



Thinking Dementia

Issue 7 – April 2018



Welcome to the seventh edition of Thinking Dementia on recent research and policy developments. This newsletter presents a selection of recent journal articles, media reports, NGO reports, university documents and international government reports related to dementia.

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Featured articles



Human rights, disability and dementia

Kate Swaffer, Chair and CEO of Dementia Alliance International explains the significant effort that will be required to achieve the World Health Organisation's Global Action Plan. She explains why human rights and the recognition of dementia as a disability are critical and must be reflected in all regional and national dementia strategies and plans. *Source: Australian Journal of Dementia*

[Human rights, disability and dementia](#)

Stigma and discrimination in the experience of people with dementia

This research with people with dementia recognised that stigma was a critical part of the lived experience of living with a diagnosis. All respondents could provide examples of discriminatory treatment, though some were reluctant to see this as rooted in stigma. The researchers concluded that disclosure had both in positioning people with dementia in a stigmatising way and acting as strategy of resistance recognising



the expertise of the person with dementia to educate and challenge others. *Source: Journal of Ageing Studies.*

[Stigma and discrimination in the experience of people with dementia](#)

Recent New Zealand papers

South Island Shared Model of Care for Dementia

The South Island Alliance's Health of Older People Services has developed a regional model of care for dementia services. It aims to reflect best practice and ensure consistency across the South Island. It includes Principle Goals such as consistent services and person centred care; a South Island specific framework covering the main stages of the dementia process; cultural equity; patient navigation services and the key elements of South Island model for care for dementia. *Source: South Island Alliance*

[South Island Shared Model of Care for Dementia](#)

NZ InterRAI report on people with dementia living in the community

The latest InterRAI Annual report includes a report (pp. 11 – 20) on Home Care assessments of people with dementia living in the community. In 2016/17 one in four who received a HomeCare Assessment reported having a dementia diagnosis. The report includes information on the level of care they required, the length of time care is provided by family, the level of troubling behaviour and whether a primary carer feels they can continue to provide adequate care. *Source: InterRAI*

[InterRAI report on people with dementia living on the community \(NZ\)](#)



Migrant workers in the aged-care sector

This report shows that a quarter of aged care workers in 5 Auckland homes are on temporary 'Essential Skills' migrant visas. It shows three associated difficulties – workers, even those working for many years, are unable to permanently settle here; while many provide excellent quality care this could be threatened if the emerging shortage is not addressed, and these skill shortages are about to be exacerbated by recent changes in immigration policy. *Source: Salvation Army New Zealand*

[Migrant workers in the aged-care sector](#)

Principles and Guidance for last days of life

Te Ara Whakapiri: Principles and guidance for the last days of life outlines the essential components and considerations for quality care at the end of life for all adults in New Zealand. It provides examples of useful approaches and tools that will serve as aids for the development of national and/or local resources as part of implementation. The accompanying *Te Ara Whakapiri: Toolkit* is a set of checklists, flowcharts, tools and patient resources to be used for individual patients at the end of life. *Source: Ministry of Health*

[Principles and Guidance for last days of life](#)

[Te Ara Whakapiri Toolkit](#)

The experience of people with dementia

Dementia and sensory challenges

This pamphlet was prepared to inform other people with dementia and providers on the sensory challenge they may face. This challenges may include seeing problems even for those with good eyesight;



hypersensitivity to noise and hallucinations. It includes peoples' descriptions of the challenges and information on ways that may reduce these difficulties. *Source: Deal with Dementia*

[Dementia and sensory challenges](#)

[Dementia and sensory challenges DVD](#)

The experience of care partners and family / whānau

Carers' experience of dementia cafes

This interview based study asked about the benefits care partners received from attending dementia cafes, which included peer support, as well as information and support from the café coordinators. The research found that they felt supported and accepted and this brought a sense of normality to their lives. Although there was a diversity in how the cafes were run and the activities there, the informants reported similar advantages. *Source: BMC Geriatrics*

[Carers experience of dementia cafes](#)

See also:

[Recommendations for dementia cafes](#)

Health and social services for people with dementia

Meaningful engagement of people with dementia

This document provides resources for people working in organisations that work with people with dementia. It is designed to build relationships between staff and with people with dementia; promote the potential of



voices of those with dementia; improve engagement and build capacity of organisations. It includes a description of meaningful engagement and how to get started; reference sheets; tips on how to listen actively and checklists. *Source: Alzheimer Society of Canada*

[Meaningful engagement with people with dementia](#)

Bridging the Gap for younger onset dementia

People with younger onset dementia often fall between the gaps between the disability and aged-care sectors. This report addresses services available in Australia. Particularly important is the specialised Younger Onset Key Worker who have been leaders in providing education and training to thousands of health care providers who work with people in their homes. *Source: Alzheimer's Australia VIC*

[Bridging the Gap for younger onset dementia](#)

Post diagnostic support

Alzheimers NZ (and the [South Island Alliance report](#)) promote the provision of 12 month post-diagnostic support as a key component of support for people with dementia and the care partners. This document by Alzheimer Scotland outlines the progress so far in Scotland and includes a 12 minute video of people with dementia and carers, as well as professionals, describing the importance of Post-Diagnostic Support and the impact of the support they received. *Source: Alzheimer Scotland*

[Post Diagnostic Support](#)



Interventions delaying functional decline of people with dementia

This Australian review explored information on non-pharmacological and alternative therapies on the activities of daily living (ADL) function in people with dementia. Acetylcholinesterase inhibitors and memantine pharmacological agents, which are widely used, were convincingly shown to be effective. There was smaller effect evidence for exercise and dyadic psychological interventions suggesting more research was needed. *Source: BMJ Open*

[Interventions to delay functional decline of people with dementia](#)

Promoting activity in dementia care homes

The study uses a large data base from 139 homes to explore factors to predict higher activity involvement in dementia care homes. The four most important factors are 1) reduce staff's routine job demands; 2) elevate their overall educational level; 3) train staff to provide suitable activities taking account of the behaviour and capacity of residents and 4) foster transition to small-scale care. This may require review of the use of financial means. *Source: BMC Geriatrics*

[Promoting activity in dementia care homes](#)

Dementia strategies and plans

National Dementia Action Plans – examples for inspiration

Alzheimer's Disease International recently released an overview of the actions taken in the previous five years by governments or associations in countries where national plans or strategies existed. It highlighted successes or best practice to help governments or associations developing



or updating plans or strategies. The 9 chapters reflect emerging areas of practices from existing plans. *Source: Alzheimers Disease International*

[Inspiring examples from National Dementia Action Plans](#)

See also:

[Global Action Plan on the public health response to dementia 2017-2025](#)

National Dementia Plan for Wales 2018 - 2022

The Welsh Plan recognises dementia as a significant health and social care issue impacting on those living with dementia, their families, friends and carers. It sets out the actions to make a real change. Plan developers included those with lived experience of dementia, their families and carers and service providers. Issues addressed included more focus on delaying onset; raising public awareness; increasing post-diagnostic support and assessment and diagnosis. *Source: Government of Wales.*

See also:

[National Dementia Vision for Wales](#) (*Alzheimer's Society and Welsh government*)

[Six Steps to Prevent Dementia](#) (Welsh government)

Alberta Dementia Strategy and Action Plan

The government of Alberta, Canada has committed to a strategy that has four main outcomes. These are; 1) Albertans understand the impact of dementia and work towards optimal brain health; 2) ensure that people with dementia and their carers are supported by their



communities; 3) receive timely diagnosis and support through primary care; and 4) experience timely and appropriate services. *Source: Government of Alberta*

[Alberta Dementia Strategy and Action Plan](#)

Dementia-Friendly Communities

Promising interventions to support living well with dementia

This report is a resource for individuals and organisations working to support people living with dementia and their care partners. It places people with dementia at the centre and focuses on what “living well” means to them. Key factors are personal wellbeing, positive relationships and active daily lives. It showcases approaches which relate to these domains. It also provides a framework that helps make sense of ways these approaches can be brought into communities. *Source: Age UK*

[Promising interventions to living well with dementia](#)

Dementia Friendly Communities in Scotland

The Life Changes Trust began funding 12 organisations in Scotland to promote dementia-friendly communities. These included a bilingual community initiative, a choir, a football club and neighbourhood groups. Over the 3 years they produced three reports on the progress of these groups. 1,322 people living with dementia and 851 carers took part in these communities. These reports focused on how the communities grew and the principles that are necessary to make them effective. *Source: Life Changes Trust*

[Report 1 – the first six months](#)



[Report 2 – the first Year](#)

[Report 3 – April 2016 – March 2017](#)

[Video of the community activities](#)

Ontario's Blue Umbrella Initiative

This evaluation followed the pilot development of dementia-friendly communities in three Ontario communities by the provincial Alzheimer's Society. The aim was to create a dementia-friendly business/service sector that was inclusive of people living with dementia and their care partners (the facilitators). The evaluation found that the business/commercial sector valued the opportunity to learn about dementia first hand from facilitators living with dementia. Facilitators valued the opportunity to participate in developing the program and its delivery.

Source: Murray Alzheimer Research and Education Programme

[Blue Umbrella dementia-friendly community pilot](#)

Dementia-friendly cinema showings

People affected by dementia often have to give up the things they love due to inaccessible and unsupportive environments. Cinemas have an important part to play in tackling the social and economic impact of dementia, by allowing people living with dementia to continue to participate in entertainment. In the UK, special sessions at theatres are increasing in number, showing movies likely to be of interest to older people and making it easier for people with dementia to find their way around.

[A guide for cinemas \(Alzheimer's Society\)](#)

See also:



[Reeling in the Years \(Guardian UK media report\)](#)

[Tyneside Theatre showings \(You Tube\)](#)

[Journeying Together – an evaluation of the Duke’s Theatre pilot \(Lancashire Age Concern\)](#)

Volunteering and dementia

Befriending projects for people with dementia

This report describes the first year of seven very different Scottish befriending projects. These work with people at different stages of their dementia. This report covers issues such as putting infrastructure in place and the initial successes and difficulties. *Source: Life Changes Trust*

[Befriending projects for people with dementia](#)

See also:

[The role of befrienders](#) (Alzheimer’s Society)

Guide to volunteering

Volunteering is becoming an increasingly important part of dementia care in the UK. The ASUME website was developed for those involved in dementia care and volunteering. It provides advice and case studies on attracting, sustaining and understanding volunteers and considers what motivates them in different volunteer environments. *Source: University of Stirling*

[ASUME Website](#)



The impact of volunteers providing care in acute hospitals

In the UK volunteers are becoming a common feature of support for people with dementia in acute hospitals. They provide social, activity-based one-to-one support. The review found that while there were a number of descriptive studies of the role it often focussed more on the impact on staff than on people with dementia themselves. The reviewers see a marked need for research to underpin this increasingly common practice. *Source: Dementia (executive summary only on-line)*

[The impact of volunteers on people with dementia in acute hospitals](#)

Does volunteering in later life reduce cognitive problems

This research explored whether voluntary work characterized by social, physical and cognitive activity in later life is associated with fewer cognitive problems and lower dementia rates. It compared groups of seniors who continuously volunteered (for a minimum of one hour a week), periodically volunteered and did not volunteer at all over a period of five years. Seniors who continuously volunteered reported less cognitive complaints such as problems concentrating, remembering or thinking clearly over time and were less likely to be prescribed with anti-dementia treatment. *Source: PLOSOne*

[Can volunteering in later life reduce cognitive problems](#)

Knowledge and awareness of dementia

Knowledge and awareness of dementia in Australia

Dementia Australia funded a short survey of the general public on awareness and understanding of dementia. The survey demonstrated that there was a limited understanding of dementia although one third respondents reported they knew someone close who had dementia. Approximately 4 in ten agreed they would feel awkward around a person



with dementia and/or would find it confronting to talk to them. *Source: Dementia Australia*

[Knowledge and awareness of dementia in Australia](#)

See also:

[Getting our heads around dementia in New Zealand](#) *Source: Alzheimers NZ*

International papers

Perspectives of policy and political decision makers to access to formal dementia care

Researchers interviewed policy and political decision makers in eight European countries on their perspectives on access to formal care for people with dementia and their family carers. Experts highlighted the need of a coordinating role and the necessity of information to address the issues of continuity of care. Other issues raised include the demand for person-centred care; multidisciplinary formal services and means of raising public awareness. Decision makers appeared well acquainted with current discussions by practitioners and researchers on approaches to dementia care. *Source: BMC Health Services Research*

[Perspectives of policy and political decision makers to access to formal dementia care](#)

General information

Spotting “false news” on dementia research

Alzheimer’s Society has produced a simple guide to telling whether news about dementia and dementia research such as ‘cures’ and



'causes' is credible. It shows the reader a number of simple tests to apply to the news they read.

[Spotting false news on Dementia research](#)



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