

Loss and grief when a family member has dementia

Looking after yourself

It is common for people to have feelings of loss and grief as their life and the life of the person they care for, is changed by dementia. These changes can have a significant impact on you and on other family members.

You are likely to experience feelings of grief as the illness progresses. It can be helpful to recognise that this is normal when a person in your family has dementia and that it is important to look after yourself in relation to these experiences. As a family member at times you may feel worried, anxious, resentful and overwhelmed. It is helpful to remember that the person with dementia can experience these feelings as their abilities change and they adjust to their diagnosis.

The changes that dementia brings

Dementia is progressive and that means that over time, the person with dementia will experience changes in how they communicate, remember, think and manage day-to-day tasks. It is not possible to say exactly how long a person will live with dementia or how their dementia will progress. For most people changes happen gradually and there is time to adjust.

These changes also impact families and you will need time to adjust both practically and emotionally. Some of the changes caused by dementia involve loss of independence for the person with dementia. Family members may have to take on new tasks such as paying bills, legal paperwork etc. This may feel overwhelming.



Alzheimer National Helpline

1800 341 341

Grief - the process of adjusting

Adjusting to the changes that dementia brings is a process. It can affect us in many different ways – emotionally, mentally, physically, and spiritually. Sometimes we can feel that we are managing well and at other times we can be surprised by strong feelings. These can include anger, guilt, frustration and resentment. This process of adjustment is similar to that of grieving – except that the person is still with you.

Such feelings are a normal part of the process of grieving. But it is important to realise that you may be under a great deal of stress and to seek emotional support for yourself.

Grief surges

A grief surge is a sudden feeling of being overwhelmed, a literal hit of grief. This sudden jolt of grief seems to come out of nowhere and strikes frightening deep pain at all levels. Something as simple as a sound, smell, picture, or phrase can bring on a grief surge. Anniversaries, holidays, birthdays etc can also trigger grief surges.

What helps

When you experience a grief surge, try not to panic, acknowledge your feelings, seek support and know that this will pass. It is a normal, though at times difficult part of the grieving process.



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Types of grief or loss

There are two types of grief that may be experienced following a diagnosis of dementia, these are:

Anticipatory Grief

Anticipatory grief is where we experience grief for losses that we anticipate in the future. There may be things that we dread, for example many families dread their loved one not being able to recognise them. Often we are able to manage these things better than we thought we would.

Ambiguous Grief

We can experience ambiguous grief when the person is physically present but psychologically or emotionally absent. For example, when the person with dementia is physically alive but no longer able to participate in conversations like they used to or have the same role in the family they had before their diagnosis. Often we are able to find new ways to engage with and spend time with the person which focuses on what they can still do.

Both of these types of grief can be difficult for others and even yourself to recognise and acknowledge. Yet they are a normal response for some people where a family is supporting a person with dementia. It is important that you can recognise if you are affected by these types of grief and seek support that will help you to cope.

What can help

Accept your feelings. Don't bottle them up. Let yourself be as sad as you want. Work through your anger and frustration. These can be healthy emotions. Know that it is common to feel conflicting emotions. Its okay to feel love and anger at the same time.

Prepare to experience feelings of loss more than once. As dementia progresses, it is common to go through feelings of grief and loss again. Accept and acknowledge your feelings. They are a normal part of the grieving process.

Talk to someone you trust about your feelings. This can be a good friend, another family living with dementia, an understanding professional, or supportive members of your family.

Relieve tension through crying or, perhaps by punching a cushion or a pillow. However make sure you do it well away from the person with dementia or you may distress them. Do something fun, get some exercise and importantly, treat yourself regularly.

Know that people may not understand your grief. Most people think grief happens when someone dies. They may not know that its possible to grieve deeply for someone who has a progressive cognitive illness.

Combating feelings of isolation and loneliness. Caregivers often give up enjoyable activities and companionship. Arrange to meet with friends to do something enjoyable. Taking a break may help you relieve stress and grief and strengthen your support network. Stay involved in activities you enjoy. Invite friends to drop in for a chat or to phone you regularly.

Seek Information and Support. Seek and accept help. Accessing information about dementia and supports and services for you and the person with dementia can be a vital step. Family carer support groups, social clubs, day centres and home care can help you to build a support network for everyone. Contact The Alzheimer Society of Ireland to find your local supports.

Make sure you see your GP if you are feeling very low or anxious or if you are very tired and unable to sleep. It is important to try to prevent your normal feelings of sadness slipping in to depression, which is much harder to deal with.



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If a person with dementia moves to a nursing home

Not every person with dementia moves to a nursing home but many people do. This can be one of the most difficult transitions for everyone involved. As a family member you may grieve another change in your relationship. Feelings of loss and grief can be mixed up with guilt and relief, which can last for a surprisingly long time.

It takes time to adjust to a move to nursing home care. It can take time for the person with dementia to settle into their new environment. It can take time for you to adjust to a new routine and you may feel a wide range of emotions. You may miss the person's presence. You may experience emptiness.

You may miss your role as a carer. You may feel very tired, both physically and emotionally. You may be relieved that the day-to-day responsibility of caring is no longer there and you may want to continue to be involved, but in a different way.

What can help

- Try to take it easy until you feel your energy levels rise again.
- Be kind to yourself, take things slowly and try to ensure that you have plenty of support from family and friends.
- If you still want to be involved in caring for your relative, speak to the staff and explain exactly what you would like to continue to do. Ask them for suggestions on how you can help.
- If your daily routine previously revolved around caring for your relative, creating a structure to your day may help you get through the difficult early months. Pick interests and hobbies that you enjoy and reach out to friends you enjoy spending time with.
- Visiting your loved one with dementia in their new home is important and can be one part of your new routine. You will gradually build a life for yourself that includes visits and you will work out the frequency and length of visits that works for you. Other family members and friends can also visit. For tips and suggestions on visiting a person in a nursing home you can contact the Alzheimer Society.
- Remember that there is no 'right' or 'wrong' way to feel. You experience your own feelings in your own way, and no one has the right to tell you how you should feel.



THE ALZHEIMER
SOCIETY of IRELAND



E2

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For further information and support

Helpline Services:

The Alzheimer Society of Ireland's National Helpline

A free and confidential service providing information about dementia, living well day-to-day and about supports and services in your locality.

Helpline: 1800 341 341

Website: www.alzheimer.ie

Information about Grief and loss:

Irish Hospice Foundation

Phone: 01 6793188

Website: www.hospicefoundation.ie

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The Alzheimer Society of Ireland, ASI, has taken great care to ensure the accuracy of the information contained in this factsheet. ASI is not liable for any inaccuracies, errors, omissions or misleading information. The factsheet was part funded with a grant from The Irish Hospice Foundation.