



For carers, By carers

Grief and loss

Carers for people with dementia can experience complex feelings of grief and loss throughout the journey from diagnosis through to the advanced stages – this is often called anticipatory or living grief. You can grieve for the loss of the person as they were and your relationship as well as your own identity. This can last long beyond the person's death. You may have been anticipating their death but this can still be a shock and you may be unprepared for how you feel. For carers the impact of the end of the caring role can be significant, both emotionally and financially in addition to the finality of the loss of the person you cared for, and this can add to the experience of grief and loss. These feelings are normal, and everyone's experience is different.



What carers would like to share with you

- There is no right or wrong way to feel. Grief is physically and emotionally exhausting – take time for yourself. Don't try to do it alone.
- Anticipatory grief does not mean you are giving up on someone. They are still here and you can make new memories together. Your relationship will change but being there with the person can give great comfort.
- You may feel guilty about some of your thoughts and feelings – you are not the only one.
- Talk about the person and share your memories. Remember all the happy times you shared. It is not wrong to smile and laugh. Don't feel guilty.
- Different members of the family may experience grief in different ways and that is fine. It could mean that you might find it easier to seek support outwith the family.
- Keep connected with friends and family and try to make some new connections if you can.
- If you have a faith this can provide a source of support and help connections.
- Try to avoid if possible making any major decisions whilst you are grieving.
- Talk to others with similar experiences. Peer support can be best.

Did you know?

There are a number of supports and organisations available to help with grief and loss:

- Alzheimer Scotland's [Grief and Bereavement](#) resource includes information on living grief, coping with grief, and tips for readjusting.
- The national [SIGN Guidelines](#) include information for carers about grief.
- [Cruse Scotland Bereavement Support](#) provides professional support, and there's also information available around [anticipatory grief](#).
- The [Carers Trust](#) offers help for carers, including coping with grief when caring ends.
- Alzheimer Scotland's 24 hour Freephone Dementia Helpline on 0808 808 3000 is available to provide emotional support and can signpost you to these and other resources.

"I did a lot of grieving as mum's dementia advanced, but a lot of those feelings came back when she died, and I wish I had known that might happen and was normal. People expected me to be relieved, and I was. But I felt desperately sad too."

Top Tips for Carers

- Put in place as soon as possible a Power of Attorney and Advance Statement that truly reflects the wishes of the person with dementia – it's key for future proofing.
- As a carer you have rights protected by legislation.
- If you provide regular care you are entitled to a Carer's Assessment which will enable Social Services to offer you advice and support.
- Don't become isolated. Engage with family, friends and neighbours. Explain the situation to help them understand your feelings.
- Keep handy a list of important phone numbers such as for the GP, Social Work and, of course, Alzheimer Scotland.
- Keep a diary of appointments where you record all the support and advice available, and any action taken.
- Technology and apps can help people with dementia to live well and safely and can provide peace of mind for carers.
- Remember that before you were a carer you were the person's family, friend, partner or neighbour – that will never change, even as your caring responsibilities increase.
- Your own health and wellbeing are VITAL. Try to make time for yourself. Continue with your hobbies and sports. Accept help.

Contact Alzheimer Scotland for more help and information

Further information

This is one of a series of 'For Carers, By Carers' leaflets:

- Going for a diagnosis
- Helping someone with dementia to live well
- Working with professionals and services
- Going into hospital
- Moving into a care home
- Looking after yourself
- When problems arise
- Grief and loss

Email activevoice@alzscot.org or

Visit www.alzscot.org/ndcan for copies.

Useful contacts

Alzheimer Scotland's
National Dementia
Advisor Service
0300 373 5774

Alzheimer Scotland's
24 hour Freephone
Dementia Helpline
0808 808 3000

www.alzscot.org



About NDCAN

We are a national, member led campaigning and awareness raising group of current and former dementia carers in Scotland. Formed in 2011, we exist to make the voices of dementia carers heard and to raise awareness of the issues impacting on carers. Find out more about NDCAN and how to join us at www.alzscot.org/ndcan

'For Carers, By Carers' were first created in 2016 by NDCAN members, with funding from The Life Changes Trust, to share their knowledge to help other carers. In 2024 members reviewed and updated them.

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