



Thinking Dementia

Issue 8 – August 2018



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

Respite Care and the best ways to deliver it are issues of particular interest in NZ at the moment. This issue includes a number of interesting papers on this topic.

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Featured articles



Living well with dementia

Dr Matthew Croucher (Otago University and Canterbury DHB) discussed how people can live well with dementia on Radio New Zealand. Important issues included increasing early diagnosis, the importance of more “person-centred” services in the community and residential care and the need for navigation services. *Source: Radio New Zealand*

[Living well with dementia](#)

See also:

[South Island model of care for dementia](#)

Improving the lives of people with dementia

This major report presents an up-to-date and comprehensive assessment of the state of dementia care in OECD countries. It advises a set of policies to improve diagnosis, improving and increasing access care services and supporting families and carers. It notes that measuring



and comparing the services is a crucial part of improving dementia care. Note: the report must be either read online or purchased. *Source: OECD*

[Improving the lives of people with dementia](#)

Recent New Zealand papers

There have been several NZ papers of considerable interest published recently. Unfortunately, only the executive summaries of most of these are available online and you will need to approach libraries for full copies.

Advance care planning for people with dementia: using everyday conversations

Family members often act as surrogates for people with dementia in advance care planning (ACP). This interview-based research explored the way that family members can use informal family conversation over years about end of life preferences with a person with dementia to make decisions on their behalf. The research was funded by the NZ Alzheimers Charitable Trust. *Source: Dementia (executive summary only)*

[Using everyday conversations for advance care planning for people with dementia](#)

Analysis of variations in age and ethnicity in New Zealand

The researchers analysed the age, sex, ethnicity, dementia sub-type and severity of 360 patients presenting to a memory service with a new dementia diagnosis in South Auckland. The researchers concluded that Māori and Pacific peoples with dementia presented at a younger age than NZ Europeans, and Pacific peoples presented with more advanced



dementia. *Source: Journal Geriatric Psychology (executive summary only)*

[Analysis of variations in age and ethnicity in New Zealand](#)

See also:

[Dementia: LILACS findings](#) *Source: Ministry of Health*

[Dementia – continuing health and ethnic inequalities](#) *Source: NZMJ (executive summary only)*

Dunedin GPs awareness of risks and protective factors

The researchers surveyed 35 Dunedin GPs on their knowledge of risks and protective factors for dementia. They found that all were knowledgeable and optimistic about their ability to modify their own risks through lifestyle interventions. *Source: NZMJ (executive summary only)*

[Dunedin GPs awareness of risks and protective factors](#)

Is boxing a cause of early onset dementia for Pacific men in NZ?

The researchers reviewed the case notes of a series of 8 Pacific men who had presented with early onset dementia at a memory clinic. They had been boxers in earlier life. The researchers concluded that further research was required on whether a history of boxing was a cause of onset. *Source: NZ Medical Journal [NZMJ] (executive summary only)*

[Is boxing a cause of early onset dementia for Pacific men in NZ?](#)

The experience of people with dementia

Younger onset dementia: Understanding your diagnosis

This booklet is designed for younger people recently been diagnosed with dementia. It provides information to help understand more about dementia, its treatment and support. It suggests ways of staying positive



and provides information how dementia can affect you if you are working or driving. *Source: Alzheimer's Society (England and Wales)*

[Younger onset dementia: Understanding your diagnosis](#)

See also:

[Support pathways for people with younger onset dementia \(Dementia Australia\)](#)

Talking Book on Information on Dementia

The digital talking book is a multi-media tool that can be viewed or listened to on computer. It provides information on dementia in plain English to make this easily accessible for people with dementia and care partners. It includes topics like diagnosis, dementia and behaviour, self-care information for people with dementia, driving and travel and planning for the future. *Source: Dementia Australia*

[Talking Book on Information on Dementia](#)

Which me am I today?

Wendy Mitchell is the author of the bestselling book 'Which me am I today?' and an Alzheimer's Society Ambassador. She often speaks to groups including conferences, training sessions and researchers on living with dementia and how to address it. She maintains a blog which she hopes will both inform people with dementia and show them how they can adapt to improve the quality of their life. *Source: Blog*

[Which me am I today?](#)

See also:

[Interview with the author: UK Guardian](#)



Shared decision making

This research explores how people with dementia, their care partners and health professionals can develop a decision-making process involving the people with dementia. Using day care as an example it suggests ways that people with dementia can be equal partners in decision making and shows the important role that professionals can play in facilitating this. *Source: BMJ Open Access.*

[Shared decision making](#)

The experience of care partners of people with dementia

Cancer and dementia: A guide for carers

This booklet provides information for care partners and other family and friends on care for people who have both dementia and cancer. It provides practical information on concerns such as symptoms, caring and/or planning for the future and practical information about obtaining help and support. *Source: Dementia UK*

[Cancer and dementia: A guide for carers](#)

See also:

[Cancer information needs and decision-making needs of people with dementia](#) – research report. *Source: BMJ Open*

Natural disasters and dementia

This new Australian guide aims to help care partners of people with dementia to prepare for a natural disaster. It was prepared with input from an expert panel of carers of people with dementia and emergency services workers. While the report is specifically for Australia it contains



much useful advice for New Zealand. *Source: Queensland University of Technology and the Australian Red Cross*

[Preparing for a natural disaster](#)

Health and social services for people with dementia

GP's educational needs

This Irish study explored the educational needs of GPs from the perspective of GPs, people with dementia and their care partners. GPs focussed on diagnosis, disclosure and behavioural and psychological symptoms of dementia. People with dementia and their care partners focussed on counselling and signposting local services.

Source: BMC Family Practice

[GP's Educational Needs](#)

The contribution to allied health professionals (AHP) to supporting people living with dementia

This document sets out how AHP services in Scotland can ensure they provide appropriate services to meet the needs of people living with dementia. It focuses on issues such as supporting families and carers as equal partners; enhancing daily living; adapting everyday environments; maximizing psychological and physical wellbeing.

Source: Scottish Government and Alzheimer Scotland

[The contribution to allied health professionals to supporting people living with dementia](#)

Specialist Dementia Care Units

Australia is establishing Specialist Dementia Care Units (SDCUs) in each health region to provide care for people with very severe and



extreme behavioural and psychological symptoms of dementia (BPSD). This document reviews the literature to answer three questions:

- 1 What specialist dementia care units have been shown to be effective in managing symptoms for people with BPSD?
- 2 What are the common elements of the effective SDCUs?
- 3 What critical success factors have been identified in the effective SDCUs?

Source: Sax Institute (Australia)

[Specialist Dementia Care Units](#)

Special topic: Respite care

Rethinking respite care for people with dementia

This Welsh report questions whether traditional respite care that relies on people with dementia being placed in residential care or day care is always in the best interests of people with dementia or their care partners. The author shows that what people often want is often more flexible help that gives time out from doing chores or being able to do things together, such as going on holiday or spending time outdoors. The report notes that this may also be more cost effective. *Source: Older People's Commissioner for Wales.*

[Rethinking respite care for people with dementia](#)

Stakeholders' experiences of respite care and it's possible developments

This review paper covered papers from 12 countries. Participants in the research included care partners and a range of other key stakeholders.



The paper identified a number of areas for improvement including improved access and transition; meaningful activities for the person with dementia; flexible and responsive person-centred dementia care. There was less agreement around the barriers to change. *Source: BMC Geriatrics*

[Shareholders' experiences of respite care and possible developments](#)

The impact of respite care on caregiver resilience

This study explored how access to different respite programmes impacts on care partners' resilience and their ability to handle demands. Issues are explored from a number of dimensions including family dynamics, isolation, financial struggles, acceptance and developing resilience. Many care partners reported that respite had positive outcomes other reported challenges. *Source: Inquiry*

[The impact of respite care on caregiver resilience](#)

Guide for respite care for carers of people with dementia

This Australian guide draws strongly on the stories and experience of carers. It includes a range of tips for effective respite care such as deciding when to use it; finding the services best for you and communicating your needs. *Source: Dementia Collaborative Research Centres and Queensland University of Technology*

[Guide for respite care for carers of people with dementia](#)

Dementia Friendly Communities

Dementia friendly rural communities

This guide reveals the plight facing many people with dementia in rural communities. It provides best practice advice on how to create a



dementia-friendly community in rural areas and shares successful case studies from across the UK. *Source: Alzheimer's Society*

[Dementia-friendly rural communities guide](#)

Dementia Friendly Communities: Municipal Toolkits

This Canadian toolkit is intended to assist municipalities and local government to make their location more dementia friendly. It introduces the concept of dementia-friendly community, how to implement one, as well as developing action plans and tools and checklists. *Source: Alzheimer Society Saskatchewan*

[Dementia Friendly Communities: Municipal Toolkits](#)

Dementia friendly radio stations

There is a growing amount of information on the [value of music](#) for people with dementia. These two media articles report on radio stations that have sessions aimed at people with dementia (in Wales and Australia).

Sources: media reports

[Sound and Memories Radio \(Wales\)](#)

[Silver memories \(ABC\)](#)

Dementia Friendly Gardens

A community worker and local group have been establishing a sensory garden in Gatton (Australia). This is intended to help with dementia to re-establish forgotten memories. It has a country theme with aspects such as scarecrows, old farming and gardening equipment placed around the area. Dementia Australia visited to look at progress and this website includes a short video. *Source: Dementia Australia.*



[Dementia Friendly Gardens](#)

International reports

USA Facts and Figures 2018

The annual Alzheimer's Association report covers prevalence, mortality and morbidity, caregiving and use and costs of health care and services. This year's report included a special assessment of the financial and personal benefits of diagnosing earlier in the disease process during the stage of mild cognitive impairment. Additional information addresses definitions of Alzheimer's and the most common cause of dementia.

[USA Facts and Figures 2018](#)



Contact us:

Alzheimers New Zealand

Postal Address: PO Box 11-288, Manners St Postshop,
Wellington 6142

Phone: 04 387 8264

Email: Stephen Lungley on policy2@alzheimers.org.nz

Website: <http://www.alzheimers.org.nz>



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Most of the articles referred to are available on the internet though the links provided.

However, access to complete copies of those labelled executive summary is only available through specialist libraries such as universities or sometimes through interloan through your local library.