

# Advancing practice in the care of people with dementia

4th Edition

## Module 4: Promoting Wellbeing



Dementia  
Training  
Australia



# Contents

## Module 4: Promoting wellbeing

Introduction .....	5
Objectives.....	5
Module topics.....	5
Suggested reading .....	5
The lived experience of dementia .....	6
Wellbeing in dementia care.....	8
Theories, models and approaches for wellbeing .....	9
Some useful resources .....	11
A human rights-based approach.....	11
Person centred care .....	12
Personhood .....	14
Context Specific approaches and models that support wellbeing .....	18
Summary.....	25
References.....	25



# Module 4: Promoting wellbeing

## Introduction

Dementia is a life changing and life limiting condition. Because of its neurological and progressive nature, dementia is often described using a narrative of decline and loss. These include the loss of physical and cognitive abilities, difficulties in maintaining independence in everyday living, as well as difficulties in maintaining meaningful activities and social engagement. People with dementia are the experts in this lived experience, and they are strongly advocating that those in health and social care reframe their perception of life with dementia to one that has a narrative of valuing the person's strengths and their capacity to live well with dementia. This module will explore the concept of living well with dementia and wellbeing and how they can be translated into approaches to care in residential, community and hospital settings.

## Objectives

On completion of this module you will:

- Have a greater awareness of the lived experience of dementia
- Recognise that people can live well with dementia, and with the right support can experience wellbeing
- Identify which legislation, guidelines and codes of practice promote wellbeing
- Be able to describe the difference between a bio-medical model of care and a model that promotes wellbeing
- Be able to describe some of the models and approaches that can be applied to the practice/care environment
- Be able to recognise how Kitwood's theories have informed current practice in dementia care
- Reflect on the programs that have successfully implemented evidence into practice to support wellbeing for the person living with dementia.

## Module topics

The lived experience of dementia

The impact of dementia

Living well with dementia

Wellbeing in dementia care

Models, approaches and wellbeing

Context specific approaches and models that support wellbeing

## Suggested reading

Brooker, D., & Latham, I. (2016). *Person-Centred Dementia Care, Making Services Better with the VIPS Framework* (2nd ed.). London, England: Jessica Kingsley Publishers.

Power, G.A. (2017). *Dementia beyond disease. Enhancing wellbeing* (revised edition). Baltimore, MD: Health Professions Press.

IDEAL study website <http://www.idealproject.org.uk/>

Guideline Adaptation Committee (2016). Clinical practice Guidelines and Principles of Care for People with Dementia. [https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/CDPC-Dementia-Guidelines\\_WEB.pdf](https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/CDPC-Dementia-Guidelines_WEB.pdf)

Fire Films short documentaries <https://www.firefilms.com.au/documentaries>

## The lived experience of dementia

Not all symptoms of dementia are directly caused by the neurological damage. The experience of dementia is different for every person because an individual will be affected by many other factors. Using Kitwood's enriched model of dementia (1997), the experience of dementia can be understood as an inter-relationship between neurological damage and social-psychological factors. Kitwood presented an equation whereby  $D = P + B + H + NI + SP$

It means that dementia (D) is a complex interaction of personality (P), biography (B), health (H), neurological impairment (NI) and social psychology (SP) and will be unique to each individual.

Dementia changes the way a person experiences the world (Power, 2017). They might struggle to comprehend the immediate environment, feel confused and disorientated, have difficulty recalling important memories, maintaining a sense of self or feeling in control over their life. Increasingly people with dementia are describing these experiences. These are valuable to those of us who can only imagine what life with dementia would be like and how our actions may impact in a positive or negative way on the persons wellbeing. Whilst people in the earlier stages of dementia are generally able to communicate these experiences, we need to be aware that people in the moderate to advanced stages of dementia often retain the ability for emotional expression and should be given the opportunity to report on their mood, quality of life and the quality of care that they receive. This may mean that the helping professions need to learn to listen differently to understand what is important to the person with dementia.

## The impact of dementia

Dementia can impact the person's life in negative and positive ways. The challenging and life changing aspects have been described as losses, feelings of isolation and fear of the future (Macdonald & Mears, 2019; Swaffer, Rahman, Rees, Taylor, & Rees, 2016). The experience of dementia plus the impact of living in a residential care setting creates further challenges that lead to feelings of "loss, isolation, uncertainty, fear, and a sense of worthlessness... frustration and anger" (Clare, Rowlands, Bruce, Surr, & Downs, 2008, p. 714 & 717).

However, there is also picture of positive impacts on a life with dementia whereby people find ways to cope (Clare et al., 2008). They:

- learn to live with dementia using humour and positive thinking (Wolverson, Clarke, & Moniz-Cook, 2016)
- maintain a sense of hope (Bryden, 2018)

- affirm a sense of self and maintain self-identity through life review (Bryden, 2018; Clare et al., 2008; Wolverson et al., 2016)
- establish a renewed purpose in life by maintaining engagement with others, seeking social support and enjoyment (Wolverson et al., 2016)
- find meaning in the present (Bryden, 2018, p. 280).

## Living well with dementia

The person's experience of living well with dementia is related to their perceived quality of life, satisfaction with life and wellbeing (Clare et al., 2014).



A large study undertaken in the United Kingdom found five factors that support a person's ability to live well with dementia:

1. Psychological characteristics and health
2. Physical fitness and health
3. Capitals, assets and resources
4. Managing everyday life
5. Social location (Clare et al., 2019)



When Australians with dementia were asked what they wanted following a diagnosis, their wishes were for “engagement and inclusion, social connection and support, continuity, dignity and respect” (Haapala, Carr, & Biggs, 2019, p. 47). The Global Dementia Charter ‘I can live well with dementia’ was launched by Alzheimer’s Disease International and BUPA to outline expectations of people living with dementia to support their journey with dementia.

### ACTIVITY

**Access these resources on the ADI website.**

<https://www.alz.co.uk/global-dementia-charter>

**Global Dementia Charter book**

<https://www.alz.co.uk/sites/default/files/pdfs/global-dementia-charter-booklet.pdf>

## Wellbeing in dementia care

From a service delivery perspective, wellbeing is clearly an important factor in supporting people to live well with dementia and is woven throughout Australian accreditation standards (Aged Care Quality Standards, 2019; National Safety and Quality Health Service NSQHS standards 2019). Yet wellbeing is another concept that has multiple definitions. Kitwood and Bredin (Kitwood & Bredin, 1992) described four global states of wellbeing for people with dementia:

- The sense of self-worth and self-esteem
- Sense of agency and ability to control your own life in a meaningful way
- Sense of social confidence and being able to interact with others
- Sense of hope and a good future

A recently published scoping review by Clarke et al. (2020, p. 4) extracted six themes related to the lived experience of wellbeing in dementia:

1. Feeling positive in the here and now. It includes hope, optimism, humour and positive attitudes
2. Life having meaning and being able to make sense of dementia
3. Positive sense of self worth
4. Keeping going and being active through a sense of agency, adaptation, resilience, purpose and autonomy
5. Good interpersonal and social relationships
6. Feeling well and satisfied with life.

The Eden Alternative™ was designed to create a person-centred care environment for people living in residential aged care. It draws on seven Domains of Wellbeing™ that are essential in a person's life.

### ACTIVITY

#### ***Navigate to the following webpage***

<https://www.alzheimerswa.org.au/about-dementia/understanding-dementia-care/models-of-care/>

Now you have heard Jason Burton from Alzheimer's Australia WA describe ways in which wellbeing can be supported...

#### ***Reflect on the environment of care that you are working in.***

To what degree does it support wellbeing? Are the efforts to support wellbeing of people with dementia fairly superficial or are they a well thought out strategy aligned to states of wellbeing?

#### ***Reflect on the people with dementia that you are supporting.***

How do you know that a person is in a state of wellbeing? Is it based on your subjective evaluation, or the observations of the team or do you use an observational measure?

When do you assess wellbeing? Is it on interaction or during activity? Or is it part of resident of the day process?

## Theories, models and approaches for wellbeing

This section will briefly examine some of the dominant theories, models and approaches in contemporary dementia care. The prevailing message is that approaches to supporting people to live well with dementia needs services to move away from traditional clinical, problem-based approaches to care and reorientate 'care' to 'enhancing life'.

### Bio-medical model

In general, a medical or bio-medical approach seeks to understand disease. It has been vital for advancing practice in the prevention, diagnosis and treatment of many subtypes of dementia. However, when applied to the provision of care and support to people with dementia, a predominantly bio-medical model of service provision will only offer a narrow focus on deficits, progression of illness and what people living with dementia cannot do (Hutchinson, Roberts, & Roach, 2019, p. 61). It is an approach to care that is marked by its failure to recognise the persons lived of experience of dementia and the relational, environmental and social impacts. Bryden, dementia advocate and person living with younger onset dementia, expresses concern that this 'clinical approach assumes that our brains, our life histories and our individual life experiences are all the same' (Bryden, 2015, p. 204). Deficit-oriented thinking and task-oriented practice are hallmarks of such an approach and if clinicians and care workers behave in this way it will have negative consequences for the person with dementia, namely; pharmacological rather than psychosocial interventions to promote wellbeing, failure to recognise behaviours as emotional distress, disempowerment and stigma (Power, 2017).

### Salutogenesis

Salutogenic theory is the opposite to the medical model as it focuses on how people remain well rather than why they get sick (Antonovsky, 1979). Salutogenic theory recognises that all people experience difficult life events and stressors, but some people thrive, and some don't. The way in which the person copes with these events and stressors will either result in relative wellbeing and empowerment or sense of failure and illbeing. Antonovsky described the factors that contribute to coping and not coping as a sense of coherence. There are three factors that support the person's ability to cope: meaning, comprehensibility and manageability (Antonovsky, 1987). These factors have been applied in settings that care for people with dementia with good effect.

Manageability is the person's ability to carry out activities of daily living. In the care setting, people often need assistance with these tasks. Importantly, manageability means supporting the person to retain as much independence and control over these daily activities as possible. Some examples of increasing a sense of manageability for the person with dementia includes opportunities to shop and prepare a meal in the kitchen, to do some gardening or work in the tool shed (Golembiewski, 2017).

Comprehensibility is the person's ability to understand what is happening, why it is happening and how to do something about it (Golembiewski, 2017). In the residential setting this means developing care routines that mirror the persons preferences, personalisation of private spaces, use of dementia friendly environmental design that reduces excessive stimulation and increases way finding (Golembiewski, 2017).

Meaning is about remaining connected with what is important to you and the world about you. Meaning is highly personal but can include making or maintaining meaningful relationships and meaningful engagement. In the residential care setting this might include provision for pets, opportunities to engage in all forms of art and maintaining religious or spiritual connections (Golembiewski, 2017).

## Strength-based approach and reablement

A strength-based approach is a way of working based on the belief that people can be empowered to harness their own strengths and assets (Hirst, Lane, & Stares, 2013). It reframes problems and what the person cannot do, to establishing the person's abilities, circumstances and resources, then focusing on how these can be used to regain the best life possible (Baron, Stanley, Colomina, & Pereira, 2019). Key principles of a strength-based approach include:

- Every person is unique and has the potential for change
- People are experts in their own lives so their autonomy should be recognised and supported
- When provided with the relevant information and support, people can make meaningful choices about their health and health care.
- Collaboration will create opportunities for success
- Staff's role is to empower people and build their capacity to maximise their potential (Pascale & Associates., 2018, p. 1).

The reablement approach that underpins the Commonwealth home support and care program is an example of a strength-based approach. Reablement is defined as:

*'time-limited interventions that are targeted towards a person's specific goal or desired outcome to adapt to some functional loss, or regain confidence and capacity to resume activities.'* (Commonwealth of Australia, 2015, p. 12).

Interventions that enhance function and independence in people with dementia are recommended by WHO Global action plan 2017-2025 (World Health Organisation, 2017). Recommendation 66 in the Australian Dementia clinical practice guidelines advises that the person's independence, function and engagement should be supported in their everyday life. Recommendations 67 and 68 advocate for interventions that create an enabling environment, promote independence in daily living activities, encourages exercise and provides education and skills training for family carers (Guideline Adaptation Committee, 2016, p. XI).

A comprehensive approach for reablement in dementia includes:

1. Initial comprehensive medical/geriatric assessment and pharmacologic approaches
2. Addressing the impact of cognitive disability on everyday functioning
3. Physical and other related nonpharmacologic approaches to support functioning
4. Targeted rehabilitation interventions following acute illness or injury
5. Assistive technology to aid function
6. Support services for the community or residential care sector
7. Caregiver support and education (Poulos et al., 2017, p. 451).

## Some useful resources

Possibility Oriented Approach and the Hierarchic Dementia Scale-Revised

<https://dta.com.au/resources/the-possibility-oriented-approach/> (accessed 9th September 2020)

Guiding occupational therapy practice for people living with dementia in the community

<https://dta.com.au/resources/guiding-occupational-therapy-practice-for-people-living-with-dementia-in-the-community/> (accessed 9th September 2020)

Supporting independence and function in people living with dementia, A handbook of reablement programs for service providers and others with an interest in improving function (2nd Edition)

<https://cdpc.sydney.edu.au/research/maintaining-function/reablement-guidelines/> (accessed 9th September 2020)

Dementia Enablement Guide (2016) (accessed 9th September 2020)

<https://clinicaexcellence.qld.gov.au/priority-areas/engagement/statewide-clinical-networks/dementia/dementia-enablement-guide-gps-and>

## A human rights-based approach

A human rights approach will recognise dementia as a disability and give people with dementia the same rights as everyone else. These rights are reflected in the Aged care quality standards as promoting dignity, respect, choice, independence and wellbeing. The Dementia Alliance International are campaigning for social change. They are calling for communities to support people with dementia based on the recognition of human rights and dementia as a disability. This will need a pathway of psychosocial and disability support to enable people to live positively with dementia for as long as possible (Dementia Alliance International, 2016). Australia is a signatory to the United Nations Convention of Rights of the Persons with Disabilities which includes people with Dementia, as covered by the definition listed in Article 1:

*“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”*

The Articles listed under the Convention of Rights also provide detailed guidance on the important areas of everyday life for people with disabilities. The Global Dementia Charter ‘I can live well with dementia’ described earlier aligns with a human rights approach. Post diagnostic care such as the

Dementia Enablement Guide developed by Queensland Health, and reablement programs such as I-HARP, COPE and LIFE Ful (described later in this module) provide pathways to disability support for people with dementia.

## Person centred care

Rather than focusing on treatment of the disease or symptoms, person-centred practice works with the person to meet their specific needs and goals. The foundation of person-centred dementia care is the work of a British psychologist called Tom Kitwood. His theories addressed the discourse of dementia, organisational culture, psychological needs of the individual and personhood (Baldwin & Capstick, 2007). Kitwood's work has offered a framework for practice that policy makers, organisations, researchers and individuals aspire to today. The theories discussed here are the enriched model of dementia, psychological needs and personhood.

*The enriched model of dementia* helps us to understand the interacting factors that contribute to the persons experience of dementia and the presentation of symptoms. The enriched model was described earlier in this chapter as a formula  $D = P + B + H + NI + SP$ . Kitwood saw these factors all combining in different ways and amounts to impact on the person (1997). Neurological impairment (NI) relates to the damage caused to the brain by the underlying disease process. In Alzheimer's disease we know this is due to macroscopic pathological changes in the cerebral cortex that include amyloid plaques and neurofibrillary tangles, in turn causing changes to thinking and functional ability (see Module 1 for more detail about causes of neurological impairment). The person's health status (H), whether physical or mental health, will impact on the person. Older people with dementia are susceptible to infection, dehydration, constipation and adverse effects of some medications, often resulting in delirium. Unrecognised and untreated pain may lead to pain related behaviours but misinterpreted as a behaviour or psychological symptom associated with dementia (BPSD). Whereas a younger person with dementia may be physically fitter and need the opportunity for exercise and activity, which if not met, may also present as BPSD. Biography (B) is the persons story. It is these past experiences that the person often draws on to make sense of what is happening to them in the here and now. A person's story is also an important factor for maintaining a sense of self (identity). Knowing the story may help to understand changed behaviours. For example, a person's behaviour may be explained by their previous occupation or a traumatic experience in earlier life. Personality (P) is developed through a lifetime, especially strengths, coping strategies and situations that make a person feel vulnerable or helpless. The person will respond to their dementia experience in accordance to these strengths and vulnerabilities. Social psychology (SP) refers to the social and psychological environment that surrounds the person with dementia. In the care setting that includes the quality of relationships, the quality of care and staff behaviours (see malignant social psychology and positive person work described in the next section).



*The psychological needs theory* helps us to understand how to support people with dementia and to create a feeling of wellbeing. Kitwood presented this as a flower where the need to be loved is central, and the petals representing comfort, identity, attachment, occupation and inclusion. The behaviour of staff can either undermine or support a person's psychological needs. Kitwood called these behaviours malignant social psychology (MSP) and positive person work (PPW) (Kitwood, 1997). Some examples are provided of these behaviours for each of the psychological needs.

**Comfort** “is the provision of warmth and closeness to others” (Brooker & Surr, 2005, p. 28)

MSP	PPW
Failing to respond to a person’s appeal for interaction or care.	Responding to a person in a way that makes them feel safe.
Providing information and choices too fast for the person to understand.	Providing care and interaction at a pace that suits the individual.

**Identity** is “to know who you are and how you think about yourself” (Brooker & Surr, 2005, p. 29). Lifestory work is important for maintaining identity.

MSP	PPW
A patronizing way of responding to a person as if they are a child.	Treating the person with respect, valuing their age and life experience.
Using a label to describe the person, for example ‘a wanderer’.	Having positive regard for the person and accepting them for who they are.

**Attachment** “relates to bonding, connection, nurture, trust and relationship” (Brooker & Surr, 2005, p. 30). p. 28)

MSP	PPW
Using deception to manipulate the person to do something.	Being honest and open in a way that recognises the persons feelings.
Not looking at the situation from the persons perspective.	Recognising the persons emotions and validating their reality.

**Occupation** is “being involved in the process of life” (Brooker & Surr, 2005, p. 31). This includes the opportunity for meaningful activity.

MSP	PPW
Disempowering the person by failing to support remaining capabilities.	Empowering the person by supporting existing capabilities.
Treating the person like an object (doing to).	Working collaboratively with the person (working with).

**Inclusion** is “being part of a group” (Brooker & Surr, 2005, p. 32). This includes reducing social isolation by facilitating engagement.

MSP	PPW
Stigmatising behaviour, where the person is treated differently because of factors like age, dementia, behaviour, sexuality etc.	Unconditional positive regard that values the persons unique qualities.
Treating the person as if they are not present, an example would be a conversation that excluded the person.	Helping the persons feel included in what is going on (conversations, activities, care).

## Personhood

The aim of person-centred care is to support the personhood of the person with dementia through positive interactions (Baldwin & Capstick, 2007; Kitwood, 1997). Personhood is “the quality or condition of being a person” as well as a human right (Smebye & Kirkevold, 2013, p. 1) There are multiple definitions of personhood, so it is easier to reflect on personhood using these questions:

1. Who am I?
2. How am I to treat others?
3. How do I want others to treat me? (Baldwin & Capstick, 2007, p. 174)

‘Identity’ and ‘sense of self’ are important components of personhood. Bryden describes three aspects of self: ‘being embodied as an I’, the relational self and narrative self (C. Bryden, 2018, p. 281). Basting (2003) describes personal identity as being formed through culture and interactions with others to give meaning of who we are as an individual; social identity is formed by the way that others see us; these identities are then experienced simultaneously to create the ‘whole’ self. It is not necessarily the dementia that affects the sense of self; it is often the changed relationship and responses from those around the person with dementia that has the biggest impact. Malignant social psychology and positive person work demonstrated by staff will undermine or support personhood.

### ACTIVITY

**First ask yourself the questions**

1. **Who am I?**
2. **How am I to treat others?**
3. **How do I want others to treat me?**

**Now think about one person with dementia in your care.**

**How well do you think you know the person?**

**How well do you know the persons wishes on how they want to be treated by others in the care setting?**

**How have you got to know the person and their wishes (is it through your relationship with them and talking to family or through the life history documentation)?**

**Do you think you should know more about the person and if so, how could you do this?**

## Principles of Person-Centred Care

The key principles of person-centred dementia care were originally described by Loveday, Kitwood, and Bowe (1998):

1. Attend to the whole person.
2. See each individual as special and unique.
3. Give respect to the past.
4. Focus on the positives.
5. Stay in communication.
6. Nourish attachments.

7. Create community.
8. Maximise freedom and minimise control.
9. Don't just give, receive as well.
10. Maintain a moral world

Over time, many definitions and explanations of person-centred care for people with dementia have been provided with little consensus. The VIPS model is a useful way to reflect on the four major elements of person-centred care (Brooker & Latham, 2016). VIPS is a clever mnemonic that also realigns the value of people with dementia as Very Important People:

**Valuing** people with dementia and those who care for them

Treating people as **Individuals**

Understanding the world from the **Perspective** of the person living with dementia

Providing a **Social** environment that supports psychological needs (Brooker & Latham, 2016).

The VIPS was also developed into a framework that provides 24 indicators by which organisations can benchmark their practice. For individual practitioners and direct care staff there are four reflective questions to examine the quality of their interactions:

1. Does my behaviour and the manner in which I am communicating with this person show that I respect, value and honour them?
2. Am I treating this person as a unique individual?
3. Am I making a serious attempt to see my actions from the perspective of the person I am trying to help? How might my actions be interpreted by this person?
4. Does my behaviour and interactions help this person to feel socially confident and that they are not alone? (Brooker & Latham, 2016, pp. 13-14)

## The evidence for person-centred care

There is increasing empirical evidence that person-centred approaches have beneficial outcomes for the person with dementia and care providers. The benefits for the person living with dementia include:

- reduced agitation (Chenoweth, Forbes, et al., 2014; Chenoweth et al., 2009; Li & Porock, 2014)
- reduced use of psychotropic/antipsychotic medications (Li & Porock, 2014)
- increased wellbeing (Brooker & Woolley, 2007; Chenoweth et al., 2009; Rokstad et al., 2013)
- increased quality of life (Chenoweth, Forbes, et al., 2014)

Benefits for staff include:

- improved work situations (Moyle, Murfield, Griffiths, & Venturato, 2011)
- improved staff care interactions (Chenoweth, Forbes, et al., 2014)
- a reduction in restrictive practices (Blake, Berry, & Brown, 2020)
- reduced job-related stress (Jeon et al., 2012)
- job satisfaction (Jeon et al., 2012)

Psychosocial interventions are an important feature in person centred care, providing a non-pharmacological option to decreasing or preventing BPSD and promoting purposeful living. These have been categorised as:

- Behavioural-oriented approaches (e.g. scheduled toileting)
- Emotion oriented approaches (e.g. reminiscence therapy, validation and simulated presence therapy)
- Cognition oriented approaches (e.g. reality orientation and skills training)
- Stimulation oriented approaches (e.g. multisensory stimulation, art therapies, recreational activities and aromatherapy)
- Exercise (Barbosa, Sousa, Nolan, & Figueiredo, 2015).

Such interventions have been found to reduce BPSD and improve wellbeing for the person with dementia (Travers et al., 2016).

## Dignity in care

Dignity is a fundamental human right (Kane & de Vries, 2017) and important for wellbeing and quality of life (Goldberg, Price, Becker, & Bindoff, 2019; Manthorpe et al., 2010). It is embedded in many of the key documents that set the standard for the delivery of quality care for Australians living with dementia and professional codes for those who deliver the care. These include but are not limited to: the Australian Clinical Practice Guidelines and Principles of Care for People with Dementia (Guideline Adaptation Committee, 2016); the Aged Care Quality Standards (Aged Care Quality and Safety Commission, 2018); the National Safety and Quality Health Service (NSQHS) Standards (second edition) (Australian Commission on Safety and Quality in Health Care, 2017); The Australian Charter of Healthcare Rights (Australian Commission on Safety and Quality in Health Care, 2019); the Universal Declaration of Human Rights (United Nations, 1964) and the International Council of Nursing Code (ICN, 2012).

Dignity is a broad concept. What dignity means, how it is perceived by the individual and preserved by others needs to be defined. Jacobson (2009) portrays dignity in two forms, human and social. Human dignity is a universal value that all human beings have collectively and individually. Whereas social dignity exists within interactions with others: it is expressed as self-respect and self-worth (dignity-of-self) and conveyed by others as respect and worthiness (dignity-in-relation). The theoretical model of the dignity experience for people with dementia has three dimensions; historical, intrapersonal and interpersonal (Tranvåg, Petersen, & Nåden, 2016). The historical dignity-dimension relates to the person's life history, life events, and socio-cultural factors and will be formed through their childhood, family life and meaningful occupation. The intrapersonal dignity-dimension is associated with the persons perception of their own self-worth, personal values and need for meaningful activity. The interpersonal dignity-dimension is connected to the respect and recognition from others within caring relationships (Tranvåg et al., 2016, p. 589).

## Dignity preserving care

Sustaining dignity is an essential task in caring (ICN, 2012) and essential to help people with dementia to live well (Power, 2017). Care provided should not undermine the persons dignity, rather dignity should be the ‘backbone of care’ (Kinnear, Williams, & Victor, 2014, p. 4), supporting autonomy, upholding the persons sense of self, self-respect and self-worth (Goldberg et al., 2019; Tranvåg, Petersen, & Nåden, 2013).

It requires:

- Social engagement (Goldberg et al., 2019; Tranvåg et al., 2016)
- Relationship centred care (Heggestad, Nortvedt, & Slettebø, 2015; Tranvåg et al., 2016)
- Life history work (Heggestad et al., 2015; Tranvåg et al., 2016)
- Strength based approaches that recognise what the person can do (van Gennip et al., 2016)
- Opportunity to maintain a meaningful life (Tranvåg et al., 2016; van Gennip et al., 2016)

Jacobson’s study identified that every human interaction provided the opportunity for ‘a dignity-encounter’ (Jacobson, 2009, p. 3). However, this encounter would be affected by the people involved, the quality of the relationship, the setting in which it occurs, and the wider social context, resulting in either the violation or promotion of dignity. The following table provides a small sample of the social processes described in Jacobson’s study; you will note that they align closely to Kitwood’s theory of malignant social psychology and positive person work.

Dignity violation	Dignity promotion
<b>Dismissal: Ignoring or discounting an actor's knowledge, skills, perceptions, concerns, needs, and feelings</b>	<b>Acceptance: Being non-judgmental of difference</b>
<b>Condescension: "Talking down to" someone or speaking to an adult "like a child."</b>	<b>Empowerment: Working with others to enhance their capacities, capabilities, and competencies</b>
<b>Restriction: Limiting an actor's ability to direct his or her own life</b>	<b>Advocacy: Standing up for, or beside, those who are oppressed.</b>
<b>Labelling: Tagging an actor with a descriptive term that carries a connotation of moral deficiency or social inferiority.</b>	<b>Courtesy: Demonstrating common respect.</b>
<b>Contempt: Treating an actor in a way that suggests he or she has no value.</b>	<b>Love: Honouring and esteeming others.</b>

The Australian Clinical Practice Guidelines and Principles of Care for People with Dementia recommended that the 10 Principles of Dignity of Care provide the standard by which person-centred care should be delivered and measured (Guideline Adaptation Committee, 2016).

## Dignity in Care Principles

1. Zero tolerance of all forms of abuse.
2. Support people with the same respect you would want for yourself or a member of your family.
3. Treat each person as an individual by offering personalised service.
4. Enable people to maintain the maximum possible level of independence, choice and control.
5. Listen and support people to express their needs and wants.
6. Respect people's privacy.
7. Ensure people feel able to complain without fear of retribution.
8. Engage with family members and carers as care partners.
9. Assist people to maintain confidence and a positive self-esteem.
10. Act to alleviate people's loneliness and isolation.

### ACTIVITY

**Navigate to a website called Fire Films** <https://www.firefilms.com.au/documentaries>

*Fire Films is a Melbourne based company that seeks to challenge inequalities in health and wellbeing and create social change. The short documentaries each feature an organisation who have embraced a model of care to support wellbeing of older people and those living with dementia.*

*Choose one documentary to watch.*

*What inspired you?*

## Context Specific approaches and models that support wellbeing

This section will explore the theories, models and approaches that have been translated into care in the residential, community and hospital settings. A selection of Australian approaches that can demonstrate an evidence-based outcome for wellbeing are described.

### Residential Aged Care

Just 5% of Australians over the age of 65 live in residential aged care (Australian Institute of Health and Welfare, 2017). However, 52% of the residential population have a diagnosis of dementia (Brown, Hansnata, & La, 2017), of which 87% will be classified as needing a high level of care (Australian Institute of Health and Welfare, 2012).

Aminzadeh et al. (2009) described the move into residential aged care as a profound experience and 'emotionally overwhelming' (p. 490). Whilst a positive aspect of residential care was the feeling of protection and safety as health and functional ability declined, people with dementia described the need to adjust from an individual way of life at home to a shared and structured way of life in communal living. They found they were more dependent on others, had limited personal space and mourned the loss of their community, their home, the memories therein as well as many of the belongings they could not bring with them (Aggarwal et al., 2003; Aminzadeh et al., 2009).

The transition into residential care can be difficult for the person with dementia and their family. The experience can be more positive if the following considerations are addressed:

- Understand the expectations of care
- Understand the losses, fears and hopes
- Support the emotional impact of the move into the facility
- Maintain the person's existing relationships in their community.

Person-centred models and interventions to support wellbeing in the residential setting are numerous.

## The ABLE model

*(Roberts, Morley, Walters, Malta, & Doyle, 2015; Winterton, Knight, Morley, & Walters, 2019)*

The ABLE model was developed by a regional health service in Victoria. The aim of the model is to support residents existing capabilities and enhance quality of life (Winterton et al., 2019). It amalgamates the Montessori approach and person-centred care with a focus on enablement. The four components of the model are:

**A** = Abilities and capabilities

**B** = Background of the resident

**L** = Leadership and organisational culture

**E** = Environment (Roberts et al., 2015)

The model was evaluated and found to be beneficial for residents living with dementia. The outcomes resulting from the implementation of the ABLE model were:

- A reduction or cessation of antipsychotic and sedative medications
- A reduction in agitated behaviour
- Increased engagement in meaningful activities
- An increase in person-centred care practices by staff
- Family satisfaction with care
- A homelike environment (Winterton et al., 2019)

## Humour therapy

Humour therapy is an art based non-pharmacological intervention that facilitates happiness and laughter. It consists of playful interactions using songs, jokes and props. The therapy has been found to reduce agitation and increase happiness for people with dementia (L. Low et al., 2014) as well as increase staff morale and job satisfaction (Chenoweth, Low, et al., 2014). Elder clowns are professional performers who receive additional training about dementia (Chenoweth, Low, et al., 2014; Kontos et al., 2016). Laughter bosses are aged care staff who receive training and mentorship by an Elder clown. Humour sessions are run once or twice a week led by the Elder clown and supported by the Laughter boss. The session is adapted to the residents preferred style of humour, their reactions and cognitive abilities (Chenoweth, Low, et al., 2014; L. Low et al., 2013).

## Intergenerational programs

Intergenerational programs provide interaction and engagement through structured or semi-structured activities between children and older adults living in residential care (Bagnasco et al., 2020). Intergenerational interventions carried out within the facility can reduce isolation, loneliness and boredom, create an enriched social environment and support relationship building between generations (Bagnasco et al., 2020; Cook & Bailey, 2013; Gerritzen, Hull, Verbeek, Smith, & de Boer, 2020). Such programs provide the opportunity for all participants to share their lived experiences and understand intergenerational differences (Cook & Bailey, 2013). For the older person it is an opportunity to share their knowledge and wisdom to the children (Cook & Bailey, 2013). Types of programs and activities include:

- Visual arts
- Performing arts and movement
- Pen pals
- Music
- Montessori
- Educational (person with dementia teaching the children)
- Narrative and story telling
- Recreational activities such as gardening, baking, table games

*(Galbraith, Larkin, Moorhouse, & Oomen, 2015)*

The Grandfriends intergenerational program took place in a residential care facility in New South Wales. Preschool children were partnered with a resident with dementia who became their Grandfriend. Once a week they do activities together such as discussions, craft and games. The benefits of the program for the person with dementia was increased engagement and enjoyment (L. Low, Russell, McDonald, & Kauffman, 2015).

## LIFE Ful – culture change approach

*(L. Low et al., 2018)*

LIFE Ful is a reablement program designed for the residential setting by the Sydney School of Health Sciences (University of Sydney). A reablement approach seeks to help the person to maintain capabilities and adapt to impairments associated with ageing and dementia. It needs staff who will engage with the person to enable their participation in daily social, recreational and self-care activities. The benefits of this reablement approach were improve mood, functioning and quality of life for residents (L. Low et al., 2018). The LIFE Ful program combined a person-centred philosophy of care with a staff behaviour change model. The interventions include:

- Establishing and supporting a leadership team in each facility to drive the practice change
- Establishing a 'Focus Carer' by matching a direct care worker with a resident who is rostered to their care for at least three shifts a week. This approach would promote relationship-centred care and improved collaboration with family.
- Introduction of a life history document called 'All about me' to improve staff understanding of the individual's psycho-social history
- 'Resident of the week' introduced within handover to promote communication within the team and reinforce staff practices
- Staff training

## Hospital

People with dementia who are hospitalised have levels of clinical complexity that are over four times higher than patients without dementia (71% compared to 16% respectively) (Australian Institute of Health and Welfare, 2019). In addition, clinical outcomes tend to be worse and lengths of stay longer than patients without dementia. Dementia and cognitive impairment are risk factors for delirium (Inouye, Westendorp, & Saczynski, 2014), however a key problem in the hospital setting is that dementia is not always recognised (Australian Institute of Health and Welfare, 2013). In order to improve the care for people with dementia, actions relating to cognitive impairment were added to the second edition of the National Safety and Quality Health Service (NSQHS) Standards following a three year Caring for Cognitive Impairment Campaign. Since the campaign, Australia has developed a number of approaches to promote wellbeing for people with dementia in the hospital setting.

## Cog Champs

*(Travers, Graham, Henderson, & Beattie, 2017; Travers, Henderson, Graham, & Beattie, 2018)*

The CogChamps program was developed in Queensland to promote best practice in the care of people with cognitive impairment and delirium in the hospital setting. A cognition champion role (CogChamp) was established to change nursing practice through an education and mentoring approach (Travers et al., 2017). The program involved upskilling the CogChamps in the assessment, management and prevention of delirium as well as change management skills. The CogChamp was supported through an expert facilitation approach. CogChamps then worked at ward level to develop action plans to improve practice, provide education to their peers, and lead practice in delirium assessments and care planning based on best evidence.

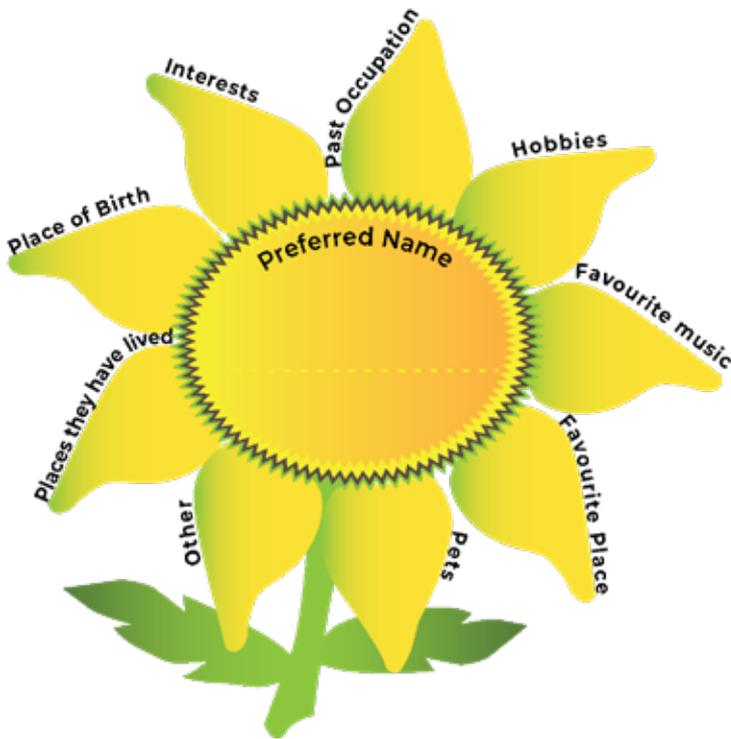
## Confused Hospitalised Older Persons program (CHOPs)

*(Kurrle et al., 2019)*

CHOPs is a model of care developed in New South Wales to improve practice in the recognition and management cognitive impairment related to delirium and dementia presentations in hospitals (Kurrle et al., 2019). The model addresses key principles for clinical practice; cognitive screening on admission, delirium risk and prevention, assessment and management of confusion. It also addresses key principles for implementation; person-centred communication, staff education and dementia friendly care environments. Implementation strategies include:

- Introduction of cognitive screening tools and delirium risk assessment tools
- Delirium alert stickers and forms
- CHOPs patient identifier
- Personal profile 'sunflower'
- Orientation resources - Large clock calendars, orientation boards, signage
- Activity resources: rummage and distraction boxes, fiddle aprons
- Information resources: admission packs, posters, brochures, lanyards, resource folders, computer resources and multilingual options for staff, volunteers, patients and visitors
- Guidelines on dementia, delirium and antipsychotic medication
- Staff education
- Dementia delirium volunteer program
- Environmental audit
- Specialised dementia unit

## Sunflower communication tool



The Sunflower was developed as part of the CHOPs program as a person-centred strategy to get to know the person receiving care. It provides a simple personal profile developed in partnership with the family that enhances communication and reassurance. The completed sunflower is laminated and either displayed at the bedside or kept in the patient file.

*Resource: Key Principles for Care of Confused Hospitalised Older Persons*

[https://www.aci.health.nsw.gov.au/\\_data/assets/pdf\\_file/0006/249171/CHOPS-key-principles1-2-web.pdf](https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0006/249171/CHOPS-key-principles1-2-web.pdf)

### ACTIVITY

**Using the search term 'life story tools dementia' Google other tools that support the collection of key information about a person that will support the delivery of individualised care.**

**Was there any particular tool that you liked?**

**Why?**

## Top 5

- T** Talk to the carer
- O** Obtain the information
- P** Personalise the care
- 5** 5 strategies developed

Top 5 was developed by Central Coast Local Health District, NSW. The aim was to engage with the family carer expertise to discover the five most important tips and strategies that could be implemented by hospital staff to lessen anxiety, confusion and disorientation for the person with dementia who had been admitted.

It involves a four-step process. The staff talk to the family carer to learn more about the person with dementia and their behaviour, particularly looking for advice on the best way to communicate with the person and how they may react to the changes in routine and environment. This information is then used to personalise the care for the individual by developing five strategies designed to support their wellbeing.

The strategies are modified to ensure they can be actioned in the care setting. The agreed strategies are recorded on an identifiable TOP 5 form, which is then included in the individual's care plan or kept in a place that enables all staff to access this information to support the care provided (Clinical Excellence Commission, 2014).

## Cognitive Impairment Identifier

The cognitive impairment Identifier is one component of the Dementia Care in Hospitals program developed by Ballarat Health (MacDermott et al., 2017). The aim is to help hospital staff identify the patient with cognitive impairment and adjust their communication strategies accordingly. All patients aged 65 years and older are screened for cognitive impairment using a validated screening tool. If the person has been identified as having a cognitive impairment, this image that you see here is placed at the persons bedside. Staff then know they should employ these nine communication strategies when engaging with this patient.

### Cognitive Impairment Identifier



® Ballarat Health

1. Introduce yourself
2. Make sure you have eye contact
3. Remain calm and talk in a matter of fact way
4. Keep sentences short and simple
5. Focus on one instruction at a time
6. Give time for responses
7. Repeat yourself...don't assume you have been understood
8. Don't give too many choices
9. Involve family carers

## Arts in health programme

An art in health program was implemented in Tasmania to address the psychosocial needs of hospitalised people with dementia (Ford, Tesch, Dawborn, & Courtney-Pratt, 2018). A dedicated space on the medical ward was set up for art activities which consisted of painting, drawing, plasticine modelling and collage; music and song; and 'tribute' artwork by a visual artist based on a person's life story. The ward environment was transformed through a combination of environmental modification, music and displayed participant artwork.

## Community

Government policy and older adults concur that home is the preferred place to receive support as people age. The National Centre for Social and Economic Modelling (NATSEM) estimated that 76% of people living with dementia in 2016 were living at home (Brown et al., 2017). At any one time, around 31% of people with dementia are in receipt of community support services (Access Economics, 2010). With the increasing prevalence of dementia it is predicted that 80% of aged care services will be delivered in the community (Productivity Commission, 2011).

Findings from an Australian study released in 2013 (Low, White, Jeon, Gresham, & Brodaty) revealed that people with dementia who received home care services defined their priorities as:

- Being able to stay at home, feel safe and have access to personalised activities and opportunities for socialisation
- Emotional support, respite and employment for informal carers
- Flexible and reliable community care services that provide adequate hours of care
- Continuity of care from appropriate well-trained staff.

Activities that have been tailored specifically for the interests and preferences of the person with dementia living at home have been found to increase quality of life, reduce the incidence of changed behaviours and improve family carer wellbeing (Möhler, Renom, Renom, & Meyer, 2020). The following programs have been implemented in Australia and are grounded in person-centred care principles.

### I-HARP reablement program

*(Jeon et al., 2019)*

The Interdisciplinary Home-bAsed Reablement Program (I-HARP) aims to reduce the risk of functional decline in people living with dementia in the community and increase quality of life (Jeon et al., 2019). The program is delivered in the persons home, but it needs community aged care and hospital-based community services to work together for the best outcome for the individual. Comprehensive assessments of cognitive and functional abilities, the environment, medication use, and other health issues such as pain, continence and depression are undertaken. Interventions are designed based on the persons needs and goals. These may include cognitive rehabilitation, task simplification, exercises to improve balance and strength, pain and mood management, medication simplification, home adaptations and assistive technology, and referrals to specialists. Carer support may also be provided within the program.

### COPE

*(Clemson et al., 2018; Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010; Rahja, Culph, Clemson, Day, & Laver, 2019)*

Another reablement program is called 'Care of People with dementia in their Environments (COPE)' (Clemson et al., 2018; Rahja et al., 2019). It requires nurses and occupational therapists to work collaboratively to support the capabilities of the person with dementia, prevent changed behaviours and support the wellbeing of the family carer. Following a comprehensive assessment, the family carer and the person with dementia receive up to 12 consultations from the health professionals over a four-month period. A range of interventions are provided which may include environmental modification, carer education and training, strategies for stress reduction and effective communication techniques, engagement in meaningful activity and task simplification (Gitlin et al., 2010). Family carers who have taken part in this program felt empowered to provide care to their loved one (Rahja et al., 2019).

## LEAP

(L. Low, Baker, et al., 2015)

The Lifestyle Engagement Activity Program (LEAP) was developed in Australia to be delivered as a component of case managed home care (Low, Baker, et al., 2015). The aim of LEAP is to change practice of care workers and case managers to include social support and recreation in care delivery. It involves staff training and development of the LEAP champions role (who are staff members of the home care provider). Training is provided to three staff groups:

- LEAP champions: change management and interpersonal skills
- Case managers: integration of meaningful recreational and social goals in care planning
- Care workers: understanding dementia and behaviours using the unmet needs model, communication skills, supporting autonomy and control, humour and reciprocity and a range of activities such as Montessori, reminiscence, music and physical activity.
- The LEAP Champion supports staff through buddy visits as they practice the client engagement techniques.

## Summary

This module has provided a brief overview of some of the key concepts that support wellbeing in people with dementia. Whilst it is acknowledged that dementia can have a profound impact on a person's life, this module has presented evidence that people can be supported to live well in all care settings. Regardless of which model or framework you base your practice upon; salutogenic theory, strengths based or rights based approaches, person centred or dignity preserving care, the prevailing message is that approaches to supporting people to live well with dementia needs services to move away from traditional clinical, problem-based approaches to care and reorientate 'care' to 'enhancing life'.

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