

Loss and Grief in Dementia



Why is this important?



“You go into the deepest grief that one can go into for the life you will never have. There’s a huge pain for families and a huge pain for yourself in realising that life will never be as it was” (Helen Rochford-Brennan, Chairperson of the Irish Dementia Working Group)



Loss and Grief are fundamental parts of the dementia experience for the person with dementia and their family. Dementia can lead to the person experiencing multiple losses throughout their journey with dementia which build in number and magnitude as the condition progresses. These types of losses can go unrecognised.

LOSS: Loss is the experience of being without someone or something that is of significance to us.

GRIEF: is the natural process of reaction and adjustment to loss and change in a person's life.

Loss and Grief commonly encountered as part of dementia experience



Ambiguous loss: Ambiguous loss can occur when the person with dementia is physically present but they are no longer the same person they once were. Ambiguous loss can lead to mixed and often quite confused feelings for family members. It may be helpful to find other ways of engaging with the person with dementia by focussing on their abilities in order to help adjust to the changes which dementia brings.



Anticipatory Loss: Anticipatory loss refers to losses which we anticipate will happen in the future in the context of facing a life-limiting illness. In dementia, anticipatory losses can happen for the person with dementia and their families.

Disenfranchised grief: Disenfranchised grief is a 'hidden' grief which happens when losses are not appreciated, recognised or understood by others. Because of this, it is not publicly acknowledged or socially shared. Grief related to the experience of living with dementia is often disenfranchised because of a lack of awareness, stigma related to the diagnosis of dementia or other reasons. This type of grief can be very isolating for the person experiencing it.



Key Considerations for Good Practice

1. Be aware that loss and grief are fundamental parts of the dementia experience
2. Develop knowledge and understanding about loss and grief
3. Recognise loss and grief when you encounter it and develop appropriate responses
4. Reflect on how the loss and grief you encounter in your work affects you in your work

Supporting the person with dementia experiencing loss and grief

1. Be aware of the types of losses commonly encountered by a person with dementia.
2. Develop skills in recognising loss and grief in the person with dementia: Grief can manifest in many different ways. As a person with dementia's ability to communicate verbally changes, it is essential that staff recognise that grief can be expressed in many ways such as anxiety, restlessness or other responsive behaviours which can indicate and express inner pain. All behaviour should be viewed as a form of communication.
3. Truth telling and dementia: deciding to tell or not to tell a person about their losses (past or present) should be done as part of a team.
4. Provide support for the person with dementia to grieve the myriad of losses they may be experiencing.
5. Explore the person with dementia's spiritual needs.

Truth telling in dementia

- ✓ People with dementia have a right to information and to make decisions about their lives. This includes the right to hear, respond and process to news relating to losses in their lives and the right to grieve.
- ✓ Always take a person-centred approach to decisions relating to truth-telling.
- ✓ Work within a team and include the person's family as appropriate.
- ✓ Always validate emotions of the person.
- ✓ Decisions about truth telling should be based on:
 - The person's current beliefs/knowledge and experience
 - An ongoing assessment of the person's capacity to register, process and retain information pertaining to their losses;
 - The person's communication skills and how best to support the person's understanding.
- ✓ Observe how the person with dementia responds to different approaches to supporting them with their losses, document what works best and be consistent in your responses to the person. However, be aware that what works well for a person today may change from day to day so there is a need to regularly review approaches taken to support a person.



Providing support for a person with dementia to grieve

1. Know the person well.
2. Validate and acknowledge the person's emotions.
3. Understand connections.
4. Use environmental cues.

Supporting families of people with dementia with loss and grief



1. Develop good working relationships with family members of the person with dementia. These relationships should be based on mutual trust, respect for each other's roles and clarity relating to expectations of one another.
2. Be aware of the types of losses and the transitions encountered by family members of a person with dementia.
3. Be sensitive to family dynamics which will change over time. Seek to meet the family where they are at.
4. Pay attention to family relationships and the losses occurring in the context of these relationships in addition to the stage of dementia which the person is at.
5. Recognise and respond to grief when you encounter it:
 - Use active listening skills
 - Validate and support the expression of thoughts and emotions
 - Encourage people to think about their support needs
 - Signpost the family to information and resources to support them with their grief
 - Support family members to recognise and respond to changes in their lives and to anticipate and plan for the future.

Guidance to support healthcare staff and organisations in the area of loss and grief is available in the guidance document.

This factsheet has been developed as a visual aid to accompany The Irish Hospice Foundation's Dementia Palliative Care Guidance Document No.3: **Loss and Grief in Dementia**. This should not be used as a stand-alone reference. The full document is available from www.hospicefoundation.ie



The Irish Hospice Foundation

Striving for the best care at end of life for all