Dementia and Loss

Exploring the unique losses and griefs associated with dementia and what can help both the person with the diagnosis and their carers to cope.”

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What dementia is like?

David Shenk described Alzheimer Disease as "death not by a thousand cuts but by a thousand subtractions". (The Forgetting, published in New York by Random House, 2001)

“Watching a wonderful lighted sculpture – where the lights are going out one at a time.” (Son whose mother has dementia)
Outline

• Grief and dementia – different types
  – Anticipatory grief
  – Ambiguous grief
  – Disenfranchised grief

• How grief can affect people
  – People with dementia
  – Carers of people with dementia

• What can help
Living with Dementia

• Alzheimer Disease and related dementias have been described as life-transforming conditions. The implications are that there are, and will continue to be, a multitude of changes in may aspects of one’s life that will require adjustment. There are, and will be, a variety of reactions and feelings to the ongoing process of adjustment and readjustment.

• From Betty Anderson (2012)  A Workbook for Dementia Caregivers – Vancouver Island Health Authority
Losses associated with dementia

What are examples of losses that you might experience as a result of dementia if you are

1. Person with dementia

2. Someone caring for a person with dementia
Losses for the person with dementia

• Diagnosis
• Loss of independence – mobility – car
• Trying to find out if and where resources are
• Change in relationships with people you are close to / some people find diagnosis hard
• Grieving over loss of faculties / security etc
Losses for the person caring for someone with dementia

- Loss of personality – relationship with the person with dementia is changed
- Becoming a carer – change in role
- Transition to nursing home care –
  - Feelings of betrayal
  - Letting go of control when person goes in to residential care but still maintaining carer role
- Relationships within family
  - The impact of family members living a long distance away from the person with dementia
  - siblings –
  - tensions within families – change in roles - expectations
- End stage dementia –
  - different challenges –
  - Advocacy role changes
PSYCHOLOGICAL STATE OF CHANGE

ENDING
- what is left behind
- what ceases to be
- letting go
- loss (grief, anger, ‘blues’)

TRANSITION “NEUTRAL ZONE”
- movement from old to new
- risk (apprehension)
- uncertainty (tension)
- ambiguity

NEW BEGINNING
- new roles/work
- involves a shift in attitude/perspective
- alignment
- gain

We adjust more readily to changes/ transitions that:
- are our choice
- have a net gain (more gains than losses)
- are final

Most of the losses of the dementia journey are none of these three - that makes the adjustment more challenging.

From Betty Anderson (2012) A Workbook for Dementia Caregivers – Vancouver Island Health Authority
Dementia – key Pinchpoints when grief is acute

- Noticing symptoms
  
  **Diagnosis**
  - Diagnosis of dementia
  - Increasing loss of memory
  - Loss of drivers licence
  - No longer can go out alone
  - No longer can be left alone
  - Help with personal care required
  - Need for outside assistance
  - Need for respite
  - Incontinence

- **Placement**

- **Death**
  - Death and bereavement

- **Aggressive or embarrassing behaviours**
  - Caregiver no longer recognised
  - Develops connection to another resident
  - Loss of communication
  - Loss of mobility
  - Inability to swallow
  - Declining health and palliative care
These losses affect people

Grief is our response to these losses

• Grieving is a process rather than an event
• Grieving is the way in which we adjust to changes in our lives and the lives of those close to us brought about by dementia
• Grieving is demanding and impacts on us in many different ways
  – Mentally
  – Physically
  – Psychologically
  – Emotionally
  – Spiritually
Grief and the grieving process

What are Loss, Grief?

• **Loss:** Losing something that is of significance to us

• **Grief:**
  – It is the natural process of reaction and adjustment to loss and change
  – Intense sorrow – mental, physical emotional and spiritual suffering resulting from loss
  – Is a transforming experience
Grief and the grieving process

“Give sorrow words: the grief that does not speak
Whispers the oer-fraught heart, and bids it break.”

Shakespeare, Macbeth Act 4, sc. 3, line 209.
Grieving – Key points

- Grief is a process which takes time.
- There is no right way to grieve.
- Each person’s grief is unique and individual.
- Grief is a journey that takes a different length of time for each person.
- Adjusting to (a new) normal routine helps.
- Strong emotions like anger, sadness etc. are a natural and healthy part of grief.
Dual process model of coping with significant loss

Loss oriented:
- grief work
- Intrusion of grief
- Breaking bonds/ties
- relocation of deceased person

 Restoration-oriented:
- Attending to life changes
- Doing new things
- Distraction from grief
- Denial/avoidance of grief
- New roles/identities/relationships
## Other factors - Gender

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<thead>
<tr>
<th>Traditional feminine/Female-valued</th>
<th>Traditional masculine/Male-valued</th>
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<tr>
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<td>Instrumental</td>
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<td>Rational</td>
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<tr>
<td>Emotion-focused</td>
<td>Problem-solving</td>
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Levels of Bereavement Care

Pyramid Of Bereavement Care

- Level 1: Information & Support
- Level 2: Extra Support
- Level 3: Prof Therapy

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*Image shows a pyramid with levels for bereavement care.*
Types of grief associated with Dementia

• Ambiguous Loss
  – Ambiguous loss is when we experience ambiguity about the loss concerned – e.g. a person physically present but psychologically / emotionally absent such as in dementia.

• Anticipatory Grief
  – Anticipatory Grief – this is where the person with dementia and/or their carers may withdraw from each other in anticipation of further losses associated with the disease.

• Disenfranchised or hidden grief
  – Disenfranchised grief is the grief that persons experience when they incur a loss that is not, or cannot, be:
    • Openly acknowledged,
    • Publicly mourned, and/or
    • Socially supported
  – There is no perceived right (or licence) to grieve
How do these losses impact on people?

• It may be more difficult to recognise losses associated with dementia as actual losses and therefore to give oneself permission to grieve for them
• You may feel overwhelmed by caring demands – some of which may be aspects of grief
• The normal grieving process may become intensified or exacerbated
• Grief may become disenfranchised – the person or others may not give themselves permission to grieve.
• Carer’s depression – not being able to recognise the impact that these losses have on you
What helps

• In your experience what do feel would help

• A person with dementia?

• Someone caring for a person with dementia?
Scenario 1

• Jim is 72 and has been recently diagnosed with early stage dementia. He is friendly and outgoing though he struggles at times to remember words. You meet him in a day centre which he attends regularly. You want to support him. You ask him what he finds most difficult about living with dementia.
Scenario 2

• Paula’s husband Joe has middle stage dementia. At times he has difficulty recognising her and other members of the family. Although he is still living at home with Paula – he is wandering a lot and Paula is wondering how much longer she can cope. You meet Paula while she is taking a short break in a coffee shop.
What helps

• Recognising the losses associated with dementia either as a person with dementia or as a carer
  1. Allowing oneself to grieve
  2. Caring for oneself
  3. Finding meaning
  4. Seeking support and avoiding isolation
What helps

• Recognising your grief
• Processing your grief
  – Writing in a journal
  – Becoming involved in artistic hobbies
  – Taking time to reflect
  – Seeking support from someone you trust
• Taking care of yourself
  – Doing things that you enjoy
• Staying connected socially
Losses does not have to devastate

Gaining meaning from ambiguous loss:

• Meaning makes a great many things endurable – perhaps everything – (Carl Jung)

• Ambiguity can make people less dependent on stability and more comfortable with spontaneity and change. Reaching this point is frightening, however, especially for those who are accustomed to being in charge. With ambiguous loss, the task is to let go, to risk moving forward, even when we do not know exactly where we are going. We move to keep from freezing in place or becoming comfortably static; and we do this with actions which are life enhancing.

• “Plan – but don’t plan as if it will all happen as you planned it …. Expect nothing and live frugally on surprise”

• Being able to live with mystery/uncertainty and also being able to do what you can do
How to support caregivers

• One to one
• Group
• Via technology (internet support groups /individual)

• Video clip
  – Supporting Dementia caregivers through loss and grief
The importance of Self-care

• Acknowledging that this is hard work
  – Worthwhile, but hard at times

• Balance in your life
  ▪ processing grief – doing job
  – Fun, exercise, other interests
  – Creativity

• Containment
  – Self reflection – rituals and practice for letting go

• Debrief
  – With colleagues / supervision

• Clarity of role, expectations and limitations
Different aspects of my life
From Trevor Powell – The Mental Health Handbook - 2008

Workplace

3. Personal beliefs and values of employee

1. Grieving process
   - Engagement with grief
   - Detachment from grief

2. Workplace culture and Norms
Caring

- In the desolate and torn terrain of suffering, there is no beauty that reaches deeper than the beauty of the healing voice. . . The ability to care is the hallmark of the human, the touchstone of morality and the ground of holiness. Without the warmth of care, the world becomes a graveyard. In the kindness of care, the divine comes alive in us.

   *O’Donohue John – Divine Beauty – The Invisible Embrace*
Seeking support

- Alzheimer society of Ireland
  - [www.alzheimer.ie](http://www.alzheimer.ie)
  - Helpline - **1 800 341 341**
  - Support groups
  - Social clubs

- Sonas APC
  Alzheimer Cafes – regular social forum for people with dementia and their carers

- Irish Hospice Foundation
  [www.bereaved.ie](http://www.bereaved.ie)
  Information on different resources around grief