

# Australian Journal of DementiaCare

For all who work with people with dementia

Vol 10 No 3 July/August/September 2021

## Multicultural providers bridge the gap



**Also inside  
this issue:**

- How allied health can help
- Dementia advocates at work
- Improving residential dementia care
- Brain plasticity

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**Editorial and advertising inquiries**

Kerry Schelks

admin@journalofdementiacare.com

**Address** Building 232 (Mike Codd), Room 113, Innovation Campus, University of Wollongong, NSW 2522, Australia

**Website**

www.journalofdementiacare.com

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# A nuanced view of dementia

By **Dr Louisa Smith**, *Australian Journal of Dementia Care* Co-Editor and Research Fellow at the University of Wollongong, Australian Health Services Research Institute



**D**ementia Alliance International has called for dementia to be understood as a disability (DAI 2019). As a disability scholar researching with people with dementia myself, I spend quite a bit of time thinking about how useful contemporary definitions of disability are for understanding dementia.

According to the World Health Organization (WHO) (2021), disability arises from the interaction of a health condition, environmental factors and personal factors. This definition may come as a surprise, because many people assume that disability refers only to the impairment itself.

What the WHO definition acknowledges is that the experience of impairments is influenced by the environment in which we live and the personal aspects of our lives. For example, if I need a wheelchair for mobility in a building that has only stairs, I am disabled by the environment in ways that I would not be if the building had lifts. Similarly, if I am white and come from a middle class family where someone works in the health sector, my ability to access the Australian National Disability Insurance Scheme will be very different from my peers who do not experience my privileges.

Applying the WHO definition of disability to dementia is useful because it shifts dementia away from being recognised as solely a medical condition with potential pharmaceutical treatments. Defining dementia as a disability also allows it to be recognised by other international instruments which protect the rights of people with disabilities, such as the United Nations Convention on the Rights of Persons with Disabilities (<http://bit.ly/UN-disability-rights>).

But the more work I do in dementia research the less satisfied I am with the WHO's definition of disability to fully capture the experience of dementia. As this issue of *AJDC* attests, experiences of dementia are also impacted by the politics of recognition and inclusion, health and social care provision and structural and legal factors. Disability scholars have called this a 'laminated' model of disability. Like the laminate used in kitchen benchtops, it involves layering different kinds of experience, one on top of another, to build a more nuanced picture of how disability is experienced (Shakespeare 2006). A 'laminated' understanding of dementia investigates not only the biological, psychological, environmental and personal aspects of dementia (Shakespeare *et al* 2019), but also the political, social, health care, legal and policy aspects.

The articles in this issue of *AJDC* illustrate this laminated model of dementia. The political representation and recognition of people with dementia is highlighted in the article written by members of the Dementia Australia Advisory Committee (see p13). The biological aspects of dementia are addressed in an explainer about neuroplasticity by Dr Lezanne Ooi (p12). The psychological complexity of dementia is made clear in my review of the film, *The Father* (p35), and also in Dr Claire Burley and colleagues' overview of the Changed Behaviours Special Interest Group (p17). The personal and social understandings of dementia are unpacked in the article on multicultural aged care providers, from Associate Professor Bianca Brijnath and colleagues (p15). And while health care provision is the underlying theme of the article by Dr Andrew Stafford about rebooting training using virtual reality (p11), its focus is firmly on empathy and compassion in dementia education. Finally, in the article on Australia's soon-to-be introduced aged care funding model for residential care, Carol Loggie and colleagues explain how the new model will impact care (p25).

It is important to acknowledge that dementia care is integral to someone with dementia's experience of their impairment as a disability. And, as demonstrated by the scope of the articles in this edition of *AJDC*, it is a broad range of issues, rather than just the individual's medical condition, which will impact this experience. ■

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How can staff have the greatest impact on quality of dementia care and quality of life for people living with dementia in residential care? Researchers Katrina Anderson and Annaliese Blair, from the Southern NSW Local Health District Aged Care Evaluation Unit, explain



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Cover image: Filming for the Moving Pictures project – a collaboration with CALD communities to increase dementia awareness. The project also highlighted the work of multicultural service providers in bridging the gap between their communities and the health and aged care systems. Photo: National Ageing Research Institute, Moving Pictures project

## News in brief

### Australian Academy of Science Fellow

Professor Glenda Halliday has been named as a 2021 Fellow of the Australian Academy of Science. Professor Halliday is a Neuroscientist in the Faculty of Medicine and Health at the University of Sydney and one of 22 scientists to be recognised with the distinguished award. She leads the dementia, ageing and neurodegeneration research domain in the Brain and Mind Centre at the university, and is known for her role in establishing the Sydney Brain Bank. She now leads a \$17 million program researching non-Alzheimer's dementias and Motor Neuron Disease.

### Queen's Birthday Honours

Dementia Australia's CEO Maree McCabe AM has been appointed a Member of the Order of Australia (AM) for significant service to people living with Alzheimer's disease and dementia, and to the aged care sector, and has been included in the COVID-19 Honour Roll for her contribution in support of Australia's response to the COVID-19 pandemic. Dementia advocate Anne Tudor OAM has also received the Medal of the Order of Australia (OAM) in the General Division, for her service to people living with dementia and their supporters.

### NHMRC at work

Two new major Australian studies are underway thanks to recent funding from the National Health and Medical Research Council (NHMRC). The MINDSET study, led by the National Ageing Research Institute (NARI), will result in specialist online dementia training for interpreters, in order to improve cognitive assessments for dementia of people from culturally and linguistically diverse (CALD) communities. The study was awarded an NHMRC Partnership Project grant of \$271,586 in late March and will be led by chief investigator Associate Professor Bianca Brijnath. Dr Jane Alty, a senior lecturer at the Wicking Dementia Research and Education Centre, is leading a team of researchers who are developing a new type of dementia screening test called TAS Test ('Tasmanian Test') with a five-year NHMRC grant of \$899,782 awarded in December 2020. The TAS Test will analyse hand movement patterns using standard home computers and smartphones to detect the very earliest stages of Alzheimer's disease pathology, 10 to 20 years before memory or thinking problems are evident. Participants from the Tasmanian Healthy Brain Project and ISLAND project will soon be invited to give feedback on the test protocol.

### Navigator evaluation report

Service users of the Aged Care System Navigator (ACSN) trials have been "very satisfied" with the services, with the vast majority saying their knowledge and confidence in the aged care system has increased as a result of their contact with the navigator programs. These findings come from the final report of the evaluation of the navigator trials, prepared by Australian Healthcare Associates, now published on the Department of Health's website (at <https://bit.ly/34BVJdZ>). Dementia Australia was one of the 29 partner organisations subcontracted by COTA Australia to deliver the trials: it ran an Information Hub and a Specialist Support Worker service at two sites: in NSW and WA. The Government's 2021-22 Budget has committed \$272.5 million to create a network of 500 Community Care Finders around Australia to assist people to access and navigate the aged care system from 2023.

### ADNeT Memory Clinics Initiative

The ADNeT Memory Clinics Initiative is conducting a research project involving small focus groups of memory clinic staff to find out their opinions about support offered after a dementia diagnosis. ADNeT would like to hear from both health and administrative memory clinic staff who have any involvement with people with dementia. Focus groups will be conducted online at a time convenient for participants. For more information, contact Sladana Pavkovic on 0468 532 399 or email [sladana.pavkovic@utas.edu.au](mailto:sladana.pavkovic@utas.edu.au)

# FDA approves new Alzheimer's drug

In a landmark decision for people living with Alzheimer's disease worldwide, the United States Food and Drug Administration (FDA) has approved Biogen's Aduhelm (aducanumab) for people with Alzheimer's disease, in the first new drug treatment approved for the disease since 2003. The FDA is, however, requiring Biogen to conduct a post-approval clinical trial to verify the drug's clinical benefit – and if it does not work as intended, the FDA will take steps to remove it from the market.

Dementia Australia welcomed the decision, with CEO Maree McCabe (pictured) saying it was exciting news for the entire dementia community globally, and acknowledging the 100 Australians who have been involved in the trials of the drug to date. "This announcement provides real hope for people who are developing symptoms and in the early stages of Alzheimer's disease," Ms McCabe said.

She said it may be some time before it is accessible in Australia however, with an announcement not expected until early 2022. The Therapeutic Goods Association (TGA) in Australia accepted Aduhelm (aducanumab) for evaluation in April 2021.

Aducanumab contains antibodies which attach themselves to and remove the amyloid beta protein plaques in the brain, and in this way work to tackle the underlying characteristic pathology of Alzheimer's disease. It is administered by a monthly intravenous infusion.

In its announcement, the FDA acknowledged the debate surrounding the approval, with the scientific community still divided on whether there is enough evidence of the drug's clinical benefits. Biogen's Phase 3 EMERGE and ENGAGE studies for testing aducanumab were ceased in March 2019 due



to disappointing results, but a larger set of data was reviewed later and in October 2019 Biogen announced it would be submitting an application to the FDA. After an independent advisory committee to the FDA declined to approve the drug in November 2020, the FDA made the decision to pursue what is referred to as 'Accelerated Approval' through the FDA – which it defines as "a pathway intended to provide earlier access to potentially valuable therapies for patients with serious diseases where there is an unmet need, and where there is an expectation of clinical benefit despite some residual uncertainty regarding that benefit".

The FDA says it based its decision on the fact that treatment with aducanumab was clearly shown in all trials to substantially reduce amyloid beta plaques and "This reduction in plaques is reasonably likely to result in clinical benefit."

Commenting on the announcement, Dementia Australia Honorary Medical Advisor Associate Professor Michael Woodward AM, said: "Aducanumab should only be used in the early stages of dementia and may not work for everyone. It can also cause side effects and these need to be carefully monitored with regular MRIs. It is possible that, if used very early in Alzheimer's disease, this drug will prevent the emergence of the symptoms of Alzheimer's, but there is still research to be done in this area."

## New dementia centres proposed

Dementia Australia Chair Professor Graeme Samuel AC used his speech at the National Press Club in April to announce that Dementia Australia was working with the Universities of Melbourne, NSW and Queensland, together with their associated major hospitals and health care networks and ADNet, to establish National Comprehensive Dementia Centres (NCDC) across Australia. He said the centres will provide diagnostic, clinical and care services, together with valuable interaction with dementia researchers.

A 12-page document setting out more detail on this proposal has also been published by the organisations, titled *We Can Tackle Australia's Dementia Epidemic*, and available on the Dementia Australia website (go to <https://bit.ly/3bUt9s4>).

"We are exploring the opportunity to establish three centres in Brisbane,

Melbourne and Sydney – the first of what we believe could be a nation-wide rollout of centres across Australia; creating an interconnected network that shares resources and research outcomes for the betterment of all Australians facing dementia," the document says.

The centres will offer four core services:

- First port of call
- Diagnosis, treatment and services coordination
- Clinical research platform and workforce training
- Dementia clinical research and innovation.

The NCDC network will be co-led by the University of Melbourne, UNSW Sydney and University of Queensland, in collaboration with the Royal Melbourne Hospital, the Royal Brisbane and Woman's Hospital, the South Eastern Sydney Local Health District, the Australian Dementia Network (ADNet) and Dementia Australia.

## DCRC NEWS

### Research funding

In April, the Dementia Centre for Research Collaboration (DCRC) announced the five successful applicants in the latest round of World Class Research Projects who together will share a total funding pool of \$1.8 million. The grants have been awarded to Professor Lynn Chenoweth (UNSW Sydney, on capacity building for healthcare staff working in sub-acute care), Professor Karen Charlton (University of Wollongong, on dietary recommendations to prevent dementia in people living with mild cognitive impairment), Dr Joan Ostaszewicz (NARI, on support for carers on incontinence), Associate Professor Kate Laver (Flinders University, on post-diagnostic support) and Dr Lily Xiao (also Flinders University, on the WHO iSupport for Dementia program). In April, smaller DCRC pilot grants of \$75,000 were also awarded to Dr Andrew Stafford, Dr Nadeeka Dissanayaka, Dr Erin Conway, Dr Angel Lee, Dr Luise Lago and Dr Samantha Loi.

### DCRC farewell after 15 years

The Directors of the Dementia Centre for Research Collaboration (DCRC) have announced that DCRC will cease operation on 23 December, 2021. Professors Elizabeth Beattie, Kaarin Anstey and Henry Brodaty (pictured left to right) made the announcement on 1 June, and used the opportunity to thank members, colleagues and stakeholders across Australia for their contribution to dementia research. They said that since 2006 the initiative has supported hundreds of researchers with small and large research grant funding, and provided forums, conferences, special interest groups and other capacity building activities and research events. An event will be held later this year to celebrate DCRC's achievements, with details to be announced.



**The Australian Journal of Dementia Care** is a multi-disciplinary journal for all professional staff working with people with dementia, in hospitals, nursing and aged care homes, day units and the community. The journal is committed to improving the quality of care provided for people with dementia, by keeping readers abreast of news and views, research, developments, practice and training issues. The *Australian Journal of Dementia Care* is grounded firmly in practice and provides a lively forum for ideas and opinions.

**Writing for AJDC:** Do you have a project or survey to report, or a change in practice organisation or structure which has worked well (or not), and would you like to share this experience with others? We welcome contributions of this kind, as well as bright ideas for improving the environment or well-being of people with dementia, and letters to the editor responding to articles in AJDC. Email the Editorial Team at [admin@journalofdementiacare.com](mailto:admin@journalofdementiacare.com)



**Dementia-friendly garden opens:** Dancers celebrate the opening of the Australian-Filipino Community Services' dementia-friendly Reminiscing Garden in Doveton, in south-east Melbourne earlier this year. The garden was developed in collaboration with the Samoan and Tamil communities with the help of a \$15,000 Community Engagement Project grant from Dementia Australia. The project engaged people living with dementia and their carers during the planning. People living with dementia, their families and friends are invited to the garden to assist in repotting plants or use the space for reminiscing, surrounded by sights and scents of familiar plants and flowers.

# Budget and Royal Commission response

The Morrison Government chose 11 May – 2021-22 Budget Day – to publish its 102-page formal response to the Final Report of the Royal Commission into Aged Care Quality and Safety and also launch its aged care reform package. The Government has accepted, or accepted in principle, 126 of the 148 recommendations in the Royal Commission's Final Report and rejected six; 12 are under consideration.

In the Budget, the Australian Government committed to injecting \$17.7 billion of new funding into aged care in Australia over the next five years, describing this as a "comprehensive response" to the Royal Commission's Final Report. The Government says it is the largest investment in aged care and the largest response to a Royal Commission in Australian history.

The Government's aged care reform plans are presented in a new strategy document also published on 11 May, titled *Respect, Care, Dignity: A Generational Plan for Aged Care in Australia*. The plan centres on 'five pillars' for reform:

- Pillar 1: Home care (\$7.5 billion), including \$6.5 billion for an additional 80,000 Home Care Packages.
- Pillar 2: Residential aged care services and sustainability (\$7.8 billion), including \$5.5 billion to reform residential aged care design and planning to better meet the needs of older Australians, particularly people living with dementia.
- Pillar 3: Residential aged care quality and safety (\$942 million), including \$67.5 million for the Dementia Behaviour Management Advisory Service and the Severe Behaviour Response Teams.
- Pillar 4: Workforce (\$652.1 million), including upskilling the existing workforce and providing training for thousands of new aged care workers.
- Pillar 5: Governance (\$698.3 million), including \$21.1 million to establish new governance and advisory structures, including a National Aged Care Advisory Council, and a Council of Elders, and to work towards establishing an office of the Inspector-General of Aged Care.

Of the total \$17.7 billion, \$229.4 million is directed towards improving quality of life and care for people living with dementia and their carers specifically. Some of the key measures include:

- More support when a person is first diagnosed with dementia, and enhanced early support for people living with dementia in the community and their carers through a significant funding increase for activities delivered under the National Dementia Support Program (NDSP).
- Dementia training to be made available for an additional 1000 GPs and GP registrars per year.
- Additional outreach capability for the National Dementia Helpline.
- An increase in the number of care minutes provided to people in residential aged care which will support the person-centred care practices that are essential for people living with dementia.
- Additional dementia training, including for 3200 personal care workers to operate as leaders in dementia care in their organisations and improved access to dementia training in regional and rural areas.
- Up to 60 learning networks will support aged care workers in adopting better dementia care practices through the opportunity to share experiences and insights.
- Documented dementia training pathways to ensure health professionals and aged care workers are more easily able to identify high-quality dementia training that is relevant to them.
- Increased availability of respite places with respite providers supported to develop dementia-specific respite plans.
- An expansion of care models which combine carer education and respite care to support 3200 families caring for a person living with dementia.
- Improvements in aged care regulation.
- Enhanced capability for positive approaches to

## RESPONSES FROM THE SECTOR

### Dementia Australia

Dementia Australia responded fulsomely to the Federal Budget, saying it welcomed the "extraordinary commitment to dementia". Its Chair, Professor Graeme Samuel AC, described the investment of \$229.4 million to improve quality of life and care for people living with dementia as "transformational".

Dementia Australia CEO Maree McCabe said this record investment will provide the impetus for systemic change required in the aged care industry. "Elevating the capability and capacity of the workforce is a focus of this budget. Dementia must be core business for aged care," she said.

Dementia Australia said it also welcomed the Government's significant broader investment in aged care, in response to the Royal Commission into Aged Care Quality and Safety. It highlighted the announcements in relation to the increase in Home Care Packages, respite services and strengthening of regulation of chemical and physical restraints as having significant benefits for people living with dementia, their families and carers.

Dementia Australia is calling for an urgent commitment to and implementation of its 2021 paper, *Roadmap to Quality Dementia Care*.

### AACC

The Australian Aged Care Collaboration (AACC), which represents more than 1000 providers, welcomed the Australian Government's formal response to the Royal Commission into Aged Care Quality and Safety and congratulated the Australian Government on agreeing to implement most of the Royal Commission's 148 recommendations.

AACC representative Patricia Sparrow said that after 20 government

reviews in 20 years, this Budget, and the Government's response to the Royal Commission's recommendations, finally addressed many of the challenges facing aged care.

"This Budget gives real hope to more than 1.3 million Australians currently accessing aged care services, to the 360,000 care staff who provide critical services around the country every day, and to the tens of thousands of Australian workers our sector will need to employ over the coming years to meet the demands of our ageing population," Ms Sparrow said.

### COTA

Council on the Ageing (COTA) Australia Chief Executive, Ian Yates, also welcomed the Budget package, describing it as, "a serious and meaningful response to the 'neglect' identified by the Aged Care Royal Commission and the need to transform the industry".

"Aged care reform needs proper oversight to get the job done. The new Aged Care Act in particular, along with the oversight mechanisms of an Inspector General, an Independent Pricing Authority, a National Aged Care Advisory Council and the Council of Elders, sets us on exactly the right path. We look forward to working with Government on the implementation of these important measures," Mr Yates said.

COTA said that it would continue to analyse the Government's comprehensive response, and that it was clear that some measures were not finalised and required further detailed consideration and consultation, which it welcomed.

## Budget and Royal Commission response *continued*

behavioural and psychological symptoms of dementia and to minimise the use of restraint, for example, increased funding for the Dementia Behaviour Management Advisory Service and the Severe Behaviour Response Teams to support a further 13,000 referrals to these services per year on average, and training for representatives of all aged care providers on managing behavioural and psychological symptoms of dementia.

A series of fact sheets has also been published on the reforms and one, *Aged Care: Reforms to Support People Living with Dementia and Their Carers*, explains the specific announcements made in relation to people living with dementia. This is available at <https://bit.ly/3wXNyEZ>

The Department is also hosting a webinar on 21 July titled 'A focus on dementia' which will report on how the aged care reforms will improve quality of life for people living with dementia (to find out more go to <https://bit.ly/3xcvszb>). The

webinar is one of a series hosted by the Department throughout June and July addressing a range of topics in relation to the aged care reforms, such as residential aged care and home care. The webinars can be viewed live or after the event. To register and find out more, go to <https://bit.ly/3zc2fpQ>

Detailed information on the entire aged care reform program is available at <https://bit.ly/3cg5ouP>

The Government says it has taken an important step to deliver its reform by introducing the first legislation in response to the Royal Commission into Aged Care Quality and Safety. The Aged Care and Other Legislation Amendment (Royal Commission Response No 1) Bill 2021 was introduced into Parliament on 27 May 2021, making the necessary changes to current aged care legislation ahead of the new Aged Care Act planned for 2023. The amendments are intended to lead to immediate changes around restrictive practices, home care assurance reviews and repealing the Aged Care Financing Authority.

## AGED CARE REFORMS

### New quality indicators

From 1 July 2021, updated and new quality indicators will be included in the National Aged Care Mandatory Quality Indicator Program (QI Program). Quality indicators on pressure injuries, physical restraint and unplanned weight loss have been updated, and two new indicators added: on falls and major injury (percentage of care recipients who experienced one or more falls, and percentage of care recipients who experienced one or more falls resulting in major injury), and on medication management (the percentage of care recipients who were prescribed nine or more medications and the percentage of care recipients who received antipsychotic medications). The new *QI Program Manual 2.0 – Part A* is available on the Department of Health's website and includes new quality indicator definitions, collection and reporting requirements for the QI Program from 1 July 2021. Part B of the manual was due to be published in June 2021.

### SIRS in practice

An updated version of *SIRS: Guidelines For Residential Aged Care Providers* is now available, from the Aged Care Quality and Safety Commission (ACQSC) (go to [www.agedcarequality.gov.au/](http://www.agedcarequality.gov.au/)), along with updated fact sheets. The guidelines have been updated following feedback from the sector and include additional information about a number of issues, including the categorisation of reportable incidents as either Priority 1 or Priority 2, reporting unexpected deaths, an additional example of 'rough handling', and the Commission's process for requesting further or missing information.

The ACQSC has published its first *Insight Report* into the SIRS, which indicates that in the first six weeks of the scheme (from 1 April to 12 May 2021) the ACQSC received 1876 notifications which fell into the Priority 1 category (an incident in a residential aged care services that has caused, or could potentially have caused physical or psychological injury to a consumer, requiring medical or psychological treatment). The most common type of reported incident was unreasonable use of force (778), followed by neglect (448). Commissioner Janet Anderson PSM said, "The notifications received to date indicate that providers are responding actively and swiftly to their new reporting obligations under SIRS."

## SECTOR RESPONSES *continued*

### Australian Nursing and Midwifery Federation

The Australian Nursing and Midwifery Federation (ANMF) described the Budget's commitment to aged care as "definitely not the 'once in a generation' reform package promised by the Morrison Government", and that the funding "won't be anywhere near enough to provide safe, quality care for vulnerable nursing home residents".

The ANMF says the commitment to introduce regulated care hours for residents was a positive step forward, but the Government should have gone further and mandated minimum staffing levels commencing now, with a registered nurse on-site 24 hours a day, as the Royal Commission's Final Report recommends.

### HammondCare

HammondCare CEO Mike Baird broadly welcomed the \$17.7 billion of new spending announced in the Federal Budget to better fund residential aged care and home care.

"These measures are a step in the right direction to ensure our elderly are valued and have the care they deserve," Mr Baird said. "We welcome that most of the recommendations of the Royal Commission into Aged Care Quality and Safety have been supported." However, he said the Federal Government needed to commit to ensuring better pay for aged care workers.

"A revitalised, valued and supported workforce is the key to delivering the quality of care older Australians rightly deserve," Mr Baird said. "The aged care sector needs more staff, more training and improved pay."

### CCTV in SA care homes

A 12-month trial of CCTV in two SA Health-operated residential aged care facilities in South Australia – Northgate House and Mount Pleasant Aged Care – has commenced. The trial involves placing recording devices in residents' bedrooms and common areas, and the technology uses artificial intelligence to identify falls, calls for help or unusual movements. This triggers an alert to be sent to operators at an independent monitoring centre, who then immediately alert nursing staff. Director of the Office for Ageing Well, Cassie Mason, said residents are able to choose whether to have their bedroom recording devices activated or not and can opt-in or out of participating at any time. "The trial will allow us to assess whether this technology can contribute to improving quality of care, while maintaining the privacy and dignity of residents," she said.

### Review of medication guidance

The Australian Commission on Safety and Quality in Health Care is currently updating two national quality use of medicines (QUM) publications: the *Guiding Principles for Medication Management in Residential Aged Care Facilities* (2012, Australian Government Department of Health), and the *Guiding Principles for Medication Management in the Community Reference Guide* (2006, by the former Australian Pharmaceutical Advisory Council), having been engaged to do so by the Department of Health. The Commission says the review process will be informed by a literature review and environmental scan, analysis of contextual documents and consultation with a broad range of stakeholders. The revised publications are due to be completed by 24 December 2021.

## AIHW report reveals lower death rates

The age-standardised death rate of Australians with dementia fell during the first 10 months of 2020, probably as a result of measures designed to prevent COVID-19 infections also limiting the spread of other infectious respiratory diseases, according to a new report from the Australian Institute of Health and Welfare (AIHW).

The report, *Dementia Deaths During the COVID-19 Pandemic in Australia*, uses provisional mortality data collected by the Australian Bureau of Statistics to examine deaths among people who had dementia recorded on their death certificates between 1 January and 27 October 2020.

“Lower rates of death were particularly apparent during the winter months, when there is usually a seasonal peak in deaths of people with dementia,” AIHW spokesperson Dr Fleur de Crespigny said.

The report says that nearly a third (257 or 30%) of the 858 people who died due to COVID-19 in the first 10 months

of 2020 had dementia. Of those 257 people, 95% were Victorian residents, with many likely living in one of the 61 residential aged care facilities in Greater Melbourne that experienced fatal COVID-19 outbreaks, and more than half (54%) were women. The remaining 5% of deaths were among NSW residents.

For people with dementia, the number of deaths due to influenza or pneumonia fell during the first 10 months of the pandemic (13 people in 2020 compared to an average of 187 people over 2015–2019); this rate is specific to people who died with dementia recorded as an underlying and/or associated cause of death on their death certificate. The report is available to download at <https://bit.ly/3wt0Hpg>.

AIHW is due to publish a report in September, *Dementia in Australia*, which will provide the latest information available on dementia, risk factors, health services, aged care services, carers and Government expenditure on dementia.

## COVID-19 vaccination mandatory for care staff

All Australian residential aged care workers must have at least one dose of a COVID-19 vaccine by mid-September 2021, with the Government announcing an \$11 million grant program to encourage providers to give staff leave to get vaccinated.

The decision was announced following a National Cabinet meeting on 28 June, amid concerns about an outbreak of the highly contagious Delta strain. Prime Minister Scott Morrison said that having a COVID-19 vaccine would be a condition of working in a residential aged care facility.

He said the COVID-19 vaccine program for aged care staff would be implemented in partnership with the Commonwealth and the States, “preferably using the same system that is used for having mandatory vaccinations for the flu for aged care workers”.

However, Mr Morrison said a further risk and benefit assessment of the decision

would be conducted, with National Cabinet advised by early August. “We need to make sure there are no unintended consequences of this decision. We want to make sure this won’t have a negative impact on the available workforce...”.

Previously, it was voluntary for aged care workers to be vaccinated and to disclose if they had received a COVID-19 vaccination. Residential aged care providers had been required to report weekly how many staff had been vaccinated.

The Federal Department of Health continues to develop a wide range of resources relating to COVID-19, including providing COVID-19 vaccine information for the residential aged care workforce in videos (available in 15 languages, at <https://bit.ly/2TpP18t>), and fact sheets, infographics and posters, with written information available in 19 languages (available at <https://bit.ly/3gwJepr>).

## International award for ADI dementia report

Last year’s *World Alzheimer Report*, titled *Design, Dignity, Dementia: Dementia-Related Design and The Built Environment*, has been awarded the European Healthcare Design (EHD) 2021 Award for Outstanding Contribution to Global Knowledge.

The substantial two-volume report from Alzheimer’s Disease International (ADI) was co-authored by Professor Richard Fleming, previously Executive Director of Dementia Training Australia (DTA), Dr John Zeisel and Kirsty Bennett (Senior Academic Consultant with DTA) and includes contributions from 58 individual authors and 84 organisations. The *ADI World Alzheimer Report* is published annually in September. Each year it addresses a different topic related to dementia.

The EHD Awards aim to recognise and celebrate outstanding excellence in healthcare design in Europe and around the world across nine different categories. The competition is part of the European Healthcare Design Congress, and was announced on 17 June.

The judges, Jonathan Erskine, Executive Director of the European Health Property Network and a researcher at the Centre for Public Policy and Health, School for Medicine, Pharmacy and Health, Durham University, UK and Göran Lindahl, Associate Professor at the Division of Construction Management at Chalmers, Sweden, described the report as “... a tour de force posing fascinating research questions; thoroughly researched, methodologically rich, full of expert analysis and comment. It struck us as a landmark publication. Its focus on patient centred services and co-design is needed and welcome”.

Professor Fleming commented, “I’m very pleased that the value of the work that went into the 2020 *World Alzheimer Report* has been recognised as a major contribution to global knowledge.”

Co-author Ms Bennett said: “The EHD Award recognises the vital importance of designing well for people living with dementia and I hope it leads to the creation of more dementia-friendly settings around the world.”

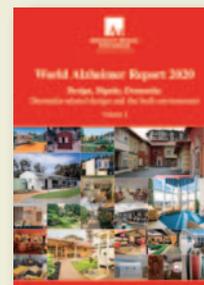
The 2020 *World Alzheimer Report* is available to access here: [www.alzint.org/resource/world-alzheimer-report-2020/](http://www.alzint.org/resource/world-alzheimer-report-2020/)

### Design manifesto launch

Since the report’s publication in September 2020, the lead co-authors, with the backing of ADI, have pursued the development of an international manifesto (one of the report’s recommendations) which succinctly brings together the core values evident in that report.

Hundreds of people – including architects, designers, researchers, care managers, people living with dementia and carers – have now signed up to the international *Dignity Manifesto of Design for People Living with Dementia* which was launched in May. The aim of the online manifesto is to arrive at an internationally accepted statement of values and principles able to guide good design for people living with dementia.

The report’s lead co-authors say that in Australia the manifesto should inform discussions on the implementation of Recommendation 45 of the Final Report of the Royal Commission into Aged Care Quality and Safety (on improving the design of aged care accommodation). The manifesto is available to read and sign up to here: <https://designdignitydementia.com/>



# Timely diagnosis of dementia: is it happening in Australia?

'AJDC asks' is a column in which we invite a range of contributors to consider topical issues relevant to dementia care



From left: Professor Dimity Pond, Professor Sharon Naismith, Dr Jane Thompson, Professor Graeme Samuel AC, Dr Meredith Gresham

### **Professor Dimity Pond** Professor of General Practice, University of Newcastle and in active clinical practice for two sessions per week

In my view as a primary care doctor, a lot revolves around the meaning of the word 'timely'. Timely is not the same as early, but it does imply some sense of urgency.

We would not consider the diagnosis timely if the person was very disabled by their dementia and no one had understood this. So I think the question is asking whether we make the diagnosis when the person needs it, to maintain safety and a good quality of life.

There is an element of the person's own openness to the possibility of dementia in this – some people don't want to know whether they have dementia. The NHMRC Clinical Practice Guidelines and Principles of Care for People with Dementia state that people have a right to know and a right not to know their diagnosis

(Recommendation 47). So this needs to be respected. On the other hand, the diagnosis may be needed by family and other carers, so that care can be provided in a safe and realistic manner.

In my view, general public awareness of and acceptance of the condition is improving and reducing the barriers to acceptance of it. Health professionals are also improving in their awareness of the symptoms and signs of dementia, and how to distinguish them from other causes of thinking problems such as medication side effects. Dementia Australia and Dementia Training Australia have made huge contributions to both these factors. Together, they are improving timely diagnosis, but we are not there yet.

### **Professor Sharon Naismith** Director of the Healthy Brain Ageing Program, Brain and Mind Centre, University of Sydney and Lead, Australian Dementia Network Memory Clinics Initiative

Over a decade ago, it was clear that we are not achieving timely diagnosis of dementia in Australia, which on average takes more than three years from the time of first health professional contact. This figure is unacceptably high and consumers raise this issue as a matter of priority.

There are clear benefits of timely diagnosis including early initiation of treatments, enabling the person with dementia to make choices about their future including financial and legal matters, a longer duration of independent functioning and delays in admission to residential care.

The contributors to untimely diagnosis are multifactorial and may relate to poor awareness of symptoms, stigma and reluctance to seek help, as well as health system and provider barriers including therapeutic nihilism, difficulty recognising dementia and limited access to specialist expertise. At least half of dementia cases in

primary care go undetected. This can reflect time pressures, unsuitability of tools for detecting early dementia and inadequate training. There is often a lack of support for GPs and inaccessible or unclear service pathways.

In a memory clinic setting, multidisciplinary and concurrent assessment usually enables expert diagnoses to be made much quicker – within weeks or a few months, but we need to improve here too! Although international guidelines propose optimal wait times of less than six weeks for first appointment, in Australia only 23.8% of public memory clinics can provide an assessment within two months. The average wait time is almost 12 weeks, compared to, for example, 35 days, 25 days and 33 days in Ireland, Canada and the United Kingdom respectively.

With the expected rise in dementia in coming decades, we need to significantly increase the number of memory clinics (especially in rural/regional areas), ensure

equity of access for all, support private services, and train and assist our GPs in achieving timely diagnoses wherever possible.

### **Dr Jane Thompson**

**An advocate for public involvement in dementia research, drawing on her professional background in research as well as her personal experience of caring for her husband Dr Alan Newsome who had Alzheimer's disease and died in 2007. Jane has contributed to numerous dementia research projects, had various advisory roles and was a member of the NHMRC National Institute for Dementia Research Advisory Board (2015-2020) and of the Dementia Australia Research Foundation Scientific Panel (2014-2019). She supports and is a member of Dementia Reframed ([www.dementia-reframed.com.au](http://www.dementia-reframed.com.au)) and Dementia Carers Australia ([dementiacarers-aust.com.au](http://dementiacarers-aust.com.au))**

Observing concerning changes in my husband Alan's behaviour and abilities, I suggested to him that we make an appointment with our GP, with whom he had a long-standing, positive, trusting relationship. He agreed – he had never adopted the heroic "I'll be right mate" attitude.

He made regular appointments with his GP, often booking the last of the day so they could have long chats – no 'long consultation charge' applied! When I raised my concerns, the GP responded immediately, referring Alan to a neurologist. We had an appointment within a month, and the neurologist referred Alan for neuropsychological testing. About three months later, the neurologist told us the testing indicated that Alan, at 69, had Alzheimer's disease. While shocking, Alan's diagnosis was early, efficient and sensitive. A good relationship with a caring GP means timely dementia diagnosis can

## **ADI on 'Journey to a Diagnosis of Dementia'**

In September 2021, during World Alzheimer's Month, Alzheimer's Disease International (ADI) will publish its annual *World Alzheimer Report* – titled *Journey to a Diagnosis of Dementia*.

Each year the report provides a comprehensive global update on a specific dementia topic. For the 2021 report, ADI commissioned McGill University Research Centre for Studies in Aging and Faculty of Medicine and Health Sciences in Montreal, Canada to investigate both current and best practice in diagnosis, gaps, barriers and facilitators. The aim was to look at the role of government, healthcare professionals and civil society to identify any gaps, and highlight the experiences of people living with dementia and their families.

Three online surveys were developed for the 2021 report; the first for clinicians and

professionals involved in making a diagnosis of dementia, with over 1000 respondents from over 100 countries. The second survey has, to date, been completed by over 1821 people with dementia and informal carers. The third survey has been sent to 105 Alzheimer and dementia associations globally to better understand if and how governments are measuring dementia diagnosis rates, to determine presence of a diagnosis strategy in national dementia plans, and to highlight the role of associations in information provision.

The *World Alzheimer Report 2022*, also in collaboration with McGill University, will specifically report on post-diagnostic support.

For further information about the *World Alzheimer Report 2021* and *2022*, visit [www.alzint.org/](http://www.alzint.org/)

happen in Australia.

However, what comes next is even more critical. The neurologist's response to my question, "So what do we do now?" was unhelpful. We left his surgery in tears, bewildered as to where to turn next.

Diagnosis is important but not enough. Post-diagnostic information must be provided. Neurologists and GPs need to know how to help us find it.

### **Professor Graeme Samuel AC Chair, Dementia Australia**

Dementia is one of the most under-diagnosed of chronic diseases.

Timely diagnosis of dementia is essential to improve care and outcomes for people living with dementia, and to make life better for their carers. Yet the average time between first symptoms and diagnosis is just over three years.

Many people with dementia and their families miss out on early intervention such as targeted medications that can help to maintain cognitive function longer; and time to develop an advance care plan for future medical treatment wishes and powers of attorney.

An integrated and comprehensive approach is needed to educate and inform health professionals across general practice, primary health, acute and aged care, to support timely diagnosis of dementia, including clear referral pathways to specialist dementia services accessible to all individuals regardless of financial situation or geographical location.

A program for community awareness to inform and educate everyone to the early warning signs of dementia and where to find help is also crucial.

These matters were acknowledged in the final report of the Royal Commission into Aged Care Quality and Safety and in the recent Federal Budget by enhanced early support for people living with dementia in the community, their families and carers through an expansion of the National Dementia Support Program, and more support at diagnosis for people to access the services they need. Dementia Australia will be leading and implementing these measures that will have a significant impact in improving timely diagnosis.

We must continue to make this a priority.

### **Dr Meredith Gresham**

**Research Fellow, Centre for Healthy Brain Ageing (CHeBA), UNSW Sydney. Meredith coordinates CHeBA's COGNISANCE Project, which aims to improve the dementia diagnostic process and post-diagnostic support (<https://cheba.unsw.edu.au/cognisance>)**

Timely diagnosis is receiving a diagnosis early in the course of dementia. Proponents of timely diagnosis champion that it decreases uncertainty, allows time to plan for financial and legal contingencies as well as services that will enable people with dementia to remain living at home.

It may mean that medication can be commenced when the person derives the most benefit. It allows time to access rehabilitation therapies to maintain or improve symptoms and wellbeing. Carers can seek proactive psychological and practical support.

Seeking diagnosis early allows the medical practitioner to assess for potentially treatable conditions with dementia-like

symptoms, such as depression.

Yet we are presented with a conundrum. Those seeking early diagnosis frequently wait and wait. Numerous international studies have found that it takes between one to two years from the seeking to receiving a diagnosis (Helvik *et al* 2018). There are estimates that over half of all people with dementia never receive a formal diagnosis (Pond *et al* 2013).

Delay to diagnosis has contributors on both sides of the diagnostic fence. People with dementia and families may delay seeking diagnosis by not recognising early symptoms, considering them just 'normal ageing'. They may fear a potential dementia diagnosis. For medical practitioners, diagnosis is complex, and the risk of labelling a person too early has significant negative impacts. They may employ a process of 'watchful waiting'. While legitimate, this places many families in a state of 'limbo'. Importantly, lack of a post-diagnostic pathway contributes to an incorrect but pervasive view that there is nothing that can be done for dementia.

Australia must recognise the need for accessible, streamlined and proactive post-diagnostic support. Knowing that something *can* be done will improve patient, family and clinician confidence in seeking and delivering diagnosis in a timely way. ■

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# Rebooting training with VR



**Andrew Stafford** introduces a new series of workshops which make use of virtual reality to explore best-practice environmental design and medication management in dementia care

**D**ementia Training Australia (DTA) will launch the first state-wide rollout of its new virtual reality-based workshop, Meaningful Spaces, in Western Australia in November this year, followed by other states and territories in the near future.

The Meaningful Spaces workshop uses virtual reality (VR) to enable healthcare workers to walk in the shoes of a person living with dementia, and experience some of the challenges they face in their everyday lives. DTA has pursued the development of this technology in light of evidence associating VR training resources with improved understanding of, and empathy and attitudes towards, dementia (Jutten *et al* 2018; Gilmartin-Thomas *et al* 2018; Slater *et al* 2019).

The workshop uses the latest Oculus® VR technology to immerse participants in several highly realistic, high-fidelity scenarios. DTA worked closely with Australian digital agency Viewport, which specialises in virtual and augmented reality simulations, to build the Meaningful Spaces VR application in 2018/19. You can watch a short video introduction to the DTA resource, produced by Viewport, at [www.youtube.com/watch?v=PpSNr8nGo0](http://www.youtube.com/watch?v=PpSNr8nGo0) and a brief news report at [www.youtube.com/watch?v=UI4WSIMtSPg](http://www.youtube.com/watch?v=UI4WSIMtSPg)

#### Successful pilot

DTA successfully piloted the Meaningful Spaces resource in a series of workshops in 2019 held with 25 staff from Ananda Aged Care, a South Australian residential care provider (for a full report on



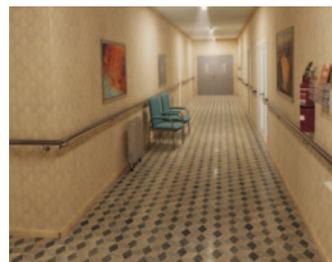
**A participant at a Meaningful Spaces training session, using Oculus® VR technology to navigate highly realistic dementia care environments**

this pilot, see Stafford & Page 2019). COVID-19 restrictions and lockdowns from February 2020 then forced DTA to postpone further Meaningful Spaces workshops until now.

During the half-day workshop, participants explore the principles of environmental design and medication management in dementia care, and how these may be used to best support people living with dementia. Participants work in pairs, supporting each other to navigate the VR scenarios before sharing their experiences with other workshop participants.

#### The workshops

Morning and afternoon sessions of the half-day workshops being held in WA in November will be available for individuals or private group bookings, with a maximum of eight attendees



per session. Each participant will be given the opportunity to use an individual virtual reality system throughout the workshop and will also receive comprehensive course notes.

Details of workshops in other states and territories will be announced in the near future. To register your interest in the Meaningful Spaces program, visit <https://dta.com.au/events/meaningful-spaces-2021/#register> ■

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■ Dr Andrew Stafford is a senior lecturer at Curtin University and a Research Consultant with Dementia Training Australia



**Still images from inside the Meaningful Spaces VR app show a poorly designed environment (left) and an enabling environment for people with dementia (right). Photos: Dementia Training Australia**

# Ask a neuroscientist...



AJDC is aimed at all who work with people with dementia, including those who are new to the dementia workforce and may want to learn more about the basics of dementia. This article is the second in a four-part series by neuroscientist and AJDC Editorial Advisor **Dr Lezanne Ooi**, who is presenting short, easy-to-read answers to questions about neurological changes to the brain with dementia. In her second article, Dr Ooi answers this question:

## ‘What is brain plasticity and does it offer hope for people living with dementia?’

**R**emember the days of playing with plasticine? As children, we would spend some considerable time creating an ornate and beautiful structure, only to squish it flat so that we could make a different shape. This concept of remoulding a material to make a different shape or structure can also be applied to the brain. To put it another way, the brain can be described as having plasticity, meaning that the cells within it can be reshaped under certain conditions.

The plasticity of the brain is important because it allows the brain to change in response to our environment. This underpins our ability to learn.

Humans have around 100 billion neurons (the brain cells that do the thinking) and each of those communicate with other neurons through connections called synapses. The average neuron has around 1000 synapses, so in other words each neuron is connected to around 1000 other neurons via super-highways – creating dense networks. The more dense these networks are, the more connections they have, and the greater the capacity of the brain to deal with disease-causing pathology or damage. (Pathology in the context of dementia means structural changes to the brain that are either a cause or an effect of the disease).

Brains with more dense networks have what’s described as higher ‘cognitive reserve’. Cognitive reserve is thought to provide protective effects that buffer the brain and allow it to compensate for injury. Brain plasticity and the dynamic

### Tips for practice

- People with dementia do have the capacity for brain plasticity.
- Physical exercise and activities that stimulate the brain can improve brain plasticity.
- Promoting engaging and meaningful activity with people living with dementia can play an important part in promoting brain health.

### Imaging methods

- Positron emission tomography (PET) measures regional blood flow in the brain.
- Functional magnetic resonance imaging (fMRI) measures blood oxygen level dependence.

ability of neurons to alter their organisation likely protect the brain by contributing to cognitive reserve.

### Do people with dementia also exhibit brain plasticity?

Even when pathology impacts parts of the brain – as explained in my previous AJDC article on brain changes in dementia ([www.journalofdementiacare.com/ask-a-neuroscientist/](http://www.journalofdementiacare.com/ask-a-neuroscientist/)) – plasticity can allow the brain to compensate by using different areas or networks to perform tasks.

Different types of tests described as ‘functional neuroimaging’ (for example, PET and fMRI, see box) allow clinicians to visualise how efficiently the brain is operating and track its changes throughout the course of normal ageing or disease, or analyse the success of treatments. These imaging methods allow us to assess in real time how much blood is flowing to certain parts of the brain while a person is performing specific tasks.

Particular areas of the brain are activated when we perform certain tasks, and therefore require blood flow to provide oxygen and energy.

People with a diagnosis of dementia show symptoms that progress at different rates. Functional neuroimaging has shown that people with dementia who are able to counteract symptoms for longer are able to recruit other areas of the brain to complete operations. This suggests that people with greater levels of brain plasticity are able to compensate for pathology by using different pathways.

### How do you increase brain plasticity?

Evidence from functional neuroimaging shows that plasticity provides an opportunity for intervention at any time of life, including following a diagnosis of dementia. Dementia is progressive and there are limits to the potential of plasticity with respect to dementia, however brain plasticity can be improved by

aerobic exercise, weight training or activities that stimulate the brain. All of these activities can delay the progression of dementia as they stimulate the generation of new neurons, new connections and/or strengthen those connections.

Just last year, a study using another brain imaging technique that is sensitive to changes in brain activity (MEG or magnetoencephalography), showed that people living with dementia have the capacity for brain plasticity and that non-pharmacological treatments (such as physical exercise, role-playing, nursing care, horticultural therapy and self-cognitive training) could be used to induce plasticity that improved cognition in those people (Shigihara *et al* 2020).

So, the good news is that the evidence shows that brain plasticity can be increased to boost cognitive reserve and it is never too late to make a positive difference to your brain health. ■

### Reference

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■ Dr Lezanne Ooi is a neuroscientist at the Illawarra Health and Medical Research Institute, Wollongong, and the School of Chemistry and Molecular Bioscience, University of Wollongong, NSW. To follow up with the author, email [lezanne@uow.edu.au](mailto:lezanne@uow.edu.au). The author is supported by a National Health and Medical Research Council (NHMRC) of Australia Boosting Dementia Research Leadership Fellowship (APP1135720)

# Dementia advocates at work

The Dementia Australia Advisory Committee (DAAC) is made up of people living with dementia. As a formal group, the committee provides strategic advice to Dementia Australia and other stakeholders on shaping dementia services, programs, policy development and advocacy goals. Informally, we all strive to help make the world a more dementia-friendly and dementia-aware place.

The committee was officially established in 2013 (known then as Alzheimer's Australia Dementia Advisory Committee) in response to people with dementia around Australia who wanted to be involved in advocating for the needs of people with dementia and their families. The inaugural Chair of the Committee, Kate Swaffer, wrote a brief history of the group in 2017 which is available to read on Dementia Australia's website at <https://bit.ly/3i78rJt>.

This is the second iteration of the group, formed when Alzheimer's Australia transformed to Dementia Australia in 2017. Currently, it comprises nine advocates drawn from across Australia: Phil Hazell (Chair), Eileen Taylor (Vice-Chair), Kevyn Morris, Juanita Hughes, Sarah Ashton, Ann Pietsch, Val Schache, Dennis Frost and Bobby Redman.

The committee aims to be a catalyst of change, working towards an inclusive future, where people living with dementia are valued and respected. They bring together a vast range of skills and experience, but in their diversity lies a common goal of helping to build a better future for all those affected by dementia.

## DAAC meetings

DAAC members have always met monthly via Zoom for

Members of the **Dementia Australia Advisory Committee\*** report on the many ways in which they, as advocates living with dementia, are shaping the work of Dementia Australia and the wider community of stakeholders



**Dementia Australia Advisory Committee (DAAC) members (from left) Eileen Taylor (Vice-Chair), Bobby Redman, Juanita Hughes, Phil Hazell (Chair), Val Schache, Ann Pietsch, Dennis Frost, Sarah Ashton and Kevyn Morris**

regular input and interaction with Dementia Australia, with additional meetings to work on specific issues. The highlights of these regular meetings have been the annual face-to-face meetings, which unfortunately have been placed on hold because of COVID-19. Everyone in the group is looking forward to the time when we will be able to hold physical meetings again.

The face-to-face meetings have occurred at a number of venues. Several have been held at national conferences that our members have been actively involved with. One took place at the NSW offices of Dementia Australia and two were held at hotel conference venues. After some disappointing experiences

with some accommodation venues, we adopted the use of an assessment tool *Make It Dementia Friendly*, based on the work of Professor Richard Fleming, and available at <http://bit.ly/Making-it-dementia-friendly>. This resulted in the selection of better-suited accommodation and conference facilities. A flow-on from this was that members of staff in these venues independently followed up on becoming more dementia aware.

The year 2020 began with our last face-to-face meeting where many ideas were discussed both formally and informally. Many of these ideas went on to be developed into actions throughout the year.

One idea was to prove very

timely. Prior to the first of the COVID-19 lockdowns, we discussed the idea of developing more useable resources to aid all advocates in using Zoom. Within a few weeks this idea was enacted, with the group developing a set of resources to help everyone better use Zoom.

These resources included a detailed guide to using Zoom as well as a number of tip sheets (and available on Dementia Australia's website at <https://bit.ly/2SONj5m>). These resources have now been used by several universities, not only to help facilitate virtual communication with research participants, but to prove to ethics committees that people living with dementia are still capable of full social

\* The article co-authors are Dementia Australia Advisory Committee members Phil Hazell (Chair), Eileen Taylor (Vice-Chair), Kevyn Morris, Juanita Hughes, Sarah Ashton, Ann Pietsch, Val Schache, Dennis Frost and Bobby Redman

interaction and able to contribute in many ways to academic research.

### DAAC at work

The DAAC has been involved in many other activities. Some of these are briefly described below. This work is a collective effort on the part of all our members. As individuals we all are involved in many aspects of dementia advocacy.

### Dementia Action Week

We generated and helped develop the idea for Dementia Australia's Dementia Action Week 2020 campaign: 'A little support makes a lot of difference'. We wanted to challenge the common preconceived idea of what someone with dementia 'looks like' and to show that you can live well with dementia, with a little support. The goal of living well with dementia is at the core of all our contributions and activities.

### Research engagement

We also advocated for Dementia Australia to address consumer involvement in the decision-making aspects of research and building capacity to achieve this. This work resulted in a dedicated position being created at Dementia Australia called 'Consumer Engagement Coordinator Research'. The purpose of the role is to focus on building the capacity of researchers and facilitating people with lived experience being involved in research in a collaborative way.

Individually, almost all of us have collaborated with numerous research groups over the past few years. Many of us (and many other dementia advocates too) hold positions advising on the lived experience to peak research bodies. We collectively hope to

raise the quality of dementia-related research and hope to see the benefits flow through to all people living with dementia.

### Emergency planning

Early in 2020 we advocated for the impact of two major events – COVID-19 and the 2019-2020 bushfire season – on people living with dementia, carers, and their families to be well understood and a priority to ensure people are supported. This included developing an accessible survey that addressed these topics and analysing the results. The survey was open for three weeks and received 86 responses.

The feedback from the survey informed Dementia Australia's submission to the Disability Royal Commission on Emergency Planning and Response, its submission to the Aged Care Royal Commission on the impact of COVID-19, and its discussion paper, published in November 2020 and titled '*One Day the Support Was Gone: The Mental Health Impact of COVID-19 on People Living With Dementia, Their Families and Carers*' (available at <https://bit.ly/3yWQEuw>), as well as ongoing advocacy during this time.

Members were also involved in making a video sharing their experiences of the impact of COVID-19 and recommendations. The video was shown at the Federal Parliamentary Friends of Dementia event on 25 November 2020 and can be found at <https://youtu.be/KD4bjimwkWM>

### A Stronger Voice Together

We collaborated with the Dementia Australia Consumer Engagement team to prepare a project proposal paper to

develop an engagement framework to ensure purposeful participation of people with lived experience of dementia within Dementia Australia. The title of this project is A Stronger Voice Together. This led to a webinar in March 2021 aimed at developing processes of co-design. Two of our group presented on their experience with co-design, as well as two external experts on the subject. This event was well attended both by Dementia Australia staff and dementia advocates from across Australia. This project will be ongoing and is, we believe, a world-first.

### Dementia care communique

In 2019 we, along with advocates from around Australia, helped formulate a document on how dementia care should work. This led to a major summit held in Canberra, which resulted in a landmark document that defines quality dementia care – *Our Solution: Quality Care For People Living With Dementia* (available at <https://bit.ly/3fGqMvg>). This communique was presented to the Federal Government in July 2019 and to the aged care sector in November 2019.

We DAAC members have also actively individually contributed to many media opportunities and presentations across a wide range of topics. We have also contributed to several international publications and presented at a number of international conferences via virtual technologies, as you may expect.

### DAAC going forward

The committee identified a list of priorities for attention in 2021. This includes, but is not limited to:

- More work and

opportunities in Aboriginal and Torres Strait Islander spaces, including further development of opportunities upon community-led co-design and collaboration.

- Further advocacy and engagement with Culturally and Linguistically Diverse communities and other minority groups.
- Awareness of younger onset dementia, in particular for the National Disability Insurance Scheme.
- Increase awareness of Dementia Australia services and programs and increased distribution of the resources that are produced by Dementia Australia.
- Further advocacy related to employment and reducing the discrimination experienced by people living with dementia.
- Increased engagement with general practitioners (GPs) and practice nurses and peak bodies that represent them, including awareness of Dementia Australia resources.
- Development of greater advocacy through mentorship programs facilitated by DAAC members and building of advocate networks.
- Increased educational opportunities for medical and allied health practitioners, including students.

### How to contact us

DAAC can be contacted via email

[DAAC@dementia.org.au](mailto:DAAC@dementia.org.au), and more information can be found at:

<http://bit.ly/DAAC-aboutus>

If anyone has issues or ideas that they would like to discuss with members of the group they are welcome to do so via the email address above. ■



DAAC members (L-R): Bobby Redman, Dennis Frost, Val Schache, Kevyn Morris, Phil Hazell, Ann Pietsch, Juanita Hughes, Sarah Ashton, Eileen Taylor

# Multicultural providers bridge the gap

**Bianca Brijnath, Josefine Antoniadou and Andrew Gilbert** share the learning that arose from asking multicultural providers how they facilitate access to dementia services for clients from culturally and linguistically diverse backgrounds

Since 2017, the National Ageing Research Institute (NARI) has been working on Moving Pictures, a collaboration with culturally and linguistically diverse communities (CALD) around Australia to create digital videos on dementia awareness (Brijnath *et al* 2019) (see box p16). During this project, we interviewed over 100 family carers of CALD people with dementia and more than 40 service providers (such as doctors, aged care providers, and community workers) working across various key dementia services.

In this article, we report on findings from our interviews with service providers, who discussed with us the work they do to facilitate access to healthcare and aged care for CALD communities. What struck us about the service providers, in particular, is how they acted as 'boundary crossers' for CALD communities (Brijnath *et al* 2021).

A boundary crosser is a person who is able to occupy two worlds: the world of health and aged care systems on the one hand, and the cultural world of the communities they service on the other. Boundary crossers do important work bridging the gap between these worlds, because they want to ensure people with dementia and carers in CALD communities get access to the care and support they need, when they need it. They can provide important insights into how to best provide dementia services for CALD communities.

## Communication

Boundary crossing starts with good communication. For example, doctors often told us that the word 'dementia'



Filming in Melbourne for the Moving Pictures project

translates into pejorative or negative terms in other languages, and that some people from CALD backgrounds might find those words offensive or confronting. Using these words can make the relationship between providers and families difficult, and may make families reluctant to follow up on treatments or supports after a dementia diagnosis. Some doctors, therefore, said they used English words like 'dementia' or 'Alzheimer's disease' instead, as these are more neutral, clinical terms, and therefore easier to accept.

Yet at the same time, there are beliefs among some CALD people that the symptoms associated with dementia, such as memory loss, are a normal part of ageing. Some providers told us that people from CALD groups might be reluctant to accept that these were symptoms of a medical condition, and labelling a person with a disease like dementia could be stigmatising in those communities. In these cases, it was sometimes

necessary for a doctor to agree with families that these symptoms are normal ageing in order to convince them to accept other forms of support, such as home care.

Ultimately, different CALD families will have different understandings of dementia and different ways of processing a diagnosis. It is necessary for services to understand these differences and work towards building trust with communities by collaborating with them.

A tailored approach is required, in which providers are sensitive to differences across, but also within, communities. To achieve this, the providers who participated in our study said they took comprehensive histories of their clients in order to understand their unique cultural backgrounds, their life experiences and their emotional state. This allowed effective communication with people with dementia, and helped establish relationships of trust with them and their families.

## Cultural brokers

Many providers working in the aged care sector highlighted that the system could be confusing for clients to navigate at the best of times. According to them, CALD clients and their families faced additional challenges to the general population, such as language barriers, which made it difficult for CALD clients to access information about services and apply for them (Brijnath *et al* 2020). The bureaucratic and technical language in government agencies or used by professionals typically compounded the stress that older CALD people and their carers often felt while engaging with the aged care system.

Boundary crossers worked hard to mitigate this. For example, we heard from a number of providers from ethno-specific organisations who offered in-language 'one-stop-shops' for members of their communities. These organisations were a single entry point into a wide range of health and aged care services. Typically, they provided respite

## About Moving Pictures

The Moving Pictures team has so far produced 15 short films on dementia with Hindi-, Tamil-, Mandarin-, Cantonese- and Arabic-speaking communities, all of which can be viewed on the project website (<https://movingpictures.org.au/>). For each of the five language groups, there are three films: Detection and Diagnosis, Navigating Care, and the Carer Journey. The Moving Pictures films include contributions from carers of people living with dementia and key service providers.

The next phase of the project, Moving Pictures II, is currently underway and involves working with the Greek-, Spanish-, Italian-, and Vietnamese-speaking communities to co-produce 12 more films, with the launch of these expected around September 2021.

The Moving Pictures website includes state-specific links to a long list ethno-specific community, aged care and health services, as well as Partners in Culturally Appropriate Care (PICAC) providers. Go to <https://movingpictures.org.au/> and search under 'Resources'.



One of the key dementia service providers who participated in the Moving Pictures project, sharing information about their work facilitating access to healthcare and aged care for CALD communities

services and home care, organised carer support groups, hosted talks and information sessions, organised community social events and provided a point of contact if older people or their carers had any questions or needed help.

Services like these acted as cultural brokers between communities and the aged care system, and were often well known, trusted and valued within their communities. Identifying and connecting with these ethno-specific services is important not only for older CALD people and their carers, but also for aged care providers who may be servicing an increasingly diverse client base. The Moving Pictures website has a list of state-specific ethno-specific services (see box px).

### Shifting boundaries

In many communities, it is expected that family members care for their loved ones at home. Seeking outside assistance can be seen as the family failing in their duty of

care. However, according to many providers we spoke to, such culturally derived ideals may not necessarily be advantageous to people with dementia or their families and can mean people do not receive the support that they need to effectively care for the family member with dementia or support themselves.

Consequently, providers considered it part of their role to shift the boundaries around family life, encouraging people with dementia and their families to accept formal services, such as home care or meals services. Aged care providers also described the sensitive conversations they had with CALD families at the transition points into more permanent care. These providers told us that by emphasising to CALD clients that formal services strengthened family relationships, rather than replacing them, they made it easier for families to recognise the benefits of residential aged care:

*"[W]e take over the dirty jobs...and [we say to the family],*

*'You can enjoy a beautiful time with your family not doing the dirty jobs'... But we always said, 'We can't take over your position as the son, daughter, or the daughter-in-law.' We [are] just the...hero behind the curtain.'* – Manager working with Chinese-speaking families in aged care.

### Conclusion

Our data is clear: providers who work with CALD people living with dementia and their families are faced with significant challenges in brokering access to dementia services. Yet, by virtue of having an in-depth and, in many cases, a shared understanding of the cultural and social complexities of a community, these providers can act as cultural brokers in facilitating access to services for their clients.

In negotiating cultural, social and professional boundaries, providers undertake multidimensional and complex work that involves education, advocacy, negotiation, navigation, creativity and emotional engagement. While hugely important to clients, this work is largely undervalued, but offers a model of care that facilitates social and community development as well as service integration across health, aged care and social services. ■

**For a more detailed analysis of boundary crossers and their important work, see our recent article published in the *Journals of Gerontology: Series B* (Brijnath et al 2021).**

### Acknowledgments

The Moving Pictures project has been funded through the Federal Government Department of Health's Dementia and Aged Care Services Research and Innovation grants. Our work has also been supported by many health and community services, aged care services and other relevant organisations as well as our numerous supporters from CALD communities. Please visit [www.movingpictures.org.au](http://www.movingpictures.org.au) to see our list of supporters as well as access our dementia short films and comics.

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**Cultural Diversity in the Aged Care Workforce: Current Implications and Future Opportunities is the title of a webinar recently hosted by two of the article authors, Associate Professor Bianca Brijnath and Dr Josefine Antoniadou. A recording of the webinar is available to view any time at [www.nari.net.au/Event/seminars-in-ageing-090221](http://www.nari.net.au/Event/seminars-in-ageing-090221)**



■ From left: Associate Professor Bianca Brijnath is Director of Social Gerontology at the National Ageing Research Institute (NARI); Dr Josefine Antoniadou is the Project Manager on Moving Pictures, a Research Fellow at NARI and Adjunct Research Fellow at Curtin University; Dr Andrew Gilbert is a Research Fellow at NARI and Honorary Associate at La Trobe University. To follow up on this article contact Dr Antoniadou at [j.Antoniadou@nari.edu.au](mailto:j.Antoniadou@nari.edu.au)

Australia's Dementia Centre for Research Collaboration (DCRC) Changed Behaviours Special Interest Group (SiG) aims to promote inclusivity and multidisciplinary collaboration to better understand changed behaviours and improve care for people living with dementia, families and care partners.

The SiG is a collective of over 175 experts in dementia from a range of backgrounds, including people living with dementia, families/care partners, healthcare professionals, care providers, clinicians, government/policy makers and researchers from around Australia (see Figure 1). SiG members are advised of events organised specifically for the group and are invited to participate and be kept informed.

Established in February 2019, the SiG was initially called the 'Behaviours and Psychological Symptoms associated with Dementia (BPSD) SiG', and now, in response to members' requests, is the 'Changed Behaviours SiG'.

The SiG aims to discuss issues and debates regarding dementia care and the way people living with dementia are viewed and treated, both in professional contexts and within society generally (Dür 2019; Hanegraaff & Poletti 2019; Jungherr *et al* 2021). These discussions guide and encourage research implementation, and foster

# Changed Behaviours Special Interest Group

With almost 200 members from around Australia, the DCRC Changed Behaviours Special Interest Group aims to improve understanding and care through discussion and collaboration between people living with dementia, family members, care providers, health professionals, researchers and policy makers. The project's investigators, **Claire Burley**, **Nadeeka Dissanayaka** and **Henry Brodaty** explain



The Special Interest Group discusses issues around dementia care and the way people living with dementia are viewed and treated. Stock image

collaborations between people living with dementia, families and care partners, service providers, government, policy makers and researchers.

The focus is on changed behaviours and psychological symptoms associated with dementia and improving care and quality of life for people living with dementia. Cunningham and colleagues

(Cunningham *et al* 2019) and Dementia Australia (2018) provide more information about preferences on terminology and language guidelines.

Working together with all stakeholders to better understand the experiences of people living with dementia will improve our ability to provide better care nationally.

## What are changed behaviours?

Changed behaviours (also known as behavioural and psychological symptoms of dementia (BPSD), neuropsychiatric symptoms (NPS), or responsive behaviours) emerge during the course of dementia. They include aggression, agitation, anxiety, apathy, depression, disinhibited behaviours, nocturnal disruption, psychotic symptoms, vocally disruptive behaviours and wandering. The language used to describe changed behaviours is a controversial topic (Cunningham *et al* 2019): terms such as 'BPSD' and 'NPS' are criticised for being too medicalised and encouraging inappropriate use of medication, whereas terms such as 'responsive behaviours' have been criticised for neglecting dementia-related changes in the brain and psychological symptoms (eg hallucinations, delusions and depression).

Changed behaviours appears to be the preferred term among professionals and people with lived experience of dementia, according to general discussion with SiG members and as revealed in our qualitative research study, conducted from December 2019 to February 2021, where we interviewed people living with dementia and families/care partners (Burley *et al* invited submission, under review).

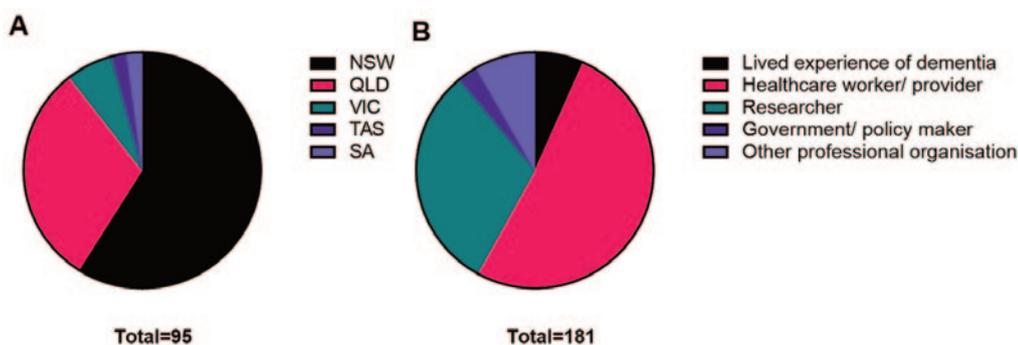


Figure 1. DCRC Changed Behaviours Special Interest Group information about members (175 members in total). A shows the Australian state where members are based, if known. B shows how people identify themselves (they can choose more than one option) (as of December 2020)

## Initial meeting and workshop

The initial SiG meeting, a roundtable discussion at the Australian Dementia Forum (ADF) in Hobart during June 2019, involved 10 professionals working in dementia care and research. The discussion focused on: (1) how we should be preventing and managing changed behaviours, (2) implementing change (ie knowledge translation), and (3) appropriate language. Proposed resolutions included:

- Developing person-centred systems involving government and policy makers that change care culture (eg, cost-effective person-centred approaches, see Burley *et al* 2020; presented at ADF 2019, government meeting, Canberra 2019, and Alzheimer's Association International Conference (AAIC) 2020).
- Developing seamless dementia care pathways (eg, Tolman & Morrisey 2016 and Co-designing Dementia Diagnosis and Post-diagnostic Care (COGNISANCE, a major research study led by the Centre for Healthy Brain Ageing (CHeBA) which aims to improve the dementia diagnostic process and post-diagnostic support).
- Increased focus on dementia-specific training for general practitioners (eg, Casey *et al* 2020).
- Person-centred approaches in residential care that reduce inappropriate use of medication (eg, Chenoweth *et al* 2019; Brimelow *et al* 2019).
- Preventative non-pharmacological approaches (ie, lifestyle).

## Positive action

Since then, workshops and symposia have taken place to continue these important conversations with all stakeholders and focus on how we translate knowledge into improved quality of life



**The Changed Behaviours SiG is just one of many initiatives needed to improve quality of life for people living with dementia. Stock image**

for people living with dementia. The DCRC also has quarterly meetings with the Dementia and Supported Ageing Branch, Australian Government Department of Health, to discuss ongoing research and government activities (eg, updating clinical guidelines, the views of people living with dementia and COGNISANCE).

In November 2019, a full-day workshop took place in collaboration with Neuroscience Research Australia (NeuRA). Ninety-five people attended the workshop, mostly healthcare professionals and researchers, along with government policy makers and several people with lived experience of dementia.

The first half of the day involved presentations focused on person-centred care and changed behaviours including sustaining desirable practice change, designing research to support older adults, a NSW Health 'extreme BPSD' policy project, partnering with government, 'beyond changed behaviours and the problem with 'BPSD', cost-effective non-pharmacological approaches, and several person-centred hospital and residential care intervention studies. The workshop slides are available at <https://bit.ly/3tZLCKj> (under 'Resources' at the bottom of the page).

During the afternoon, attendees brainstormed ideas about improving care, future

dementia research priorities and improving language use. Priority areas identified were: (1) continued growth of dementia-specific education and staff training, (2) improving policies (eg, sufficient number of qualified nursing staff on shift where people living with dementia are receiving care), (3) better support services and clearer 'pathway' from early concerns regarding cognition/memory, through to diagnosis and beyond, (4) person-centred and non-pharmacological approaches, and (5) increased societal awareness of dementia and reducing stigma (eg, ageism).

Feedback was very positive, with 91% of the 66 attendees who completed the survey reporting that their knowledge of changed behaviours improved; and 97% reporting that they would apply their learnings to their workplace to raise awareness. Of the nine consumers who completed the feedback survey, two reported their knowledge had not improved, though all but one were satisfied with the workshop overall.

## Online symposia

In response to COVID-19 physical distancing restrictions during 2020, we hosted two half-day symposia online (both can be viewed at <https://bit.ly/3tZLCKj>). Each of these events attracted over 100 participants and provided opportunities for attendees to hear about the latest research,

listen to and participate in expert panel discussions and talk about issues focused on improving quality of care for people living with dementia.

The first symposium focused on changed behaviours. Presented abstracts included the knowledge translation pipeline (Dementia Training Australia), implementation of individualised music in residential care (University of Newcastle) and a national database for holistically assessing interventions (Dementia Support Australia).

The expert panel discussion, hosted by Glenn Rees AM, Chair of Alzheimer's Disease International (ADI), posed the question of where we need to go next to improve care in light of the Royal Commission into Aged Care Quality and Safety. This instigated ongoing collaborative discussion between people with lived experience of dementia, residential care providers, and researchers (eg DCRC and other university research centres) to discuss and write grant proposals for future research projects (eg person-centred care in hospital settings).

Other expert panel presenters were from Aged & Community Services Australia (ACSA), Australian Health Services Research Institute (AHSRI), Montefiore Homes, the Centre for Medicine Use and Safety, and the Dementia and Supported Ageing Branch, Australian Government Department of Health. This collaborative effort is vital in moving forward and accelerating improvements in care for people living with dementia.

The SiG collaborative is unique in that it is continually growing and responding to the changing landscape of dementia (ie, current priority areas, including improving care, language use and future research, are driven by the views of the group) and is inclusive of people living with a diagnosis of dementia. (You can view the expert panel

discussion here <https://bit.ly/3tZLCKj>.) The second symposium launched a new research network focused on Anxiety and Depression in Dementia Research (ADDResearch).

### ADDResearch Network

In 2020, the ADDResearch Network was created by the DCRC hub at UNSW Sydney, which focuses on changed behaviours, and Dr Nadeeka Dissanayaka (co-author here), from the University of Queensland, to encourage collaboration between people with a particular interest in anxiety and depression in dementia research.

In November 2020, ADDResearch hosted a dedicated online symposium, which included four research presentations on effective non-pharmacological approaches for depression (DCRC), social support for depression and loneliness (National Ageing Research Institute), psychotherapy for anxiety in people with cognitive impairment (University of Queensland), and neurobiology of anhedonia, apathy and depression in frontotemporal dementia (University of Sydney).

This was followed by four expert panel presentations and a discussion led by Professor Henry Brodaty (co-author here) from the DCRC, UNSW Sydney. Topics included evaluation of anxiety and depression in dementia, diagnostic support tools, involvement of care partners, and psychosocial interventions. The discussion focused on the future of research into anxiety and depression in dementia.

Overall, gaps in current research were highlighted, including reducing inappropriate prescription of psychotropics, developing person-centred interventions, and advancing knowledge in interacting brain mechanisms underlying anxiety, depression and dementia. People with lived experiences of dementia and their care partners provided valuable input.

### Future events

To progress, we need to give sufficient attention to individual changed behaviours and provide opportunities for people to learn from experts (both professionals and people with lived experience).

In 2021, the DCRC Changed Behaviours SiG is hosting three online symposia in each of the following topics: disinhibited behaviours (with Dementia Training Australia) (held on Friday 18 June 2021), sleep disturbances (Friday 16 July), and anxiety and depression (with ADDResearch) (Friday 17 September), with each session held via Zoom from 10am-12.30pm AEST. The symposia are free and registration details can be found at <https://bit.ly/3tZLCKj>.

DCRC will also host an online workshop, from 10am-4pm AEDT on Friday 19 November, on 'Making person-centred care a reality'. This event will reflect on progress, challenges and future priorities since the Royal Commission into Aged Care Quality and Safety. This free workshop will also be held via Zoom. Depending on physical distancing requirements and the pandemic status, Sydney-based attendance may also be arranged. For registration details, visit <https://bit.ly/3tZLCKj>.

### Conclusion

The Changed Behaviours SiG is just one of many initiatives needed to drive change and improve quality of life for people living with dementia. We need to continue to encourage more people living with dementia to be involved and share their experiences. Ongoing communication between the SiG and DCRC's new Consumer Involvement Coordinator, Deborah Brooks, and Dementia Australia Consumer Engagement Coordinator, Kate Harding, will help facilitate this.

While it's too soon to be able to quantify the SiG's impact, our group is excited about receiving feedback from stakeholders and potentially developing a Community of Practice which

includes people living with dementia.

### How to get involved

If you are interested in joining the SiG or would like to find out more, please email Dr Claire Burley, Postdoctoral Research Fellow at the University of NSW (UNSW), Sydney at [c.burley@unsw.edu.au](mailto:c.burley@unsw.edu.au).

### Information and resources

More information, including resources from previous events and registration information for future events, is available on the DCRC Changed Behaviours SiG resource page at <https://bit.ly/3tZLCKj> ■

**DCRC update: The Dementia Centre for Research Collaboration (DCRC) will be ceasing operations on 23 December 2021. However, we plan for the SiG and ADDResearch Network to be relocated to another dementia organisation, and for future events to be organised. Details will be provided when confirmed.**

**Please email [c.burley@unsw.edu.au](mailto:c.burley@unsw.edu.au) (for the SiG) or [n.dissanayaka@uq.edu.au](mailto:n.dissanayaka@uq.edu.au) (for ADDResearch) if you would like to be kept informed and are not already a member of the group.**

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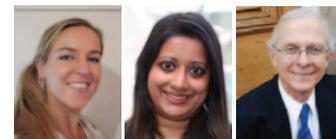
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■ From left: Dr Claire Burley is a Postdoctoral Research Fellow, Dementia Centre for Research Collaboration (DCRC), School of Psychiatry, UNSW Sydney; Dr Nadeeka Dissanayaka is a NHMRC Boosting Dementia Research Leadership Fellow, Dementia & Neuro Mental Health Research Unit, UQ Centre for Clinical Research, Faculty of Medicine, The University of Queensland, Brisbane; Professor Henry Brodaty is Director, Dementia Centre for Research Collaboration (DCRC), School of Psychiatry, UNSW Sydney and Co-Director, Centre for Healthy Brain Ageing (CHeBA), School of Psychiatry, UNSW Sydney

For people with dementia and other forms of cognitive impairment, the hospital experience can be overwhelming, distressing, confusing, disorienting and exhausting. In the busy hospital environment, these patients can receive inadequate, inappropriate or delayed care because their dementia isn't identified or their symptoms are misdiagnosed as being part of their dementia.

Specific actions to improve the health care provided to people with cognitive impairment, including dementia, are included in the second edition of Australia's National Safety and Quality Health Service (NSQHS) Standards (<http://bit.ly/safety-and-quality-standards>), published in 2017. The NSQHS Standards, developed by the Australian Commission on Safety and Quality in Health Care (the Commission) in consultation with the Government, providers, clinical experts, patients and carers, provide a nationally consistent statement of the level of care consumers can expect from health service organisations.

Since January 2019, implementation of the cognitive impairment actions has been assessed during accreditation to ensure all hospitals have systems in place to meet the requirements for safety and quality. The three specific actions about cognitive impairment are: developing a system for caring for patients with cognitive impairment (action 5.29); clinicians use the system for caring for patients with cognitive impairment (action 5.30); and recognising acute deterioration in mental state (action 8.5).

There are other actions relevant for all patients that are particularly critical for patients with cognitive impairment or at risk of delirium, and actions that support or enable safe and high-quality care for these

# Thousands take action to improve hospital experience

Five years after the launch of Australia's Caring for Cognitive Impairment Campaign, **Victoria Young** reflects on its key achievements, including attracting more than 2000 champions committed to improving the care and experience of people with cognitive impairment in hospital



**NSW Health Dementia and Delirium Clinical Nurse Consultants photographed during the Caring for Cognitive Impairment Campaign**

patients (see <http://bit.ly/NSQHS-user-guide> and <http://bit.ly/cogcare-factsheet>).

## The campaign

In January 2016, the Commission launched a Caring for Cognitive Impairment Campaign to support hospitals prepare for the new cognitive impairment actions. Running until June 2019, the campaign focused on raising awareness, sharing information and increasing knowledge. It recognised that everyone who works with people with cognitive impairment can help to improve their health outcomes and experience in hospital.

## Learning through sharing

A total of 2266 people took up the invitation to join the campaign as individual champions committed to tailored actions. Their stories, from people living with dementia, carers and family members, and hospital workers, are published on the

Cognitive Care website ([www.cognitivecare.gov.au](http://www.cognitivecare.gov.au), on the 'Individuals' page).

Hearing the personal stories of those with lived experience and their carers is an essential part of providing better person-centred care. Some of the individual stories show how things can go wrong if hospital staff don't listen to the family of the patient with dementia or other cognitive impairment.

The stories generously shared for the campaign are opportunities for staff education and healthcare improvement. The stories from hospital staff are also valuable resources for others who work in this area.

Thirty-seven organisations joined the campaign as supporters, with a commitment statement about the importance of the campaign and their motivation for joining. They included allied health associations, professional colleges, public health networks, research

organisations, non-government organisations and other health agencies.

Success stories published on the Cognitive Care website include the Royal Australasian College of Physicians' (RACP) contribution to the global RACP and physician-led movement Evolve ([www.evolve.edu.au](http://www.evolve.edu.au)), which aims to drive high-value, high-quality care.

The RACP story, published on the Cognitive Care website (see the 'Supporters' page), summarises the implementation of its research to identify how hospitalisation can be an opportunity to reduce inappropriate polypharmacy in older adults with multi-morbidity.

Several of the 232 hospitals that joined the Caring for Cognitive Impairment Campaign also provided their stories. In addition, hospitals had the option to nominate a Lead Cognitive Champion whose contact details would be available on the website. The Lead Champion was a knowledgeable contact point for hospital staff providing care to people with cognitive impairment, as well as a driver for increasing cognitive impairment education for hospital staff and advocating for patients with cognitive impairment and their families.

## Highlighting new initiatives

The campaign built on the work already being done around Australia, and the dedicated website continues to share new initiatives for improving cognitive care. A recently submitted story from Port Pirie Regional Health Service reported a reduction of

incidents of delirium as a result of its strategies. Port Pirie was the first major country hospital to implement the Country Health South Australia's Comprehensive Care of Older People model of care project as part of its commitment to the campaign.

This integrated health service model includes implementation of delirium prevention and management strategies for older people with deteriorating brain function from dementia and other brain diseases. More detail about the model is available in SA Health's Health Service Framework for Older People 2009-2016 (<http://bit.ly/framework-for-older-people>).

Port Pirie's story is a great example of how a project lead, education of clinical and non-clinical hospital staff, a patient and family-centred approach, and communication can improve outcomes for patients. They experienced a dramatic increase in staff and patient engagement and a demonstrated decrease in incidences of hospital-acquired delirium. Some of the strategies included:

- Investing in extensive staff education resources.
- Collaborating with community members and support groups to enhance the service's ability to provide an individualised patient and family-centred approach to cognitive impairment care delivery.
- Upgrading the inpatient multi-disciplinary whiteboards to include a column for cognitive impairment (using the CII symbol), which triggers a high-priority pharmacy review and medication reconciliation.

New stories about successful initiatives are always welcome and can be sent to [cognitive.impairment@safetyandquality.gov.au](mailto:cognitive.impairment@safetyandquality.gov.au), or submitted on the Cognitive Care website at <https://cognitivecare.gov.au/share-your-story/>

The Cognitive Care website was central to the campaign and continues to provide a platform for ongoing work in cognitive care. The site is not only for health professionals – it also provides a range of information, educational resources and helpful tips to support people living with dementia and their families.

### Maintaining engagement

While sharing stories and initiatives was one way the campaign maintained engagement over 3½ years, the program also offered webinars with dementia and cognitive impairment experts, clinicians and researchers. These are all available on the website, along with many other educational videos on a range of relevant topics. One of the webinars is titled *Improving the Hospital Environment for People with Cognitive Impairment* (available at <http://bit.ly/hospital-environment>), featuring representatives from Dementia Training Australia. Videos include *Recognising Delirium in Emergency Departments – A Nurse's Perspective*, *Dementia and Delirium – The Facts* by specialist geriatrician Professor Sue Kurlle, *Dementia Care in the Hospital Emergency Department*, and *Dementia and Delirium – Communication at Transitions of Care* (all available at <https://cognitivecare.gov.au/videos>).

The *Cognitive Impairment Newsletter* that commenced at the start of the campaign was another way to share up-to-date information, knowledge, news, events and resources and keep people connected. Although the official campaign has ended, the Cognitive Impairment Program team continues to write, publish and send the newsletter to subscribers twice a year to let everyone know about the work happening to continually improve cognitive care.

Organisations, hospitals and researchers continue to submit reports on initiatives, programs and studies for publication in the newsletter

and on the Cognitive Care website. The number of newsletter subscribers continues to grow and has now reached more than 2000.

The campaign's level of engagement and momentum over almost four years, and the outcomes of strategies resulting from the campaign, have been positive.

### Where to next?

The Commission continues to work to improve the care of all people with dementia and other forms of cognitive impairment.

### Website and newsletter

The Cognitive Care website and *Cognitive Impairment Newsletter* will continue to be a source of current information, resources, events, research, and updates on the work of the Cognitive Impairment Program. In the spirit of collaboration and cohesiveness, the Commission continues to liaise with researchers around the country to gather and share new research in dementia, delirium and other forms of cognitive impairment on the 'Programs, Networks and Research' page.

### Advisory group

A new Cognitive Impairment Advisory group has been established by the Commission to provide guidance on the next areas of work. Along with clinicians, researchers and representatives from relevant organisations, a consumer representative living with dementia has been appointed to this new group.

### Reducing antipsychotics

The Commission continues to work with partner organisations to reduce the inappropriate use of antipsychotic medications to treat symptoms of dementia. It is important that antipsychotic medicines are only used under very specific circumstances – as a last resort, when all other options have been tried to reduce distress and remove

danger to the patient and others.

### Improving transitions

Other work is currently underway focusing on improving transitions of care – ensuring that communication about conditions, medications and medical history goes with the patient when they enter and leave hospital, to reduce the risks of miscommunication and misdiagnosis.

This work will involve a literature review and consultation with health services, clinicians, people living with cognitive impairment and the Cognitive Impairment Advisory Group. This will inform the development of appropriate resources for clinicians and consumers.

### Resource development

The Cognitive Impairment Program also addresses other forms of cognitive impairment. It is currently developing a resource to emphasise how actions in the NSQHS Standards can improve the health care for people with intellectual disability.

### More information

To find out more about the Commission's cognitive impairment work, visit [www.cognitivecare.gov.au](http://www.cognitivecare.gov.au) and the Commission's website [www.safetyandquality.gov.au](http://www.safetyandquality.gov.au). ■



■ Victoria Young is Project Officer (Cognitive Impairment) with the Australian Commission on Safety and Quality in Health Care. Contact her at [cognitive.impairment@safetyandquality.gov.au](mailto:cognitive.impairment@safetyandquality.gov.au)

# How allied health can help

In the first of a two-part series, geriatrician **Dr Clair Langford** discusses the vital contribution that allied health professionals make to the support of people living with dementia and their carers (below). On the following pages, three allied health professionals (dietitian **Lilliana Barone**, occupational therapist **Donna Horan**, and neuropsychologist **Penny Steele**) explain what this support looks like in practice. Part two, in the next issue of *AJDC*, will focus on the role of physiotherapists, speech pathologists, clinical nurse specialists and dementia advisors

**A**llied health is a term used to describe a range of health professionals who are not doctors, dentists or regular nurses. Allied health professionals aim to prevent, diagnose and treat a range of conditions and illnesses and work with doctors and nurses to optimise patient outcomes.

They include: physiotherapists and exercise physiologists, occupational therapists, social workers, neuropsychologists and clinical psychologists, dietitians, speech pathologists, Aboriginal and cultural and linguistically diverse health workers, counsellors, podiatrists, dental hygienists, dementia advisors, diversional therapists, music therapists, pharmacists, optometrists and audiologists.

The different types of dementia and different stages of dementia may require the input of different allied health professionals at different times.

It is not uncommon for dementia to be first flagged by an allied health professional while seeing a person for a routine issue. For example:

- A pharmacist may notice the person is missing tablets in a blister pack or that scripts are being renewed too often or not enough.
- A physiotherapist might notice the person is not remembering an exercise from one visit to the next or not remembering to use their walking aid.
- An optometrist or audiologist may not be able to fix a sight or hearing problem because the brain is not understanding what the person sees and hears – it is not processing the information correctly.
- The person may be losing weight and a dietitian realises that they are forgetting to eat.

These allied health professionals will then contact the person's GP and recommend further assessment.

As a geriatrician, working at the Bulli Hospital and Aged Care Centre (see box right), I often contact our allied health professionals early in the assessment and treatment process. When assessing



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patients, our clinical nurse specialist, Alexia Bradley, particularly looks for issues that could be addressed with allied health support. For example:

- I might ask a **physiotherapist** to assess and treat balance and walking problems for people experiencing falls because of vascular dementia or Lewy body dementia.

- A **neuropsychologist** might help because the type of dementia isn't clear or the person needs to understand what aspects of their brain are still working well and where there is difficulty, especially if it is a more uncommon type of dementia.
- I often call the person's **pharmacist** to clarify their medication history. I may ask them to track back as far as 20 years to understand why someone is on a particular medication and how it might be impacting their health, and most especially their brain.
- An **audiologist** may be engaged if it becomes clear the person is not hearing what is said, is guessing poorly but often guessing incorrectly, and so giving bizarre answers. So many people are too proud to wear hearing

## A team approach to care

Bulli Hospital and Aged Care Centre is a new, purpose-built facility for aged care services, operated by the Illawarra Shoalhaven Local Health District (ISLHD), in NSW.

Opened in August 2020, it's designed to meet the needs of the region's ageing population and provides inpatient, outpatient and allied health services.

There are currently six geriatricians (including Dr Clair Langford, author of the accompanying article) who work within the centre's outpatient services clinic, which runs Monday to Friday. Each week the clinic sees an average of 10 new clients and reviews a further 25 clients.

The clinic provides a team of health professionals including allied health, geriatricians and clinical nurse specialist, working together to provide comprehensive care for older clients and their carers living in the community. A neuropsychology team works externally to the clinic on a referral basis. Similar

clinics operate in other NSW area health services. Typically, people are referred to the clinic by their GP if they are over the age of 65, with one or more of the following:

- Concerns with memory decline
- Concerns with increasing confusion
- Recurrent falls
- Assessment and opinion on driving
- Concerns about functioning at home alone
- Concerns with multiple medications
- Concerns with multiple health conditions.

On their first visit, new clients will undergo a comprehensive geriatric nursing assessment by a clinical nurse specialist before seeing a geriatrician. The areas assessed include: eyesight and hearing, falls history, exercise, continence, nutrition, medication use and management, pain, functional ability and independence, home environment, cognitive ability, mood and social activity.

# Illawarra Dementia Forum

The articles on these pages are edited versions of presentations given at the 2021 Illawarra Dementia Forum – *Dementia Support: How Allied Health Can Help You* – live-streamed on 10 March 2021. The annual forum is aimed at people living with dementia, their families and carers living in the community. The articles are published here with the permission of the speakers and the Illawarra Shoalhaven Local Health District (ISLHD). Information relating to clients and carers has been de-identified.

Geriatrician Dr Clair Langford was the forum's keynote speaker, with other presentations given by the allied health professionals featured in the articles in this series (parts 1 and 2), along with clinical nurse specialist Alexia Bradley. Dementia Training Australia (DTA) Executive Director, Professor Belinda Goodenough, hosted the forum's panel discussion.

This year's event was supported by Dementia Australia, DTA, ISLHD, University of Wollongong and the Multicultural Communities Council of Illawarra.

A webinar recording of the forum is available to watch at <https://dta.com.au/resources/illawarra-dementia-forum-2021/>

aids, but it can make them appear to have dementia when in fact they are just not hearing correctly and are misunderstanding people all the time.

- A **psychologist** or **counsellor** might be asked to help if the diagnosis is extremely distressing, particularly if past experiences of someone close to

them having dementia is traumatic.

- As the dementia progresses, we may need to offer help to enable the person to navigate the My Aged Care system by providing a **CALD worker** for culturally and linguistically diverse patients or an **Aboriginal support worker** for someone from our Indigenous community. Sometimes I ask one of our **hospital nurse specialists** or consultant to help if the person has no one else that can help them.
- A **dietitian** might assist with creating healthier food plans.
- A **speech pathologist** may be called on to help if the person has communication difficulties or swallowing problems.
- **Music therapists** or **diversional therapists** usually assist at day centres and facilities and occasionally at home to help a person engage in new things or old things differently, when the ability to do past music, craft and sports activities has declined.

## THE NEUROPSYCHOLOGIST



### Penny Steele

Clinical Neuropsychology Registrar  
Rehabilitation and Medical Psychology Department  
Illawarra Shoalhaven Local Health District

A neuropsychologist is a psychologist who specialises in understanding the relationship between the physical brain and a person's behaviour and thinking.

People are typically referred to a neuropsychologist to help understand whether there has been a change in brain functioning – particularly if there are concerns about the way someone is thinking, remembering, or acting – and, if there has been a change, why that might be the case. For example, someone with dementia might have difficulties with their thinking skills, such as memory, language, concentration, visual skills, or they might have changes to their mood or personality (eg, be more irritable or more impulsive).

For people with dementia, a neuropsychologist is mostly involved in the early stages of the disease, including assisting with diagnosing the particular type of dementia, determining the progression of symptoms, and identifying cognitive strengths and weaknesses to assist with implementing tailored strategies to compensate for difficulties on a day-to-day basis.

At the initial appointment, we ask some questions about the problems the individual may have, as well as other background details (eg, medical information, schooling, occupation history) to get a better understanding of their personal history.

We then complete tests to measure many functions of the brain, for example memory, attention, language, problem solving, and other thinking skills. The testing may involve completing paper- and pencil-based tasks, doing puzzles, remembering information, and answering questions. The pattern of test scores is then compared to those of other people of a similar age and education, as well as the person's own baseline ability. This tells us whether or not there has been a change in any thinking skills and can help us better understand a person's current abilities.

### How can a neuropsychologist help?

The following is an example of someone with dementia and who I saw recently and who benefited greatly from neuropsychology input.

This elderly gentleman had recently received a dementia diagnosis during an admission to hospital following a several-year history of cognitive decline. He and his wife hadn't received much information about how dementia would affect his day-to-day life, and his family requested my help in understanding his diagnosis.

I saw him over several sessions, beginning with an initial cognitive assessment to understand how his dementia was affecting the different areas of his thinking. This helped to identify his main weaknesses, which included learning and recalling information, as well as his personal strengths, which included his ability to recall information when prompted by others. I then worked with the family to come up with some ideas which incorporated this area of strength. For example, the family purchased a calendar whiteboard to remind him of upcoming appointments. They also wrote a list of instructions for common household tasks, like brushing his teeth, preparing small snacks, and getting ready for bed. He could look at these lists whenever he was having trouble doing one of these tasks.

### In summary

Neuropsychologists are like detectives. We use a wide range of information about a person's history and cognitive ability to determine whether a person has dementia and understand how dementia impacts that person's day-to-day functioning.

No two people with dementia have the same difficulties or strengths. Some might have problems with learning, others memory, others language skills. By better understanding a person's specific strengths and weaknesses, we can empower them and their carers to compensate for their daily challenges by developing a personally-tailored set of recommendations to fit their specific circumstances.

A dementia diagnosis can seem daunting at first, however there is still so much that someone with dementia can achieve with a good understanding of their current ability level, and with the right supports and strategies in place.

- There may also be the need to support the carer with **counselling and education** about strategies and the help available.
- Special equipment might be needed as physical function declines, and so we call in our **occupational therapist (OT)**. If I'm unsure if it is safe for the person to drive their car or electric scooter I will refer them to an OT for further assessment.

In the future, we hope to slow the onset of dementia and there is a lot of exciting work being done around diet and lifestyle interventions. Allied health professionals are very likely to help us all take some of these strategies on board.

At any time, other health events for a person living with dementia may complicate the journey and the interaction with these allied health professionals may need to be modified. Carers may need to prompt the person with dementia to do their exercises or assist and motivate them to attend classes after a significant fall and fracture or a stroke. Communication boards or technology may need to be used to help those with loss of speech indicate their needs. A transitional care package of support might be needed to work out what will and will not work for a client and their carers in their own home, along with counselling support from social workers and advisors.

## Conclusion

Sadly, sometimes I have heard people make comments like "This patient doesn't need to see a therapist because they have dementia" and "They will not be able to remember the therapy or follow instructions". So often there can be innovative ways of addressing these issues by thinking outside the square and learning from each other ways of solving the problems. It is always better to have more than one head trying to work out possible solutions for the person with dementia and their carer.

There is no one-size-fits-all in dementia. Every person has their own unique experience and may need assistance and interventions from different professionals at different stages of their disease course. It is true that we can't fix everything, but we must look at the individual and what they still can do, as well as the willingness and abilities of their support team before dismissing an opportunity. ■



■ Dr Clair Langford is a geriatrician, based at Bulli Hospital and Aged Care Centre, Illawarra Shoalhaven Local Health District, NSW

## THE DIETITIAN



**Lilliana Barone**  
Clinical Lead Aged Care Dietitian  
Department Nutrition and Dietetics  
Illawarra Shoalhaven Local Health District

Dietitians can offer practical ways to support a person with dementia with eating and drinking across all stages of the disease, often in collaboration with other allied health professionals, especially speech pathologists.

To illustrate, take the case of John\*, who is living with dementia, and Mary\* his wife and carer. John was referred to me because he was not eating as much as usual and had lost weight. Mary was also struggling with the stress of care and not eating properly herself.

Here are some of the strategies we discussed and that Mary and John adopted:

- I encouraged Mary to eat with John, rather than do some jobs around the house whilst he ate at the table. This way both focused on eating with no other distractions.
- We created a shopping list of nourishing snack foods that Mary could leave on John's TV table and on the deck. These included cheese and biscuits, yoghurt, dairy snack desserts, peanut butter sandwich fingers, fruit toast, hummus with vegetable sticks and crackers, and fruit pieces. I also encouraged Mary to have some too.
- I gave Mary ideas to organise the fridge so that John could easily see what was there and access as he wanted.
- I gave ideas on how to make 'every mouthful count' and add more nutrition to their meals and drinks (eg, by adding oil, margarine and/or grated cheese to cooked vegetables and mashed potato; sour cream to soups; grated cheese to omelettes and scrambled eggs; skim milk powder to a glass of milk; and avocado on sandwiches).

As a result, Mary became less stressed about what food to offer John, was able to look after herself better and John was eating more in the day.

*\*The information presented here is de-identified*

## THE OCCUPATIONAL THERAPIST



**Donna Horan**  
Senior Occupational Therapist  
Bulli Hospital and Aged Care Centre  
Illawarra Shoalhaven Local Health District\*

As an occupational therapist (OT) my job involves an initial assessment to establish a person's needs within their own home environment (functionally, cognitively and socially) and then equipping them with the tools to carry out their everyday tasks as independently and safely as possible.

The shared goal is generally to establish safer, easier routines for the person with dementia and their carer, finding the most cost-effective solutions for equipment and modifications, and accessing the services they need to thrive at home.

Pam's\* story illustrates how occupational therapy helped overcome some of the difficulties she faced due to rapidly progressing Alzheimer's disease. When I first saw her, Pam was predominantly non-verbal, unable to walk, and she sat in a wheelchair for most of the day. She could be assisted to stand and step to transfer from wheelchair to bed or toilet. Her husband John\* saw to all Pam's care needs.

Because Pam was seated in the wheelchair for most of the day she was at increased risk of developing a pressure injury. One of the first things I did was prescribe a pressure relief cushion for her wheelchair. I also helped John apply for other equipment to assist them, including an adjustable bed base, pressure relief mattress, a transfer aid, sling, hoist and shower commode chair.

John and I then practised together to use the equipment until he felt comfortable. We also trialled a more supportive and comfortable wheelchair for Pam, which provided benefits of pressure care, pain management, eating safely and manual handling.

Pam was later approved for a Home Care Package and Pam has been able to remain at home. It is a successful example of a Home Care Package supporting a devoted carer to keep someone out of hospital with the help of allied health.

*\*The information presented here is de-identified*

**\*Donna has recently taken up another position within the aged care sector.**

# The new aged care funding model explained

Carol Loggie, Anita Westera, Conrad Kobel and Kathy Eagar present this overview of the new funding instrument to be implemented for residential aged care, the Australian National Aged Care Classification (AN-ACC), developed at the Australian Health Services Research Institute

A recurring theme within the aged care sector – particularly residential aged care – has been the inadequacy of funding available to provide safe and quality care. In part, this is due to the overall amount of funding available to the sector, as highlighted in the findings of the Royal Commission into Aged Care Quality and Safety. However, it is also due to the way funding is distributed to aged care providers.

Following endorsement by the Royal Commission, the Australian Government has confirmed that the Australian National Aged Care Classification (AN-ACC) will be implemented for residential aged care funding from October 2022, as part of the aged care reforms announced alongside the May 2021 budget.

The current funding model in residential aged care, the Aged Care Funding Instrument (ACFI), has been in place for more than a decade. During this time, there has been a significant shift in the care needs of people living in residential care. They are now older when they enter residential care (half are aged over 84), have more complex care needs, and many are approaching end of life (half of all residents die within two years).

## Why the ACFI is being replaced

We conducted a review of aged care funding models and instruments in 2017, including a review of the ACFI (McNamee *et al* 2017). This review found that the ACFI assessment tool does not discriminate sufficiently between resident care needs and their associated costs, and it does not take into account the interactions between the different care needs.

Within ACFI, each resident is assessed against a number of items which are grouped into three domains (activities of daily living (ADLs), cognition and



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behaviour, and complex health care). Each domain is then rated to a funding level (high, medium, low, or nil). The subsidy paid is the combined amount that is payable for each of the three domains. This additive type model assumes that care needs are met item by item rather than in any sort of combination, which is not clinically plausible.

The review also found that the ACFI creates perverse incentives, effectively 'rewarding' providers with more funding for conditions/behaviours that are potentially able to be prevented or improved. It is administratively burdensome for clinicians and, importantly, it was found to result in funding disparities across different geographical areas. The review concluded that the ACFI was no longer fit for purpose. Furthermore, it found there was no existing model available that was suitable for use in Australia.

## A new funding model

In 2018, researchers (including the authors) at the Australian Health Services Research Institute (AHSRI) at the University of Wollongong, NSW, were engaged by the Australian Government Department of Health to design a new funding model that could more appropriately capture the care

needs of residents in aged care and the relative costs of providing care. Named the Resource Utilisation and Classification Study (RUCS), this research involved 1877 resident assessments and 315,029 staff time activity records collected by 1600 staff in 30 participating care homes (Eagar *et al* 2019a). Clinical advice was received from four expert clinical panels that were consulted throughout the study. The outcome was the development of the AN-ACC, which includes an assessment, resident classification and funding model.

## A brief description of the AN-ACC

The AN-ACC represents a fundamental change in how funding for care is allocated, and offers many benefits for the funders, the providers and the recipients of residential aged care. It focuses on the resident and care home characteristics that influence the cost of providing care (the cost drivers), including those related to a resident's individual care needs (variable costs) and those costs of care that benefit all residents (shared or fixed costs).

It comprises six key design elements and introduces some new concepts into residential aged care funding:

### Assessment

1. Assessment of the resident *for funding* is separate from the assessment *for care planning* purposes.
2. Assessment for funding purposes is undertaken by independent external assessors, capturing only the information necessary to assign a resident to a particular class for funding.
3. Assessment for care planning purposes is undertaken by staff within the residential aged care home who know the resident well. This assessment should be comprehensive and person-centred, based on residents' needs, strengths, preferences and appetite for risk.

## Payment model

4. A 'variable' payment per day for the costs of individualised care for each resident, which is based on their AN-ACC casemix class (casemix is explained in more detail later in the article).
5. A 'fixed' payment per day for the costs of care that are shared equally by all residents, which varies by location and other care home characteristics.
6. A 'one-off adjustment' payment is available for each new resident in recognition of the additional, but time-limited, resource requirements when someone initially enters residential care.

## AN-ACC assessment

Assessment under AN-ACC differs considerably from the ACFI in two ways. The first key difference is that it is undertaken by an independent, skilled assessment workforce that is external to the care home. The second key difference is that the role of care planning is undertaken by staff within the care home who know the resident well. This solves the current problem where assessment is more focused on maximising funding than on planning for the care of residents.

The AN-ACC assessment tool has been purpose-designed to capture those resident characteristics that best predict the costs of care to meet resident needs. Importantly, our study showed that no specific medical diagnoses, including dementia, are cost drivers per se. Rather, cost is driven by the consequences and impacts of a person's medical conditions and health issues. As an example, if someone has cognitive impairments, whether or not the underlying cause is dementia does not matter. What matters is the extent of the cognitive issues, what other care needs the resident has, and the effects this has on the care required.

The research underpinning the development of the AN-ACC showed clearly that the key cost drivers in residential aged care are *needs* due to: end of life, frailty, functional decline, cognition, behaviour, and technical nursing requirements. These needs may be related to one diagnosis, such as dementia, or multiple diagnoses.

The AN-ACC assessment comprises seven instruments, plus items related to palliative care, frailty and technical nursing. It is designed for use by independent clinical assessors to be completed in one session, with minimal burden on the resident. Importantly, the assessment captures the *capacity* of the resident, as this is what drives care needs and costs, taking into account:

- physical ability (including pain)
- cognitive ability (including the

resident's ability to communicate, sequence, socially interact and problem solve, and their memory)

- mental health issues (including depression and anxiety)
- behaviour (including cooperation, physical agitation, wandering, passive resistance, and verbal aggression).

## AN-ACC payment model

The AN-ACC includes three funding components: two reflecting 'daily' costs of providing care and the third a **one-off adjustment** payment addressing the costs associated with entering care. The daily payment is made up of two components, each contributing around half the total payment. The first is the **variable** payment that covers the costs of individualised care for residents. The second is a base care tariff to cover the **fixed** costs of providing the care that all residents receive equally. Each funding component is explained below.

### Variable payment

The variable payment is determined using a casemix classification. The AN-ACC Version 1.0 casemix classification comprises 13 payment classes (see Figure 1 p27). Each class groups together residents:

- with similar needs for care,
- who cost about the same to care for each day,
- and whose clinical risks and outcomes are similar.

The branching structure of a casemix classification 'splits' into the different classes using those characteristics that are found to drive individual care costs (Eagar *et al* 2020).

In the AN-ACC model, each resident is assigned to one of the 13 payment classes based on their assessed care needs using the AN-ACC assessment tool. This class determines the amount paid for the variable component of each resident's care. This ensures funding is appropriately distributed to care homes according to the mix of residents within each care home.

The AN-ACC includes one class for 'admit for palliative care' and 12 other classes that are split across three branches based on the resident's mobility (measured by the de Morton Mobility Index (DEMMI): 'independent mobility', 'assisted mobility' and 'not mobile' (see Figure 1 p27).

A number of other measures that explain differences in care needs are used in each of these branches (referred to as 'compounding factors'), both as single items and in combination, to create the final branches of the classification. These

include cognition, function, risk of pressure injury, behaviours, communication, and technical nursing requirements, among others.

### Fixed payment

With the AN-ACC model, on average around half of the total daily payment is based on a fixed base care tariff that reflects the cost of care that is shared equally by all residents in a care home, such as infection control manager, quality manager, and dining room supervision. There are six different base care tariffs reflecting care home characteristics, including facility size, geographic location and specialisation (Indigenous or homeless services).

### One-off adjustment payment

The funding model also includes a one-off adjustment payment for each new resident to cover the additional resources required when someone first enters residential aged care.

## The AN-ACC classification and funding model

The assessment and payment details described above form part of a broader AN-ACC classification and funding model that includes 30 detailed recommendations to support implementation, operation and monitoring of the new model. These include protocols for reassessments, payment of supplements, ongoing system refinements etc, and can be found in *AN-ACC: A National Classification and Funding Model for Residential Aged Care Synthesis and Consolidated Recommendations* (Eagar *et al* 2019b).

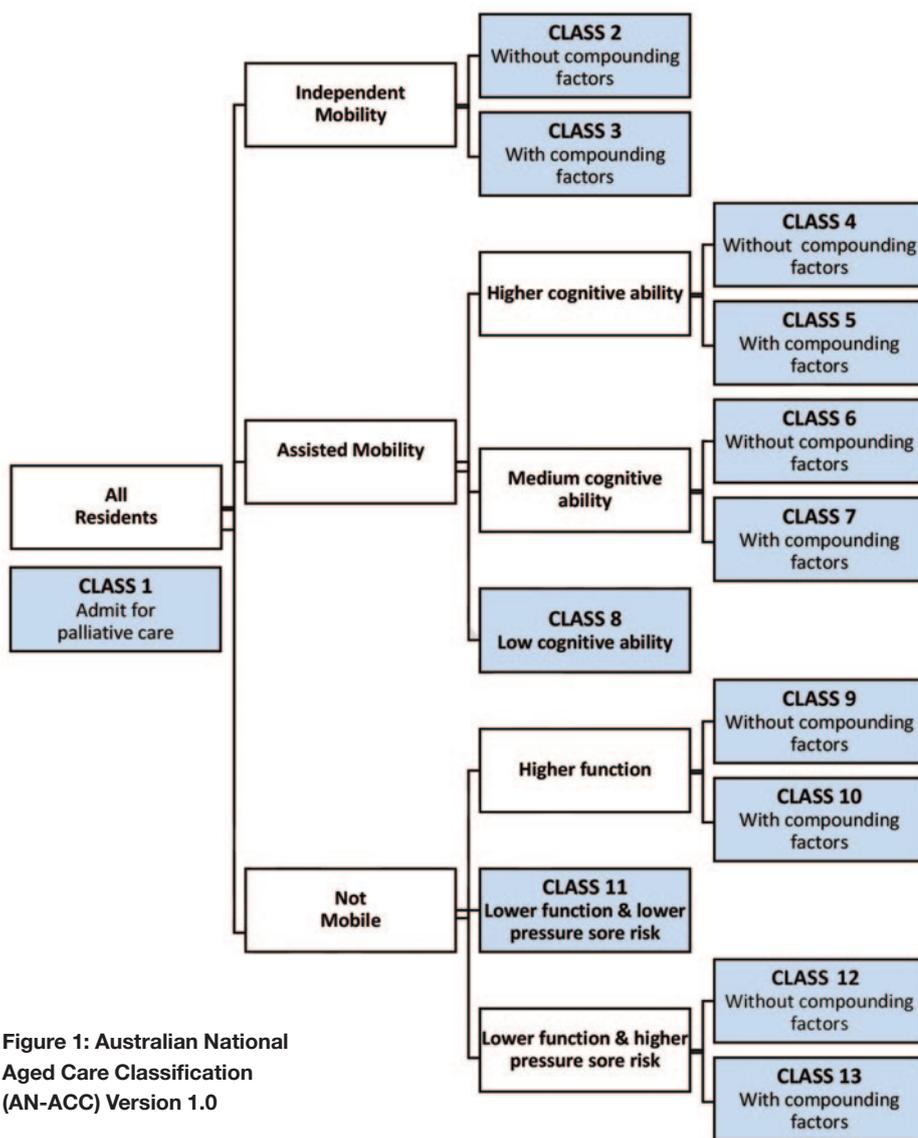
The Australian Government has not committed to including the 30 recommendations in the new funding model.

## What does the AN-ACC mean for residential aged care?

The AN-ACC is a fit-for-purpose model that is based on evidence, meaning that there is an explicit relationship between funding and the actual costs of providing resident care. The cost of caring for residents with underlying conditions, such as dementia, are reflected in the AN-ACC class to which each resident is assigned.

Although it is a more sophisticated model than the ACFI, it is a streamlined model that is administratively simple. The variability between residents is captured in only a small number of classes, with the relativities between the classes informing the price paid.

The key benefit of the AN-ACC is that it provides, for the first time, a clinically meaningful description of the residents



**Figure 1: Australian National Aged Care Classification (AN-ACC) Version 1.0**

living in care homes, and better data to understand their profile and their changing needs and costs. This can also be used to inform staffing requirements that are adjusted to reflect the needs of the mix of residents within a care home. For example, a care home which has an average of high-cost residents will receive more funding and have higher staffing requirements than a care home with a mix of residents with lower-cost care needs.

The classification system supports quality improvement and benchmarking between comparable services, for example national quality indicators such as pressure sores can be adjusted for the complexity of the residents. This will also support decision-making for consumers regarding their choice of care home.

Importantly for providers, the AN-ACC will also assist in the future planning and management of services. Aged care providers will have greater certainty regarding their funding, due to the approximate 50% of funding that is provided through the fixed payment

component. Aged care clinicians working in care homes will be relieved from the administrative burden associated with ACFI and instead be able to focus on applying their skills in care planning, clinical leadership and supervision, and direct care provision.

An overview of the key changes is presented in Table 1 (see p28).

### Conclusion

As a funding model, the AN-ACC provides greater stability for government and care providers. It provides the means for addressing critical issues around care quality, including appropriate staffing and more transparent and equitable funding. It puts the focus of funding in aged care directly back on the care needs of the residents, and supports other much-needed reforms, including the initiatives around minimum staff time with residents and five star public reporting, which have also been announced by the Government.

We recommended that the five star

reporting system be underpinned by automated payroll data submission of nursing, allied health and personal care hours by providers to government. The Government has chosen not to implement this system, rather it will rely on providers submitting their data independently.

The implementation of AN-ACC is a first step towards achieving sustainable aged care reform. However, to really benefit from the opportunities the AN-ACC presents, we argue that a far more comprehensive reform agenda is required, one that truly integrates aged care with health, guarantees supply of an appropriately skilled workforce (including allied health), and regulates to ensure AN-ACC funding is used for the purposes it is intended – that is, delivery of care to residents. ■

### Acknowledgments

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### What's next?

The Australian Government has announced that the AN-ACC will be used for residential aged care funding from October 2022.

Developments are already well underway for the commencement of the new model, with a budget commitment of \$189.3 million over four years from 2020-21 for implementation. These include the passage of relevant legislation, and completion of a 'shadow' assessment period between April 2021 and September 2022, during which AN-ACC assessments will be completed for all aged care residents (excluding those with palliative care) by a trained workforce of experienced aged care clinicians.

The AN-ACC assessment and classifications will be used to determine the Government subsidies paid to care homes from 1 October 2022, replacing the ACFI from that date.

**Table 1: Summary of key changes**

AN-ACC feature	Key change in aged care practice from current ACFI system
External assessment for funding	No ACFI assessments, documentation, audits.
Internal assessment care planning	Staff focus on care planning and delivery, monitoring and clinical leadership.
Reassessment protocols	No requirement for resident reassessment once admitted (annual 'cost of care' studies will pick up changes in costs per class); reassessment allowed for 'significant' increase in care needs – hospitalisation, mobility, standard time period.
Incentives	Evidence-based care driven by resident need, not as prescribed by the funding instrument.
Funding certainty	Base care tariff component (~50%), system stability, transparency.
Quality improvement	Comparing 'like' with 'like' using casemix classification.
Accountability	Facilitates comparable public reporting.



■ From left: Carol Loggie is a Research Fellow (Health Services Research), Anita Westera is a Research Fellow (Health Services Research), Dr Conrad Kobel (not pictured) is a Senior Research Fellow (Applied Statistics), all with the Centre for Health Service Development at the Australian Health Services Research Institute (AHSRI), University of Wollongong; Professor Kathy Eagar is Director, AHSRI. To follow up on this article, contact Carol Loggie at [cloggie@uow.edu.au](mailto:cloggie@uow.edu.au)

➤ (Accessed 01/03/2021). Eagar K, Gordon R, Snoek M, Loggie C, Westera A, Samsa P, Kobel C (2020) The Australian National Aged Care Classification (AN-ACC): A New Casemix Classification for Residential Aged Care. *Medical Journal of Australia* 213(8) 359-363. McNamee J, Poulos C, Seraji H, Kobel C, Duncan C, Westera A, Samsa P, Eagar K (2017) *Alternative Aged Care Assessment, Classification System and Funding Models Final Report, Volume One: The Report*. Available at: <http://bit.ly/funding-models-final-report>. (Accessed 01/03/2021).

# National Dementia & Aged Care Conference

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This section aims to provide a channel of two-way communication between researchers and practitioners in the expanding field of social, psychological and nursing research in dementia care, including all aspects of nursing and care practice, communication and the environment.

The Research Focus section of the *Australian Journal of Dementia Care* aims to keep readers up to date with the fast expanding field of social, psychological and nursing research in dementia care. By this we mean every aspect of person-to-person communication, nursing and care practice and organisation, and the influence of all aspects of the environment. The aim is to provide a channel of two-way communication between researchers and practitioners, to ensure that research findings influence practice and that practitioners' concerns are fed into the research agenda. We would like to hear from you, specifically with:

- notice of the publication (recent or imminent) of peer reviewed papers with practical relevance to dementia care;
- research reports available for interested readers;
- requests or offers for sharing information and experience in particular fields of interest.

## What works to improve residential dementia care?

How can staff have the greatest impact on quality of dementia care and quality of life for people living with dementia in residential care? Researchers **Katrina Anderson** and **Annaliese Blair**, from the Southern NSW Local Health District Aged Care Evaluation Unit, explain

In response to the Royal Commission into Aged Care Quality and Safety, nearly \$8 billion has been announced in the Federal Budget to transform residential aged care in Australia, with \$229.4 million aimed specifically at people living with dementia (Australian Government Department of Health 2021).

There is vigorous public debate about how to ensure that these funds are targeted in areas most likely to improve care and quality of life. One thing is clear – residential aged care staff are at the centre of many of the suggested improvements, from increased care staff hours to increased training. While lived experience and expert opinion form an important part of the debate, it is also crucial to ask – what does the evidence say about where and how it is most effective to intervene with staff in order to improve residential dementia care?

To answer this question, we embarked on a series of studies aimed at identifying key factors relating to care staff that lead to good quality of



**More positive physical and verbal behaviour by staff to residents was a particularly influential aspect of improving quality of care.**

Photo: [www.freepik.com](http://www.freepik.com)

care and quality of life for residents with dementia. Contrary to popular opinion, we found that increasing staff numbers and the amount of time Registered Nurses (RNs) spend with individual residents is not the whole solution.

In July 2020, we submitted the findings from these studies and our recommendations (outlined later in this article and in the Key Targets infographic on p32) to the

Royal Commission into Aged Care Quality and Safety, some of which are reflected in the Royal Commission's *Final Report* (Commonwealth of Australia 2021).

### Literature review

Firstly, in 2016 we conducted two systematic reviews of the published international scientific literature over the previous 20 years (1995-2015) with the aims of:

- Determining which aspects

of residential care staff experience, practice, belief, or deployment it would be most beneficial to target in interventions aimed at improving residential dementia care and quality of life (Anderson *et al* 2016), and;

- Identifying interventions with staff that have successfully improved quality of dementia care and quality of life (Bird *et al* 2016).

The reviews indicated that for residents with dementia:

- When staff treat and interact empathetically and humanely in care, these staff behaviours are associated with better mood for residents, delayed functional dependence and better food intake (Amelia 1999; Chappell & Reid 2000; McGilton *et al* 2012; Sjögren *et al* 2013; Zuidema *et al* 2010).
- Where there are more RNs, there is lower use of psychotropic medications (Kim & Whall 2006; Kleijer *et al* 2014).

Staff	Facility	Quality of Care	Quality of Life	Control
Dementia qualifications	Facility provided training	Treatment for food intake	Overall QoL	Proportion with dementia
Education	PCA minutes per resident	Treatment for fluid intake	Frailty	Number of beds
Staff position	RN minutes per resident	Psychotropic medications	Depression	Environmental audit tool
Experience	Shift organisation	Restraint use	Pain	Carlson Comorbidity Score
Strain	Proportion permanent staff	Staff treatment (ratings)	Agitated behaviours	Age
Dementia knowledge	Manager experience	Staff treatment (observed)	BMI	Psychiatric co-morbidities
Restraint attitudes	Manager qualifications (RN)	Activities	Food intake	
Fall and pain attitudes	Structured activities	Adverse incidents	Fluid intake	
Recent training	Access external health professionals	Overall QOC	Mortality	
Time with residents		Assistance with meals	Positive expressions	
		Communicating about residents	Ease/engagement with staff	
		Person-centred care		
		Usage other health professionals		

**Table 1: A summary of the measures used by the authors in their research to identify which factors have the greatest influence on quality of dementia care and quality of life**

- Empathy around the risk of residents falling or being in pain is not enough; staff also need to be educated about the dangers of restraint (Dever Fitzgerald *et al* 2009).
- There have been high-quality interventions that have improved the way staff interact with residents, including restraint reduction and improving personal care, with effects maintained after the intervention phase has finished (Dever Fitzgerald *et al* 2009). However, these interventions are intensive, requiring extensive on-site emotional and practical support.
- There were still many unanswered questions regarding how to assist staff to have the greatest impact on dementia care and quality of life (Anderson *et al* 2016).

### Our study

Following these reviews, we conducted an observational longitudinal research project from 2017-2019 to identify which staff factors have the greatest influence on quality of dementia care and quality of life.

We have published comprehensive findings from this study (Anderson & Blair 2021) to guide clinicians and researchers to focus on the most useful targets for intervening with staff to improve the quality of care they provide; targets that are not simply subjective but are evidence-based. The results, published in the *Archives of Gerontology and Geriatrics*, are freely available at <http://bit.ly/what-have-staff-got-to-do-with-it>

Over a 10-month period, we followed 247 older adults with

dementia from 12 not-for-profit residential care facilities, their families/care partners (n=225), managers (n=12) and staff (n=228). Facilities ranged in size from 10 to 137 beds and were located across remote, rural and metropolitan areas of NSW and the ACT. Data was collected over three time points using staff surveys, resident file audits, family member and resident interviews, resident and staff observations and organisational audits of staffing, skill mix and staff education.

Quality of care was broadly defined as anything done to or with the resident by the facility or staff, and quality of life as the resident's standard of health, participation in life and comfort. In order to encompass all aspects of these broad

definitions, a large range of measures were chosen based on the systematic review articles. The table above is a summary of the measures used.

### What did we find?

Overall, we confirmed that the quality of the care provided by staff is integral to the quality of residents' lives. The findings are grouped under four key areas: care, staff training and qualifications, organisational factors, and restraint use. The key findings are summarised below. Specific outcomes for each area are detailed in our published study (Anderson & Blair 2021).

### Care

*The quality of the care provided by staff is integral to the quality of residents' lives.*

It has pervasive and consistent influences on multiple quality of life measures, such as pain, depression, agitated behaviours, resident ease and engagement with staff, and overall quality of life.

Particularly influential aspects of care for improving quality were: minimal or no psychotropic medication use; more positive physical and verbal behaviour by staff to residents; and better overall quality of care. As noted in the systematic review (Bird *et al* 2016), it is possible to successfully reduce psychotropic medication use and change staff behaviour but this requires intensive resourcing. It is not the work of a moment.

*Providing greater assistance during meals is crucial to resident wellbeing.*

Having more staff available to monitor, encourage and assist residents with dementia at mealtimes resulted in less pain, higher fluid intake and greater ease and engagement for residents.

The beneficial effects of skilled staff interacting with residents aligned with the overall findings of the systematic review; when staff treat and interact empathetically and humanely in care, there is a relationship with better resident affect, delayed functional dependence and better food intake (Anderson *et al* 2016).

### **Staff training and qualifications**

*The focus, timeliness and quality of the qualifications or training courses need to be scrutinised.* Greater dementia knowledge and more training that is seen by staff as relevant to their work was associated with better staff treatment of residents. In turn, this led to an increase in the number of residents with higher Body Mass Indexes (BMIs) and who were more at ease and engaged with staff.

*But, prioritising formal qualifications in dementia, at least*

*in their current form, did not necessarily lead to tangible improvements in the care, and therefore the quality of life, of residents.*

Having vocational or higher qualifications and increased levels of training provided by the facility were all associated with more adverse incidents, including falls, hospitalisations, and pressure sores. We are unable to explain this finding and suggest further research is required.

The large amount of training required by accreditation and the large number of staff involved meant much training was conducted in a didactic manner (usually online) with little opportunity for engagement or hands-on learning to ensure quality outcomes (for example, learning how to shower a resident via an online learning course).

*Managers must listen to staff about the training they need.* Staff ratings of the usefulness of training for their everyday work were associated with better staff treatment of residents, indicating that staff are well placed to tell their managers what training they require to improve care. It would also be helpful if those delivering the education have clinical experience at the care coalface.

*Work with staff who are not RNs to increase communication around residents; and, work with RNs to implement structural changes to enhance behaviours towards residents.*

Personal care assistants were more likely than RNs to provide empathic, warm care and were more likely to provide assistance during mealtimes; RNs, particularly more experienced staff, communicated more about residents than personal care assistants.

While recognising that RNs and care staff do perform different roles (Aged Care Workforce Strategy Taskforce 2018), there should be greater recognition of the value of all

roles, ensuring that communication exists across roles and that all care tasks involving residents are carried out with empathy.

### **Organisational factors**

*Finding a balance between invigorating staff with rotating shifts and capitalising on the long-term relationships acquired through stable shifts could be an important consideration when looking to improve the quality of life of residents.*

Rotating shifts, where staff rotate through various areas of the facility, rather than being permanently assigned to only one area, promoted greater mealtime assistance, more treatment of food and fluid issues and higher recreational activity engagement.

Permanent shifts led to improved overall quality of care. This could be explained by staff on rotating shifts being energised and predominantly engaged in the physical aspects of care, whereas permanent shifts allow staff to connect with residents in a more individualised, personal way.

*Engaging residents in recreational activities is equally important as good physical care for improving quality of life.*

The way facilities are staffed and organised had the greatest impact here: more experienced managers, greater access to external health professionals, rotating shifts, and higher RN-to-resident ratios but lower personal care assistant-to-resident ratios all promote more activity engagement.

Higher levels of dedicated activity staff did not necessarily lead to increased activity involvement for residents. Having all staff skilled to support meaningful and spontaneous occupation and activity is an alternative to dedicated activity staff (Morgan-Brown *et al* 2013).

*Having a higher proportion of permanent staff is not the panacea.*

This had a positive impact in terms of the overall care of residents, but at the expense of increased restraint and psychotropic use.

*Overall, more experienced managers with a background in registered nursing promoted better quality of care.*

*Improving care is not as straightforward as increasing the amount of time each RN has to spend with each resident.*

On the positive side, when RNs had more time to spend on care, restraint use appeared lower and activity levels were higher. On the negative side, more adverse physical incidents occurred and the quality of the care and treatment of the residents was reduced. This may be because time-poor RNs are too rushed to provide empathic care, with most facilities in our study allocating between five and 29 minutes of RN time per resident per day.

*Simply increasing personal care assistant numbers is also not the whole solution.*

Higher restraint use and lower activity levels occurred when personal care assistants had more time to spend with residents. These outcomes may be due to personal care assistants having less education about the dangers of restraint use, leading them to increase restraint and reduce activity in well-intentioned, but misguided, attempts to protect residents from falls.

### **Restraint use**

*Physical restraint is unequivocally damaging for residents.*

Physical restraint led to more pain and depressive symptoms, lower food intake and BMIs, less ease and engagement with staff, and fewer positive expressions (eg, smiling) and more negative expressions (eg, pacing).

The use of psychotropic medications led to overall reduced quality of life and fewer positive verbal and physical expressions by

residents. It increased resident depression, pain and agitated behaviours.

*Reducing restraint is not as straightforward as having well-intentioned staff who care and are concerned about the residents.*

When staff were more concerned about a resident falling or being in pain, they tried to reduce this risk in various ways. Some of these risk management strategies were well informed and helpful (eg, assistance with meals), while others led to greater harm (eg, increased use of psychotropic medications and restraint). Upskilling staff in the most helpful ways to respond to their concerns about pain and falling is crucial.

*It is possible to effectively reduce restraint use over the medium- and long-term.*

This is possible through basic staff education about the dangers of restraint and the alternatives to restraint, plus mentoring of the staff (Bird *et al* 2016). From our study, reliance on restraint use and psychotropic medications also appeared less prevalent when the facility manager was a RN.

### Key recommendations

We submitted the findings summarised above, along with recommendations arising from our study (see Key Targets infographic below) to the

Royal Commission into Aged Care Quality and Safety in July 2020. Some of these recommendations are reflected in the Commission's *Final Report* (Commonwealth of Australia 2021). Our recommendations are:

1. *Restraint reduction is an obvious target* when you look at the unequivocal harm caused by physical restraint use and the effectiveness of intervening in restraint use. This would not necessarily be difficult or expensive, given that it is possible to effectively reduce restraint use through basic staff education around restraint, plus mentoring of staff or similar support (eg, Gulpers *et al* 2011; Westbury *et al* 2018).
  2. *During meals, increase the amount of monitoring, encouragement and physical assistance provided to residents by staff.* Specially-trained volunteers have successfully been used in acute hospital settings to provide assistance with meals and fluids for patients with cognitive impairment (Blair *et al* 2018, 2019).
  3. *Support and upskill care staff so that they treat and interact empathetically and humanely with residents.* Whilst intense resourcing would be needed, with extensive, ongoing onsite emotional and practical support, this is at the heart of the quality of life
- of residents in residential aged care. For example, *Bathing Without a Battle* (Barrick *et al* 2008, <https://bathingwithoutabattle.unc.edu/>) provides practical approaches to supporting empathetic care and reducing anxiety for the person with dementia. A number of other education resources have been developed using this approach (Bird *et al* 2016).
4. *Increase recreational activities for residents* by training and involving all staff rather than only dedicated activity or lifestyle staff.
  5. *Increase RN time whilst upskilling RNs in empathetic care* to allow them time to provide good quality care.
  6. *Provide pathways for RNs to upskill and transition into management roles* as managers with a nursing background are more likely to promote better quality of care overall.
  7. *More training and qualifications does not necessarily translate to better care.* To ensure relevance, care staff should be consulted about what training would be most useful in their day-to-day work, with training ideally provided by those with clinical experience. Training should be evaluated by its ability to be translated into both increased knowledge and changes in care.

8. *Reconsider the accreditation requirements around training.* Consider striking the balance between ensuring necessary legal and accreditation obligations (eg, work, health and safety) are covered and ensuring staff receive training that is relevant to how they provide empathetic and humane care (eg, psychosocial alternatives to restraint use).
9. *The vocational and higher qualifications sector needs overhauling* to ensure that any qualifications in aged care or dementia care are relevant to the physical and emotional care that is actually required. Practical placements and observations of care provision are necessary to ensure that intellectual knowledge translates to humane care.

### Conclusion

While the Royal Commission recommendations and subsequent funding for restraint reduction and increased staffing and training align with the findings of our research, the detail will be important. Simply increasing staffing will not solve all issues and may create others. Upskilling staff requires good quality, interactive training, ideally provided by clinicians who are then able to provide ongoing mentoring and support to ensure that knowledge is translated into practice.

Ultimately, any changes

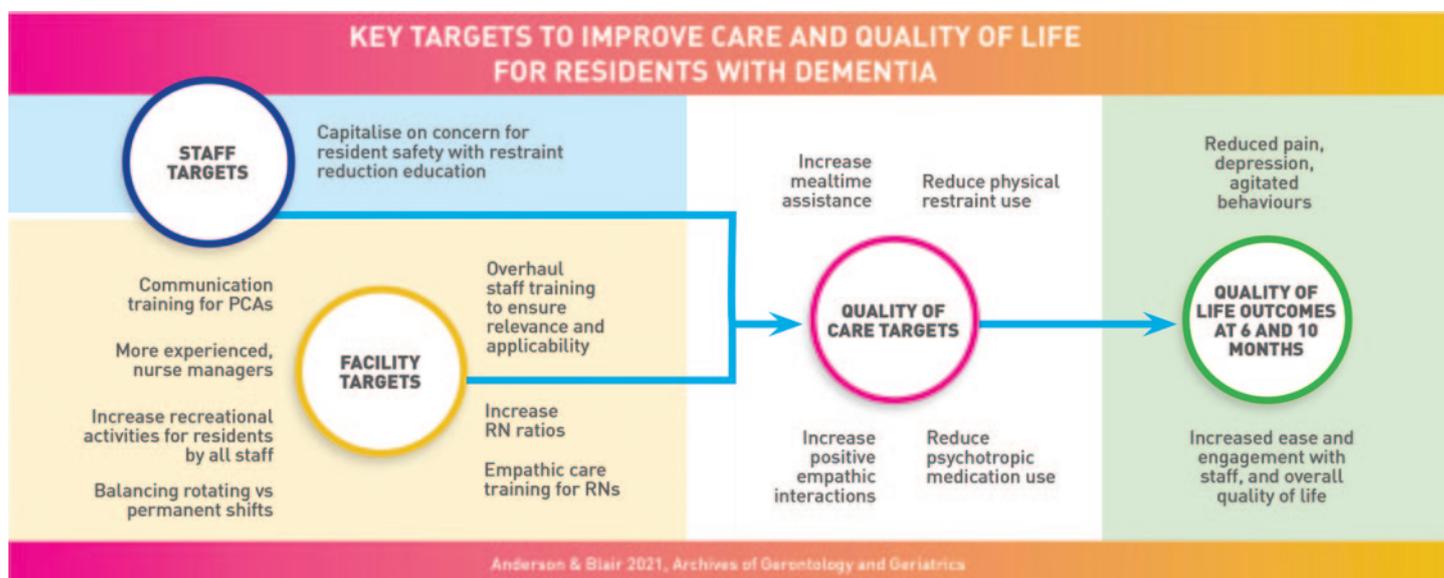


Image created by Katrina Anderson and Annaliese Blair. Reprinted here with their permission

must be rigorously evaluated and adjusted for their effects on the most important goal: improved quality of life for people with dementia. ■

The full publication of the research discussed in this article is available via open journal access at: <http://bit.ly/what-have-staff-got-to-do-with-it>

#### Acknowledgments

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■ Dr Katrina Anderson (left) and Annaliese Blair are Clinical Research Officers with the Aged Care Evaluation Unit, Southern NSW Local Health District. To follow up on this article, contact Annaliese at [Annaliese.Blair@health.nsw.gov.au](mailto:Annaliese.Blair@health.nsw.gov.au)

## Dementia Enquirers project

Dementia Enquirers is a UK project being supported by Innovations in Dementia, and funded from 2018 to 2022 by the National Lottery Community Fund. The project aims to develop a new approach to research or ‘enquiry’ by supporting DEEP groups (peer support and advocacy groups for people living with dementia) to carry out their own research projects.

Final Reports from the first tranche of Dementia Enquirers Individual Projects to be funded under this program have now been published, and cover a wide range of practical questions, chosen based on interests and concerns of the different groups.

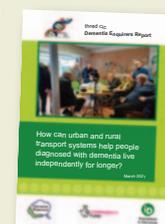
From the project so far, Dementia Enquirers project leads say some key messages are emerging:

- People with dementia can lead their own research projects – both drawing on previous life skills and learning new ones to explore the questions that most interest them.
- The research questions that people with dementia generate can be different

from existing research questions. They are based on lived experience – on topics that will make a real difference in people’s lives.

- “Being in the driving seat of research” doesn’t mean that you have to do everything yourself. Teamwork and support can really help. But controlling the research and leading the way gives people with dementia a huge boost in confidence.
- Making the language and processes of research more accessible helps everyone.
- Research between people with dementia makes communication and engagement more possible, because having something in common increases trust.

All the individual project reports are available to read on the Dementia Enquirers website, along with a range of other resources related to the project (films, podcasts and webinars); go to <https://dementiaenquirers.org.uk/>



# RESEARCH NEWS

The latest published dementia research from Australia and around the world. Compiled by *AJDC* Contributing Editor **Catherine Ross**



## Care refusal in acute settings

A team of UK researchers has investigated the particular communication challenge faced by health care professionals when a person living with dementia refuses care in a hospital setting.

They say that typically staff have not received training in responding well in these situations and that, despite the availability of resources on this topic, the content may not be applicable in a hospital situation or not be evidence based.

The researchers used a method called conversation analysis (CA) to examine 41 video recordings of a mix of health care professionals (26 in total, including medical, nursing and allied health staff) interacting with a person living with dementia (26 also in total), recorded in three acute inpatient wards, while the staff members undertake a range of health care tasks. From this material, they identified the nature of the refusals (such as overt, mitigated by the patient, or ambiguous), what strategy was offered by the staff member, and explored the requests that preceded them in terms of 'entitlement' (a CA term that refers to how much the speaker / staff member assumes agreement from the patient) and 'contingencies' (another CA term, which refers to how difficult the speaker acknowledges the task to be). They also examined situations where the staff member's

request preceded agreement from the person with dementia.

Their conclusion is that a person with dementia is more likely to accept a request if the health care professional uses higher 'entitlement' requests, and the lowering of 'contingencies'. Examples of lower entitlement requests include 'Is it okay if...?' and 'Just wondering...?' while higher entitlement requests were 'I am going to...?' or 'Let's...?'. The authors say that while these lower entitlement communication strategies are respectful of patient autonomy, they may pose challenges if it opens up opportunities for refusal from a person with dementia, particularly if the care required is essential.

They acknowledge that there is no single way of making a request of a person with dementia which will always lead to an acceptance or agreement, but say their findings show how important it is to examine the context of an interaction between a health care professional and a person with dementia, and the impact that these requests can have on care delivery.

O'Brien R, Beeke S, Pilnick A *et al* (2020) When People Living With Dementia Say 'No': Negotiating Refusal In The Acute Hospital Setting. *Social Science & Medicine* 263, October, 113188: <https://doi.org/10.1016/j.socscimed.2020.113188>.

## Incontinence: causes and consequences

Researchers from the University of Southampton in the UK have conducted a qualitative study exploring incontinence among people living with dementia at home.

The aim of the study was to establish the range of causes, consequences and potential solutions of toilet-use and incontinence problems for people living with dementia and their family carers. They say that currently there are no evidence-based interventions to help family carers of people living with dementia who are having difficulty coping with incontinence issues.

Semi-structured interviews were undertaken with 45 people: two people living with dementia, 26 family carers and

17 health care professionals (nine continence and eight dementia nurses). The researchers heard a range of complex causes to explain problems with toilet-use and incontinence:

- Dementia (such as lack of insight into toileting needs or how to use the toilet).
- Physical reasons (the person had existing bladder or bowel issues or poor mobility).
- Psychosocial factors (eg inability to ask for help for incontinence).
- Societal issues (fear of stigma).
- Care systems (lack of expert knowledge) or products (eg, poor fit or confusing for users).

The consequences of these

problems were harm to physical and mental health, social isolation, increased carer workload and care system resource implications.

The research has been conducted as part of the Dementia and Incontinence at Home (DINAH) project, which will use the study findings to help develop and evaluate a dementia and incontinence handbook for family carers, and modify and evaluate a continence product decision aid.

Murphy C, De Laine C, Macaulay M, Hislop Lennie K, Fader M (2021) Problems Faced By People Living At Home With Dementia And Incontinence: Causes, Consequences And Potential Solutions. *Age and Ageing* 50(3) 944-954, doi: 10.1093/ageing/afaa262.

## Harmony in the Bush research study

Findings from the Australian 'Harmony in the Bush' research study have now been published. The quasi-experimental intervention study was conducted in five rural aged care homes in Queensland and South Australia, with 74 residents with dementia and 87 staff.

The project involved staff training in workshops which focused on the theory of the Progressively Lowered Stress Threshold principles and delivery of person-centred care plans with integrated music interventions. Staff completed the Caregiver Stress Inventory at four weeks before and after the intervention. Changes in residents' agitation was measured using the Cohen-Mansfield Agitation Inventory.

The researchers say the results showed statistically significant decline in aggressive behaviours, physically non-aggressive behaviours, verbally agitated behaviour and hiding and hoarding, and that there was a similar reduction in staff stress in the domains of aggressive behaviours, inappropriate behaviours, resident safety, and resource deficiency.

They conclude that the Harmony in the Bush model is effective in reducing agitation among residents living with dementia, with significant reduction in staff stress levels in aged care homes in rural Australia.

Isaac V, Kuot A, Hamiduzzaman M *et al* (2021) The Outcomes Of A Person-Centered, Non-Pharmacological Intervention In Reducing Agitation In Residents With Dementia In Australian Rural Nursing Homes. *BMC Geriatrics* 21 193, doi: 10.1186/s12877-021-02151-8.

# *The Father* captures dementia's power to change reality

**Dr Louisa Smith**, a researcher working with people living with dementia, reflects on how the film *The Father* offers an opportunity for viewers to step into the shoes of a person with dementia in a real and authentic way

**B**ased on the award-winning play of the same name, *The Father* seems at first a regular family drama, familiar to anyone who has experience with dementia. Anne (Olivia Colman) is struggling to support her father, Anthony (played by Anthony Hopkins), who has dementia, to stay living in his apartment. Anthony refuses to have a carer to look after him: "I don't need anyone", "I can manage on my own," he says. Anne wants to move to Paris, but is worried about leaving her father alone.

However, after a few scenes, you realise that this film is not going to go the way you expect, as Anthony's experiences of the world become our own. *The Father* feels at times like a thriller and at others like a dystopian horror film.

There are clues from the beginning that we are in Anthony's head. The film opens with the camera following Anne walking, determined and disappointed, through London's streets (one of the few exterior scenes in the entire film). But it is the music that really captures your attention. It is the haunting counter tenor of Henry Purcell's lament, *Cold Song*: The Spirit of the Cold has been brought back from the dead, wishing he could go back there again. He sings, "What Power art thou / who from below / Hast made me rise / Unwilling and slow... I can scarcely move / Or draw my breath... Let me, let me / Let me freeze again... / Freeze again to death".



Anthony Hopkins plays Anthony in *The Father*. Photo courtesy NIXCo

It is not until minutes into the film that we see Anthony wearing headphones, and we realise that the music is his choice (his lament?) and that we have been in his head all this time. The lyrics of the song are unrecognisable, but knowing them it's hard not to recognise that the 'Power' mentioned in the song is dementia. And indeed it is on the power of dementia that this film turns: its power to change reality, make new realities and alter time.

In one scene, Anthony is talking to his daughter, Anne, about her moving to Paris to be with her boyfriend. In the next scene, Anthony finds an unknown man in his living room, who claims to be Anne's husband (Paul, played by Rufus Sewell). Anthony can't remember him, or his name. The husband calls Anne and when she returns she is a different Anne (played by Olivia Williams).

As scenes like this accumulate, where people and details change, we, as the audience don't know which

story is 'true'. Is Anne going to Paris? Is she married? Who is she married to? As our own questions and confusions mount, the characters have their own mundane and repeated questions which anchor the film in the everyday realities of dementia. Anthony repeatedly loses his watch, which is very important to him, and continually asks where it is or who stole it. Others are always asking Anthony, "Have you taken your medication?" and inserting the question, "You remember?" at the end of each statement.

The apartments in the film become characters in their own right. Anthony is still living in his own apartment and we see him navigate the kitchen with a body memory around routines. Stills of the rooms in the apartment show the life and memory of each object.

For all its cleverness in terms of offering up Anthony's perspective, it is how this perspective is set

alongside scenes of intimacy that makes the film most meaningful: when we see Anthony alone in his apartment, dressed immaculately, humming and listening to music; when we see him touch his daughter's face and ask, perplexed, "Why do you keep looking at me like something's wrong?"; or the incredible cruelty of moments when all inhibition disappears, and Anthony speaks hurtful half-truths. There are also glimpses of the joys of dementia too, when Anthony recalls that he was a dancer, or in the circus, and performs.

As a researcher in disability who works with people with dementia, I am always seeking ways to encourage my moral and care imagination: ways to foster empathy and help me imagine the perspective of someone with dementia. *The Father* provides an opportunity to step into the shoes of a person with dementia in a real and authentic way. Watching the film, I found myself doubting my own sense of reality, and being confronted with the feeling of not being certain of who was who, or what was what. ■

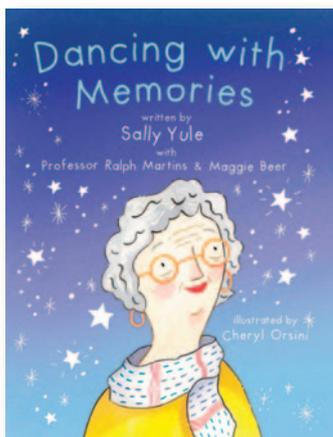
**The Father (rated M) was released in April 2021 and is screening in selected cinemas around Australia.**



■ Dr Louisa Smith is a Research Fellow at the University of Wollongong (UOW), Australian Health Services Research Institute (AHSRI), and *Australian Journal of Dementia Care* Co-Editor

Dementia Australia's Centre for Dementia Learning and Deakin University's Applied Artificial Intelligence Institute (A<sup>2</sup>I<sup>2</sup>) have collaborated with care staff to develop a new educational resource to help care staff improve communication skills with people living with dementia. **Talk with Ted** is a one-hour online simulation, designed to be a safe and effective way to practise communicating with a person with dementia. Ted is an artificially intelligent avatar (pictured right) who shows symptoms commonly associated with dementia. Dementia Australia says that participants who have experienced Talk with Ted were able to recall their learnings up to eight weeks after the training, and say it has improved the overall quality of care they give. Dementia Australia CEO Maree McCabe described the resource as a "world-first in dementia education". The cost for the one-hour online session is \$99 per individual, with discounts available for groups. Talk with Ted can be purchased by individuals and aged care providers across Australia through Dementia Australia's Centre for Dementia Learning, at [dementialearning.org.au/technology/talk-with-ted/](http://dementialearning.org.au/technology/talk-with-ted/)

**Dancing With Memories** is the title of a new children's book on dementia, written by first-time author Sally Yule, with illustrator Cheryl Orsini, and backing and input from Professor Ralph Martins and Maggie Beer. Sally has worked with people living with dementia



in aged and health care for 30 years. The book's main character is Lucy, who is living with dementia. Sally hopes that, through learning about Lucy, children will understand how it feels to forget and become confused, and the many ways they can help a person living with dementia. The book is available to buy from the book's own website at [www.dancingwithmemories.com.au/](http://www.dancingwithmemories.com.au/) for \$17.95 (paperback) or \$11.95 (Kindle and eBook). \$1 from each book sale is donated to the Maggie Beer Foundation and the Lion's Alzheimer's Foundation.

A new project called **Brain Bootcamp** is offering a toolkit to older adults to help promote

better brain health – all while they contribute to ongoing research on public health initiatives to promote brain health. The **Brain Bootcamp Box** is aimed at people who are aged 65 and over and includes an information booklet, a brain health profile and five practical items inside to help users make small lifestyle changes to reduce dementia risk. The project is led by Dr Joyce Siette, a Research Fellow from Macquarie University, and was initially limited to the first 1000 NSW residents who signed up to receive the resources and be involved in the research, but is now accepting people onto a waiting list. It's funded by the NSW Government and sponsored by Macquarie

University. Details: <https://brainbootcamp.com.au/>

Alzheimer Scotland has published a series of five short films, developed by the organisation's allied health professionals, each exploring a particular topic related to care and support for people living with dementia. The five films are: **Eating Well at Home; Footcare at Home; Physical Activity at Home; Activities at Home: Getting Started and Environment;** and **Activities at Home**. The films are aimed at people living with dementia and those who support them, and each film is approximately 10-12 minutes long. Access at: <https://bit.ly/3ezbhEU>

The National Ageing Research Institute continues to run its **Seminars in Ageing** program, with all sessions available to view after the event. Several 2021 sessions relate specifically to dementia care, for example: 'A Mixed-Methods Investigation of the Experiences of Migrant Care Workers Caring

## AJDC Read and Quiz series

DTA has launched five short online learning modules with each module linked with one of five recent *Australian Journal of Dementia Care (AJDC)* articles. DTA, which manages *AJDC* on behalf of the publisher, the University of Wollongong, is launching the new resources as a way of making the quarterly publication more accessible to the health and aged care workforce.

Topics covered in the **AJDC Read and Quiz** series include: death and dying in dementia care, supported decision-making with people living with dementia, working alongside family carers, supporting meaningful activity in a hospital setting, and rethinking rural dementia care during COVID-19 lockdowns.

Learners are asked to first read the article (available as a PDF) or instead listen to the audio version, spend time reflecting on its content and key messages, and then answer some questions. Practice-oriented resources related to the topic are also introduced, and then learners can access a certificate confirming completion of the module.

Each module should take about 30 minutes to finish, and can be completed in any order. Access at: <https://dta.com.au/online-course-modules/>

## Sedatives short course

Nurses, pharmacists and other allied health professionals wanting to learn more about the **Appropriate Use Of Benzodiazepines And Other Sedatives** with people living with dementia can now take up the chance to do a new short online course developed by Dementia Training Australia (DTA) on this important topic.

The course introduces learners to a range of tools and frameworks for reviewing the care of a person with dementia who is experiencing a responsive behaviour and working as a team to establish the best way forward. The course consists of four modules: Introduction to appropriate use of benzodiazepine and other sedatives; Target responsive behaviours; Developing a management plan; and Developing a withdrawal plan. Each module takes one hour to complete. The course includes interactive case studies and enables learners to understand how best practice guidelines could support future prescribing, if medication is absolutely necessary.

Access the modules at: <https://dta.com.au/online-courses/intro-benzos-and-sedatives/>

For People With Dementia in Australian Residential Aged Care Facilities' by Bola Adebayo from Curtin University; 'Pre-Death Grief and Preparation for End Of Life in Family Carers of People Living with Dementia' by Dr Kirsten Moore from NARI; and 'Sensory Decline and Future Risk of Dementia: an Update' by Associate Professor Hamid Sohrabi from Murdoch University. All the webinars are available to view at [www.nari.net.au/Pages/Events/Category/seminar-recordings](http://www.nari.net.au/Pages/Events/Category/seminar-recordings)

The Centre for Cultural Diversity in Ageing is hosting a series of webinars from April to November 2021, covering a range of topics related to diversity in aged care. All the webinars can be accessed for free later, with the session's PowerPoint slides and case studies also available to view.

**Applying a Diversity Lens to Dementia Care** is the title of a 1.5-hour session in June, led by Dementia Care Navigator for CALD communities in Western Sydney, Nina Catalano. Two other April webinars of interest include 'Working Effectively with Interpreters in Aged Care' and 'Accessing Culturally Appropriate Resources for your Consumers'. To find out more, go to <https://bit.ly/3xZCzMp>

Dementia Alliance International (DAI) continues to host its engaging series of **Meeting of the Minds** free webinars, with many available to view later. In May, Dr Monica Cations spoke on 'Maximising mental health while living with dementia', and Dr Regina Koepp spoke on 'Ageism and your health'. To find out more, go to [www.dementiaallianceinternational.org/blog/](http://www.dementiaallianceinternational.org/blog/)

The Centre for Healthy Brain Ageing (CHeBA) at UNSW Sydney launched its **Visiting Lecture Series** in 2020, and the full program for the remainder of 2021 has now been announced. The free, interactive webinars allow time for questions, and are open to the public. Presentations of interest to *AJDC* readers include

a lecture from Professor Yaakov Stern from Columbia University on 'Update on Cognitive Reserve' (26 May); Professor John O'Brien from the University of Cambridge on 'Improving the diagnosis and management of Lewy body dementia' (July 21); 'Professor Gill Livingston from University College London on 'Preventing dementia: what should we do?', and Professor Rajesh Kalra from Newcastle University on 'Post-Stroke dementia' (16 November). All the lectures can be viewed later, including the 2020 sessions. Details: <https://cheba.unsw.edu.au/visiting-lecture-series>

A Phoenix Australia-hosted webinar on **Trauma-Informed Care Strategies to Support Residents with Trauma and Dementia** is freely available to view on the organisation's website. The hour-long webinar, held in February 2021, includes contributions from several Phoenix Australia staff as well as Arsh Katoch, Service Manager with Dementia Support Australia. The webinar explores how aged care workers can support people affected by

dementia and trauma. It is aimed at health and aged care staff as well as aged care leaders and managers. Access here: <https://bit.ly/3bjpRhT>

The Australian Centre for Grief and Bereavement (ACGB) has received Federal Government funding to provide an **Aged Care COVID-19 Grief and Bereavement Service** to people who are living, working and caring in the aged care sector, and who have been impacted by COVID-19. Support and advice is available by phone and in person to individuals including aged care recipients, their family members and aged care staff (call 1800 22 22 00). ACGB can also provide support to organisations, for example with planning a response to COVID-19 or more intensive face-to-face support. ACGB's website ([www.aged.grief.org.au](http://www.aged.grief.org.au)) also contains a range of resources on grief and loss (fact sheets, an app, and a webinar) for those who live, work or care in the aged care sector.

The Aged Care Quality and Safety Commission's range of **Serious Incident Response**

**Scheme (SIRS) resources** continues to expand, with the following now available via the Commission's website: a new set of factsheets (one for each of the reportable eight incidents), a frequently asked questions section, a poster, five webinars and four videos as well as the all the approved forms and the two sets of guidance (SIRS Guidelines For Residential Aged Care Providers, and Best Practice Guidance On Effective Incident Management Systems). All the resources can be found at [www.agedcarequality.gov.au/sirs/resources](http://www.agedcarequality.gov.au/sirs/resources)

Medicines use in older people is one of six key areas examined in detail in the **Fourth Australian Atlas of Healthcare Variation**, prepared by the Australian Commission on Quality and Safety in Health Care and the Australian Institute of Health and Welfare, and published in April. The Atlas aims to highlight areas of marked variation in healthcare and makes recommendations for measuring and addressing the variation over time. The Atlas found that, in 2018-19, the rate of people aged 75 years and over dispensed five or more medicines was about six times higher in the local area with the highest rate than in the area with the lowest; rates of polypharmacy were higher in major cities than elsewhere, and rates increased with socioeconomic disadvantage, except in remote areas. It also found that the rate of people aged 75 years and over who had at least one Medicare Benefits Schedule-subsidised service for a Residential Management Review or Home Medicines Review was almost 12 times higher in the local area with the highest rate than in the area with the lowest rate (about 5.4% of people had a review); rates again were higher in major cities and increased with socioeconomic disadvantage. The Commission makes a series of recommendations to address these issues including, for example, the need to

### Memory clinics survey

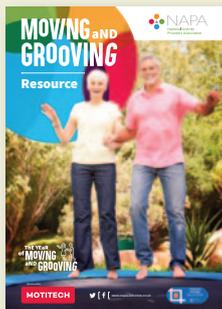
The findings from a 2019 ADNeT **survey on memory clinics** has now been published online in *BMJ Open*. The national survey asked clinicians and administrators from Australian memory clinics to report on their current organisational aspects (staffing, waiting lists, follow up and so on) and on assessment procedures (including tools and tests used). Over 150 respondents completed the survey.

The authors say the findings show that there is "considerable heterogeneity with some common core elements" across memory clinics in Australia, and that the results will inform the development of national memory clinic guidelines. To access the article, see doi:10.1136/bmjopen-2020-038624

### Services map

The ADNeT Memory Clinics Initiative has also published a national **map of memory clinics and cognitive decline assessment services** on the ADNeT website ([www.australiandementianetwork.org.au/](http://www.australiandementianetwork.org.au/)) then go to 'Initiatives' and 'Memory clinics'. The map currently lists 102 clinics, services and stand-alone practitioners working in the area of cognitive decline across Australia: it is not a comprehensive list of all services operating in Australia, but is updated regularly as clinics and services choose to be published on the Australian Dementia Network. Multidisciplinary clinics, specialist clinics, group private practice and solo practitioners are invited to register to be included in the map by completing a short questionnaire with their clinic details: go to <https://redcap.link/q9oua992>

## New resources from NAPA



The National Activity Providers Association (NAPA) in the UK produces a wide range of practical resources to promote activity, arts and engagement with older people, mainly aimed at activity or leisure coordinators working in residential aged care. Its latest resource, **Moving and Grooving**, is part of NAPA's 2021 campaign to prioritise physical activity among older people, with the aim of improving physical, psychological and social wellbeing. The free, colourful 26-page resource sets out over a dozen engaging activities and uses a coding system to help practitioners match activities to a person's cognitive abilities. The guide presents clear guidance on what equipment is needed (if any) to deliver the activity, and instructions for how to present the activity. Access the guide here: <https://bit.ly/3heiETZ>

**Getting Creative with Tech** is another practical new resource from NAPA. The guide presents 14 different tech-supported activities for offering in the aged care sector, with clear step-by-step instructions for each. Topics covered include Alexa-based activities, staying connected with family and friends online, online chat groups, dominoes using tech, and more. Apps specifically recommended for people living with dementia are also introduced. The resource is available at <https://bit.ly/3y3nTf9>



with dementia and shares a number of personal stories on this topic contributed by other people living with dementia. It covers reasonable adjustments that could be made to support a person with dementia to continue working, advice for those who are thinking about or have given up work due to a diagnosis, and suggestions for alternatives to paid work. Although written for a UK audience, some key ideas are relevant to Australian readers too. The booklet can be downloaded from <https://bit.ly/3oOx0fL>

Alzheimer's Disease International (ADI) has concluded that not enough is being done globally to meet the commitments set out in the WHO Global Action Plan on the public health response to dementia 2017-2025. The report, **From Plan To Impact IV**, is the fourth in a series of reports produced annually charting progress around the world towards implementing each of seven action areas within the WHO Global Action Plan. The

develop nationally consistent guidance for people taking multiple medicines. Access the report at <https://bit.ly/3yGXXGu>

NPS MedicineWise has developed a substantial number of resources as part of its focused work since 2020 on **Dementia and Psychotropic Medicines**. Resources include two webinars available to view at any time ('Dementia: a multi-disciplinary approach to caring for people with changed behaviours' and 'Working together to enhance transitions of care for people with dementia'), two educational programs related to professionals working in residential aged care, involving visits (one aimed at GPs, the other at nurses and pharmacists), two podcasts (Dementia and Changed Behaviours: A Person-Centred Approach and A Lived Experience Of Dementia and Changed Behaviours), several online articles, a resource directory, and a tool to facilitate multidisciplinary review of antipsychotic medicines prescribed for people with dementia experiencing changed behaviour ('Reviewing and tapering antipsychotic medicines for changed

behaviour'). The webinars and educational programs may be counted as CPD, with guidance on times for self-directed CPD. All the resources and educational offers are available for free at [www.nps.org.au/professionals/antipsychotic-medicines](http://www.nps.org.au/professionals/antipsychotic-medicines)

The Life Changes Trust in the UK has published a new 'Peer to Peer Resource', titled **Work After A Diagnosis Of Dementia**. The 26-page booklet is written by Martin Robertson who lives with Posterior Cortical Atrophy. The book is aimed at people living

## WHO's dementia resources

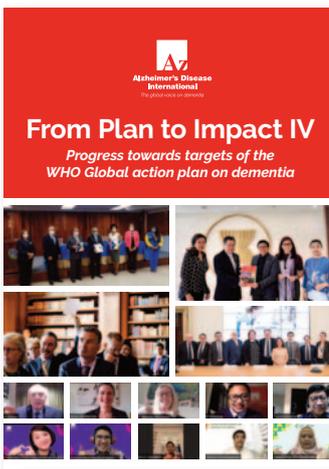
### Knowledge exchange

In May, the World Health Organization (WHO) launched its **Global Dementia Observatory Knowledge Exchange Platform** (GDO KE Platform). The GDO KE Platform is intended as a space for stakeholders to share free resources (policies, guidelines, case studies and examples of good practice) to support the implementation of WHO's 'Global action plan on the public health response to dementia 2017-2025'. Resources are grouped according to the action plan's seven strategic action areas: dementia policy; awareness and inclusion; risk reduction; dementia diagnosis, care and support; caregiver support; dementia monitoring; and research and innovation. Resources may be submitted by anyone with an interest in dementia and are then reviewed by a panel of peer reviewers, a focus group of people with lived experience of dementia and the WHO Secretariat. The WHO hopes that the platform will facilitate mutual learning and promote the exchange of knowledge in dementia. The GDO KE is available at <https://globaldementia.org/en>

### Prevention and support

WHO is continuing to develop resources that can be delivered through mobile devices to support health promotion (called mHealth), with its latest two modules focusing on dementia prevention (aimed at people in mid-life and older, to manage modifiable risk factors) and dementia support (aimed at family carers of people living with dementia, and based on the WHO iSupport program). The new mDementia handbook (**Be Healthy, Be Mobile: A Handbook On How To Implement mDementia**) sets out how to implement these two modules at scale, covering operations management; technology specifications; content development and adaptation; promotion, participation and retention; and monitoring and evaluation.

The WHO says that the content can be adapted to support countries' own national guidelines and existing health system interventions and to the local context and culture. The resources were developed by the WHO Mental Health and Substance Use Department and BeHe@lthyBeMobile (BHBM), a joint initiative between the World Health Organization and the International Telecommunications Union. The handbook is available here: <https://bit.ly/2RaDB7F>



report was launched at a side event to the 74<sup>th</sup> World Health Assembly on 26 May 2021, which was held virtually. ADI says that of the 194 WHO Member States that have committed to developing a national dementia plan, only 32 have so far been developed; 28 new plans are needed annually to reach the WHO target of 146 plans by 2025. It says disruption caused by COVID-19 has exposed limitations on health and social care in low- and middle-income countries due to fragile economies and weak infrastructure. The report includes case studies and examples of good practice and challenges faced, including as a result of the COVID-19 pandemic. The report is available at [www.alzint.org/resource/from-plan-to-impact-iv/](http://www.alzint.org/resource/from-plan-to-impact-iv/)

### Books

Dr Kailas Roberts is the author of a new book from the University of Queensland Press titled **Mind Your Brain: The Essential Australian Guide to Dementia**. Dr Roberts is a consultant psychiatrist and psychogeriatrician working in Brisbane in private practice, and the book, he says, is a way of sharing the knowledge he has learnt from talking with and supporting people living with dementia and family carers. The book is set out in two parts: 'Understanding dementia' (on brain functions in the healthy brain, and defining dementia) and 'Living with dementia' (on assessment, post-diagnostic

day-to-day issues, and issues related to the caregiving role). The 300-page, accessible book aims to provide advice on all the key issues related to dementia and is targeted at anyone with an interest in learning more about dementia – for their own brain health and dementia prevention, or to better support someone who is living with dementia. The author says his intention is to spread a message of hope in relation to living well with the illness, and to help readers be better informed should they be diagnosed with dementia. The softback book costs \$34.99 and is available from a range of outlets.

In **Dementia-Friendly Communities: Why We Need Them and How We Can Create Them** author Susan McFadden, formerly a professor of psychology at the University of Wisconsin Oshkosh, explains the changes that have taken place in the dementia field, from the transformative writing of Tom Kitwood in the 1990s, through to the current work of dementia advocates worldwide to change the narrative about living with dementia (in a section titled 'Telling a new story'). The book presents an overview of the dementia-friendly communities movement, reporting on initiatives from across the world, such as Dementia Friends, memory cafes, and the work of creative arts organisations such as TimeSlips. The book's key sections are on 'Hearing their voices', 'Friendship and community inclusion', and 'Creativity and the human spirit', and one closing chapter suggests new directions for

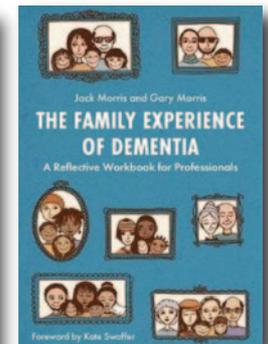
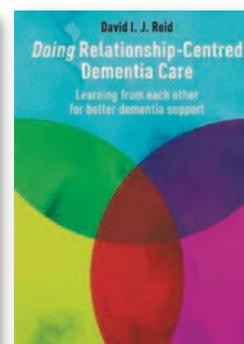
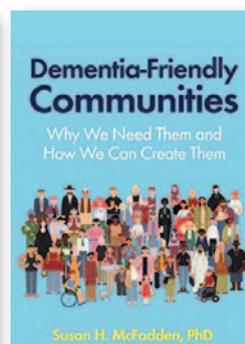
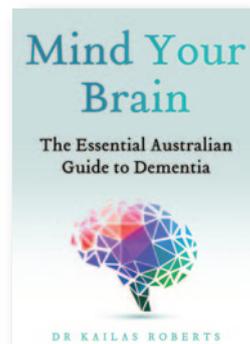
dementia research, practice and policy in light of the book's contents. The Jessica Kingsley Publishers (JKP) book is available in Australia for \$51.99 from Woodslane (see <https://www.woodslane.com.au/>).

**Doing Relationship-Centred Dementia Care: Learning From Each Other for Better Dementia Support** is the title of another new JKP book, written by David Reid, a senior lecturer from the University of Sheffield in the UK. The author introduces the relationship-centred approach and goes on to show how experiences of living with dementia, family members' awareness, professional knowledge, and health, social care and housing options are all linked – and how good dementia care depends on the relationships between these groups. Contents covered includes learning from people with dementia and family members, practitioners' experiences of dementia, creative approaches to exploring practitioners' private experiences of dementia, and engaging with dementia communities of practice. The book sets out practical steps for carrying out relationship-centred dementia care, with examples of common obstacles and how to overcome them. The book is available in Australia from Woodslane for \$33.99.

**The Family Experience of Dementia: A Reflective Workbook for Professionals** is a new book written by Jack Morris and Gary Morris, and also published by JKP. Throughout, the authors present the unfolding story of the fictional

Lawrence family, where Peter has been diagnosed with younger onset dementia, with perspectives from each family member featuring throughout the book. The book is set out in three parts: 'First experiences' (on first signs, getting a diagnosis), 'Living with dementia' (on making sense of the present, and starting the dementia journey), and 'Living beyond dementia' (on dementia champions, and exercise). Each chapter includes a range of reflective prompts, including activities, an exercise (as an aid to group facilitation), and links to other reading and research. The book aims to provide practitioners with strategies to support whole families throughout the dementia journey, based on an understanding of the lived experience of dementia, for everyone involved. The book is available in Australia from Woodslane for \$55.99. <https://www.woodslane.com.au/Book/9781785925740/The-Family-Experience-of-Dementia>

**Dementia-Friendly Hospital Buildings: Construction and Design Manual** is the title of a new 128-page book, published by the German publisher, DOM Publishers. Authors Kathrin Büter and Gesine Marquardt summarise research in this field before going on to present design principles as well as practical examples. The guide is aimed at all stakeholders involved in hospitals and promotes interdisciplinary planning processes. The book is available from the publishers at <https://dom-publishers.com/>, and costs 38 Euros (about \$A60).



Dementia care event listings are available on the AJDC website at [www.journalofdementiacare.com](http://www.journalofdementiacare.com)

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