

# Loss and Grief in Dementia



## Why this is important?



Loss and Grief is a fundamental part of the dementia experience. Living with dementia can lead to the person with dementia experiencing multiple losses throughout their journey with dementia, which can build upon each other. These types of losses can go unrecognised. Losses and the grief that can occur as a reaction to those losses can occur for the person, their families and for you as a staff member.

**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.

## Types of loss commonly encountered as part of the dementia experience



**Ambiguous loss:** Ambiguous loss occurs in dementia when the person remains physically present but is no longer the person they once were. Ambiguous loss may lead to very mixed and often confused feelings for family members. It is possible to find different ways of engaging with the person and adjusting to the changes which dementia brings.

**Anticipatory Loss:** Anticipatory loss refers 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 :** This refers to grief which is hidden. It is not validated, appreciated or understood by others, it is not publically acknowledged or socially shared (28). 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 (\* key consideration 3 is related to staff only)

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

**“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)

This factsheet is a visual aid to accompany IHF Guidance Document 3: **Loss and Grief in Dementia**. It is available to download on [www.hospicefoundation.ie](http://www.hospicefoundation.ie)



**The Irish Hospice Foundation**

Striving for the best care at end of life for all

## Supporting the person with dementia with 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 dementia: Grief can present in many ways. When a person cannot verbally communicate their losses, grief or pain, it is essential that you develop skills in observing and facilitating communication in a number of different ways.
3. Truth telling and dementia – deciding to tell or not to tell a person about their losses 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 a person with dementia's spirituality

### 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
- ✓ 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.



### 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
5. Explore the person's spiritual needs

## 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.