

Grieving following the death of someone with dementia

Looking after yourself



Alzheimer National Helpline

1800 341 341

The grief process

Grief is both a universal experience and a unique experience. Grief does not happen in any set way, or have any defined stages. Grief is a natural process of reaction and adjustment to loss and change. When we lose someone or something that is important to us, we grieve.

The feelings and thoughts of grief come and go in waves. Sometimes you may feel you are coping quite well and then experience a burst of grief as you are reminded of your loss.

The truth is we don't "get over" grief. It is not like having the flu, where you feel very ill and then begin to feel a bit better until you finally return to being your old self again. Grief is a process that changes us and challenges us.

Most people find that over time and with the help of supportive family and friends they find their way through grief, and while they still may have low days or difficult days, their grief recedes and they can pick up the parts of their life that have been put on hold.

- Grief is a process and it takes time
- Everyone's grief is different and unique
- There is no right or wrong way to grieve
- Strong emotions and thoughts are part of grief

The experience of grief

The experience of bereavement can at times be painful and confusing. Even if a person has had a long illness such as dementia and death was expected, there may still be a feeling of shock and strong emotions and thoughts. Grief can be experienced emotionally, physically, socially and spiritually.

Feelings

The finality of a death may bring a sense of pain and sadness, and it may also bring other feelings, such as relief, guilt, anger, feeling depressed, lonely, frightened or helpless. Feelings are a part of grief, but there are no 'right' feelings and feelings come and go.

Physical

You may feel more tired than usual, yet find it hard to sleep. It is not unusual to have very vivid dreams. Your appetite may change and energy levels may be low. Your concentration may be low so that you are absent-minded or have difficulty absorbing new information. These are grief and stress reactions which are often experienced.



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The experience of grief

Thoughts

You might find you spend a lot of time thinking about the loss and the events leading up to it. It is normal to spend time thinking about 'if onlys' and how things might have been different. Many people find they think a lot about why it happened. Although you know the person has died, you may 'forget' briefly, particularly when you wake up. You may imagine you see or have contact with the person who died. These thoughts can be overwhelming or frightening at times but they are grief reactions.

Social changes

You may find you need time alone or you may feel a need to tell the story of your loss many times over. You may find you seek out people who can understand your need to talk and distance yourself from people who are uncomfortable with this. You may be surprised at who can support you and who cannot. You may miss the people who cared for your loved one while they were ill and miss the routine in your life, for example going to a day centre or visiting a nursing home.

Spiritual struggles

You may struggle with questions about the meaning of life, your relationship with God and your beliefs about what happens after death. Although it may be difficult to imagine in the early days of grief, as time goes on you will find resources and strength within yourself that you didn't know you had. Even as we struggle with grief, we can learn and grow with it.

What can help?

Accept your feelings

Try to express them with a good friend or write them down. Know that it is common to feel conflicting emotions. Relief is often mentioned as a feeling by family members of someone who died with dementia. Allow yourself to notice and accept any feelings of relief. Acknowledging feelings of relief is not disloyal - the person who has died was still loved and valued by you.

Remember

Talk about the person, taking time to remember stories from his or her life before they had dementia and during their illness.

Take care of yourself

Try to sleep and eat well, and to take some gentle exercise.

Be informed

Consider reading about, or talking to other people whose relative died with dementia. While no two experiences are the same, you may share something in common. Seek out accurate information about grief and loss.



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What can help?

Accept help

Accept emotional and practical support from friends and family.

Know that people may not understand your grief

People may have different ideas or expectations about bereavement - if a person had been ill for a long time some people may think you have had time to come to terms with the loss. Your grief is your grief, not every one may understand the complexity of dementia and the toll it takes.

Talk to someone you trust about your feelings

This can be a good friend, another carer, an understanding professional, or supportive members of your family. The important thing is that you feel safe and accepted.

Combat feelings of isolation and loneliness

Over time, try to develop some new routines. You may find you have gaps in your day, particularly if you were a carer, and so you may risk becoming isolated. Arrange to meet with friends to do something enjoyable. Taking a break may also help to relieve stress and grief and strengthen your support network. Stay involved in activities you enjoy and consider new hobbies.

Remember that grief comes and goes

Even though you may be coping quite well most of the time, there may be times when you feel particularly sad or upset. You may be reminded of the person by something you see or hear, or certain significant days like anniversaries or birthdays which can bring on a surge of grief. This does not mean that you are not making progress, this is simply the normal process of grief which ebbs and flows, a bit like waves on a beach.



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When to seek extra help

Because grief and loss are normal life experiences, most people find their way through the pain with support from friends and relatives.

Some people may find it helpful to attend a bereavement support group, or one-to-one support in their locality. This may be helpful if you would like to talk to people outside of family and friends, or if you feel you would like extra information.

It is a good idea to talk to your General Practitioner (GP), if:

- you are feeling very low or anxious
- you are very tired and unable to sleep
- you are worried about how you are coping
- you have been bereaved for more than six months and feel your grief is not progressing

A very small number of people get stuck in their grief and your GP can help identify supports, such as professional counselling.

For further information and support

Directory of Bereavement supports in Ireland

Website: www.tusla.ie
Services: www.tusla.ie/services/family-community-support/counselling/

Website: www.healthpromotion.ie

Information about Grief and loss:

Irish Hospice Foundation

Phone: 01 6793188
Website: www.hospicefoundation.ie
www.bereaved.ie

Helpline Services:

The Alzheimer Society of Ireland's National Helpline

Helpline: 1800 341 341
Website: www.alzheimer.ie

Senior Helpline

Senior Help Line is a confidential listening service for older people:
LoCall: 1850 440 444

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