimes just a little bit of help can make all the difference.

If you have any questions about local respite care, please speak with your GP or local social services. For any advice on coping with guilt, your financial entitlements, how to look into respite services, or anything else about dementia, call the Admiral Nurse Dementia Helpline on **0800 888 6678**.

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support Dementia UK, please visit dementiauk.org/donate or call **0300 365 5500**.

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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email helpline@dementiauk.org

Open Monday – Friday, 9am – 9pm
Saturday and Sunday, 9am – 5pm



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