World Health Organisation Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

World Health Organisation Principles of Palliative Care

Palliative care:
- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

World Health Organisation www.who.int/cancer/palliative
Learning Objectives
- Define Dementia and list 5 causes
- List parts of the brain affected by dementia
- Identify Advanced Dementia
- Define Palliative Care
- Describe what is meant the Palliative Approach
- Discuss the interconnection of Dementia and Palliative Care
- Describe the role of the home care worker

Definition
Dementia is a syndrome, the umbrella term used to describe the symptoms of a large number of brain illnesses that cause a progressive decline in a person’s ability to function.

- It is a broad term used to describe a loss of memory, intellect, rationality, social skills, and normal emotional responses
- It is progressive and irreversible

(Alzheimer’s Australia, 2005)

Dementia is a terminal illness. There is no cure at the present time.

Exercise 1.
In the box below, write down any symptoms of dementia that you know of or are aware from your work or any reading you have done.
Functions and parts of the brain affected by dementia

The brain is comprised of two cerebral hemispheres. The dominant side of the brain is on the left in most people. The non-dominant side is on the right. There is a small strip down the centre that controls movement. The left side moves our right arm and leg. The right side moves our left arm and leg. The rest of the brain controls our behaviour and all that makes us human: our thinking, emotions, behaviour and personality.
### Table 1

<table>
<thead>
<tr>
<th>Area of brain damaged</th>
<th>Common effects on behaviour</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Temporal lobe</strong>&lt;br&gt;<em>Memory centre</em>&lt;br&gt;• Verbal memory – is controlled from the dominant side of the brain (left) – hence we largely think with words&lt;br&gt;• Visual memory – non-dominant side (right)</td>
<td>Unable to remember words that are spoken, read, seen or heard (memory) (NB. Frequently recalled memories are usually more easily remembered e.g. names/faces of people close to us)</td>
<td>Forget:&lt;br&gt;• People and events&lt;br&gt;• Recent memories – quickly lost&lt;br&gt;In time, longer-term memory may also be affected</td>
</tr>
<tr>
<td><strong>Dominant parietal lobe</strong>&lt;br&gt;<em>Analytical and logical centre</em></td>
<td>Unable to use language (speech, reading and writing) to communicate&lt;br&gt;Unable to calculate</td>
<td>Difficulty:&lt;br&gt;• Saying precisely what they want to say&lt;br&gt;• Naming common objects&lt;br&gt;• Understanding what is said to them&lt;br&gt;Doing math/ knowing correct change required</td>
</tr>
<tr>
<td><strong>Non-dominant parietal lobe</strong>&lt;br&gt;<em>Spatial location centre and 3 dimensional centre</em></td>
<td>Unable to locate position of self, others or objects in space (spatial awareness)</td>
<td>Difficulty:&lt;br&gt;• Knowing how to get somewhere&lt;br&gt;• Locating the car in the car park</td>
</tr>
<tr>
<td><strong>Both parietal lobes</strong></td>
<td>Unable to recognize things (agnosia)&lt;br&gt;Unable to carry out planned or learned patterns of movement – purposive movements (apraxia)</td>
<td>Unable to recognize:&lt;br&gt;• Family members&lt;br&gt;• Objects e.g. knife and fork&lt;br&gt;• Surroundings e.g. their house, area they live in&lt;br&gt;Difficulty&lt;br&gt;• Putting clothes on in the correct order&lt;br&gt;• Using appliances e.g. stove, car&lt;br&gt;• Putting tablecloth on the table&lt;br&gt;• Following instructions (although they may do if they decide to do it – paradoxical behaviours – involves different pathway in the brain)</td>
</tr>
</tbody>
</table>
### Frontal lobe – Lateral
*Executive centre*

Unable to plan or organize
Unable to learn new things
(Planning/learning)

- Shop without money
- Don’t dress appropriately but believe they have
- Not aware of state of tidiness of the house

### Frontal lobe – medial
*Executive centre*

Unable to start and action
‘Starter motor’ not working
(initiation)
Unable to stop once starting or saying something
(perseveration)

<table>
<thead>
<tr>
<th>Appear:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apathetic</td>
</tr>
<tr>
<td>Not to understand</td>
</tr>
<tr>
<td>Unmotivated</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Repeat:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Questions</td>
</tr>
<tr>
<td>Statements</td>
</tr>
<tr>
<td>Actions</td>
</tr>
</tbody>
</table>

### Frontal lobe – orbitobasal
*Executive centre*

Unable to keep on track and control social behaviour
(regulation)

- easily distracted
- wander
- talk over others

### Limbic region
*Connecting system*

Unable to connect behaviours, emotions and memories
Vegetative functions – eating, sleeping (connection)

- angry responses
- accusations of stealing
- disruptions to sleep/eating patterns

### Synthesis of symptoms

Symptoms can all add together to result in a behaviour e.g. Insight poor – feedback person with dementia gets is incorrect – verification incorrect (perception wrong). The brain is deceiving them so may not see their behaviour as problematic and thus may misunderstand what others do

© 2007 Alzheimer’s Australia NSW. Based on the DVD Brain and behaviour with Dr Helen Creasy
### Table 2 - Causes/Types of Dementia

<table>
<thead>
<tr>
<th>Disease</th>
<th>Age of onset</th>
<th>Key features</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s disease</td>
<td>40-90yrs</td>
<td>• Memory problems</td>
</tr>
<tr>
<td></td>
<td>Usually &gt;65yrs</td>
<td>• Word finding difficulties</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Taking longer with routine tasks</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Deterioration in social skills</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>40-65 years</td>
<td>• Impairment of attention and executive function – difficulty with tasks that</td>
</tr>
<tr>
<td></td>
<td></td>
<td>require conscious control and planning</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Stepwise progression</td>
</tr>
<tr>
<td>Dementia with Lewy Bodies</td>
<td>50+</td>
<td>• Fluctuation in mental state</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Visual hallucinations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Parkinsonism – gait changes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Difficulties judging distances</td>
</tr>
<tr>
<td>Frontotemporal dementia</td>
<td>50-60 years</td>
<td>• Behavioural and/or language changes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Personality changes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• May become obsessive or repetitive</td>
</tr>
<tr>
<td>Huntington’s Disease</td>
<td>35-44 years</td>
<td>• Uncontrolled movements</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Personality changes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Impaired attention, slow to process info</td>
</tr>
<tr>
<td>Alcohol related dementia</td>
<td>Variable</td>
<td>• Visual disturbances</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Gait abnormalities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Cognitive changes</td>
</tr>
</tbody>
</table>

![Healthy Neurons vs Damaged Neurons](image)
Stages of Dementia

Dementia is a progressive condition and the person with dementia will gradually experiences losses in cognitive and functional ability. The deterioration experienced is usually classified into 3 stages. While we use these stages for ease of identification, it is important to remember that not all people with dementia will go through each stage or experience all of these losses.

Table 3 - Stages of Dementia

<table>
<thead>
<tr>
<th>Early Stage</th>
<th>Middle Stage</th>
<th>Advanced Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subtle changes will appear in behaviour, personality and intellectual functioning. Some are:</td>
<td>Losses are more apparent and are more disabling.</td>
<td>The person is totally dependent.</td>
</tr>
<tr>
<td>• Poor recent memory</td>
<td>• Profound memory loss, both remote and recent</td>
<td>• Severe impairment of all cognitive functions</td>
</tr>
<tr>
<td>• Difficulty finding the correct word (anomia)</td>
<td>• Short attention span</td>
<td>• Motor impairment – unsteadiness, repeated falls, reduced mobility, bedfast</td>
</tr>
<tr>
<td>• Personality and mood change</td>
<td>• Agnosia</td>
<td>• Total loss of ability to care for oneself – incontinence, eating difficulties</td>
</tr>
<tr>
<td>• Lack of initiative</td>
<td>• Apraxia</td>
<td>Mutism (AA, 2005)</td>
</tr>
<tr>
<td>• Poor judgment</td>
<td>• Severe impairment of judgment</td>
<td></td>
</tr>
<tr>
<td>(ACH group, 2006:11; AA, 2005)</td>
<td>• Restlessness</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Changes in behaviour</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(ACH group, 2006:12; AA, 2005)</td>
<td></td>
</tr>
</tbody>
</table>

Note: An expanded version of Table 3 is included in the Appendices at the back of the workbook
About Palliative Care

Exercise 2.
Refer to the information about Palliative Care at the beginning of the workbook. How might palliative care be appropriate for people with dementia? Discuss with another member of the group. Write your answer in the box below.
Exercise 3.

Based on what you observe in the DVD, ‘She Misses Him’, make a list of what you think will be the personal comfort needs of this man and his wife at the end of his life. Consider his physical, emotional and spiritual needs and practical tasks. List them under these headings in the box below.

Physical:

Emotional:

Spiritual:

Practical:
Understanding Pain in Dementia and at End of Life

‘Pain impacts on dementia and dementia impacts on pain’.
Dr. W. McClean, DSDC, Stirling
Understanding Pain in Advanced Dementia and at End of Life

Learning Objectives
- Define Pain and list 4 types
- Identify individual response to pain
- Identify Chronic non-malignant pain in people with advanced dementia
- Identify myths about pain in people with dementia
- Identify barriers to pain management in people with advanced dementia

Pain is difficult to define and describe, however, it is well documented that pain in older people frequently goes unrecognized and therefore remains undetected and untreated. This leads to a poorer quality of life for the person.

Definition

*Pain is whatever the experiencing person says it is, existing whenever he/she says it does.* (McCaffery cited in McCaffery and Pasero, 1999).

*Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.* (International Association for the Study of Pain).

Exercise 4.

Think about a time when you experienced pain. Do the definitions help describe your experience(s) of pain?

In the box below list as many words as you can to describe a personal experience of pain that you have had in the last few months or weeks. Pain, e.g. throbbing. Also, try and write what pain was for you in that situation.
The international Association for the study of Pain says that it is an unpleasant sensory and emotional experience that we associate with tissue damage. This may be from illness or injury and some researchers have proposed that there are three elements to the experience of pain. These are

- the actual physical sensation
- the knowledge about the pain
- the emotional aspect

A Case History

The following exercise will help you to see how pain involves these three elements. Think about the following story and comment on the questions in the boxes.

George was 65 years old. He was not very physically active. One day he decided to do some gardening. He spent most of the morning digging and bending over weeding. That night he had a hot bath and went to bed. The following morning he had what he described as stiffness and soreness in his shoulders and his back. George commented to his wife, “I must have done some good exercise, because I’m aching in muscles I never knew I owned.”

Exercise 5.

In the box below, write down what you think George’s emotional state was that morning when he commented to his wife about the aches in his muscles?

George continued to have these aches in his muscles. The pains were no worse; they just persisted. Eventually after two weeks he went to his doctor who examined him and ordered some blood tests and x-rays.

Exercise 6.

In the box below, write down what you think George is feeling now.
George went back to the doctor to obtain the results of his tests. His doctor told him that one of the tests was abnormal and that George may have cancer of the prostate which may have spread to the bones.

**Exercise 7.**

In the box below, write down what you think George is feeling about the aches now. Do you think that they seem worse or better than when he first experienced them? Why?

More tests were ordered. When George went to the doctor for his report his wife went with him. They were very relieved to find out that the tests were clear and that the cause of the pains was a simple disease that could be treated with some physiotherapy and that George should be free from symptoms in a couple of weeks’ time.

**Exercise 8.**

Do you think that the pains worried George now? Why?

Although George’s sensation of pain may not have increased at the time he was concerned about having cancer, the actual pain experience would have been more unpleasant. His knowledge led to a change in the emotional aspect (how he thought and felt) of the pain. Perhaps you can see how pain involves the actual sensation which may have certain characteristics of intensity, position etc. However, it has emotional meaning and it is also affected by what we know about the pain. The pain we experiences is a complex combination of these three aspects: sensation, knowledge and emotion.

An older person or person with dementia may have long-term memories of childhood pain experiences which were very frightening. These memories may revive even in dementia to make the pain of late life much more distressing.
Exercise 9.
How else may the progression of dementia interact with one or more of these three aspects of the pain experience?

(Reproduced in full by kind permission of Colm Cunningham, from McLean, W & Cunningham, C., Pain in Older People and People with Dementia: A practice guide, 2007)
The Impact of Dementia

- The person’s ability to communicate through language is lost
- Long-term memories of previous pain experiences may revive in dementia
- The person may not be able to reason that the pain is not threatening and may not be understood. This lack of understanding may cause the person to react more violently than those without dementia expect or think appropriate
- The person’s reaction may result in inappropriate sedation and/or treatment with ‘behavioural’ medications
- People with dementia do not see or read ‘clues’ that a painful situation is about to occur (e.g. seeing a syringe with a needle, the stimulus is therefore greater than in a person who cognitively anticipates the pain
- Untreated pain can lead to fear, frustration, anxiety, sleeplessness and restlessness all of which may impact negatively on the person’s quality of life

**Exercise 10.**

*Discuss with your group members what some of the beliefs about pain in older people and people with dementia might be. Record your answers below.*
### Types of Pain

<table>
<thead>
<tr>
<th>Chronic Pain</th>
<th>Chronic Pain of relatively recent onset which normally lasts less than a month and resolves as tissue healing occurs</th>
</tr>
</thead>
</table>
| **Acute Pain** | • It may be associated with physiological changes such as pallor, sweating, low BP, increased pulse, and changes in breathing pattern  
  • However, these physiological changes may not occur in older people |
| **Chronic or Persistent Pain** | • Continues after healing or is not amenable to cure  
  • This pain usually has no physiological signs and is associated with longstanding functional and psychological impairment  
  • Is said to exist if it persists for more than a month beyond the course of an acute illness or a reasonable time for healing to occur, or if it recurs at intervals for months or years |
| **Chronic Malignant Pain** | Pain where cancer is suspected as being the cause |
| **Chronic Non Malignant Pain** | The most common pain among older people; it is ongoing, often the most difficult to treat and causes a lot of disability |

**Pain Threshold** – the point at which the person experiencing an unpleasant sensation decides it as “painful”

**Pain Tolerance** – the amount of time that someone can tolerate a particular level of pain before they act to avoid, stop or manage the pain

Note: Each and everyone of us has our own pain threshold and tolerance levels
Pain Assessment Tools

Pain scales are available that record, in an objective manner, the signs and symptoms that are likely to indicate the existence of, and gauge the intensity of pain that a person with terminal dementia is experiencing. It is important that there is an ongoing and systematic approach to recording, assessing and managing pain.

As with all treatment options, pain management strategies must be provided in response to an individual's assessed wishes, likes, preferences and/or needs. Pain management strategies are non-invasive comfort measures that, perhaps in conjunction with pain medication, can relieve physical pain and discomfort.

Pain Assessment in Advanced Dementia (PAINAD) Scale

Five item observational tool. Total scores range from 0 – 10 (based on a scale of 0 – 2 for five items), with a higher score indicating more severe pain (0= no pain, 10= severe pain).

| Components & Scoring of the Pain Assessment in Advanced Dementia (PAINAD Scale) |
|-------------------|-----------------|-----------------|-----------------|-----------------|
| Breathing independent of vocalization | Normal | Occasional laboured breathing | Short periods of hyper-ventilation | Noisy, laboured breathing. Long periods of hyperventilation. Cheyne-stokes respiration* |
| Negative vocalization | None | Occasional moan or groan | Low level speech with a negative or disapproving quality | Repeated, troubled calling out | Loud moaning or groaning | Crying |
| Facial expression | Smiling | Inexpressive | Sad | Frightened | Frowning | Facial grimacing |
| Body Language | Relaxed | Tense, Distressed, pacing, Facing | Rigid, Fists clenched, Knees pulled up, Pulling or pushing away, Striking out |
| Consolability | No need to console | Distracted or reassured by voice or touch | Unable to console, distract or reassure |

Score:


See Appendix C for complementary notes on observational factors
# Pain Assessment Tools

## Abbey Pain Scale

*For measurement of pain in people with dementia who cannot verbalise.*

<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1</td>
<td>Vocalisation eg whimpering, groaning, crying</td>
<td>Absent 0 Mild 1 Moderate 2 Severe 3</td>
</tr>
<tr>
<td>Q2</td>
<td>Facial expression eg looking tense, frowning, grimacing, looking frightened</td>
<td>Absent 0 Mild 1 Moderate 2 Severe 3</td>
</tr>
<tr>
<td>Q3</td>
<td>Change in body language eg fidgeting, rocking, guarding part of body, withdrawn</td>
<td>Absent 0 Mild 1 Moderate 2 Severe 3</td>
</tr>
<tr>
<td>Q4</td>
<td>Behavioural Change eg increased confusion, refusing to eat, alteration in usual patterns</td>
<td>Absent 0 Mild 1 Moderate 2 Severe 3</td>
</tr>
<tr>
<td>Q5</td>
<td>Physiological change eg temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor</td>
<td>Absent 0 Mild 1 Moderate 2 Severe 3</td>
</tr>
<tr>
<td>Q6</td>
<td>Physical changes eg skin tears, pressure areas, arthritis, contractures, previous injuries</td>
<td>Absent 0 Mild 1 Moderate 2 Severe 3</td>
</tr>
</tbody>
</table>

Add scores for 1 - 6 and record here: **Total Pain Score**

<table>
<thead>
<tr>
<th>Score Range</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 2</td>
<td>No pain</td>
</tr>
<tr>
<td>3 - 7</td>
<td>Mild</td>
</tr>
<tr>
<td>8 - 13</td>
<td>Moderate</td>
</tr>
<tr>
<td>14 +</td>
<td>Severe</td>
</tr>
</tbody>
</table>

Now tick the box that matches the **Total Pain Score**

Finally, tick the box which matches the type of pain:

<table>
<thead>
<tr>
<th>Type of Pain</th>
<th>Chronic</th>
<th>Acute</th>
<th>Acute on Chronic</th>
</tr>
</thead>
</table>

Abbey, J; De Belle, A; Piller, N; Esterman, A; Giles, L; Parker, D and Lowcay, B.

Funded by the JH & JD Gunn Medical Research Foundation 1998 - 2002

(This document may be reproduced with this acknowledgement retained.)
Pain Management Process

1. Pain identified
2. Is pain new?
   - No: Treat as per existing plan
   - Yes: Complete assessment documents
3. Is suitable treatment already planned?
   - No: Plan treatments within own scope of practice
   - Yes: Report to senior staff & multidisciplinary pain team
4. Document care
5. Reassess regularly
6. Is pain controlled?
   - Yes: Begin treatment
   - No: Document care

Reproduced by kind permission of The Australian Pain Society
Signs of Pain in Older People

- Facial expressions: Frowning, Grimacing, Rapid blinking, Sad expression
- Movements: Tense or rigid posture, Guarding/protecting body part, Fidgeting, pacing, rocking, Difficulty moving, decreased movement, Changed gait - walking strangely
- Activity levels: Appetite - not eating, Rest patterns, sleeping a lot or very little, Wandering, Changes in normal routine or activity
- Mental state: Confusion, Crying, Irritability, Distress
- Noises: Sighing, moaning or groaning, Grunting, Chanting, Calling out, Noisy breathing, Asking for help, Verbal abuse, swearing
- Personality: Aggressiveness, Fighting or resisting care, Avoiding socialising, becoming withdrawn, Inappropriate or disruptive behaviour

Learning Objectives

- Define spirituality and religion and recognize the similarities and differences
- Investigate our own spirituality
- Identify the spiritual needs of the person living and dying with dementia
- Identify barriers to the delivery of spiritual care in the person with advanced dementia

Introduction

Attending to the spiritual needs of the person with dementia and their family and carers is a key element of the palliative approach to dementia care. “To be with a person at the end of their life and offer spiritual nourishment is to receive from them as well. Caring is a two-way path that can lead to enlightenment for both the carer and the dying person.” (Robertson-Gillam, K. 2008) Yet research demonstrates that spirituality can be a difficult concept for people to grasp, that the spiritual needs of persons with dementia are largely unrecognised and/or poorly understood. Some are even of the belief that a spiritual life for persons with dementia is impossible or unnecessary. (Lighting up Lives a report on the palliative care needs of people with end stage dementia 2004/2006)

Exercise 11.

Think of the term ‘spirituality’. What does it mean to you? What do you think of when you hear someone describe themselves as ‘spiritual’? Do you consider yourself to be spiritual? Write your thoughts in the box below.
Notions of spirituality

“A person’s spirituality is linked to their sense of identity.” (Tom Kitwood)

‘... the way in which an individual responds to and makes sense of the raw experience of life - for instance moments of delight and sorrow, understanding and bewilderment, hope and despair. These can be interpreted within or without a religious framework.’ (Alison Johnson, Talk in Medway 23 January 2008 (http://www.levesoncentre.org.uk)

‘... something that takes you above everyday problems ... things, like the beauty of a sunset or a rainbow after a storm, that you don’t have to think about or try to remember.’ (John, person living with dementia, 2010)

Exercise 12.
How do your own ideas of spirituality compare with those of the other group members? Are your ideas on spirituality:

a) the same as everyone else’s in the group

b) similar, but not identical

c) completely different

Why do you think is so? Write your answer in the box below
Definition of Spirituality
‘A transcendent meaning about life, which can be expressed through religion, nature, energy, force, belief in all good, in importance of family and community, music, art, dance.’ (Robertson-Gillam, 2008)

Definition of Religion
‘Religion is any specific system of belief about deity, often involving rituals, a code of ethics, and a philosophy of life.’ (Retrieved from www.religioustolerance.org/var_rel.htm)

Religion derived from Latin word ‘religare’ meaning to bind together.

‘A structured belief system that addresses universal spiritual questions.’ (Robertson-Gillam, K. 2008)

Spirituality may exist independent of a structured belief system. The important element is that each provides hope.

‘Spirituality may find expression through the rituals and practices of religion, but for many it has other associations or avenues of expression. Similarly, spirituality may have God or a supreme being as its centre of focus, but need not.’ (Alzheimer’s Australia, 2006, Paper No.7)

Exercise 13.

Find a partner, preferably someone you do not know. Now, sit facing each other and hold hands. Nominate who will be Person A and who will be Person B, then hold each other’s hands. If you are Person A, shut you eyes. Person B - observe the breathing pattern of Person A. Now match your breathing to their breath patterns and breathe their rhythm. Stop and swap. Discuss your experience with each other and then, record some of the feelings you experienced in the box below.
Exercise 14.
Your final thoughts on spirituality:
A True Story

Looking splendid in her twinset and pearls, Molly sidled up to the visitor who was standing in the doorway of the aged care facility lounge room. “I haven’t seen you around here before,” she said. “Have you come to join me in God’s waiting room dear?”

“Oh no, I’m just visiting,” the visitor replied, “waiting for the staff to.......” Molly threw back her head and roared with laughter. “Well my dear, you had better take a seat, it’s going to be a very long wait!” Before the visitor could sit, a staff member appeared at her side saying, “Oh, don’t listen to Molly, she’s always upsetting people, saying that she wants to die, thinking that God has forgotten her.” “I do want to die. I was ready to die last year but you wouldn’t let me. I do want to die.” Molly sounded as though she meant business. “Don’t say that Molly, of course you don’t want to die!” the staff member reprimanded as she lead the visitor away. The visitor had time to ask Molly one quick question before she was whisked from ‘God’s Waiting Room’. “How many birthdays have you had Molly?” “Ninety-nine” she snapped back, “and I don’t want a letter from the Queen!”

When I tell this story people usually laugh and yes, it is humorous in retrospect, but for me as the visitor this brief interaction made me sad. To think that after almost a century of living, this lady could not express her desire to die and have it heard! It reminded me of a line in David Kessler’s book ‘The Needs of the Dying’, in which he said, “Allowing the dying to be heard is one of the greatest gifts that we can offer them.” I wondered how that could be achieved if we don’t listen to the living when they want to talk about dying. (Georgene McNeil, Educator, Alzheimer’s Australia NSW)

It is hoped that the exercises contained in this workbook and the information contained in the education session so far will give you the courage, not only to examine your own attitudes to and beliefs about death and dying but the confidence to listen and hear the person living and dying with dementia, even when language has been lost, connecting with them as you tend to their comfort in the end stages of their illness and life.
End-of-Life: Death and Dying

Learning Objectives

- Identify the final stages of advanced dementia
- Identify when the person with dementia is actively dying
- Differentiate between a good death and a bad death
- Discuss ethical dilemmas at end-of-life

Introduction

Regardless of the quality of care provided and regardless of where that care is given, there will come a time when the damage to the brain of the person living with dementia will be so extensive that the body’s functions will close down. At this time, the person will enter the final stages of life and is considered to be ‘actively dying’. Unfortunately, dementia is still not accepted as a terminal illness and the person’s death is often viewed by family members as a failure of care of the medical profession and medicine itself. (Focus Group, 2010)

‘Our ancestors were all too familiar with serious illness and death. Few lived to old age, and death often came suddenly from infections or accidents. Today, science and modern medical technology have given us different expectations.’ Rosalyn Carter, in Foreword, Handbook for Mortals


What are some of the expectations that you have about illness and death? What expectations might others have? Write your thoughts in the box below.

Me:

Others:
Exercise 16.
Given your expectations, take a few minutes to think about the end of your life, the final days and hours. What would represent a ‘bad’ death for you? What would a ‘good’ death look like? Write your thoughts in the table below.

<table>
<thead>
<tr>
<th>Good Death</th>
<th>Bad Death</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Perceived requirements for an optimal end-of-life
- Knowing when death may occur and knowing what to expect
- Having your wishes respected and honoured
- Retaining dignity
- Good pain management and relief of distressing symptoms
- Having a choice about where death occurs
- Having access to information and quality care
- Having access to spiritual and cultural support
- Planning care in advance of advanced illness
- Not having life prolonged inappropriately

(ACH group, 2006:18)
Indicators of End-of-Life
Recognising when someone is actively dying is difficult to determine.
The most common symptoms in the last year of life are

- Urinary incontinence
- Pain
- Low mood
- Constipation
- Loss of appetite

Symptoms in the last 48 hours of life commonly include:

<table>
<thead>
<tr>
<th>Signs of Active Dying</th>
<th>Signs that death has occurred</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in cardiac output; increased pulse/decreased blood pressure</td>
<td>Absence of pulse</td>
</tr>
<tr>
<td>Decreasing level of consciousness, unresponsive to verbal or physical stimuli</td>
<td>Breathing stops</td>
</tr>
<tr>
<td>Decreasing appetite/food intake</td>
<td>Pupils of the eye are fixed and dilated</td>
</tr>
<tr>
<td>Decreasing fluid intake</td>
<td>The body becomes pale</td>
</tr>
<tr>
<td>Unable to focus eyes</td>
<td>Body temperature drops</td>
</tr>
<tr>
<td>Uncharacteristic restlessness or agitation/muscle twitching</td>
<td>Muscles and sphincters relax</td>
</tr>
<tr>
<td>Surface of the skin becomes cool and moist</td>
<td>Urine and faeces may be released</td>
</tr>
<tr>
<td>Peripheral shutdown. Blood circulation slows – hands, and feet will feel cold and</td>
<td>Eyes may remain open</td>
</tr>
<tr>
<td>have a blue or purplish tinge</td>
<td></td>
</tr>
<tr>
<td>Fever</td>
<td>Jaw may fall open</td>
</tr>
<tr>
<td>Reduced kidney output</td>
<td>Body will become cold</td>
</tr>
<tr>
<td>Laboured, irregular breathing – “Cheyne-Stokes” breaths.</td>
<td>Rigor mortis will eventually set in</td>
</tr>
</tbody>
</table>

(ACH group, 2006:16, 19)
Complex issues - Nutrition and Hydration at end of Life

Food and eating are, in the modern world, associated with caring, nurturing, socialization and pleasure. Consequently, it can be distressing and difficult for families and carers when the person with dementia begins to refuse food. They often feel that they have failed in their duty of care.

Death is generally expected within about two weeks in the absence of eating.

It is well documented however, that:

‘Tube feeding in residents with advanced dementia does not increase survival. It does not prevent aspiration pneumonia, malnutrition or pressure ulcers. It does not reduce the risk of infections or improve functional status or comfort of the patient.’ (Volicer, 2005)

- Be Aware! Food forced upon the unwilling person may lead to aspiration and cause pneumonia
- This is a specific opportunity to implement the palliative approach to nurture and support the person through the dying process

Exercise 17. Ethical dilemma.

What would you say to a primary carer, with whom you have had a long and supportive relationship, who tells you that he is going to have his wife of 60 years tube fed and hydrated intravenously? You know that these interventions can cause the person discomfort and do not necessarily prolong life in a person with advanced dementia? Write your response in the box below.
Hydration at End-of-Life

It is also normal for people who are dying to stop drinking. Most experts feel that dehydration in the last days and hours of living does not cause distress, but may stimulate endorphin release that promotes the person’s sense of well-being.

- Low blood pressure or weak pulse is part of the dying process, not an indicator of dehydration

Note: Intravenous fluids may sometimes be useful if terminal delirium is present, however,

- Excess fluids can lead to fluid gathering in the lungs, abdomen and legs
- Excess fluid in the lungs cause breathlessness, coughing, sweating and bronchial secretions, all of which are exacerbated by loss of weight and muscle

In other words, fluids at end of life may cause the person to drown in their own fluids as the lungs are unable to clear the fluid of their own accord.

Use of Antibiotics in the final stages of living (Volicer, 2005)

- Antibiotic therapy does not seem to prolong survival and is not necessary for symptom control
- When antibiotics are used, they may cause significant adverse effects, and the diagnostic procedures associated with use of antibiotics add to the resident’s confusion and discomfort
- Antibiotics have minimal effect in the presence of recurrent infections and in the final stages of life

Caution! As with any therapy or intervention, it is important to the person with dementia that each episode of infection be considered on a case-by-case basis.

(Henderson, J. Making Difficult Decisions, Unpublished article, 2009, cited Alzheimer Scotland, Palliative Care in Dementia Education Resource for Health and Social Care Staff Workbook)

CPR (Cardiopulmonary Resuscitation)

‘Aggressive medical treatment for residents with advanced dementia is often inappropriate for medical reasons, has a low rate of success, and can have negative outcomes that hasten functional decline and death.’ (Volicer, 2005)

In frail older people, CPR can lead to broken ribs and punctured lungs. It is not the lifesaving procedure of TV dramas!

NOTE: It is important that care workers neither make suggestions, nor recommend procedures or treatment nor impose their own views, desires, wishes, religious or cultural values upon the person or the family carer at any time throughout their relationship with the person and the family.
Exercise 18.
Learning Check. Your facilitator will ask you to form groups to complete this exercise. Write down as many palliative options as you can think of in the right hand column of the table below.

<table>
<thead>
<tr>
<th>Non-Palliative Option</th>
<th>Palliative Option</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Prevent’ death from hunger via tube feeding</td>
<td></td>
</tr>
<tr>
<td>‘Prevent’ death from dehydration by administering intravenous fluids</td>
<td></td>
</tr>
<tr>
<td>Revive the person via CPR, admit to hospital and ICU for further aggressive and invasive treatments</td>
<td></td>
</tr>
<tr>
<td>Administer antibiotics every time an infection is diagnosed,</td>
<td></td>
</tr>
</tbody>
</table>
The Role of the Care Worker at End-of-Life

In the true spirit of the Palliative Approach, your role is to continue to contribute to the comfort care of the person with dementia who is dying at home.

This is achieved through honouring their wishes, treating them with respect, preserving their dignity and ensuring their continuing comfort and quality of life right up to the end.

The role of all of the people involved in the care of the person in the final stages of their life is an extremely important one:

*It is particularly useful at this time if you are aware of the end of life wishes the dying person. Refer to their life history or Advanced Care Plan, ask family members for information that will help you to provide care that best reflects the person’s wishes.*

You may assist with the **practical** tasks such as moistening the person’s mouth with the liquid of their choice – some people will opt for champagne or red wine - or ‘feeding’ them with melted chocolate or mashed strawberries!

Other physical tasks may include:

- Coating the lips and the area just inside the nose with a thin layer of petroleum jelly to reduce evaporation.
- If eyelids are not closed, moistening the eyes with an eye lubricant or artificial tears to avoid painful dry eyes.
- Attending to oral hygiene; keeping the mouth clean and fresh is important to comfort.

You may provide **emotional** support through massage, hand holding or gentle touch, or through gentle conversation; you may use the time to talk quietly with the person, say goodbye, recall some of pleasurable or fun times you have had with them.

You may choose to support the person **spiritually** through prayer, singing, music or religious rituals that are relevant to them, their culture and beliefs.

Many care workers often intuitively know the right thing to do!

At all times, the care you deliver is directed to the comfort of the person who is dying.
Avoid

• Taking over, being bossy or becoming the expert
• Ignoring the wishes of the person who is dying, or those of the primary carer
• Making assumptions or assuming that you know best
• Dispensing advice, medical, legal or otherwise
• Imposing your own values and beliefs on the person or primary carer

Do

• Observe the person closely
• Report back to your provider on any concerns you may have, particularly where you suspect pain or delirium is present and untreated
• Offer practical support to the primary carer
• Expect to be personally affected by the person’s death. You may find yourself teary or out of sorts in the days or weeks following the death. It is important that you find someone to talk to and practice self-care.

When the person dies

If you are present when the person dies, or arrive at the home shortly after, they need to inform the coordinator that the person has died.

The family may wish to spend some time with the person and there may be no urgency to contact the GP or funeral director (ideally this should have been arranged previously). Others may prefer for this to be done straight away. This is a time to be sensitive to family preferences and cultures.

At some point the GP will need to be informed of the death as a GP needs to verify death before the funeral director can remove the body. The funeral director will need to be advised when the family will be ready for the body to be removed from the home.

You can do some simple and practical things at this time which may be helpful for everyone, such as making a cup of tea for those present or making phone calls as required. Always know your agency policies and procedures before you do anything.

It is important that you care for yourself and find someone that you can talk to and share your grief with. When you have been caring for someone for a long period of time, it is only natural that you will be upset, but the family have their own grief and cannot be expected to comfort you. Seek a colleague, coordinator or friend to share your sadness with.

(Provide Palliative Care for People with Life-Limiting Illness in the Home Care Setting, p 67)
Crossing the Line: Relationships, Boundaries and Caring at End-of-Life
Case Study 1

Sophie is a 56 year old woman who cares full time for her 30 year old daughter who is quite severely disabled with Down syndrome. Approximately twelve months ago, due to issues with her own health, Sophie reluctantly realized that she was going to have to have some help with the care of her daughter. Subsequently help was arranged; four days each week Zina now has several home care workers who attend to her personal care needs on a rotating roster and for two hours each fortnight Sophie also receives assistance with housework.

Over this period, Sophie has developed a good relationship with Sally, one of the carer workers; they usually have lunch together as the care worker only has half an hour between finishing with her previous client and starting at Sophie’s house. Sophie enjoys the chat and company over lunch as she tends to be somewhat isolated and is unable to accept evening invitations to go out with friends due to her caring situation. Sally is a great source of advice to Sophie, recommending various strategies to manage Zina’s sometimes difficult behaviours and keeping her up-to-date with all the specials at the supermarket. They even gave each other presents at Christmas. Recently, Sophie had been unwell and needed to go back to the doctor’s late one afternoon to receive results of blood tests and scans. As her appointment was for 4.30 she asked Sally if she would mind ‘staying back’ to mind Zina while she went to see the doctor. Sally willingly agreed; after all it was at the end of her shift and she wasn’t in a rush to get home.

A couple of weeks later, Sophie took Sally out to lunch on her day off to say thank you for minding Zina. At lunch, Sophie told Sally her exciting news. She had booked a trip to Europe and would be going for three weeks. Sophie was flabbergasted when, instead of being happy for her, Sally responded with a very indignant, “What! How can you afford to do that? You’re on a carer’s pension!” Sophie was upset and replied, “That’s very rude of you to ask me that. I’ve never asked you how you afford to go on your trips three or four times a year with your mother.” “That’s different;” replied Sally,“I work.......and anyway my mother pays.”

Sophie countered the last remark with a request for an apology which Sally refused. The next week, Sally turned up for lunch as usual and acted as if nothing had ever happened. Sophie, however, is considering asking for someone to replace her as she is still feeling hurt and upset by Sally’s remarks at lunch and her refusal to apologies. Sophie confided to her mother “friends don’t treat each other like that!”
Exercise 19.

Who has crossed the line? And how?

How could this situation have been avoided in the first place?

What should happen now?
Case Study 2

Julie is a home care worker with over ten years work experience. In this time she has cared for a number of frail elderly people and her clients speak highly of her.

Her newest client is Muriel, an 85 year old with advanced dementia, who is cared for by her husband John, 89. They were childhood sweethearts and have been married for over 65 years. John is determined to keep Muriel at home and allow her to die in the familiar and comforting surrounds of their married home.

John is troubled by arthritis, as was Muriel “prior to her coming down with this terrible condition” John tells Julie. He has also confided in Julie that he doesn’t know how he will go on if anything should happen to Muriel; they have never spent more than one night apart in 65 years and he doesn’t want her to suffer. Julie assures him that most people with dementia just sleep away and that he shouldn’t waste time worrying about something that probably won’t happen.

A couple of months later Julie returns from her annual holiday to discover that Muriel has just returned from hospital following a bout of aspiration pneumonia. John is very distressed as Muriel has started to refuse food and he is afraid that Muriel is going to die of starvation. He asks Julie if there is anything that he can do. The doctor at the hospital mentioned something to him about feeding Muriel by tube but he was distressed at the time and can’t remember the details of the conversation.

Julie tells him that she’s pretty sure the doctor would have been telling him that he could consider having Muriel artificially fed and hydrated by PEG, a tube that goes straight into the stomach. Her mother had this done for her grandmother and she ‘just slept away’. John asks her if she thinks it would be a good idea for him to have Muriel ‘peg fed’. Julie tells John that she thinks it would buy him some more time with Muriel, if that’s what he wants but that she has heard from a nurse that it requires an operation and could be uncomfortable for her. On the other hand it might stop her from starving to death, she supposed.

Following this conversation, John decides that having Muriel peg fed sounds like a good option and maybe he should also ask the doctor about having her fluids administered in the same way since it seemed to work for Julie’s grandmother.

John is distraught when the doctor advises against the procedure. He told John that PEG feeding is unlikely to prolong Muriel’s life and that intravenous fluids may actually cause her to drown in her own fluids as her kidneys may not be strong enough to process so much fluid. He thinks the doctor just doesn’t value Muriel because she has dementia and Julie agrees with him.
Exercise 20.

What has happened here?

Has Julie crossed the line?

What do you think Julie would have been better to do or say?
Case Study 3

George is a 92 year old man, in the late-moderate stage of dementia. You are assigned to him five days per week to take care of his personal hygiene needs and you also do four hours each fortnight of domestic duties.

George has a daughter, Emily, who is 45. She has three children still living at home and a busy law practice that she oversees. She doesn’t have much time to do the “hard yakka” of care, as she calls it and she really appreciates that you are reliable, obliging and extremely kind to her father. She isn’t the kind of person to take advantage of anyone and would like to give you a couple of pieces from her late mother’s jewellery collection as a token of her appreciation. You are flattered that she thinks so highly of you and you accept a small diamond brooch and a ring from the impressive collection that belonged to Emily’s mother.

The following week, Emily rings to say that she will be late home and asks if you would mind staying with her father until she gets there as he can’t be left alone. She expects to arrive by 6.30pm, so you are happy to help. At 7.30 she rings again to say that she has been held up and now won’t arrive at her father’s until at least 8.30. You were planning to go to the gym and then meet a friend for coffee but you have already had to cancel your plans for the evening. You feel a little irritated but you don’t feel that you can object. After all Emily did give you the ring and the brooch and you have found out that they are actually worth a fair sum of money.
Exercise 21.

Who has crossed the line in this scenario?

Consider the possibility that Julie may now think that you ‘owe her’ and that she may begin to expect you to stay back on a regular basis. You want to stop this before it gets out of hand. You like George and would like to continue caring for him. How will you resolve this situation?
Case Study 4

It’s Monday morning. You have just arrived at the house of Fran and Guiseppe and find out that between leaving on Friday afternoon and this morning Guiseppe had a ‘bad turn’ and spent a night in hospital. He was discharged on Sunday afternoon. Fran tells you that the tests show he had a mini-stroke, but that there is no apparent residual effect. It is very hard to tell anyway as Guiseppe is living with moderate to advanced dementia and is unable to communicate verbally.

While you are there, Fran and Guiseppe’s daughter rings from Melbourne. Fran answers the phone but after a short conversation the daughter asks Fran to put you on the phone so that she can find out what’s going on with her father. Your organization has rules that do not allow you to talk to family members. You tell Fran that are unable to take the call and advise that her daughter should ring the co-ordinator. Fran’s daughter is not happy with this response and yells at her mother who bursts into tears and begs you to talk with her daughter. This causes you a dilemma as you don’t want to break the rules but you don’t like seeing Fran so upset especially after what she’s been through at the weekend.
Exercise 22.

What do you do and why?

Do you live by the code that “rules are rules” not to be broken under any circumstances?
## Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dysphagia</strong></td>
<td>Difficulty swallowing</td>
</tr>
<tr>
<td><strong>Dyspnoea</strong></td>
<td>Difficulty with breathing</td>
</tr>
<tr>
<td><strong>Empathy</strong></td>
<td>The ability to ‘put oneself in another person’s shoes’</td>
</tr>
<tr>
<td><strong>End-of-life care</strong></td>
<td>An important part of palliative care in the final stage of life; it may include actions such as moistening the mouth with ice or orange slices, oral hygiene, gentle touch or massage, singing, reminiscing, music or religious or spiritual rituals. Death can be expected within a period of hours, days or weeks. Determining when this phase begins can be difficult. Some authors refer to this as ‘terminal care’ and others refer to end of life care over a much longer time period.</td>
</tr>
<tr>
<td><strong>Ethics</strong></td>
<td>Moral principles or values held by individuals or groups around a particular issue eg. Euthanasia, PEG feeding, CPR</td>
</tr>
<tr>
<td><strong>Grief</strong></td>
<td>The normal response to loss</td>
</tr>
<tr>
<td><strong>Holistic care</strong></td>
<td>Care based on the emotional, mental, spiritual and physical needs of a person</td>
</tr>
<tr>
<td><strong>Incontinence</strong></td>
<td>The loss of ability to control bladder and/or bowel movements</td>
</tr>
<tr>
<td><strong>Infection</strong></td>
<td>Condition caused by contamination by bacteria or a virus</td>
</tr>
<tr>
<td><strong>Intravenous</strong></td>
<td>Administration of fluid or medications via a tube into the vein</td>
</tr>
<tr>
<td><strong>Loss</strong></td>
<td>The severing of an attachment to someone or something</td>
</tr>
<tr>
<td><strong>Malignant</strong></td>
<td>Harmful; life-threatening; usually associated with cancer</td>
</tr>
<tr>
<td><strong>Non-malignant</strong></td>
<td>Benign, non-cancerous</td>
</tr>
<tr>
<td><strong>Opiates</strong></td>
<td>Sedatives containing opium eg. Morphine. This type of drug is commonly used in palliative care and has a painkilling and sedating effect. It does not hasten the end of life.</td>
</tr>
</tbody>
</table>
| **Pain**              | ‘Pain is whatever the experiencing person says it is, existing whenever he/she says it does’. (McCaffery cited in McCaffery and Pasero, 1999)  
‘Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.’ (International Association for the Study of Pain) |
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain Threshold</td>
<td>The point at which the person experiencing an unpleasant sensation decides it as “painful.”</td>
</tr>
<tr>
<td>Pain Tolerance</td>
<td>The length of time that someone can tolerate a particular level of pain before they act to avoid, stop or manage the pain.</td>
</tr>
<tr>
<td>Palliative care</td>
<td>A holistic approach to care for the person with a terminal illness; it aims to maximise the quality of life through the provision of pain relief and attention to the physical, spiritual, emotional and practical needs of the person with dementia and their carers.</td>
</tr>
<tr>
<td>PEG feeding</td>
<td>Percutaneous Endoscopic Gastostomy. A feeding tube.</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>The degree to which a person’s physical, emotional and spiritual needs are met determine their quality of life</td>
</tr>
</tbody>
</table>
| Signs and symptoms                        | Signs are what we may notice about the illness e.g. memory loss, personality changes  
Symptoms are what the person experiences e.g. confusion |
| Spirituality                              | Means different things to different people; is often associated with ways in which attribute meaning to life and a sense that we are more than the physical aspects of our body; it is about transcendence and does not need to be connected to religion although it often is. |
| Terminal agitation or restlessness         | The unsettled or restless behaviours and actions that may be observable in the last days and hours of life; symptoms may include jerking or twitching movements, grunting or calling out. |
| Well-being                                | Can be observed by the way a person looks physically and how they appear emotionally e.g. sad/withdrawn, peaceful, smiling                                                                                   |
Appendices

Appendix A - Stages of Dementia expanded version

<table>
<thead>
<tr>
<th>Early Stage</th>
<th>Middle Stage</th>
<th>Advanced Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>The person with dementia may appear normal but subtle changes will appear in behaviour, personality and intellectual functioning. Some of these changes may include</td>
<td>The losses become more apparent and are more disabling. Some of the changes that may be experienced include</td>
<td>The person is severely disabled and totally dependent. Features of this stage include:</td>
</tr>
<tr>
<td>Poor recent memory</td>
<td>Profound memory loss, both remote and recent</td>
<td>• Severe impairment of all cognitive functions</td>
</tr>
<tr>
<td>• Has difficulty with new learning and making new memories</td>
<td>• Makes up stories to fill in gaps of memory</td>
<td>• Motor impairment – unsteadiness, repeated falls, reduced mobility, bed fastness</td>
</tr>
<tr>
<td>• Loses or misplaces things by hiding them in odd places or forgets where things go, such as putting clothes in the dishwasher</td>
<td>• Has trouble following written notes or completing tasks</td>
<td>• Sleeps for increasing periods of time</td>
</tr>
<tr>
<td>• Easily loses way going to familiar places</td>
<td>• Cannot organize thoughts or follow logical explanations</td>
<td>• Shows little awareness of environment and activities</td>
</tr>
<tr>
<td>Difficulty finding the correct word (anomia)</td>
<td>Problems recognising people</td>
<td>• Increased restlessness</td>
</tr>
<tr>
<td>• May substitute or make up words that sound like or mean something like the forgotten word</td>
<td>• Mixes up identity of people, such as thinking a son is a brother or that a wife is a stranger</td>
<td>• Mute</td>
</tr>
<tr>
<td>• May stop talking to avoid making mistakes</td>
<td>Agnosia</td>
<td>• Responds through the senses</td>
</tr>
<tr>
<td>Personality and mood change</td>
<td>• Unable to identify a familiar object</td>
<td>(AA 2005)</td>
</tr>
<tr>
<td>• Loses spark or zest for life</td>
<td>• May take things that belong to others</td>
<td>The person is at increased risk for pressure sores and infections of the urinary and respiratory tracks and aspiration pneumonia.</td>
</tr>
<tr>
<td>• Is irritable, less sensitive to others’ feelings, uncharacteristically angry when frustrated or tired</td>
<td></td>
<td>The course of dementia and how fast changes occur depends on the individual.</td>
</tr>
<tr>
<td>• Takes longer to do routine chores and becomes upset if rushed or if something unexpected happens</td>
<td></td>
<td>The time from the beginning of symptoms until death can range from 2 to 20 years.</td>
</tr>
<tr>
<td>Early Stage</td>
<td>Middle Stage</td>
<td>Advanced Stage</td>
</tr>
<tr>
<td>-------------</td>
<td>--------------</td>
<td>----------------</td>
</tr>
<tr>
<td><strong>Lack of initiative</strong></td>
<td><strong>Restlessness</strong></td>
<td></td>
</tr>
<tr>
<td>• Does not start anything</td>
<td>• Has restless, repetitive movements in late afternoon or evening, such as pacing, trying doorknobs</td>
<td></td>
</tr>
<tr>
<td>• Withdraws, loses interest</td>
<td>• Continuously repeats stories, favourite words, statements, or motions like tearing tissues</td>
<td></td>
</tr>
<tr>
<td>• Has shorter attention span and less motivation to stay with an activity</td>
<td>• Changes in behaviour</td>
<td>(ACH group, 2006:11; AA, 2005)</td>
</tr>
<tr>
<td>• Resists change or new things</td>
<td>• May become verbally and/or physically aggressive due to frustration</td>
<td></td>
</tr>
<tr>
<td><strong>Poor judgment</strong></td>
<td>• Has trouble organizing and thinking logically</td>
<td>• May become untidy or forget manners</td>
</tr>
<tr>
<td>• Loses judgment about money – forgets to pay, pays too much or forgets how to pay</td>
<td>• Has trouble making decisions</td>
<td>• May see, hear, smell or taste things that are not there</td>
</tr>
<tr>
<td>• Has trouble organizing and thinking logically</td>
<td>• This stage is difficult because the person still has some insight into his or her condition yet cannot understand or cope with the changes being experienced</td>
<td>• May exhibit inappropriate sexual behaviours</td>
</tr>
<tr>
<td>• This stage is difficult because the person still has some insight into his or her condition yet cannot understand or cope with the changes being experienced</td>
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Person-centred care

Professor Tom Kitwood spearheaded a new approach to dementia care in 1995. This came to be known as person-centred care.

Person-centred care focuses on the individual with the disability, not just the disability. Person-centred care is characterized by two main components:

- An ethical foundation that acknowledges and respects the human spirit that exists in everyone
- A body of knowledge or understanding of appropriate care practices that will support the individual with dementia to maintain quality of life and independence despite the physical changes to the brain that accompany dementia

The person-centred care approach grew out of the work pioneered by:

- Social psychologists and counsellors
- The struggles of disability rights campaigns
- Advances in caring for people with learning disabilities
- The reminiscence and validation approaches
- Other creative therapies

This approach has resulted in a great many changes to the way in which we view the care practices and principles of carers of people with dementia. (Morton, I. Journal of Dementia Care, May/June 2000:28)

Person-centred care represents a cultural shift in the care of people with dementia. Until recently, carers of people with dementia focused almost exclusively on the progressive cognitive damage that occurs in the brain.

Carers sought to ‘take over’ where the brain left off by meeting the physical needs that the person was no longer able to do, such as prompting them, or helping with eating and drinking, showering, and dressing etc. Since the person was often unable to remember to complete even these basic tasks, participation in other activities was not thought possible or worthwhile.

Dementia was seen as a ‘living death’. People with dementia were viewed as indifferent to the actions of others and oblivious to the outside world. Over time, we have come to realise that in fact, the spirit that makes us human, and the ability to feel emotions such as joy, sadness and fear is not lost to people with dementia.

Thus, person-centred care involves looking beyond the brain damage to the uniqueness of each individual, their personality, their achievements and their life history.
Carers working with the person-centred care approach should:

- Focus in the remaining abilities of people with dementia and maintain independence for as long as possible
- Acknowledge the particular uniqueness of each individual, in spite of damage to the brain
- Promote opportunities to participate in meaningful and enjoyable activities
- Maintain and improve quality of life

Steps involved in successfully implementing the person-centred care approach include:

- Developing relationships with others significant to the person with dementia
- Developing a comprehensive life history of the person with dementia
- Having unconditional positive regard for the person with dementia despite changes in their behaviour
- Acknowledging the feelings underlying confused speech and behaviour
- Reflecting on your personal interactions with the person with dementia to ensure you continue to acknowledge their unique personhood


Old dementia care culture:

- Views dementia as a living death
- Focuses on physical destruction of brain cells
- Shows little recognition of skills and abilities retained by the person with dementia
- Places emphasis on meeting the physical needs of the person (e.g. nutrition, hygiene, clothing, mobility)
- Is characterized by showing little recognition of the effects of the actions of others on the person with dementia

Person-centred dementia care:

- Involves looking beyond the diagnosis of dementia to understand and respect the individual
- Is a holistic approach to physical and mental health issues
- Includes a knowledge of the biography, achievements and life story of the individual
- Includes listening to the individual and maintaining their rights
- Is aware of the effects of care practices on ‘personhood’
Appendix C - PAINAD Scale Observation Items

Breathing
1. Normal breathing is characterized by effortless, quiet, rhythmic (smooth) respirations.
2. Occasional labored breathing is characterized by episodic bursts of harsh, difficult or wearing respirations.
3. Short period of hyperventilation is characterized by intervals of rapid, deep breaths lasting a short period of time.
4. Noisy labored breathing is characterized by negative sounding respirations on inspiration or expiration. They may be loud, gurgling, or wheezing. They appear strenuous or wearing.
5. Long period of hyperventilation is characterized by an excessive rate and depth of respirations lasting a considerable time.
6. Cheyne-Stokes respirations are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

Negative vocalization
1. None is characterized by speech or vocalization that has a neutral or pleasant quality.
2. Occasional moan or groan is characterized by mournful or murmuring sounds, wails or laments. Groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
3. Low level speech with a negative or disapproving quality is characterized by muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining, sarcastic or caustic tone.
4. Repeated troubled calling out is characterized by phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.
5. Loud moaning or groaning is characterized by mournful or murmuring sounds, wails or laments much louder than usual volume. Loud groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
6. Crying is characterized by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

Facial expression
1. Smiling is characterized by upturned corners of the mouth, brightening of the eyes and a look of pleasure or contentment. Inexpressive refers to a neutral, at ease, relaxed, or blank look.
2. Sad is characterized by an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
3. Frightened is characterized by a look of fear, alarm or heightened anxiety. Eyes appear wide open.
**Body language**

1. Relaxed is characterized by a calm, restful, mellow appearance. The person seems to be taking it easy.

2. Tense is characterized by a strained, apprehensive or worried appearance. The jaw may be clenched (exclude any contractures).

3. Distressed pacing is characterized by activity that seems unsettled. There may be a fearful, worried, or disturbed element present. The rate may be faster or slower.

4. Fidgeting is characterized by restless movement. Squirming about or wiggling in the chair may occur. The person might be hitching a chair across the room. Repetitive touching, tugging or rubbing body parts can also be observed.

5. Rigid is characterized by stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding (exclude any contractures).

6. Fists clenched is characterized by tightly closed hands. They may be opened and closed repeatedly or held tightly shut.

7. Knees pulled up is characterized by flexing the legs and drawing the knees up toward the chest. An overall troubled appearance (exclude any contractures).

8. Pulling or pushing away is characterized by resistiveness upon approach or to care. The person is trying to escape by yanking or wrenching him or herself free or shoving you away.

9. Striking out is characterized by hitting, kicking, grabbing, punching, biting, or other form of personal assault.

**Consolability**

1. No need to console is characterized by a sense of well being. The person appears content.

2. Distracted or reassured by voice or touch is characterized by a disruption in the behavior when the person is spoken to or touched. The behavior stops during the period of interaction with no indication that the person is at all distressed.

3. Unable to console, distract or reassure is characterized by the inability to soothe the person or stop a behaviour with words or actions. No amount of comforting, verbal or physical will alleviate the behavior.

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