

PALLIATIVE CARE FOR THE PERSON WITH DEMENTIA

## GUIDANCE DOCUMENT 3

# Loss and Grief in Dementia



This guidance document is a product of the Irish Hospice Foundation's Changing Minds Programme. Changing Minds is a three year project which is co-funded by the Irish Hospice Foundation and The Atlantic Philanthropies. This document entitled "Loss and Grief in Dementia" is the third in a series of seven guidance documents for healthcare staff in promoting and enabling excellence in end-of-life care for people with dementia.

## **DISCLAIMER AND WAIVER OF LIABILITY**

This guidance was developed after careful consideration of the evidence available at the time of publication. Whilst every effort has been made by the authors to ensure the accuracy of the information and material contained in this document, errors or omissions may occur in the content.

This guidance document is not intended as a sole source of guidance on loss and grief in dementia. It is not intended to replace ethical and clinical judgment or to establish a protocol for people living with dementia. Guidance documents do not purport to be a legal standard of care. This guidance document does not override the individual responsibility of healthcare staff to make decisions appropriate to each person with dementia's individual circumstances. Adherence to this guidance will not ensure successful outcomes for the person with dementia in every situation.

## **ACKNOWLEDGEMENTS**

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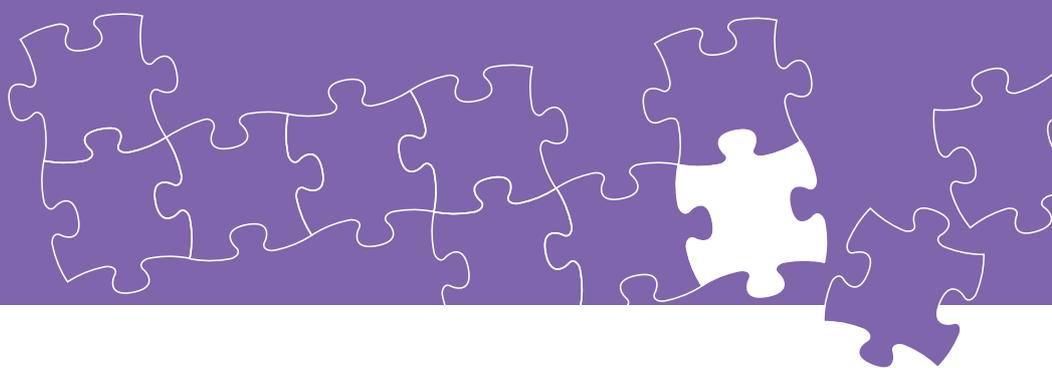
Finally, the Irish Hospice Foundation would like to thank all of the individuals and organisations who gave feedback as part of the consultation process (see Appendix 3 for a list of submissions received).

## **REFERENCE:**

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## GLOSSARY OF TERMS

- Loss:** Loss is the experience of being without something or someone that is of significance to a person (1).
- Grief:** Is the natural process of reaction and adjustment to loss and change in a person's life (Adapted from (1)).
- Anticipatory Loss:** Anticipatory loss refers to losses which we anticipate will happen in the future in the context of a life-limiting illness (2).
- Ambiguous Loss:** Ambiguous loss occurs when the person with dementia is physically present but psychologically or emotionally altered in some way (3).
- Complicated grief:** Complicated grief is a specific diagnosis which is made when a person gets 'stuck in their grief' and grief has a pervasive impact on their ability to function over a long period of time. CG can be diagnosed following a thorough clinical assessment as early as six months' post-bereavement (4). CG affects 2-3% of the population but this rate may be as high as 20% for family carers of people with dementia (5,6).
- Disenfranchised Grief:** Disenfranchised grief is a 'hidden' grief. This happens when losses are not appreciated/recognised or understood by others and this means that losses are not openly acknowledged or socially sanctioned/ shared (7).
- Grieving Style:** Grieving style refers to how a person experiences their loss internally and how they express their loss to the outside world. There are three major types of grieving style used in this document – intuitive, instrumental and blended (8).
- Grief work:** This is the intellectual, emotional, physical and spiritual effort of adaptation that is required after any personally significant loss/ change (9).
- Grief surge:** A grief surge is a sudden feeling of being overwhelmed by grief (10).
- Compassion fatigue:** This refers to physical, emotional and/or spiritual exhaustion where healthcare staff lose their ability to provide the same level of compassion and care to people and their families as they had previously (11).
- Stress:** Is the pressure we encounter in our daily lives. Stress can be positive or negative. We can thrive on positive stress but negative stress can be a threat to our physical and mental health (12).

**Burnout:**

Is a common response to persistent stress (11).

**Personhood:**

A standing or status that is bestowed upon one human being, by others, in the context of relationship and social beings, implying recognition, respect and trust (13). The aim of dementia care is to maintain personhood in the face of a condition which causes progressive decline in the person's abilities.

**Person-Centred Care:**

Is care which is founded on the ethic that all human beings are of absolute value and worthy of respect, no matter their disability, and on the conviction that people with dementia can live well with dementia and lead fulfilling lives (14).

**Responsive Behaviours:**

this is a term which refers to responses which a person with dementia may use (such as words, sounds, actions or gestures) to express something important about their personal, social or physical environment. All personal expressions have meaning and behaviour should always be viewed as a method of communication.

## BACKGROUND AND CONTEXT

Dementia is an umbrella term used to describe a range of conditions which cause changes and damage to the brain. Dementia leads to a progressive decline in multiple areas of a person's ability to function on a daily basis: in their memory, their communication skills, their ability to perform daily tasks, and in their physical abilities (15). The specific symptoms that someone with dementia experiences will depend on the parts of the brain that are damaged and the disease that is causing the dementia (16). The number of people living with dementia in Ireland in 2016 is estimated to be over 50,000 and this number is set to treble by 2045 (17).

Dementia is a chronic, life limiting condition (18–20). People with dementia have a unique set of care needs which include; a progressive cognitive impairment, diminishing capacity, communication difficulties, possible responsive behaviours and a prolonged illness trajectory leading to uncertainty in relation to prognosis (15,21)<sup>1</sup>. People living and dying with and or/from dementia are therefore a particularly vulnerable group who require healthcare staff to have knowledge, skills, competence and confidence relating to dementia and palliative and end-of-life care (22). Palliative dementia care involves supporting the person and their family to address and relieve the pain, distress and discomfort associated with advancing dementia and inviting them to make decisions about their future care needs (23). Providing this care and comfort presents services with a significant challenge as each person's journey through dementia is unique with huge variability in the length of the final phase, difficulties in communication and a lack of awareness about the terminal nature of dementia (20,24). This is often compounded by healthcare staff lacking basic knowledge, awareness and skills in supporting people with dementia (25,26). It is recommended that palliative care principles are introduced in the person's care early on, ideally soon after diagnosis when the person can meaningfully engage in discussions about their future care (18,23,24).

As illustrated, there has been growing recognition of the complexities involved in providing end-of-life care for people with dementia in the literature; however, there is a notable void of practice guidelines to support healthcare staff in delivering excellence in end- of-life care for people with dementia. In order to support healthcare staff in meeting the palliative care needs of people with dementia, there was a call for the development of practice guidelines within the Irish context (23,27–29).

In 2013, the Irish Hospice Foundation (IHF) embarked on a three year programme entitled *Changing Minds: Promoting Excellence in End-of-Life Care for People with Dementia*. The aim of this programme is to enable more people, particularly those living with dementia to live and die with dignity at home or in residential care settings.

The programme seeks to achieve the following:

- Ensure that palliative care for people with dementia is prioritised and developed in all care settings and more people are supported to be able to die well at home.

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<sup>1</sup> See page 64 and 65 for further information on the progression of dementia and the trajectory of dementia.

- Better end-of-life care in residential care settings for older people, with a particular focus on people with dementia.
- Increased public discourse on death and dying, with a focus on those with dementia engaging in early advance planning.

The programme has six projects, one of which has a dementia specific focus. The aim of this project is to develop and adapt practice tools and service models for people with dementia. The project committed to develop a suite of guidance documents in order to support healthcare staff working with people with dementia across all care settings in addressing specific aspects of dementia palliative care. These documents aim to consider all stages of dementia and include consideration of all people impacted by dementia (e.g. people with young onset dementia, people with intellectual disabilities and dementia etc.).

In order to determine the focus for the guidance documents, a desktop review of Irish literature on the topic of dementia and palliative care was completed and compared against an Irish review of the educational needs of healthcare staff working with dementia. An Expert Advisory Group was convened to develop each guidance document which had links to a Project Advisory Group (see Appendix 1 for membership of both groups for this document).

Following a process of consultation and feedback with the Project Advisory Group, the following care domains were agreed upon as a focus for the suite of guidance documents:

- 1. Facilitating discussions on future and end-of-life care with a person with dementia.**
- 2. Advance Care Planning and Advance Healthcare Directives with a person with dementia.**
- 3. Loss and Grief in Dementia.**
- 4. Pain Assessment and Management.**
- 5. Medication and Dementia: Palliative Assessment and Management.**
- 6. Management of Hydration and Nutrition.**
- 7. Ethical decision making in end-of-life care for the person with dementia.**





## INTRODUCTION

**Grief has been described as the “constant yet hidden companion of Alzheimer’s Disease and other related dementias. It is ever-present for the person with dementia and accompanies their families and friends throughout the illness and after death”**

(30).

As healthcare staff<sup>2</sup>, you may think about grief as something which only occurs following the death of a person. However, grief can occur as a reaction to losses which occur in many different aspects in our lives (e.g. the loss of a job, the loss of a pet, changes in roles, the loss of a pet etc.).

Loss and grief is one of the most significant and under recognised issues faced by people with dementia and their families (31). People with dementia experience multiple losses in different areas of their lives, and these losses build in number and magnitude as the disease progresses (32-34). Grief occurs in different ways at all stages in the dementia journey for the person, for the family and for healthcare staff supporting them (35). Recognising, validating and supporting people experiencing loss and grief is an essential part of good person-centred dementia care and good end-of-life care.



<sup>2</sup> For the purposes of this document the term ‘healthcare staff’ has been used to refer to health and social care staff.

## Aim of this guidance document

The aim of this guidance document is to inform and guide healthcare staff on issues related to loss and grief in dementia.

## Scope of this guidance document

This guidance document will:

- List 4 key considerations to inform good practice in working with loss and grief in dementia.
- Provide guidance on 4 areas related to loss and grief in dementia.

## Who is this document for?

This document has been written for all health and social care staff who work with and support people with dementia across different settings (e.g. in the home, in long term care units, in hospitals etc.).

This document should be used by staff within their own scope of practice, professional guidelines and standards. It should be considered as an adjunct to: existing best practice guidelines in dementia care, best practice guidelines in end-of-life care, and national and local policies and procedures which relate to working with people with dementia and older people.

Working in a person-centred way with a person with dementia and their family needs a whole team approach: all healthcare staff supporting people with dementia interact and engage with the person with dementia and their families in different ways dependent on their roles. Each of those roles are interconnected and are key to delivering good person-centred care. Therefore, all healthcare staff need to develop competence and confidence in supporting people through loss and grief within their own scope of practice.

## How to use this document

Changing attitudes, cultures and care practices takes time. You may use this document in different ways in order to inform and guide practice in a meaningful way that leads to better outcomes for the person with dementia, their families and you as a healthcare staff member supporting them. You may decide to use it within your healthcare staff team to support peer learning, hold information sessions and journal clubs or use it to develop practice within your setting.



It is recommended that if a person is not familiar with the document that they take the time to read it in its entirety as each section builds on the knowledge and information shared in the previous section. The factsheet which accompanies the document should serve as a visual reminder to people who have read the whole document. It is not recommended as a standalone item.

## Structure of guidance document

This guidance document is based on key themes which emerged from the literature review and a process of consensus building by the Expert Advisory Group (see Appendix 2 for methodology).

The document is divided into 4 sections:

### Section 1: Background and Context

### Section 2: Introduction

### Section 3: Four key considerations to inform good practice

The four key considerations should be applied as foundation knowledge for healthcare staff supporting people with dementia and their families in the area of loss and grief.

### Section 4: Guidance and Resources

There are four areas related to loss and grief in dementia where the reader is offered guidance and signposted to additional resources.

### Section 5: Additional Resources

This section contains some additional information and resources to support learning. It includes the factsheet which was developed to accompany this document.



## FOUR KEY CONSIDERATIONS TO INFORM GOOD PRACTICE

*“We must never lose sight of the individual who must be afforded sufficient choice and the opportunity to live well with dementia and to be treated with dignity, kindness and respect”*

(27).

Recognising, acknowledging and supporting people who are experiencing loss and grief are essential components of good person-centred care. At the heart of person centred care are meaningful relationships where there is a mutual trust and connection between the person with dementia and those supporting them. It is through these relationships that a person with dementia and their families learn to trust you and connect with you as a healthcare staff. In the context of these supportive relationships, people are more likely to share their thoughts and views with you in an open way, including those relating to the losses they are experiencing in their lives.

This section explores four key considerations for healthcare staff to be aware of when supporting people with dementia and families on loss and grief in dementia. The key considerations for good practice should be applied as foundation knowledge for all healthcare staff in supporting people with dementia and their families. These are as follows:

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 and respond to 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.**



Each of these considerations are explored further overleaf

### 3.1 Be aware that loss and grief are fundamental parts of the dementia experience

***“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 National Dementia Working Group (39)).

It is essential that healthcare staff supporting people with dementia and their families recognise that dementia brings many different types of losses throughout the person’s journey with dementia. Grief as a reaction to these losses can be experienced by the person with dementia, by their families and by healthcare staff at every stage of the disease as well as after the person’s death (35). In order to try to understand the experiences of people with dementia and their family members, it is important to develop awareness of the types of losses which can occur for people with dementia and their families. Unlike death related grief which begins at a single point in time, dementia grief begins with living circumstances and changes over multiple points in time (40).

The table below outlines some of the losses typically encountered as part of the experience of living with dementia.

#### Loss and Grief commonly encountered as part of the dementia experience

##### Ambiguous loss

***“It’s a rare kind of grief because of the circumstances. She’s there but she’s not there. And that’s what the others aren’t able to see”***

(family member cited in (41)).

Ambiguous loss occurs in dementia when the person remains physically present but they are no longer the person they once were - they are emotionally or psychologically changed in some way. This grief is not understood as it is not clear what has been lost - the loss is ambiguous (7). Ambiguous loss may lead to mixed or often confused feelings. It is different to the loss which occurs after a death as the person is still alive. It has been described as ‘the long goodbye’ and ‘the goodbye without leaving’.

Grief resulting from these ambiguous losses can be particularly heightened for family members when:

- The person with dementia’s personality and behaviour changes, causing them to act in a way which is not in keeping with how the person would have behaved previously (42)).
- The person with dementia is unable to recognise or name family members (32,43–46).

Ambiguous losses may be further complicated by the fact that people with dementia can often experience periods of lucidity. This variability in how a person is from day to day can further heighten family member's mixed feelings. These type of losses can lead to increased stress and depression for family carers (3,47).

For some family carers, their feelings of ambiguity can lead to them avoiding spending time with the person with dementia or distancing themselves from becoming involved in their care (48).

### **Anticipatory Loss**

Anticipatory loss refers to losses which we anticipate will happen in the future in the context of a life-limiting illness (2). The anticipatory losses experienced in relation to dementia is somewhat different to the anticipatory loss and grief which can occur in other illnesses. The person with dementia may anticipate loss in their abilities to be independent and their communication. Families may anticipate the loss of the person as they are and the death of the person. The progressive decline in communication and memory caused by dementia may mean that there is no longer the chance for family members or friends to finish unfinished business or to share feelings as the condition progresses (34,46,49). These losses and the grief resulting from these losses are further complicated by the ambiguous or mixed feelings described above.

### **Disenfranchised Grief**

This refers to grief which is hidden or not validated. Losses are not appreciated or understood by others, publically acknowledged or socially shared (30).

Disenfranchised grief occurs at all stages of the dementia journey for the person, for their families and for healthcare staff. Grief can be disenfranchised due to a lack of awareness, stigma that can come with the diagnosis of dementia. This type of grief can be difficult as the person experiencing it can feel very isolated and alone (31,50).

Many of these losses, and the grief experienced as a result of these losses can be occurring simultaneously for the person with dementia and their families. Many of them can be experienced on a daily basis by people with dementia and their families..

In addition to having knowledge of the types of losses encountered in dementia, it is important that healthcare staff understand dementia as a condition and develop skills in providing person-centred care and support to people with dementia. The needs of each person with dementia will differ widely (e.g. a person with young onset dementia's needs will be very different to the needs of an older person with dementia or a person who has an intellectual disability and dementia). Each person interacts with and experiences their world in a different way and will cope with loss and change differently. It is therefore essential that you take an individualised approach to working with people with dementia and their families and recognise the magnitude and complexity of the situation for them. Recognising and responding to loss and grief is further explained in Section 4.

## 3.2 Develop knowledge and understanding about loss and grief

This key consideration covers two fundamental points which need to be understood about grief:

- i. Grief is a dynamic and fluid process
- ii. People respond and cope with grief in different ways

### i. Grief is a dynamic and fluid process

Grief is not a linear event which a person has to work through to get to a final point. It is a *process* of constant adjustment and change which brings emotional and practical challenges. Grief affects people in many different ways including physically, emotionally, psychologically and spiritually. The table below (1) shows some of the reactions that people may have to loss in each of these areas:

Physical	Emotional	Psychological	Spiritual
Tiredness	Sadness	Difficulty concentrating	Trying to make sense of what has happened
Sleep disturbances	Anger	Disbelief	Hostility towards God
Appetite disturbances	Guilt	Confusion	Searching for meaning
Crying	Relief	Preoccupation with the person who has died	Questioning
Weakness in muscles	Anxiety	Dreaming of the deceased person	
Feeling flat and lacking enthusiasm	Loneliness		
Breathlessness	Helplessness		
	Numbness		

Positive and negative feelings can happen spontaneously for people who are grieving and this can often be confusing or challenging to the person experiencing these emotions.

## ii. People respond and cope with grief in different ways

**“Grief is based upon the unique perception of loss by the griever”** (51).

Although there are commonalities in grief, each person’s grief is unique. There is no ‘normal’ or ‘right way’ to grieve. How a person grieves and deals with their loss will depend on a number of factors such as the nature and extent of their grief, their relationship with the person, their culture, their personality, their gender and their own personal history, the support they receive, the meaning they find in their loss and their own internal resources (30,52,53). Researchers have identified a number of grieving styles based on how a person experiences their loss internally and how they express their loss to the outside world (8). The three major types of grieving styles are as follows: **intuitive, instrumental and blended.**

**Intuitive grievers** tend to experience their grief as waves of feeling and they show their feelings externally to others by crying, talking about their loss and connecting with others about their experiences. Intuitive grievers tend to cope by taking time to grieve and sharing feelings with others (54).

**Instrumental grievers** tend to experience their grief in a more cognitive way and are less likely to display emotions as overtly as intuitive grievers. They tend to try and keep their feelings under control and tend to engage in problem-solving activities related to the loss instead of focusing on the pain of the loss itself. They may seek out social support but are unlikely to spend this time sharing their feelings. They may show grief by becoming anxious/agitated/hyper energetic or by immersing themselves in tasks and projects (31).

In summary, **Intuitive grievers ‘feel’ the grief while instrumental grievers ‘do’ the grief** (31)

**Blended grievers** experience and express their grief using a mix of both cognitive and emotional coping styles.

While some people may be very strongly oriented towards one style, many people will fall somewhere along the continuum below:



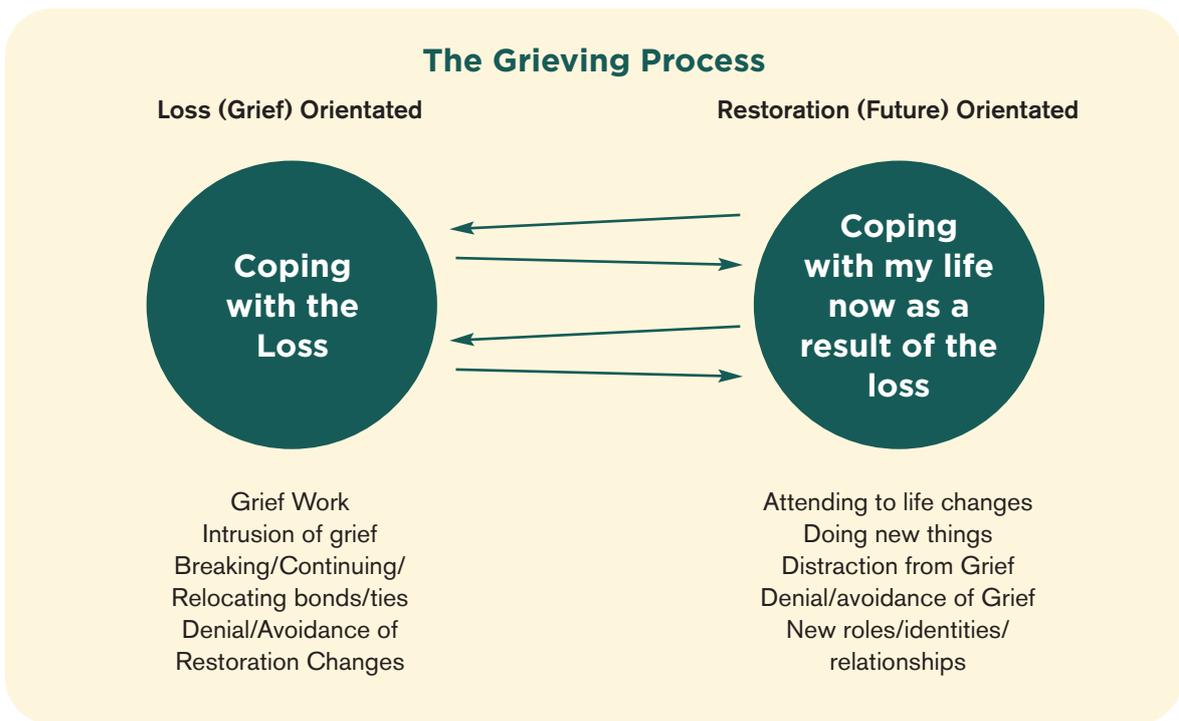
In addition to grieving styles, there are some common tasks which people generally need to attend to in the grieving process (55). People do this in their own time and in their own way. The tasks usually involve constant reworking. These tasks are as follows:

1. **Accepting the loss:** this means accepting that the loss has occurred.
2. **Experiencing the pain:** there is no shortcut through grief. It is only by experiencing the pain of grief that a person can start to heal and adjust to the loss.

- 3. **Adjusting to a new environment:** this means adjusting to a 'new normal' that has come about as a result of the loss experienced. This may mean living with a person who is changed in some way and adapting to changes that brings or it may mean adjusting to living without the person if they have gone into care or learning to live without the person after they have died. This can be challenging but it may also offer the bereaved person new opportunities.
- 4. **Finding a new emotional place for the person who has died:** this involves creating new ways of remembering the person who has died, so that they continue to be part of the bereaved person's life (50).

Grief does not stay still. People who are grieving often cope by engaging with and detaching from their grief. This means that at times they will want to talk about their losses and think about their losses. At other times they need to be able to detach themselves from their loss and grief and concentrate on other things.

As people make sense of their loss, they will move between the two strands shown in the model below from Stroebe and Schut (56).



### 3.3 Recognise loss and grief when you encounter it and develop appropriate responses

The previous section describes loss and grief as fundamental parts of the dementia experience for people with dementia and their families. As outlined in the first key consideration, it is essential that healthcare staff are skilled and sensitive in supporting the person with dementia to communicate and that they are aware of the types of losses that a person with dementia encounters in order to enable them to recognise loss and grief reactions. As a person with dementia's ability to communicate verbally changes, the responsibility lies with healthcare staff and family members to appreciate the connection between dementia and grief, to recognise that that can be communicated in many ways and respond to it appropriately (67).

It is equally important to develop knowledge of the types of losses which family members encounter and to learn how best to respond to family members experiencing loss and grief. Section 4 contains guidance on recognising, responding and acknowledging grief in a person with dementia, family members and healthcare staff.

### 3.4 Reflect on how the loss and grief you encounter in your work affects you

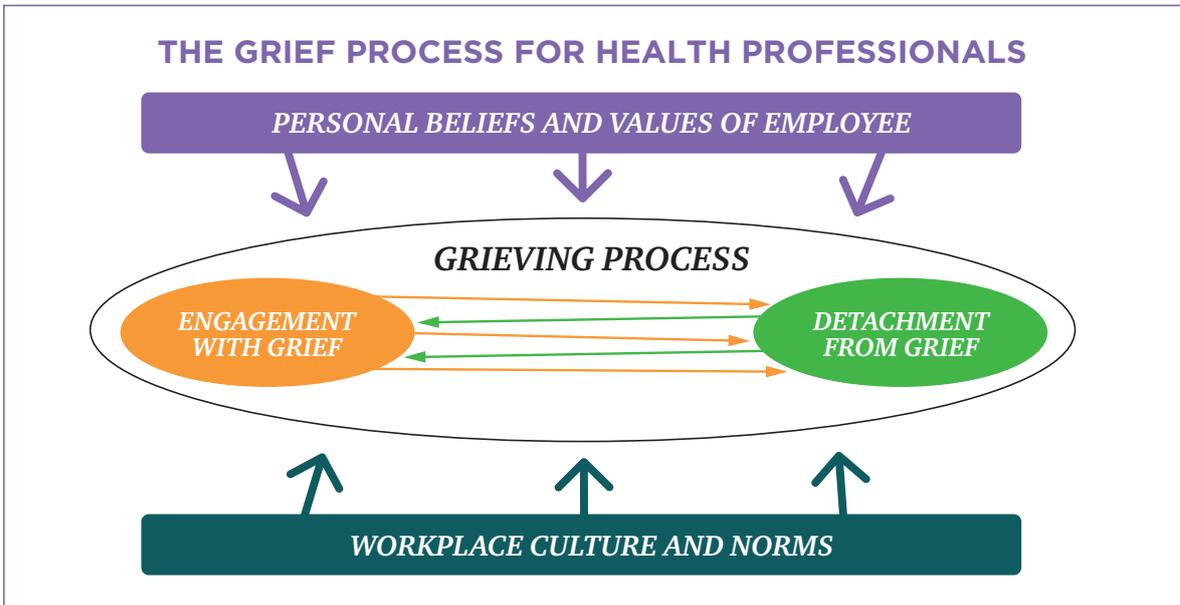
As a healthcare staff, your responses to the people you meet in your work are shaped by your past experiences in and outside of work. You will meet a person with dementia and their family through your own experiences of dementia and your experiences relating to loss and grief. Working in an environment where you encounter multiple losses can put you in touch with and remind you of your own personal losses. Your past experiences may affect your ability to care, your ability to connect with people you support and your ability to remain compassionate in your role as a healthcare staff (57, 58).

In addition to some of the grief reactions outlined on page 12, some additional manifestations of grief reported by healthcare staff are as follows:

- Feeling sad and tearful (59)
- Feeling guilt about what was not possible to achieve
- Feeling emotionally depleted/ depressed
- Physical manifestations – aches and pain (43)
- Feeling a sense of powerlessness – this can occur when a decision relating to a person with dementia's end-of-life care is made which is contrary to the healthcare staff's ethical or moral stance (35).

Healthcare staff need opportunities to engage with and detach from their grief. The added dimension of grief in a healthcare setting is that loss and grief is a part of everyday work and how that is experienced by you as a healthcare staff will depend on the culture of a workplace and other factors such as your personal beliefs, values, history and personality in addition to the functioning of the team within which you work.

The figure below (adapted from Papadatou (60)) illustrates the grief process for health care professionals.



Healthcare staff can build up very meaningful relationships with people with dementia and their family members over years (61,62). When a person's condition begins to deteriorate, when they move settings or when they die, staff can experience profound grief (60,63,64). Staff in residential care settings may feel that their loss is not legitimate and that their relationship or connection with the person does not entitle them to feel or express their grief in their workplace (63). Additionally, some settings may encourage that staff keep a 'professional distance' or 'boundaries' (63). These factors can result in staff experiencing disenfranchised grief in the workplace, where their grief is not recognised, acknowledged or publically sanctioned (30,35,43).

Many healthcare staff, particularly in residential care settings report that they do not feel supported in sharing their grief due to lack of time or heavy workload and they can end up bringing their grief home (65). When grief is unattended to it cannot resolve or heal and the effects of grief can accumulate over time. Unattended grief can lead to reduced quality of end-of-life care being delivered, higher rates of healthcare staff turnover and absence, lower morale and innovation, poor teamwork and healthcare staff experiencing burnout and compassion fatigue (66). People working in settings where they feel isolated, overloaded and underappreciated and who do not acknowledge the effect that their work has on their emotions are at high risk for both burnout and compassion fatigue (11). It is therefore essential to understand, acknowledge and attend to your own grief in order to allow you and your team to continue to provide compassionate care. Section 4 has more information and guidance on strategies for healthcare staff to use in order to reduce and manage burnout and compassion fatigue.

## GUIDANCE AND RESOURCES

This section covers four areas of guidance in relation to loss and grief in dementia. The first area for guidance covers how best to respond to loss and grief generally and this is followed by specific information on supporting the person with dementia, family members and healthcare staff. The four areas for guidance are as follows:

1. Responding to loss and grief.
2. Supporting the person with dementia experiencing loss and grief.
3. Supporting family members and family carers with loss and grief.
4. Supporting yourself (healthcare staff) with loss and grief.



Each section has guidance followed by relevant resources to support learning, development and practice in that area.

### 4.1 Responding to loss and grief

***“When people are talking, there’s no need to do anything except listen. Listen to what they are saying. Care about it. Most times, caring about it is even more important than understanding it”*** (68).

Knowing how best to respond to people who are experiencing multiple losses and multiple transitions over a long period of time is a significant challenge for healthcare staff working with people with dementia and their families. Staff may worry about what to say, when to say it and how best to begin a conversation to acknowledge a person’s losses and emotions. Many healthcare staff report feeling unprepared or lacking in confidence in discussing issues relating to loss and grief. This may be due to a lack of training, fear of upsetting the person, time constraints, lack of role clarity and death anxiety (26,69–72). These anxieties can be heightened when a person has dementia. One of the four key considerations is that you as a healthcare staff recognise grief when you encounter it. The next step is to learn how best to respond to that grief. Overleaf are 4 recommendations that you should follow when responding to loss and grief in your work. These are followed by resources which will support you to develop your knowledge and practice in this area.

## 4.1. GUIDANCE: RESPONDING TO LOSS AND GRIEF

- a. Always acknowledge the person's losses.
- b. Validate the person's grief responses.
- c. When interacting with a person who is experiencing loss and grief you should:
  - Use active listening skills
  - Encourage people to think about their support needs.
- d. Be clear on your role and seek extra help if you need it.

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## INFORMATION AND RESOURCES TO SUPPORT GUIDANCE 4.1

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***“When it comes to grief, non-judgemental listening and open discussion may be the best tools for discovering what a person is truly experiencing and for offering meaningful emotional support”***

(40).

Below are some tips which may support you in communicating with people in relation to loss, grief and bereavement in your work:

### **a. Always acknowledge a person's loss(es)**

Acknowledging loss will usually provide comfort and consolation to the person. This can be done in many ways - by being present with a person through actions, gestures or words. It may be uncomfortable but it is extremely important that you acknowledge a person's loss. Not acknowledging losses can lead to disenfranchised grief which can be a very isolating experience.

- ✓ Saying something such as *“I can see this is a really tough time for you”* or *“I'm sorry this is happening to you”* can often be enough to acknowledge and validate a person's emotions.
- ✓ Avoid using cliches such as *“she's not aware of what's happening, it's probably for the best”* or *“well at least they're no longer suffering”* or *“they are in a better place”* Comments such as these invalidate a person's experiences and are not helpful. Avoid using any judgements or personal opinions when speaking with someone who is grieving. It is counterproductive and will often shut a conversation down.

## b. Validate the person's grief responses

A person who is experiencing grief may experience a range of positive and negative emotions all at once. This can be confusing and cause them to feel guilty, anxious, angry and many other emotions. There is a need to let people know that it's ok to feel whatever emotion that they are feeling (40).

- ✓ The person may need reassurance that their grief is a normal reaction to the losses they are experiencing. Saying something like ' I'm not surprised you feel like that...most people would' may be helpful.
- ✓ Respect a person's story: do not assume you know what they believe or what they feel. While we may identify with parts of another person's story, we can never truly know what another person is feeling. Be aware that the person's story is *their* story and your role as a support is to listen to and support them.
- ✓ Emphasise that there is no 'normal' way to grieve – everyone has their own way of responding to and coping with grief.

## c. Interacting with a person who is experiencing loss and grief

**Use active listening skills:** The use of active listening skills is particularly important when talking to a person who is grieving. This involves fully attending to the person and letting them lead without disruptions. Some specific skills which are known to help the other person continue their story are:

- ✓ **Use conversational encouragers:** these are nonverbal actions such as head nods, positive facial expressions, open body language and minimal verbal feedback such as “mmm”.
- ✓ **Paraphrasing:** this involves summarising the essence of what has been said e.g. “So you are feeling.....”
- ✓ **Clarifying** or “Am I right in thinking you feel....”
- ✓ **Silence** is an important part of listening, accepting their story and being respectful.
- ✓ **Use open-ended questions** such as:
  - What is that like for you?
  - What gets stirred up for you?
  - What is most important for you now?
  - How would you usually cope?

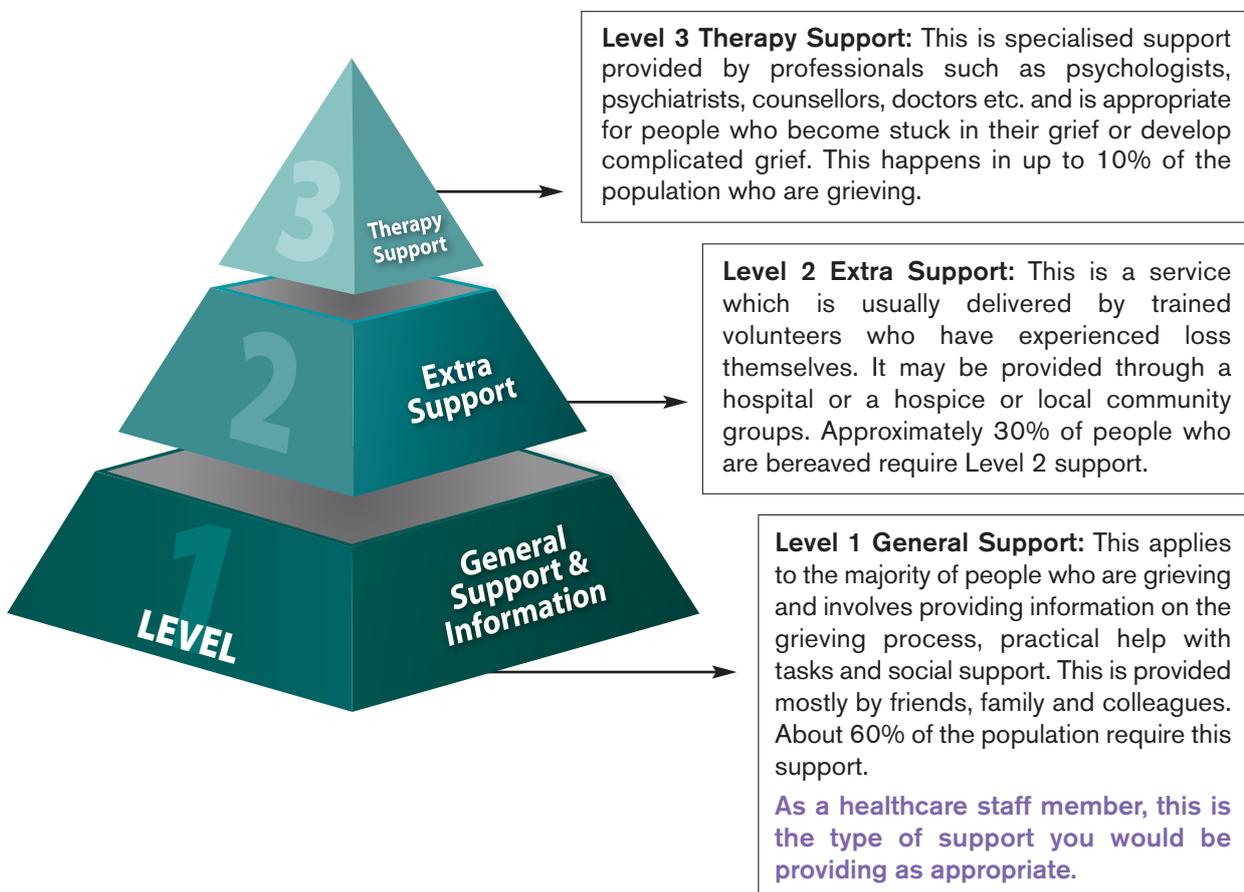
**Encourage the person to think about their support needs:** It is important for people to have a balance between the demands of caregiving and/ or grieving. Prompting people to think about some of the things below may be helpful:

- Prompt people to think about who is in their circle of support (e.g. who do they turn to at times of crises or celebration). Prompt people to think about what support they could realistically seek from different members of their circle
- What gives you strength and support?
- What helps to replenish your energy levels?
- What brings you joy?

Adapted from (73).

#### d. Be clear on your role and seek extra support if you need it

Different emotions and experiences will dominate at different points throughout a person's journey through grief. Therefore, the type of support needed by people who are grieving will differ widely and may be emotional, practical, social support or a combination of these. Most people find their own way through their grief journey with the support of their natural network of family and friends, and their acute grief transitions naturally to integrated grief. This means that the person is no longer overwhelmed by their grief. However, others may need more support to enable them to work through their grief. For those with dementia and those who are the family member of a person with dementia, these figures may be higher due to the long trajectory of the condition, the multiple compounded losses they experience and the various transitions people with dementia and their families go through on their journey (5). Your role as a healthcare staff in supporting people with loss and grief is to provide general support: to listen to the person and to normalise and validate their grief. The pyramid below shows the different types of support people who are bereaved in the general population need (74).



Some of the signs which indicate that a person needs additional supports in working through their grief are:

- If the person feels unable to cope.
- If they do not have many social supports available to them.
- If they are having difficulty functioning in their daily life (e.g. they cannot sleep, they feel very low or anxious).

### Where to seek support

If you are concerned about someone coping with loss and grief, some of the steps you could take are as follows:

1. Suggest the person talks with their GP.
2. If the person or their family member has contact with a hospital/ residential care centre or a hospice, they may be able to access support through the social work, counselling or psychology teams within those services. They may also be able to access support in a local support group or by phoning a helpline.

It may be helpful to have a listing of the contact details of local support groups / organisations available to people accessing your service and to healthcare staff in order to support them in their work and enable them to signpost people to the appropriate supports.

Some of the national support organisations and contact details are listed in Appendix 4. You may wish to photocopy this and supplement it with local information which is relevant to your setting. This should be updated regularly to support the people you work with.

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## ADDITIONAL RESOURCES:

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1. The Irish Hospice Foundation have produced a suite of bereavement information leaflets which have helpful information on different aspects of bereavement. These are available on: <http://hospicefoundation.ie/bereavement/bereavement-leaflets/>
2. The Irish Hospice Foundation collaborated with The Alzheimer Society of Ireland to produce information leaflets:
  - Loss and Grief when a Family Member Has Dementia
  - Understanding Late Stage Dementia
  - Loss and Grief Following the Death of Someone with Dementia.
 These are available on [www.hospicefoundation.ie](http://www.hospicefoundation.ie) or [www.alzheimer.ie](http://www.alzheimer.ie).  
 Alternatively phone the free Alzheimer Helpline on 1800 341341.
3. The HSE have produced information on their website about what to do if you are worried about another person's mental health. Information and guidance for healthcare staff is available on <http://www.yourmentalhealth.ie/Mind-Yourself-Support-Others/Concerned/Worried-about-someone-else/>
4. The Irish Hospice Foundation provide an e-learning course entitled "Lost for Words – Words for Loss". This course gives healthcare staff information on how to support a person who is bereaved. See [www.elearning.hospice-foundation.ie](http://www.elearning.hospice-foundation.ie)

## 4.2 Supporting the person with dementia with loss and grief

***"The acknowledgement of the ongoing process of grief, the rolling and cumulative changes in what is being grieved for is very valuable. I spent a lot of time after my diagnosis beating myself up a bit for falling into grief in strange and unlikely moments, but realised this wasn't just indulgence or lack of rigour in accepting the reality, it was a new grief for a new realisation"***

(Ronan Smith, vice-chairperson of the Irish Dementia Working Group, personal communication).

To be able to recognise loss and grief in a person with dementia, you need to have an understanding of the types of losses that a person with dementia commonly encounters, in addition to having knowledge about dementia as a condition and how best to support the person to communicate. While it is recognised that each person with dementia is unique and should be treated in a person-centred way, there are two groups of people with dementia who may require additional considerations from you as a healthcare staff. These are people with intellectual disabilities and dementia and people with young onset dementia (people who develop dementia under the age of 65).

### **People with intellectual disabilities and dementia**

In the context of an ageing population of people with intellectual disabilities living in Ireland, the prevalence of dementia within the population of people who have an intellectual disability is rising (77). People with intellectual disabilities are three to four times more likely than the general population to develop dementia and this prevalence rises where a person has a diagnosis of Down Syndrome (76).



The grief reactions of people with intellectual disabilities are generally in keeping with those expected within the general community (78, 79). For people with intellectual disabilities, grief may:

- Be expressed in unconventional ways due to communication difficulties, meaning it may not be recognised as grief (80).
- Be delayed and be of longer duration (81).
- Be converted into physical reactions such as nausea, stomach pains or headaches (79,82).
- Be disenfranchised due to societal views about the person with intellectual disability's ability to experience emotions loss or grief (83,84).

There can often be a significant amount of staff or family discomfort about upsetting the person or staff not feeling equipped to have supportive or therapeutic conversations with people with intellectual disabilities who may communicate differently (85). Those who have a diagnosis of dementia are often not told of their diagnosis, which can cause people upset and confusion as many people with intellectual disabilities have awareness that changes are occurring for them (86-88). Additionally, people with intellectual disabilities are more susceptible to experiencing secondary losses such as a move of residential centre following a diagnosis or a death in the family/ changes in day service provision.

Finally, the living situations of many adults with intellectual disabilities in Ireland currently tend to be in small group-based community homes (89). In these homes, people with intellectual disabilities may be living together over the course of their lives and can build up deep-rooted connections with one another. This means that for people with intellectual disabilities and dementia, the support needs of their peers/ housemates need additional emphasis. It is important to facilitate open and honest discussions to address concerns within a household when there are losses and changes occurring. Peers who have a sense of what is happening to the person with dementia tend to have more supportive attitudes to the person with dementia, particularly where they have had long term relationships with the person with dementia (90).

All of the points raised above require consideration and development within services to support people with intellectual disabilities and dementia in addition to people with intellectual disabilities sharing accommodation with those who develop dementia with issues relating to loss and grief.

### **People with young onset dementia:**

It is estimated that there are approximately 4000 people living with young onset dementia in Ireland in 2016 (25). People with young onset dementia are more likely to be in employment at the time of diagnosis, have dependent children and/or elderly parents and have financial commitments such as a mortgage (83). People with young onset dementia often have to retire from work prematurely along with their carers leading to a double loss of income along with other losses related to independence and autonomy (84). More than 71% of people with young onset dementia experience anxiety and up to 50% experience depression as part of their experience of living with dementia (85). There is a need to recognise that people with young onset dementia have different needs to other groups of people with dementia. Their experience of dementia and the loss and grief that is part of that experience may be very different and require additional emphasis and planning within services in order to ensure that they are supported in a meaningful way.

The guidance overleaf outlines how to support a person with dementia experiencing loss and grief. This is followed by resources and information about loss and grief in a person with dementia to support your development and learning.

## 4.2 GUIDANCE ON SUPPORTING A PERSON WITH DEMENTIA EXPERIENCING LOSS AND GRIEF

- a. Be aware of the types of losses commonly encountered by a person with dementia.
- b. Develop skills in recognising loss and grief in people with dementia. In order to do that, it is important to:
  - Take a person-centred approach and know the person well.
  - Develop good observation and communication skills in order to recognise the many ways in which grief can present for people living with dementia.
  - Observe how the person is presenting each day – do they seem happy/ sad/tearful/anxious? Are they sleeping/ eating well?
  - Work as part of a team – share information/ observations with other staff and family as appropriate to ensure loss and grief is recognised and responded to appropriately.
- c. Truth telling in dementia: Deciding whether to tell a person with dementia the truth relating to their losses (past or present) should be done within a team taking account of the following:
  - The person's current beliefs / knowledge and experience.
  - The person's capacity to register, process and retain the information pertaining to their losses.
  - The person's communication skills and how best to support their understanding.
- d. Provide support for a person with dementia to grieve the myriad of losses they are experiencing.
- e. Explore the person with dementia's spiritual needs.

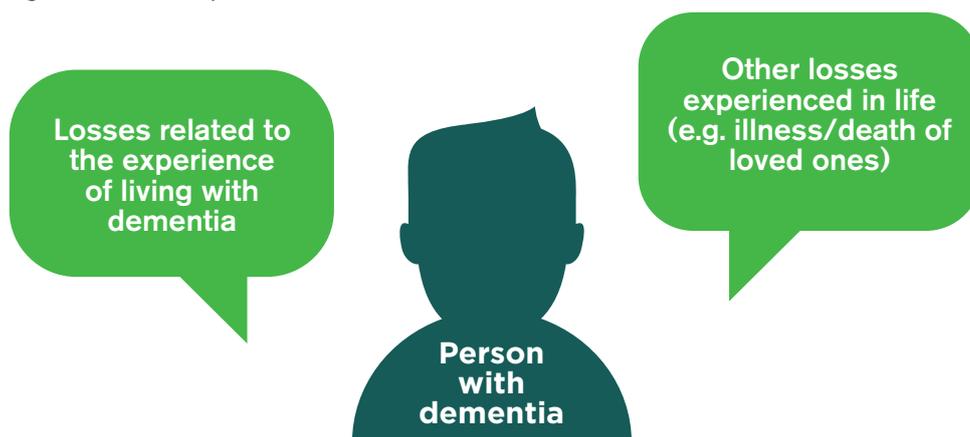
## INFORMATION AND RESOURCES TO SUPPORT GUIDANCE 4.2

### a. Be aware of the types of losses encountered by a person with dementia

*"I grieve being unable in these moments to be who I have been. It would be nice if one could grieve such losses once and be done with it. But grief keeps popping up in many ways in many situations"* (75).

As illustrated in the figure below, a person with dementia can experience losses which relate directly to their experience of living with dementia in addition to many other losses which can occur in their lives such as the loss of a loved one/ illness/ the loss of a pet etc. (30). All of these losses are interconnected and are unique to each person. It is important to respect each person's individual story and set of circumstances and that you do not assume anything.

A person with dementia has to simultaneously deal with the practical and everyday changes which dementia brings in addition to processing and adjusting to the ongoing profound and multiple losses they are experiencing (105). With each new transition point or change which dementia brings, grief may be heightened for the person with dementia.



Some of the many losses which are commonly reported by people with dementia are as follows:

- **Loss of memory** (95,96): The impact which loss of memory has on all aspects of a person's life is profound. Memory is what links us together –our histories and relationships are built on a shared history. Dementia can mean that those shared memories and stories are difficult to track and the person's ability to engage with others and the world around them is significantly altered as their condition progresses.
- **Loss of independence and personal freedom** (97,98): in the early stages of living with dementia, the person may need additional support with tracking appointments, medication etc. Loss of independence may impact driving, financial independence, the ability to handle all aspects of one's own life. Towards the later stages of dementia, the person will become increasingly dependent upon others to support them with basic activities of daily living such as dressing, eating etc.
- **Loss of roles and identity** (35): the person with dementia's roles in relation to others in their family and in their wider community and workplace will change as their dementia progresses. This can mean many different things - the loss of being an equal partner in a relationship, loss of being in a parent role with children or the loss of being a figure in the community/ at work etc.

- **Loss of ability to communicate verbally** (70,99–101): Dementia changes a person's ability to communicate. As dementia progresses, a person becomes increasingly reliant on people around them knowing them really well and picking up on their nonverbal communication. Relating to people and communicating is an integral part of our lives and how we experience the world (102). The prospect of losing the ability to communicate verbally can be extremely daunting and may be a source of fear for many people living with dementia.
- **Loss of control** (97,103,104): Receiving a diagnosis of dementia can introduce huge uncertainty into the person with dementia and their family's lives about what the future may hold - hopes, dreams and plans can change in an instant. As the disease progresses, people with dementia may experience the feeling of no longer being in control of their own lives. They may struggle to retain their autonomy while those supporting them may be taking increasing levels of control over different aspects of their lives.

The losses outlined on the previous page may be occurring at the present time or they may be losses which are anticipated to happen in the future.

## **b. Develop skills in recognising loss and grief in people with dementia**

***“A person’s intellectual level influences how they express loss and grief. It does not influence the fact that he/ she feels and suffers “*** (106).

People with dementia's grief is often disenfranchised due to misconceptions that a loss of memory or cognition equates to a loss of feeling, rendering the person incapable of experiencing or sustaining grief (35). For the person with dementia, feelings continue to be experienced and felt but the way in which those feelings are expressed may change. A person with dementia has the complicating layer of trying to absorb and experience their losses through a progressive memory loss, cognitive impairment and a communication difficulty (98, 108).

In the context of dementia, grief responses remain unique to the person. When a person with dementia experiences a loss, they are often expected to experience it in the same way as they would have before they had dementia, however, this will not always be the case (51). While the manner in which people express their grief may change dramatically, others responses will be in keeping with their former selves. For example, a person may have been characterised as having a 'stoic' or 'unemotional' personality style before they developed dementia and as the disease progresses, they may become more emotional and cry frequently which is not in keeping with their previous personality style. It is important not to judge a person with dementia's reaction or response to a loss. Always respect the person and maintain the dignity of your interactions with them, recognising that their ability to process the loss and express their reaction may be changed.

As a person with dementia's condition progresses, they may no longer be able to cognitively experience loss and grief and a sense of specific loss and deterioration may be replaced by a generalised feeling of 'wrong-being', a vague sense that something is not right. This may manifest in many ways such as anxiety, agitation, restlessness or other responsive behaviours which can indicate and express inner pain (30). It is important to recognise all behaviour as being a form of communication and to be aware that responsive behaviours may be a manifestation of a person's grief. As the person's condition progresses and their ability to verbally communicate changes, it becomes the responsibility of healthcare staff to appreciate the connection between dementia and grief (67).

Feelings which are commonly reported by people with dementia in the literature are:

- Irritation
- Frustration
- Uncertainty/ fear
- Stress
- Confusion
- Insecure about the future
- Misunderstood
- Under supported
- Isolated
- Lost
- Fearful of becoming a burden
- Sadness
- Despair
- Guilt - the person with dementia may feel responsible for suffering of family members
- Feeling of letting loved ones down (62-65,67).

**In the later stages of dementia, the person who is grieving and/ or bereaved may:**

- Lose the ability to register the loss
- Lose their ability to verbally communicate their sense of loss
- Confuse the present loss with an earlier loss in their lives
- Retain a belief that a person who is deceased is still alive
- Mistake someone else for a dead relative
- Dwell or ruminate on certain events or conversations
- Disengage from social situations
- 'Recycling of their grief' each time they are told about their loss due to their memory loss
- Have difficulty with regulating and modulating emotional responses (18,61).

### c. Truth-telling in dementia: to tell or not to tell?

***“In developing intervention approaches, one must rely on good judgement, common sense and a wealth of empathy”*** (67).

When a person has a diagnosis of dementia, this can often cause tensions about whether to tell the person the truth or not about various aspects of their life and care for fear of upsetting the person.

Respect for the person with dementia's autonomy and self-determination are core guiding principles in the recently enacted Assisted Decision Making (Capacity) Act (106). This legislation requires healthcare professionals to presume that a person with dementia has capacity and it places a requirement upon healthcare professionals to make information accessible and easy to understand<sup>3</sup>. In a situation where grief reactions would be expected, a person with dementia has the same ethical right to be able to hear, respond, process to news and to be able to express their loss and grief (108). However, while people with dementia have a right to know the truth, they do not have a duty to know it and should not have information forced upon them (86). You should always follow the person with dementia's lead and be guided by them and the team around you when making decisions about truth-telling.

<sup>3</sup>. For further information on the Assisted Decision Making (Capacity) Legislation, please see Guidance Document 2: Advance care planning and advance healthcare directives with a person with dementia in this series.



**Truth- telling re diagnosis:** Many people with dementia may not be informed about their diagnosis. The disclosure of diagnosis can lead to many outcomes for the person with dementia, including the opportunity to engage in future planning and understand of their symptoms in addition to experiencing the many emotional reactions that can occur in the context of a life limiting condition (110). Denying that any changes are taking place can be very confusing for the person, as their experiences and emotions do not match what they are being told (86).

**Truth- telling re death:** Throughout the course of the condition, a person with dementia may repeatedly ask for a person who died many years ago or look for someone from their childhood days. When a death occurs, people with dementia can be over-protected and denied their right to hear about the death of a loved one. Family members and staff may be anxious about telling the person with dementia about the imminent or actual death of a loved one. Tensions can arise about whether or not to tell the person, what to tell them and how to tell them about a death that has occurred or to remind them that their loved one died many years ago.

Loss of cognition should never be confused with loss of ability to feel. People with dementia can be very aware of the emotional climate around them and they will often perceive the sadness of their loved ones and respond to the emotions with distress even if they don't understand the reason for the sadness (109). Protecting a person with dementia from the truth can sometimes cause further confusion because the story they are being told does not match with their reality or lived experience.

If a person has become ill or died who was a significant figure in the person with dementia's life and one with whom they had regular contact, it is highly likely that the person with dementia will register the absence of this person on some level. If news of a death is not told to a person with dementia, they are denied the right to participate in the usual rituals such as attending a funeral/ wake/family gathering. By attending these events, people with dementia are supported and enabled to begin to process the news and begin the usual process of grieving (108).

In the absence of evidence on how best to approach truth telling in dementia at this time, taking an individualised, ethical and person-centred approach is considered to be best practice. This may involve trying out a range approaches in order to find one which best supports each individual person. Overleaf, you will see some key questions you need to consider when tasked with delivering bad news to a person with dementia or deciding on whether to tell them /remind them of a death which has occurred in the past.

## **TO TELL OR NOT TO TELL?** Adapted from (111)

**Below are key questions to consider in communicating bad news to a person with dementia:**

### **1. What does the person know already?**

Try to ascertain what the person with dementia's understanding of their current situation is.

### **2. How much information can the person with dementia cope with at a time?**

Be aware of how best to support the person's communication skills. What is the best way to give information in a way the person will understand?

**3. Are they able to understand this information at this point in time?**

A person with dementia's ability to understand can often fluctuate throughout the day – consider when they are best able to understand and interact.

**4. What is the best way/ place/ time to give the person with dementia the best chance of understanding?**

Many people with dementia may understand best through verbal and nonverbal communication but also through experiences in their own social context. Using a combined approach may work best.

**5. Who can best support their understanding and ability to communicate?**

For many people this may be a family member, or there may be a particularly skilled member of staff with whom the person has a good relationship. The use of visual supports such as pictures, objects or writing down key words may help the person to understand the information they are receiving.

**6. Can this person be harmed by receiving this information at this point in time?**

If a person with dementia is constantly reminded that their loved one has died each time they ask for them, they may experience a strong distressing emotional reaction to that loss each time they hear it, as if it were the first time. If the person has difficulty in retaining the information, they may be harmed by receiving it. This has been called the retraumatization phenomenon and may undermine the person with dementia's sense of security and well-being (62,73,112). If you think this will be the case, discuss this with other team members and agree on a consistent response to the person which validates the person with dementia's feelings and acknowledges their concerns. Be aware that there is a need to regularly review the approach you take as what works well for the person with dementia can change from day to day.

**7. Consider the person's capacity to register and take in information about the loss (Remember you must always presume that the person with dementia has capacity unless the opposite is proven)**

- If you do decide to deliver the news of a death to the person, see pages 30 and 31 for guidance.
- If you have concerns about the person's capacity to understand the information relating to the loss, discuss with others on how best to build the person with dementia's understanding. This may be done in many ways such as using photographs/ objects and other items associated with the person who died/ attending memorial services/ visiting the grave etc. Where the person died a long time ago and the person with dementia lacks capacity to register/ process that loss, it may be decided that deflecting/ distracting works best. E.g. saying something like *'tell me about the person'* or reminiscing about the person may work better. You should always respond to and validate the person with dementia's feelings, regardless of the approach you decide to take. See pages 30 and 31 for more information.

## TELLING A PERSON WITH DEMENTIA ABOUT A RECENT DEATH from (34,63).

### 1. DELIVERING THE NEWS OF A DEATH:

- Deliver a warning shot such as "I have some bad news about...." and assess if the person wants to have more information. Respect their wishes not to know if they indicate this to you.
- Find a suitable time of day when the person is at their best and well rested. Be aware this may need to be judged on a day to day basis, as it can fluctuate for the person with dementia.
- It is best if news is delivered in a quiet space on a one to one basis rather than in a large group.
- Use body language to express your sadness, hold the person's hand or hug them, whichever is most appropriate to your relationship with them.
- Avoid euphemisms like 'passed on' or 'passed away'. Use the word 'died' or 'dead'.
- Allow lots of time for the interaction and be prepared to repeat the information.
- Give the person a chance to absorb information in their own way. It may be helpful to use visual supports such as photos or pictures to support the person to receive information in a way that they can understand.
- Be prepared to deal with whatever response the person has – the person may react in a way which would not be considered to be a conventional response to the news they have been given. They may appear not to respond or notice or they may laugh or cry – accept whatever happens.

### 2. OBSERVE THE PERSON WITH DEMENTIA'S REACTION TO THE NEWS

- Pay attention to the person's response to facts about their loss. Does the knowledge seem to register with them cognitively or emotionally? What do they believe to be the case about the deceased person?
- Monitor the person's behaviour after exposure to the loss – Did the person show signs of disengagement, withdrawal, anxiety, agitation or sadness after exposure to news of the death? Are these new behaviours? If they have been noted before, have they increased in intensity/frequency? Other changes such as changes in sleep patterns, appetite, level of activity may indicate the person's level of distress either specific to the loss or specific to the circumstances surrounding the loss (e.g. family dynamics and reactions).
- It may be appropriate to record this information in the person's care / support plan. Ensure that your approach and observations are updated regularly in liaison with the team.

### 3. INVOLVE AND SUPPORT THE PERSON WITH DEMENTIA TO BE PART OF THE RITUALS FOR THE DECEASED PERSON

- If the person who died was close to the person with dementia, they should be involved as much as possible in discussions about the funeral and in making arrangements.
- If appropriate, involving the person with dementia in funeral planning will help to embed awareness of the death and create more references for gentle reminders such as sympathy cards etc. (64).
- Give the person the opportunity to be part of the rituals involved in a death and observe their communication and level of distress throughout these events. It may be appropriate to visit the church/ funeral home/wake at a quiet time if possible before the funeral.
- Involve the person in the usual rituals which are appropriate to their relationship with the person who died. This may involve sorting out possessions of the deceased or give them some particular items to support them in remaining connected to the person. This can help embed the information that the person has died and support them to reminisce. Use photos, tell stories, visit the grave – it is important to give opportunities to the person to process their loss and allow them to share how they feel.

## TELLING/ REMINDING A PERSON WITH DEMENTIA ABOUT A LOSS WHICH OCCURRED IN THE PAST

A person with dementia may repeatedly ask for a person who died many years ago or look for someone from their childhood days. This creates a dilemma for family members and healthcare staff – do you tell them that a person is dead each time they ask or do you deflect or distract the person. Below are some tips to guide your practice:

1. Consider key questions about the person and their ability to register, process and react to the loss (see page 29)
2. If you do decide to tell/remind the person about their loss, be very clear on your reason for doing so. Be aware that the person with dementia may be experiencing a different reality and you need to always promote and respect their personhood and take a person centred approach.
3. Always validate the person's emotions by paying attention to the feeling behind the words. If a person with dementia is looking for their mother for example, they may be looking for security, comfort or familiarity/ home. Use photos, music, smells, objects, stories or other mementos to support the person to remember and connect with their loved one.
4. Work as part of a team: It is not recommended that you make decisions related to truth-telling alone. Find out about the person's previously stated will and preferences. Talk to the family about how they respond to their family member. Agree as a team how best to deal with difficult questions relating to losses which may have occurred a long time ago.
5. Where a person has more advanced dementia, you may need to use a variety of approaches before finding one which works best for the person. It may help to remind them of the death or it may be better to reassure and distract the person while validating their emotions. Objects and photos may support some people while not be a support to others. Once you have developed an approach that works well, document what works best for them and ensure that everyone supporting that person gives the same/ similar response. This may be recorded in a care plan. Having a consistent response is very important to ensuring a person with dementia feels secure and trusting of those supporting them.
6. Think about what will best support the person or comfort them in the event they become upset and share this information with the team.
7. Review your approach regularly based on the person's changing condition and ability to process and react to the information they are given.

#### d. Supporting a person with dementia to grieve the myriad of losses they are experiencing.

*“Please try to make sense of the feelings we are trying to convey...try to understand the meaning of what we intend to say”* (109).

When a person with dementia does not have their needs met (these may be emotional, psychological, spiritual or physical), the person may become withdrawn and socially isolated (13). It is essential to provide support for the person with dementia to express and cope with the loss and grief they experience in a way that is meaningful to them. The framework outlined below was developed by Force (67) and can be used as a way of guiding your practice in supporting a person with dementia experiencing loss and grief. This framework is used in the case studies that follow to support your learning.

**In order to support a person with dementia experiencing loss and grief you should:**

- a. Know the person well
- b. Validate and acknowledge the person’s emotions
- c. Understand connections
- d. Use environmental cues.

Force (67).



##### a. Know the person well

While this seems like a very obvious statement, it cannot be emphasised enough. Working with people with dementia demands sensitive skilled communication which promotes personhood at all stages of the person’s journey with dementia (38). In order to deliver person-centred care and support people effectively, you need to know the person with dementia and what matters to them in their lives.

- ✓ People with dementia should be valued as people who have a unique history, values and preferences. Healthcare staff should support the person with dementia to maintain their personhood and sense of identity throughout all stages of their journey with dementia.
- ✓ You can get to know a person well through spending time interacting with them and their families, doing life story and reminiscence work and working with others in the person’s circle of support to gain a deep understanding of the person and what matters to them. It is the context of this relationship that you meet the person and their concerns in a meaningful and compassionate way.

##### b. Validate and acknowledge the person’s emotions

People with dementia are often grappling with trying to remain in control in addition to coping with the losses they encounter. The following tips may help:

- ✓ As with any person who is experiencing loss and grief, a person with dementia may wish to tell their story again and again. This may be further affected by their memory loss. Allow the person time and space to express themselves.
- ✓ It can be useful to use language like *“It sounds like”* or *“you seem”* or *“it looks like”* and label what the person seems to be presenting as at that time (e.g angry/ sad/ distressed etc). This is a way of normalising and acknowledging the person with dementia’s feelings.

- ✓ It is important not to deny the person with dementia the opportunity to say/ show how they are feeling. Listen (with your whole self), observe and be present with the person.
- ✓ It may be useful to focus on the feelings or intent behind the words rather than on the words themselves to foster successful interactions.
- ✓ Provide support for difficult emotions and explore other channels with the person about ways they can express their grief (e.g. music therapy/ art/ drama etc).
- ✓ **Connect, don't correct:** If the person with dementia is saying something which is factually inaccurate, think carefully about your response. If the person seems unaware of any change and is not distressed, it may not be appropriate to continually force reality on them (113). Maintain the dignity of the interaction by acknowledging the person and listening carefully for significant words/ feelings which they may express.
- ✓ **Be consistent:** By knowing the person really well, over time you will learn how best to respond to that person in relation to their loss and grief, their mood and overall presentation each day. Find what works best for the person; share the information with the team and family to support consistent and reassuring interactions with the person. This is essential in supporting the person with dementia to feel validated, supported and secure. Be aware that this may change dramatically over time and needs constant reviewing.

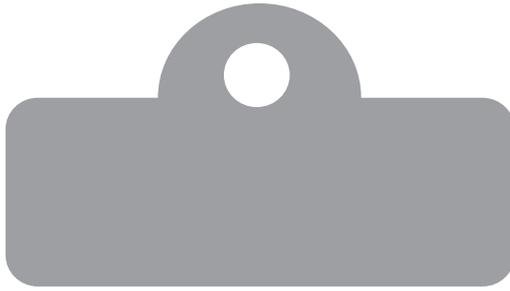
### c. Understand connections

How a person with dementia experiences loss and grief will depend on many things such as their temperament, their relationships and connectedness with others and the stage of their dementia (67). As a healthcare staff it is important that you appreciate the significance of different relationships for the person with dementia and how that is affecting them with their experiences of loss and grief.

### d. Use environmental cues

The Continuing bonds approach (114) is defined as the presence of an ongoing inner relationship with the deceased person. Connections can be supported using objects, photos and other items which may ease the anxiety of separation and promote security through the person's sense of presence. This may be a particularly useful approach to support the person with dementia to continue to feel connected to their identity and/or to a deceased relative/their past with that person. This can be done in many ways such as through life story work (115) and using objects/ photos/furniture and other meaningful things which would promote reminiscence.

There are four case studies presented overleaf which apply this framework to practice.



### CASE STUDY 1 | **Edna** (70)

*Edna is a 79-year-old woman who has late stage dementia. She lives in a residential care centre. Two months ago, her husband Eddie died – they had been married for 48 years.*

*She has been in the residential care centre for the past six weeks. Family members and healthcare staff are very concerned as Edna is becoming increasingly agitated and upset. Edna says “I don’t know what kind of illness this is supposed to be. My family are afraid of what I might do. They are afraid I won’t remember my name. I told them I will wear a bracelet. I want to be at home. What do I have to do? For how long? Will it get worse? The things I forget are not important. I can’t believe I can’t go home. I have had this brain all my life. I know my husband is dead but I can’t remember that. In a way, it would be better for me to remain here, rather than going home and creating difficulties. But I want to go home. I am not having any problems. I have lost a lot” As a healthcare staff member, what do you do?*

Edna has expressed a range of concerns including despair, grief and confusion. Use the framework to guide your approach

- **Know the person well:** Take time with Edna to learn about her life story and what matters to her
- **Validate and acknowledge Edna’s feelings:**
  - It may be helpful to break up Edna’s concerns into things which are manageable – listen to her concerns and develop them into areas that can be worked on.
  - Focus on the reality of the moment and answer Edna’s concerns directly and honestly – Edna is an adult who has lost her life partner and should be treated as such – she is entitled to an adult exchange. Maintain the dignity of the interaction and listen closely for significant words and feelings.
  - Talk openly with Edna about her concern about her memory loss and why she is living in the residential care centre. It helps to let her know that she is important to many different people and that her family are concerned.

## CASE STUDY 1

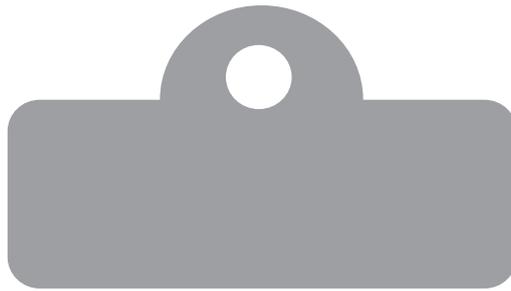
- You may need to repeat information in a quiet but clear voice and the use of active listening and supportive touch may be needed. Edna may ask the same questions over and over, she may dwell on the topic of going home.
- Develop a consistent response and share this with the team e.g. *“Edna you are not feeling settled here – what do you miss most about home?”*
- You may consider developing a care plan to support Edna and ensure a consistent response among all those supporting Edna.

**Understand Connections:**

- In relation to the loss of her husband – acknowledge and validate her emotions *“Edna I know this is a really hard time for you now with the death of your husband Eddie. It is a really hard time. Anytime you want to talk I’m here for you”* or you may use reminiscence as a way of connecting with and supporting her as appropriate *“Edna tell me how you and Eddie met/ what was he like”* etc
- It may be helpful to spend time sharing information with the family and the team of healthcare staff to ensure that the responses given are somewhat consistent. This will support Edna in processing the many losses she is experiencing and to feel validated and in control in a new and unfamiliar environment and routine.

**Use Environmental Cues**

- It may be helpful to use things such as photographs, objects, furniture from Edna’s home if possible or other items which would support Edna to maintain her sense of identity and connect with her past in a meaningful way. It may also be helpful to support Edna to do some life story work/ make a photo album or gather music which was important to her and Eddie in the past.



## CASE STUDY 2 | **Tom** (adapted from 26)

*Tom is a 71-year-old man with an intellectual disability and a diagnosis of dementia. He lived in a house with five others for 20 years. He recently moved into residential care centre which is home to 19 other older people with higher levels of dependency and medical needs. Many of them also have a diagnosis of dementia.*

*Tom communicates using some sounds, words and gestures. He is reliant on staff knowing him well to be able to understand what he is communicating and to communicate with him in a meaningful way. He shows signs of depression and is on anti-depressant medication. Recently, Tom was informed that his 93-year-old mother Mary died. He was not facilitated to attend the funeral at his family's request. Healthcare staff are very concerned about Tom's emotional state. He is very withdrawn and uncommunicative and is refusing to eat. He is awake at night and very restless.*

*You are a healthcare staff member working in Tom's residential care centre. What do you do?*

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It is not uncommon to find this type of grief reaction to a significant loss. People with intellectual disabilities and dementia express their grief in the same individualised and unique way as others. Tom was not supported to go through the removal or funeral. These rituals often aid us to begin to process our loss and begin grieving. Your response as a healthcare staff member should be guided by the framework:

- **Know Tom well:** Tom is likely to be experiencing an overwhelming sense of loss in relation to his mother. He has recently had a major transition to a larger, less personalised setting where he has not yet developed close and trusting relationships with healthcare staff. It may take him a long time to get to know new people and to feel comfortable. This may be even more difficult for him in light of his bereavement.
- **Using a life story approach** with Tom may help him to process and understand the many changes which have happened to him. It would support healthcare staff in getting to know him well, understanding his life history, his family and his likes and dislikes. Life history work is as much about the process of engagement with the person and their family as it is the product. Take time with Tom to look at photos and support him to express his emotions. Part of this work may involve taking Tom

## CASE STUDY 2

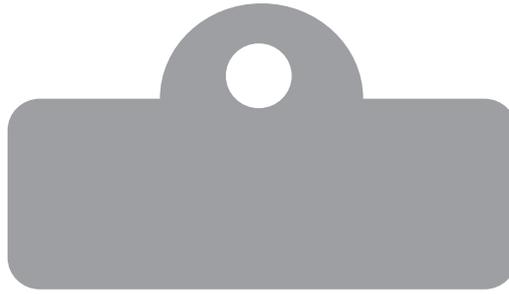
to visit his old friends to begin to process his change in environment. It may also involve working with his family to develop an understanding of the things that matter to Tom and to give you some information about Tom's mother which may support him. For more information on life story work as an approach please see (115).

**Validate and acknowledge Tom's emotions**

- **Labelling Tom's emotions** may be a helpful way of engaging with him. Saying something like *"Tom I see you're really sad/upset today". Will we talk about it?* Something practical like doing an activity Tom likes or going for a walk/ leaving the residential care setting may be a good way to connect and engage with Tom.
- **Support Tom to express himself and to grieve on his terms.** It may be useful to speak with the family about how best to support Tom with his grief. Visiting his mother's grave and/ or the family home may be supportive to him in beginning to grieve. Using art or music therapy may be other useful avenues to support Tom in expressing his grief.

**Understand connections**

- **Support Tom** to maintain his relationships with his family and friends. This will help to allow him feel connected and supported in a new environment after a major bereavement.
- **Use environmental cues:** It may be useful to have a photo of Tom's mother and some objects which he would relate to her as a way of supporting him to continue to feel connected to his mother.



### CASE STUDY 3 | Joe

Joe is a 75-year-old man with a diagnosis of Alzheimer's disease. He has been living with Alzheimer's disease for seven years. Joe lives in his own home with his daughter Emma. He has a homecare package, with staff coming into the home to assist him 3 times a day. Joe's wife Mary died five years ago. You are a healthcare staff who regularly works in the house in the morning times. The past few mornings, Joe appears to be anxious and keeps asking for Mary. His daughter told you that she has tried a number of approaches to dealing with his question – she has tried to tell him that Mary is dead and also tried to avoid the topic and distract him. Joe asks you where Mary is and is pacing up and down. How do you respond?

- **Validate Joe's emotions and tune into the emotion behind the words.** Joe might be missing Mary, feeling lonely, wondering why she is not around and be feeling fearful, distressed, suspicious or concerned. Sometimes labelling emotions can be helpful to a person who is struggling to say what they are feeling *"You sound like you're really upset about Mary. Tell me what she was like/ what you miss about her"* or *"You sound really lost/ frightened/ angry, let me help you"*.
- There may be a practical thing you can do – Joe may be upset about something Mary would have typically done. It may be helpful to say something like *"What would Mary do if she were here?"* Often a person with dementia may give a very practical response which you can do (e.g. help with dressing/ breakfast/ going out etc).
- Use the past tense when referring to the person *"I heard that Mary used to make a lovely chocolate cake, didn't she?"*
- Be responsive to Joe's mood and respond accordingly. If he seems sad/ angry/ has another change in his behaviour, provide support for those emotions.
- Be consistent – develop a response which best supports Joe and share which approach seems to work best for Joe with Emma his daughter and other key people who support Joe.

**Understand connections:** Accept that Joe might want to talk about Mary frequently or infrequently. Follow his lead.

- Look for patterns in when Joe is asking for Mary– is it morning/ evening? Is it related to a particular routine they did together? What works best to support Joe? Does it seem more helpful to deflect his attention to another topic or to talk about Mary?

**Utilise environmental cues:** Use photos or other objects relating to Mary to support Joe express his grief but also to reminisce about and remember his wife.



## CASE STUDY 4 | Irene

Irene is a 60-year-old woman who was diagnosed with young onset dementia at the age of 58. She has three daughters aged 16, 19 and 24 and is married to Jack. Her children are all in full time education. Irene worked full time as a bank manager and enjoyed engaging in a wide range of leisure activities such as book clubs, running, yoga and she acted as President of the local St. Vincent DePaul conference for many years. She has lots of friends and enjoyed socialising on a regular basis.

Since her diagnosis, Irene has experienced a myriad of losses – she has had to give up her work, resulting in a significant loss of income to the home and she has begun to struggle with reading and ‘keeping up’ in social situations. She describes each day as ‘a battle’. While she continues to volunteer with her local Vincent DePaul group, she has stepped down as president. You are a healthcare professional who meets Irene at your local Alzheimer Cafe. While you are chatting over a number of weeks, she reveals that she is anxious, lonely and afraid to share her feelings with her family in case they get upset. She says she is trying to mask her difficulties from everyone around her and is struggling to cope with all of the changes which are happening in her life. She is worried about her family’s future and does not want her children to become her carers at such a young age. She cannot access many of her local services due to her young age. In that moment, what do you do?

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Irene is experiencing a myriad of losses in her life and experiencing a range of emotions.

**Know the person well:** While you have known Irene for a short time, she has chosen to confide in you. **Recognise the opportunity for discussion and be open to it.**

**Validate and acknowledge the person’s emotions:** Use Active Listening and respect Irene’s story.

- ✓ **Use these nonverbal encouragers:** these are nonverbal actions such as head nods, positive facial expressions, open body language and minimal verbal feedback such as ‘mmm’
- ✓ **Silence** is an important part of listening, just accepting Irene’s story and being respectful.

Continued Overleaf ►

## CASE STUDY 4

- ✓ **Use of open-ended questions** such as:
  - What is that like for you?
  - What is most important for you now?
  - How would you usually cope?
  - Help Irene to consider her support needs and sources of support in her life
- ✓ Saying something such as *“I can see this is a really tough time for you”* or *“I’m sorry this is happening to you”* can often be enough to acknowledge and validate a person’s emotions.

**Understand connections** – recognise the changes in Irene’s role as a mother and a wife, as a friend and a figure of authority in the community (in her job and volunteer work). Ask what that means for her. Consider exploring some new connections which Irene may be able to make.

**Use environmental cues:** Explore the use of a diary/ journaling for Irene to cope with day to day demands. Explore the possibility of Irene meeting smaller groups of friends or inviting a friend to accompany her in situations which may be difficult for her. Be led by Irene in the conversation. Your role is as a support.

Signpost Irene to existing supports available to her.



### e. Exploring a person with dementia's spiritual needs

*“Spiritual care is care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction need requires”* (116).

Spiritual care is a core part of good person-centred care. Receiving a diagnosis of dementia, living with dementia and facing the prospect of dying with dementia can prompt profound questions as to a higher meaning and purpose in life for the person with dementia and their families. The losses that are experienced along the person's journey with dementia can cause spiritual, emotional and psychological pain for the person with dementia. This pain is not often recognised or considered in the same manner as physical aspects of care for people with dementia (117)<sup>4</sup>.

Spirituality is a complex issue and is intensely personal and unique to each person. Definitions of spirituality vary widely but include the following elements:

- It is expressed by the **search for meaning, purpose and value** in a person's life. This may be found in religion, relationships or any other thing which gives meaning in a person's life (119). While religion may be chosen as a core part of a person's spirituality, spirituality does not always need to equate to religion alone
- Spirituality provides the person with an inner force to go beyond their personal circumstances (117).
- Human spirituality involves relationships with other people.

#### ***Spirituality and dementia***

*“Dementia can involve fear, insecurity, vulnerability and a sense of disconnection from place, particularly where there is difficulty for the person to identify others and sometimes his or herself, and yet the need for love, affection and spiritual expression is universal”* (120)

Like each one of us, people with dementia may or may not present to you as having unmet spiritual needs. Below are some tips on how best to approach exploring a person with dementia's spiritual needs.

### **EXPLORING A PERSON WITH DEMENTIA'S SPIRITUAL NEEDS**

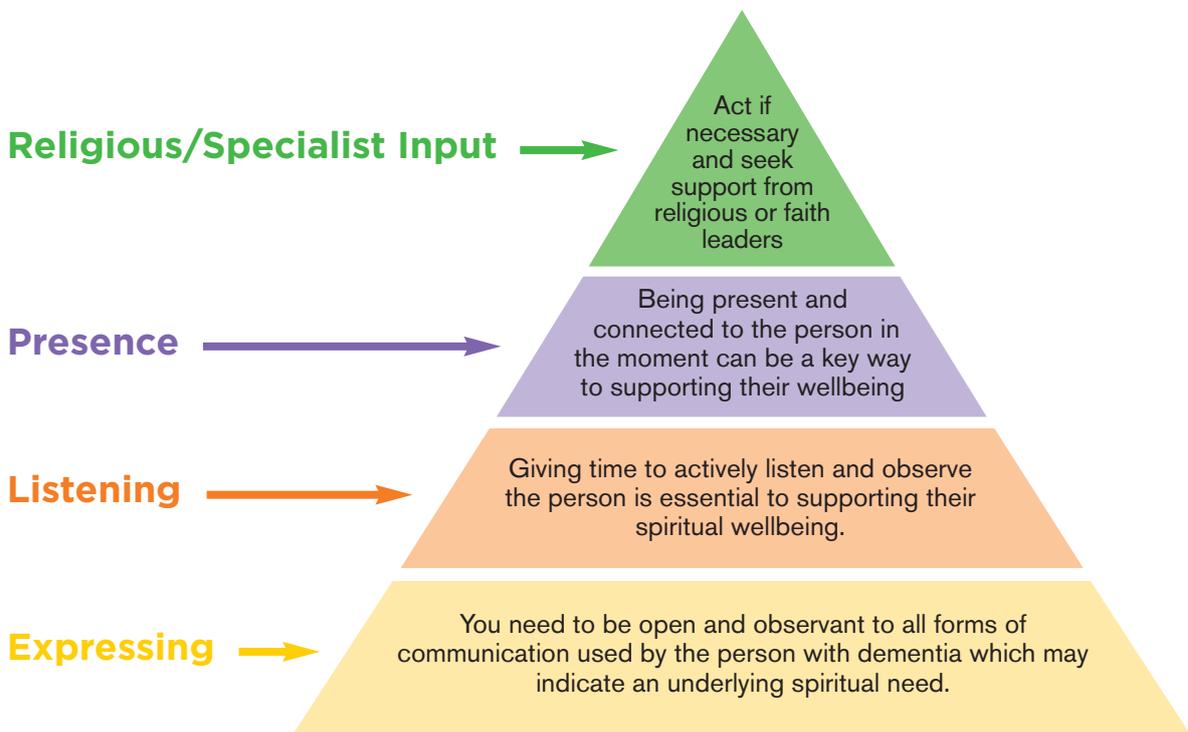
1. Recognise that every person with dementia has unique spiritual needs.
2. Adopt a person-centred approach to exploring spirituality:
  - Connect with the person in a meaningful way.
  - Observe a person and listen to them for possible spiritual needs.
  - Know your limitations and seek support as you need it.
3. Support the person with dementia to connect with people/ things/ rituals which are meaningful in their lives and which give them a sense of peace.

<sup>4</sup> For further information on total pain and pain assessment, the reader is directed to Guidance Document 4 in this series on pain assessment and management (116)

**Exploring Spiritual Needs**

An invitation to explore a person's spiritual needs should always be initiated by them. The person with dementia may express a possible spiritual need in many different ways and should be respectfully explored by healthcare staff.

It is essential that you do not impose your own beliefs or views of spirituality on a person with dementia and that you are guided by the person. Do not assume that the person with dementia has unmet spiritual needs or that they wish to discuss it with you - *always be guided by the person's expressed needs*. Where a person indicates that they do not wish to talk about their beliefs or needs, you must respect their wishes. As a person with dementia's condition progresses, they may rely on a range of other people such as family, friends or staff to support their identity, belonging and spiritual wellbeing (123). It may therefore be necessary to learn about the person's religious/ spiritual inclinations from family / friends (124). Maintaining spiritual well-being of people with dementia can often be met by connecting with significant people and by having companionship in their environments (125,126). The figure below is adapted from McSherry (127) and shows a hierarchy of support which people may need to maintain spiritual wellbeing. Many of these types of support are provided in everyday interactions in the context of caring relationships



Some of the questions which may support you as a healthcare staff when exploring spirituality with the person with dementia are below. They are written in person first language to enable you to consider these questions from the person with dementia's perspective.

- What gives meaning, purpose and value to me in my life?
- What do I need to be at peace with myself, others and the world?

***What gives meaning, purpose and value to me in my life?***

*“I connect at the deeper level of spirituality, so I treasure your visit as a ‘now’ experience in which I have connected spirit to spirit. I need you to affirm my identity and walk alongside me. I may not be able to affirm you, to remember who you are or wherever you visited me. But you have brought spiritual connection to me; you have allowed the divine to work through you. This can happen across cultures and languages, and is a very meaningful depth of communication, one that perhaps we should all strive for”* (Christine Bryden, self-advocate living with dementia in (109))

People with dementia may get a sense of meaning, purpose and value from their faith, their family, or from other things which support them to explore and express their spirituality. Some of the things you may consider when exploring spirituality with a person with dementia are:

- Current religious attachments /Religious symbols (121). People, for whom faith practices have been important in their lives may be assisted to cope by accessing faith activities (such as attending church/ prayer meetings etc) (128). Both religiosity and personal spirituality have been related to maintaining a good quality of life for people with dementia in many studies (128–131).
- The person's past activities – social, cultural, religious, spiritual.
- Past strategies and coping mechanisms.
- The person with dementia's interpretation of the dementia experience.
- The person with dementia's sense of hope and what gives them hope.
- The person with dementia's sense of connectedness with others.
- The presence/ absence of spiritual / religious literature/ rituals/objects and practice.
- Childhood memories and life story work which can support the person to engage in reminiscence and explore the meaning they attach to their experiences (132).
- Art therapy (133).
- Outdoor activity (134).
- Meditation (135).

***What do I need to be at peace with myself, others and the world?***

Bycok (136) identified some of the tasks which people at the end of their life may wish to achieve in order to be at peace. Some of the commonly listed tasks are having a sense of completion of worldly affairs/ responsibilities, a sense of meaning about one's life, forgiving one's self and others, acceptance of the finality of life and a surrender to the transcendent or 'letting go'. There may be some practical things you can support the person with dementia to do to assist them to achieve peace, for example they may be concerned about a family member/ practical issues in the home. They may be concerned about their future and what the plan is for them particularly in relation to their wishes in the event of illness and death. Having plans in place can be important for people with life-limiting illnesses to be at peace.

As a healthcare staff, you may be able to support this planning by:

- Facilitate discussions with the person in relation to their future and end-of-life care and supporting them to engage in **advance care planning** if it is their wish to do so (see guidance documents 1 and 2 in this series for further information).
- **Address the person's hopes, fears and concerns** – use active listening and support emotions. Seek support from colleagues or more senior members of healthcare staff as required.

- **Keep the person connected** to things that have meaning for them. This will mean different things for different people – it may be supporting them to attend to their religious beliefs, it may be supporting them to remain connected with friends and family or many other things to ensure they remain connected to their identity and the world around them.

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## ADDITIONAL RESOURCES TO SUPPORT A PERSON WITH DEMENTIA WITH LOSS AND GRIEF

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1. The Alzheimer Society of Ireland and The Irish Hospice Foundation booklet ***'I have dementia... How I plan for the future?*** This is a useful booklet for people diagnosed with dementia. Available from Alzheimer Society Helpline 1800341341 or website: [https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/publications/Alzheimer\\_PlanForFuture-Brochure\\_web1-\(1\).pdf](https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/publications/Alzheimer_PlanForFuture-Brochure_web1-(1).pdf)
2. The Alzheimer Society of British Columbia have produced an information booklet for people with dementia and their families: ***Ambiguous loss and grief in dementia:***  
[http://www.alzheimer.ca/~media/Files/national/Core-lit-brochures/ambiguous\\_loss\\_family\\_e.pdf](http://www.alzheimer.ca/~media/Files/national/Core-lit-brochures/ambiguous_loss_family_e.pdf)
3. ***Freedem Videos:*** these are a series of short videos produced in Trinity College Dublin. They give viewers a good outline of dementia. Their video on emotional memory is particularly relevant to the area of loss and grief. These videos are available on: <http://freedemliving.com/>
4. Alzheimers UK have produced two useful factsheets in this area:
  - ***Grief, loss and bereavement :***  
[https://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1796](https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1796)
  - ***Making decisions and managing difficult situations***  
[https://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1929](https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1929)
5. Alzheimers Scotland have produced a factsheet on loss and bereavement which has lots of useful information: [http://www.alzscot.org/assets/0000/0176/loss\\_bereavement.pdf](http://www.alzscot.org/assets/0000/0176/loss_bereavement.pdf)
6. The Irish Hospice Foundation have a number of resources available to support healthcare staff working with people with dementia:
  - <http://hospicefoundation.ie/wp-content/uploads/2013/10/Module-2-The-Ethics-of-Breaking-Bad-News.pdf>
  - <http://hospicefoundation.ie/wp-content/uploads/2013/04/How-Do-I-Break-Bad-News.pdf>
  - <http://hospicefoundation.ie/education-training/video-wall/communication/>
  - <http://hospicefoundation.ie/wp-content/uploads/2013/08/Delivering-Bad-News.pdf>
  - Guidance Document 7: Ethical Decision Making in End-of-Life Care for a person with dementia has an ethical decision making framework which would be useful to guide practice when supporting people with dementia. This is available on <http://hospicefoundation.ie/healthcare-programmes/introduction-to-dementia-palliative-care-2/guidance-documents/>

- The Irish Hospice Foundation have produced a number of prompts for good practice guides on:
  - Delivering Bad news
  - Good end-of-life care for people with dementia
  - Responding to difficult questions
  - Communicating with a person with dementia

These are available to download here: <http://hospicefoundation.ie/education-training/healthcare-staffdevelopment/prompts-for-good-practice/>

- The End-of-Life Care Map has useful information for healthcare staff on different aspects of end-of-life care. This is available to download on: <http://hospicefoundation.ie/wp-content/uploads/2013/04/End-of-Life-Care-Map-2013-version.pdf>
7. **Jenny's Diary** is a resource which was developed to support conversations about dementia with people who have a learning disability. It is available on <http://www.uws.ac.uk/jennysdiary/>
  8. The Living with Dementia Programme in Trinity has produced a leaflet to support people with dementia coping with the early stages of dementia. This is available to download here: [http://socialwork-socialpolicy.tcd.ie/livingwithdementia/assets/pdf/Early\\_Dementia.pdf](http://socialwork-socialpolicy.tcd.ie/livingwithdementia/assets/pdf/Early_Dementia.pdf)
  9. The Social Care Institute of Excellence (SCIE) in the UK have a module on the emotional impact of dementia in addition to information on the impact of a diagnosis on a person with dementia. These are available on: <https://www.scie.org.uk/dementia/after-diagnosis/knowning-the-person/life-is-changing.asp>
  10. The HSE National Dementia Programme has a range of videos on responding to people with dementia on responsive behaviours. These are available on [http://www.hse.ie/eng/about/Who/ONMSD/eductraining/dementiaeducation/ResourcesNursesHealthcareHealthcare staff.html](http://www.hse.ie/eng/about/Who/ONMSD/eductraining/dementiaeducation/ResourcesNursesHealthcareHealthcare%20staff.html)
  11. **Spirituality:**
    - The Sacred Art of Living and Dying has excellent resources on different aspects of spirituality: [www.sacredartofliving.org](http://www.sacredartofliving.org)
    - The Foundation for People with Learning Disabilities has produced a factsheet on faith for people with intellectual disabilities. This is available here: [http://www.learningdisabilities.org.uk/content/assets/pdf/publications/what\\_about\\_faith\\_briefing.pdf?view=Standard](http://www.learningdisabilities.org.uk/content/assets/pdf/publications/what_about_faith_briefing.pdf?view=Standard)
    - The NHS Scotland have produced an introductory resource for staff called 'Spiritual Care Matters' - <http://www.nes.scot.nhs.uk/media/3723/spiritualcaremattersfinal.pdf>
    - The Royal College of Nursing have produced a pocket guide called: 'Spirituality in nursing care: a pocket guide' [https://www2.rcn.org.uk/\\_\\_data/assets/pdf\\_file/0007/393154/guide\\_003887.pdf](https://www2.rcn.org.uk/__data/assets/pdf_file/0007/393154/guide_003887.pdf)

### 4.3 Supporting Families with loss and grief

***“I grieve the things that have become impossible for my husband to do. I sit and wait for the next change to happen. Sometimes the change happens quickly whereas other times I seriously think that he is starting to come back. My life has become a nightmare. I am always waiting for the bottom to drop. That is why I grieve – I want my life back”***

(A wife of a man with dementia (104)).

To be able to recognise loss and grief in family members who you support, you need to have an understanding of the types of losses that family members of people with dementia commonly encounter. Unlike death related grief which begins at a single point in time, family members' grief begins with living circumstances and changes over multiple points in time (40). Family members have described their grief as a 'triple grief' – the grief due to the changes in relationship, grief at the time of admission to a nursing home or residential care setting and grief which occurs after a person with dementia dies (137). As outlined on page 11, dementia can be characterised by a sense of ambiguity, multiple losses and the feeling of losing control (104). Below is guidance on how best to support family members experiencing loss and grief and this is followed by resources and further information.

#### 4.3 GUIDANCE: Supporting Family Members of a Person with Dementia with Loss and Grief

- a. 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.
- b. Be aware of the types of losses and the transitions encountered by family members of people with dementia
- c. Be sensitive to family dynamics which will change and seek to meet family members where they are at.
- d. 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 (18,104,138).
- e. 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.

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## INFORMATION AND RESOURCES TO SUPPORT GUIDANCE AREA 4.3

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### a. Be aware of the types of losses and the transitions encountered by family members of people with dementia

As described in the four key considerations to good practice, individual and family reactions to dementia are unique. Families can experience profound grief as they watch the slow deterioration of the person they love in many aspects of their lives (35). The grief experienced by family members needs to be considered both in the context of their relationship with the person with dementia and in the context of the family unit. Every family member's relationship with the person with dementia is different. Families' relationships are interdependent and intertwined; while loss affects each person at an individual level, there is a need to consider that the losses encountered have a wider impact on roles, relationships and grief on the immediate and wider family context of the person with dementia. Some of the factors which may affect the grief response of the family are the circumstances surrounding the loss, individual and familial coping capacities and grieving styles, the availability of extended family and broader relationship resources to serve as support for the family's grief, the functional position of the person with dementia and the level of family cohesion and maturity (35,139).

Anticipatory loss and ambiguous loss are commonly reported by family members as part of the experience of living with a person with dementia. Remember that loss is unique and subjective to each person's experience and relationship with the person with dementia. In order to support you to develop an understanding of some of the losses which may be occurring for families. Some of the losses commonly encountered by family members are outlined below:

- **Loss and changing roles in the family** (140): Being a family member of a person with dementia can mean the change of a relationship that was central to one's life and this can lead to a number of conflicting emotions. Children may experience role reversal and struggle with making that change. There may be additional or secondary losses associated with dementia such as loss of employment and income.
- **Loss of hopes and dreams for the future** (97)
- **Psychosocial Loss:** The person with dementia's identity may appear to be so changed that family have described this loss as the 'death of the person that once was' (3).
- **Loss of companionship and intimacy** (103,104,141,142): Relationship losses are extremely significant for both the children of the person with dementia and their spouses.
- **Loss of control:** over one's life due to new and ever changing circumstances of living with a family member who has dementia (97,103,104).

## b. Recognising Loss and Grief in family members of people with dementia

Family members may confuse grief with stress and may only recognise their emotions as being a manifestation of grief after they are explicitly told that is what they are experiencing (143). Some family carers will not accept/ allow themselves to grieve. This is called self-disenfranchisement - where a family carer feel it is unfair to their relative or 'self-indulgent' for them to grieve (144). This is particularly the case when the person with dementia is still living. Some of the commonly reported feelings of family carers of dementia in the literature are as follows:

- Despair
- Chronic sorrow and heartfelt sadness for the person with dementia (98)
- Anxiety (34)
- Worry and isolation (98)
- Anger (141)
- Frustration (97,145)
- Guilt (97,146).
- Confusion and mixed emotions: many people with dementia can vary hugely in how they present each day. They may have episodes of lucidity where they seem more verbal, connected and insightful only to revert back to struggling with communication and this can lead to difficult and confused feelings for family members (147). Day to day variability in the person with dementia's presentation can be especially difficult to cope with.

Some family members may refuse to accept the losses which dementia brings and deny the effects of the disease and try to retain the person who once was. This can be problematic where a family may presume that the person has control over their behaviour (34,35).

Another factor which has a profound impact on the grief response of individuals and families is the experience of caregiving. The nature of dementia and how it progresses means that some family members will gradually increase their level of care for the person with dementia and take on the role of a family carer. The experience of caregiving can result in both positive and negative outcomes for family members (148). Some of the negative outcomes which can result from this experience are social isolation, burden, depression, emotional and physical strain, poor physical health and a decreased ability to work (149–151). Positive aspects of the caregiving role include gaining a sense of meaning, satisfaction, well-being and improved quality of relationships (142,152–154). These positive aspects of caregiving can act as a source of hope and may help to sustain family carers in their work (154). When a person with dementia dies, many family carers experience the primary loss of losing their loved one in addition to secondary losses which are associated with the caregiving role such as loss of a meaningful and fulfilling role, loss of social contact with healthcare staff involved in the person's care and loss of routine (140).

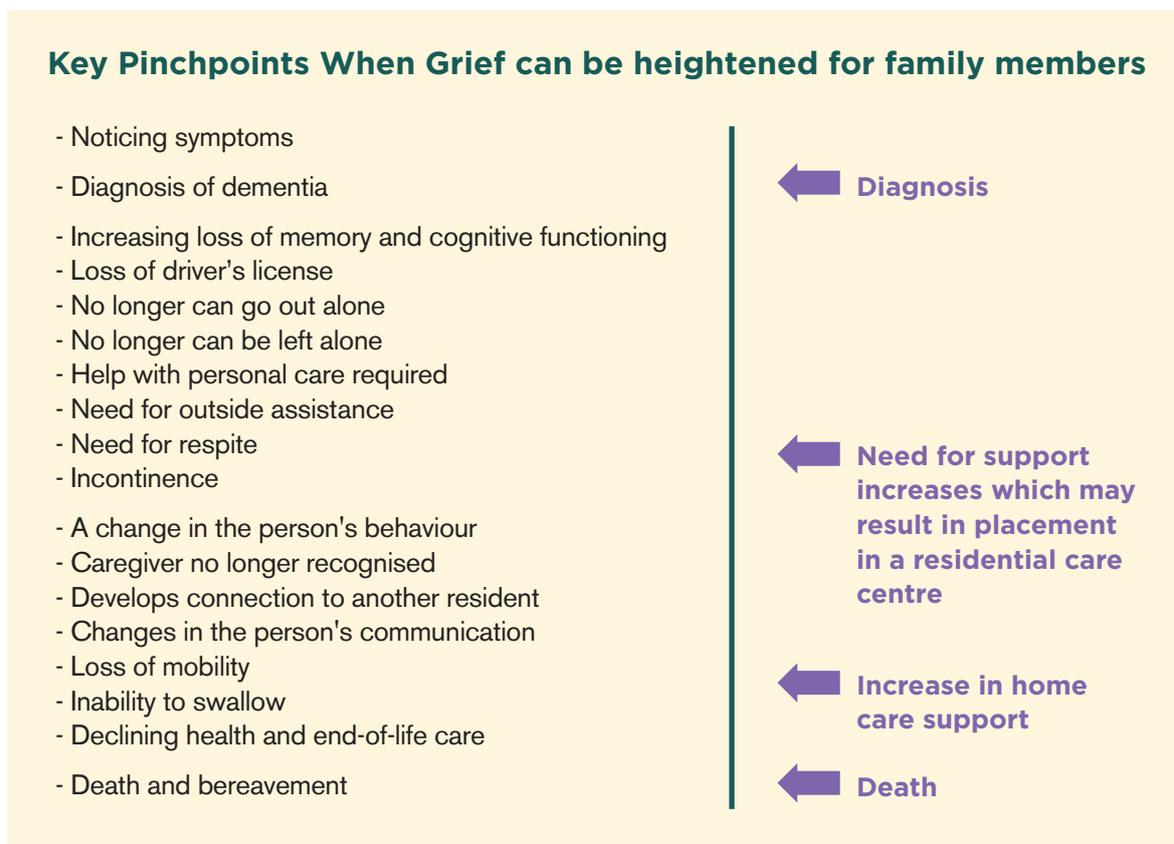
It is essential that you pay attention to relationship losses and the unique nature of the losses encountered by family members and be aware that these losses can differ significantly depending on whether the relationship with the person with dementia was that of spouse or an adult child (32,145,146,155). Spouses are more intensely affected than adult children (141) and this grief increases as the person with dementia's condition deteriorates (35). The table overleaf is taken from Adams et al (146) and is intended to be used to inform and guide your practice on some of the differences which you may encounter between adult children and spouses in your work. Please remember that each person is unique and this is intended to aid your learning. Always be guided by the people you work with in relation to their unique perspectives and meet a family where they are at.

	<b>Adult Child</b>	<b>Spouse</b>
<b>Early Stages / Mild Dementia</b>	<p>Low grief intensity</p> <p>Loss is focussed mainly on personal sacrifices</p> <p>Caregiving generally involves assisting tasks of daily living such as paying bills/ tracking appointments etc.</p> <p>Grief is present but subtle</p>	<p>Tangible sadness is evident</p> <p>Focus of the loss is on the person with dementia and their changes in stance</p> <p>Spouses tend to speak more openly than adult children</p>
<b>Middle Stage</b>	<p>Adult children providing care demonstrate high grief intensity and a number of dominant reactions including guilt, anger and resentment</p> <p>Shift in roles is now clear</p>	<p>Grief intensifies</p> <p>Dominant feelings are compassion, frustration, sadness and a loving redefinition of the relationship</p> <p>Emphasis is on finding meaning and encouragement from small successes in the present</p>
<b>Late Stage</b>	<p>Grief intensity remains high but pattern shifts from anger and frustration to sadness, regret and resignation</p> <p>If the person with dementia goes into a nursing home/ care placement, adult children appear to experience 'true grief'</p>	<p>Grief intensity remains high</p> <p>If the person goes into a nursing home, this can symbolise the end to married life which brings its own set of emotional struggles</p>
<b>After death</b>	<p>Bereavement is associated with a wide range of reactions- grief responses but also relief, resilience and recovery</p>	<p>Death changes focus of the spouse's grief – spouse may be dealing with primary loss of the person and secondary losses associated with the role</p> <p>May experience mixed feelings relief and guilt and intensified grief</p> <p>Sense of finality</p>

### c. Transitions encountered by family members of people with dementia

The number and frequency of transitions into different healthcare settings varies for any individual and each change brings with it a need for new adjustments. These can cause periods of acute grief or 'grief surges' for family members. There are commonly reported 'pinch points' when grief is acutely felt.

The figure below is taken from (156) and gives the reader a sense of the key points along the person and families journey with dementia where grief is heightened.



Family members can experience intense feelings of guilt, particularly when there is a need for external involvement in the person's care such as beginning to engage with home help services, going to respite or going into a nursing home. They can feel guilty if the person is unsettled, they can compare themselves to others and their ability to cope, they may find it very hard to see the person very settled in a new environment or having good relationships with healthcare staff when they had been very unsettled at home (157). It is vital to be sensitive to families at this highly emotional and stressful time. What may seem like an angry/ pedantic family member may in fact be a person trying to exert some level of control over a situation which is intensely stressful and overwhelming for them.

Moving into a long term care setting is a time where family members experience acute or heightened grief reactions (141,158). Many family members can be overwhelmed with feelings of guilt, loss and grief. Healthcare staff and family members can often misinterpret each other's communication, or each other's motivations and this is a common source of complaint in healthcare settings (159). It is extremely important to support family carers to continue to be involved and connected with their relative and provide emotional support to help them positively adapt to their new situation (160).

The figure below (adapted from (157)) demonstrates some of the thought processes which may be happening for family members and healthcare staff.



#### HEALTHCARE STAFF THOUGHTS....

- They visit too often
- They're always having a go and asking questions
- They exaggerate things which appear trivial
- They are too demanding – feeling of being underappreciated / undervalued
- I'm never going to be good enough so what's the point



#### FAMILIES' THOUGHTS....

- Maybe I should have done more to try and keep him/her at home.
- I miss my partner
- I'm lonely
- I wish I could do more
- I used to make all the decisions and now I don't know what's going on
- I'm really upset

#### d. Supporting Families through loss and grief

**“Good communication in the patient, relative and healthcare staff triad that addresses knowledge, emotional needs and practical planning may facilitate management of uncertainty and preparation for death”** (161).

As outlined in guidance area 4.1, one of your key roles as a healthcare staff member is to recognise, acknowledge and validate a family members' grief reactions. Emotional experiences need emotional responses: think about where the person and their family are on their journey and what their priorities for care are at this point. Help should be designed to meet those needs – these may be physical, psychological, informational, spiritual or more general support. By engaging in open, respectful and positive interactions with family members and being mindful of the difficulties they are encountering in their current role(s), it is likely that you will support them to cope better and feel more positive about the difficult transitions they are facing. For the purposes of this document, the remainder of this section is divided into different points on a family's journey where they may need additional supports. These are:

- a) Supporting families when they are directly caring for their family member with dementia
- b) Supporting families when their relative enters their final days/weeks
- c) Supporting families at the time of a person with dementia's death
- d) Supporting families after a person with dementia dies.



a) Supporting families when they are directly caring for their family member with dementia

***“It’s a paradox. Something is lost but something is not lost. So I started to look for things that were still part of my mom. My mom still has a sense of humour and I can still share a laugh with her. She still has an emotional part to her so I zero in on the emotion of the event because it’s on a level where she gets it. She may forget my name but she knows who I am”***

(Daughter quoted in (50)).

It is important when beginning a new relationship with a family that you actively seek their unique knowledge and input and agree on a way of working and communication which will work for both of you. Discuss expectations and what is feasible in terms of a point of contact (157). Remember to always value a family members role and do not strive to take over completely (162).

Family members are a huge source of information and support for healthcare staff and have a key role to play in supporting the person with dementia to maintain their identity and connection to the things which matter to them. (163).

The profound transformations that occur amid the losses and grief can give rise to new hope, purpose and meaning in the lives of family carers (31). Paradoxical thinking can be a helpful way to support families to explore, learn to tolerate or live with the many uncomfortable ambiguities of the disease. This involves acknowledging the range of feelings that are going on simultaneously (31). For example, a spouse may feel married on the one hand to their spouse with dementia and not married on the other. They may love the person deeply and yet be angry or hurt in relation to some of their reactions and behaviours. This causes confusion and can cause a lot of mixed emotions. It is important that family members learn to recognise, understand and hold the paradox and accept two opposing ideas at the same time (50).

Helping family members plan for their future can be supportive and help them to cope with current losses and anticipate their life as it may be in the future.

## **SUPPORTING FAMILIES WHO ARE DIRECTLY CARING FOR THEIR FAMILY MEMBER WITH DEMENTIA:**

1. Communicate openly and honestly with the person and their family.
2. Offer the family information and education about:
  - Dementia and what to expect as the condition progresses
  - Losses which commonly occur for family members and the range of grief reactions which can occur (164).
3. Encourage family members to engage in paradoxical thinking as a way of understanding and coping with living with dementia.
4. Support families to anticipate and plan for the future as appropriate to them.
5. Support the family to engage with the person with dementia in creative ways - this can often be a good way to maintain and develop new connections together (31).

## b) Supporting families as the person with dementia enters their final days/ weeks of life

***“We weren’t told that she was going to die. We should have been told. We didn’t realise that her death was so close – it came as a shock”*** Family member , personal communication.

Family members often journey through dementia with their family member and witness a slow deterioration in their relative’s abilities over a long number of years. People dying with dementia have an ambiguous/ uncertain trajectory towards death which can lead to difficulties for healthcare professionals in recognising when the person is dying (19,20,166). As a result, families may be unprepared for their relative’s death and key discussions with family members may not often take place in time. There is an association between being unprepared for death and higher levels of grief and depression in bereavement and it is therefore essential that families are kept informed at all times of their relative’s condition (167).

It is important to note that as a person with dementia reaches the end of their life and becomes dependent on others for all aspects of their care, the emotions of family members can be fraught. Difficulties with service provision such as poor communication/ difficulties with decision making or routine care being delivered in a way which is not congruent with the person with dementia’s will and preferences can become emotionally charged due to the grief which is mounting for family members (168). The extent to which family members can engage with the person with dementia before they die is also seen as an important aspect of shaping the experience of their death and have an impact on their outcomes when they are bereaved (105).

Clear open lines of communication between healthcare staff and family which address knowledge, emotional needs and practical planning are of utmost importance and may facilitate the management of uncertainty and preparation for death (161,169). Knowing when a person with dementia will die is difficult so discussions need to take account of the fact that the person may or may not die within days but that the prospect is becoming more likely (170). Drawing the family together to discuss their current situation, formulate care plans and talk about their feelings may help to mobilise family resources and prove helpful in bereavement (108).

Tips on how to best to support families at this time is given below:

### **SUPPORTING FAMILIES AS THE PERSON WITH DEMENTIA ENTERS THEIR FINAL DAYS/WEEKS**

1. Communicate openly and sensitively with the family about the person with dementia’s condition within your own scope of practice and role. Maintain open lines of communication. You may do this in many ways such as giving the family a key contact person and a phone number and ensuring that the healthcare team checks in with the family regularly.
2. Facilitate a family meeting to ensure a shared approach to the person with dementia’s care and to talk about their feelings relating to the situation.
3. Provide emotional and spiritual support for the family during the person with dementia’s final days by:
  - Recognising, acknowledging and validating emotions
  - Providing support which the family requires (this may be practical, spiritual or emotional)
  - Signpost family members to information and supports they may need

### c) Supporting families at the time of the person with dementia's death

Relatives of a person with dementia may need additional support at the time of the person's death.

#### SUPPORTING FAMILIES AT THE TIME OF THE PERSON WITH DEMENTIA'S DEATH

1. Communicate openly.
2. Give the family space and privacy to spend time with the person with dementia.
3. Facilitate the family to be able to say goodbye to the person with dementia.
4. Give the family information on what to expect and what will happen next as appropriate.
5. Provide space and support for the family to express their emotions.

### d) Supporting families after the death of the person with dementia

***“The physical death of a relative with dementia is not the end of the journey. The bereavement experience following the bodily death of a person with dementia can be profound”*** (105).

When a person with dementia dies, grief of their family members changes focus. The grief experienced by family carers is often complicated by all of the feelings that arose in the course of caregiving. For some, the death may be a liberating loss while others may grieve the loss of the caregiving role (30). Death has often been described by family members in paradoxical or contradictory ways- e.g. as both a tragedy and a blessing (171). Bereavement is associated with a wide range of reactions including not only grief but also relief, resilience and recovery (172).

Some family carers have reported that they missed the professional support of healthcare staff after the person with dementia died (49). Tips on supporting families after the death of their relative with dementia is below:

#### SUPPORTING FAMILIES AFTER THE DEATH OF A PERSON WITH DEMENTIA

1. Give family members information on grief and additional supports they can access.
2. Consider offering the family to meet at least once after the person's death has taken place.
3. Develop other rituals such as a memorial tree/ book in your care setting and invite families to place a photo/ memory of their family member in it.
4. Hold an annual memorial service for family members of those who have died while in your healthcare setting.

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## ADDITIONAL RESOURCES FOR FAMILY MEMBERS:

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1. The Dementia Elevator Programme has a new free online module available for family carers of people with dementia. Coping Skills for families and carers: <http://elevator-carers-coping-skills.com/>
2. The Living with Dementia Programme in Trinity College have produced a booklet for family members – “Life for Caregivers after placing a relative with dementia in a nursing home: A guide for family caregivers and nursing home healthcare staff”. This gives caregivers practical advice on coping with this transition. It is available to download on: [http://socialwork-socialpolicy.tcd.ie/livingwithdementia/assets/pdf/Life\\_for\\_Caregivers\\_After\\_Placing\\_a\\_Relative\\_with\\_%20Dementia\\_in\\_a\\_%20Nursing\\_homedf.pdf](http://socialwork-socialpolicy.tcd.ie/livingwithdementia/assets/pdf/Life_for_Caregivers_After_Placing_a_Relative_with_%20Dementia_in_a_%20Nursing_homedf.pdf)
3. The Irish Hospice Foundation and the Alzheimers Society of Ireland have produced leaflets for people with dementia and their carers on the following:
  - Understanding late stage dementia
  - Loss and Grief when a family member has dementia
  - Loss and Grief following the death of a family member with dementia.

These are available from the Alzheimer’s Society of Ireland on 1 800 341 341 and on both the Irish Hospice Foundation and the Alzheimer Society websites [www.hospicefoundation.ie](http://www.hospicefoundation.ie) and [www.alzheimer.ie](http://www.alzheimer.ie)

4. The Irish Hospice Foundation has produced a ‘just in time guidance’ for healthcare staff supporting families at the end-of-life. This is available here: <http://hospicefoundation.ie/wp-content/uploads/2013/08/Supporting-Families.pdf>
5. The Alzheimer Society of British Columbia has produced a six part education series called ‘Coping with Transitions in Dementia Caregiving: Dimensions of Loss and Grief. The workbook for carers is available to download on: <http://www.viha.ca/NR/rdonlyres/4D7BC242-87F1-4B7C-BBBC-95C935E5AF46/0/dementiaworkbookgriefloss.pdf>
6. Videos on Loss, Grief and Dementia : <http://www.viha.ca/seniors/dementia.htm>
7. The Alzheimer Society of British Columbia have produced a booklet for healthcare providers called ‘ Ambiguous Loss and Grief: A resource for Healthcare Providers’. At the back of this booklet (page 17) has useful tips and strategies to support family carers in living positively with their losses. This is available to download on: [http://www.alzheimer.ca/mb/~media/Files/national/For-HCP/for\\_hcp\\_ambiguous\\_loss\\_e.pdf](http://www.alzheimer.ca/mb/~media/Files/national/For-HCP/for_hcp_ambiguous_loss_e.pdf)
8. The Alzheimer Society of British Columbia have produced a booklet for people with dementia and their families called “ Ambiguous Loss and Grief: A resource for people with dementia and their families” Available on [http://www.alzheimer.ca/~media/Files/national/Core-lit-brochures/ambiguous\\_loss\\_family\\_e.ashx](http://www.alzheimer.ca/~media/Files/national/Core-lit-brochures/ambiguous_loss_family_e.ashx).
9. Alzheimers UK have produced a useful factsheet for family members on end-of-life care. This is available to download here: [https://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileD=2267](https://www.alzheimers.org.uk/site/scripts/download_info.php?fileD=2267)
10. Carer Alliance have developed a booklet to support family carers transitioning to their life after caring for a relative. This is available to download: <http://www.carealliance.ie/userfiles/file/LifeAftercareBookletFinalWebVersionOct2011.pdf>

## 4.4 Supporting yourself as a healthcare staff member

***“Close emotional relationships form the foundation of compassionate well-informed quality care, specifically the kind of care that is necessary in providing good palliative care”*** (173).

Staff providing care and support for people with dementia often form deep and meaningful attachments and relationships with them, which can be akin to family like relationships (63, 174, 175). The losses experienced by people with dementia and their families and witnessed by healthcare staff on a daily basis can result in varied degrees and forms of grief reactions of staff in anticipation of losses, losses experienced during the person's illness and grief following the person's death. Exposure to these losses, as outlined in the key considerations for good practice, can also put staff in touch with their own losses.

Providing care and end-of-life care has an emotional cost for healthcare staff (176,177). Healthcare staff have reported experiencing tremendous loss and grief when a person they have cared for dies (170). Healthcare staff grief in working with people with dementia can be disenfranchised in many ways:

- It may be viewed as being 'unprofessional' to grieve in the workplace. Healthcare staff may not even recognise their own grief and just see it as part of their role.
- The relationship which the healthcare staff member has/ had with the person with dementia is not recognised as having significance.
- Staff are expected to support others in their loss without the acknowledgment that the death is a loss for them too (178). Those working a long time with people (this can be particularly relevant in intellectual disability services) tend to experience the most grief related symptoms (179).
- Healthcare staff can be excluded from attending the funeral or engaging in grieving rituals (43,66).

How staff are supported to express and cope with loss and grief has a direct impact on the quality of care a person with dementia will receive (173). Each staff members' experience of grief is individualistic, with a complex set of personal and organisational circumstances affecting the grief burden (173).

When grief is unattended to it cannot resolve or heal and the effects of grief can accumulate over time. Unattended grief can lead to reduced quality of end-of-life care, higher rates of healthcare staff turnover and absence, lower morale and innovation, poor teamwork and healthcare staff experiencing burnout and compassion fatigue (66). When healthcare staff feel undervalued / their feelings are not validated by their colleagues, managers or organisations, this can lead to healthcare staff becoming detached, stressed or burned out in their roles. Staff who perceive that their feelings of loss were validated experienced greater feelings of growth from their losses (173). Supporting staff grief can also contribute to improving retention of staff by enhancing their feelings of satisfaction and well-being (173).

It is essential to acknowledge and attend to your own grief in order to allow you and your team to continue to provide compassionate care. Overleaf is guidance on supporting yourself in your work.

## 4.4 GUIDANCE: SUPPORTING YOURSELF AS A HEALTHCARE STAFF MEMBER

1. **Develop an awareness of your own support needs and what supports you in your life and your work.** Reflect on what you give and what you get when you provide care and support to people with dementia and their families
2. **Engage in self-care; This may include:**
  - Practicing relaxation techniques
  - Acknowledging and normalising your own feelings of loss
  - Reminiscing and expressing your feelings
  - Asking to attend the funeral/ memorial service when a person you cared for died as appropriate
  - Starting up or contributing to a memory book of people who you have cared for
  - Saying your own private goodbye.
3. **Communicate with others about your experiences and your feelings:** This may be with a colleague you feel comfortable with, a friend or your manager.
4. **Seek out support** if you are experiencing difficulties with eating, sleeping or feel overwhelmed. Speak with your GP about it.

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## INFORMATION AND RESOURCES TO SUPPORT GUIDANCE AREA 4.4

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This section will cover the following areas:

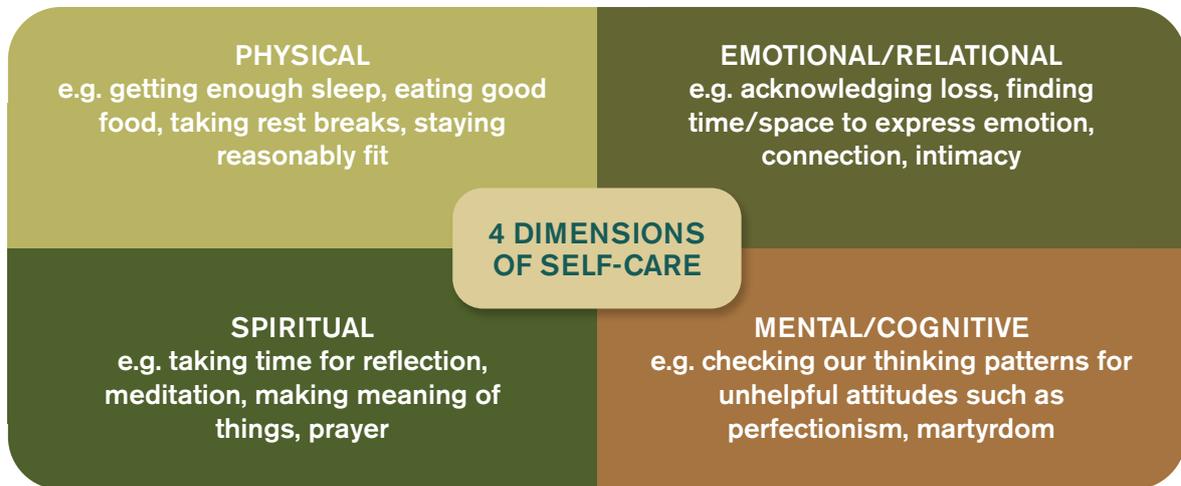
1. Self-care for healthcare staff
2. Supporting colleagues and promoting a supportive team
3. Supportive Organisations

### 1. Self-care for healthcare staff

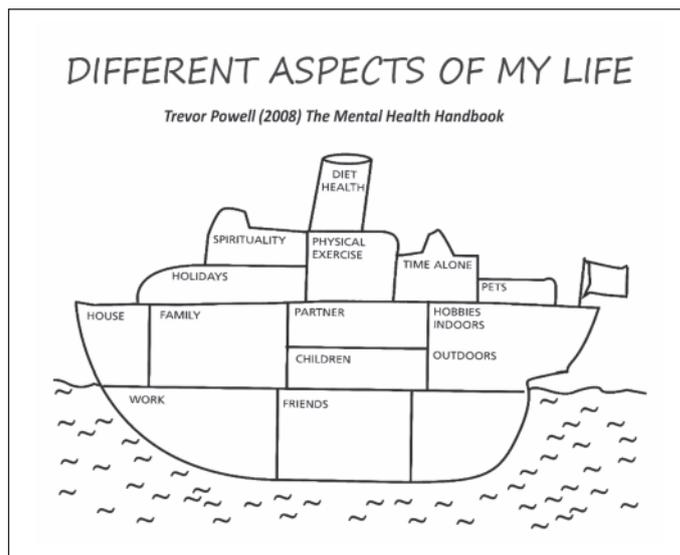
***“You can only do what you can do in a day! Live your life fully. You are out there everyday doing your best work/ So at the end of the day know that you have done your best take good care of you , go home and hug your family and friends and take the best possible care of you”*** (180).

As a healthcare staff, it is essential that you attend to your own health in order to continue to do your job well and provide support for people with dementia and their families. Many healthcare staff will argue that they simply do not have the time to attend to self-care but you need to find a way of building self-care practices into your day to maintain your own health and wellbeing (181).

The figure below shows four key aspects of self-care for healthcare staff working in end-of-life care (182).



In addition to the four aspects outlined above, the use of humour is an important aspect of relieving tension and mitigating grief (181,183).



As people, we are multidimensional. We should strive to achieve a balance between different aspects of our lives. It is important to acknowledge your own personal needs (body-mind-spirit) and how you can maintain your wellbeing.

Being aware of and being able to identify stress, burnout and compassion fatigue is essential to your wellbeing in your work.

It is important that you are aware of your internal feelings as you go about each day. Think about what your personal stress triggers are and monitor them as you go about your day. Consider the following questions:

- What is your level of energy and balance today?
- Are you stressed out, overwhelmed/ anxious? Are you balanced, serene, calm and at peace? Or are you somewhere in between those?
- What helps you replenish your energy?
- What helps you feel mentally and physically refreshed?
- How do I care for my mind, body and spirit? (156).

### Develop awareness of the impact loss and grief has on you

Your responses as a healthcare staff member are shaped by your experiences. You will meet a person with dementia and their family through your own experiences of dementia and your own experiences relating to loss and grief. It is important that you remember the following points when you are working with people with dementia and their families:

- You are not immune to grief.
- You need to take care of yourself in order to be effective and resilient in this work.
- You need to be aware of your feelings about and approach to loss and to death.
- You need to have a sense of what draws you to this work and what you get out of it.
- You need a safe place to process your own feelings.
- You need to have a sense of what helps you to stay healthy and committed to this work.

It is important to recognise the opportunities for personal growth which the experience of grief brings (60). Healthcare staff's ability to attribute meaning to life, death and to the contributions they make in the caregiving process helps them to integrate loss experiences into his/ her personal world and attribute a positive meaning to one's role which enhances one's purpose and meaning in life (59).

### 2. Supporting colleagues and promoting a supportive team

***“Once a resident dies and the room is cleared of the body and the relationship with the family abruptly ends – there is an emotional loss of both the resident and their family for healthcare staff”*** (173).

At the heart of good end-of-life care lies good teamwork. In order to be able to cope with the demands of your role as a healthcare staff, it is essential that you and your team members support each other. The multiple losses and deaths the staff team encounters will impact on each person differently and each person will cope in their own way. Be respectful of each other and different grieving styles and responses. Some people may wish to speak with team members or colleagues while others will cope with grief alone.

## SUPPORTING COLLEAGUES AND PROMOTING A SUPPORTIVE TEAM

1. Take time to interact with and engage with your colleagues and form good working relationships.
2. Recognise your own limitations and learn to share out the workload and rely on colleagues as you need to.
3. Notice changes in your colleagues behaviour and offer support or respite to one another as required in the course of your work. Rotate responsibilities where possible.
4. Be mindful of external stressors happening in your life or the life of your colleagues and be aware of the impact that can have on your work as a team.
5. Take small breaks during the working day for debriefing as needed.
6. Promote teamwork through coffee mornings/ team meetings/ team building exercises – this will foster an open culture where healthcare staff feel able to share their thoughts and concerns with one another

### 3. Supportive Organisations

***“Creating a work environment where healthcare staff are able to express their grief, work within a supportive clinical team and create a meaningful context in which to place death are all identified ways in managing grief”*** (173).

To provide good person-centred care for a person with dementia, organisations must also support the healthcare staff. Team organisation and environmental culture plays a key role in creating an atmosphere in which healthcare staff feel able to discuss pressures in relation to the situations they encounter at work. How open a workplace is to talking about issues relating to loss and grief and its impact on healthcare staff will affect healthcare staff’s ability to provide good care to clients and cope in that environment. While the aim of this guidance document is to provide guidance for frontline healthcare staff, it is important to highlight some of the findings which are recommended in terms of organisational responses to loss and grief for healthcare staff. While we acknowledge that this is an area which is outside your remit as a frontline member of healthcare staff, it is important to be aware of things which may support you in your work at a wider level.

The following tips are recommended as good practice for organisations in supporting healthcare staff with loss and grief.



## TIPS FOR ORGANISATIONS ON SUPPORTING HEALTHCARE STAFF

**1. Providing healthcare staff support** is a core part of creating a supportive and open culture which supports healthcare staff to provide compassionate, person-centred end-of-life care. Managers and supervisors play a key role in cultivating and maintaining a culture which encourages an open attitude and approach to loss, grief and bereavement. Support can take many forms but it is essential that it is not imposed upon a team or unit and that it fits the needs of the organisation/ healthcare staff as they see it. Support can be formal or informal (see below).

**a. Informal Supports:** Fostering a culture which values the people who work within the organisation and acknowledge the work they do is very important for healthcare staff morale and wellbeing. Open lines of communication are essential to achieve this. Bullet this list. Informal support such as:

- allowing time for healthcare staff to debrief among themselves
- allowing a structure for more experienced staff supporting those who are less experienced
- offering opportunities, space and time for healthcare staff to develop self-care skills
- giving healthcare staff time to reach out to other residents, families and other staff when a resident dies
- Enabling healthcare staff to attend the removal/ funeral in work time
- Acknowledging or recognising staff feelings of loss and grief and provision of positive feedback by management to employees.

**b. Formal Supports:** This may include:

- **Developing/having a bereavement policy**
- **Employee assistance programmes and occupational health promotion**
- **Review meetings after the death of a resident and peer led debriefing**
- **Forming healthcare staff support groups**
- **Regular team meetings**
- **Supervision and mentoring**
- **Spiritual care services:** such as offering voluntary counselling or having an assigned colleague who is available to speak with healthcare staff
- **Open Communication channels:** Ensuring that all healthcare staff are informed of a death of someone they supported and the arrangements.

**c. Collective rituals / memorial services:** Things such as an annual memorial ceremony are important rituals for healthcare staff to be given an opportunity to acknowledge their collective losses. Within units things such as memory books or creating a memory tree with anecdotes/ photos/ stories of residents or people who have been supported are also helpful ways of remembering those who healthcare staff cared for and their families. Creating an environment which encourages expressions of spirituality (such as memorial services and other rituals) may increase healthcare staff resilience.

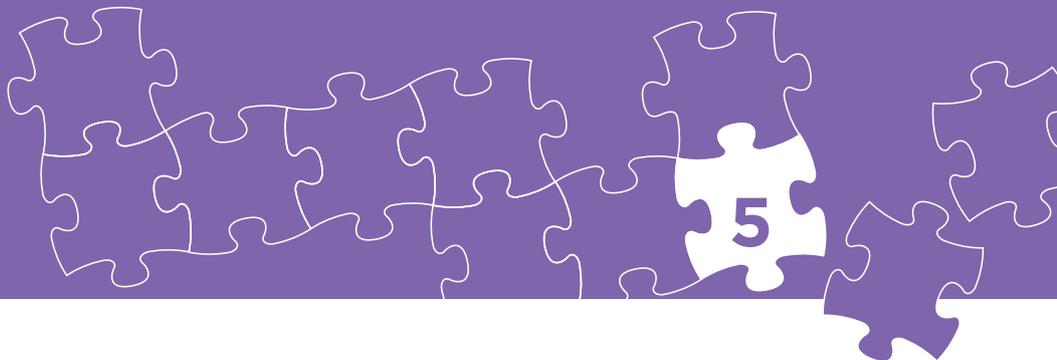
- 2. Provide ongoing education and training:** Training programmes for healthcare staff should include issues relating to loss, grief and bereavement. Organisations should ensure that healthcare staff are aware of the stresses, strains and also the opportunities for personal growth which are involved in working with people at the end of their lives. Helping healthcare staff to develop coping strategies and strategies for self-care should also be a core part of any educational programmes. This should begin from an employee's point of entry into a workplace and form part of their job orientation programme. Having information on grief and bereavement for healthcare staff which includes signposting for family support has been reported to be useful by healthcare staff.

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## ADDITIONAL RESOURCES ON HEALTHCARE STAFF SUPPORT

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1. The Irish Hospice Foundation has created a series of resources and training programmes for organisations and healthcare staff to help them understand grief, the impact it has on the bereaved and their colleagues and ways in which they can be positively supported. These are available on [www.griefatwork.ie](http://www.griefatwork.ie)
2. The Irish Hospice Foundation produced a series of Prompts for Good Practice and 'Just in Time Guidance'. One of these is called 'Caring For yourself in end-of-life care work. This is available here: <http://hospicefoundation.ie/wp-content/uploads/2013/08/Caring-for-Yourself-in-End-of-Life-Care.pdf>
3. The Alzheimers Association of Canada has produced a booklet for healthcare staff called 'Dementia and staff grief: A resource for healthcare providers. Available here [http://www.alzheimer.ca/~media/Files/national/For-HCP/staff\\_grief\\_e.pdf](http://www.alzheimer.ca/~media/Files/national/For-HCP/staff_grief_e.pdf)
4. Webinar on Acknowledging Healthcare staff Grief when working with dementia: It is vital – available here <https://vimeo.com/119876282>
5. Coping with Loss and Grief in the Aged Care Industry <http://www.nalag.org.au/Brochures/Aged%20Care%20Industry-%20Version%201.4%20WEB.pdf>
6. The Psychological Society of Ireland has produced a useful one page leaflet which has 40 tips for mental health, well-being and prosperity. This is available on <http://www.psihq.ie/files/UserFiles/PSI%2040%20Tips%20Flyer%200511%20Web%20.pdf>
7. Carers Victoria have produced a booklet called ' An unrecognised grief: loss and grief issues for carers: worker's guide. This is available on: <http://www.carersvictoria.org.au/Assets/Files/Loss%20and%20Grief%20-%20A%20workers%20guide%20REV.pdf>



## ADDITIONAL RESOURCES

### 5.1 Factsheet on loss and grief in dementia

#### FACT SHEET 3

# 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

## FACT SHEET 3

## 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](http://www.hospicefoundation.ie)



 **The Irish Hospice Foundation**  
Striving for the best care at end of life for all

## 5.2 Understanding the progression of dementia

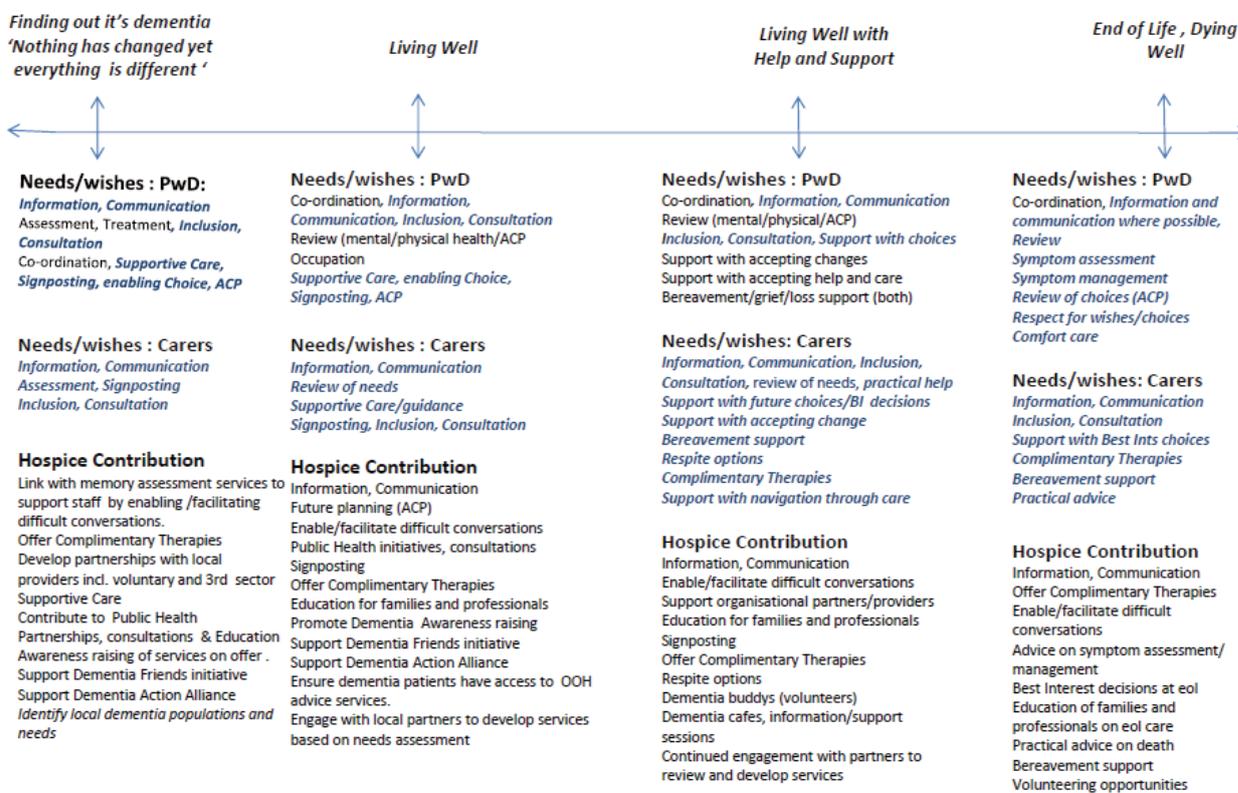
It is important that healthcare staff have a good understanding of how dementia can affect a person as the condition progresses. This sections aims to provide some general information on the typical progression of dementia. It is important to remember that each person with dementia is unique and their experience and journey through their condition will reflect that.

### Typical Stages and Symptoms:

To understand dementia, it can be useful to consider the condition in four stages; early, moderate, late and final stage. There are typical traits and symptoms associated with each stage but equally these symptoms and stages can fluctuate and overlap. The chart below describes the changes that may present for the person with dementia in the different stages, and has been copied from a publication from the Alzheimer Association in Illinois, USA (184).

Changes in Memory, Thinking, Language and Mood			
Early Stage	Middle Stage	Late Stage	Final Stage
<b>Memory and Thinking Skills</b>			
<ul style="list-style-type: none"> <li>• Difficulty with short-term memory</li> <li>• Loses things</li> <li>• Poor attention</li> <li>• Difficulty with calculations and organizational skills</li> </ul>	<ul style="list-style-type: none"> <li>• Difficulty with short-term and long-term memory</li> <li>• Forget parts of ones history</li> <li>• Has trouble solving simple problems</li> <li>• Becomes disorientated easily</li> </ul>	<ul style="list-style-type: none"> <li>• Mixes up recent and past events</li> <li>• Forgets friends and relatives</li> <li>• Cannot follow a two-step command</li> </ul>	<ul style="list-style-type: none"> <li>• No apparent awareness of past or future</li> </ul>
<b>Language</b>			
<ul style="list-style-type: none"> <li>• Trouble finding words or names</li> <li>• Repeats statements or questions</li> </ul>	<ul style="list-style-type: none"> <li>• Has trouble tracking conversations</li> <li>• Has difficulty forming complete sentences</li> </ul>	<ul style="list-style-type: none"> <li>• Unable to carry on a meaningful conversation</li> <li>• Words and sentences often disconnected</li> </ul>	<ul style="list-style-type: none"> <li>• Cannot speak or uses only a few words</li> </ul>
<b>Behaviour/Mood</b>			
<ul style="list-style-type: none"> <li>• May become distressed, withdrawn or irritable</li> </ul>	<ul style="list-style-type: none"> <li>• More easily upset or withdrawn</li> </ul>	<ul style="list-style-type: none"> <li>• May express urgent need by yelling/calling out</li> <li>• Difficult to engage</li> </ul>	<ul style="list-style-type: none"> <li>• Severe decline in ability to show emotion</li> </ul>
Changes in Ability to Care for Oneself			
Early Stage	Middle Stage	Late Stage	Final Stage
<ul style="list-style-type: none"> <li>• Needs help with household affairs such as cooking and paying bills</li> <li>• Trouble managing money and medications</li> <li>• May get lost or confused when driving</li> </ul>	<ul style="list-style-type: none"> <li>• Needs reminders or practical help with personal care</li> <li>• Slowed walking and reaction time</li> <li>• No longer safe to drive</li> <li>• Fatigues easily</li> </ul>	<ul style="list-style-type: none"> <li>• Loss of control of bowel and bladder</li> <li>• Trouble with balance and coordination</li> <li>• Sleeps often</li> </ul>	<ul style="list-style-type: none"> <li>• Needs total assistance with personal care</li> <li>• Unable to walk and shows little movement</li> <li>• Poor appetite and has swallowing problems</li> <li>• Sleeps most of the time</li> </ul>

**Dementia Trajectory supported by Hospice Enabled Dementia Care** (black =hospice contribution)



The figure above is taken from Hospice UK (185) and gives the reader an overview of the dementia trajectory using a palliative care approach/framework. What is known is that people dying with dementia have an ambiguous/ uncertain trajectory towards death. It is important to note that different types of dementia have unique characteristics and may have different trajectories. Trajectories will also be influenced by the person's co-morbidities. Below is taken from (186) and gives a sense of some of the differing presentations, however this is a guide only and does not replace the need to take an individual person-centred approach to supporting people with dementia.



Trajectory Table

Disease	Trajectory
Alzheimer's disease	High level cognitive functioning is initially lost, followed by basic functioning, including ability to complete ADL's and basic motor skills. Eventually the person will lose the ability to chew, and then the ability to swallow. This is a slowly progressive illness with a predictable decline but REMEMBER there are always individual variations.
Vascular Dementia	Cognitive and physical function is lost in a step-like fashion. Abilities will decline based on the area of the brain affected by a large or small strokes. Therefore, the ability to swallow may be lost before the ability to walk. Death is more likely to occur suddenly due to cardiovascular disease.
Lewy Body Dementia	The person experiences clear periods amidst ongoing confusion. Hallucinations are a hallmark of this disease even at the onset and the person may have periods where their function is better than others – for example: walking one day and unable to the next.

**Progression of Dementia:**

Three important influences on the life-span of dementia are the type of dementia, the stage of dementia and whether the course of deterioration is rapid or slow (110). The Functional Assessment Staging Test (FAST) is a validated measure of the course of dementia (187).

**Life expectancy of the person with dementia:**

Although dementia is a progressive, life limiting and an incurable condition, it is not possible to clearly predict a person's life expectancy and this uncertainty can be very challenging for the person with dementia and their relatives/friends. Although, specific life expectancy cannot be provided, there are some indicators below that healthcare staff can provide on the probable life expectancy of the person:

- 4.5 years is the average survival time for a person living with dementia (188). However, some people can live for 20 years post diagnosis.
- Half of the people with late stage dementia will die within 1.3 years (189).



## 5.3 Responding to difficult end-of-life questions

### RESPONDING TO DIFFICULT END-OF-LIFE QUESTIONS

When a person is concerned about something and they want to talk about it, they will *choose* who to speak to, and they will make this choice based on their sense of who they think might be the best person.

The 'best person' may be the person who has most information, or it may be the person who is most likely to listen or to have time to talk, or it may well be the person who is going to be the most empathetic.

If someone is seeking to talk to you, it is because they believe you will help. Your job is to accept that trust and explore their concerns with them.

Some effective and simple responses to someone asking to talk to you might be:

- "Are you worried about something?"
- "Are you feeling that bad today?"
- "Are you worried about anything in particular?"
- "How can I help?"

#### KEEP TALKING

There may be an issue for non-clinical staff about how much they might be 'allowed' to say (how much clinical information they're allowed to provide), but the key is that conversations are allowed to happen, that the person is allowed to ask for information, and is not shut down. Keep the communication open.

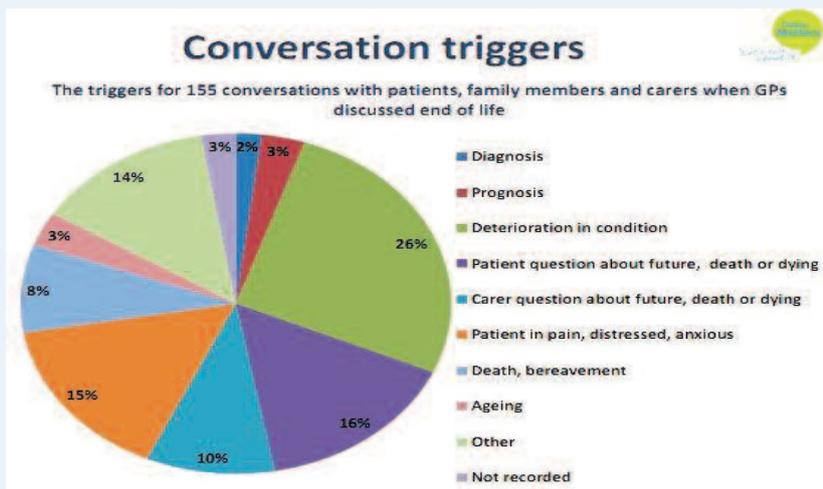
*"Am I dying?" • "I am not getting better, am I?"*  
*"Can I go home?" • "How long have I got?"*

Being around people who are upset or who are at end of life challenges all of us on many levels. There is a focus on keeping patients happy and comfortable.

This is not always possible and patients will often flag their concerns, sometimes when it is least expected. For example, you may be taking a BP, doing a person's dressings, or giving out medication, and you might hear comments (flags) such as "these tablets are not really working anymore, are they?" or "it's not really getting better, is it?". While helping a person to wash, you might even hear "I think I've had it" or "I think I am dying...".

Such statements are often met with "you're grand" or "don't worry" or "not on our shift". But these statements really demand more attention of you as a care provider. Whilst it is normal to feel uncomfortable when difficult questions are asked, it's important not to panic and to find out what lies behind the question.

The diagram below shows how conversations between patients and healthcare staff can arise. Typical triggers for such discussion are: when a patient knows of or hears that their condition is deteriorating, when they are in pain, or when they or their family/carers are concerned or anxious about their future. The diagram below suggest that a deterioration in a person's condition is the most frequent trigger for conversations about end of life:



Research has found that end of life care decisions which are made too close to death can cause unnecessary stress for both patient and families (C. Grbich et al., 2006)

Lack of discussion can lead to questionable 'decisions' made in crisis, e.g. unnecessary hospital admissions, lack of support being available, family wanting 'everything' done because they haven't had time to process what is happening...

## DEALING WITH DIFFICULT QUESTIONS



Evidence shows that when people are approaching the end of their lives, they are often excluded from meaningful discussion about what matters to them.

When you think of yourself in your health care role, can you make sure this does not happen to those in your care?

Always remember :

1. Deal with people's concerns before getting into details.
2. Take a moment to ask: what is this person most worried about at the moment.
3. You may not have the answer, but you can listen and link the patient up with someone who can.



The difficulty in responding to difficult questions can often be our own anxiety about 'saying the wrong thing' or having the right answer for the person and wanting to make them feel better. It is not about having the right answer. It is about allowing the person to express what it is he/she is worried about, and accessing support for them.

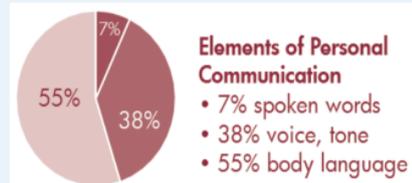
A national audit on end of life care (IHF, 2009) revealed that staff are more comfortable discussing the person's needs with the family rather than with the person him/herself.

### REMEMBER

- Don't panic! Don't avoid the question or close it down with well-meaning euphemisms ("ah, sure, you're as strong as an ox!") or busying yourself around the person.
- Don't rush a response based on your own discomfort.
- Keep communication open in as far as you can. Gently probe to find out what's behind the question: "What makes you ask that?" or "How are you feeling?" or "What is your biggest worry at the moment?", "Are you feeling worried/afraid?" or "What do you understand by what the doctor said?" or, simply "How can I help?"
- It's also okay to say "I don't know" if you don't. It might be appropriate to say you cannot answer the question but you will try to find someone that can help.

### BE AN ACTIVE LISTENER

- Give your full attention to the person—there is no better way of showing your respect.
- Be aware of your body language—if possible, sit down with the person at a 45-degree angle.
- Maintain good eye contact, and nod every so often to emphasise that you are taking in what they person is saying. If possible sit down with the person.
- Don't interrupt, even if silences occur. You can show you're listening by paraphrasing ("What I hear you saying is...") and by clarifying, but keep and questions until there is a natural pause. Do not pretend to understand if you do not.
- Acknowledge the person's concerns ("I can hear that you're really worried about...").



### AFIRM—AN AUSTRALIAN MODEL FOR SPONTANEOUS CONVERSATIONS

- ✓ **A**cknowledge the concerns of the person (relative/friend)
- ✓ **F**ind out what they already know about the resident's condition
- ✓ **I**mmEDIATE concern addressed—provide an appropriate and factual response to the question
- ✓ **R**espond to subsequent questions—continue to provide factual responses that are within the scope of your work role
- ✓ **M**eeting arranged—suggest that you arrange a meeting for them to discuss their relative's condition with the relevant clinical personnel (nurse, GP, etc.).

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Revised February 2016, Bereavement Education and Resource Centre

## 5.4 Supporting families at end-of-life

# SUPPORTING FAMILIES AT END OF LIFE

*Family is who the patient says it is*

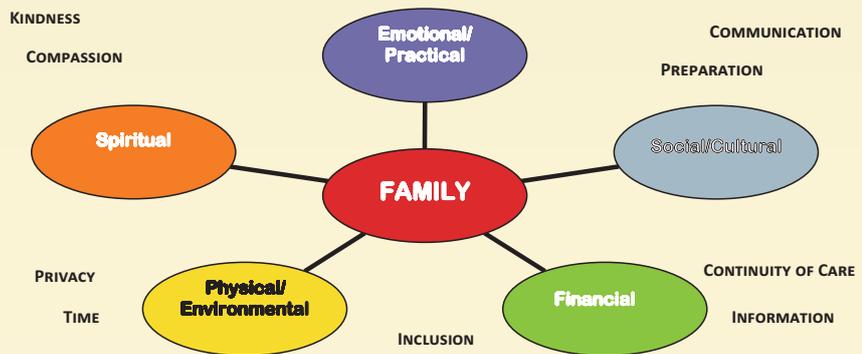


### WHEN A RELATIVE IS NEAR END OF LIFE—KEY POINTS WHEN SUPPORTING FAMILIES

- ‘Family’ can be defined as ‘those closest to the patient in knowledge, care and affection’. This broad definition includes the natural or biological family, the family of acquisition (related by marriage, civil, same sex and *de facto* partners or adoption), and the family of choice and friends.
- Communication is key: listening, asking, telling.
- Families need time, space, privacy and compassion.
- Families need support with both the practical and with the emotional aspects of the anticipated loss of someone close and when the person has died.
- It is important to be mindful of the issues that may arise within different death scenarios – for example, expected death, sudden death, the death of a child, miscarriage, intra-uterine death, still-birth, neonatal death.

Fundamental to good end of life care is the support we give to the family of the person we are caring for before, during and after death. While we always need to keep the patient at the centre of care, patient care includes family care. Family-inclusive end of life care should aim to identify the unique needs and abilities of families and to open the lines of communication between family members. We can enhance family support by good communication. Families usually provide the primary support for the person and may also act as mutual support for each other. Support given to families should encompass the domains of care depicted below while recognising social and cultural difference, and diverse family situations and make-up.

### DIFFERENT DOMAINS OF CARE—DIFFERENT ASPECTS OF FAMILY INVOLVEMENT



### SOME OF THE THINGS FAMILIES HAVE SAID MAKE A DIFFERENCE\*

The care and attention received was excellent, considered, respectful and dignified

To be told we could visit any time and to be asked if we would like to stay overnight. I would have stayed with my husband if someone told me I could.

More communication between medical staff and family

My relative's spiritual needs were fully met

We were often left in the dark about what was happening and were left on our own mostly.

We needed to be told she was dying so we could plan our last days with her

No children were ever allowed to visit... and my mother loved her grandchildren and great-granddaughter so much

Pain management and palliative care should have been available

A member of staff could bring family members to the morgue. My family and I were alone and very upset.

(\*Responses received from family members in Audit and Review of End of Life Care meetings, Hospice friendly Hospitals, 2013)

This leaflet is part of a larger collection of good practice resource leaflets (TOOLBOX TALKS) available from the HSE: [http://www.hse.ie/eng/about/Who/qualityandpatientsafety/Local\\_Quality\\_and\\_Patient\\_Safety\\_Offices/QPS\\_DNE/Tool-box\\_Talks/](http://www.hse.ie/eng/about/Who/qualityandpatientsafety/Local_Quality_and_Patient_Safety_Offices/QPS_DNE/Tool-box_Talks/)

# HOW TO SUPPORT FAMILY MEMBERS



## WAYS YOU CAN HELP

1. Involve family members at the level of involvement that they want to have.
2. Provide information and enable family involvement in care.
3. Recognise and allow for the different coping styles of different family

*"We would like to be involved, but our mother's wishes are paramount."*

*"We weren't told that she was going to die. We should have been told. We didn't realise that her death was so close – it came as a shock".*

### COMMUNICATION

- All communication between health care staff and family should be governed by the expressed wishes of the patient and, where these are not known, by the best interests of the patient.
- Clear decision-making processes should be in place and adopted by all staff. These processes should also cover circumstances where a patient does not have mental capacity.
- Information should be given sensitively and in a planned way to ensure time and privacy. Language should be clear and understandable, avoiding jargon. Written information may be given to family to take away.
- Try to support individual family members in their communication with their relative. Each person may need time on his/her own with the patient but they may not feel they can ask for this.
- Communicate regularly with the family members about the care being provided, and about any changes in the condition of the patient and about the dying process.
- Prepare families, especially when death is imminent. If families are not aware of what is happening, they may miss the chance to say what they need to say to their dying relative.

### INVOLVEMENT IN CARE

- With the consent of the patient, families should be offered the choice to be involved in all aspects of care. However, it is important to involve family members at the level they wish to have—some may prefer to have a hands-on involvement, others may be happier staying further back.
- Family members may come to you to talk or ask about different care or treatment options. If/when they do, remember that they are simply advocating for the patient.
- Family members should be encouraged to voice any worries or concerns they may have.
- Family members can play an important role in assisting with communication with the patient, and in assisting with providing personal care to the patient (if they wish).
- In keeping with the wishes of the patient, flexible visiting arrangements should be in place. Family members may wish to be present with their relative as much as possible, including staying overnight.

### FACILITATING FAMILY MEETINGS

Family meetings can provide the opportunity to:

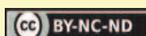
- Create a shared approach to the care of the person who is dying.
- Listen to family members and clarify each person's understanding of their relative's prognosis.
- Anticipate family members' needs in terms of support. What are they struggling with most at the moment?
- Enable their involvement in care, including symptom management, communication and assisting with the physical care needs of the patient if they wish.
- Explore how the death of the patient may impact, emotionally and physically, on different members of the family.

When facilitating family meetings, it is useful to be aware of the fact that each family member is an individual with his/her own needs and coping skills/styles. Also, it is important to be alert to the possibility of family conflicts (old or newly-arising) and to ensure a safe place for people to express concerns.

### For further information:

- **Quality Standards for End of Life Care (Hospice Friendly Hospitals, IHF)**
- **National Consent Policy (HSE, 2013)**
- <http://hospicefoundation.ie/education-training/>

Revised February 2016. Bereavement Education Resource Centre, Irish Hospice Foundation



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## 5.5 Caring for yourself in end-of-life care work

# CARING FOR YOURSELF

## IN END OF LIFE CARE WORK

### END OF LIFE CARE

Caring for people at end of life, especially people in residential care settings where there are long-term relationships, can be hugely rewarding and can also be very draining. Caring is emotional work. People working in palliative and end-of-life care often describe feelings of great job satisfaction, gratitude and enhanced appreciation of the spiritual dimensions of life.

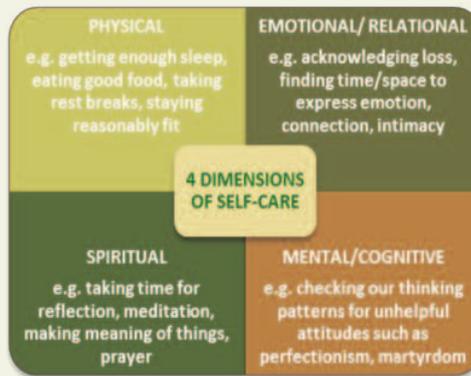
However, the very nature of end of life care involves, amongst other things, the experiencing of loss of relationship — through death, and also through the decline in capacity which arises from enduring illnesses such as dementia. These losses can contribute to feelings of stress, compassion fatigue and burnout.

*“Self-care is not about self-indulgence, it’s about self-preservation.”*



### SELF CARE IN END OF LIFE CARE

The vast majority of healthcare staff are people who are highly motivated to care for others. This predisposition, and the nature of care work itself, mean that particular attention is needed if staff are to avoid compassion fatigue and burnout.



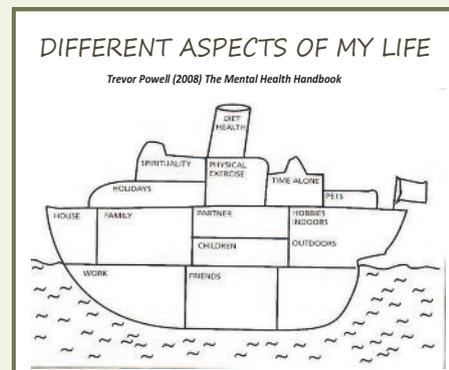
Compassion fatigue has been likened to over-caring, or caring too much. It is often characterised by an inability to switch off, by intrusive thoughts or dreams about work, by avoidance and ‘not wanting to go there again’, and by irritability. If we do not attend to it, and especially if it is accompanied by overwork, it can lead to burnout, which is a defensive reaction and which is characterised by emotional exhaustion, detachment (not caring at all), powerlessness, and cynicism. None of these feel good and none of these are good for the staff member or for the residents/patients.

If you are working with residents and families facing death and dying, it is useful to remind yourself of the following:

- You are not immune to grief
- You need to take care of yourself in order to be effective and resilient in this work
- You need to be aware of your own approach to loss and to death
- You need to have a sense of what draws you to this work and what you get out of it
- You need a safe place to process your own feelings
- You need to have a sense of what helps you to stay healthy and committed to this work.

There are many ways in which you can attend to your self care. A good way to start is to appreciate that we are multi-dimensional and that care—for us and for residents—is best practised when it works across all of these different dimensions.

The diagrams here suggest a number of different dimensions of self care, and we can work on some or all of these at any one time. In addition, there are several more suggestions overleaf as to how we can increase our care of ourselves.



## “The heart must first pump blood to itself”

Shapiro SL, *The Art and Science of Meditation*, 2008

### SOME SUGGESTIONS FOR SELF CARE

- As you walk from your car to your workplace or through the corridors of your workplace, attend carefully to the sensation of contact between your feet and the ground.



- Set your watch or telephone alarm for midday each day. Use this as a prompt to centre or ground yourself in the here-and-now e.g. take 4 deep slow breaths, think of a loved one, recite a favourite line or poetry, prayer or a verse of song.
- Call a ‘time out’ (usually, a few minutes is enough) as a way of dealing with emotional flooding after a traumatic event—for example, tell your colleagues that you need to take a five-minute walk or break.
- Stop at a window in your workplace and notice something in nature — consciously give it your attention for a few moments.
- Before going to the next resident, pause and bring your attention to the sensation of your breathing for 2 to 5 breaths.

- Don’t go without food or fluid.
- Stay connected to the outside world during the day, e.g. phone home or check in with loved ones.
- Use hand hygiene activities as meditative rituals.
- Deliberately make connections during the day with colleagues, residents and families and, where possible, use humour.
- Keep a notebook and write ‘field notes’ on traumatic or meaningful encounters and events
- Deliberately develop a role-shedding ritual for the end of the day — for example, changing out of work clothes, using the drive home from work to sing, taking five minutes on the way home to breathe some fresh air, listening to music or audiobooks, etc.
- Give yourself permission to do what you need to do to look after yourself, to care for yourself.
- Allow yourself to dance in and out of grief—as the diagram alongside suggests, people who work in healthcare move from periods of engaging with grief to times of detaching from it. How this is handled will depend on your values and beliefs about what is ‘right’ in grief, as well as on the culture and norms of your workplace.

Adapted from ‘Self-care of Physicians Caring for Patients and the End of Life’ Kearney, M. et al (2009) JAMA Vol 301, No 11 and Papadatou, D. (2000) A proposed model of health professionals’ grieving process. *Omega*, 41



### SOME SUGGESTIONS FOR TEAM CARE

- If you don’t already have team meetings, start them! Use them to talk to your colleagues about the rewards and challenges of end of life care.
- Peer support and acknowledgement are powerful mechanisms to help alleviate stress—peer support mechanisms can include buddying, peer learning meetings, peer learning groups, and debriefing meetings after traumatic or difficult events.
- Other ways in which you can get some support include finding a mentor, investing in teambuilding and team relationships, and ensuring that you and your team are aware of the sorts of stresses and strains (and associated symptoms) of providing care at end of life.

Revised February 2016. Bereavement Education Resource Centre, Irish Hospice Foundation



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## APPENDIX 1

### Membership of the Dementia Palliative Care Project Advisory Group

Name	Organisation	Profession/ Role
Mary Manning (Chairperson of PAG)	National Dementia Office, Services for Older People, Social Care Divison HSE	General Manager Former Director of NMPD, Office of Nursing and Midwifery Directorate, HSE
Dr Emer Begley	Alzheimer's Society of Ireland	Policy and Research Manager
Anne Quinn	5 Steps to Living Well with Dementia Project, South Tipperary	Advanced Nurse Practitioner for Dementia
Caroline Clifford	Carlow/Kilkenny Psychiatry of Later Life Team	Clinical Nurse Specialist in Psychiatry of Later Life. Dementia Champion.
Jacinta Kelly	North West Hospice, Sligo	Specialist Palliative Care Nurse
Jean Barber	St Michael's Hospital, Dublin	Clinical Nurse Specialist in Palliative Care
Carmel Hoey	National Clinical Programme for Older People (NCPOP), HSE	NMPD Officer
Prof Willie Molloy	University College Cork	Geriatrician and Head of the Centre for Gerontology & Rehabilitation in UCC
Dr. Suzanne Timmons	University College Cork	Geriatrician & Senior Lecturer in the Centre for Gerontology & Rehabilitation in UCC
Cecelia Hayden	St. Vincent's Hospital, Athy	Clinical Nurse Specialist in Dementia Care
Aideen Lawlor	St. Mary's Hospital, Dublin	Speech & Language Therapy Manager
Lasarina Maguire	Stewarts Care, Palmerstown	Nurse Practice Development Coordinator
Deirdre Shanagher	Irish Hospice Foundation	Development Officer
Marie Lynch	Irish Hospice Foundation	Head of Healthcare Programmes
Sarah Cronin	Irish Hospice Foundation	Dementia Development Officer

### Membership of the Expert Advisory Group for this Guidance Document

Name	Organisation	Profession/ Role
Sarah Cronin (Project Lead)	Irish Hospice Foundation	Dementia Development Officer
Orla Keegan	The Irish Hospice Foundation	Head of Education, Research and Bereavement
Dr Susan Delaney	The Irish Hospice Foundation	Psychologist and Bereavement Services Manager
Breffi McGuinness	The Irish Hospice Foundation	Bereavement Services Training and Development Manager
Laura Rooney Ferris	The Irish Hospice Foundation	Information and Library Manager
Annie Dillon	The Alzheimer's Society of Ireland	Acting Information and Helpline Manager
Marie Lynch	Irish Hospice Foundation	Head of Healthcare Programmes

#### International Reviewers:

Kenneth J Doka, PhD, Professor, The Graduate School, The College of New Rochelle, Senior Consultant, The Hospice Foundation of America. Email: KnDok@aol.com

A. E. (Betty) Andersen, MA, Registered Psychologist. #103, 832 Fisgard Street, Victoria, BC, Canada V8T 4E9. Tel: 250-361-9999. Email: bandersen@lawvictoria.com

## APPENDIX 2: METHODOLOGY

### Development of the Guidance Document

These guidelines were developed using the following process:

1. The IHF Project Advisory Group established an Expert Advisory Group to develop this guidance document (See appendix 1 for membership of the group).
2. A narrative literature review was undertaken by the project lead (Sarah Cronin) using English language articles selected through a systematic search strategy (see below). Key themes were identified and presented to the Expert Advisory Group.
3. Key themes were collated to inform (a) the key considerations and (b) the guidance areas by the Expert Advisory Group.
4. Draft 1 was prepared for comment by the expert advisory group.
5. Draft 2 was prepared for expert review and external consultation (see appendix 3 for list of submissions received).
6. Feedback from external consultation to develop final draft. A consultation report was prepared and available on request to those who submitted.
7. Final version published.

## Literature Review:

## DEMENTIA &amp; GRIEF - LITERATURE SEARCH

Identified Search Strands	
1	The person with dementia
2	The healthcare staff
3	The family
Suggested Terms	Related MeSH Term
Dementia	<ul style="list-style-type: none"> <li>• Dementia</li> <li>• Frontotemporal Dementia</li> <li>• Delirium, Dementia, Amnesic</li> <li>• Cognitive Disorders</li> <li>• Dementia, Multi-Infarct</li> <li>• Dementia, Vascular</li> <li>• Alzheimer Disease</li> <li>• Lewy Body Disease</li> <li>• Frontotemporal Dementia (With Motor Neuron Disease)</li> <li>• Frontotemporal Dementia, Chromosome 3-Linked</li> <li>• Dementia, familial (British)</li> <li>• Presenile And Senile Dementia</li> <li>• Presenile dementia, Kraepelin type</li> </ul>
Bereavement	<ul style="list-style-type: none"> <li>• Bereavement</li> </ul>
Grief	<ul style="list-style-type: none"> <li>• Grief</li> <li>• Complicated grief</li> </ul>
Anticipatory Loss	<ul style="list-style-type: none"> <li>• Bereavement</li> </ul>
Dementia carers	<ul style="list-style-type: none"> <li>• Caregivers</li> <li>• Dementia &amp; caregivers</li> </ul>
Residential care home	<ul style="list-style-type: none"> <li>• Residential Facilities</li> <li>• Nursing homes</li> </ul>
Nursing home healthcare staff	<ul style="list-style-type: none"> <li>• Nursing healthcare staff</li> <li>• Personnel, Health</li> <li>• Health Care Providers</li> <li>• Health Care Provider</li> </ul>

## Database searches

Database Used	Search Type	Search Terms	Number of articles generated
Medline (Ovid Medline)	Combined MeSH Search	Delirium, Dementia, Amnestic, Cognitive Disorders OR Dementia, Vascular OR Dementia, Multi-Infarct OR Dementia/ OR Frontotemporal Dementia  AND exp Grief/ or exp Bereavement/	118 results  <b>Limiters Applied</b> : date limit = 2005- 2015  <b>Results</b> = 55 Articles
CINAHL	CINAHL headings – Combined Terms Search	MH "Dementia+") OR (MH "Frontotemporal Dementia+") OR (MH "Dementia, Vascular+") OR (MH "Delirium, Dementia, Amnestic, Cognitive Disorders+") OR (MH "Dementia, Multi-Infarct") OR (MH "Lewy Body Disease") OR (MH "Dementia, Senile+") OR (MH "Dementia, Presenile+") OR (MH "Kohlschutter-Tonz Syndrome")  AND MH "Bereavement+") OR (MH "Grief+") OR (MH "Complicated Grief")	<b>Initial Results:</b> 256 results  <b>Limiters Applied:</b> Date 2005-2015 – Peer reviewed items  <b>Results</b> = 73 articles
Web of Science	Combined topic search	Dementia AND bereavement	Date 2005 -2015 - article or reviews  <b>Results:</b> 95 articles

**Results of searches:** 223 Articles were screened for relevance and 101 articles were deemed appropriate. In addition to journal articles, grey material was sourced which comprised of three books and twenty six sets of guidelines or factsheets relevant to the guidance document. Ongoing hand searches of best practice guidelines, healthcare policies, key Irish and international reports and reference lists of sourced materials took place throughout the development of this guidance document in order to inform and populate resources.

**Literature Review:** Three additional literature reviews informed this document. These literature reviews were carried out by the Irish Hospice Foundation and relate to the following areas:

- The Palliative Care Needs of People with Intellectual Disabilities and Dementia
- The Palliative Care Needs of People with Young Onset Dementia.
- End-of-Life Care and Supporting Healthcare staff.

**Themes:** All sourced material outlined above was reviewed in detail and analysed for common themes by Sarah Cronin (IHF) with oversight from the expert advisory group. The themes and subthemes that emerged from the literature are as follows:

- Responding to loss and grief in dementia
  - Ambiguous loss and grief
  - Disenfranchised grief
  - Anticipatory grief
- Loss and Grief for the person with dementia
  - Recognising losses encountered
  - Recognising loss and grief
  - Supporting a person with dementia
  - Spirituality and dementia
- Loss and grief for family members
  - Recognising losses encountered
  - Responding to loss and grief
- Loss and grief issues for healthcare staff
  - Self-care
  - Need for organisational supports

**Collation of themes/ Consensus Building:** These key themes were presented to the expert advisory group who considered them in relation to their own experience and practice. Based on the literature review, it was agreed that the following were appropriate areas for guidance: Supporting the person with dementia with loss and grief, supporting families with loss and grief and supporting yourself (healthcare staff) with loss and grief.

**Limitations:** The approach used to develop this guidance document was based on methods outlined in the National Clinical Effectiveness Committee (NCEC) Standards for Clinical Practice Guidance (93). Literature was examined for relevance and graded. However, it was difficult to explicitly link recommendations or guidance to the supporting evidence at all times, as recommended in NCEC Standards for Clinical Practice Guidance due to the nature of the subject matter being discussed (93). Evidence on effectiveness and cost effectiveness was not explored due to time and resource constraints. Upon completion of the suite of seven guidance documents the plan for their implementation will commence. This will include involvement of key stakeholders, realistic timelines and integration of key guidance areas from each document into clinical practice.

## APPENDIX 3: LIST OF SUBMISSIONS RECEIVED

A total of 27 submissions were received as part of the public consultation. These comprised of 11 organisations and the remainder of submissions were made in a personal capacity. Personal submissions were made from allied health professionals, family carers, people working in academia and former family carers.

Organisation
Care Alliance
The Irish Association of Palliative Care (IAPC)
The National Clinical Programme for Older People (NCPOP), HSE
The Progressive Supranuclear Palsy Association (PSPA)
The Nursing and Midwifery Planning and Development Unit West/ Mid-west, HSE
Mayo University Hospital
The Irish Nurses and Midwives Association (INMO)
The Northern Ireland Hospice
SAGE support and Advocacy Service for Older People
The Irish Dementia Working Group
Letterkenny University Hospital
Co. Donegal Public Health Nursing and Specialist Palliative Care Nursing Services
The National Clinical Effectiveness Unit, CMO, Dept of Health

## APPENDIX 4: CONTACT DETAILS OF SUPPORT ORGANISATIONS

### Contact details of Support Organisations

#### The Alzheimer Society of Ireland:

**Free Confidential Helpline:** 1 800 341 341 and **email:** [helpline@alzheimer.ie](mailto:helpline@alzheimer.ie)

**Website:** [www.alzheimer.ie](http://www.alzheimer.ie)

The Alzheimer Society of Ireland provides information, advice and support to people living with dementia, their families and healthcare professionals. See the website for a broad range of information or contact the helpline to discuss specific individual issues.

#### The Irish Hospice Foundation

**Website:** [www.hospicefoundation.ie](http://www.hospicefoundation.ie) and [www.bereaved.ie](http://www.bereaved.ie)

The Irish Hospice Foundation has produced a range of videos on grief and a suite bereavement leaflets.

**Phone:** 01-6793188 **Email:** [info@bereaved.ie](mailto:info@bereaved.ie)

**Senior Helpline Senior Help Line** is a confidential listening service for older people

LoCall: 1850 440

**The Bereavement Counselling Service** offers a volunteer-led bereavement support service.

Phone: 01-8391766

**The Samaritans** offer a 24-hour listening service Phone: 1850 609090

**Irish Childhood Bereavement Network:** Information on how best to support children experiencing loss and grief is available at [www.childhoodbereavement.ie](http://www.childhoodbereavement.ie)

#### Directory of Bereavement Supports in Ireland

Website: [www.tulsa.ie/services/family-community-support/counselling](http://www.tulsa.ie/services/family-community-support/counselling)

#### Health Promotion:

<http://www.yourmentalhealth.ie/About-Mental-Health/Common-problems/Things-that-impact-our-mental-health/Bereavement-loss/>

### Counselling and Therapy Organisations:

#### The Irish Association of Counselling and Psychotherapy

**Website:** <http://www.iacp.ie> **Phone:** 01-2723427

#### The Irish Association of Humanistic and Integrative Psychotherapy

**Website:** <http://iahip.org/> **Phone:** 01-2843868

#### The Psychological Society of Ireland (PSI)

**Website:** <http://www.psihq.ie/> **Phone:** 01-6717122

**Turning Point** offer training in bereavement counselling and bereavement counselling services.

**Website:** <http://www.turningpoint.ie/> **Phone:** (01) 280 7888



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