



APPENDICES

6



**UNDERSTAND ALZHEIMER'S
EDUCATE AUSTRALIA**
FIGHTDEMENCIA.ORG.AU

NATIONAL DEMENTIA HELPLINE 1800 100 500

APPENDIX I: MODELS, PRINCIPLES AND THEORIES OF PERSON-CENTRED CARE

Models and theories

Alzheimer's Australia. (2003). *Quality dementia care. Position Paper 2*. http://www.fightdementia.org.au/common/files/NAT/20030200_Nat_NP_2QualDemCare.pdf

Context of care – Residential and community and aged care

Professional group – Generic

Focal group – Dementia-specific

Evidence base – Theoretical

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

Context of care – Generic

Professional group – Generic

Focal group – Dementia-specific

Evidence base – Theoretical

Edvardsson, D, Winblad, B & Sandman, P. (2008). Person-centred care for people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology*, 7: 362–367.

Context of care – Clinical care

Professional group – Care staff

Focal group – Dementia-specific

Evidence base – Literature review

Principles of person-centred care

- Valuing the worth of every person
- Relating to the person rather than the illness
- Maximising autonomy, independence and participation
- Responding to the needs of the whole person
- Providing an environment and experiences that are enriching and meaningful
- Recognition of the importance of working partnerships with family and friends

The VIPS Framework:

- Valuing people with dementia and those who care for them
- Treating people as individuals
- Understanding the world from the perspectives of the person living with dementia
- Providing a social environment that supports psychological needs

Components of person-centred care for people with severe Alzheimer's disease:

- Seeing the 'self' of the person living with dementia as hidden not lost
- Acknowledge the personhood of people with Alzheimer's disease in all aspects of care
- Personalising care and the environment; making room for shared decision-making
- Interpreting behaviours from the person's viewpoint; integrating care tasks in relationships

Models and theories

Loveday, B, Kitwood, T & Bowe, B. (1998). *Improving dementia care: a resource for training and professional development*. London, Hawker Publications.

Context of care – Generic

Professional group – Generic

Focal group – Dementia-specific

Evidence base – Theoretical

Principles of person-centred care

Ten Key principles of person-centred care

- Attend to the whole person
- See each individual as special and unique
- Give respect to the past
- Focus on the positives
- Stay in communication
- Nourish attachments
- Create community
- Maximise freedom and minimise control
- Don't just give – receive as well
- Maintain a moral world

Slater, L. (2006). Person-centredness: A concept analysis. *Contemporary Nurse*, 23, 135–144.

Context of care – Health care

Professional group – Multidisciplinary

Focal group – General population

Evidence base – Literature review

Attributes:

- Recognition of personhood
- A therapeutic relationship between the person and health care provider
- Respect for the person's individuality
- Care that reflects professional ethical standards
- Identification and reinforcement of strengths
- Acknowledgment of the person's lived world
- Empowerment of the person to make decisions

Victorian Department of Health. (2012). *Best care for older people everywhere. The Toolkit 2012*. <http://docs.health.vic.gov.au/docs/doc/Best-care-for-older-people-everywhere-The-toolkit-2012>

Context of care – Health services

Professional group – Multidisciplinary

Focal group – Older people

Evidence base – Evidence-based

Principles of person-centred practice:

- Getting to know the person
- Sharing power and responsibility
- Service flexibility
- Coordination and integration
- Environments

Models and theories

McCormack, B, Dewing, J, Breslin, L, Coyne-Nevin, A, Kennedy, K, Manning, M, Peelo-Kilroe, L, Tobin, C & Slater, P. (2010). Developing person-centred practice: nursing outcomes arising from changes to the care environment in residential settings for older people. *International Journal of Older People Nursing*, 5, 93–107.

Context of care – Hospital

Professional group – Nursing

Focal group – Dementia-specific

Evidence base – Literature review

Picker Institute. (2012). *The eight picker principles of patient-centered care*. <http://pickerinstitute.org/about/picker-principles/>

Context of care – Hospital

Professional group – Multidisciplinary

Focal group – General population

Evidence base – Evidence-based

Dow, B, Haralambous, B, Bremner, F & Fearn, M. (2006). *What is person-centred health care? A literature review. Report to the Department of Human Services*. Melbourne: National Ageing Research Institute.

Context of care – Health services

Professional group – Multidisciplinary

Focal group – Older people

Evidence base – Evidence-based

Principles of person-centred care

Constructs:

- Prerequisites – attributes of care workers
 - The care environment – systems, relationships, shared power, innovation and risk taking, physical environment
 - Person-centred processes – working with beliefs and values, engagement, sympathetic presence, shared decision-making, holistic care
 - Outcomes – involvement in care, satisfaction with care, feeling of wellbeing, a therapeutic environment
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Principles:

- Respect for patients' values, preferences and expressed needs
 - Coordination and integration of care
 - Information, communication and education
 - Physical comfort
 - Emotional support and alleviation of fear and anxiety
 - Involvement of family and friends
 - Transition and continuity
 - Access to care
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Principles of person-centred care within the concept of partnership:

- Getting to know the client as a person – holistic and individual approach
 - Sharing of power and responsibility – client as expert, shared decision-making, information
 - Accessibility and flexibility
 - Coordination and integration – from the point of view of the service user
 - Environment – conducive to person-centred care
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Models and theories

Mead, N. & Bower, P. (2000). Patient-centredness: a conceptual framework and review of the empirical literature. *Social Science and Medicine*, 51, 1087–1110.

Context of care – Medicine

Professional group – Doctors

Focal group – General population

Evidence base – Empirical literature review

Nolan, M, Davies, S, Brown, J, Keady, J & Nolan, J. (2004). Beyond person-centred care: a new vision for gerontological nursing. *International Journal of Nursing*, 13, 3a, 45–53.

Context of care – Generic

Professional group – Generic

Focal group – Older people

Evidence base – Evidence-based

Alzheimer's Society Canada. (2011). *Guidelines for Care Framework: person-centred care of people with dementia living in care homes*. http://www.alzheimer.ca/~media/Files/national/Culture-change/culture_change_framework_e.ashx

Context of care – Residential aged care

Professional group – Multidisciplinary

Focal group – Dementia-specific

Evidence base – Rapid evidence assessment

Principles of person-centred care

Principles:

- Biopsychological perspective
 - The 'patient as person'
 - Sharing power and responsibility
 - The therapeutic alliance
 - The 'doctor as person'
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The Senses Framework:

- Security – to feel safe within relationships
 - Belonging – to feel 'part' of things
 - Continuity – to experience links and consistency
 - Purpose – to have a personally valuable goal or goals
 - Achievement – to make progress towards a desired goal or goals
 - Significance – to feel that 'you' matter
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Core concepts of a person-centred philosophy:

- Dignity and respect – people are recognised as individuals
 - Information sharing – unbiased information is communicated and shared completely
 - Participation – people with dementia and families participate in care
 - Collaboration – there is collaboration with people with dementia and families in policy and program development
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Models and theories

Hughes, J, Bamford, C & May, C. (2008). Types of centredness in health care: themes and concepts. *Medicine, Healthcare and philosophy*, 11(4), 455–463.

Context of care – Generic

Professional group – Generic

Focal group – General population

Evidence-based – Literature-based research

Principles of person-centred care

Summary of 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 National Care Forum. (2007). *Key principles of person-centred dementia care: statement of best practice*.

http://www.derbyshire.gov.uk/images/NCF%20%20Key%20principles%20of%20person-centred%20dementia%20care_tcm44-159567.pdf

Context of care – Dementia care services

Professional group – Generic

Focal group – Dementia-specific

Evidence based – Unsure

Key components of quality:

- Assessment, care planning and review
- Valuing communication
- Access to services
- Wellbeing and fulfilment
- Staff support and development
- Embedding a person-centred approach
- The care setting

APPENDIX 2: ADDITIONAL RESOURCES

PERSON-CENTRED PRACTICE	
Reference	Description
<p><i>The 'how to' guide: turning knowledge into practice in the care of older people.</i> Developed by Project Health commissioned on behalf of the Australian Health Minister's Advisory Council (AHMAC) by the AHMAC Health Care of Older Australians Standing Committee, 2008. Available at: http://docs.health.vic.gov.au/docs/doc/7B5FF979EF83ED01CA2578520012E9AD/\$FILE/howto-knowledge-into-practice.pdf</p>	<p>Developed to support the care of older Australians. It aims to help health care organisations use the knowledge resources to inform quality improvement in the care of older people.</p>
<p>National Ageing Research Institute (NARI). <i>Person-centred health care.</i> http://www.nari.unimelb.edu.au/pchc/index.htm</p>	<p>The website provides access to resources and initiatives used to improve person-centred health care.</p>
<p>Victorian Government Health Information. <i>Person-centred practice: guide to implementing person-centred practice in your health service.</i> http://www.health.vic.gov.au/older/toolkit/02PersonCentredPractice/</p>	<p>The website provides links to a range of resources and tools to assist in improving person-centred care in practice.</p>
<p>Stirk, S. & Sanderson, H. (2012). <i>Creating person-centred organisations. Strategies and tools for managing change in health, social care and the voluntary sector.</i> London, Jessica Kingsley Publishers.</p>	<p>The book shares stories and examples from a range of care organisations in implementing person-centred practices.</p>
<p>Registered Nurses' Association of Ontario. (2012). <i>Toolkit: implementation of best practice guidelines</i> (2nd ed.). Toronto, ON, Registered Nurses' Association of Ontario. http://rnao.ca/bpg/resources/toolkit-implementation-best-practice-guidelines-second-edition</p>	<p>The Toolkit was designed to assist health care settings in maximising the potential of Best Practice Guidelines.</p>
<p>The Picker Institute (PI). http://pickerinstitute.org/publications-and-resources/</p>	<p>The Picker Institute sponsors education and research in patient-centered care by fostering a broader understanding of the practical and theoretical implications of the approach.</p>
<p>Abbey, J, Palk, E, Carlson, L. & Parker, D. (2008). <i>Clinical practice guidelines and care pathways for people with dementia living in the community.</i> Brisbane, QUT. http://eprints.qut.edu.au/17393/</p>	<p>The Guidelines and Pathways are part of the Cognition/Dementia Care System, and promote the adoption of those principles in practice.</p>

QUALITY IMPROVEMENT

Reference

Australian Commission on Safety and Quality in Health Care.
Measurement for improvement toolkit.
<http://www.safetyandquality.gov.au/wp-content/uploads/2012/01/measurement-for-improvement-toolkit-a.pdf>

The National Institute of Clinical Studies. (2006). *The NICS barrier tool.*
<http://www.nhmrc.gov.au/nics/materials-and-resources/nics-barrier-tool>

The Victorian Quality Council. (2007). *Process mapping: a guide for health service staff.*
http://www.health.vic.gov.au/qualitycouncil/downloads/process_mapping.pdf

Description

A practical resource for health care professionals and organisations to facilitate measurement in key areas of patient safety.

The Tool helps health professionals identify the barriers and enablers to applying evidence and changing practice in Australian health care.

This paper will assist anyone who wishes to review processes in their workplace, using a structured approach.

CHANGE MANAGEMENT

Reference

Victorian Quality Council. (2006). *Successfully implementing change.*
http://www.health.vic.gov.au/qualitycouncil/downloads/successfully_implementing_change.pdf

Change Management Institute (2012). *Organisational Change Management Maturity.*
<https://www.change-management-institute.com/sites/default/files/CMI%20White%20Paper%2C%20Change%20Agility%20-%20Feb%202012.pdf>

The change management toolkit.
<http://www.change-management-toolbook.com/change-management>

Kotter International.
<http://www.kotterinternational.com/our-principles/changesteps/changesteps>

William Bridges' transition model.
<http://www.mindtools.com/pages/article/bridges-transition-model.htm>

Description

Discusses common issues and outlines strategies that may improve the likelihood of success of change.

The Change Management Institute view is that organisational change management should be viewed as the approach the whole organisation uses to manage change well. This document describes the behaviours, practices and processes of an organisation that enable reliable and sustainable outcomes.

The Toolkit is a collection of tools, methods and strategies to apply during different stages of change.

Kotter's 8-Step Process for Leading Change.

Mind Tools provides a summary of the Bridges Transition Model.

APPENDIX 3: ORGANISATIONAL SELF-ASSESSMENT TIME LINE WORKSHEET

Step	Activity	Due date
Step 1: Plan the assessment (see Section 4, pages 33–37)	Confirm authorisation and commitment	
	Understand the Framework and assessment process	
	Decide on the approach for your organisation	
	Nominate a leader or team	
	Decide the sample size and approach	
	Determine the time frame for the assessment process	
	Consider the needs of participants	
Step 2: Conduct the assessment (see Section 4, pages 38–40)	Communicate the assessment process	
	Engage with consumers	
	Engage with staff	
	Add participants	
	Individuals complete the surveys	
	Enter the data	
Step 3: Interpret your results (see Section 4, page 41)	Identify your strengths and opportunities for improvement	
	Apply results to the Framework	
Step 4: Where to next? (see Section 4, pages 42–45)	Implement a quality improvement action plan	
	Share the results	

APPENDIX 4: TIPS FOR CONDUCTING THE CONSUMER OSAT AS AN INTERVIEW*

Where possible a staff member known to the individual should conduct the interview.

Touching someone, for example on the arm, can signal that you want to have a conversation.

Always introduce yourself.

Take time to establish a good relationship before starting the interview. Perhaps use whatever the person is doing or saying to give you a starting point.

Hold the interview in surroundings familiar to the interviewee.

Involve carers or family members so they can support the person living with dementia.

Ensure minimal background noise.

Make sure the interview is scheduled at a time of day that suits the person.

Use an individual approach depending on individual preferences.

During the conversation watch for non-verbal communication that may alert you to that the person is not comfortable about the question.

Speak slowly and clearly, and allow time for the person to understand what is being said.

Listen actively, make sure that people understand before proceeding and if in doubt think of a simpler way to phrase the question.

Include pauses and relaxed small talk to allow the person to rest if required.

Accept the emotional reality of the words of the person.

Use the OSAT flexibly; modify the order and content of questions if required.

If the respondent is anxious, conduct the interview on another day or on more than one occasion.

Follow up the interview with contact to talk about the results.

*Adapted from van Baalen, A, Vingerhoets, A, Sixma, H. & de Lange J. 2010. How to evaluate quality of care from the perspective of people with dementia: an overview of the literature. *Dementia*, 10(1), 112–137.

APPENDIX 5: ALZHEIMER'S AUSTRALIA STATE AND TERRITORY OFFICES CONTACT DETAILS

Alzheimer's Australia ACT

159 Maribrynong Avenue
Kaleen ACT 2617
Phone: (02) 6255 0722

Alzheimer's Australia NSW

Gibson Denney Centre
Building 21, 120 Coxs Road (Cnr Norton Road)
North Ryde NSW 2113
Phone: (02) 9805 0100

Alzheimer's Australia NT

Suite 3/18 Bauhinia Street
Nightcliff NT 0810
Phone: (08) 8948 5228

Alzheimer's Australia QLD

825 Stanley Street
Woolloongabba QLD 4102
Phone: (07) 3895 8200

Alzheimer's Australia SA

27 Conyngham Street
Glenside SA 5065
Phone: (08) 8372 2100

Alzheimer's Australia TAS

85 Creek Road
New Town TAS 7001
Phone: (03) 6279 1100

Alzheimer's Australia VIC

155 Oak Street
Parkville VIC 3052
Phone: (03) 9815 7800

Alzheimer's Australia WA

9 Bedbrook Place
Subiaco WA 6008
Phone: (08) 9388 2800
