



Thinking Dementia

Issue 9 – January 2019



Welcome to the ninth edition of Thinking Dementia on recent research and policy developments. Thinking Dementia presents a selection of recent journal articles, reports and advice produced by support organisations, NGO reports, university documents and international government reports and media reports, video and radio content related to dementia.

Communication between people with dementia and their professional and personal carers is a special topic in this issue.

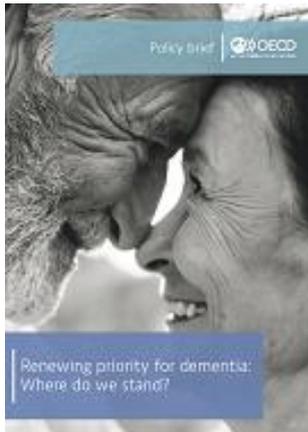
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Featured articles

OECD policy brief on the priority of dementia



In 2015 the World Dementia Council (members of the G8) held its first conference on the priority of dementia and how to address it ([Conference Report](#)). This OECD Policy Brief reviews progress, or the lack of, since the first conference. [More countries](#) (not including New Zealand) have national dementia plans though implementation varies. The diagnostic process is still poor, and poor-quality care persists. We will highlight the conference report when this appears. *Source: OECD*

[OECD policy brief on the priority of dementia](#)

This is not my home – consent and aged care



This series of essays addresses the situation of aged people in residential care where the resident hasn't provided consent to living there. Issues addressed include human rights issue; audits of legal authority in Aged Residential Care and safeguards for people with impaired capacity. Many of the presenters argue the law is too complex and not fit for purpose. *Source: Human Rights Commission*

[This is not my home: aged care without consent](#)



Documentary - Every Three Seconds



At the Chicago conference, Alzheimer's Disease International (ADI) released the documentary 'Every Three Seconds'. The New Zealand section includes information on recent developments including Dementia Friends. The full video focuses on the factors that are shaping the global approach to dementia.

[NZ section](#)

[Full documentary](#)

Global burden of Alzheimer's disease and other dementias



The Global Burden of Disease Study 2016 showed that the number of people living with dementia in 2016 was 43.8 million. This was an increase of 117% since 1990. The main cause for this increase was population ageing and growth. More women than men

had dementia and dementia was the fifth leading cause of death. The authors noted that internationally there was a need for improvement in the way that data on dementia was collected. *Source: Lancet*

[Global burden Alzheimer's disease and other dementias](#)

Recent New Zealand papers

Day care programmes in the community: A case study

In 2015 a case study of successful day care programmes in New Zealand showed five core elements for success. These included the importance of activities aimed at improving client functioning, caregiver benefits and cultural responsiveness. This update reveals a number of



successes and challenges in these programmes in the period since.

Source: Internal Medicine Review

[Day care programmes in the community](#)

Awareness and perceptions of dementia

Summerset Group Holdings surveyed 1,000 New Zealanders about their knowledge and attitudes to dementia. This online report covers issues such as personal experience of dementia, knowledge, perception of the scale of dementia in NZ, diagnosis and risk factors. Some of these can be compared with the [2017](#) and earlier Alzheimers NZ surveys. *Source: Summerset Group Holdings, Dementia NZ and NZ Dementia Cooperative.*

[Awareness and perceptions of dementia](#)

Loneliness in Aotearoa

This report uses interRAI-HC home care data to explore the living arrangements, ethnicity and loneliness among older people living at home. Most people (79%) said they weren't lonely. There were differences between ethnic groups among those who were lonely. Those living with a spouse were less likely to be lonely than those living with a child. The complex findings show that efforts to reduce the negative effects of loneliness need to be nuanced. *Source: Australian Journal of Ageing*

[Loneliness in Aotearoa](#)

Dancing and dementia

This newspaper report describes the PhD research of an Auckland student looking at the benefits of dance for people with dementia. Previous international research has explored the benefits of dance but the question of how and why dance benefits people with dementia has



not been answered. Her research is exploring this and whether different types of dance are better than others. *Source: New Zealand Herald*

[Dancing and dementia](#)

See also:

[Dancewise](#) – an Australian dance programme for people with dementia

[Dance Seniors](#) – A Canadian study of how dance can improve social inclusion for people with dementia and their care partners

The experience of people with dementia

I'm not done yet - stigma and dementia

At the recent ADI Conference Christine Thelker made a powerful presentation on the experience that being diagnosed and the resulting impact stigma has had on her life. The speech recording and her full speech notes can be found at this link. *Source: Dementia Alliance International*

[I'm not done yet – stigma and dementia](#)

Dementia friendly swimming sessions

This qualitative research explored the experience of a local group that is part of the UK national dementia swimming initiative. Interviews were held with people with dementia, their care partners and the organisers of the group. This found that people enjoyed the swimming. It built confidence and empowered participants. It shows how participants enjoyed being part of a group with a similar purpose. *Source: Dementia – executive summary only online.*

[Dementia friendly swimming sessions](#)

See also:



[Building confidence with swimming \(The Elder UK\)](#) – Stories of people with dementia who enjoy swimming

The experience of care partners of people with dementia

Quality end-of-life care for people with dementia

This research explores the views of care partners on quality end-of-lifecare for people with dementia. The authors found care partners were less concerned about medical than psycho-social aspects of care. Key concerns were maintaining a sense of the person within to ensure that they were still treated as a person, dignity, caring, kindness and compassion. *Source: Palliative Medicine*

[Quality end-of-life care for people with dementia](#)

Internet-based interventions to support family caregivers

This review explored articles on internet-based interventions to support family care partners. They identified those most valued by family caregivers and considered the effectiveness of these interventions. They noted that younger (<70) people were [more likely to have positive responses](#) to internet interventions. Important issues included contact with professionals and peer support, provision of information and psychological support. *Source: Journal Medical Internet Research*

[Internet-based interventions to support family caregivers](#)

Global report on caregiving

This report explores policies and programmes supporting carers in six countries. These include information on programmes to support carers' health and wellbeing, respite care and flexible workplaces. The authors



note that internationally carers face similar financial, emotional and physical strains. *Source: International Alliance of Carer Organisations*

[Global report on caregiving](#)

Carers NSW survey

The survey gathered information from 1,830 voluntary carers. Issues addressed included the caring relationship, services and supports and health and wellbeing. Key results included that 40% reported difficulty meeting their living expenses over the last twelve months; there was a relatively low uptake of carer support services; one in three wanted more access to respite, counselling or carer support groups, and carers were more likely to be included in decisions about services for the person they cared for than their own needs. *Source: Carers NSW Australia*

[Carers NSW Survey](#)

Health and social services for people with dementia

NICE Guidelines for care of dementia

These updated NICE Guidelines provides recommendations on assessment, management and support for people with dementia and their care partners. It addresses issues such as involving people with dementia in decision making, pharmacological interventions and staff training and education. *Source: NICE*

[NICE Guidelines for care of dementia](#)

Triangle of Care: Welsh edition

This document describes the therapeutic relationship between the person with dementia, their care partner and staff members in acute hospitals. It focuses on promoting safety, supporting communication and sustaining wellbeing. The report identifies six standards including



identifying the key role of carers, having defined positions responsible for carers and providing carer support services. It includes a self-assessment tool. *Source: Royal College of Nursing and Carers Trust Wales*

[Triangle of Care: Welsh edition](#)

Dementia Friendly Hospital Charter 2018

The revised document provides high level principles of what a dementia-friendly hospital should look like and recommended actions that hospitals can take to fulfil them. The update includes a section for hospital volunteers. There are seven Standards and notes for self-assessment. *Source: Dementia Action Alliance*

[Dementia Friendly Hospital Charter 2018](#)

GPs' attitudes and management of pain for people with dementia

This Irish survey found that only 10% of GPs were aware of any dementia-specific pain assessment tool. The majority believed people with dementia could not self-report pain. The qualitative component highlighted the importance GPs placed on surrogate reports of pain. The researchers concluded that existing guidance on pain management was not translating into clinical practice. *Source: BMC Family Practice*

[GPs' knowledge and attitudes to management of pain for people with dementia](#)

Effective dementia case management

This research interviewed 99 professionals involved with case management in focus groups. They identified five facilitating factors promoting efficiency with case management including good cooperation between partners; independence of case managers and competent case managers. *Source: Dementia (executive summary only).*



[Effective dementia case management](#)

Communicating a diagnosis of dementia

This research explores practitioners' practices and attitudes in communicating a diagnosis of dementia. It found that factors influencing GPs' decisions included their own beliefs about treatment efficacy, patient circumstances such as level of awareness and family support, health care issues such as access to specialist and diagnostic services, and cultural norms such as stigma and common clinical practice. The authors propose guideline development; offering post diagnostic treatment and support and sufficient reimbursement. *Source: Dementia (executive summary only)*

[Communicating a diagnosis of dementia](#)

My Future Wishes

This document is designed to assist practitioners and providers of dementia care to create opportunities for people living with dementia to develop an Advance Care Plan (ACP). Contributors to its development included carers of people diagnosed with dementia, health and social care professionals, NHS Foundation Trusts, charities, hospices and care homes. *Source: National Health Service*

[My Future Wishes](#)

Special topic: Communication

Good conversation with people with dementia

This study sets out to assist support staff and carers to improve communication with people with dementia. It is based on analysis of video recording of group discussions of people with dementia and advice



from a group of people with dementia. Copies of these videos are available. *Source: Bristol University and DEEP*

[Good conversation with people with dementia](#)

A fuller report can be found [here](#) (see pp11-15)

Links to training videos developed from the research can be found [here](#)

Dementia communication skills training

Health care professionals often report problems with communication with people with dementia. The authors developed a training programme (VOICE) and piloted it. The evaluation found that one month after the training participants reported increased knowledge of dementia and confidence and that they had used the skills they learnt. *Source: PLOS One*

[Dementia communication skills training](#)

Human rights and dementia

Submission on dementia as a disability

This submission on dementia as a disability was recently presented to UK Parliament. It outlines the ways that people with dementia are treated differently, the challenges they face and the actions needed to address these challenges. *Source: DEEP and Innovations in Dementia*

[Submission on dementia as a disability](#)

Current Evidence on Dementia Rights in the UK

This report to the United Nations Convention on the Rights of Persons with Disabilities draws on information from a number of sources including [Dementia Diaries](#), blogs and a range of submissions. It addresses issues such as stereotypes and stigma, accessible transport



and care and independent living. *Source: Dementia Policy Think Tank, DEEP Network and Innovations in Dementia*

[Dementia Rights in the UK](#)

I am a person with dementia and a person with rights

In this three-part blog Canadian Phyllis Fehr writes about the changes that inspired her to advocate for dementia rights, how the UN Convention on Human Rights can improve peoples' quality of life and how human rights and dementia are addressed in Canada. *Source: Alzheimer Society Canada Blog*

[I am a person with dementia and a person with rights](#)

International reports

Australian mortality report 2015

Dementia became Australia's second leading cause of death in 2013, overtaking strokes for the first time. The number of dementia deaths have continued to rise in 2015 (the subject of this report). Dementia continued to be the leading cause of death among Australian women, and the second leading cause of death of all Australians. The report found deaths from dementia increased from 33.1 per 100,000 people in 2008, to 41.6 deaths in 2015. The median age of dementia related deaths was 88.8. *Source: Australian Bureau of Statistics*

[Australian mortality report for dementia 2015](#)

Alzheimer's Disease International – World Alzheimer Report 2018

This year's report, 'The state of the art of dementia research: New frontiers' focuses on a broad range of research topics written by leading researchers. These include the challenges of diagnosis, the possibility of a cure and ways to reduce risk. It highlights the need for increased



research funding. The report is presented in lay terms by a leading science journalist. *Source: Alzheimer's Disease International*

[World Alzheimer Report 2018](#)



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