Come Into My World

How to Interact with a Person who has Dementia:

An educational resource for undergraduate healthcare students on person-centred care.

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The Australian Government's Dementia Initiative was funded in 2005 to provide significant additional support to Australians living with dementia, their carers and families. Programs have been established to increase the capacity of both the health and aged care sectors to undertake research and provide for evidence-based early intervention, assessment, treatment and care initiatives. This includes the establishment of Extended Aged Care at Home Dementia Packages and dementia-specific training for aged and community care staff and residential care workers, carers and community workers such as police and ambulance officers.

The SA & NT DTSC is one of four Centres nationally that promote dementia studies in Australian graduate and undergraduate curriculum as well as providing tertiary dementia career pathways

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Preface

As the world's population ages, dementia as a progressive illness with a variety of cognitive and behavioural changes, will impact not only on those who age, but also on those who will be required to care for them. The burden of dementia to public health is increasing with an associated escalation of social and public health issues. Many healthcare professionals currently working with people with dementia have expressed the need to educate undergraduate students about dementia care prior to them commencing their clinical placements and career. This is because the impact of negative interactions for the new healthcare professional can result in distress and an unwillingness to work with people who have dementia, as well as adversely impacting on the person with dementia. On the other hand, if person-centred care is practiced, then the experience can be a positive one for all concerned. Preparation in and an understanding of dementia care using a person-centred approach will assist students to identify both the positive and negative effects of their interactions with people who have dementia.

The purpose of this educational resource is to illustrate that by using a more person-centred care approach, undergraduate healthcare students can improve both the quality of their practice and the wellbeing of the person with dementia. The educational resource consists of a multidisciplinary DVD with a supporting workbook based on the work of Professor Tom Kitwood (1997) and Professor Dawn Brooker (2007). The workbook interrelates with the re-enacted case scenarios created from healthcare professionals' experiences of caring for people with dementia. It is envisaged that the combined use of the DVD and workbook, by illustrating examples of the person-centred care approach in real-life situations, will help undergraduate healthcare students to enhance their professional practice. As such, the resource demonstrates positive and negative interactions by healthcare professionals and others in realistic scenarios.

The workbook begins with the aetiology and epidemiology of dementia as an introduction to the condition. The theoretical underpinning of person-centred care is then explained using Kitwood's (1997) positive person work concept to illustrate best practice outcomes. Malignant social psychology causing problems in practice and deterioration in the person with dementia are also illustrated. The theoretical underpinning is then correlated with the student learning objectives and reflective questions related to each scenario in the DVD.

A filmed interview with Professor Dawn Brooker, an acknowledged expert in the area of person-centred care, introduces positive person work and malignant social psychology and their meaning in practice. Excerpts of additional interviews with other healthcare professionals provide additional insights for students on how person-centred care can be practiced in these professions.

This educational resource will illustrate the necessity of practicing person-centred care with people who have dementia. Though the educational resource has been developed for undergraduate students in the first instance, it is also intended to be helpful for educators across multiple undergraduate healthcare disciplines. Following are the student learning objectives developed for this educational resource.

Student Learning Objectives

The aim of this resource is to educate undergraduate health care students about how to interact with people who have dementia using a person-centred approach in practice.

After reading the workbook, viewing the DVD and considering the reflective questions, the student will be able to:

1) Articulate the prevalence of dementia.

2) Understand the different types of dementia and their aetiology.

3) Understand and articulate the concepts of personhood and person-centred care.

   Identify, explain and apply the 12 elements of Positive Person Work as described by Professor Tom Kitwood (1997).

   Identify and explain the 17 elements of Malignant Social Psychology as described by Tom Kitwood (1997) and the impact these may have on the person with dementia.

   Identify, explain and discuss the VIPS framework of person-centred care developed by Professor Dawn Brooker (2007). The acronym VIPS stands for Valuing the person, Individual care, a Personal perspective and the Social environment as necessary elements for engaging in person-centred care.

   Understand the role of Dementia Care Mapping (DCM).

4) Recognise behaviours as an expression of a need for the person with dementia.

5) Critically analyse and reflect on practices and biases in caring for a person with dementia.

6) Recognise how practices and diverse settings might impact on caring for the person with dementia.

7) Recognise and relate strategies of positive interactions with people who have dementia to prevent the potential of negative outcomes.

A Review of Dementia, Person-centred Care and Healthcare Practice for the Person with Dementia

Introduction

It is inevitable that most undergraduate students across multiple healthcare disciplines will work with people with dementia. These students, some of whom may never have previously interacted with a person with dementia, will need guidance in learning how to interact with these clients in a way that creates a positive experience for both of them. Healthcare students require strategies to assist a person with dementia with their Activities of Daily Living (ADL's), as well as their biopsychosocial needs. Strategies should include not only providing healthcare, but also how to help people with dementia make decisions, cope with feelings, manage their relationships with others and maintain their independence for as long as possible (Australian Institute of Health and Welfare, 2007).

The Australian Government's National Framework for Action on Dementia provides an overarching vision for Australia's dementia care and support systems through improvement in the care of people with dementia and support for those who care for them (Australian Health Ministers' Conference, 2006). The plan recognises this can only occur using a person-centred approach supported by specific and relevant training for health, community and aged care professionals, families, careworkers and newly diagnosed people with dementia. A person-centred approach is required because of a prevailing absence of this approach in current healthcare environments (Australian Health Ministers' Conference, 2006). Contemporary healthcare requires inclusion of practice and systems of care that respect the right to dignity and a quality of life that values the person. With dementia, the person-centred approach places the affected person, rather than the illness, at the centre of care. In contrast, the medicalisation of dementia with a focus on illness, has carers and the people who experience dementia reporting that the person inside is lost or ignored (Edvardsson, Winblad, & Sandman, 2008; Nuffield Council on Bioethics, 2008). The history of nursing older people is one where they have not been treated as persons, but rather as objects required to conform to organisational needs of the institutions in which they reside (McCormack, 2004; Brooker 2007).

Person-centred care means establishing the personhood of the person by acknowledging and entering their world so that their rights, values, meaning and potential, as well as shared decision-making about and for them, can be supported (Brooker, 2007; Nuffield Council on Bioethics, 2008). It is also acknowledged that people with dementia will, at some time, have behaviours that can create distress for them and those who care for them, including nurses, doctors and other allied health professionals (Australian Institute of Health and Welfare, 2007). Understanding this behaviour is even more difficult when the person with advanced dementia is no longer able to verbally communicate their needs.

Consequently, emotions and behaviour may become the only means of communicating their individual needs. It is necessary to understand the behaviour and empathise with its meaning if distressing and stressful consequences engendered are to be reduced (Australian Institute of Health and Welfare, 2007; Brooker, 2007; Nuffield Council on Bioethics, 2008). Furthermore, a negative approach by the healthcare professional can cause deterioration in the pathological state of the person with dementia which may compromise their wellbeing (McCormack, 2004). Conversely, actively using the person-centred approach can maintain and improve the wellbeing of the person with dementia.

Understanding who the person is in the present (as experienced in the moment) and who they were before, as well as the events that shaped the person's life, allows the healthcare professional to recognise 'that the person's character is not lost but rather is concealed' (Edvardsson, Winblad, & Sandman, 2008, p. 362). Sometimes, not knowing or understanding the difference between who the person is now compared to who they were before can lead healthcare professionals to place social responsibility on the person with dementia that demands more of the person than they are capable of at that moment (Nuffield Council on Bioethics, 2008). Thus, education is essential for undergraduate healthcare students in the early stages of their professional experience. This resource will assist students in their preparation for clinical placement to provide care that is not laden with value or moral judgment, but rather is positive and enriching for the person with dementia and themselves in their professional practice.

Defining Dementia

The general definition of dementia relates to any organic condition where there is an irreversible loss of cognitive capacity and memory, such that there is a decline in a person's ability to function socially, physically and emotionally over time (Kitwood, 1997, Chen, Foo, & Ury, 2002; World Health Organisation, 2007). The kinds of cognitive disturbance that occur include:

> 'memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation' (World Health Organisation, 2007).

Dementia as a syndrome relates to at least 60 different disease processes that result in neurological failure (Jacques & Jackson, 2000; Ritchie & Lovestone, 2002). Progressive deterioration in more than two cognitive domains along with behavioural changes, as well as depression and other affective disorders observed at the same time, are primary indicators of the disease (Bozoki, Giordani, Heidebrink, Berent, & Foser, 2001; Koltai, Welsh-Bohmer, & Schmechel, 2001; World Health Organisation, 2007). This progressive deterioration may occur over a long period of time during which physical ability is maintained but independent functioning is compromised. At present, there is no medical cure for dementia and treatment focuses on medications that reduce the severity of symptoms and may allay the progression of the disease. In the absence of any cure, therapies and care are directed towards enhancing the lives and wellbeing of people with dementia and their carers.

Table 1 illustrates some of the different types of dementia, their incidence and the ways in which they differ as a guide to understanding the more common types of dementia and the symptoms generally associated with them. It should be remembered that dementia is a very individual illness and the manner in which it manifests itself and the symptoms displayed will be highly idiosyncratic. Alzheimer's Disease (AD), originally described by Alois Alzheimer in the early 1900's, currently accounts for the majority of cases of people with dementia and has been used as the basis for categorisation (Walker, Payne, Smith, & Jarrett, 2007). Advanced AD affects all structures of the brain but predominantly the cortical structures. Over time the cortex shrinks impacting on thinking, coordination and memory loss. As the cortical mass shrinks, the ventricles enlarge with the hippocampus (new memory formation) the most affected structure during this time (Alzheimer's Association, 2008).

Table 1: Types of dementia: Causes and Symptoms

Type of Dementia	Causes and Symptoms
Alzheimer's Disease (AD)	This is the most common type accounting for over 50% of cases of dementia. Abnormal proteins form microscopic tangles (made of tau protein) inside brain cells while plaques (made of amyloid protein) form within the substance of the brain. These proteins gradually accumulate leading to the death of brain cells and remain behind as abnormal depositions of protein at post mortem. Tangles and plaques disrupt messages between brain cells affecting assimilation and retrieval of information. AD can affect all areas of the brain with functions and abilities lost as different areas are affected. The most common presenting symptom is memory loss with planning, reasoning, speech and orientation variably affected.
Vascular Dementia (VaD)	VaD may appear similar to AD and is the second most common type of diagnosed dementia. People may have a combination of both AD and VaD. This dementia is due to the accumulated effects of multiple Cerebral Vascular Accidents (CVAs) on brain function. When CVAs have occurred over large areas this is known as Multi-Infarct Dementia (MID). When the infarcts are deep in the brain or small (in the white matter) this is known as Binswanger's disease or sub-cortical vascular dementia. VaD is associated with hypertension, atherosclerosis and an inadequate blood flow to the brain. There is usually a history of CVAs with failure to recover fully afterwards and memory affected. VaD may be accompanied by dysphasia, hemiplegia, dysphagia and/or visual impairment.
Dementia with Lewy Bodies (DLB) Also known as Lewy Body Dementia	DLB is another progressive dementia that is sometimes difficult to distinguish from AD, VaD and/or Parkinson's disease. Lewy Bodies accumulate throughout the brain and are abnormal spherical structures which develop in nerve cells and lead to death of the cells along with cognitive and memory disturbances. Visual hallucinations often occur and the person may also experience Parkinson-like symptoms. It is a condition that tends to fluctuate rapidly.

Dementia associated with Parkinson's Disease	Parkinson's Disease is a progressive disorder of the central nervous system affecting motor functioning. Approximately 30% of people with Parkinson's disease may develop dementia in the later stages of the illness through the accumulation of Lewy Bodies deep inside the nerve cells of the brain. Parkinson's Disease is characterised by tremors, stiffness, slowness and often speech impediments. Drugs may help the motor disorder but the dementia can also induce hallucinations, delusions and temporary worsening of confusion. A lack of motivation along with memory loss may occur as a result of either the Parkinson's Disease or the dementia.
Frontotemporal Lobar Degeneration (FTLD)	Though less common, this form of dementia is increasing in incidence. FTLD includes Frontotemporal Lobe Dementia; Progressive Fluent and Non-Fluent Aphasia; Semantic Dementia and Pick's Disease. It is caused by the degeneration in one or both of the frontal or temporal lobes of the brain. Approximately 50% of those with FTLD have a family history of the disease. The condition is caused by an abnormal amount of the tau protein produced inside nerve cells which later die. There may be a disturbed drive and motivation, a lack of inhibition or inappropriate behaviour. Memory loss may not be as prominent as with AD.
Korsakoff's Syndrome	This is an alcohol-related dementia caused by the intake of alcohol in preference to nutritious food leading to a deficiency in thiamine (Vitamin B1). This type of dementia particularly targets the memory, leaving other thought processes intact.
Creutzfeldt-Jacob Disease	This form of dementia is extremely rare. It is caused by protein particles called prions which accumulate in nerve cells. Symptoms include failing memory, changes in behaviour, spontaneous jerks and a lack of coordination. In animals, it is also known as Mad Cow Disease.

(Jacques & Jackson, 2000; Alzheimer's Association, 2005; Walker et al., 2007)

Prevalence of Dementia

In 2007, approximately 30 million people worldwide were identified as living with dementia and this number is expected to increase over the next 20 years as the world population ages (Alzheimer's Australia, 2007). The World Health Organisation commissioned an integrative analysis of statistical information revealing the extent of dementia across the world. Consisting of an analysis of 47 surveys across 17 countries, the rate of dementia for those aged 60 to 69 years of age was found to be approximately 1%, rising to approximately 39% in persons aged 90 to 95 years of age (Mathers & Leonardi, 2000). As such, prevalence has been found to double with every five years of age within the older age ranges (80 years of age and older) and is generally not affected by gender or place of living (Mathers & Leonardi, 2000). AD is the predominant type of dementia for the majority of the 10% of the population over age 65 with dementia in North America and has been shown to be twice as prevalent as VaD in Korea, Japan and China (Mathers & Leonardi, 2000).

In Australia, it is estimated that the number of people with dementia will grow from over 175,000 in 2003 to almost 465,000 in 2031 (Australian Institute of Health and Welfare, 2007). Research shows that 227,300 people currently experience the disease in Australia and there are approximately 57,000 new cases of dementia each year (Alzheimer's Australia, 2007). Of the people with dementia, 64% are female and 81% are aged 75 or older (Australian Institute of Health and Welfare, 2007). At a state level, it is estimated that the total number of people in South Australia and the Northern Territory combined who will have dementia will be approximately 21,760 in 2010 rising to 28,000 by 2020 (South Australian Government Department of Health, 2008). By 2051, it is projected that South Australia will have the oldest population in Australia with nearly 31% of the South Australian population being over 65 years of age (South Australian Government Department of Health, 2008) and a large proportion of these people will experience some form or level of dementia barring any changes to treatment or cure of the disease (Australian Institute of Health and Welfare, 2008; Low, Gomes, & Brodarty, 2008).

In summary, as the prevalence of dementia increases with the ageing of the world population, a significant burden will be placed on healthcare services in all countries. People who have dementia will need to be provided with services that include not only medical services, but also physical, social, psychological and emotional support.

Non-English speaking People with Dementia in Australia

At present, the majority of people with dementia in Australia speak English as their first language, however, a significant number (12.4% or 1 in 8 people on average) were born overseas in Non-English speaking countries and do not speak English at home (Access Economics, 2006). Table 2 illustrates the composition of Non-English speaking people with dementia for each of the Australian states and territories.

Table 2: Non- English Speaking People with Dementia in Australia

State	Rates of NES People with Dementia	Percentage (%)
Northern Territory	1 in 5	21.0
Victoria	1 in 6	16.9
Australian Capital Territory	1 in 7	14.7
New South Wales	1 in 8	12.9
South Australia	1 in 9	12.0
Western Australia	1 in 9	11.5
Queensland	1 in 15	6.8
Tasmania	1 in 29	3.5

(Access Economics, 2006)

Higher proportions of people who do not speak English at home are directly related to significant cultural populations in particular jurisdictions for example, Indigenous populations in the Northern Territory (Hayward, 2008) and Greek populations in Victoria (Access Economics, 2006). Overall, in the period 2001 to 2050 there is projected to be a fall in the proportion of Australians speaking English (83.8% to 82.4%) and other European languages (7.6% to 6.0%), with a greater proportion speaking Asian (6.0% to 8.3%) and Middle Eastern (1.8% to 2.3%) languages creating a need for dementia care that is culture specific (Access Economics, 2006).

Approximately 2,100 Indigenous Australians are affected with dementia at a prevalence rate five times higher than non-Indigenous Australians (Access Economics, 2006; Hayward, 2008; Western Australian Centre for Health and Ageing, 2009). Recent research conducted by the Western Australia Centre for Health and Ageing found that the difference in dementia levels between Indigenous people and non-Indigenous people are due in part to a new assessment instrument picking up levels of dementia that were not recorded previously (Hayward, 2008). This instrument, called KICA (Kimberley Indigenous Cognitive Assessment) was produced using knowledge and everyday language and tools familiar to Indigenous people within this region to assess for cognitive decline (Western Australian Centre for Health and Ageing, 2009). Further research in this area will investigate whether the overall health risks that Indigenous people incur also contribute to the prevalence of dementia in this population (Hayward, 2008).

Young Onset Dementia

Other groups of people who are being diagnosed with dementia include those younger than would normally be associated with this disease. Young Onset Dementia (YOD) is defined as dementia experienced by people under the age of 65. In the United Kingdom, approximately 1 out of 1,000 people between the ages of 45-64 present with YOD (Harvey, Skelton-Robinson, & Rossor, 2003; Sampson, Warren, & Rossor, 2004). In Australia, approximately 1700 people (or 0.01% of the population) have YOD, however, these statistics are felt to be representative of an underreporting in this cohort due to the difficulty in diagnosing dementia (Access Economics, 2005; Alzheimer's Australia, 2007) Mathers and Leonardi (2000) identified some of the risk factors for AD and YOD which included increasing age, family history, head injury, previous depression, Down's syndrome and a genetic factor, Apolioprotein A epsilon 4 genotype, that may lead to YOD. Several studies on YOD have shown dementia could also be due to nondegenerative, nonvascular causes such as cancer, chronic alcoholism and chronic mental illness with no reversibility or cure of the dementia when underlying conditions are changed (Knopman, Petersen, & Cha et al., 2006; Landers, 2008). The implications of YOD for the person with this type of dementia and their carer is significant considering they may still be raising families and in the middle of their careers.

Current Treatment Regimes for Dementia

Current treatments for dementia, including YOD, centre on preventative strategies, such as maintaining good health and daily exercise, as well as, non-pharmacological therapies and medications. Keeping mentally active and physically fit have been found to act as protective factors that may allay the risk of dementia with anti-inflammatory drugs also being found to play a preventative role (Mathers & Leonardi, 2000; Australian Government Department of Health and Ageing, 2008). Research into new medications seeks to prevent the progression of AD once a diagnosis has been made (Bullock, Touchon, & Bergman et al., 2005; Australian Government Department of Health and Ageing, 2008; Hampton, 2008). Some of these medications include cholinesterase inhibitors, amyloid-lowering agents and tau inhibitors, as well as enriched nutrient drinks to increase synapse formation (Hampton, 2008). Though these and other medications have had limited success to date, the number of clinical trials, medications and other types of medical therapies such as gene therapy are increasing in line with the expectation of the need to treat more people in the future (Australian Government Department of Health and Ageing, 2008).

Non-pharmacological interventions used for the person with dementia include such therapies as validation therapy, music therapy, narrative therapy and reminiscence therapy, as well as others (Alzheimer's Australia, 2008; Australian Government Department of Health and Ageing, 2008). In this resource, a reminiscence therapy booklet is used in the case scenario 'Come Dance With Me' to investigate behaviours of concern in one of the characters of the film. Reminiscence therapy involves using personal photographs with pleasant memory associations for the person with dementia (Alzheimer's Australia, 2008; Australian Government Department of Health and Ageing, 2008). However, appreciating that reminiscence therapy may also provoke unpleasant memories in a person with dementia should also be considered so photographs need to be chosen carefully.

Diagnosis of AD

Diagnosis of dementia can be difficult, especially in younger age groups where it is least expected. Because symptoms vary across a range of cognitive functions and may be impacted upon by other underlying disease processes, trying to untangle which symptoms are dementia-specific is an area constantly evolving in line with research on drug and treatment therapies. Attempts have been made to objectively measure the progression of the disease through behaviours, abilities and disabilities displayed in the early, middle and late stages of the disease In order to develop an objective template for diagnosing dementia, Sclan and Kenowski (2001) created a list of Global Deterioration Stages (GDS) that categorises differences between the medically normal cognitive changes that occur with ageing compared to the person with AD. The list is neither definitive nor representative of any particular person, but rather is a guide for awareness of when further investigation into cognitive functioning may be necessary. This guide gives examples across the whole of a person's cognitive functioning and it should be noted that the different examples given can happen at different stages of the dementia process as lucidity and confusion fluctuate, not just at those times described in the list. Tables 3-5 show these seven stages of global deterioration in the three areas of thought processing namely, cognitive changes, alterations in ADLs and emotional/behavioural symptoms.

Global Deterioration Stages between Normal Ageing and AD – Tables 3, 4 and 5

Table 3: Cognitive Changes

GDS Stage 1: Normal
No complaints of cognitive decrease, may be some slowing of processing.
Cognitive performance on assessment equal to past ten years.

GDS Stage 2: Normal Ageing
Subjective complaint of cognitive loss, unable to remember new or important ideas.
Recent "word-finding" problems or spelling difficulties.
No objective decrease in formal testing.

GDS Stage 3: Incipient AD
Notable deficits in orientation (may forget day of week), some 'blank spots' in personal past memory.
Objective evidence of cognitive and psychomotor decline on formal cognitive testing.

GDS Stage 4: Mild AD
Significant decline in past memory, concentration and recent memory.
Generally, significant deficit in all cognitive functions on objective cognitive assessment.

GDS Stage 5: Moderate AD
Considerable decline in past and recent memory, concentration and orientation.
Difficulty or inability to recall day, month, year, season, weather, anniversary, and decline in spontaneous speech.

GDS Stage 6: Moderately Severe AD
Usually unaware of time and place but still knows name.
Only personal memory remaining is country of birth, names of parents, former occupation.
Continued decline of spontaneous speech.

GDS Stage 7: Severe AD
No knowledge of recent/past events/own name, parents or spouse.
Cannot count forward from 1-10, speech declines to 1-2 words, then none.

(Sclan & Kenowski, 2001)

Table 4: Alterations in Activities of Daily Living

GDS Stage 1: Normal
No complaints.

GDS Stage 2: Normal Ageing
Complains of forgetting where objects are kept.
Confused about sequence of steps in doing things
Does not recognise familiar items or has difficulty understanding new information at work.

GDS Stage 3: Incipient AD
Significant difficulty in completing once familiar tasks.
Preparation of food difficult without written instructions.
Unable to do more than one task without becoming confused.

GDS Stage 4: Mild AD
Unable to handle personal finances.
Difficulty carrying out household tasks.
May not recognise familiar voices on telephone.

GDS Stage 5: Moderate AD
Not able to maintain themselves without help of caregivers.
Inappropriate clothing.
Inability to heat or cool foods.
Medication supervision necessary.
Difficulty using telephone.

GDS Stage 6: Moderately Severe AD
Entirely dependent upon others for survival.
Initially, lose ability to dress self, then bathing and toileting.
At later stages may need help to eat.

GDS Stage 7: Severe AD
Loss so severe, person requires continuous assistance to survive, including being fed, mobilising, positioning and holding up head independently.
Person may appear to sleep for longer and longer periods of time.

(Sclan & Kenowski, 2001)

Table 5: Emotional and Behavioural Symptoms

GDS Stage 1: Normal
No emotional changes attributable to cognitive changes.

GDS Stage 2: Normal Ageing
Occasional anxiety and/or dysphoria associated with awareness of what symptoms mean for patient's future.

GDS Stage 3: Incipient Alzheimer's disease
Increasing anxiety may occur.
There is repetitive questioning because of memory failure.
Occasional dysphoria.

GDS Stage 4: Mild AD
Flattening affect may occur emotionally (no joy, sadness, happiness – same emotional response for all situations).
Occasional utterances of not wanting to be alive or being a burden to family.

GDS Stage 5: Moderate AD
Development of behavioural difficulties; e.g. sleep disturbance (frequently awakening at night).
Paranoia or delusions (people stealing things, spouse isn't who they say they are).

GDS Stage 6: Moderately Severe AD
Continuance and escalation of behavioural difficulties.
Sleep disturbance day rather than night.
Wandering.
Verbal/physical aggression toward caregiver.

GDS Stage 7: Severe AD
Nonverbal agitation in some people (kicking, hitting, screaming, moaning, resisting behaviours).

(Sclan & Kenowski, 2001)

The effects of the global deterioration processes can be counteracted to maintain the social being of the person with dementia using support processes and interactions that enable their personhood and wellbeing to be maintained. The most well known of these interactions is that of person-centred care. The following section focuses on the theory of person-centred care through the philosophy of personhood as developed by Professor Tom Kitwood (1997) and more recently by Professor Dawn Brooker (2007) and others.

Philosophy of Personhood

Kitwood (1997) promotes that the person with dementia is equal to that of the person who is caring for them. He emphasises that personhood is about the morality of accepting and acknowledging the right of each person within the care relationship to be accepted as a person with the same needs, worth and wellbeing as other members in the relationship. This entails 'negating the separation of one person from another or placing one person above the other' (Kitwood, 1997, p. 41). To see 'the person' means to understand all that influences his or her experiences in the world, whether he or she is cognitively impaired or not, as it is these influences which will shape the person with dementia and their response to the world. This was not acknowledged in the past, when most people with a mental health issue were simply locked away from a society that had no knowledgeable response to their condition (Brooker, 2007). Mozley, Huxley, & Sutcliffe, et al.'s (1999) research illustrates an example of the voice of the person with dementia identifying the need to be accepted as a person who is still capable of making decisions and able to respond to the effects and contexts of their care. The aim of the research was to try and understand just how much decision-making capacity people had in their diagnosed state of dementia. The research supports the view that people with dementia are still able to negotiate simple decision-making even with cognitive impairment, 'especially when certain levels of cognition remain intact namely orientation to place, attention and language skills' (Mozley et al., 1999, p. 782). This is summarised eloquently by a quotation from one of their participants that was used in the title of their research article: "Not knowing where I am doesn't mean I don't know what I like" (Mozley et al., 1999, p. 776).

Many researchers in the field of dementia agree that, despite a loss of cognition, the person who has dementia is still a person with the same attributes of a human being as any other person (Kitwood, 1997; Brooker, 2007; Dewing, 2008). This means that a person with dementia still requires all of the social interactions that a person without dementia requires to make their life fulfilling, including making decisions about how and what care they receive. According to Kitwood (1997) it is the interplay of physical care, social care and psychological events that 'creates' the person with dementia and their capacity to make decisions about their care, even when their cognitive state has been compromised or has deteriorated. In general, Kitwood (1997) describes it as follows:

D=P+B+H+NI+SP with

       D (Dementia) = P (Personality) + B (Biography) + H (Physical Health)

                   + NI (Neurological Impairment) + SP (Social Psychology).

Included in this interplay is the time and setting of the interaction with the whole creating the embodied experience and personhood of the person with dementia. It is a development of self both within the person's own identity, as well as in their relationship to others (Garratt & Hamilton-Smith, 1995).

To illustrate this in a more personal sense, Christine Bryden, a young person with dementia describes the process as 'life in the present without a past or future' (Bryden, 2002, p.153). This comment exemplifies why understanding not only the past but also the here and now of the person with dementia is so important. Bryden (2002, p. 154) describes dementia as the brain developing 'coping mechanisms in the face of internal devastation'. She recommends a focus on the social aspects of life using therapies such as: reminiscence and validation therapies (used to enhance past remembrances of positive social associations and relationships, thereby validating the person with dementia's existence and interactions); rehabilitation strategies; spirituality; and cognitive behavioural therapy. Any, or all of these, can be important in helping the person with dementia to live within the disease (Bryden, 2002).

Kontos (2005) describes how Professor Kitwood's model of what happens in the dementia experience pivots on the interplay between the social being and the physical being with a person's self residing simultaneously in the brain and in the social nexus. These concepts reflect the attempt to describe the embodied experience of the person with dementia by recognising that the learned or innate practices of the body constitute individual selfhood (Kontos, 2005). Kontos and Naglie (2007, p. 565) then explored how the communicative capacity of the body connects the healthcare practitioner to the 'personhood of their care recipients, thereby fostering sympathetic care'. They concluded and emphasise that healthcare practitioners can better achieve person-centred care by recognising the self that exists beyond the deteriorating cognitive state and how it is expressing itself at the time of care (Kontos & Naglie, 2007). They claim this will 'promote better time management, planning and practice as the practitioner learns to identify and accept the state of embodiment the person with dementia is experiencing' (Kontos & Naglie, 2007, pp. 568-569). In accepting the embodied person with dementia, the healthcare professional and student can provide care that centres on the overall needs of the person not just the symptoms being treated, leading to a person-centred approach in their professional practice.

Person-centred Care

Dr Carl Rogers, an American psychologist of the late 20th century, created the concepts of client-centred counselling, student-centred education and person-centred approaches to human relations and community (Rogers, 2008). However, it was Professor Tom Kitwood who later integrated these concepts with the philosophy of personhood to define person-centred care for people with dementia through positive person work and the influence of malignant social psychology (Kitwood, 1997; Brooker, 2007; Dewing, 2008).

Professor Kitwood became well known for his theory of a person-centred approach to dementia care and applied the application of his theory in interactions with all people with whom he engaged but especially with those living with cognitive impairment. When he focused on the person with dementia, his primary interest was of the quality of care they received in institutional environments. He observed and brought into focus how the social context of a person's experience influences their state of behaviour (Kitwood, 1997; Bryden, 2002). He found that the impact of experience and behaviour can influence a person's personhood or the 'status that is bestowed upon one human being, by others, in the context of relationship and social being. It, (personhood) implies recognition, respect and trust' (Kitwood, 1997 p.8). McCormack's (2004) work, as shown in Table 6, connects Professor Kitwood's definition of personhood to the concepts of person-centred care for people with dementia.

Table 6: Links between Person-centred Care and Personhood

Concepts of Person-centred Care	Link with Kitwood's definition of Personhood
Being in relation	People exist in relationships with other people
Being in social world	People are social beings
Being in place	People have a context through which their personhood is articulated
Being with self	Being recognised, respected and trusted as a person impacts on a person's sense of self

(McCormack, 2004)

For example, the overall concept of 'being in relation' expresses Professor Kitwood's definition that people exist not only as their own person, but also as a person who is part of a relationship with others. These social relationships allow personhood or a sense of self to remain intact to some degree. Therefore, to exclude people with dementia from relationships due to their cognitive impairment is to deny them an aspect of their existence. Kitwood (1993) elaborated further on the factors that influence a loss of personhood in the person with dementia as illustrated in Table 7.

Table 7: Factors Influencing a Loss of Personhood in Dementia

Personality	Personality includes all those components of self that enable us to cope with crisis, loss and change, anxiety and being open to others. In dementia, psychological defences to uphold these characteristics of self are broken down.
Biography	When a person has their psychological defences intact, their personal biography or story includes an ability to withstand the uncertainties that life proffers. People with dementia may have this destabilised, which can affect their ability to make sense of their story in later life.
Physical Health Status	Acuity of the senses may heighten or diminish depending on the person with dementia's general health at the time.
Neurological Impairment	Because impaired cognition is present and advancing in the person with dementia, their capacity to store and process information will fluctuate over time.
Social Psychology	Social psychology encompasses the sense that we make in our daily interactions. In particular, our sense of security and value is either enhanced or diminished in these interactions. For the person with dementia, these interactions remain just as important as to the person without cognitive impairment.

(Kitwood, 1993)

Undergraduate students from across healthcare disciplines will be placed in positions of trust with people who may not be able to fully articulate who they are or what relationships they hold, including the relationship they have with the healthcare student or professional. Because of this, Kitwood (1993) emphasises the importance of the quality of interactions between the healthcare professional and the person with dementia and how this interaction will influence the sense of personhood for the person with dementia. McCormack (2004) contends it is the nurturing of this relationship component of personhood that will help provide and maintain the connection between the healthcare professional and the person with dementia. This allows for person-centred care to be practiced in a way that prevents deterioration in the person with dementia's condition and wellbeing through enhancement of their personhood and maintaining their dignity, thus preventing challenging behaviours from occurring.

The Impact of Adverse Care Practices on Personhood

Davis (2004) discusses the sociological and philosophical constructions of dementia and identifies the theoretical tensions in naming dementia simply as an organic disease of the body and not recognising the person within. Dwelling only on the pathological consequences of dementia in a medical model intimates that dementia may or may not be able to be treated like any other disease. However, this negates the other psychosocial degenerative changes that occur throughout the body as it ages in the context of the person's own life cycle and the effects of these changes on their personhood.

This supports the definition of the body as one that includes social, psychological and neuropathological factors that act together to create the person within (Bryden, 2002; Davis, 2004; Kontos, 2005; Kontos & Naglie, 2007). Understanding all of these relational aspects of dementia enables more positive interactions with the person who has dementia. Conversely, the practice of malignant or negative interactions by healthcare professionals can lead to organic and behavioural deterioration of these same elements in the person with dementia. Thus, the theory of personhood and person-centred care strives to bring the moral ideals of protecting and nurturing to the fore when caring for people with dementia, rather than simply addressing bodily needs. To describe and highlight positive care interactions from negative ones, Kitwood (1997) defined the two groups of interactions that typically occur in the care of people with dementia as Positive Person Work (PPW) and Malignant Social Psychology (MSP) as seen in Table 8. Kitwood (1997) defined PPW as having 12 aspects of interaction which create positive experiences for the person with dementia. Conversely, MSP comprises 17 interactions which create negative experiences for the person with dementia. Kitwood (1997) identified that both types of interaction play a major role in affecting the wellbeing of people with dementia.

Table 8: Categorisation of Interactions by Professor Tom Kitwood

Positive Person Work (PPW)	Malignant Social Psychology (MSP)
Celebration	Accusation
Collaboration	Banishment
Creation	Disempowerment
Facilitation	Disparagement
Giving	Disruption
Holding	Ignoring
Negotiation	Imposition
Play	Infantilisation
Recognition	Intimidation
Relaxation	Invalidation
Timalation	Labelling
Validation	Mockery
	Objectification
	Outpacing
	Stigmatisation
	Treachery
	Withholding

(Kitwood, 1997)

To illustrate the specific ways in which these interactions take place between the person with dementia and the people providing their care, PPW and MSP have been summarised for this resource with examples of their application in practice. The categorisation of interactions can overlap and have similar characteristics within each of these categories.

Positive Person Work (PPW)

The following explanations of the different aspects of PPW have been interpreted, developed and expanded upon based on Professor Kitwood's body of work. These interactions have been labelled positive because they assist to maintain and enhance the personhood, dignity and wellbeing of the person with dementia (Kitwood & Bredin, 1992; Kitwood, 1997).

Celebration

When a person with dementia celebrates their being alive with joy and gratitude, the healthcare professional should be accepting and open in encouraging this. Being expansive and convivial with them helps the person with dementia know that you accept their celebration. It is a time when the person's ego becomes overshadowed by expanding self-hood in an almost spiritual aspect to the moment. An example would be joining in the celebration with the person with dementia who is happy and rejoicing for whatever reason by singing or whistling with them or acknowledging their happiness during an event.

Collaboration

When power relationships are discarded, a true collaboration and a partnership can develop with the person who has dementia. Coercion or imposition should not be part of interacting with the person who has dementia. Assistance should be given to enable the person to engage with everyday tasks as best they can, for example having a bath and getting dressed in ways that are comfortable and routine for them, including choices about how and when these are accomplished. Including the person with dementia in any decisions that will affect them with their ADL's or their healthcare in whatever capacity they are able to participate is an important collaborative behaviour.

Creation

Allowing creativity to flourish for the person with dementia without seeking control is encouraging the person with dementia to be creative. This acknowledges that this creativity can be therapeutic for the person with dementia. Examples include spontaneous dancing, encouraging reading, talking and listening activities, and also engaging the person with dementia in activities where creativity can be enhanced, such as flower arranging or other past interests.

Facilitation

Facilitation is sharing in the gestures and meaning of gestures offered by the person with dementia by knowing them well enough to enable their responses when pieces of the action or conversation are missing. Facilitation includes understanding simple gestures, like a nod of the head or a moan and reacting to them with knowledge and insight. Examples may include, taking a person with dementia for a walk when they get restless or want to go outside or leave a setting by acknowledging their need. Another example includes facilitating an activity that is pleasurable for the person with dementia based on their preferences and interests.

Giving

Accepting, on the part of the healthcare professional, involves being humble enough to accept whatever gifts of kindness or support the person with dementia bestows. By accepting their concerns, gratitude and affections, warmth and sincerity between the person with dementia and the healthcare professional or student can be created. For example, a person with dementia may want to share food with the healthcare professional or may wish to give a small gift of affection like a flower.

Holding

Holding is remaining fully present (in a metaphysical sense) with the person, especially in stressful times, providing both physical and psychological support. It is a matter of remaining passive and not reacting negatively to behaviours being displayed by the person with dementia. Allowing the person with dementia to express themselves and their emotional state as an expression of an unmet need requires acceptance and investigation. This means providing them with a safe psychological space for conflict and trauma to emerge. Through giving steady, calm and reassuring responses, the healthcare professional absorbs the negative emotions without reacting to them. People with dementia are extremely vulnerable during these states and need to know that no matter how they express themselves the healthcare professional will not be driven away or react negatively. For example, if a person with dementia is distressed, do not leave them alone or confine them. Rather, remain present and accepting of their emotional state and validate this with them without trying to stop them, ignore them or react in a negative way.

Negotiation

Negotiation requires interacting with the person with dementia by asking, consulting, listening to their requests and acting on their cues. This means learning their preferences, desires and needs rather than asking them to conform to another person's expectations. Consultation should take place across the range of everyday events from what clothes to wear and when they would like to have a meal, to decisions about their healthcare. Encouraging negotiation with the person with dementia puts the power back into their hands instead of the institution or healthcare professional. For example, if negotiating the possibility of entry into a residential aged care facility, the healthcare professional should listen to the wishes of the person with dementia and acknowledge their validity in the decision-making process.

Play

Everyone likes to have fun, including people with dementia. Games and storytelling are useful interactions to promote fun. Spontaneity and self-expression through laughter or game playing are important ways people with dementia can continue to engage with the world socially and should be fostered when appropriate and possible. For example, having a joke or sharing funny stories acknowledges the sense of humour of the person with dementia which they may retain. It may also involve kicking a football or turning an assessment process into a game.

Recognition

Recognition requires an open and unprejudiced attitude to the person with dementia. There can be no stereotyping. Instead, the uniqueness of the individual should be identified and accepted. Simple acts of greeting or listening carefully to what is said provides recognition of the quality and worth of the person. These acts could be verbal or may be as simple as giving eye contact (when culturally appropriate) and being present for the person. For example, when greeting a person with dementia and their spouse, the greeting should be directed to the person with dementia in the first instance with the appropriate name rather than greeting the spouse first and conversing with them. Eye contact and body language are important components to use to demonstrate the healthcare professional's presence for the person with dementia.

Relaxation

Relaxation allows for both the person with dementia and the healthcare professional's bodies and minds to have respite and rest. This means stopping active work for periods of time, as well as slowing down activities and conversation. It may be that the only time a person with dementia feels able to relax is in the presence of another person and may be an expression of needing that company in order to relax. Allowing the person with dementia to determine the conversation or silence in a calm and relaxing atmosphere may involve listening to music together, watching birds or animals or just listening to the conversation of other people. This can create a restful mood that relaxes both the mind and the body.

Timalation

The person caring for the person with dementia and healthcare professionals should try to interact in a way that is directly pleasurable to the person with dementia. This could mean using senses to engage the person's body, such as providing different taste sensations during meals, aromatherapy or, where appropriate, massage therapy. These types of interactions provide contact, reassurance and pleasure without placing any demands on the person with dementia. Other examples could be going for a walk, listening to music, sitting in a pleasurable environment or choosing a relaxing setting when interviewing the person with dementia.

Validation

Validation involves being sensitive to heightened emotional states and engaging in empathy for the person with dementia. This is observed by making each experience for the person with dementia a robust one, accepting and acknowledging their reality and the power of that experience to them on an emotional level. It also involves developing a high degree of empathy for them and trying to understand the person's frame of reference, no matter how chaotic, paranoid or hallucinatory. For example, if the person with dementia is distressed about a person who is absent, acknowledge their distress and ask them about the person or what about this person is upsetting them. It involves conversations about what the person with dementia is verbalising or acting in the moment and not being dismissive of any conversation or activity the person with dementia may be expressing.

In summarising PPW, Kitwood (1997) attributed each of the positive psychosocial communicative interactions as ways in which the use of these skills with people who have dementia could create a positive experience for both the healthcare professional and the person with dementia. These positive interactions inform the focus of the person-centred approach promoted in this educational resource. In the following section, negative interactions that make up MSP as identified by Kitwood (1997) are elaborated upon. These are in opposition to PPW, but important for healthcare professionals and students to recognise in their own practice and that of others, so as not to perpetuate them.

Malignant Social Psychology (MSP)

Contrary to PPW are the negative behaviours Kitwood (1997) classifies as Malignant Social Psychology (MSP). A negative interaction with a person with dementia can affect their wellbeing and the way they conduct themselves with other people. Negative interactions on the part of healthcare professionals or students can engender deterioration in the state of dementia in a person, creating a spiralling effect that leads to greater confusion and more disruptive behaviours. To better clarify what negative interactions are and how they affect the person with dementia, the following section describes the interactions that may create a malignant outcome.

Accusation

Accusation involves blaming the person with dementia for their actions or inactions when they lack understanding. This can lead them to feel rejected by the healthcare professional or student. Examples might include chastising the person for not eating when they have actually reached the stage of requiring prompting. It can also mean blaming them for frustrations possessed by the healthcare professional. For example, a healthcare professional stating to the person with dementia that 'they are very busy' and the person with dementia 'is holding them up from their work' is blaming the person with dementia for the healthcare professional's inability to interact with them and determine their needs.

Banishment

This very destructive form of malignant social interaction involves excluding the person with dementia psychologically, socially and/or physically, including unnecessary restraint, either physically or chemically. It includes care given without regard to the person with dementia's wellbeing as though they did not exist as a sentient being. Examples of banishment might include rough handling or discussion with others that excludes the person with dementia deliberately. It may also include sending a person to their room away from others as a form of punishment or refusing to let a person in or out of a room imposing social isolation upon them.

Disempowerment

Disempowering the person with dementia involves the healthcare professional or student taking away what powers still remain to the person with dementia. Not allowing them to complete buttoning their shirt or taking over doing something because the person is doing it too slowly are examples of disempowerment. A further example might be making healthcare decisions for the person with dementia without their participation or denying their input into decision-making that is still within their capacity to make. Inclusion of the person with dementia needs to be attempted and revisited continually to prevent disempowerment from occurring.

Disparagement

Disparagement involves deliberately damaging the self-esteem of the person with dementia. Any criticism of the actions of the person with dementia that damages their self-esteem, especially telling them they are incompetent, useless or worthless is disparaging to that person and does not maintain their dignity or personhood. Disparagement involves dialogue and actions on the part of the healthcare professional or others that are demeaning. For example, healthcare professionals or students may talk about the person with dementia and the difficulties they are having with them in the presence of the person with dementia. Ridiculing someone as 'demented' is another example of a disparaging interaction.

Disruption

Disruption occurs when the healthcare professional or student interrupts the person with dementia's concentration as they are engaged in a task or conversation. This breaks their frame of reference and inhibits their ability to impart information or dialogue. Intruding on the person with dementia's actions or inactions when they may need to go slowly or by not allowing rest periods creates disruption of mood and their ability to perform at their own pace. For example, stating that the person is repeating themselves and asking them to stop, or interrupting the person with dementia brusquely while they are knitting or sleeping are forms of disruption. Another example is interrupting the person with dementia when they are engaged in an activity to meet the needs of the organisation without consideration of the person with dementia's needs.

Ignoring

Similar to banishment, ignoring is about having conversations with others in the presence of the person with dementia without including them in the conversation or activity. This is commonly done while having conversations with other people involved in providing care. Existence of the person with dementia is denied through a lack of interaction or communication. An example includes talking about the person with dementia going into an aged care facility while in their presence, but ignoring any protestations, body language or noises they may make at hearing this information. Another example would be simply ignoring the person with dementia's reactions, conversation or behaviour when they may be trying to express an unmet need.

Imposition

Imposition involves forcing someone else's values on the person with dementia. Doing this negates the person with dementia's ability to choose or exercise personal autonomy. This can also mean forcing someone to do something against their will. For example, stating to the person with dementia that their behaviour is 'bad' or 'not right'; not recognising their religious beliefs or cultural perspectives; or trying to force other cultural beliefs or perspectives onto the person with dementia. Another example is making a person with dementia sit next to a person who causes them anxiety because of prescribed seating arrangements. It would also include telling a person with dementia to stay in bed when they wish to be up and about.

Infantilisation

This MSP involves not treating the person with dementia with the respect their age would entail in general and in particular. Infantilisation includes patronising and punitive behaviour or treating and talking to the person with dementia as though they were a child. An example of this might be the way that a person who requires assistance with feeding is treated as a baby, hurrying food into them or playing games with their food to get them to eat it. Another example is stating 'you're tired' or 'go to sleep' or 'don't dribble' when the person is not exhibiting these behaviours at the time or has no control over them. Included in this MSP is calling the person by 'love' or 'sweetheart' without regard for their preferences.

Intimidation

Intimidating behaviour includes threatening or physically manipulating the person with dementia to induce fear or anxiety in them. This could mean turning out the lights before the person is safely in a bed or chair because they are not moving quickly enough. Also included in this category may be threatening to tell other people or authorities about some behaviour of the person with dementia that the healthcare professional does not like, in order to coerce them into a different behaviour. This could be threats of smacking, locking in a room or the use of physical or chemical restraint. At the extreme end, this could entail or lead to physical, emotional, psychological or financial abuse, as well as neglect.

Invalidation

Invalidation includes not giving credibility to the reality of the experience of the person with dementia. This especially holds true for the way the person with dementia is feeling and occurs when the healthcare professional or student does not pick up on these feelings, displayed through speech, body language or behaviour. It also includes not trying to understand what feelings the person with dementia may be having about situations they are encountering. For example, a healthcare professional or student might tell the person with dementia they have no reason to be unhappy, anxious or agitated without acknowledging the person with dementia's dialogue or reactions. This can be avoided by identifying meaning in the person with dementia's actions or words, known generally as validation therapy.

Labelling

Identification of a person by naming them through their behaviour or condition is called labelling. This involves creating categories of people with dementia based on their condition and behaviour rather than the person that they are. Examples could include being known as 'the stripper' or by a category such as 'demented' or 'the demented person in bed 3'. Another example is calling a person 'hopeless' or 'crazy'. Being labelled as 'the absconder' or being a 'nasty piece of work' are additional examples. Any derogatory term used for the person with dementia would be included in this category.

Mockery

Mockery means making fun of the person with dementia as if they were unaware of what is being spoken about. This includes teasing to the point of humiliation or pointing out or making fun of their behaviour or actions. An example may include exaggerating or laughing at their actions or dialogue. Another example would be making a joke about the person with dementia to someone else in the vicinity and within hearing of the person with dementia that was in some way detrimental, sarcastic or cynical. Mockery is not to be encouraged at any time, whether the person with dementia is present or not, and is viewed as incompetence in codes of professional conduct.

Objectification

Objectification involves not treating the person with dementia as a sentient being who thinks, feels and breathes, but rather treating them as though they were an object. Poking, prodding or pushing the person are examples of this negative interaction and includes speaking of the person with dementia as though they were an object. Another example of objectification includes providing nursing care without talking to or explaining what is going to happen or is happening to the person with dementia. Objectification is closely related to ignoring and can occur across all MSP interactions.

Outpacing

Healthcare professionals who interact too quickly for the person with dementia to understand and keep up with them in conversation or with instructions are outpacing them. This includes applying pressure for actions faster than the person is capable of doing or comprehending and providing information too fast for the person to respond to or understand. For example, stating to the person with dementia that they are going to have a shower, eat breakfast, go to a doctor's appointment and have some morning tea before their relative picks them up, all in one sentence, is outpacing. Outpacing can also include two people talking about events concerning the person with dementia that the person with dementia cannot keep up with as the conversation proceeds. Arranging a discharge or instructing people who have dementia about new medications too quickly for the person to understand are other examples.

Stigmatisation

In stigmatising the person with dementia, they are treated as though they were diseased, an alien or a different species with no worth and no need for social interaction. Stigmatisation includes labelling the person with dementia as though they were an object or outcast, not someone who is part of human society with human feelings and emotions. An example of stigmatisation could include treating people with dementia as if they were all the same with their state of 'dementia' explaining their behaviours and emotions, rather than looking at the individual with individual needs of worth. As one healthcare professional describes in an interview that accompanies this workbook, "When you have met one person with dementia, you have met one person with dementia".

Treachery

Treachery involves using deception to distract or manipulate a person with dementia. It also includes making promises that cannot possibly be kept to get the person with dementia to cooperate. People often use treachery innocently to get a person to comply with their instructions. An example could be hiding medication in food to get the person with dementia to take the medication without telling them. Another example might be telling the person with dementia that a procedure will not hurt when it will, or stating that a relative is in the room to get the person with dementia back into their room when they have been wandering.

Withholding

Withholding is refusing to meet the needs of the person with dementia in something they require and is the opposite of holding. Refusing to provide affection or comfort when distressed or not accepting their anxiety or distress as an expression of a need is an example of withholding. Not providing contact when the person with dementia reaches out is another form of withholding. For example, the person with dementia may want to show affection but the healthcare professional denies them the opportunity to do so by pushing them away or by admonishing them for their display of affection.

In summary, Kitwood (1997, p. 14) attributes MSP behaviour to 'defensive reactions by carers and healthcare professionals from anxiety caused when situations out of control of the healthcare professional arise in the relationship with the person with dementia'. He believes these negative interactions may not be done with intent but, rather 'as the result of the individual carer or healthcare professional associating the conditions of frailty and dependency with the twin fears of mental instability and confrontation of death that society sees in the person with dementia' (Kitwood, 1997, p. 47).

Most people harbour fears about a loss of memory, loss of independence and a prolonged or unpleasant death. With appropriate education and understanding, healthcare professionals can allay these fears if they maintain their focus on the person being cared for rather than what their disease process represents personally or what the organisational culture demands. To do this requires recognising positive interactions and negative interactions so healthcare professionals and students can distinguish which ones they are practicing, and tailor their responses to the person who has dementia to encourage positive interactions rather than negative ones. In recognition of this, many educational institutions, government healthcare agencies and others are shifting the focus from organisational demands that promote malignant social psychology to the person-centred care approach advocated by Kitwood (1997) and others (Dewing, 2004; Australian Health Ministers' Conference, 2006; Alzheimer's Australia, 2007; Brooker, 2007; South Australian Government Department of Health, 2008). McCormack (2003, 2004) and McCormack and McCance (2006) advance the use of person-centred care by healthcare professionals and students with a framework to help conceptualise both the person with dementia under their care and the context of that care. This framework uses 29 principles that can be adopted when caring for a person with dementia and is described as follows:

Principles of Care that Inform the Person-centred Approach

1. Make explicit the care agenda.

2. Recognise that the way one questions a person affects the ability of the person to contribute to the setting of the care agenda and their contribution to a conversation. If too many questions are asked at once, the person may not be able to provide required answers in the sequence or time required.

3. Be aware that actions to achieve one outcome might have an effect on a previously unrecognised need.

4. Have a repertoire of interactional approaches that will enable personal decision-making and participation in the planning of care plans.

5. Pose specific and clearly formulated questions that have a clear aim.

6. Respect individuals' important routines in daily life and negotiate new components of the care agenda each day.

7. Be aware that some people depend on professionals to minimise or prevent constraints on their autonomy.

8. Listen to people and allow them to tell their story as a legitimate part of the assessment processes.

9. Wherever possible, encourage the person to identify solutions for existing problems and care needs, set within negotiated parameters of risk taking.

10. Get to know the person and establish a negotiated level of engagement before decisions about degrees of risk taking are made.

11. For informed decision making to be facilitated in a person-centred way, refrain from imbuing decision-making processes with one's own values.

12. Suspend the use of prior knowledge about a person and their social context until they have been enabled to tell their story.

13. Recognise organisational routines can limit a person-centred approach to decision making that prevents recognition of a person's unique experiences.

14. Accord the person's perceptions of their care situation equal status to those of the   healthcare professionals or organisation.

15. A person's subjective view of their lives should be respected in decision making.

16. To facilitate individual participation, understand and be confident with the boundaries of an individual's decision-making potential.

17. Adopt a person-centred approach to risk assessment and risk taking.

18. Be explicit about the intent and motivation for action and the parameters within which decisions are set.

19. Maximise a person's independence through the balancing of personal narrative with established care policies and procedures.

20. Make decisions within a framework of negotiation with clearly established care goals that are regularly reinforced and reviewed.

21. Make time to help a person integrate new care decisions and options into their already established care program.

22. Acknowledge and facilitate a person's emotional responses as an important part of facilitating individual participation.

23. Create opportunities for reciprocity in relationships with people.

24. Do not allow age related perceptions of an individual's ability to limit their participation.

25. Help people to see beyond their own limited expectations of their involvement in care and their deference to others.

26. Continuously reinforce the value of an individual's decisions.

27. Facilitate a person's emotional coping ability in order to enhance their independence.

28. Recognise that while people want to be consulted about care decisions they do not always want to be the final arbiter of decisions.

29. Recognise that people should have their beliefs and values considered in the making of decisions, but being the final arbiter of decisions is not of prime importance.

(McCormack, 2003, pp. 208-209)

These principles are a way of engaging in recognition of the personhood status of the person with dementia under care. The beginning premise of this framework is to recognise the 'authentic consciousness' or embodiment of the person (McCormack, 2003, p. 204). To do this means healthcare professionals need to understand the authentic belief and value systems of the individual so the individual's actions can be placed in context. This will enable the person with dementia to have more autonomy in decision-making as the healthcare professional or student gets to know the person as a whole being (McCormack, 2003). Importantly, it also identifies that the healthcare professional or student's care will be 'imperfect' until this knowledge is attained (McCormack, 2003, p. 204). The emphasis is that when someone cares for a person with dementia, it will not be as easy as just doing things or making decisions for them. The healthcare professional or student will need to get to know the person before any choices the person with dementia makes can be understood based upon their conception of the action rather than the professional requirements involved (McCormack, 2003).

Healthcare professionals and students need to recognise that 'self-determination is a fundamental human right and that they can assist the person to make individual choices by offering support and practical expertise without dictating the care to be given' (McCormack, 2003, p. 205). Adams and Gardiner (2005) propose that person-centred care be practiced in the healthcare workplace from the time of initial assessment. They recommend the use of the 'triad' (person with dementia, carer and healthcare professional) communicating with each other and forming a relationship (Adams & Gardiner, 2005, pp. 199-200). This fosters critical self-assessment by healthcare professionals about their own practice and supports McCormack's (2003, 2004) and Nolan, Davies, & Brown, et al. (2004) assertions about the importance of building relationships that will foster the person-centred approach. Healthcare professionals who understand person-centred care should be able to practice it in their day to day interactions whether or not supported by cultures and systems of organisation. When person-centred care is used, the personhood of a person with dementia is preserved in a manner that promotes the ideal while practicing in the real world of the current healthcare systems.

The Impact of Care Settings on Person-centred Care

McCormack (2003) and Hickman, Newton, & Halcomb, et al. (2007) both identify the need for specialised care contexts, environments or organisational units that will promote person-centred care. In their literature review of best practice interventions in the acute care setting, Hickman, et al. (2007, p. 123) identified that best practice is composed of a multidisciplinary approach, gerontological expertise, environmental design incorporated into units for care of the elderly and communication strategies that involve care across the life continuum. Understanding and accepting the individual's concept and value of their wellbeing and health are essential in promoting person-centred care even when organisational structures seem to impede the process (McCormack, 2003; Hickman et al., 2007).

McCormack (2004) accepts that nursing care, in particular, can be hindered by organisational structures that centre on tasks rather than the person for a variety of reasons. This, however, should not preclude the use of person-centred care and rather than striving for the ideal, the focus should be on inducing a constant state of person-centeredness in care. Recent attempts to use person-centred care in practice have generated much literature about the necessity of doing so, but don't 'address workplace culture issues of time management, too few staff and underdeveloped and underfunded resources' in a way that emphasises or allows its daily practice (Dewing, 2008, p. 8). Addressing workplace culture is important because the stress that changing behaviours can have on healthcare professionals, students and the person with dementia have been identified as being of concern (Brooker, 2007; South Australian Government Department of Health, 2008). Of particular concern is how people who have dementia and mental health issues that lead to distressing behaviours have higher rates of institutionalisation (South Australian Government Department of Health, 2008). Healthcare professionals and students who interact with people with dementia using a person-centred care approach can help to prevent distressing behaviours that may have an impact on future care arrangements for the person with dementia.

When the reality of the workplace culture is blended with the person-centred approach of care, a time-rich and reflective analysis of the impact of the care that the embodied person is receiving will generate relationships of care that are serviceable for both individuals and institutions. Indeed, Kontos and Naglie (2007) found that when people engage their imagination to accept the personhood of the person with dementia, then sympathetic understanding of the bodily experiences of the person with dementia can be realised. This then improves the time efficiency of clinical practice and may reduce the need for pharmacological interventions or restraints. To evaluate staff care practice within a facility and engage them in changing their care practice to use a person-centred approach, Kitwood and Bredin (1992) developed an assessment tool which they called Dementia Care Mapping. This tool has since undergone further development by Brooker (1999) and Brooker and Rogers (2001) and is outlined in this resource for a basic understanding of cultural change possibilities.

Dementia Care Mapping

In 1992 Dementia Care Mapping (DCM) was developed for evaluating the quality of care in context (Kitwood & Bredin, 1992). DCM involves an observer making detailed observations of the pattern of care being given to a person with dementia and has been defined as both an audit tool and a process for cultural change (Brooker, 1999; Brooker & Rogers, 2001). It was developed specifically to identify person-centred care patterns or the lack thereof (Woolley, Young, Green & Brooker, 2008). Brooker & Rogers (2001, p. 21) describe DCM as 'a change agent' and a process that is complex. It was explored as a means of filling in the gaps that other methods of assessment were unable to capture. The tool uses four coding frames based on the PPW and MSP listings of interactive behaviours developed by Professor Kitwood to record both the quantity and quality of behaviours occurring at the time and in that particular setting (Innes & Surr, 2001). An underlying principle of using DCM is transparency in the conduct of the observations to include everyone involved in the care at the earliest possible stage (Brooker & Rogers, 2001; Innes & Surr, 2001). Thus, DCM is used to measure the quality of care being given to people with dementia in correlation with both their quality of life and the impact of the care setting in meeting their social, psychological and physical needs.

Analysis of observations, through methods like DCM, can show which parts of care are person-centred interactions and which are malignant interactions that may be influenced by the environmental setting and not the person giving care. Brooker & Rogers (2001, p. 22), state that it is important 'with DCM to make sure that it is the best tool it can be, within the best setting conditions'. So, if the environment is not supportive of the technique, then the efficacy of DCM in promoting and enhancing person-centred care can be thwarted. Research into how DCM correlated behaviour with the wellbeing of the person with dementia showed that improvement in wellbeing occurred when behaviour was approached with PPW, rather than necessarily eliminating MSP. For PPW to be effective, time, perseverance and a major re-think in organisational structure of care is needed and not just the removal of negative interactive behaviours (Innes & Surr, 2001). It is suggested that if the area in which DCM is being used is well resourced with emotionally supported staff who are motivated and confident enough to develop or improve their skills in interacting with people with dementia, then DCM is a step in the right direction (Beavis & Simpson, 2002). Brooker (2007) found that people generally want to be compassionate when caring for others, but do not have a framework that helps ground them to the reality of the care they are giving. She acknowledges that evaluation and revision of the application of person-centred care, through tools like DCM and others, has led to improvements in the implementation of the philosophy of person-centred care and generation of frameworks to assist in providing person-centred care. To specifically address current workplace issues and settings, Brooker (2007) created a new framework based on PPW, MSP and person-centred care that was conceived after many years of experience working with DCM, other instruments and the Bradford Dementia Group.

VIPS Framework of Person-centred Care

VIPS stands for four major elements of care; Valuing people, Individualised care, Personal perspectives and Social environment. Each of the elements has six key indicators. Healthcare professionals and students are encouraged to think through and use this framework to articulate the person-centred care needs of those in their care in a systematic way on organisational and individual levels. Ways of applying the VIPS framework are illustrated in Table 9.

Table 9: Elements of the VIPS framework

V = Valuing People
Every person has value regardless of age or cognitive status

Vision – is there a vision and mission statement about providing care that is person-centred?

Human Resource Management – are systems in place to ensure that staff believe they are valued by their employers?

Management Ethos (Belief System) – are management practices empowering staff delivering direct care?

Training and Staff Development – are there systems in place to support development of a workforce skilled in person-centred care?

Service Environments – are there supportive and inclusive physical and social environments for people with cognitive disability?

Quality Assurance - are continuous quality improvement mechanisms in place, driven by knowing and acting upon needs and concerns of service users?

I = Individualised Care
Using an individual approach that promotes the uniqueness of the individual

Care Planning – have individualised care plans been created that identify the strengths and weaknesses of the individual?

Regular reviews – are these care plans reviewed on a regular basis?

Personal possessions – do individuals have their own personal clothing and possessions for everyday use?

Individual preferences – are individual likes/dislikes, preferences and routines known by staff and acted upon?

Life history – are care staff aware of the person's life history, especially critical moments that illustrate proud moments in their life and, if so, are they used regularly?

P = Personal Perspectives
Acknowledge and understand life from the perspective of the person with dementia

Communication with service providers – are carers asking about the individual's personal preferences, consent and opinions?

Empathy and acceptable risk – are carers thinking about the decisions made by the individual from the individual's point of view?

Physical environment – is the carer aware of the physical environment of the individual and how they are reacting to noise, temperature and comfort levels?

Physical health – is the carer monitoring the health aspects of the individual, like pain, sight, hearing and incorporating this knowledge into their care?

Behaviours of concern as communication – does the carer try to discover the underlying causes for the behaviour?

Advocacy – does the carer seek to protect the individual's rights when their safety and those of others around them may be compromised?

S = Social Environment
Providing a social environment designed to meet psychological needs of the individual

Inclusion – do staff seek to include the individual in conversations with those around them and assist the individual to relate to others?

Respect – are individuals treated with respect with no labelling or demeaning behaviour by the carer?

Warmth – is the individual part of a warm and accepting atmosphere by carers or is the individual subjected to intimidation and neglect?

Validation – does the carer take the individuals' fears seriously? Are episodes of emotional distress attended to immediately or is the individual left alone for long periods of time in this condition?

Enabling – does the carer help the individual to engage with their care and activities in their environment? Are individuals treated with dignity and compassion or are they treated as objects with no feelings?

Community – are carers using local community facilities with regular visits from people in the local community?

(Brooker, 2007, pp. 27-83)

The VIPS framework can be adapted by healthcare professionals or students in the place of their interactions or organisational settings where care is delivered to the person who has dementia. In validating the VIPS framework, Davis, Cornman, Lane, & Patton (2005) used an early, modified version of VIPS in their training procedures for case advisers. They discussed four actions namely, education, expectation, facilitation and documentation modelled on the VIPS framework to engage staff in better person-centred practices. They found the framework assisted their staff in better provision of consumer-driven care (Davis, et al., 2005) and confirmed that use of the VIPS framework can provide healthcare practitioners with a method to develop person-centred care within their own practice and organisation.

Conclusion

The information contained in this workbook outlines a basic theoretical underpinning of dementia aetiology and epidemiology, person-centred care, examples of psychosocial interactions that are positive and negative, as well as ways in which organisations and healthcare professionals or students can promote the use of a person-centred approach within their organisations or while on clinical placement. The type of interactions that undergraduate healthcare students engage in during care of people who have dementia will determine not only their practice outcomes, but also their contribution to the promotion or detriment of the wellbeing of the person with dementia.

Pivotal to person-centred care is interacting and communicating with the person who has dementia as a sentient being with feelings, emotions and value. To do this, it is essential to validate the actions and dialogue of the person with dementia in a way that recognises their expression of emotions, behaviours and needs, as well as their dignity and personhood as people with dementia can behave and act in as many varied ways as there are individuals.

The five filmed case scenarios in the enclosed DVD demonstrate how person-centred care may or may not be practiced during routine and challenging care situations. The poor practices demonstrated are for teaching purposes only and highlight interactions that demonstrate malignant social psychology. The theoretical underpinning of person-centred care is interrelated with the scenarios depicted in the DVD and the reflective questions listed after each scenario will assist healthcare students to reflect on their own practice and that of others. The DVD begins with an interview with Professor Dawn Brooker discussing her personal history relating to dementia and person-centred care. In addition, interviews with healthcare professionals precede each scenario and discuss why caring for people with dementia is a special part of their practice and how they use a person-centred approach. The following sections introduce each scenario of the DVD and can be read for background information before viewing the scenario. After viewing the docu-dramas, the reflective questions can be used to apply the theoretical underpinning of this resource, as well as highlighting other issues healthcare professionals and students may face in the reality of practice when caring for people who have dementia.

VIDEO - Dawn Brooker interview

17:46 mins

Safety Statement

Please be aware that some of the filmed scenarios contain coarse language and some violence. Material viewed in the DVD may be confronting to undergraduate healthcare students and other viewers and may cause responses unanticipated prior to viewing. For this reason, it is suggested that consideration be given in advance of a person that can be approached to discuss any feelings or emotions that may arise as a result of this viewing.

These scenarios contain some examples of poor practice that are for teaching and educational purposes only.

Come Walk With Me

This scenario begins with an interview by Stephanie Altus, a paramedic who discusses the multiple levels of interaction paramedics' face when called to the home of a person with dementia. Often, they must deal with family members who are in disagreement about care requirements while trying to focus on the person with dementia who requires care.

In this scenario, we meet:

- John, an elderly Australian man with possible early AD
- Anne, a community nurse
- Kerrie, his youngest daughter and his main carer
- Jenny, his eldest daughter
- Phil, a senior Paramedic
- Steve, a junior Paramedic

The setting is John's own home in a suburban community where he has lived for many years.

John is experiencing symptoms of AD. Prior to his wife's death, John cared for his wife who had cancer. John is a fiercely independent man who has been a successful business man. His memory has become increasingly impaired so his daughter Kerrie has looked after him and supported him to remain at home. Her sister, Jenny, runs her own business and has limited time to contribute to her father's needs.

Kerrie has recently gone on a holiday and asked her sister, Jenny, to look after their father while she was away. Jenny, as the favourite daughter, is her father's pride and joy and gets anything that she wants from her father, as well as making decisions for him that Kerrie, as the primary carer, sometimes does not know about.

Anne, who is John's community nurse, comes to pay him a visit as she has done monthly since his wife's death and finds him in a distressed state. There is evidence that John has a scalp laceration that suggests he has had a fall, so Anne contacts Kerrie and Jenny, as well as the paramedics to transport John to hospital for assessment.

VIDEO - [Come Walk With Me](#)

7:18 mins

Sub themes for reflection and further study:

- Duty of care, role and function of healthcare professionals in relation to this scenario
- The impact of family dynamics on the quality of care of the person with dementia
- Vulnerability of the person with dementia to exploitation and abuse
- Independence versus risk to personal safety and security of environment

Positive interactions demonstrated:

Recognition   Holding   Relaxation   Validation   Negotiation

Negative interactions demonstrated:

Treachery   Objectification   Disempowerment   Infantilisation   Intimidation

Outpacing   Invalidation   Ignoring   Disruption

Questions for Reflection

1. What are the negative and positive interactions in this scenario? Describe who displays which ones, as well as how and why they may be interacting in this way.

2. What were John's responses to any unhelpful or malignant interactions?

3. How does Anne demonstrate the positive interactions of recognition and validation?

4. How well does Anne exercise the interaction 'holding' when responding to John's anxiety about hospitals?

5. What were the main objectives of the paramedics and how did they achieve this?

6. Did you find the paramedics in this scene performing in a best practice approach to care? Was Anne, the community nurse, right to call the paramedics and if so, why? If not, why not?

7. Reflect on the family dynamics being displayed. What repercussions might these have for John and the healthcare professionals?

8. How did Anne handle Jenny's comments to her?

9. What would Anne, Phil and Steve be assessing in protection of John's best interests?

10. How did John react to the people around him and what was his part in the decisions being made?

Extension Questions

1. What signs of memory loss, disorientation and confusion are evident in John's behaviour and conversation?

2. What are the requirements under a duty of care for healthcare professionals in this scenario?

3. Discuss the vulnerability of the person with dementia to exploitation by others. What strategies are available to protect John's interests?

4. Discuss the family discordance evident in this scenario. How might these concerns be addressed?

5. Were there any indications of possible elder abuse? Discuss the different types of elder abuse that may present in practice.

Come Listen To Me

At the beginning of this scenario, Pauleen Bond, a team manager for ACH Group Dementia Services, discusses why it is important to listen to the needs of the person with dementia first before family and others make decisions about their care.

In this scenario, we meet:

- Jacob, 72 year old male with early dementia symptoms and probable AD
- Christine, 64 year old wife of Jacob, who has limited knowledge of dementia
- Michael, a social worker
- May, tea attendant
- Sue, an RN who has contacted the social worker for Christine and Jacob

The setting for this scene is an acute care facility. The scenario highlights practices that may be familiar to viewers with an emphasis on the effect this style of interacting has on the person with dementia.

Michael, a social worker in the hospital, responds to a call from Sue, an RN involved with Jacob's care. Sue gives Michael a brief background on Jacob and Christine's history and advises Michael to talk with Christine separately, emphasising that Christine is having difficulty coping with Jacob having dementia and the changes in him.

VIDEO - Come Listen To Me

4:55 mins

Sub themes for reflection and further study:

- Grief and loss experiences of a family member
- The unwanted carer role and expectations imposed by this
- Exploration of malevolent styles and patterns of interacting with the person who has dementia
- Requirements for best practice in interviewing techniques for the person with dementia and their family members
- Independence versus risk to personal safety
- Aged care facility placement
- Autonomy

Positive interactions demonstrated:

There are no examples of positive interaction from the perspective of Jacob. However, the request by Sue to discuss Jacob's situation in private with Christine is an example of a heightened awareness of the situation and leads off with PPW.

Negative interactions demonstrated:

Treachery	Disempowerment	Infantilisation	Intimidation
Labelling	Stigmatisation	Outpacing	Invalidation
Objectification	Ignoring	Imposition	Withholding
Accusation	Disruption	Mockery	Disparagement

Questions for Reflection

1. What are the negative and positive interactions in this scenario? Describe who displays which ones, as well as how and why they may be interacting in this way.

2. How do you think Jacob feels and what cues does he display regarding his feelings?

3. How does Jacob indicate his dislike of what is happening around him?

4. What response might better encompass positive person approaches when Jacob says "listen to me!"?

5. Christine is using different mechanisms of accusation when describing her and Jacob's situation. Can you identify examples of this?

6. What would you say to May to help her understand that while she is intending to be kind and well meaning her style of interacting is not person-centred and why? What suggestions for future interactions could be made to her?

7. With reference to the VIPS framework, what are the likely factors that would account for the behaviour of Michael and May?

8. Does Michael handle Christine's concerns in an appropriate manner for Jacob?

9. Summarise Christine's concerns about Jacob's behaviour. How can Christine be assisted with the grief and loss she is experiencing?

Extension Questions

1. Was it appropriate for Michael to suggest nursing home care without consulting other healthcare professionals or Jacob himself?

2. What processes and requirements need to be fulfilled when considering placement in a residential aged care facility or remaining at home?

3. What was important about Michael speaking to the RN prior to meeting Christine and why?

4. What was Sue intending to achieve by discussing Jacob and Christine with Michael?

5. What resources are available for families and carers in the community?

6. How could Jacob's preference to return to his home be supported?

7. How would the ongoing care of Jacob be best resolved?

Come Meet With Me

This scenario begins with an interview by Joanne Molsher, a Clinical Nurse Consultant at the Repatriation General Hospital. She talks about the need to understand the behaviour of a person, their history and how they interrelate with each other.

In this scenario, we meet:

- Alan, mid-50s a former businessman with YOD, specifically Frontal Temporal Lobe Dementia
- Fiona, a registered nurse
- Daniella, an enrolled nurse
- Marion, a behaviour consultant
- Grace, a physiotherapist
- Peggy, a visiting friend of Alan's

This setting is in an aged care facility. The case scenario includes observing Alan over several days and during different times to see how the healthcare professionals can improve their practice to help with Alan's sometimes unpredictable behaviour.

Alan is a former businessman with Frontotemporal Lobe Dementia a common form of Younger Onset Dementia where emotional and sexual etiquette is disinhibited and where episodes of aggressive behaviour can occur without warning. Two nurses in the facility, Fiona and Daniella, regularly take care of Alan and have their own individual approach to handling his behaviour.

The first scene begins at the end of the late shift. Both Fiona and Daniella genuinely like working in aged care, however, they find Alan's behaviour confronting and demanding of their skills and so negotiate care of Alan between them. The next day, Grace, the physiotherapist tries out some new mobility aids on Alan. After some discussion with Grace, Fiona calls in Marion to try and come up with strategies for staff and Alan on how better to understand and respond to his behaviour. In the final scene, Alan has a conversation with another resident about events in the facility.

VIDEO - [Come Meet With Me](#)
12:33 mins

Sub themes for reflection and further study:

- Friendships with and grief over the change in friends wiho have dementia
- Environmental settings and limitations
- The importance of recognising the uniqueness, past experiences and history of the person with dementia
- Incorporation of person with dementia into daily routines
- The strengths to a team approach to problem-solving
- Empowering the person with dementia
- Supporting the maintenance of friendship in the life of the person with dementia
- The selective use of touch as a therapeutic tool

Positive interactions demonstrated:

Recognition   Negotiation   Collaboration   Celebration   Validation

Holding   Facilitation   Creation   Giving

Negative interactions demonstrated:

Treachery   Disempowerment   Infantilisation   Outpacing

Invalidation   Banishment   Objectification   Ignoring

Imposition   Disruption   Mockery

Questions for Reflection

1. What are the negative and positive interactions in this scenario? Describe who displays which ones, as well as how and why they may be interacting in this way.

2. What attempts does Alan make to express his needs?

3. Describe how Fiona and Daniella each use different interactions in their approach to Alan, including Fiona telling Alan to 'go to sleep'. Which person shows more of the person-centred care approach and why?

4. Grace's approach towards Alan demonstrates outpacing. How could Grace approach her intervention in a different manner?

5. How does the setting of the residential care facility impede or assist in providing person-centred care?

6. Why does Marion's strategy of taking Alan to a team meeting work? How would Alan have responded if he hadn't been able to get to his 'important meeting'?

7. How did staff members respond at that meeting?

8. What statements by Fiona indicate that she has moved from 'getting along' and coping with Alan to genuine collaboration with him?

Extension Questions

1. What could Fiona have done to better support Peggy's experience with Alan?

2. From the observation of the residential care facility and staff in the video, what evidence is there of organisational support in providing person-centred according to the VIPS framework?

3. Alan constantly states 'don't touch me' during his interactions with many of the staff. Fiona also uses touching in her interaction style with Alan. Discuss the incident in the corridor where Alan lashes out at Fiona's touching of him and her response. What different strategies could Fiona use in the future for reassuring Alan?

4. What could be the underlying cause for Alan's reaction to being touched? How does this impact on his relationship with Fiona?

5. Why is the conversation Alan has with the resident in the last scene important? Is it important for residents in a residential aged care facility to develop relationships with the other residents? If so, why? If not, why not?

Come Feel With Me

A private practice podiatrist, Peter Bertram, opens this scenario by describing the enjoyment he gets from working with people with dementia. This includes the satisfaction of seeing his clients become more mobile and regaining independence through appropriate treatment of their feet.

In this scenario, we meet:

- Mrs Beryl Wilson is aged 75 and has multi-infarct dementia, epilepsy, and, difficulties with communication
- Lisa, a Registered Nurse on night duty with little understanding of person-centred care
- Olivia, a nursing student on night duty who is influenced by senior staff
- Virginia, a senior Registered Nurse, on day shift
- Dr Trudy David, a Registered Medical Officer for the ward and the doctor on-call
- Tony, a junior podiatrist with little understanding of person-centred care
- Nick, a senior podiatrist, more knowledgeable in using person-centred care in practice

This setting takes place in an acute care facility.

Mrs Wilson was brought into the hospital in a very agitated state earlier in the evening. She had a seizure and became disruptive at her residential care facility. She has low communication skills and is now amnesic, paranoid, impulsive and easily agitated. Beryl is insistent on wearing her beloved beanie of 'The Crows', one of the football teams in the Australian Football League. Since she has arrived in the hospital she has been cursing and wanting to leave and has delusional beliefs. She paces in an awkward fashion as her feet are sore and painful.

Lisa and Olivia are the nurses on night duty. Olivia, the nursing student, is unsure how to help Beryl and is scared of Beryl's swearing and demeanour. Lisa tries to ignore Beryl's behaviour but can only manage for so long. Lisa uses her own approach to settle Beryl which Olivia, as the junior nurse, is encouraged to comply with.

The next morning, Mrs Wilson is delusional and gesturing oddly at the nurse's station as well as creating a clamour disturbing other patients. The day shift RN, Virginia, and the doctor plan to sedate Beryl to ease her psychological distress. The next day, Mrs Wilson is taken to see the hospital podiatrist but this does not work out well. Nick, another podiatrist with more experience in interacting with people who have dementia visits Beryl.

VIDEO - [Come Feel With Me](#)
11:09 mins

Sub themes for reflection and further study:

- Indoctrination of new health care practitioners into adherence with existing workplace culture and practice
- Worker fatigue and apathy
- Anxieties and challenges for new healthcare practitioners delivering treatment interventions
- Negative attitudes towards the person with dementia
- The use and abuse of chemical and physical restraints
- Occupational Health and Safety of staff and patients

Positive interactions demonstrated:

Recognition	Negotiation	Collaboration	Relaxation
Validation	Facilitation	Holding	Timalation

Negative interactions demonstrated:

Treachery	Disempowerment	Infantilization	Intimidation
Labelling	Stigmatisation	Invalidation	Banishment
Objectification	Ignoring	Imposition	Withholding
Disruption	Disparagement		

Questions for Reflection

1. What are the negative and positive interactions in this scenario? Describe who displays which ones, as well as how and why they may be interacting in this way.

2. What was Olivia's contribution in this scenario and how she could be better supported as a nursing student.

3. What expressions reveal what Olivia feels when she sees how Lisa handles Beryl? Which malignant interactions does Olivia see being displayed by Lisa? Which ones by Virginia?

4. Describe Olivia's position on the ward and how that may compromise her behaviour with Beryl. Should this be the case?

5. Describe how Lisa and Virginia differ in their approach to Beryl. Which person shows more of the person-centred care approach and why? Why would Lisa have chosen the approach she used?

6. At one point, both Olivia and Virginia approach Beryl from behind and to the side. Is this appropriate? If not, how could their approach be improved?

7. Tony provokes Beryl to be angry in what way? Is Tony focusing on Beryl or his own values and beliefs?

8. Describe how Tony and Nick each use different interactions in their approach to Beryl. Which positive interactions would have benefited Tony in his approach to Beryl's care?

9. Does Nick's strategy work for him in providing care to Beryl? How does Virginia assist Nick with his strategy?

10. What factors may have enabled Beryl to have her feet attended to by Nick?

Extension Questions

1. What aspects of Beryl's behaviour can be attributed to her foot pain and which ones to her symptoms of multi-infarct dementia?

2. How could the VIPS framework address this workplace's culture on person centred care?

3. What attitude does Lisa display in the last scene with Beryl? How did Virginia approach Lisa in this situation and what may have been said?

4. What could assist Lisa in developing a different attitude to Beryl and what would be appropriate for Virginia to address with her?

5. Lisa is acting unprofessionally when carrying out restraint procedures on Beryl. What are the best practice guidelines on restraint procedures that dictate professional practice? What risks must be considered? What protocols must be in place?

6. Was Beryl having hallucinations, illusions or delusions? What is the difference and how should these be responded to?

Come Dance With Me

In this last scenario, Stephanie Altus, a paramedic, discusses the challenge of trying to connect with the person who has dementia. Often paramedics will scan the environment of the person with dementia to see how they live, what they do and their connections to family and friends.

In this case scenario, we meet:

- Violetta, an Italian divorcee in her 60's with probable early Alzheimer's Disease
- Sue, a speech pathologist with dementia care training
- Daniel, an interpreter of Italian
- Paolo, one of her two sons
- Mayumi, a nutritionist and dietician
- Marilyn, a clinical behaviour consultant
- Dianne, a careworker inexperienced in caring for a person with dementia

The setting is a large, metropolitan residential aged care facility.

Violetta is an Italian divorcee who raised her two sons and developed a successful career in fashion. Her two sons adore her and helped to care for her in the earlier stages of her dementia. However, as planned and agreed between the three of them, as Violetta's day to day needs increased she has come to live in a residential aged care facility that can provide for her healthcare needs and offer social activity and the company of others.

Violetta's way of eating interferes with the other residents of the facility with the resulting upheaval annoying Dianne, a careworker. Her irritability at bedtime and communication in both Italian and English also disrupts the other residents and makes evening duties difficult for staff. Sue, the speech pathologist, has already assessed Violetta for any swallowing difficulties with no abnormalities detected. She contacts an interpreter, Daniel, and on the advice of Marilyn, a clinical behaviour consultant, uses a reminiscence book designed for Violetta to explore Violetta's past life experiences of eating as a way of better understanding her and providing for her nutritional needs in the facility. The overriding objective of reminiscence therapy is to create pleasant memories for the person with dementia, but occasionally these positive associations can slip into a negative one.

Marilyn and Sue call a team meeting with Mayumi, the dietician for the facility and Dianne. They discuss strategies to ensure that Violetta's nutritional requirements are being met and devise a way for her to join the other residents for meal times without annoying them. Dianne begins to change her attitude in the way she cares for Violetta and becomes interested in exploring positive ways of interacting with her.

VIDEO - [Come Dance With Me](#)
11:08 mins

Sub themes for reflection and further study:

- Strategies that promote the inclusion of people from Culturally and Linguistically Diverse Backgrounds (CALD) within the dominant culture of the residential facility
- A person whose first language is not English
- Challenging stereotyping and cultural assumptions on the part of the staff
- Assisting others to contribute to person-centred care as an organisational philosophy
- The use of reminiscence therapy, interpreters and diversional activities

Positive interactions demonstrated:

Recognition	Negotiation	Collaboration	Play
Timalation	Celebration	Relaxation	Validation
Holding	Facilitation	Creation	Giving

Negative interactions demonstrated:

Disempowerment	Intimidation	Stigmatisation	Invalidation
Imposition	Accusation	Disruption	Disparagement

Questions for Reflection

1. What are the negative and positive interactions in this scenario? Describe who displays which ones, as well as how and why they may be interacting in this way.

2. Describe how Dianne, the careworker, changes over time in her care approach. How does Dianne's anger with Violetta impact on Violetta? How does Dianne explain her anger in the team meeting?

3. Which negative interactions did Dianne display in the beginning of the scenario and which positive ones did she display at the end?

4. What was Dianne's reaction to the affection that Violetta gives to her? Discuss this in the context of her practice?

5. What principles of care and strategies inform the person-centred approach and were employed to support Violetta's personhood by those concerned?

6. How important was Paolo's information to the team? Which interactions did it support or reject?

Extension Questions

1. Discuss the team dynamics displayed. Were Sue, Dianne, Marilyn and Mayumi able to adequately assist with Violetta's needs?

2. What are the socio-cultural issues raised in this scenario?

3. An unintended consequence of the use of the memory book was that Violetta became tearful. How did Sue respond? What is reminiscence therapy and how is it used? Was it used appropriately in this scenario?

4. In the last dance scene, there was another person who had dementia other than Violetta. Could you identify who it was?

Interviews with healthcare professionals
The following video presents extended interviews with four healthcare professionals on their experiences of working with people who have dementia.

VIDEO - [Interacting With People Who Have Dementia](#)

7:27 mins

Epilogue

Several years ago, while facilitating a song writing workshop for Alzheimer's Australia, I came across a story I found so moving and inspirational that I couldn't help but take my 'facilitator' hat off and pick up the guitar. As part of Dementia Awareness Month, we were writing songs based on transcripts of interviews with people caring for a person with dementia.

From the transcript, there came a love story.

Fifty years ago in a quintessential Australian country town a beautiful woman appeared on the horizon. She was spotted by a man who told her he had never seen such 'a beautiful view'. They married and spent fifty years together in a lifetime of hopes, dreams, fears, love and accomplishments. Then dementia took hold of her. She now lives in a high care facility. He visits her every day and thinks maybe he needs those visits more than she does but he wouldn't change a thing, including her dementia. This was their story, their life together. She is the love of his life and always will be.

That was the story, then came the song.

Later that year, I was at the gala dinner on the last night of the Alzheimer's Australia conference 2005. A big band was playing music from a long time ago and elderly couples began to dance. Husbands, wives, friends and their partners moved across the floor, their bodies remembering the dance. They all moved so elegantly around the room that those with dementia were indistinguishable from their partners. It was a truly beautiful moment of connection and love recreated through the music and dance. As I watched, I thought the dancers might be thinking: *"I want to hold this moment just as long as I can. If we had our time over, I would do it again. Dance with me."*

This thought became the focus for the following lyrics:

Dance With Me

Beautiful view
I'll always remember
The moment I fell for you
Such a beautiful view

Come and dance with me
I'll follow your lead
Come on and dance with me
Cause right now
You're everything I need

Years gone by
So many memories
I see in the light in your eyes
All those years gone by

By Chloe Hall

Come and dance with me
I'll follow your lead
Come on and dance with me
Cause right now
You're everything I need

I want to hold this moment
Just as long as I can
If we had our time over
I would do it again
Come and dance
Dance with me

And when the tables turn
We'll be watching the bridges burn

And I need you now
I try to let go

But I just don't know how
And I need you now

Come and dance with me
I'll follow your lead

Come on and dance with me
Cause right now
You're everything I need

I want to hold this moment
Just as long as I can
If we had our time over
I would do it again

Come and dance
Dance with me
Dance with me

VIDEO - [Trailer and Soundtrack]

3:59 mins

Credits for DVD Production

Cast

Come Walk With Me

Anne	*John*	*Kerrie*
Wendy Abigail	Ian Rigney	Alison Hutton

Jenny	*Dave*	*Steve*
Mel George	Phil Knight	Steven Hambling

Come Listen To Me

Sue	*Jacob*	*Michael*
Maree Khoo	Brian Messenger	Bill Costain

Christine	*May*	
Bev George	Louella Bailey	

Come Meet With Me

Fiona	*Alan*	*Daniella*
Pauline Guerin	Michael (Bob) Hooper	Lana Zannettino

Marian	*Grace*	*Peggy*
Susan Golley	Lydia Paton	Zetta Karay

Nola	*Valda*	
Nola Heffernan	Valda Gene Haines	

Come Feel With Me

Beryl	*Olivia*	*Lisa*
Jude Brennan	Casey Hazel-Polkinghorne	Penny Bell

Virginia	*Trudy*	*Tony*
Didy Button	Kerrie Stockley	Kym Barker

Nick		
Peter Bertram		

Come Dance With Me

Violetta	*Marilyn*	*Dianne*
Karen Wotton	Elizabeth Bleby	Ailsa N'ha Winifreyda

Mayumi	*Daniel*	*Paolo*
Mayumi Kako	Paolo Nocella	Andrew Benton

Sue	*Diversional Therapist*
Sandra L Bradley	Patrick Lang

Extras

Colin Ball	Anita Ball	Jolan Benko
Jean Clothier	Gwen Conroy	Blanche Evans
Evelyn Graham	Peg Jury	Sumiko Rolfery
Raie Rose	Eluned Smith	

Featuring Interviews with:

Professor Dawn Brooker
Chair in Dementia Care Research and Practice,
Bradford Dementia Group, University of Bradford

Stephanie Altus
Paramedic, South Australia Ambulance Service

Peter Bertram,
Podiatrist, Glandore Podiatry Clinic

Pauleen Bond
Team Manager, ACH Dementia Group Services

Joanne Molsher
Clinical Nurse Consultant, Repatriation General Hospital

Crew

Producer, Writer and Director Alison Wotherspoon	**_Co-Producer and Script Consultant_** Anita De Bellis	**_Associate Producer_** Sandra L Bradley
Camera Sian Bates Simone Mazengarb	**_Camera Assistant_** Luke Marsden	**_Production Assistant/Continuity_** Sarah Bond
Location Sound Patrick Lang Bruce Hatfield Dane Hirsinger	**_Editor_** David Raftery	**_Sound Post Production_** Best FX
Sound Editor Scott Illingworth	**_Mixer_** Pete Best	

Music

"Dance With Me"
Artist: Chloe Hall
Written by: Chloe Hall
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One Tree Hill Records
Licensed courtesy of Shock Music Publishing

Additional Resources

South Australia & Northern Territory Dementia Training Study Centre
27 Conyngham Street
Glenside, SA 5065
PH: 08-8372-2100
Email: dtsc@alzheimerssa.asn.au
Web address: www.santdtsc.edu.au

Dementia Collaborative Research Centres
Queensland University of Technology
Victoria Park Rd
Kelvin Grove, QLD 4059
Web address: www.dementia.unsw.edu.au

Alzheimer's Australia (for all states)
Web address: www.alzheimers.org.au

Department of Health and Ageing
Central Office Postal Address
GPO Box 9848,
Canberra ACT 2601, Australia
Switchboard: (02) 6289 1555
Freecall: 1800 020 103
After hours: (02) 6122 2747
http://www.health.gov.au/internet/main/publishing.nsf/Content/health-central.htm

Dementia Resource Guide
Restraint Reduction
Department of Health and Ageing
http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-dementia-resource-guide.htm~ageing-dementia-resource-guide-9.htm~ageing-dementia-resource-guide-9-11.htm

Guidelines with coping on violence in the workplace
International Council of Nurses
http://www.icn.ch/guide_violence.pdf

University of Bradford, School of Health Studies
Bradford Dementia Group
25 Trinity Road, Bradford BD5 OBB UK
Tel: +44 01274 236367
Fax: +44 01274 236302
http://www.bradford.ac.uk/acad/health/dementia/intro.php

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Positive Person Work (PPW)	Malignant Social Psychology (MSP)
Celebration	Accusation
Collaboration	Banishment
Creation	Disempowerment
Facilitation	Disparagement
Giving	Disruption
Holding	Ignoring
Negotiation	Imposition
Play	Infantilisation
Recognition	Intimidation
Relaxation	Invalidation
Timalation	Labelling
Validation	Mockery
	Objectification
	Outpacing
	Stigmatisation
	Treachery
	Withholding

Kitwood (1997)