

Person-centred models in dementia care



Summary



Person-centred care is a philosophy of care based on knowing the individual and their unique background, needs and preferences and tailoring support and care accordingly



Every individual's experience of dementia is different suggesting that a person-centred approach is the most appropriate way to deliver high quality dementia care



A person-centred philosophy of dementia care aligns with a human rights-based approach, and this must underpin dementia care in every Australian health care, home and community setting



Embedding a person-centred approach requires commitment at all levels of a workplace or organisation and ongoing health care workforce education and support

Background

The history of dementia care has been described as ‘anything but humane’.¹ As recently as the 1960s, people living with cognitive impairment were concealed at home, rendered homeless by their impairment or institutionalised in state run psychiatric hospitals. In these settings, the lack of knowledge and awareness about dementia resulted in care that was rudimentary at best and consisted of a blunt divide between medical and physical care interventions. In institutional settings, physical and pharmacological restraints were used as routine measures. The legacy of this approach persists to varying degrees in the contemporary Australian residential aged care sector with deleterious and often fatal consequences for the person living with dementia.

Knowledge about dementia has evolved in the intervening decades and there have been significant and necessary shifts in attitude and understanding about how best to care for and support someone living with the condition. Three decades ago, Tom Kitwood’s appeal for a shift away from a biomedical model of dementia and towards a ‘positive transformation of care practice’ was decisive in changing attitudes to dementia care.² His person-centred philosophy focussed on the importance of knowing the person as a unique individual whose experience of dementia was singular and who required a correspondingly individualised approach to care and support. Kitwood argued that the individual, rather than the health professionals and others around them, was the ‘expert’ and should be central to determining their own care needs. Kitwood’s ideas were instrumental in focussing care practices less on ‘what’ is done in favour of ‘how’ it is done.

“ It is putting the person at the centre of their care, knowing their likes and dislikes, giving them choice and control over the things that are important to them. ”

-Person living with dementia

Recent research has noted the complementarity of a person-centred philosophy of dementia care with the FREDA principles of human rights (Fairness, Respect, Equality, Dignity, and Autonomy), with the important addition of identity (FREIDA).³ Preserving identity is crucial for the person living with dementia, and its inclusion in the FREIDA framework underscores the need to acknowledge and support this in the provision of care in all settings.

Issue

Conceptions of person-centred dementia care have been developed, implemented and refined across a range of global health care settings. In the broader health care context, research has found that person-centred care can have a significant impact on the quality of care including improved satisfaction with care, positive impacts on health outcomes and active involvement in decision-making.⁴

However, the legacy of an institutionalised, task-focused approach to dementia care and lack of clarity and understanding around what constitutes 'person-centredness' has meant that the approach has not been consistently embedded in Australian health care settings. The reasons for this vary depending on the health care context. As leading international dementia care proponent Dawn Brooker has noted "... there is a tendency for person-centred care to mean different things to different people in different contexts."⁵

Widely adopted internationally, Brooker's guiding principles of person-centred care have addressed this inconsistency by nominating four key elements: valuing people regardless of their cognitive ability; individualising care and support; adopting the perspective of the person with dementia and emphasising the importance of relationships and the social environment.

The interpretative uncertainty around person-centred care combined with the rapid increase in research developing related concepts including patient-centred, client-centred, consumer-oriented, and relationship-based approaches, has further complicated the person-centred picture. In addition to this, the difficulty of demonstrating the benefits of complex, individualised, psychosocial interventions has produced a limited evidence base supporting the efficacy of the approach.

Longstanding and systemic aged care workforce issues identified in the recent Royal Commission into Quality and Safety in Aged Care, including inadequate education and support in dementia care, have contributed significantly to the uneven implementation of a person-centred approach in the Australian aged care sector and other health care settings.

“ Person-centred care should also mean that you have properly trained staff in dementia. ”

-Person living with dementia

Dementia Australia's position



Dementia Australia acknowledges the development of different definitions, interpretations and models of person-centred dementia care over the last three decades but strongly believes that the broad philosophy is fundamental to the provision of high quality dementia care. Adopting FREIDA, a human rights-based approach with a dementia-specific focus recognising the importance of preserving identity, aligns with and should underpin the provision of person-centred dementia care in all care settings.



Dementia Australia believes there are two factors critical to success in achieving long term and sustained implementation of high quality person-centred dementia care across health care, home and community settings. The first is an understanding of and commitment to a person-centred philosophy of care, and how to embed it, at every level of an organisation and workplace.

“ From an organisation’s point of view, it [person-centred care] has to be important too; there has to be a commitment from the top down, and not just [nursing] staff but cooks, cleaners, gardeners...everyone. ”
-Person living with dementia



Delivery of best practice, person-centred dementia care education for the health care workforce is equally crucial. Dementia Australia supports the urgent need for funding to deliver education in person-centred dementia care, effective leadership, culture change and other initiatives required to build person-centred knowledge and capacity in the aged care sector and other health care settings. Given the modest evidence base for the efficacy of person-centred approaches to dementia care and the paucity of funding and incentives for psychosocial research, Dementia Australia also advocates strongly for increased funding to support research endeavours in this field.

Related Dementia Australia Position Statement

- Dementia education and the residential aged care workforce

¹MacKenzie, M, A History of Dementia Care in the Age of Alzheimer’s Disease”, American Educational History Journal; 2004; 31, 2; p. 19

²Kitwood, T. (1997). Dementia reconsidered: the person comes first. Buckingham, UK: Open University Press, p. 144.

³Butchard, S., & Kinderman, P. (2019). “Human rights, dementia, and identity”. European Psychologist, 24(2), 159–168. <https://doi.org/10.1027/1016-9040/a000370>

⁴McMillan SS, Kendall E, Sav A, King MA, Whitty JA, Kelly F, Wheeler AJ. “Patient-centered approaches to health care: a systematic review of randomized controlled trials”. Med Care Res Rev (published online July 2013)

⁵Brooker, D (2007). Person-Centred Dementia Care: Making Services Better, Jessica Kingsley Publishers, London and Philadelphia, p. 11