

# The Palliative Care Journey

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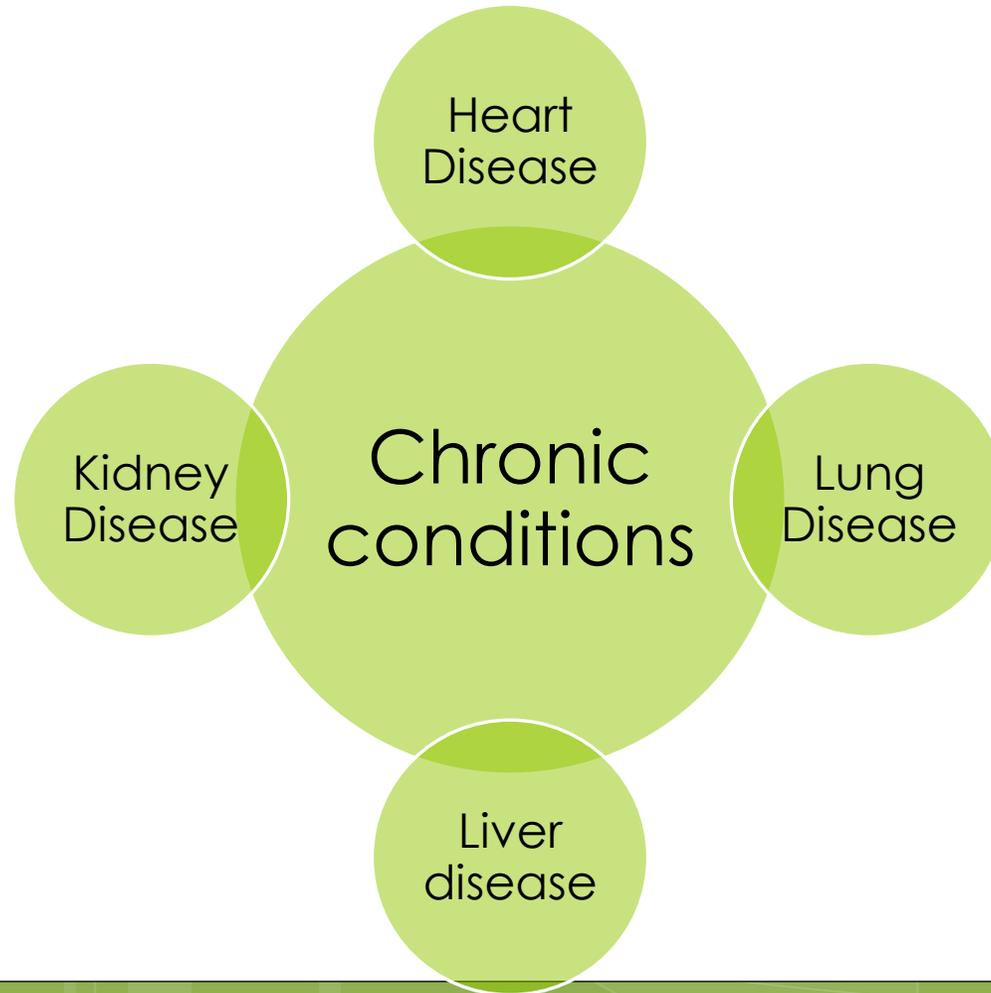
# Aims

1. To provide an overview of what palliative care involves.
2. Identify, at what stage should Dementia be acknowledged as a palliative condition.
3. Recognise the symptoms associated with chronic illness and how they present differently in individuals living with dementia and what are the consequences for the residents.
4. Discuss issues around grief and loss for residents and families.
5. Progressing to end of life and our role in caring for these residents.

# What is palliative care?

- Provides relief from distressing symptoms; including pain, depression, anxiety, fatigue, shortness of breath, constipation, nausea, loss of appetite and difficulty sleeping.
- It helps individuals gain the strength to carry on with daily life.
- Palliative care affirms life and regards dying as a normal process.
- Palliative care intends to neither hasten nor postpone the dying process.
- Offers a support system to help the family cope during the patient's illness and in their own bereavement. (The World Health Organization's 2009)

# Chronic conditions considered most for palliative treatment .....



SO..... This poses a question we should ask ourselves.....

**How do we expect people with dementia to live out the rest of their lives?**

- In pain, or living with symptoms of other chronic illnesses they may have.
- Anxiety, and fear of the unknown, perhaps fear relating to death and dying, however they have trouble communicating these fears due to their cognitive decline.
- As a result they are seen to be challenging, responsive and agitated (difficult to manage).



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## Facts relating to palliative and end of life care in dementia

- High risk of receiving poor end-of-life care.
- Often not recognised as a progressive or terminal illness.
- Less likely to be referred to specialist palliative care.
- At risk of poor symptom management and the inappropriate use of treatments –restraints/medications /artificial nutrition and hydration/being transferred to hospital inappropriately.
- Have a unique set of care needs, therefore carers require additional emphasis and skills to meet the needs of this vulnerable group.
- Should have opportunities to make informed decisions about their future care at an early stage of their condition and have their palliative care needs addressed.
- Planning future care can optimise comfort care at end of life, enabling a person with dementia to live well until they die.

## When should dementia be recognised as a palliative illness

- Dementia is unique as it is recommended that palliative care is introduced early in the disease trajectory.
- Dementia is an irreversible condition, palliative care should begin from diagnosis, with the aim of improving one's quality of living.
- The palliative care approach to dementia care, has been motivated by concerns that those dying with advanced dementia are often not seen as having a terminal condition, therefore they are much less likely than others to be managed palliatively.
- Dementia causes a person to have difficulties in areas which are key to planning for and ensuring a peaceful death. Lacking in the ability to communicate, or having a diminished capacity results in uncertainty about their prognosis, therefore decisions regarding end of life care can be difficult for people to discuss.

# Dementia and loss

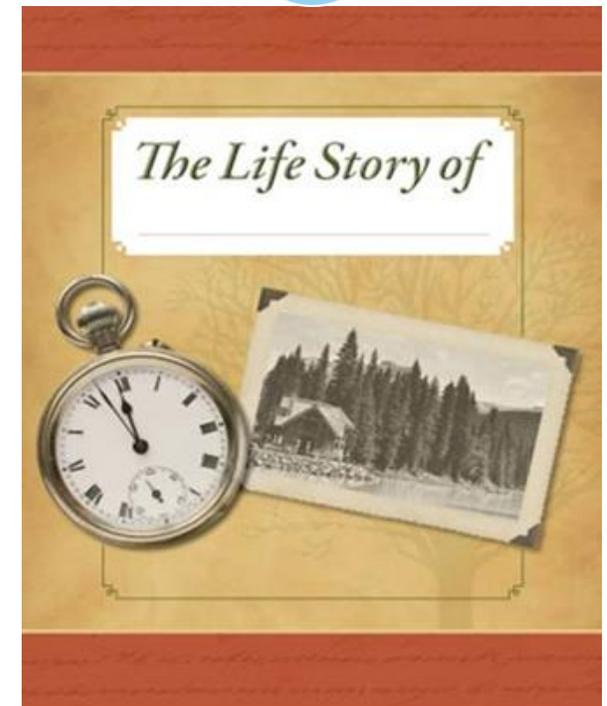
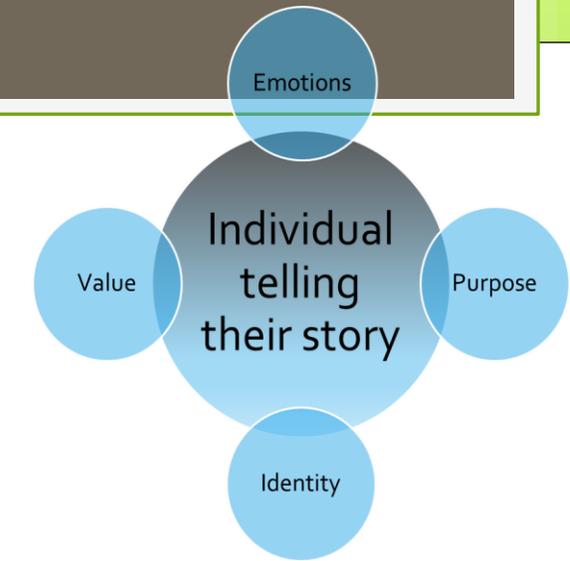
- Loss and grief is one of the most significant and under recognised issues faced by people with dementia and their families.
- People with dementia experience multiple losses in different areas of their lives, and these losses build in numbers, as the disease progresses.
- Grief occurs in different ways at all stages in the dementia journey for the person, for the family and for healthcare staff supporting them.

# Dementia and loss

- 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 difficult in care homes and community settings, as families may not recognise what is best for the individual and the stage they are at, due to denial.
- 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.

# How can we as a health care workers support a person living with dementia experiencing loss.

- Be aware of the types of losses commonly encountered by a person with dementia, identity, values, beliefs, job, financial provider for the home, parent etc.
- Take a person-centred approach and know the person well, get to know their story and value them for who they once were and who they are today.



# Your role when resident progresses to end of life care

- Carers are often the most deeply involved and consistent care providers to dying residents.
- Healthcare assistants often develop deep relationships with individuals and their families.
- Direct personal care is particularly important as patients near the end of life and become totally dependent on nursing and care staff for all care and activities of daily living.

# To recognise symptoms

- Persons sleep pattern can increase: the person begins to sleep for long periods. This can be distressing for relatives, but it's important to understand that even the mildest physical exertion for someone approaching death can be exhausting, and for the moment all effort is being put into staying alive. Nearer the end, the dying person may increasingly drift in and out of consciousness.
- Appetite reduces: the body knows it no longer needs fuel to keep it going so those who are dying often lose their desire to eat or drink. They can begin to lose weight, sometimes rapidly. It's important not to force food or drink onto someone who no longer wants it. But do take guidance from the nursing staff.

# Pain

- Assessment of pain in people with dementia is particularly challenging due to the loss of communication ability.
- Knowing a person with dementia can improve the recognition of pain and the interpretation of pain behaviours.

Behaviours include:

- Anxiety or restlessness
- Constant pacing, moving or unwillingness to sit down this can still occur even the final days and hours of life, due to pain.
- Moaning, crying, sighing and even heavy breathing
- Frowning, or grimacing
- Sleeping all day or not being able to sleep
- Very rigid, striking out or resistive

# What can you do as a healthcare assistant to identify pain

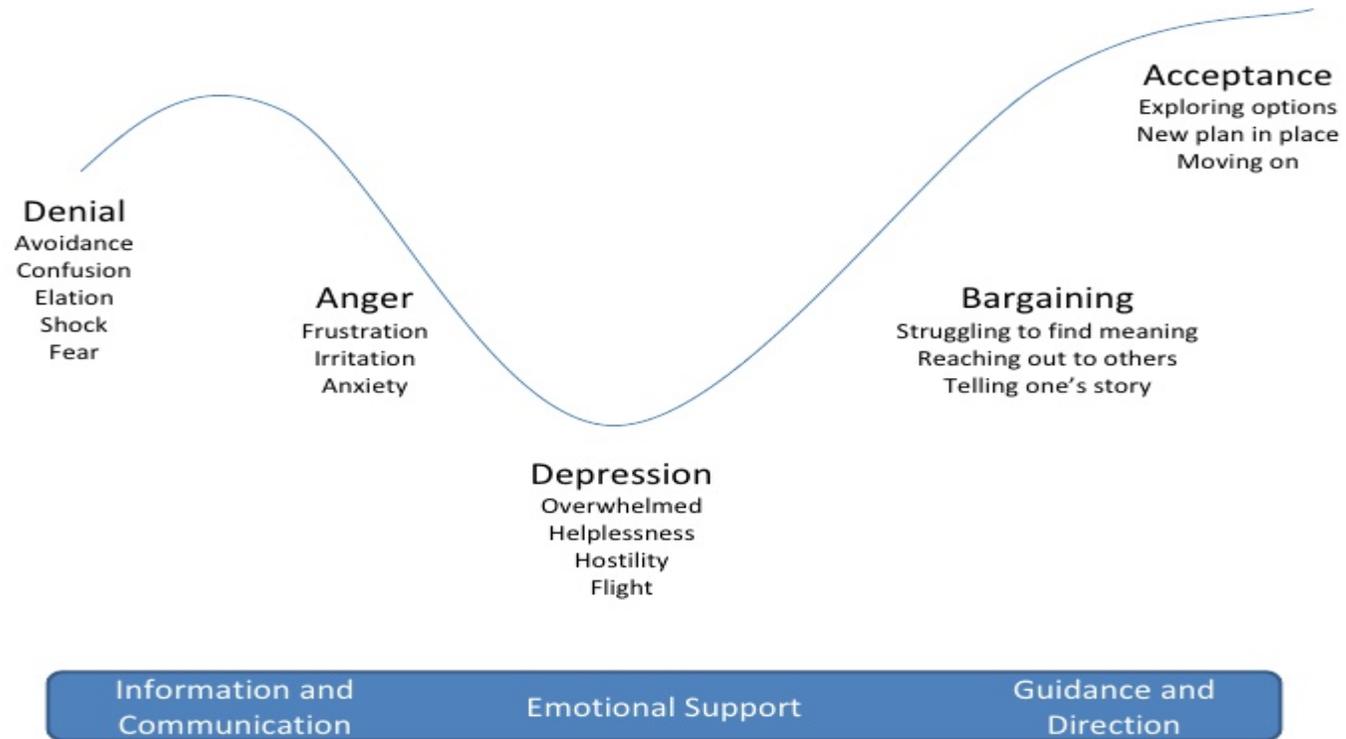
- Report any behaviours to nurse, family, and GP.
- Assessment begins by asking an individual about their pain because only the individual can determine how much pain they are experiencing, despite their cognitive impairment.
- Consider, interventions that can be done by you, at the time of pain, ie Pressure care, hunger, hydration, distraction, oral care and reassurance.
- Monitor for interventions that relieve or worsen pain.

# Assessing pain

- P = pick up on mood changes
- A = Asses verbal ques
- I = Inspect facial expression's
- N = Notice body language

Elizabeth Kubler- Ross wrote on death and dying and first mentioned the five stages: Denial, Anger (emotions), bargaining, depression and acceptance.

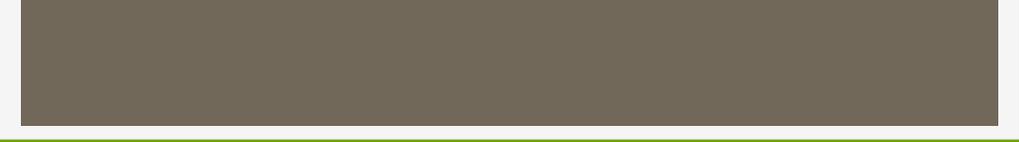
## Kübler-Ross Grief Cycle



# Support families and residents by being aware of the stage they are at:

## Stages of a grief

- Denial : It's a difficult thing to accept a devastating reality, and many people refuse to believe it.
- Emotions—anger: This can manifest itself in many different ways. Some people feel angry with themselves; other times their anger is taken out on others around them. There is a feeling of wanting to blame somebody for what is happening. Very often presents as the difficult families..
- Bargaining: If a person has a God he/she believes in, there is usually pleading or bargaining with Him to spare the life of the ill person.
- Depression: This is similar to grief. but with depression comes an emotional attachment with a sort of acceptance. Each person handles depression differently, but usually a person who is depressed detaches themselves from others, preferring to be alone with their feelings of despair. It's natural to feel sadness, regret, fear, etc. These are the steps to acceptance.
- Acceptance (Emotional and real): This varies greatly from person to person, but generally there is some sort of emotional detachment as the person accepts what is to come. The person diagnosed with an illness usually comes to this point much sooner than the family/friends they leave behind (Kübler-Ross E. On Death and Dying Routledge, 1969).



# Resources

- Palliative Care Competence Framework Steering Group. (2014). Palliative Care Competence Framework. Dublin: Health Service Executive
- 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/wpcontent/uploads/2013/08/Supporting-Families.pdf>
- How can we assess pain in people who have Dementia – HSELandD (2016)  
<http://www.hseland.ie/nmlead/Portals/nmlead/Dementia/Pain%20Article.pdf>
- Kübler-Ross E. On Death and Dying (Routledge, 1969).