Advancing care in the practice of dementia

3rd edition

Module 6:

Philosophy of care

Dementia Training Australia

Contents

Module 6: Philosophy of care

Introduction

It is now accepted that a person-centred approach to care and practice informed by research evidence is the basis of quality health professional care. Having some understanding of the personal experiences of dementia and of the care that people receive enhances the ability of a health professional to provide person-centred care. Drawing on evidence-based resources, this module aims to assist the health professional to see and feel what person-centred care could look like in practice in their workplace. It provides a number of resources to help define and measure person-centred care as well as how it relates back to your organisational vision, values and commitment to person-centred care.

Objectives

- On completion of this session you will be able to:
- Understand the importance of a shared vision and values for person-centred care and its link to the delivery of a quality service to people living with dementia
- Empathise with the person's experience of dementia
- Increase your awareness of how care practices impact on those you support
- Discuss what is meant by person-centred care
- Measure person-centred care

Module topics

Philosophy of Care

Person-centred Care

The Experience of Dementia

The Experience of Care

Being Person-centred

Suggested readings for this module

Downs, M., & Bowers, B. (2008). *Excellence in Dementia Care. Research into Practice.* OUP: England

Brooker, D. (2007). *Person-centred dementia care: making services better*. London: Jessica Kingsley Publishers.

Kitwood, T. M. (1997). *Dementia reconsidered*. Bristol: Open University Press.

Care Fit for VIPS website www.carefitforvips.co.uk

Stirk, S., & Sanderson, H. (2012). *Creating Person-Centred Organisations: Strategies and Tools for Managing Change in Health, Social Care and the Voluntary Sector*. Jessica Kingsley Publishers.

What is it and why do we need one?

Philosophy of Care

A philosophy of care is a system of principles, beliefs, goals or values that guide and direct the services and care we provide or aspire to provide to people in our care. This philosophy is often reflected in the organisation's vision and mission statement and drives the culture of the organisation, teams and the care provided.

Person-centredness has become strongly associated with the care that health and aged care providers strive to achieve, particularly for people with dementia. Person-centred care provides the philosophy and principles that can be translated into organisational values and practice.

There are an increasing number of person-centred care models, some of which are described later in this section. Dawn Brooker's VIPS model provides a straightforward approach to person-centred thinking. 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 **I**ndividuals

Understanding the world from the **P**erspective of the person living with dementia

Providing a **S**ocial environment that supports psychological needs.

Returning to the mission and vision statement.

The vision statement describes the ultimate goal the organisation wants to achieve. In turn, this provides a clear sense of direction and purpose upon which to build service delivery. The values and beliefs will describe what person-centred dementia care looks like for the organisation, the team, individual staff and the service user. When developing the organisational vision and values it is important to include the perspectives of consumers and stakeholders of your service.

Activity

Locate your organisation's vision/mission statement and values
Register and log into Care Fit for VIPS website
http://www.carefitforvips.co.uk
and self-rate your organisation's philosophy of care against the Vision statements under the VALUES tab.

Enacting your values through language

The language used across the organisation is reflective of the way organisational values are enacted.

Language and behaviours used by staff that undermine personhood and person-centred care are indicative of a negative attitude, particularly where derogatory labels are used to describe the person as 'demented', a 'wanderer' or 'attention- seeking.' Examination of approaches to care may reveal practices and procedures that concentrate on the person's deterioration and losses, focusing on what they cannot do, or they promote the use of medication or restraint as first-line treatment to symptoms of dementia (Alzheimer Society Canada). http://www.alzheimer.ca/~/media/Files/national/Culture-change/culture_person_centred_language_2012_e.pdf

In an organisation with a person-centred culture, the language of staff will be enabling, respectful and inclusive towards the person they are supporting as well as to each other. Leaders and dementia champions can advocate and model person-centred thinking, behaviours and language in their day-to-day work, potentially reshaping the thoughts, attitudes and actions of those around them.

Activity

Listen to the language used by your staff in handovers, in meetings and on direct contact with the person with dementia and their families.

- Does it reflect organisational values?
- Is it person-centred and respectful?
- What can you do to promote person-centred language, attitudes and practices towards people living with dementia in your workplace?

The quality agenda and person-centred care

It is thought that person-centred care has the same constructs as good quality care (Edvardsson, Fetherstonhaugh, Nay et al., 2010; Brooker, 2004). In turn, quality of care becomes linked to quality of life. The relationship the person with dementia has with direct care staff and the way in which care is experienced will directly affect the way in which service quality is perceived (Qureshi, 2000; Van Baalen et al., 2011). The experience of living with dementia will also impact on the perceived quality of care (Van Baalen et al., 2011). Care quality is also measured in relation to the way it contributes most to the wellbeing of the person (Slagsvold, 1998 cited in Qureshi 2000).

Quality standards have been defined and incorporated into the respective service accreditation processes to ensure Australians are receiving the best care possible in our health, community and residential aged care services..

Health Services

The National Safety and Quality Health Service Standards published by the Australian Commission on Safety and Quality in Health Care (2011) were introduced into the accreditation process in 2013. Ten standards focus on governance, partnerships with consumers and key clinical processes

	Standard
1	Governance for safety and quality in health service organisations.
2	Partnering with consumers.
3	Preventing and controlling healthcare-associated infections.
4	Medication safety.
5	Patient identification and procedure matching.
6	Clinical handover.
7	Blood and blood products.
8	Preventing and managing pressure injuries.
9	Recognising and responding to clinical deterioration in acute health care.
10	Preventing falls and harm from falls

Community Services

The Community Care Common Standards were introduced in 2012 across the Home Care Packages and National Respite for Carers Program. There are three standards and 18 expected outcomes

	Standard	Number of Expected Outcomes
1	Effective management.	8
2	Appropriate access and service delivery.	5
3	Service user rights and responsibilities.	5

Residential Aged Care

The residential aged care accreditation standards are managed by the Australian Aged Care Quality Agency. Four standards must be met and 44 outcomes identify what people should expect when homes meet the standards.

	Standard	Number of Expected Outcomes
1	Management systems, staffing and organisational development.	9
2	Health and personal care.	17
3	Resident lifestyle.	10
4	Physical environment and safe systems.	8

Person-centred care

What is person-centred care?

Carl Rogers developed the concept of person-centred care (Rogers, 1951), which is based on a belief in genuine connection and communication (Rogers, 1951).

The notion of personhood and person-centred care of people with dementia was introduced by Tom Kitwood (1997). He promoted respect and preservation of dignity as core principles in providing care. He stated that these principles can only be upheld if caregivers recognise and incorporate understanding of the experience of living with dementia into care planning.

Person-centred care is therefore much more than providing choice. It is about relationship and connection with the individual. Nay, Bird, Edvardsson, Fleming, and Hill (2009) emphasised this in stating:

> *"The need for a recognition of, and connection with, the person, a focus on the person's strengths and goals, an interdisciplinary approach, and recognition of the centrality of relationships" are essential components of person-centred care* (Nay et al., 2009, p. 109).

Common core elements

Ten Key Principles of Person-centred dementia care were originally described by Loveday et al. (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.**

There are many definitions and explanations of the meaning of person-centred care; although common themes present, many people have a different understanding of what person-centred care is and what it looks like in practice. This is reflected even in the terminologies used over the years such as patient-centred, client-centred, consumer-centred, relationship-centred and person-centred care. Hughes et al. (2010) reviewed many types of centredness and found ten common themes:

- Respect for individuality and values
- Meaning
- Therapeutic alliance
- Social context and relationships
- Inclusive model of health and wellbeing
- Expert lay knowledge
- Shared responsibility
- Communication
- Autonomy
- Professional as a person.

The UK has supported an approach to their personalisation and person-centred care agenda, through the introduction of 'Person-centred thinking'. Bowers et al. (2007) describes the fundamental skill to person-centred thinking 'as being able to separate what is important to someone, from what is important for them' (p. 11). This is a useful approach for health professionals during the assessment and planning phases of care, as it promotes collaboration, choice and control for the person with dementia.

Given that person-centred care for people with dementia has been increasing in popularity over the past three decades, some difficulties remain in applying the concept into practice. Dow et al. (2006) have identified a number of barriers to person-centred care; these include:

- Poor clarity about what constitutes person-centred care
- Time restrictions
- Limited staff autonomy to choose to practice in a person-centred way
- Organisational needs being prioritised over the consumer's needs.

Dow et al. (2006) and Tinney et al. (2007) also identified a number of aspects that facilitate person-centred care:

- Knowledgeable and skilled dementia champions
- Stakeholder participation in service development
- Staff training and education
- Organisational support
- Delivering the service in the person's home.

The evidence base for person-centred care

There is increasing empirical evidence that person-centred approaches have beneficial outcomes for the person with dementia and care providers. In Australia a number of research findings have been published

The CADRES study (Chenoweth et al., 2009) provided first level evidence through a cluster randomised trial that investigated the efficacy of person-centred care and dementia care mapping on the reduction of agitation in people with dementia. They found that person-centred care:

- Reduced agitation
- Increased resident wellbeing
- Improved staff interactions
- Improved care quality.

Following on from the CADRES study, the research team undertook The PerCEN study that looked at outcomes of person-centred approaches and person-centred environments. They found that by combining these, there were the following benefits for residents:

- Reduced agitation
- Reduced incidence of depression
- Increased quality of life
- Increased functional ability
- Positive emotional responses to care.

The Australian EN-ABLE project used the TEAM approach to implement person-centred care to reduce need-driven behaviours. This study found statistically significant results in:

- Reduced incidence and severity of agitation
- Reduced incidence of falls and injuries
- Increased care quality

https://www.qut.edu.au/research/research-projects/enable-project-toolkit-dementia

An interesting practice development project from the Republic of Ireland by McCormack and Dewing, who implemented a model of person-centred care called the Person-centred Nursing Framework (McCormack et al., 2010) in combination with a practice development approach across 17 residential facilities. The outcomes were:

- Enhanced care for older people
- Increased staff awareness of person-centred principles and change in practice towards person-centred care
- Personal and professional growth of staff
- Improved culture of care.

Later in this module a number of tools that have been developed and validated to measure person-centredness in care provision have been described. Together, the research and validated tools provide the wherewithal to apply person-centred approaches into practice.

Self-identity and personhood

The sense of self and self-identity is our existential core; in person-centred care this is described as personhood. Self is an "inner essence" consisting of qualities and characteristics created throughout the person's life that are unique to them and forms their identity (Crisp, 1999). 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. Our role as care providers is to support the person living with dementia to maintain personhood. We can achieve this through person-centred care, the quality of the relationship we develop with the person, and understanding the person's experience of dementia and of the experience of care.

The Experience of Dementia

In order to be person-centred it is important that we attempt to understand what it is like to live with dementia. The experience of dementia will be different for every person with the disease. While there is an understanding of how dementia affects the brain, and the brain damage that can be expected in the various disease categories of dementia, the personal journey of disease progression will vary from person to person. Religious and spiritual beliefs, cultural backgrounds and socioeconomic circumstances will shape how a person with dementia views both normal life and life with dementia.

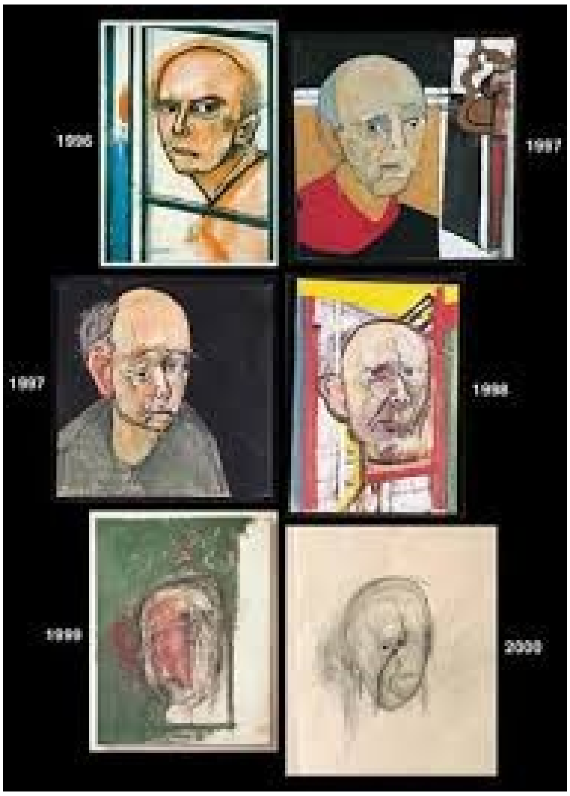
There are many ways we as health professionals can begin to engage with the person's lived experience of dementia; the personal stories told by people with dementia through the media, books, poetry and art; hearing their voice through research, experiential learning and most importantly engaging with our clients, patients or residents to hear their story, through the life history commonly collected as part of the service admission process. Added to this are opportunities to engage with people who work as advocates in the public eye; as ambassadors, champions and members of consumer advisory groups at organisational and governmental levels.

Awareness through personal stories in media, poetry, books and art

There are an increasing number of narratives that describe the experience of dementia from the perspective of the person with the diagnosis or of close family and other advocates.

Well-known autobiographies have been penned by Hazel Hawke (1993) and Christine Bryden (2005), supported by their respective families and friends. There is inspirational poetry facilitated by authors such as John Killick and Graham Stokes.

Hopefully you have been fortunate enough to see the insightful photography by Cathy Greenblat.



In the world of art, the images by William Utermohlen provide a powerful artistic portrayal of the experience of dementia. The first self-portrait was completed in 1996 a year after the artist was diagnosed with Alzheimer's Disease. He continued to complete self-portraits over an eight-year period, adapting to the limitations in perception and motor skills brought about by the dementia.

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Cathy Greenblat photography: http://www.cathygreenblat.com

Awareness through research

In a review in understanding subjective experiences of dementia by Alison Phinney (2009), she describes how research has identified the profound negative and positive effects that the experience of dementia can have on the person.

Social disconnectedness resulting from:

- Fewer opportunities to connect with others
- Being treated differently by others
- Exclusion
- Loss of friends
- Loss of valued social roles.

Negative feelings that include:

- Intense anger and frustration, which is usually self-directed but occasionally directed at others
- Fear about the future and the experience of confusion in the moment
- Loss of confidence in their ability to carry out everyday activities; to participate in conversations, to maintain control over their lives and remain independent
- Loss of self-esteem resulting from the feelings of uselessness, unproductivness, incompetence, a burden and unimportant
- Sadness and hopelessness of the situation, for their losses and feeling a burden on others.

But research has also helped to identify the strengths and coping mechanisms that people draw on in oder to adapt to the challenge of dementia. People with dementia describe the following practical problem-solving strategies:

- Using memory stratgeies such as making notes and lists
- Developing systems to keep organised and in control
- Plan ahead of time and practice activities
- Simplifying tasks and activities and allowing more time to achieve them;
- Simplifying and maintaining a routine
- Lowering their personal expectations and demands of themselves
- Avoiding or taking time out from difficult or challenging situations
- Seeking and accepting practical and emotional support from others
- Keeping active and finding ways to be of help or value to others in a way that gives their life meaning and purpose.

People living with dementia have also described emotion-focused strategies that enable them to remain positive whilst living with the disease. First is to downplay or minimise the impact of dementia with common behaviours such as:

- Denial or refusal to think about the diagnosis
- Minimise the level of impairment
- Normalising the symptoms as common to ageing.

The second strategy is to maintain a positive outlook with hope, humour and to enjoy living in the moment.

> *Many people with dementia say they have chosen to not worry about their future, but rather strive to appreciate and enjoy what they have today.* Phinney (2009) p. 3

Activity

Visit the following websites, which give insight into the experience of dementia from the perspective of the person with dementia:
http://www.dementiajourney.ca/Home.aspx
http://www.nhs.uk/Conditions/Dementia/Pages/Denisesstory.aspx
http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pspages/ps_alzheimers_disease?open

Awareness through Life History

A person's history tells us what is important to them and how they would like to be supported (Sanderson and Lewis, 2011). Engaging with the person living with dementia and their family by collecting the life history is a powerful and enjoyable opportunity to understand the person, help maintain personhood and enhance care. Increasingly, aged care service providers are realising the benefit of life history information for person-centred practice, improving quality of care and quality of life.

Life history can be used effectively to support staff to understand the person's experiences of dementia, their needs and behaviour in the context of their life and enable them to:

- Provide emotional care by developing an understanding of the person's past experiences and the way they have coped with life events
- Support the person's identity (personhood)
- Build relationships with the person and their family as well as to support the person to develop a sense of belonging and meaningful connections with their peers
- Support interaction and communication (verbal and behavioural)
- Provide individualised care such as maintaining habitual routines and access to preferred occupation and activities.

Information collected from a person’s life history includes details about the person’s:

- Interests
- Routines
- Social networks
- Social roles
- Cultural background
- Spirituality

Sexuality and special or traumatic events in their life (Burns et al., 2012)

For life history work to be beneficial to the staff and the person with dementia it needs to be communicated to the care team.

Activity

1. Randomly choose a person’s care notes/medical notes and locate any documented life history information that may have been gathered.
2. Review the care plan. Can you see any evidence of this information being translated into individualised interventions?

Think of ways in which the person’s life history could be communicated across the care team.

Awareness through experiential learning

There is no way for health professionals to share the experience of dementia but it is possible to gain some understanding through experiential learning.

The Perc Walkley Dementia Learning Centre is a recent innovation from Alzheimer’s Australia Vic. It utilises multi-sensory simulation using light, sound, colour and visual content on a platform of gaming technology to create a virtual reality experience of living with dementia for professional carers. The virtual dementia experience can be accessed through the Alzheimer’s Australia Vic. education and training calendar. An experiential workshop ‘Experiencing Dementia’ developed by Bundoora Extended Care Centre provides health professionals with a brief glimpse into the experience of having dementia and being admitted to a hospital or residential care facility. This powerful workshop involves each participant adopting the role of a person with dementia and through this experience provides insight into what it might be like to be living with dementia.

Experiencing Dementia: an experiential workshop. Facilitator's Package. (2007). Bundoora Extended Care Centre: Melbourne.

The Virtual Dementia Experience: Alzheimer's Australia Vic education and training calendar http://www.fightdementia.org.au/victoria/education--training-in-vic-1.aspx

Ambassadors and Advocates

Increasingly, the voices of people with dementia are being heard and valued in policy, research and organisational development. Advocates include the Consumer Dementia Research Network (CDRN), a national group of 25 people who either have dementia or are carers of a loved one with dementia. The CDRN set priorities for research and maintain active roles in research activities in dementia-related research centres.

Kate Swaffer describes herself as an advocate and activist for aged and dementia care. Find her on her website and blog www.kateswaffer.com

The takeaway message is that active inclusion of the consumer voice in organisational quality and development processes will promote the development of quality processes and approaches that promote satisfaction with care

The Experience of Care

As we embrace a person-centred approach we need to recognise how our care practices impact on the person and their families. There is consensus that staff need to move away from ways of working that are centred on the task or medical condition to see the person behind the disease (Edvardsson et al., 2010). The experience of being a care recipient of hospital, community or residential aged care has been described and induces service providers to ensure their practices promote quality of care and quality of life for the recipient.

Hospital

It is estimated that 20% to 30% of people in Australian hospital wards will have dementia (MDAG, 2012). Failure to recognise that the person has dementia early in their hospital admission is likely to prohibit them from receiving the specialised care that they require to enable a good experience and outcomes (AIHW., 2012, Thompson, 2011).

For a person with dementia, hospitalisation can be strange and unfamiliar, resulting in some profound experiences and unwanted outcomes:

- One in every five people with dementia are discharged into residential aged care (AIHW 2012)
- The average length of stay for a person with dementia is 16 days compared to six days for other patients (AIHW 2012)
- Communication and sharing of information with the person with dementia and their family is poor (Moyle et al., 2010)
- The person is often discharged with a reduced level of functioning (Lackey, 2009).

The person with dementia is likely to experience distress, often leading to the behavioural and psychological symptoms of dementia. Some of the causative factors are:

- Difficulty communicating their needs (such as hunger, thirst, pain, comfort and elimination)
- Delirium
- Multiple moves within and between wards
- Unfamiliar, busy and noisy environment
- Lack of staff continuity
- Staff care practices based on a biomedical model rather than a holistic person-centred approach.

Efforts to promote better dementia care in hospitals are underway both in Australia and internationally. This includes adjustments to the environment to make them more dementia friendly; ensuring staff have the core skills and knowledge in dementia care as well as access to dementia experts (Edvardsson, Koch, & Nay, 2010).

The Royal College of Nursing in the UK promote five principles to support good dementia care in the hospital environment using the mnemonic 'SPACE'(2013):

Staff who are skilled and have time to care
Partnership working with carers
Assessment and early identification
Care that is individualised
Environments that are dementia friendly

http://www.rcn.org.uk/__data/assets/pdf_file/0011/480269/004235.pdf

Australia and the UK have developed resources to guide staff in the provision of care for people with dementia in the hospital environment.

The DTSC EN-ABLE toolkit for staff in residential aged care facilities is a comprehensive evidence-based dementia care package founded on person-centred care (PCC) and the need-driven behaviour model (NDB). The package includes an education program, resident assessment tools, an implementation strategy and evaluation tools; it is designed to educate care staff on ways of optimising communication with residents, minimising the risk of negative behaviours, and how to assess and understand the person and their behaviour.
https://www.qut.edu.au/research/research-projects/enable-project-toolkit-dementia

Getting to Know Me: http://www.gmhiec.org.uk/training-materials/view/getting-to-know-me

Best care for older people everywhere toolkit:
http://www.health.vic.gov.au/older/toolkit/
The aim of *The toolkit* is to assist clinical staff to minimise the functional decline of older people in hospital

Community

Government policy and older adults concur that home is the preferred place to receive support as people age. In 2011 it was estimated that 70% of people with dementia live at home (DoHA, 2012). 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 (ProductivityCommission, 2011).

Findings from an Australian study released in 2013 by Low et al. 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.

There is evidence to show that quality community aged care services can have a positive impact through:

- Reduced likelihood of hospitalisation (Draper, 2011)
- Delayed entry into residential care (Draper, 2011)
- Better management of medications (Kralik et al., 2008)
- Increased carer health and wellbeing (Brooker, 2007).

Exploring and addressing the needs of family and other informal carers is of paramount importance as they provide a considerable proportion of support to people living with dementia in the community (Access Economics Pty Ltd, 2009). It has been identified that they are more likely to provide 40 or more hours a week of care (AIHW 2012).

When compared to other carers, the caring role for relatives caring for a person with dementia is likely to result in a higher incidence of:

- Exhaustion
- Anxiety and depression
- Stress-related illness
- Sleep disturbance (AIHW 2012).

Carers for people with dementia need access to effective interventions that can reduce the risk of experiencing depression, strain, social isolation and financial burden (Parker et al., 2008).

Community-based informal carers have identified the need for:

- Responsive service provision, including information and support
- Recognition of the carer's role by professionals
- Recognition of the health costs of caring
- Identification and support of the hidden carer.

Carer health is explored in detail in module 10.

Residential

In residential aged care, 53% of residents have dementia, of which 87% will be classified as high care (AIHW, 2012). The reasons for entry into an aged care facility include:

- Physical and functional disability
- Mental health issues
- Apathy
- Carer stress and breakdown
- Inadequate living environment
- Loneliness and isolation.

(Fossey, 2008)

Whilst dementia care mapping provides an observational tool to measure care experiences from the perspective of the person with dementia, researchers have sought this information directly from the person. Aminzadeh et al. (2009) described the move into residential aged care as ‘a profound experience’ and ‘emotionally overwhelming’. Whilst a positive aspect of residential care was the feeling of protection and safety as health and functional ability declines, 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.

A good transition can be achieved by engaging with the person and their family carer and fully involving them in the life of the resident and the care processes for the individual. There are a number of ways to get to know a resident, encourage partnership and relationship building:

- Life history work that understands what is important to the person
- Planning care together.

Activity

Looking at the care environment in which you work, what practices do you and your team have to ease the person’s transition into the residential home?

Imagine yourself as a patient, resident or client in your workplace and consider the following:
How would the care team know ***what is important to you***?
What choice do you get in determining ***what care is important for you***?
How is your sense of self supported within the care relationship and care environment?

Resources	Royal College of Nursing. (2013). *Dementia: Commitment to the care of people with dementia in hospital settings.* London: Royal College of Nursing.
Recommended reading	Cathy Greenblat (2012). Love Loss and Laughter. Seeing Alzheimer's Differently http://www.lovelossandlaughter.com John Killick (see website) http://www.dementiapositive.co.uk Graham Stokes (2010) And still the music plays – Stories of People with Dementia Hazel May et al. (2009). Enriched Care Planning for People with Dementia A Good Practice Guide to Delivering Person-Centred Care Jackie Pool (2011). The Pool Activity Level (PAL) Instrument for Occupational Profiling - A Practical Resource for Carers of People with Cognitive Impairment

Being Person-Centred

A whole of organisation approach

We are learning that successful person-centred care approaches are created and sustained in person-centred environments. A whole of organisation approach is required to effectively implement person-centred care. Nay et al. (2009) identify that a person-centred organisation will have:

- A person-centred philosophy that is understood and embraced by all staff

Leadership that models person-centredness in all actions and decisions

- Relationships across the organisation that demonstrate valuing of employees
- Flexible systems and processes that enable staff to move away from task-oriented care
- Environments that value and support people living with dementia, families and staff
- Acknowledge the importance to wellbeing of supportive relationships

Person-centred culture

The development of a person-centred culture of care will be driven by the organisational vision and its values base. Understanding the meaning of person-centred care and how it would look for your organisation or team is an important first step that can be supported by referring to a published person-centred model or framework.

Models

The following models or frameworks are useful across disciplines and care environments but are specific to certain populations:

Model or Framework	Population
The VIPS Framework Brooker (2007)	Dementia specific
The senses framework Nolan et al. (2004)	Older people

The following models or frameworks more suited to the health or residential environment; the multidisciplinary team and the general population.

Model or Framework	Environment	Profession	Population
Person-centred Nursing Framework McCormack et al. (2010)	Residential and Health care	Nursing	General
Eight Dimensions of Person-Centred Care. (Picker Institute (2012))	Health Care	Multi - disciplinary	General
Best care for older people everywhere. The toolkit. Person-centred Practice. Dept.HealthVictoria (2012)	Health care	Multi - disciplinary	Older people
Patient-centredness: a conceptual framework Mead and Bower (2000)	Medicine	Doctor	General

Person-centred Leadership

Person-centred leaders are not necessarily senior members of the leadership team.

They can be found across staff groups and are often described as champions. Williams and Sanderson (2006) describe a leader as ‘anyone who helps to define and change the way that things are done’ (p. 8). They have “we can do it” attitudes and are willing to challenge poor practice. These leaders will promote the vision for person-centred care and lead by example. The Williams and Sanderson document ‘What are we learning about person-centred organisations’ is freely available online http://www.helensandersonassociates.co.uk. It provides a useful description of leadership roles for care workers, qualified staff and the executive team.

The growth of a person-centred leadership team starts with the organisation’s vision and the commitment at executive level to invest in and support the growth of their leaders. A stable leadership promotes strong teamwork, staff retention, empowerment, and successful introduction of planning and delivery of person-centred care (Jeon, 2012). Stirk and Sanderson (2012) identify the tasks of person-centred leadership as:

- Retaining a central focus on what is important for staff and consumers

- Promoting continuous learning and improvement of self, staff and organisation
- Establishing inclusive relationships that are appreciative of others and bring about trust
- Facilitating teamwork
- Addressing behaviour that is not person-centred
- Enabling choice and control for consumers and staff in their lives

Activity

What have you done today that reflects the values of the organisation in which you work?

Person-centred work place

Kitwood (1997) strongly advocated that in order for staff to provide person-centred care they need to experience a person-centred workplace. Stirk and Sanderson (2012) describe some effective workplace factors that support person-centred care:

- A shared sense of purpose driven by the vision and values of the organisation
- Good leadership
- Values their employees
    - providing opportunities for education, reflection and continuous improvement
    - providing opportunities for staff to use their skills, interests and strengths in the work they do.

Job satisfaction is a good measure of supported and valued staff. The CADRES study also explored the impact of person-centred care on staff outcomes (Jeon et al., 2012) and found the following benefits:

- Decreased staff stress
- Increased psychological wellbeing
- Job satisfaction
- Improved attitudes and reactions to people experiencing the behavioural and psychological symptoms of dementia
- Improved quality of care
- Perceived support from their managers.

Making PCC tangible and measureable

We now have access to an increasing number of tools that measure person-centred care. These provide leaders and managers opportunities to self-assess, benchmark and evaluate change in person-centred practice over time. A number of tools are described in the following section.

Tools to measure PCC in any setting

Tool	Description
Care Fit for VIPS www.carefitforvips.co.uk Brooker UK	25 outcomes across the four VIPS elements. Self-assessment tool based on a quality improvement cycle and supported by a library of resources.

Tools to measure PCC in residential care

Tool	Description
TURNIP: The Tool for Understanding Residents' Needs as Individual Persons Edvardsson et al., 2011 Australian	39 items across five subscales: 1. The care environment 2. Staff members' attitudes towards dementia 3. Staff members' knowledge about dementia 4. Care organisation 5. Content of care provided. The tool can be used as a base for clinical interventions; promoting discussions about the quality of current care; and how to increase person-centredness of the care provided.
P-CAT: Person-centred Care Assessment Tool Edvardsson et al., 2010 Australian	The tool consists of 13 items across three subscales: 1. Personalising care 2. Organisational support 3. Environmental accessibility. It provides a self-report assessment scale which measures the extent to which staff rate their settings to be person-centred.
DCM: Dementia Care Mapping Bradford dementia group UK (requires training to use)	Consists of four coding frames 1. Behaviour categories (23 items) 2. Mood enhancers (6 item scale) 3. Personal detractors (17 items on a 2 point scale) 4. Personal enhancers (17 items on a 2 point scale) It is an observational tool that views the experience of care from the perspective of the person with dementia.

QUIS: Quality of Interaction Schedule Dean et al., 1993 UK	Observation tool that measures quality of life and social interations
Individualised Care Inventory Chappell et al., 2007. Canada	Three tools for measuring long-term aged care staff perceptions of individualised care Tool 1 “knowing the person” in 13 items. Tool 2 “resident autonomy” in 15 items Tool 3 “communication” through 18 items
Long-term care improvement guide self-assessment tool Picker Institute US	The tool has seven performance areas: 1. Building community 2. Individual and community life 3. Culinary engagement 4. Authentic experiences that promote wellbeing 5. An environment of living 6. Community connections 7. Transitions of care Plus an initiative prioritisation tool. The assessment tool is organised around important aspects of a resident-centred culture based on Kotter’s change management principles. http://www.residentcenteredcare.org/Pages/About%20the%20guide.html

Tools to measure PCC in health care

Tool	Description
POPAC: The Person-centred care of Older People with cognitive impairment in Acute Care Scale. Edvardsson et al., 2013 Australia	15 item scale with three subscales 1. Using cognitive assessments and care interventions 2. Using evidence and cognitive expertise 3. Individualising care. Development of best practice nursing care for patients With cognitive impairment in the acute hospital environment.
The Person-Centred Climate Questionnaire staff and patient versions. Edvardsson et al., 2008, 2009, 2010. Validated in Australia	Two tools that aim to measure the extent to which the Psychosocial environment of health care settings is Perceived to be person-centred. The staff tool contains 14 items in four subscales: 1. Safety 2. Everydayness 3. Community 4. Comprehensibility. The patient tool contains 17 items in two subscales: 1. Safety 2. Hospitality.
PCIS: The Person-Centred Inpatient Scale. Coyle and Williams (2001) Validated in Australia	A tool to assess person-centeredness in health care. The tool measures recipient experiences of care and contains 20 items in five sub-scales: 1. Personalisation 2. Empowerment 3. Information 4. Approachability/availability 5. Respectfulness.

Tools to measure PCC in the community

Tool	Description
The Client-Centred Care Questionnaire (De Witte et al., 2006).	A 15-item questionnaire measuring the extent to which older people receiving home care experience the care as being client-centred
Valuing People Alzheimer's Australia (2014). www.valuingpeople.org.au	This is a guidance tool based on five guiding VALUE's for person-centred care.

Activity

Choose and locate a PCC measurement tool that is appropriate for your work environment (hospital, residence or community) from the list above. Complete the tool as objectively as possible. Do you agree with the results? If you have identified areas that could be improved, how would you do it?

Other useful tools for supporting PCC

- **Educational Package for Person-Centred Care (EPP-CC) (Edvardsson, Nay & Fetherstonhaugh, 2010)**
- The Environmental Assessment Tool (EAT) (Fleming & Forbes)
- Building Effective Engagement Techniques (BEET) Tool (Lawless & Walsh, 2008).

Summary

This module has explored the concept of person-centred care and what this would look and feel like in your workplace. It has briefly addressed some key components for creating person-centred approaches in your team or organisation. This must begin with empathy for the person's lived experience of dementia and an understanding of how care practices can support or undermine the person's identity.

Resources and References

Alzheimer's Australia. Valuing People: The preferences, needs and values of people living with dementia and their carers to lead decision-making in dementia care http://www.valuingpeople.org.au/

Dementia Dynamics Toolkit http://www.dementiadynamics.com.au/

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