

Australian Journal of **DementiaCare**

For all who work with people with dementia

Vol 10 No 1 January/February/March 2021

Dementia care in rural & remote Australia 48-page special issue



**Also inside
this issue:**

- Telehealth in Indigenous communities
- Rethinking rural care
- The right to public space
- Dementia-inclusive theatre

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Dr Chris While, Training Consultant, Dementia Training Australia; Research Fellow, La Trobe University and the Australian Centre for Evidence Based Aged Care

Publisher: The *Australian Journal of Dementia Care* is published by the University of Wollongong and managed by Dementia Training Australia, including website and administrative support from: Owen Wilkinson, Emma Paul, Janice Hurley, and Vanessa Bussoletti

Printed by iPS, Sydney.

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ISSN 2049-6893

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

Subscriptions \$99 (four issues)

(see page 48 for details).

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AJDC DEADLINES 2021: April/May/June:

27/01/21 (submissions); 12/04/21 (publication);

July/Aug/Sept: 23/04/21 (submissions);

12/07/21 (publication); Oct/Nov/Dec: 23/07/21

(submissions); 11/10/21 (publication). **Details:**

<https://journalofdementiacare.com/submissions/>

Improving rural dementia care

By **Professor Jane Farmer**, Director,
Swinburne Social Innovation Research Institute



Having spent much of my career researching rural communities and services, I suggest there are three issues that – if tackled – would help to make a difference in rural and remote dementia care. These are reflected in articles in this issue of *AJDC* and in the recent book I co-edited, *Remote and Rural Dementia Care: Policy, Research and Practice* (Innes *et al* 2020) [see p44]. They are:

- Better operationalising care as an ecosystem that makes best use of what is available locally, distant and online.
- Embracing people living with dementia as integral to our rich, ongoing community life.
- Understanding dementia as a multi-faceted phenomenon, woven from different cultural, social and biomedical aspects.

As Gardiner *et al* highlight in this issue (see p35), rural is a distinct service provision space. Internationally, rural populations are ageing, so proportionately rural regions are more affected by dementia than cities. Small numbers of people living with dementia in individual rural places means practitioners may lack experience with dementia. Rural people tend to experience layers of adversity, including higher levels of poverty, fewer economic opportunities and reduced access to services compared with cities (Lawrence-Bourne *et al* 2020). Consequently, dementia may not have highest priority.

Care ecosystems: discussion of services for rural places can sometimes seem like a contest between online and on-the-ground provision (Perkins *et al* 2019). Articles in this issue highlight that, in fact, marrying across service offerings is a sensible way ahead. Internationally, there exist some good ideas that can support rural dementia care: WHO has the mhGAP program, a toolkit that can build local skills and knowledge in dementia care (WHO 2019) and Austria developed the Dementia Service Centre model that helps rural families, carers and service teams work together around the evolving needs of a person living with dementia (Auer *et al* 2020).

'It takes a village': as highlighted by Leone *et al* in this issue (p24), people with dementia should be able to access the full range of services and amenity, as their human right. However, there are gaps in opportunities for people with dementia to lead enjoyable, thriving lives in communities once they are diagnosed – an issue which surely mitigates against seeking out the early diagnosis that professionals advise. Empathy is a powerful force, and when I read this lived experience – written for inclusion in our book – my understanding of some of the challenges rural residents face began to take shape:

"When I was told I had early onset Alzheimer's disease I was alone, and I had to get into my car and drive alone for two hours afterwards... for a long time, I couldn't find the courage to tell anyone. Living in a rural area, everyone knows everyone. I had owned a business and lived on the main street... I worried about the reaction of my town. Would they think I was mad?" (Rochford-Brennan 2020 pp268-272).

The author concluded that ultimately though "it takes a village to support a person living with dementia" (p267). With determination, Helen Rochford-Brennan found new ways to live her life in the village, in the process educating her neighbours that people living with dementia can continue to lead valuable thriving lives.

Two-eyed seeing: Lastly, my readings in rural dementia care have led me to understand the value of seeing dementia experiences from the perspectives of different knowledge systems and cultures. In our book, Jacklin and Chiovotte (2020) discuss working with Canadian First Nations communities and the significance of marrying Indigenous beliefs about dementia with Western biomedical perspectives: "two-eyed seeing" they called it, noting that, "Indigenous populations place less emphasis on the Western diagnostic labels and biomedical perspectives associated with cognitive decline" (p246). The authors depict dementia care with Canadian First Nations communities as best achieved through interweaving traditional cultural beliefs, biomedical interventions and feelings and experiences related to colonisation. In line with this, it was interesting to read Haszard's commentary in this issue (p32) about a DSA consultant in Alice Springs who adopted the Malparara Way – "a cross-cultural practice model developed in the early 1990s".

While the issues I've discussed above for improving rural dementia care are significant in all places, perhaps there are more opportunities to achieve change in rural places where people still tend to know each other, to look out for each other and where there are policy moves to more place-based delivery. The pandemic has shown that service provision can change overnight, as the examples highlighted in this issue show. ■

*The Reference list is available on the *AJDC* website, www.journalofdementiacare.com

This special 48-page issue of *AJDC* focuses on dementia care in rural and remote areas of Australia, with articles describing how service organisations and researchers are addressing the specific challenges of providing care and support services in these locations.

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New beginnings: design to support engagement 12

Samantha Neylon and Ruth Payne describe the process of transforming a former convent building into a purpose-built dementia-friendly care home supporting a Montessori approach to dementia care

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Reimagining Dementia is an international group of dementia activists and allies who share a vision that challenges biomedical and institutional approaches to care. Coalition Coordinator Mary Fridley explains

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Gwen Korebrits explains how Dance Health Alliance has enabled people living with dementia to keep active and dancing throughout the COVID-19 lockdowns

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The University of Queensland's Centre for Online Health (COH) is an internationally regarded leader in the field of telehealth. In this article, Anthony Smith (COH Director) and members of his research team explain how telehealth is being used to connect dementia specialists to selected Aboriginal and Islander Community-Controlled Health Services in Queensland

A rights-based approach to dementia-inclusive public spaces 24

People living with dementia and their carers in rural and regional areas face particular challenges around loneliness and isolation, heightened by a lack of access to dementia-inclusive outdoor and public spaces. Carmela Leone, Rachel Winterton and Irene Blackberry are undertaking a study in rural and regional Victoria exploring the rights of people with dementia and carers

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KT shapes new environments resources 28

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Rethinking rural dementia care 30

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Community links key to pandemic support 32

Andrew Haszard explains how Dementia Support Australia and its team of Dementia Consultants have supported people with dementia and care services in rural and remote areas of Australia before and during the COVID-19 pandemic and the specific challenges faced by people in those communities

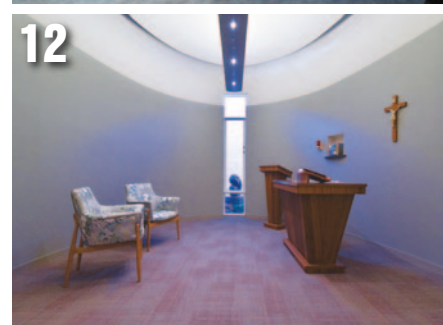
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Cover image: Herb, a Royal Flying Doctor Service (RFDS) patient in Tilpa, in Far West NSW. See article pp35-37. Photo: Royal Flying Doctor Service of Australia

News in brief

DCRC grants announced

The Dementia Centre for Research Collaboration (DCRC) has announced the successful applicants for an Implementing Research Evidence into Practice Grant 2020. The grants, of up to \$50,000 each, have gone to Dr Claire O'Connor, Dr Christine While (both *AJDC* Editorial Advisors), Dr Jane Sluggett, Associate Professor Lyn Phillipson (*AJDC* Co-Editor), Dr Loren Mowszowski, Associate Professor Susan Slatyer and Trinidad Valenzuela. The grant scheme's main purpose is to support the implementation into practice of an existing knowledge product or program that has previously been developed and piloted. Associate Professor Phillipson from the University of Wollongong, for example, will be looking at the use of Talking Mats for supported home care planning for people with dementia, while Associate Professor Slatyer from Murdoch University will be exploring the use of the 'Focus on the Person' form. Details: <https://dementiaresearch.org.au/>

Joint statement on carers

Carers Australia and Dementia Australia issued a two-page Joint Position Statement during National Carers Week (11-17 October 2020) on the issue of discrimination faced by people living with dementia and also their family and care partners. The two organisations say the key to systemic change is better educated communities and better educated families. The Statement outlines seven recommendations to alleviate discrimination faced by carers of people living with dementia, including an awareness campaign, additional carer support services (respite, support groups, counselling), education and training for carers, holistic assessment and support for carers within aged care support packages. "It is vital that the unpaid carers of people living with dementia are able to live a life free from discrimination," said Carers Australia CEO Liz Callaghan and Dementia Australia CEO Maree McCabe.

Hearing loss and dementia study

The Royal Perth Hospital (RPH) Research Foundation is giving \$600,000 to support a 24-month randomised clinical trial involving a team of Western Australian researchers and healthcare workers joining forces to find out if using hearing aids is an effective way to delay the onset of dementia symptoms. The trial is being led by Dr Andrew Ford of the East Metropolitan Health Service (EMHS) and Dr Dona Jayakody, Audiologist and Research Lead for the Cognition and Hearing Loss Project at Ear Science Institute Australia (ESIA). RPH Research Foundation CEO Joce Young said she looked forward to seeing the multidisciplinary teams translate their novel ideas into significant community healthcare innovations. To register interest in participating in the study, email jennifer.marks@earsience.org.au or phone 0409 623 367. Participants must be over 69 years, fluent in English, experiencing hearing loss in both ears (age-related hearing loss) and not have had hearing aids before.

Disability Royal Commission's Reports

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) released its Interim Report on 30 October 2020, as well as a special COVID-19 report in November. The Interim Report sets out what the Royal Commission has done in its first 15 months, up until 31 July 2020 (which includes three public hearings, private sessions, engagement with the disability community, publication of issues papers, consideration of submissions) and the areas that the Royal Commission has identified as needing further investigation. It says that people with disability experience attitudinal, environmental, institutional and communication barriers to achieving inclusion within Australian society and that a great deal needs to be done to ensure that the human rights of people with disability are respected and that Australia becomes a truly inclusive society. The Interim Report is available in a variety of formats from the Royal Commission's website.

Govt funds 33,000 new home care packages

For a third year in a row, the Government has used the Mid-Year Economic and Fiscal Outlook (MYEFO) in December to make new commitments to funding aged care – on top of its October budget commitment of \$1.6 billion for an additional 23,000 home care packages.

The additional funding announced in December amounts to \$1 billion, a large part of which (\$850 million) will fund a further 10,000 home care packages for older Australians. The Government says it is continuing to build on the reform process for the delivery of care in the home as proposed by the Royal Commission into Aged Care Quality and Safety.

The December funding announcement also includes:

- An additional \$57.8 million for aged care under the National Partnership on COVID-19 Response.
- \$63.3 million to support increased access to allied health services and improved mental health care supports for people in residential aged care.
- \$8.2 million to extend the Victorian Aged Care Response Centre until 30 June 2021.
- Another \$11.1 million over five years to help fast-track the implementation of the Serious Incident Response Scheme (SIRS) (taking the total investment in the program to \$67.2 million).

The October budget announcement committed a total of \$23.9 billion of funding for aged care in 2020-2021. It included more than \$746 million in aged care COVID-19 response measures as part of the \$1.6 billion in COVID-19-specific support in aged care, as well as investment of \$408.5 million for aged care reform initiatives to improve the quality of care, further respond to the urgent issues raised by the Royal Commission into Aged Care Quality and Safety and lay the foundations for future reform.

Particular commitments within the allocation for aged care reform (\$408.5 million) included:

- dementia training and psychosocial support (\$11.3 million)
- implementation of the Aged Care Workforce Strategy (\$10.3 million)
- keeping young people out of residential aged care (\$10.6 million)
- preparatory work for a new funding model to support better care (\$91.6 million)
- support for the Royal Commission (\$4.1 million)
- support through the Business Improvement Fund (\$35.6 million)
- investment in the Serious Incident Response Scheme (\$29.8 million); and
- developing the single in-home support program for older people at home (\$4.6 million).

Younger people in aged care strategy

The Morrison Government has announced new funding and a strategy for reducing the number of younger people living in residential aged care.

According to the Minister for the National Disability Insurance Scheme, Stuart Robert, and Minister for Aged Care and Senior Australians, Senator Richard Colbeck, the initiative includes \$10.6 million in the 2020-21 Budget for a national network of up to 40 system coordinators to help younger people find age-appropriate accommodation and supports to allow them to live independently in the community.

Mr Robert said the Younger People in Residential Aged Care (YPIRAC) Strategy 2020-2025 charts the course to meet the strengthened targets set by the Government in late 2019 and builds upon the YPIRAC Action Plan released in March 2019. The YPIRAC targets seek to ensure, apart from in exceptional circumstances, there are no people under the age of 65 entering residential aged care by 2022; no people under the age of 45 living in residential aged care by 2022; and no people under the age of 65 living in residential aged care by 2025.

By Request campaign brings aged care residents and musicians together

Anglicare Southern Queensland's Abri Aged Care Home in Southport hosted a memorable concert on 21 October 2020 – with four-time ARIA award winner Katie Noonan performing with resident Paul 'Fluffy' Jansen in front of 20 other residents.

The event was part of the provider's campaign called By Request: A Playlist of Memories, which has brought together aged care residents and talented musicians from across Australia. The livestreamed concert can be watched here:

<https://bit.ly/by-request-concert>

The By Request campaign began with eight 'everyday Queenslanders' living in aged care homes being filmed sharing the personal story behind their favourite song, which was then performed – to the resident's surprise – by a well-known Australian musician. This series of performances, and the concert



Four-time ARIA award winner Katie Noonan and Abri Aged Care Home resident and drummer Paul 'Fluffy' Jansen soak up the applause after the concert

in October, have both been live streamed to all of the providers' aged care homes in Queensland.

Artists who participated in the project included Katie Noonan, Isaiah Firebrace, Jess & Matt, Rai Thistlethwayte (Thirsty Merc), Adam Eckersley and Brooke McClymont, Emma Birdsall, and Kate Miller-Heidke.

Anglicare Southern

Queensland Executive Director Karen Crouch said, "The By Request series was produced across three states during COVID-19 restrictions, with the artists filming their own videos and our team editing them together with our residents' reactions," she said.

Ms Crouch said while it was critical that aged care providers remained focused on their COVID-19

preparedness, it was equally important to consider the mental wellbeing of residents. She said the campaign provides a great example of how technology can be harnessed to keep people connected and lift spirits.

In November, Anglicare Southern Queensland was named as the Asia-Pacific's 'Best Home Care Operator' in the Eldercare Innovation Awards in Singapore.



Paul 'Fluffy' Jansen on drums

Alzheimer's drug decision due in March: The US Food and Drug Administration (FDA)'s Peripheral and Central Nervous System Drugs Advisory Committee met in November and delayed a decision on approving aducanumab – Biogen's new drug for treating Alzheimer's disease – with a decision on whether to approve the drug expected on 7 March 2021. Biogen's Phase 3 EMERGE and ENGAGE studies for testing aducanumab were ceased in March 2019 but in October 2019 the company announced it would seek FDA approval after analysis of a larger dataset showed promising results. Aducanumab is an antibody treatment that targets and clears amyloid plaques from the brain and is administered by a monthly intravenous infusion.

DEPARTMENT OF HEALTH NEWS

SIRS to commence

The Federal Government has brought forward the introduction of the Serious Incident Response Scheme (SIRS) to 1 April 2021, subject to parliamentary processes, with an additional \$29.8 million of funding for SIRS for residential aged care. The Government says \$26.3 million has already been spent establishing the new system for reporting abuse or serious incidents in aged care facilities. As part of the SIRS, residential aged care providers will be required to manage all incidents, with a focus on the safety and wellbeing of consumers and reducing preventable incidents from reoccurring. The Aged Care Quality and Safety Commission will be responsible for administering the SIRS and will have powers to take regulatory action where appropriate to address non-compliance.

New quality indicators

Medication management is to feature as one of two new quality indicators to be included in the National Aged Care Mandatory Quality Indicator (QI) Program from 1 July 2021. The two new quality indicators relate to 'Medication management' (percentage of care

recipients who are prescribed nine or more medications; and percentage of care recipients who received antipsychotic medications) and '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). The new quality indicators are being included following an extensive development process and national trial.

AN-ACC tool

The Australian Government says it has not made a final decision on whether to implement the new funding model for residential aged care – known as the Australian National Aged Care Classification (AN-ACC) tool – but that it will fund a year of 'shadow assessment' to start in the first half of 2021. During this assessment period, the AN-ACC tool will be used to assess all existing and new aged care residents, and assign them with an AN-ACC class – even though the current funding assessment tool, the Aged Care Funding Instrument (ACFI) will continue to operate during this period and be the mechanism through which funding assessments continue to be made.

Dementia Innovation Readiness Index

London has ranked the highest of 30 major cities globally, and Sydney eighth, in terms of city-level 'innovation readiness' to dementia. The ranking is presented in Alzheimer's Disease International's (ADI) latest *Dementia Innovation Readiness Index*, launched by ADI with the Global Coalition on Aging (GCOA) and the Lien Foundation.

The Index reviewed 30 cities globally and concluded that cities around the world have not fully leveraged opportunities to support the development or adoption of innovations in dementia care, treatment and support and must take on a leadership role. It says a willingness to act at a local leadership level is crucial to a city's preparedness and ability to innovate. The report includes a number of 'Promising Practice' profiles.

COVID-19 NEWS

Support line expanded

In November the Australian Government announced it would be investing \$2.5 million in extending and expanding the Older Persons COVID-19 Support Line until 30 June 2021 – with the extended service to include outbound calls to carers of people living with dementia, as well as more specific community supports for culturally and linguistically diverse (CALD) older people.

Updated Department of Health information

The Department of Health has issued a seventh edition of its 'National COVID-19 Aged Care Plan'. This includes an appendix titled 'Annotated summary of COVID-19 aged care resources', which lists over 60 resources from a range of government agencies and organisations with a brief introduction to each resource. Go to www.health.gov.au/ and click on 'Resources'.

Govt 'failed to prepare sector': report

In December, the Senate Select Committee tasked with reviewing the Federal Government's response to COVID-19 published an interim report, a chapter of which focuses on the aged care sector. The Committee's conclusion is that the Australian Government "failed to adequately prepare the aged care sector for COVID-19, was too slow to respond to issues with outbreaks in residential aged

Visiting guidance

In May 2020, 13 aged care peak bodies and consumer advocacy organisations released the 'Industry Code for Visiting Residential Aged Care Homes during COVID-19' to facilitate a nationally consistent approach ensuring residents can receive visitors while minimising the risk of spreading COVID-19. The code has since been reviewed on multiple occasions, with a fifth version released on 20 November 2020. To access the code, go to COTA Australia's website (www.cota.org.au/).

In November, the Australian Health Protection Principal Committee (AHPPC) issued updated 'Visitation Guidelines for Residential Aged Care Facilities' which presents a new three-tier escalation plan, outlining how providers can respond to the COVID-19 threat level in the local community and ramp the response up or down as needed. The Australian Government has also issued a three-tier guidance on actions aged care providers should take in response to a situation of escalating or de-escalating COVID-19 threat level in the local community. All documents can be accessed via the Department of Health website (www.health.gov.au/).

care facilities, and failed to accept full responsibility for the sector despite being the government responsible for funding and regulating aged care in Australia". It also says that the Aged Care Quality and Safety Commission failed to use all of its available regulatory powers to ensure the safety of aged care residents. Coalition members of the Committee produced a dissenting report setting out responses to the interim findings, including actions taken by the Government that they say disprove the findings.

Federal Government support for sector

A proactive engagement program to help alleviate the impacts of lockdown on aged care residents living with dementia is a new service from Dementia Support Australia being offered as part of the Federal

Government's Grief and Trauma Response Package, announced in October 2020.

Dementia Support Australia is one of three organisations tasked with delivering the Federal Government's Grief and Trauma Response Package – aimed at ensuring support is available across Australia for those affected by COVID-19 across the aged care sector. The \$12.4 million package is part of the \$171.5 million COVID-19 response plan announced by the Government in August 2020.

The other services include:

- Specialist information and support to residential aged care and home care recipients and their families who have been affected by COVID-19, from The Australian Centre for Grief and Bereavement.
- Sector-wide trauma-informed care package that provides trauma training

and resources for aged care residents, their families and aged care staff, including through the establishment of a dedicated website, from Phoenix Australia, the Centre for Posttraumatic Mental Health.

Dementia Australia paper

One Day the Support was Gone is the title of Dementia Australia's latest discussion paper, which explores the mental health impact of COVID-19 on people living with dementia, their families and carers in Australia.

The discussion paper presents findings from a June 2020 survey of Dementia Australia's Dementia Advocates (people living with dementia and family carers) on the impact of COVID-19 on people living with dementia and carers, combined with analysis of qualitative and quantitative primary research conducted by a research team led by Professor Yun-Hee Jeon at the University of Sydney, and data obtained from the National Dementia Helpline.

The paper's findings confirm that people living with dementia are experiencing poorer mental health outcomes from COVID-19 and the associated restrictions, and that families and carers are also reporting higher than usual levels of stress and fatigue in caring for someone at home. Further, respite services are not meeting the increased demand.

Alzheimer's Disease Data Initiative launched to share research worldwide

A new medical research organisation, Alzheimer's Disease Data Initiative (ADDI), has been launched, along with its key offer – the AD Workbench. This is a cloud-based data platform to help dementia researchers share data, resources and tools. ADDI has been created by a coalition of partners, led by Gates Ventures, to increase sharing of dementia-

related data among researchers from around the world. ADDI's work has three parts: the AD Workbench; the development of Tools for researchers; and funding for researchers, data scientists and anyone within the broader dementia community, in order to crowd-source or promote the development and sharing of new data, tools, and analytics. AD

Workbench allows researchers to search existing databases on existing platforms, add new multidimensional datasets, combine data across multiple platforms and analyse new and existing datasets using in-platform models. ADDI says AD Workbench is open, inclusive, global and easy to use. Find out more at www.alzheimersdata.org/

Dementia Essentials

Provide support to people living with dementia (CHCAGE005)

Build your team's expertise with this fully funded, nationally accredited course designed for aged care, healthcare and disability workers. This course offers skills and strategies to help with communication, planning, developing activities and understanding changed behaviours in people living with dementia.

Staff can choose a mode of learning that works for their needs. We offer learning face-to-face, online via our virtual classroom – or a combination of both.

This course is highly structured, combining theory and practical components for an engaging learning experience. Participants receive ongoing support from experienced facilitators throughout the program.

Learn about:

- person-centred care
- the nature of dementia
- effective communication
- impact of dementia
- activities for engagement
- identifying elder abuse and restrictive practices
- understanding changed behaviours and developing effective responses
- creating supportive environments.



Delivery options:

- face-to-face (18 hours) **or**
- online and face-to-face (18 hours) **or**
- online and virtual classroom (18 hours)

For more information please visit
dta.com.au/dementia-essentials

\$150m for rural, remote areas

The Federal Government is making \$150 million in capital grants funding available as part of the latest Aged Care Approvals Round, which opened on 18 December, with the focus on improving access to residential aged care services in areas outside major cities. Priority will be given to applications that involve improving access to dementia care and improving service environments to be more dementia friendly.

Minister for Aged Care and Senior Australians, Senator Richard Colbeck, said the \$150 million in grant funding represents a major commitment to regional, rural and remote Australia.

"Now is the time to back providers to develop and deliver quality residential care services where they are needed most, as well as boost the economy through jobs creation in the construction and aged care sectors," Minister Colbeck said.

The Prime Minister Scott Morrison's Cabinet reshuffle in December saw the aged care portfolio elevated into Cabinet, with Greg Hunt (Health Minister) taking on the additional responsibility for the Government's response to the Royal Commission into Aged Care Quality and Safety. Senator Richard Colbeck retains responsibility for aged care services and regulation, as well as retaining his responsibilities for Senior Australians and as Minister for Sport.

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

The Australian Journal of Dementia Care is a multidisciplinary 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.

AUSTRALIAN DEMENTIA NETWORK NEWS

Volunteer Portal: The Australian Dementia Network has set up an ADNeT Volunteer Portal, a register for people who would like to participate in research into the causes, prevention, and treatment of dementia. ADNeT is now inviting people aged 50 years and older who would like to be involved to review the participant information sheet and then supply answers to a few questions through a secure site. People living with dementia, as well as people who do not have dementia, are welcome to register. Depending on ADNeT's current research needs, the person will then be contacted in relation to a more detailed assessment. To find out more, go to ADNeT's site at www.australiandementianetwork.org.au/

Australian Dementia Forum: The Australian Dementia Network (ADNeT) is to host the Australian Dementia Forum in 2021. The event will be delivered as a fully virtual conference in lieu of the face-to-face meeting originally scheduled for the Adelaide Convention Centre and will be held on 31 May 2021 to 1 June 2021. Keynote speakers have been announced for the virtual conference which will include live sessions, pre-recorded presentations and live Q&As, interactive panel sessions, poster sessions, a Virtual Exhibit Hall, and on-demand access to selected content for registered attendees following the conclusion of the conference. The call for abstracts has now closed but registration for the event opens on 1 February 2021. Find out more at <https://eventstudio.eventsair.com/adf2021/>

ClinTrial Refer app: ADNeT has joined forces with Neuroscience Trials Australia and with ClinRefer to launch the Dementia Trial App on the ClinTrial Refer app platform. ClinTrial Refer app is a free app which can be downloaded to a smart phone, enabling both clinicians and volunteer participants to have access to the latest information on dementia trials available in Australia, as well as information about recruitment status, trial sites and contacts. A web version of the app is also available at www.clintrial.org.au (search all trials, select discipline: neurology, then select dementia).

ROYAL COMMISSION NEWS

Final hearing and recommendations

Counsel Assisting the Royal Commission into Aged Care Quality and Safety has set out 124 recommendations it considers the Royal Commissioners should make in their final report, due on 26 February 2021.

Headline recommendations include a new Act based on human rights principles for older people, a new planning regime for aged care which provides demand-driven access rather than the current rationed approach, a new and independent process for setting aged care quality standards, mandated staffing ratios in residential aged care, and the establishment of an independent Australian Aged Care Commission that will be responsible for administering and regulating the aged care system.

Some of the other key recommendations include dementia and palliative care training for workers, establishment of a dementia support pathway, a review of specialist dementia care services, improving the design of aged care accommodation (by developing national aged care design principles and guidelines on accessible and dementia-friendly design for residential aged care), and immediate funding for education and training to improve the quality of care (and including on dementia).

The Counsel Assisting's final written submissions were presented on the final hearing day of the Royal Commission, on 22 and 23 October 2020, at which Senior Counsel Assisting, Peter Gray QC and Peter Rozen QC presented verbal submissions.

As well as the detailed recommendations proposed, the Counsel Assisting also included a summary of the evidence about what is wrong with the existing aged care system and outlined how the current aged care system should transition to the new system. The submissions can be viewed here: <https://agedcare.royalcommission.gov.au/hearings-and-workshops>

Dementia Australia said it welcomed the inclusion of dementia-specific

recommendations by Counsel Assisting. Dementia Australia CEO Maree McCabe said, "The proposed recommendations in the final submissions indicate to us that concerns of people living with dementia, their families and carers have finally been heard."

COVID-19 report and response

A month after the Royal Commission into Aged Care Quality and Safety published its special report into aged care and COVID-19, the Australian Government has responded by tabling its Implementation Progress Report in Parliament on 30 November 2020.

The Government said it had accepted and was acting on all six of the Royal Commission's recommendations, investing a further \$132.2 million in funding to do so.

The Royal Commission's recommendations addressed a range of issues, including the provision of allied health services, the need for infection control officers within facilities, and the need for a national aged care plan for COVID-19.

The Government's \$132.2 million package to deliver on the recommendations includes:

- \$63.3 million for a range of Medical Benefits Schedule (MBS) measures including mental and allied health support, and additional allied health group services.
- \$57.8 million to fund jurisdictions to support Infection Prevention and Control training within facilities.
- A further \$11.1 million toward a Serious Incident Response Scheme.

The Government says these measures offer not only an improvement in access to mental and allied health services for senior Australians in aged care, but also provide additional funding to GPs and allied health professionals delivering in-person care in facilities nationwide. It also confirmed that the Department of Health has released an Updated National COVID-19 Aged Care Plan (7th Edition).

Dementia-inclusive theatre

Althea Gordon and **Tina Firth** report on the results and lessons learnt from an innovative arts project in which aged care residents living with dementia participated in eight performances held in their aged care home, in front of audiences of carers, families and the wider community

In September 2019, residents of aged care home Mercy Place Mandurah in Western Australia took centre stage for a one-of-a-kind musical theatre production of *A Year With Frog and Toad*. People living with dementia were involved in every aspect of the production, along with other residents, staff, families and the local community. The performances brought music, theatre and creative arts directly to people living with dementia and their support networks.

The project was led by Western Australian based not-for-profit arts charity Mind The Change Inc which, in collaboration with Mercy Place, developed and orchestrated eight live performances in the care home over two weeks during Dementia Awareness Month. A total of 463 people directly engaged with the project, including almost 200 audience members. In the process, Althea Gordon (co-author here and Mind The Change Inc Artistic Director) and her team discovered ways of using everyday activities to connect, have fun and share meaningful time with the people living with dementia at the residence.

A role for everyone

Of the home's 90 residents at the time, 20 were living with dementia and all took part in some way – either on stage, in the chorus or behind the scenes helping to make props, the show poster or program. Some participants gave feedback throughout the rehearsals, while others were involved more passively but sat and made eye contact for an hour with a big smile. Some



Cast members, including residents living with dementia, are pictured above, and on the following page, during performances of *A Year With Frog and Toad*, at the Mercy Place Mandurah care home. Photos courtesy Mercy Place Mandurah

of the more physically able residents were ushers during the performances. The cast also included people from the local theatre community and schools, while others from the Men's Shed and the community helped backstage with sound, lighting, set and props, or front-of-house.

As a 'situational theatre' production, the show was performed 'in situ' – meaning the care home was used as the stage and the audience came into the home. There were five dedicated spaces within Mercy Place set up as theatre spaces for the various scenes. At the end of each scene the audience moved on to the next space, where the actors for that scene were waiting. Staging the performance in the care home and moving the audience from space to space meant any resident could participate, no matter their physical or cognitive ability.

All five spaces selected were communal spaces, such as dining and lounge areas and the main foyer/entrance to the home. The spaces were selected by the working group based on their ease of access, size and familiarity to the residents.

The show was the first of its

kind in Western Australia (and potentially nationally, too). People have previously put on shows for residents but not with the residents. The aims of the project were to:

- Increase awareness of dementia in the Mandurah community.
- Increase community engagement and build a sense of community around the Mercy Place home by collaborating with local groups and schools, using performing arts as the platform.
- Showcase the ability of not only those living with dementia, but older adults in the community, and their desire to still be included in community events and activities.
- Increase the wellbeing of residents, their families and the production cast.
- Develop and foster intergenerational relationships between members of the production.

The value of storytelling

'Play' and 'storytelling' are well-known activities that provide distraction from the difficulties of life, and are equally important for health as nutrition and sleep, as

illustrated by Dr Stuart Brown in his book *Play: How It Shapes the Brain, Opens the Imagination, and Invigorates the Soul* (2010). Theatre is now recognised as being able to assist people living with dementia by supporting their emotional, social and cognitive wellbeing. This has been further identified through the Veder Method research study, which reported that people with dementia participating in the living room theatre sessions had increased cognition and improved communication (van Dijk *et al* 2012). An Australian study also uncovered similar positive findings on wellbeing when observing a group of people living with dementia who participated in drama activities compared with the control group who only watched movies (Jaanieste *et al* 2015).

The musical theatre project *A Year With Frog and Toad* built upon the approach described by Brown by using theatre as a medium to explore which aspects of the creative process carried the most positive impact – not just for those participants living with dementia but also for their carers, families and the wider community.

This article follows an earlier report on this production published in the August-September 2019 issue of *AJDC*, two months before opening night. Here we describe the methods used to support people with dementia to take part, how the production was developed and key results from our qualitative evaluation of the project's impact, along with lessons learnt, in the hope that others may be inspired to start

a similar project in their aged care facility.

Method

Nine months before the face-to-face groundwork for this production began, the team at Mind The Change Inc identified Mercy Place Mandurah as an aged care facility that had previously showcased art-based work with its residents and had a staffing cohort receptive to change.

Project champions

After discussing and agreeing to collaborate to stage a production, Mercy Place Mandurah's management team worked closely with Mind The Change Inc to identify key personnel within the home to act as 'champions' for the project. These champions were selected for their interest in the project, creative capacity, willingness to try something new, and their availability to take on a new project.

These champions offered ongoing support and feedback throughout the process, which also meant the project could progress outside of the direct contact hours with the Mind The Change Inc project facilitators.

Similarly, community champions, local businesses, organisations and schools were also sought via referral, expressions of interest and local advertising. Those with a passion for community involvement, interactions with older adults and the arts were engaged and briefed about the production, its capacity-building elements and opportunities for engagement. An in-house working group was then established at Mercy Place to enable ongoing input from residents, families and staff.

The production chosen, *A Year With Frog and Toad*, is a jazz-style musical score based on the *Frog and Toad* children's books by Arnold Lobel, that is light and humorous. It follows the adventures of two friends: the cheerful, popular Frog and the rather grumpy, anxious Toad, along with their

companions, as they celebrate and rejoice in the differences that make them unique and special.

Supporting engagement

In March 2019, production, auditions and rehearsals began. Residents were invited and supported to be involved in every step of the process. Invitations were sent out to all residents and small gatherings were held to ensure everyone had the opportunity to ask questions and understand what would take place. More specifically, those residents living with dementia were supported to attend the gatherings and were continually supported by Mind The Change Inc facilitators to engage with the development process.

All activities were made accessible for people with dementia including being a member of the community audition panel; developing the program and scene layout; preparing and constructing props, costumes and the set; as well as learning the songs and dances during rehearsals. Through the connections with local government offices and theatre groups, organisations such as a Men's Shed and Bunnings came on board to provide support by designing and building the set. The donated materials, expertise and volunteers allowed the set to be of a standard comparable with local theatre productions.

Most rehearsals took place at Mercy Place Mandurah. Along with volunteers, some of the residents chose to assist in front-of-house roles during the

eight performances. This included ushering audience members to the various performance spaces throughout the show, ticketing, program sales, refreshments and public announcements. As the paying audience were unfamiliar with the venue (and it was not a regular theatre with signage), they needed extra support to know where to go, where to sit and what to do during the performance. Regular theatre etiquette is that you sit in your seat, you're quiet and you clap at the end of each scene. As this show was performed in situ, the residents and volunteers in the front-of-house roles provided prompts to help the audience understand and follow what was expected or 'okay' in this new space.

The production was advertised to the public using several methods selected by the residents including posters in the care home, the local community and schools, as well as articles in the local newspapers.

Having a high-quality set, professional lighting and sound, and a principle cast of eight actors from the local Mandurah community chosen by a resident-led panel, gave the production a feeling of authenticity which supported the residents to commit to their roles in the performances.

Risk management

Some of the potential risks identified for this project, and the strategies used to manage them, were:

- Increased volumes of people entering and exiting the home. The solution was

having a volunteer on the door at all times.

- People who weren't staff, residents or family members constantly on site. The solution was to sign up the cast and crew as 'volunteers' for the purposes of liability and security.
- People tripping or being reluctant to step over electrical cords and cables running across the floor. To minimise the risk, gaffa tape in a similar colour to the flooring was used to minimise visual obstruction for those needing to cross and, where possible, cables were run along and up the walls.

Results

Community awareness

The production highlighted to the Mandurah community the prevalence of dementia in an ageing society. The local council was happy to promote the production with flyers distributed within the council's library network. Relationships built during the production have been maintained post-production, with the Men's Shed and Bunnings continuing to contribute to the Mercy Place Mandurah Lifestyle team's activities. The strengthened relationships between residents and children from the local primary school and with library staff continue as they make regular visits to the home. These relationships keep the wider community aware of the Mercy Place residents and engaged with their activities.

The production was also acknowledged by the Independent Theatre Association for its contribution to community theatre in Western Australia, receiving an Adjudicator's Award for Community Engagement at the 2020 Robert Finley Awards.

Increased engagement

The 'community' that developed around the project increased the types of interactions that the residents and staff would usually have. Even the different demographics of the cast members resulted in



intergenerational relationships developing that would not normally be facilitated by the aged care home's usual activities. Qualitative data collected from residents through informal discussions about their thoughts around involvement in the project revealed overall positive feelings of increased engagement with these community members.

Increased wellbeing

The increased engagement between residents and the wider community also led to observable differences in residents' wellbeing. For example, one resident who was previously known to walk the halls without stopping to eat, drink or sit still for more than five minutes was observed by nursing staff to change his behaviour. Throughout the production, this resident found interest in talking to cast members and would focus long enough to sit, watch and follow the entire 70-minute performance. It was also noted that he had an improved ability to sit and eat at meal times. Staff reported that he was still displaying this changed behaviour six weeks after the production.

An unexpected finding from the project was that residents understood that they could increase their wellbeing through participation, why it was important to be involved with a project that has meaning and value and one where they can interact with others. When discussing the importance of participation, one 93-year-old male resident said: "I felt like I was contributing to it. And this is what I have got to do, because I've still got to retain my memory. It [the production] was something to keep my mind active. This is what I have to keep doing, keeping my mind active."

Intergenerational ties

The regular interaction between the residents and younger cast members helped facilitate a bond between these groups. These were created both

formally and informally, such as the post-performance staff-organised supper and the story-telling soirees started by a resident. The core resident chorus group also led an after-show party, inviting the lead cast to attend. Allowing time for friendships to develop between the lead cast and the residents was crucial for the success of the project. What began with small talk evolved into conversations built on trust and a sense of security for those living with dementia because the cast were living in their moment.

This element of 'having fun' and validating their purpose was noted by clinical staff and therapy teams to be reducing these residents' anxiety by acknowledging their worth, promoting their self-esteem and a sense of joy. As performers, they were able to enter the reality of those living with dementia by building empathy and finding connections that were meaningful and purposeful through this engagement. Post-production, some of these friendships have continued, with one of the lead cast (a young woman in her twenties) remaining in contact with a resident by becoming pen friends.

Project limitations

To our knowledge, as this style of project has never been undertaken in Australia before, Mind The Change Inc had no local resources or knowledge to draw upon. Therefore, a lot of learnings developed as the process unfolded. For example, there were limitations around the technology that could be used during the production, and the number of audience members that the venue could support. Holding rehearsals in the care home was both an advantage and a limitation. While it allowed maximum participation by residents, it was also problematic when the home encountered a lockdown due to illness and rehearsals had to be cancelled.

A lot of people were needed to help the residents living with

dementia to participate in the production and if the required number were not available, it was difficult for those residents to join in. For this same reason, there were obstacles to conducting the pre- and post-production interviews with this group. As some information was collected second-hand from family members or staff, this must be taken into account when interpreting the results of this project.

Key lessons learnt

- Collaboration is essential for success. This production would not have been as successful without the high level of engagement achieved with community, local businesses and key stakeholders.
 - Flexibility is key. When working with the aged care industry, flexibility and creativity of applied processes are essential to a project's success.
 - Stakeholder engagement and ownership: all parties need to be a part of the process to build sustainable long-term relationships.
 - Planning and pre-production work were a necessity. Timelines, project planning, communication and risk management were just as important as the rehearsal/'action' phase.
- Never disable people with limited abilities. Placing the decision in the hands of those taking part allowed for a much richer experience. By engaging the residents in every step of the production process, they helped shape and create the end result and the production held greater value for them.

Conclusion

This theatre project set out to explore which aspects of the creative process carried the most positive impact. A key result highlighted throughout the process was the benefit of community engagement for the residents. This is important as extensive research has established that people need this connection to feel like a valued member of their

community. This was a successful capacity-building project because it supported residents to take ownership by enabling them to be involved in key decisions and the direction of the production, and helped to facilitate valued interaction in more ways than one.

In this project, people living with dementia were empowered to participate in a way that many had doubts could be possible. With the correct support and a clear vision, people living with dementia can indeed foster and develop relationships using performing arts as the platform to increase their feelings of wellbeing. ■

To find out more about Mind The Change Inc or how you can start a project like this in your aged care home, contact Artistic Director Althea Gordon on admin@mindthechange.org or 0438 326 327.

Acknowledgments

Healthway, Act-Belong-Commit, David Templeman MLA, City of Mandurah, Mercy Place Mandurah, Bunnings Halls Head, Timber's Edge Men's Shed, Bold Park Performing Arts, Carole Dhu and Lifespan Dance.

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■ Althea Gordon (left) is Artistic Director of Mind The Change Inc, Western Australia. Althea's mother has been living with younger onset dementia for more than 10 years; Tina Firth is a board member of Mind The Change Inc

New beginnings: design to support engagement

Samantha Neylon and **Ruth Payne** describe the process of transforming a former convent building into a purpose-built dementia-friendly care home supporting a Montessori approach to dementia care, and lessons learnt

Villa Maria Catholic Homes (VMCH) is a not-for-profit organisation providing aged care, retirement and disability services to over 9000 people across Victoria. VMCH Corpus Christie Aged Care Residence, in the Melbourne suburb of Clayton, undertook a \$900,000 project to refurbish the adjacent Cluny Convent into Cluny House, a 12-bedroom Memory Support Unit which opened to residents in July, 2019. Being a former convent, all the building's existing elements were suitable for minor internal modifications to easily convert to a dementia-specific unit. Therefore demolition was not considered nor would



The refurbished VMCH Corpus Christie Aged Care Residence in Melbourne. All photos: Michelle Despot from M Style & Co

it have been feasible.

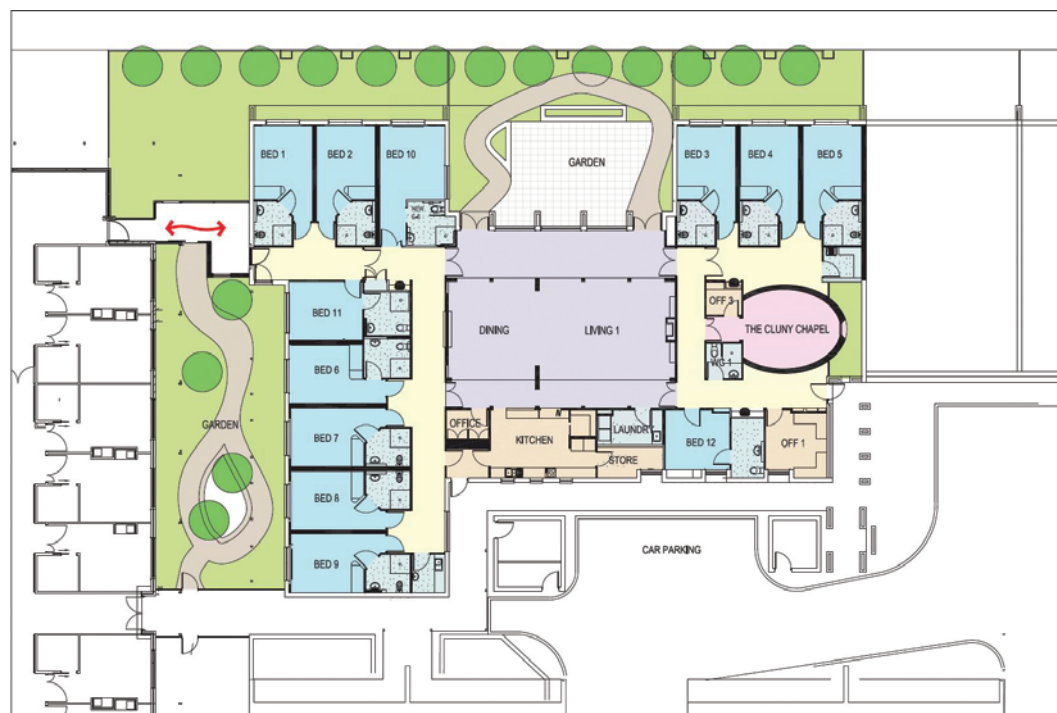
Cluny House has been designed to support the organisation's Montessori approach to dementia care (see box p15). This approach has a key focus on residents 'doing and participating' through the provision of an environment

rich in opportunities for independent engagement. This enables the person living with dementia to have a meaningful place within their community, make autonomous choices and contribute to life in their home.

The scope of works included:

- Reconfigure the existing layout to include an additional three bedrooms with ensuite bathrooms.
- Upgrade fire compartmentation and services required to comply with the National Construction Code 9c building classification (aged care), as the building was originally classified as Class 3 (hostel).
- Upgrading the interiors in line with recommendations for a Memory Support Unit based on VMCH's Montessori learnings to date.
- Remodelling the existing kitchen so that staff and residents could use it effectively and safely.
- Addition of a domestic laundry for use by residents.
- Construction of a new passageway connecting Corpus Christi and the new Memory Support Unit to improve access for both staff and residents.
- New landscaping in the north-facing garden with appropriate features for residents with dementia to engage.

These works are reflected in the Cluny House floor plan at left.



Floor plan of the 12-bedroom refurbished Cluny House Memory Support Unit, which opened in 2019

The project brief

VMCH approached Perth-based living environment specialist company deFiddes, which provides person-centred design solutions for residential aged care,

retirement, dementia and disability care, to refurbish Cluny House with a homely, updated aesthetic. Finishes, loose furniture and accessories were selected in a mid-century modern style to evoke memories for residents living with dementia and create a comfortable, calming and enabling environment, whilst ensuring the Montessori approach could be effectively delivered by the Cluny House staff.

Taking inspiration from the location and build typology of this single-storey dwelling, the intention was to deliver a contemporary, yet intimate and homely design sympathetic to the cohort of residents from predominately Australian and European backgrounds who would be living there. It was important that the environment felt comfortable and welcoming, not intimidating or unfamiliar, and also included a subtle nod to the Mediterranean.

This was achieved using recognisable themes in each zone, with supporting artworks and accessories to incorporate sensory and lifestyle elements. Key dementia design components including colour, contrast, perception, scale and form were considered.

Independence, engagement

Architectural features and finishes were selected to be hard-wearing whilst echoing the design aesthetic. An



The open plan living and dining areas are divided into zones to provide cues for residents

outstanding feature of Cluny House is the short corridors which lead to communal areas with additional points of interest, such as an internal garden nook and textured wall hangings. The recessed shelving along the corridors holds memorabilia such as chinaware, glassware and trinket boxes for residents to observe and engage with. These items change according to current resident preferences and aid with wayfinding and ease of moving around the home.

The project also required the redesign of bedrooms and ensuites with the addition of a resident laundry and separate activity area. Key components of the brief were access to outdoors, storage, and ample natural light and clear visual access.

The predominantly open

plan living and dining areas are divided into zones to make it easier for residents to recognise what each space is used for. Furniture and accessories are placed in such a way as to facilitate simple decision making and provide cues for task participation by residents. The carefully delineated spaces also provide a sense of intimacy and domestic scale.

The joinery incorporated storage wherever possible. The combination of easily-opened drawers, bench tops and open shelving supports ease of access, visual cueing and independence for residents.

The installation of internal windows to all the communal areas and hallways, and easy-opening doors, further embedded this concept. Additional clinical requirements such as hand-wash stations were built into the walls as part of the joinery to soften their appearance and have them recede into the background.

All the furniture was assessed and approved by a seating specialist occupational therapist from the deFiddes team to provide an appropriate range of seating options to accommodate residents of different sizes and mobility. Furniture was selected based on functionality, comfort, safety and longevity, whilst also taking into account the

required design and form to suit the mid-century modern style.

Whilst the accessories were themed to suit the residents' relationship with the era, the sensitive approach conveys meaning which endures beyond that time. Interior finishes including wall vinyls and paint colours, along with corresponding artwork and accessories, were specifically selected to assist resident wayfinding and familiarity.

For example, terracotta and blue, in keeping with a Mediterranean palette, have been used as a feature wall colour and in the furniture fabrics. Birds and florals were among the themes used to identify different areas of the home, with artwork and accessories reflecting those themes. The psychology of colour and the effect it has on moods and behaviours were considered, such as the introduction of the cool (blue) and warm (terracotta) in areas to either calm or stimulate.

In line with the Montessori approach, the kitchen needed to be domestic and accessible so residents could participate in meal preparation and serving should they wish to do so. Key to this was the open design of the kitchen and the use of removable heated units which only sit on the benchtop during meals. This ensures the kitchen is familiar and inviting to residents without large built-in commercial-size bain-



The joinery incorporated storage wherever possible. The combination of easily-opened drawers, bench tops and open shelving supports ease of access, visual cueing and independence for residents

maries and servery units. A resident laundry was designed and installed to facilitate the Montessori approach, where residents are provided with opportunities to contribute to the running of the house.

Also integral to the VMCH mission is supporting residents' spiritual needs and the existing chapel at Cluny House was refurbished to provide a contemplative sanctuary.

Noticeable changes

Helen Haynes, VMCH Montessori Change Lead, has reported that the new environment at Cluny House, coupled with the Montessori approach, has produced noticeable changes in residents in a short amount of time.

"The residents are able to wake up and choose to eat breakfast, which they serve themselves, at a time which suits them," Helen said. "They can even come to the dining room in their dressing gown if they feel like it. The self-service dining has proved very successful; residents select their meal and put it on their own plate. Having the choice also means they tend to eat more, so there's also less need for supplement drinks."

Helen also reported a reduction in responsive behaviours, with residents taking more interest in activities and tasks. This has enthused staff who look forward to seeing even more improvements and supporting residents to reconnect with aspects of their life as they



The kitchen at Cluny House is designed to enable residents to participate in meal preparation and serving should they wish to do so

knew it before the onset of dementia.

Exciting challenge

Kathryn Lamond, deFiddes' senior interior designer, walked through the site before building works began to get a feel for the space and a clear vision to support the brief provided. Kathryn said it was an enjoyable and exciting challenge to come up with specific selections for Cluny House and she found the process to be very rewarding.

"When I visited Cluny House again just before the residents were due to move in, I was overwhelmed by the serene and calming sense of the space and how it all came together," Kathryn said. "I remember feeling extremely excited and satisfied and

couldn't wait to tell the rest of the team. It was a very special project and it was done with the greatest intent to create a space for residents that really did help them feel at peace and at home, and I felt immediately we all had achieved this vision."

Achieving positive resident outcomes was the ultimate goal for both organisations, beautifully captured by a Cluny House resident who said "This feels like home".

Lessons learnt

As with any project, there are lessons to be learnt and often these are only identified once the space is being occupied and used:

- Storage was considered and implemented, however more space is required for the Lifestyle team to store their resources.
- In hindsight, installing automatic doors would have facilitated residents' easy and unsupervised access to the courtyard, further enabling their independence and ensuring they could move freely around Cluny House as if they were in their own home.
- Similarly, the location of the laundry is not ideal. It would have been better positioned closer to the garden so it would be easier for the

residents to hang out their washing.

- Additional open shelving in the nooks at the end of corridors would provide more opportunities for resident engagement, either independently or with others.
- The addition of smaller 'withdraw' or solitary sitting areas (other than the chapel) off the main living areas would have been beneficial to provide the option of smaller intimate nooks – but that was not within the scope of this project.

VMCH has since completed another two Memory Support Units which have incorporated these valuable lessons.

The key learning identified by deFiddes was to recommend all future refurbishment projects include pre and post measures in the scope of works so that the value of projects can be quantified and qualified – particularly from the residents' perspective. Some of the measures recommended for assessment and evaluation before and after a refurbishment include:

- Lighting: what were the lux levels (unit of illumination of one square metre area) originally and what are they once the upgrades have been



The existing chapel at Cluny House was refurbished to provide a sanctuary and space for contemplation

implemented? Do residents and staff observe or report any improved functional outcomes as a result? It has been reported that the lux levels are often too low for optimum visibility through older eyes, in addition to limited ability to adjust lighting to suit different task requirements, so studies examining this would be beneficial.

- **Furniture:** how do the specifications of new furniture compare to the original furniture and accommodate people of different sizes and shapes? For example, are residents observed to sit comfortably for longer periods with ease of movement?
- **Wayfinding:** is there a change in the residents' ability to find their way around the care home? Are the staff more or less involved in assisting residents to rooms such as bedrooms?
- **Resident engagement:** is there a change in the frequency and type of independent engagement by the residents with the new environmental interventions? Are there particular elements which seem to provide the most stimulation?

Assessment tools

There are a number of assessment tools that evaluate the environment, as well as those that evaluate quality of life and resident outcomes. The list of available assessment tools is extensive,

but could include the following: Dementia Services Development Centre's Dementia Design Audit Tool (DDAT); Dementia Training Australia's Environmental Assessment Tool (EAT); HammondCare's DesignSmart; the Residential Aged Care Built Environment



A range of seating options were chosen to accommodate residents of different sizes and mobility

The Montessori approach: resource tips

The Montessori approach to dementia care (referred to in this article) is based on the educational methods pioneered by the Italian physician Dr Maria Montessori over 100 years ago.

The person-centred approach is strengths-based and promotes independence in activities of daily living and sensory stimulation.

To find out more, check the resources below.

Purposeful Activities for People with Dementia:

This Dementia Australia resource includes six films showcasing the Montessori approach to care and how it can enrich the lives of people living with dementia. It comes with an accompanying workbook with key points for reflection, and is available at: <https://bit.ly/purposeful-activities>

Montessori... but isn't that for children?

This 45-minute video from Dementia Training Australia provides an overview of the key Montessori principles and presents a selection of case studies to show how a prepared environment, activities, roles and routines can enrich the lives of care home residents. Resource available here: <https://bit.ly/but-isnt-that-for-children>

Origins of Montessori Programming for Dementia:

In this journal article, Dr Cameron Camp explains how the Montessori approach

can be translated into development of activities for people with dementia, and shares learning from a range of research studies related to the implementation and evaluation of Montessori methods in dementia care. Read the article here: www.ncbi.nlm.nih.gov/pmc/articles/PMC3600589/

Montessori for dementia: Dementia Australia's Centre for Dementia Learning runs a three-hour training course delivered onsite for staff teams in any care setting entitled 'Montessori for dementia', which introduces the main components of the Montessori approach and presents strategies to implement Montessori-based programs for people living with dementia. Find out more at: <https://dementialearning.org.au/course/montessori-for-dementia/>

Montessori Ageing Support Services (MASS):

Montessori Ageing Support Services (a division of the Montessori Australia Foundation) is the national peak body for supporting quality of life for older Australians through the Montessori approach. It oversees training, consulting, promotion and endorsement of enriched Montessori environments for older people receiving care services. More information: www.mass.au/about-mass

Audit Tool (RACBEAT); Adult Social Care Outcomes Toolkit (ASCOT); and ICEpop CAPability measure for Older people (ICECAP-O).

These assessments could be completed before and after refurbishment works to compare and contrast project interventions and the benefits they bring to residents. Ideally these evaluations would then be shared – and not just within the project team, but widely amongst the residential aged care sector. Continuous learning and improvement is essential to build on the existing knowledge base in order to improve living environment outcomes for people living with dementia.

Conclusion

This project collaboration between VMCH and deFiddes to deliver a customised design consistent with residents'

preferences, memory support, latest products and evidence-based research has provided Cluny House residents with a premium home now and into the future. ■



■ Dr Samantha Neylon (left) is Clinical Director at De Fiddes. She has worked in service development, management and occupational therapy in the aged care and disability sectors for over 20 years. Contact her at Samantha@dfdesign.com.au; Ruth Payne is an architect and Senior Development Manager at Villa Maria Catholic Homes (VMCH), specialising in the field of design for older people, particularly people living with dementia. Contact her at Ruth.Payne@vmch.com.au

Reimagining Dementia: A Creative Coalition for Justice

Reimagining Dementia is an international group of dementia activists and allies who share a vision that challenges biomedical and institutional approaches to care. Launched in the midst of the global pandemic, the Coalition has issued a call to action to people with dementia, their families, communities and care organisations to create environments in which everyone is supported to thrive and grow. Coalition Coordinator **Mary Fridley** explains

After COVID-19 made its first appearance in early 2020 it soon became clear that this global pandemic was having a disproportionate and devastating impact on the lives of older adults and people living with dementia in nursing and other care homes. Like so many around the world, my East Side Institute colleague Dr Susan Massad and I wanted to find a way to make a difference, so we reached out to others who shared our commitment to transforming the dementia conversation from one that produces stigma and shame to one of possibility and growth.

Joining the conversation

We invited them to join us in a virtual (and longer-term) conversation about how we can use this extended moment of living in such uncertain times to harness our collective creativity and radical humanism to proactively and positively impact on the lives of everyone who lives and works in the dementia space. Susan and I had no idea if something would emerge, but if it did, we felt confident about two things: it would come from the grassroots – and lead with creativity. We were thrilled that 19 people from the US, UK, New Zealand and Canada agreed to come together in April to begin a process that would eventually give birth to Reimagining Dementia: A Creative Coalition for Justice.

Susan and I are members of



Reimagining Dementia

A Creative Coalition for Justice

the East Side Institute (www.eastsideinstitute.org) in New York City, where I am Director of Special Projects and Susan, a retired physician, is a faculty member. The institute is an independent international educational and research centre for developing and promoting alternative humanistic approaches in psychology, education and community building. As part of our work we also lead a workshop series for people with dementia and carers, called *The Joy of Dementia (You Gotta Be Kidding!)*, based on improvisational play.

Joining Susan and I in developing the Creative Coalition for Justice were Helen Abel and Jill Battalen (Life Performance Coaching, US); Frances Bottenberg (University of North Carolina at Greensboro, US); Pam Brandon, (AGE-u-cate® Training Institute, US); Kyrié Carpenter (ChangingAging, US); Jennifer Carson (Dementia Engagement, Education and Research Program, School of Community Health Sciences, University of Nevada, Reno, US); Joan Devine (Pioneer Network, US); Sherry L Dupuis (Partnerships in

Dementia Care Alliance, University of Waterloo, Canada); Kate Fassbender (Dementia Letters Project, US); Emma Finn (Sunnyside Community Services, US); Dawn Hagen, (Parker Jewish Institute for Health Care and Rehabilitation, US); Pia Kontos (KITE-Toronto Rehabilitation Institute and the University of Toronto, Canada); Jennifer Kulik (Silver Kite Community Arts, US); David McDonough (Flourishing Lives, UK); Nicola Pauling (Voice Arts, New Zealand); Mary L Radnofsky (Human Rights Advocate for People with Dementia, US); Kari Rogenski (The Hummingbird Project by Sage Eldercare Solutions, US); Carol Varney (Timeslips Creative Storytelling, US) and Peter Whitehouse (Case Western Reserve University and University of Toronto, US and Canada).

Anger and outrage

As it became clear that 70-80% of COVID-related deaths in the US, Australia, Canada, the UK and several European countries in March and April 2020 were associated with often under-resourced aged care homes, with the majority being people living with

dementia, we were angry. And while the percentage of aged care home deaths has since dropped, they continue to represent between 42% and 75% of all COVID deaths around the world (see Thompson *et al* 2020; Cousins 2020).

Our early anger quickly turned to outrage with the media coverage of the pandemic that virtually ignored the role of stigma, racism, poverty and other social factors in shaping care practices and public health response strategies to COVID-19, and which are having a profound impact on people living with dementia, their care partners and loved ones.

The role of stigma

The role of stigma was addressed in an article published on 5 August 2020 in *The Conversation*, by the University of Toronto's Alisa Grigorovich and Pia Kontos. Both critical social scientists with expertise in dementia, ethics, and long-term care, they wrote, "Collectively our work is motivated by a shared concern about how stigma associated with dementia consistently enables and legitimises restrictions on the freedom of individuals living with dementia, and denies them the opportunities to pursue life-enhancing relationships and activities... We have traced this stigma to two cultural narratives about dementia: with memory loss there is a

total erasure of the self; and the medicalisation of memory loss, which reduces nursing home care to supporting basic physical safety and comfort. Together these narratives perpetuate a collective representation of persons living with dementia as 'non-persons'. This highlights the inherent ableism and ageism that dehumanises and demarcates the lives of people living with dementia as disposable."

While the stigma of dementia touches everyone, when taken together with systemic racism, economic inequality, lack of access to care and anti-poor attitudes and policies, the consequences of COVID have been especially serious for communities of colour, native/Indigenous people and other impoverished and marginalised populations (see Lagasse 2020).

Our call to action

After four months of formal and informal Zoom conversations, the founding members of our Creative Coalition for Justice developed a specific call for the radical transformation of the very attitudes and conditions that are contributing to the isolation, abuse, and neglect within and outside of long-term and community-based care settings by means of, for example, the medicalisation and pathologising of human experience, and the use of chemical, physical, and environmental restraints.

On 8 September 2020, Reimagining Dementia: A Creative Coalition for Justice was formally launched, with founding members and other friends, colleagues and supporters disseminating the 'call to action' to their networks.

To date, a diverse group of 400 people from Australia and 19 other countries have joined – including people living with dementia; family care partners; artists, advocates and activists; academics and researchers;

ageing and dementia policy advocates; health care, mental health, social service and dementia professionals; residential care personnel; and community members. The organisational affiliations of our Australian members include Artful Connections, Barossa Village, Caladenia Dementia Care, Daniella Greenwood & Associates, Leef Independent Living Solutions, Meaningful Ageing Australia, TRICE, Unique Collaborations, University of Technology Sydney and University of NSW.

Forging alliances

We believe that a coalition is what is needed to forge alliances across the globe and work collaboratively to challenge the stigma associated with dementia, and to mobilise the practices and political processes required to finally achieve a humanising vision of care and support that promotes inclusion, relationality, creativity, and the possibility of growth for everyone living with, and impacted by, dementia.

Unique to this Coalition is our belief in the power of creativity – the arts, theatre, music, movement, improvisation, performance and much more – to bring us together and innovate new ways to address the social injustices that people living with, and impacted by, dementia face.

There are, of course, many local, national, and international examples of individuals and organisations making important strides to achieve culture change – our membership powerfully represents much of this work. Thus, our focus with the Reimagining Dementia Coalition is to leverage these and other collective initiatives, resources, expertise, and passion to organise and mobilise strategies, processes and practices. Given just how hard culture change work is, such a collective effort seems to be the most productive way forward.

Sharing ideas, aspirations

In October 2020, Reimagining Dementia hosted three online member gatherings in which 90 members from nine countries began exploring how we can creatively come together to transform the culture of dementia. We also hosted three online gatherings in December 2020 that brought together 120 members, and have released a survey for members to share what 'reimagining dementia' means to them, along with their ideas, dreams and aspirations for the Coalition.

In one of the October gatherings, a small group of members created this poetic "note to the researchers, scientists, academics and policy makers":

*Thru playing together we can
flatten the hierarchy
Can we make the arts, play,
performance the centerpiece of
dementia care?*

*If people do not have new
experiences, how do we create
new ways of seeing?*

*Give people opportunities and
permission to break out of their
boxes*

*Life with dementia is fluid and it is
not all the same for every person.
We are all unique human beings.*

Tara Ernst is a high school principal from Calgary, Canada whose mother and father were both diagnosed with dementia. Like many carers, she was desperately looking for positive ways to support her parents in their often difficult journeys. For her, joining the Reimagining Dementia Coalition meant meeting a "...community of people seeking the same thing [supporting people with dementia] and strong advocates who are determined to change their loved ones' worlds and the worlds of complete strangers. Discovering it gave me hope... it is an honour to volunteer and work towards its mission."

Joining the Coalition

It is our hope that everyone committed to culture change will also join us in this

grassroots effort to recreate and redirect the global conversation on ageing and dementia. To become a member of the Reimagining Dementia Coalition, visit our Facebook page (<https://m.facebook.com/reimaginingdementia>), read our Call to Action and sign up – or contact us via email at reimaginingdementia@gmail.com. We will then be in touch about member gatherings, other activities and ways we can work together. We look forward to hearing from you! ■



■ Mary Fridley is Coordinator of Reimagining Dementia: A Creative Coalition For Justice and pro-bono Director of Special Projects at the East Side Institute in New York City. She is also a teacher, co-leads two workshop series, 'The Joy of Dementia (You Gotta Be Kidding!)' and 'Laughing Matters', and is a playwright and theatre director. Contact her at: mfridley@eastsideinstitute.org

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Dancing through lockdown

Gwen Korebrits explains how Dance Health Alliance has enabled people living with dementia to keep active and dancing throughout the COVID-19 lockdowns

People living with dementia and their carers have faced a particularly challenging time over the past 12 months due to COVID-19, and the impact of the resulting social isolation and inactivity within the community and aged care facilities will continue its ripple effect into the coming years.

Dance Health Alliance (DHA), an Australian not-for-profit organisation facilitates dance programs in residential aged care homes and the community for people living with dementia and cognitive decline, movement-restricting conditions, mental health issues and the elderly, to improve their quality of life and regain freedom through movement. No dance experience is necessary and the classes are open to people of all ages and levels of mobility.

Our belief is that 'movement is medicine' and it is important for people not to miss out on their daily 'dose'. So when COVID-19 prevented us running face-to-face classes we quickly transitioned our DanceWise program, specifically designed for people living with dementia and their carers, online, including pre-recorded classes and live classes through Zoom.

The online DanceWise classes proved so successful during 2020 that we are continuing them in 2021, with 30-minute classes running every Tuesday at 10am via Zoom from 2 February.

Mood enhancer

Dance has always been a great mood enhancer, stimulating the release of 'feel good' hormones including serotonin, oxytocin and dopamine. The physical benefits include improvement in cardiorespiratory fitness,



Dance Health Alliance CEO Gwen Korebrits pre-records a DanceWise class (above) and with one of her team (right, inset)

strength and flexibility. Dance encourages muscles to become active and pump oxygen around the circulatory system. The music unlocks memories of forgotten moments and song lyrics.

The DanceWise interactive online program eases people back into reconnecting with others, moving their bodies and activating their minds through a series of gentle but effective seated dance, stretching and breathing exercises, with the aim of improving lung capacity, stamina, balance and flexibility as well as confidence, memory and mood, set to a playlist of suitable and eclectic music.

DHA also provides a certified teacher training program for dancers as well as carers, therapists and medical and allied health care professionals so they can

incorporate the DanceWise program into their own practice or facilities.

The most positive feedback we have received for the classes is from those aged care facilities or organisations who had trained their staff in the DanceWise program prior to COVID. This allowed them to function independently during the lockdown periods, so the residents and staff have not stopped dancing. It has been a tremendously morale-boosting activity that has inspired staff and residents during these challenging times.

Karn Nelson, Executive General Manager Strategy and Innovation at The Whiddon Group, says the DanceWise program has been a huge hit with residents and staff, "with some residents and their allied health specialists reporting significant improvements in balance and coordination. It is



also a great social opportunity...".

For further information, email info@dancehealthalliance.org.au or sign up for classes and training via the DHA website at www.dancehealthalliance.org.au ■



■ Gwen Korebrits is CEO and Co-founder of Dance Health Alliance Limited. Contact her at gwen@dancehealthalliance.org.au

Disclaimer: The mention of trade names, commercial products or organisations in the *Australian Journal of Dementia Care* does not imply endorsement by the editors or publisher of the journal.

Extending dementia care into Indigenous communities

The University of Queensland's Centre for Online Health (COH) is an internationally regarded leader in the field of telehealth. In this article, **Anthony Smith** (COH Director) and members of his research team, **Helen Haydon, Emma Thomas, Centaine Snoswell** and **Liam Caffery** explain how telehealth is being used to connect dementia specialists to selected Aboriginal and Islander Community-Controlled Health Services in Queensland. These projects build on the skills of a strong local workforce, and help raise awareness of dementia within Aboriginal and Torres Strait Islander communities

The delivery of health services to people living in rural and remote areas is considerably more challenging than for those living in city locations. However, regardless of location, telehealth can increase access to care (Smith *et al* 2020).

Telehealth has been shown to be useful for people of all ages, for a broad range of conditions, and in a range of different settings. The benefits are not limited to rural or metropolitan populations. Telehealth services can be delivered in real-time (eg video consultations), asynchronously (eg email and patient portals), or through remote monitoring (eg use of a non-invasive technology to collect and transmit vital signs from a patient to a clinician).

Aboriginal and Torres Strait Islander people (for brevity, herein respectfully the term Indigenous Australians will be used) have a much higher level of risk and need for dementia services than the general population. The prevalence of dementia in Indigenous Australians is three to five times higher than their non-Indigenous counterparts (Flicker & Holdsworth 2014). The quality of care available to people with dementia in remote Australian Indigenous communities is considered poor (Smith *et al* 2010). Since nearly half of Indigenous Queenslanders live in outer regional or remote areas, we sought to explore opportunities where telehealth could be used to improve access to specialist care.

Dementia management

Whilst there is no specific cure for dementia, there are a range of therapeutic interventions which can help manage symptoms and slow the progression of the disease. This is why early detection is particularly important for dementia management. Lack of detection (or late-stage diagnosis) is a significant barrier to improving the lives



Badu Island, in the Torres Strait, Queensland, was one of the communities involved in the DREAMT telehealth trial. Photos: Centre for Online Health, The University of Queensland

of people with dementia, their families and carers (Strivens and Craig 2014). Dementia Australia estimates that for Indigenous Australians, the time between the onset of symptoms and dementia diagnosis often exceeds three years, which could potentially be reduced by increasing access to specialists by telehealth (Flicker & Holdsworth 2014).

The risk of developing dementia can also be reduced with appropriate community education and preventative healthcare (Livingstone *et al* 2020). Attention to cardiovascular risk factors, physical and cognitive leisure activities, and diet can improve cognitive function and /or reduce dementia risk. Indigenous Health Workers (IHWs) are considered an effective strategy to deliver risk-reduction programs and education

within local health services (Smith *et al* 2010).

Combining the management of dementia with health promotion programs has the potential to reduce the population prevalence of dementia and its associated social and clinical burden, and increase quality of life for Indigenous Australians.

Telehealth for dementia care

As many specialist services are concentrated in metropolitan areas, patients from rural and remote areas often need to travel to access care. Telehealth enables healthcare to be delivered to remote communities, which provides patients with a choice about how they access care. Additionally, a patient's out-of-pocket expenses associated with travel (eg transport,



Health workers and members of the DREAMT project. The project explored ways in which telehealth could be of value in improving access to specialist dementia services in Indigenous communities

accommodation, lost income) can be substantially reduced when they access care via telehealth (Bradford *et al* 2016; and Snoswell *et al* 2019). Telehealth models of care for dementia management can improve the timeliness and accuracy of detection which, in turn, can facilitate early intervention and management, leading to improved patient outcomes.

Indigenous communities

Recent reviews have demonstrated a broad range of benefits associated with the use of telehealth for people living in Indigenous communities. Telehealth services delivered to people in Aboriginal and Islander Community-Controlled Health Services (AICCHS), from a specialist located in tertiary hospitals, are thought to be the optimum telehealth-facilitated model of care for Indigenous people (Caffery *et al* 2018). Advantages of this telehealth model include: providing care in a familiar and culturally appropriate environment; reducing or eliminating the need for travel; reducing out-of-pocket expenses for the patient; engaging a salaried local workforce; and providing opportunities for Medicare funding, which improves the sustainability of the service.

Dementia care

The evidence regarding telehealth use for dementia care in remote Indigenous populations is quite limited. However, there is collateral evidence that supports the use of telehealth for dementia care. For instance, Indigenous-specific dementia screening tools (such as the Kimberley Indigenous Cognitive Assessment tool (KICA-Screen); LoGiudice *et al* 2006) have been validated for use by videoconference (Russell *et al* 2019). There is also evidence that

telehealth in non-dementia contexts was an effective way of delivering health services to remote Indigenous communities, with Indigenous Australians reporting positive experiences using telehealth. In a 2016 systematic review, we identified specific outcomes associated with the use of telehealth for the provision of healthcare to Indigenous Australians. These included: improved social and emotional wellbeing, clinical outcomes and access to health services (Caffery *et al* 2016).

The DREAMT Project

DREAMT was derived from the words: Dementia, Regional and remote, Empowering Aboriginal and Torres Strait, Medicine and Telehealth. The project was funded through the Department of Aged Care Services (DACs) Fund, under the broad strategy of improving access to specialist dementia services in Indigenous communities. Engaging with

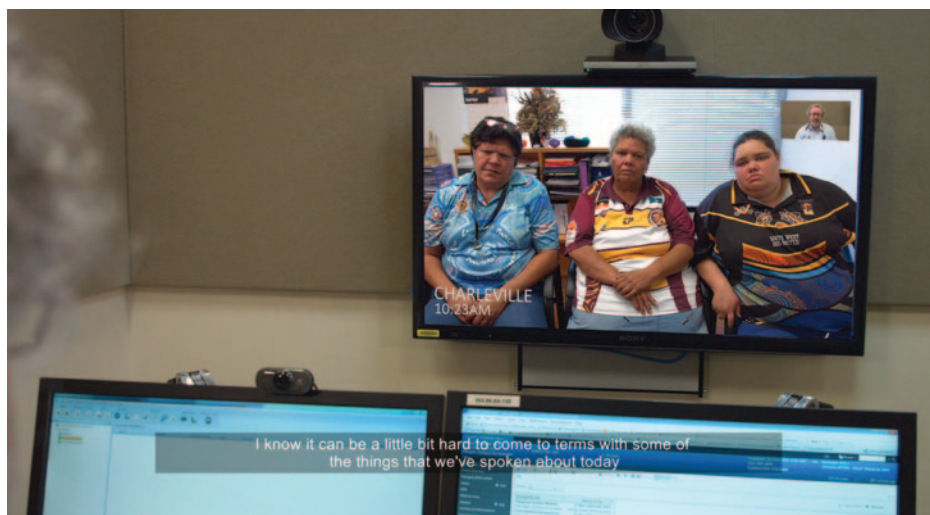
communities in the south-west region of Queensland (Cherbourg, Cunnamulla and Charleville) and up through the Torres Strait (Badu and Mabuiag Islands), we explored ways in which telehealth may be of value.

The DREAMT project (www.coh.centre.uq.edu.au/project/dreamt) ran from July 2017 to June 2020. Its main objectives were to:

- engage with Aboriginal and Torres Strait Islander communities, and better understand current impressions and awareness of dementia
- provide dementia education and training
- promote the use of a culturally sensitive routine dementia screening assessment (the Kimberley Indigenous Cognitive Assessment (KICA) tool) and,
- develop referral processes for telehealth consultations with a geriatric specialist.

Our funding allowed for the employment of a part-time IHW in each of the community health services in south-west Queensland (Cherbourg, Cunnamulla and Charleville). We were unable to employ any IHWs in the Torres Strait due to Queensland Health governance and approval processes. Instead, we developed educational videos which could be used to raise awareness of dementia and telehealth (covered in more detail below).

Supported by the 12-person DREAMT project team (comprising people from COH, the Princess Alexandra Hospital in Brisbane and Cairns Base Hospital), the health worker was the primary contact in each community, responsible for activities related to raising dementia awareness (education and training), promoting routine dementia assessment,



A DREAMT telehealth consultation conducted in Charleville, Queensland

and telehealth uptake (service development). The IHW selected by each community had varying levels of experience and qualifications. Most had a Certificate IV-level qualification. Some were working towards the qualification or very close to completion.

The teleconsultation process facilitates interaction between the IHW and geriatric specialist. This leads to increased knowledge in dementia management, and increased empowerment for the IHW, the community-controlled health service and/or aged care facility.

Health interventions for Indigenous Australians need to be tailored to the needs of the community. There's no such thing as one model suits all. This was apparent during our visits to each community, where valuable yarning sessions were held with local community members, elders, health workers, families and service managers.

Community yarning

The DREAMT project team learnt a lot thanks to the generosity of all communities involved in the project. The engagement process involved extensive travel around Queensland to some very remote locations; and priceless opportunities to hear from local community members and better understand everyone's impression of dementia, and how this affects life in each community. It's estimated that we had direct contact with at least 150 community members, including health service staff, health workers, local residents, government and council representatives and local elders.

Yarning opportunities happened in pre-planned meetings, but most often through ad-hoc conversations in supermarkets, on fishing jetties, in health centres and along local streets. This was the perfect opportunity to get to know one another, share stories and really begin to understand the needs of each community.

Everyone had a story about dementia – whether that involved a parent or grandparent, a neighbour, a work colleague, or just someone living in the community. Whilst most people had a general understanding of dementia, there were many different interpretations of exactly what it was, its causes and treatment options. In some cases there was acknowledgment about low awareness of strategies to treat dementia and factors which can reduce or slow the onset of dementia. Occasionally, stories would reflect an element of fear or stigmatisation, where one felt more



Thursday Island, in the Torres Strait, one of the communities involved in the DREAMT project

comfortable just pretending that everything was okay and that certain behaviours were just part of ageing.

Community members also shared their experience navigating a complex health system, where often they would not know how to get support and assistance when caring for someone living with dementia. Another interesting challenge was associated with the high degree of respect shown for Elders, and a reluctance by younger health workers to ask certain questions (during the dementia assessment), in fear of appearing disrespectful.

Community discussions revealed the needs of the communities to increase access to services. Specifically, the following themes were found:

- the need for increased access to specialist services
- positive experiences with telehealth
- the need for dementia education
- strategies to assist with different viewpoints about dementia (what it is, the causes, and how to deal with it), and
- the impact on families who are living with someone with dementia.

In response, some of the educational requirements were captured in two short DREAMT films which displayed the magical beauty of each region, and the process of engaging with health services and specialists by telehealth.

Dementia on the big screen

The DREAMT films showcased an Aboriginal community in south-west

Queensland and a Torres Strait Island community which allowed the uniqueness of each community to shine through. Aiming to increase dementia awareness at a community level, the films target IHWs, people with younger-onset dementia and their families, and are freely available. They have been actively shared in public places (such as airports, hospitals and community health centres) and universities around Australia. These films were shortlisted for the 2019 Australian Teachers of Media (ATOM) Awards, which recognise film and media excellence in education and industry. Links to the videos are available here: www.coh.centre.uq.edu.au/project/dreamt.

Project findings

The delivery of the DREAMT project within a two-year period was a challenging task, mainly due to the time needed for proper community engagement. For our project, two years included site visits and engagement; service planning; service implementation and some evaluation to better understand community perspectives, the uptake of routine dementia screening and the use of telehealth. What we appreciated was the significance of working with community, understanding community requirements, and the importance of tailoring services based on community needs.

Our team of Indigenous Health Workers were extremely passionate about their role in the DREAMT project but, on a day-to-day basis, were also

managing multiple roles and responsibilities in the community health service. Health workers wore many hats – and when one of these hats involved leading dementia training or organising an assessment, there was always the risk that other competing activities would get in the way. Prioritising dementia care in a community with so many other health and social challenges is difficult.

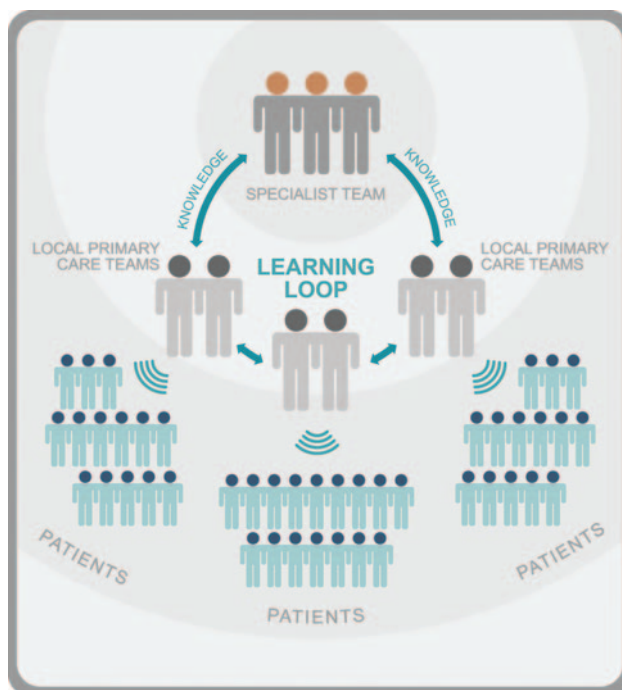
The introduction of routine screening processes for dementia as part of the project meant some changes to the usual assessment tools used by the health workers, and increased burden of time due to additional questions and concerns which needed to be addressed. These responsibilities were supported by specific training services provided by Dementia Australia and the COH during the course of the DREAMT project.

This training included tailored workshops on dementia assessment and management, and how to support people living with dementia. These workshops also gave participants the opportunity to use a dementia virtual reality tool called EDIE (Educational Dementia Immersive Experience) – which allows participants to see and experience the world through the eyes of a person living with dementia (Dementia Australia 2020).

Workforce training and support is important to ensure local health workers and other clinicians are familiar with evidence-based approaches to dementia care; and are confident delivering these as part of routine practice. To help with the coordination of the DREAMT program, we also developed practical guidelines to simplify the steps involved in screening documentation, prioritisation of patients, patient education, telehealth referral processes and billing procedures.

The uptake of telehealth was slow during the project. Of the first 20 KICA assessments done during the project, only six patients (30%) required a telehealth appointment with the geriatrician. We attributed the low numbers of patients screened during the project to delays in establishing routine dementia screening services, the availability of health workers to complete the assessments, as well as the competing health priorities mentioned above.

While funding allowed for the employment of an IHW in each community for the duration of the project, we have managed to maintain ongoing access to telehealth services for those



Stage 2 of the project is Dementia ECHO, based on the Project ECHO model which uses hub and spoke knowledge-sharing networks to create a learning loop (above)

communities. We have a geriatrician who runs a telehealth clinic every week. Sites involved in the DREAMT project can continue to refer patients to the geriatrician for assessment and management advice. The same geriatrician will be involved in our next project, Dementia ECHO (described below), as the medical specialist on the panel.

Future directions

The focus of the DREAMT project was mainly on Indigenous Health Workers who were employed to act as the local dementia contact – responsible for screening, community and patient education and referral to specialists. In hindsight, we believe that a more productive approach would be to engage the wider primary care team – including GPs, nurses, allied health staff and IHWs. Developing new systems or services which promote closer engagement between these primary care service providers and dementia specialists may be what is needed to encourage the translation of expert knowledge into local services.

In some communities, the connection between primary- and tertiary-level care is fragmented. The next stage of our project is called Dementia ECHO and involves the development of a Queensland-wide education and telementoring program. The project, which started in July 2020 and runs to June 2022, will use the Project ECHO

(Extension for Community Healthcare Outcomes) guided practice model (www.hsc.unm.edu/echo/) to deliver an innovative 'hub-and-spoke' telementoring service where expert teams lead virtual clinics.

Dementia ECHO

Based on what we have learnt from the DREAMT project, the COH will establish, manage and evaluate a telementoring program for dementia services. Supported by funding from the Australian Government (Indigenous Australians Health Program), Dementia ECHO will be available to selected AICCHS in Queensland. The main aims are to: build up local skills, enable easier access to specialist services normally only available in city locations, and encourage regular communication between specialists and primary care

teams responsible for the delivery of health services to Indigenous Australians.

The service will link a Dementia ECHO panel (medical, nursing and allied health) with AICCHS staff. The monthly videoconference sessions, scheduled to begin in February 2021, will include a short 10-minute didactic lecture on a dementia topic and discussion of a case put forward by an AICCHS clinician. Case conferences will involve the presentation of de-identified cases and discussion with the expert members.

The process is designed to encourage closer collaboration between primary care and specialist services; increase clinical peer support between communities and increase the capabilities of local health services. Dementia ECHO topics will relate to dementia knowledge, dementia assessment, telehealth case preparation, telehealth coordination, and community education.

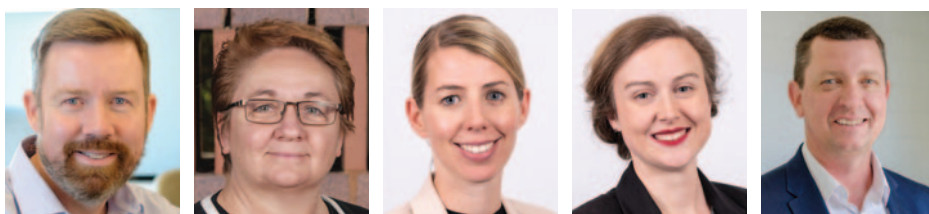
To assist with the promotion of the project and its delivery throughout Queensland, the COH is partnering with the Queensland Aboriginal and Islander Health Council (QAIHC). ■

For further information about the Dementia ECHO program, contact The University of Queensland's Centre for Online Health (COH) (Dr Helen Haydon) by email: h.haydon@uq.edu.au

For more information about the DREAMT project and the work of the COH, visit www.coh.centre.uq.edu.au

Acknowledgments

The Centre for Online Health acknowledges the Traditional Custodians of the land, and pays respect to Elders past, present and future and acknowledges Aboriginal and Torres Strait



From left: Anthony Smith, Helen Haydon, Emma Thomas, Centaine Snoswell and Liam Caffery

■ Professor Anthony Smith is Director of the Centre for Online Health, Centre for Health Services Research, The University of Queensland (UQ) Australia, and Adjunct Professor of Digital Health and Telehealth, Centre for Innovative Medical Technology, University of Southern Denmark; Dr Helen Haydon, Dr Emma Thomas, and Dr Centaine Snoswell are Research Fellows at the Centre for Online Health; Associate Professor Liam Caffery is a Principal Research Fellow at the Centre for Online Health. To follow up on this article contact Professor Anthony Smith at asmith@uq.edu.au

Islander people's relationship with Country, and their cultural and spiritual beliefs.

We thank the DREAMT project team which was comprised of researchers, research assistants, project managers, cultural advisors, geriatric specialists and technology support staff. In particular, we thank Christine Howard who was the project manager for the DREAMT project. Core funding was provided by the Australian Government: Dementia and Aged Care Services (DACs) Fund. The Dementia ECHO project is funded by the Australian Government: Indigenous Australians Health Program. We also thank all of the health service staff and communities in Cherbourg, Cunnamulla, Charleville and throughout the Torres Strait Islands for their contribution and support of the DREAMT project; to Metro South Health (Department of Geriatric Medicine and PAH Telehealth Centre) for the provision of specialist geriatric telehealth services; to Dementia Training Australia (via Dementia Australia) for providing valuable resources and expertise; and to QAIHC for its ongoing support.

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Dementia and changed behaviours

NPS MedicineWise has launched a new national education program focusing on the care of people living with dementia, which aims to reduce unnecessary use of antipsychotics and benzodiazepines and to improve the use of non-pharmacological techniques to support people with dementia who are experiencing changed or responsive behaviours. The program – **Dementia and Changed Behaviours: A Person-Centred Approach** – is aimed at GPs, pharmacists and nurses who care for people living with dementia in the community and in residential aged care facilities, as well as people living with dementia and family carers.

NPS MedicineWise says the program's key elements include educational visits to individual GPs and small groups in general practices who work in the aged care sector; a multimodal educational program for aged care facilities aimed at supporting champion nurses and pharmacists working in the sector; webinars for GPs, pharmacists and nurses; and online resources for consumers and GPs. Two webinars are already available to view on demand: 'Working together to enhance transitions of care for people with dementia', and 'Dementia: a multi-disciplinary approach to caring for people with changed behaviours'.

According to NPS MedicineWise medical adviser and GP Dr Anna Samecki, the program's main focus is on the importance of person-centred care.

"Antipsychotics and benzodiazepines have a limited role and they should not be used first line. If they are needed, the program highlights the importance of collaboration between the person or carer and the healthcare team in management decisions, which includes obtaining informed consent. These medicines should be used at the lowest possible dose, with a plan in place to review, wean and stop," says Dr Samecki.

The program has been developed in consultation with key stakeholders in aged care including Dementia Training Australia (DTA); Ellie Newman, Dr Andrew Stafford, Dr Margaret Winbolt and Dr Allan Shell from DTA have been part of multidisciplinary panels within the program's webinars. The program has also collated a collection of guidelines and resources relating to the topic which is available on NPS MedicineWise's website.

For more information on the program, go to <https://bit.ly/33fH5IT>

A rights-based approach to dementia-inclusive public spaces

People living with dementia and their carers in rural and regional areas face particular challenges around loneliness and isolation, heightened by a lack of access to dementia-inclusive outdoor and public spaces. **Carmela Leone, Rachel Winterton** and **Irene Blackberry** are undertaking a study in rural and regional Victoria exploring the rights of people with dementia and carers to participation, inclusion and access to public space

Without access to public spaces, people living with dementia and their carers are denied

opportunities to create and build social relationships and participate in their communities. For those living in rural areas, the combination of a rural setting and dementia symptoms can lead to further exclusion (Forbes *et al* 2011).

People living with dementia have a right to participate in community life (Downs 2013), and dementia-friendly communities need to ensure they are inclusive of and accessible for people living with dementia – otherwise they inadvertently encourage segregation through defining people merely by a diagnostic label (Rahman & Swaffer 2018).

This article argues for a rights-based approach to dementia-inclusive spaces in response to the stigma, isolation and social exclusion experienced by both people living with dementia and carers, with a focus on those living in rural and regional communities.

Stigma and social exclusion

People living with dementia often experience social exclusion due to predominantly negative public perceptions (Biggs *et al* 2019). Stigma associated with dementia contributes to social exclusion and isolation, even though people living with dementia are able to perform usual activities in the early stages and, with some adaptation of activities, in the middle and later stages (Alzheimer's Disease International 2012). Despite heightened public awareness campaigns, many people are still unaware of the progression of dementia and hold inaccurate assumptions about its effects, as well as negative stereotypes about behaviours associated with dementia (Alzheimer's Disease International 2012).

Attitudes and assumptions about people living with dementia contribute to the way that public spaces are designed, planned and used. Misconceptions that dementia is



Adapting streets to include distinctive landmarks such as street furniture or gardens to act as visual cues can contribute to creating 'dementia-friendly' public spaces

a normal part of ageing, and that nothing can be done to improve the wellbeing of people living with dementia, have resulted in less prioritisation and action among policy makers (Banerjee 2010). Outdoor environments and public spaces such as parks and shopping centres, are rarely thought of as spaces where people living with dementia might spend time and thus, accessibility and amenities for people living with dementia are often neglected (Blackman *et al* 2003).

A lack of understanding around the effects of impairment and the practical difficulties experienced by people living with dementia has resulted in the failure to adapt or design outdoor environments like streets and gardens to enable people living with dementia and carers to remain active and engaged (Milligan & Thomas 2016).

Ensuring footpaths are wide, flat and not slippery, and adapting streets to include distinctive landmarks such as street furniture or trees at junctions (Mitchell & Burton 2010) and gardens to include distinctive entrances, with ornaments and bright or scented plants as visual cues (Mitchell *et al* 2003) can contribute to creating 'dementia-friendly' public spaces.

Public spaces that are unsafe or inaccessible for people living with dementia are not only due to a neglect of accessibility needs, but also because of ableist values, that is, discriminatory attitudes and assumptions that exclude people with disability, which are reflected in the spaces created by designers and planners (Blackman *et al* 2003).

Perceptions and responses to dementia in the public domain generate their own forms of exclusion and disadvantage, both for people living with dementia and their carers (Biggs *et al* 2019). Stigma associated with dementia can negatively affect people living with dementia and their carers (Phillipson *et al* 2018), and for both parties, their roles within their communities and social networks are threatened early in the dementia journey (Henwood & Downs 2014). Furthermore, people living with dementia and their carers experience social exclusion through the loss of friends and shrinking social circles (Biggs *et al* 2019).

Just as people living with dementia are at risk of exclusion and isolation in their communities (Miles & Pritchard-Wilkes 2018), so too are their carers (Greenwood *et al* 2018). In rural areas, carers of people

living with dementia can face particular challenges around loneliness and isolation (Keating *et al* 2011), and the lack of anonymity often characteristic of rural communities may limit their participation in local support groups and carer activities (Forbes *et al* 2011).

For people living with dementia in rural communities, the combination of a rural setting and dementia symptoms can lead to further exclusion (Forbes *et al* 2011). Issues such as distance and relative isolation, access to services, a lack of resources, and a fear of stigmatisation associated with living in small communities, exacerbate the exclusion experienced by people living with dementia (Forbes *et al* 2011).

Dementia-friendly communities

There are dementia-friendly communities around the world, addressing the stigma and social exclusion experienced by people living with dementia and their carers (Phillipson *et al* 2018). Definitions of 'dementia-friendly' and 'community' are varied, and a dementia-friendly community can cover a diverse range of activities, projects and /or initiatives (Williamson 2016). It may be a place or culture, an organisation, a group of individuals, a virtual community, or social and physical environments (Lin 2017).

Dementia-friendly communities can be geographical communities or communities of interest with the aim of including, empowering and supporting people living with dementia and their carers in all areas of life, from services to public transport (Buckner *et al* 2018). Another recent research project undertaken by our team aimed to bridge the geographical barriers faced by those living in rural areas, by creating a virtual dementia-friendly community called Verily Connect (www.verilyconnect.org.au) (Blackberry *et al* 2019). This is an online meeting place for carers to support each other in a dementia-friendly community.

Despite their growing popularity, there is no single model for what a dementia-friendly community looks like (Biglieri 2018; Williamson 2016), no one template, and definitions of 'dementia-friendly' are varied (Williamson 2016). Diverse models of dementia-friendly communities reflect the reality that each community is in itself diverse and made up of different histories, cultures and perspectives (Williamson 2016).

While the lack of a standard approach to establishing a dementia-friendly community might invite criticism, there are advantages as one size does not always fit all. A diversity of approaches to

The rights-based approach

A rights-based approach to dementia considers:

- Human rights
- Inclusion
- Equality
- Participation
- Social justice
- Personhood
- Social model
- The collective
- Home
- Capabilities
- Assets
- (Cahill 2018)

dementia-friendly communities can inspire different ways of thinking about dementia, particularly where models emphasise participation, inclusion and access for people living with dementia (Williamson 2016).

Violation of rights

The exclusion of people living with dementia from public spaces and neighbourhoods essentially violates their rights to participation, inclusion and accessibility (Steele *et al* 2019). Moreover, while the rights of people living with dementia are often cited as the foundational basis for dementia-friendly communities, a political understanding of genuine participation is often lacking (Williamson 2016).

Few dementia-friendly communities explicitly identify human rights as a theoretical underpinning (Hebert & Scales 2017), and few focus on rights as a starting point or make explicit reference to a rights-based approach (Buckner *et al* 2019). Consequently, some researchers have suggested that dementia-friendly communities fail to achieve genuine rights-based environments for people living with dementia (Alden *et al* 2018). Notably, some communities aim to be 'dementia-inclusive' as distinct from 'dementia-friendly', aiming for greater depth of activity than initial public engagement and awareness-raising (Chadborn & van der Marck 2019).

A rights-based approach

Calls for a rights-based approach to dementia (see box this page) recognise that people living with dementia face challenges due to social and material/built environments (Alden *et al* 2019; Milligan & Thomas 2016; Thomas & Milligan 2018). Discriminatory attitudes coupled with outdoor environments/public spaces that fail to accommodate the needs of people living with dementia create barriers to social inclusion and community participation.

A rights-based approach to dementia

aims to remove socially imposed barriers and challenge human rights violations (Shakespeare *et al* 2019). Furthermore, it repositions the person living with dementia as a citizen, invoking words such as 'entitlement', 'fairness' and 'justice', which can reframe the needs of people living with dementia as legitimate and having value (Bartlett & O'Connor 2010).

Recognising people living with dementia as citizens with rights can help challenge the attitudinal barriers and ableist values that influence the design, planning and use of public space.

A rights-based study

Research currently being undertaken by our team at the John Richards Centre for Rural Ageing Research, La Trobe University in Bendigo, Victoria, uses a rights-based approach to explore attitudes and assumptions towards rights to public space for people living with dementia and carers. The PhD study, which is being funded by, and conducted as part of the Webster Rural and Regional Dementia Care Project, focuses on the rights to participation, inclusion and access, with a view to building a foundation for developing dementia-inclusive environments.

The study involves community stakeholders, people living with dementia, and carers as research participants, and is part of a larger, ongoing project which involves consultation with carers, and working with key stakeholders and community members in the City of Greater Bendigo to improve dementia care pathways within rural and regional Victoria.

The study addresses a knowledge gap relating to understanding attitudes and assumptions that contribute to the lack of access to public spaces for people living with dementia, as while access to the outdoors is essentially a matter of human rights and social justice (Argyle *et al* 2016), people living with dementia continue to be 'left behind' in terms of inclusion and access to built environments (Swaffer 2020).

The study will involve participants from both the regional centre and outer rural areas of Bendigo. In rural communities, strong social networks and informal social support can play an important role in creating dementia-friendly communities (Wiersma & Denton 2016). Social networks are also important to the uptake of care services, as they can facilitate the collection and sharing of health-related information and have the potential to change patterns of access to health care (Griffiths *et al* 2012). Public spaces facilitate social connection (Clark 2009), and as spaces for dialogue

and exchange, public spaces are therefore important for people living with dementia and their carers (Charras 2020).

The study is seeking to attract participants (see below) from diverse social networks in regional and rural areas, including Heathcote, Victoria, where a dementia-friendly village project is currently being planned (with Irene Blackberry as advisor, who is currently working with Rachel Winterton to develop a research program for the Heathcote project).

Findings from the City of Greater Bendigo PhD study will inform rights-based dementia education and awareness-raising programs. These will be aimed at Bendigo community stakeholders and community groups that play a role in the design/planning of public spaces, such as local government, or that are involved in the use of public space, by way of commercial or community activities, such as businesses that operate shopping centre cafes or organisations that conduct walking groups. The implementation of these programs can then form the foundation for a rights-based dementia-friendly community in the City of Greater Bendigo. The PhD study will be completed in 2022. ■

To hear Carmela Leone discuss the project described in this article, visit:
https://youtu.be/bt_ly8RncBI. For more information about The John Richards Centre for Rural Ageing Research projects visit www.latrobe.edu.au/jrc

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■ 'Dementia-friendly communities in practice', see Research News p42.



■ From left: Carmela Leone is a PhD candidate with the Webster Rural and Regional Dementia Care Project, at the John Richards Centre for Rural Ageing Research, La Trobe University; Dr Rachel Winterton is a Senior Research Fellow at the John Richards Centre for Rural Ageing Research, La Trobe University; and Professor Irene Blackberry is the John Richards Chair of Rural Ageing and Aged Care Research and Director of the John Richards Centre for Rural Ageing Research, La Trobe University. If anyone is interested in learning more about this study, please contact Carmela at C.Leone@latrobe.edu.au

AJDC Journal Club at work

Transitional Nurse Practitioner **Sandy Everson**, from the Mid North Coast Local Health District in NSW, explains how she uses the *AJDC* to facilitate a Journal Club with her team, and the positive actions that have resulted

We began our Dementia Care Journal Club in August 2019 as one part of a joint work program involving Dementia Training Australia (DTA) and the Coffs Clinical Network, where DTA developed a Tailored Training Program to provide education and support to nursing staff.

I am a Transitional Nurse Practitioner in Psychogeriatrics and I facilitate the Dementia Care Journal Club across three sites within the Mid North Coast Local Health District: a medical unit at Coffs Harbour Health Campus, a general ward at Macksville Hospital and Hartley House ward at Bellingen Hospital.

Each month I identify an article from the *Australian Journal of Dementia Care* that is relevant to those working in an acute care setting and circulate the article to nursing staff at the three sites. All staff on those wards are invited to be part of the Journal Club and to read the article at their leisure.

From August until early 2020, any nurses who wished to attend the Journal Club discussion could do so, either on-site or via videoconferencing. We generally had about a dozen or more staff attend in total. I prepared some questions to aid discussion and together we share ideas for how concepts from the article can be adapted into local



Sandy Everson (far left) facilitates a meeting of The Mid North Coast Local Health District's Dementia Care Journal Club with nurses from one of the medical units at Coffs Harbour Health Campus

ward settings. For example, in one session we brainstormed strategies that nurses can use in hospital to support sensory changes for a person with dementia.

Since the COVID-19 pandemic, I have still distributed an article and discussion points to the teams on a monthly basis, with suggestions for how to put the ideas in the article into practice. Two of

Complimentary offer for rural and remote workforce

Dementia Training Australia (DTA)* supports the dementia care workforce in rural and remote Australia with training and resources. Until 31 March 2021, DTA is offering eligible aged care organisations in rural and remote Australia a complimentary 12-month subscription to the *Australian Journal of Dementia Care* (*AJDC*), including access to the *AJDC* Journal Club Discussion Guides (four issues, valued at \$99, including GST and postage). The aim is to assist rural and remote organisations better access dementia-related news, views, research and professional development.

The complimentary subscription includes a free Journal Club Discussion Guide with each issue of the *AJDC*. The Guide contains questions relating to four published articles in each issue of the *AJDC*, along with links to resources and additional reading. It offers dementia care staff an opportunity to reflect on practice and consider how the ideas in *AJDC* articles might be used in practice.

Journal Club is ideal for team discussions, in-house training and individual professional development.

If you, or someone you know, works in dementia care in rural or remote Australia, your organisation may be eligible. Register via the DTA website at www.dta.com.au. (Please note: postcodes will be used to determine eligibility; one subscription per organisation; offer not available to existing *AJDC* subscribers).

The *AJDC* Journal Club is an initiative of DTA and the *AJDC* and is available only to eligible aged care organisations as part of this complimentary subscription offer, and to DTA's Tailored Training Package clients who are new subscribers to the *AJDC*. For information about DTA's Tailored Training Packages visit www.dta.com.au/tailored-training-programs/

*Dementia Training Australia manages the *Australian Journal of Dementia Care* on behalf of the publisher, the University of Wollongong.

the three teams have used these resources within their own local education sessions. We are hoping to get going with videoconferencing again soon to be able to link teams up for a broader discussion.

Articles discussed by our Journal Club include:

- 'Toilets: no laughing matter' (from *AJDC*, Feb/Mar 2019).
- 'Look elsewhere: the need for alternatives to antipsychotics' (from *AJDC*, Oct/Nov 2012).
- 'Making communities more dementia-friendly' (from *AJDC*, Aug/Sep 2019).
- 'New reports on hospital care, medication use' (news article in *AJDC*, Oct/Nov 2019).
- 'Seeing dementia through the senses' (from *AJDC*, Oct/Nov 2019).
- 'Royal Commission News: 'Neglect' Interim Report published' (news article in *AJDC*, Dec 2019/Jan 2020).

As a result of the discussions, staff have taken some positive actions such as improving the signage for toilet areas, and putting up posters on how to complete the TOP 5 tool. They are also showing an improved awareness of the side-effects of antipsychotic medications.

Overall, the Journal Club has ensured an ongoing focus on caring for people with a cognitive impairment in hospital. By promoting discussion and reflection on interesting topics that are relevant to time-poor nurses working in the acute care setting, we are taking a creative approach to education. ■

■ Sandy Everson is a Transitional Nurse Practitioner in Psychogeriatrics with Mid North Coast Local Health District in NSW. Sandy can be contacted via Sandra.Everson@health.nsw.gov.au



Each month Journal Club facilitator Sandy Everson identifies an article from the *AJDC* that's relevant to those working in acute care, for discussion at Journal Club

KT shapes new environments resources

Fallon Forbes (pictured), Service Manager with DTA's Environments Team, shares how Knowledge Translation (KT) principles helped inform the team's response to meeting the education and training needs of the dementia care workforce, especially those in regional, rural and remote Australia – in the year of a pandemic



Dementia Training Australia's (DTA) Environments Team has a long and dedicated history of delivery to regional, rural and remote Australia. *The World Alzheimer Report 2020* highlighted the extensive nature of DTA's onsite education service since its inception, with 53% of the consultations taking place in regional and remote locations across Australia in a typical year (Fleming *et al* 2020, p187). The consultancy program, funded by the Department of Health, enabled DTA's expert team to go onsite, minimising the need for those who live in regional and remote communities to travel extensively for education, as they are so often required to.

Then, 2020 happened. The Environments Team could no longer go onsite to deliver education on how to use existing environments effectively, and restrictions only emphasised how important it was to use the environment in meaningful ways.

The KT framework

DTA's education and training is developed within a Knowledge Translation (KT) framework, whereby resources and services aim to guide learners from 'thinking' to 'doing'. A key KT component is the assessment of potential barriers that might impede the implementation of new knowledge, and then tailoring educational interventions to overcome them (Powell *et al* 2015). If there was anything that 2020 was rich in, it was barriers to education and

implementation – which presented us with an opportunity to review our services and resources.

During the development and review of knowledge products, knowledge translators must consider the development of resources not only in terms of the needs of the audience, but also how to frame the key messages so the knowledge is consumable in a variety of formats to accommodate different audiences (Grimshaw *et al* 2012).

This approach led our team to develop and launch a suite of Environments Activity Cards, a new webinar series, an online course and a multimodal approach to the Environments Consultancy Service during 2020.

New approaches

With an aged care workforce under considerable pressure, the Environments Team wanted to provide short yet practical, evidence-based information on how to improve existing environments.

Activity Cards

In October 2020 we launched the first set of Activity Cards. The cards aim to deliver information that is responsive to the current needs of the industry. The first series addressed COVID-19 challenges experienced by aged care staff, with each card providing an example of a change that could improve a person living with dementia's quality

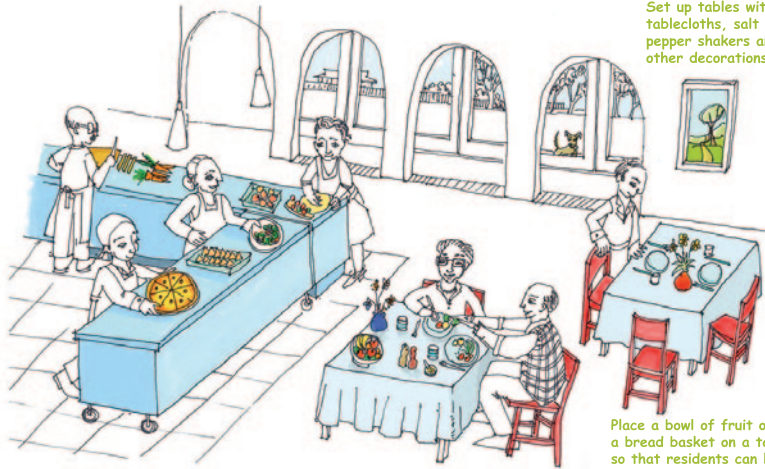
Activity Card #3

Make Lunch into a Richer Experience

Some food preparation visible prior to a meal so residents can see, hear and smell it.



Set up tables with tablecloths, salt and pepper shakers and other decorations



Place a bowl of fruit or a bread basket on a table so that residents can help themselves or be assisted

Design Principle 7 Create a Familiar Place
Aged Care Quality Standard 5 Service environment

dta.com.au

DTA Activity Card 3 from Series 1, titled *Ideas To Spark Conversation At Work For Life In COVID-19 Times*. The full series of Activity Cards is available from the DTA website

of life, for example how to create stimulating activities while providing opportunities to be alone or engage with others. The cards were emailed to all on the DTA mailing list and each card has been downloaded over 12,000 times. The second set of Activity Cards will be released early in 2021.

Webinar Series

The themes of each Activity Card are also addressed in the DTA Environments Webinar Series, guiding the target audience further down the learning pathway.

The webinar series was launched in November 2020 with 'Meaningful Engagement Outdoors', followed by 'Meaningful Engagement Using Indoor Spaces', building on the practical examples offered in the first series of Activity Cards. The first two webinars were attended by 702 participants, with roughly a third from regional and remote Australia attending the first session (data was not available for the second session at the time of going to press).

Participants were invited to engage with the content by providing examples of challenges they were currently experiencing or how they had overcome them. The aim of these webinars is to create a virtual community where those in the aged care workforce can seek advice from a team of experts in

environments and design, but also learn from the experiences of others engaged with the same learning opportunity. The webinar series will continue early in 2021.

e-Learning course

After six months of development, DTA launched its first environment-specific e-Learning course in September 2020. The Environments Team developed 'Creating supportive environment for people living with dementia', a three-hour course aimed at introducing learners to why environments matter and the role staff play in remaking environments every day (see article from the Oct/Nov/Dec 2020 issue of *AJDC*, *Creating Supportive Environments*, at www.journalofdementiacare.com).

The course received over 2000 enrolments within the first eight weeks of release, with 585 completions by November 2020. Of those who completed the course, 32% of learners were from regional, rural and remote Australia.

Each person who has completed the course was invited to attend webinar sessions in December so the Environments Team could continue to engage with learners via the virtual community.

A key objective of these discussions was to engage with those from rural and remote Australia, directing them to

further services and resources, ensuring that we continue to meet the needs of these areas.

Looking forward

We will also be launching a Regional Workshop series from February 2021, which will involve DTA Environments staff visiting regional locations across Australia to run half-day workshops on 'Creating supportive environments'. These workshops aim to support care staff, service managers and building professionals both to use existing environments to better support people living with dementia, as well as to develop better buildings.

2020 certainly presented many challenges that would be better left in the past, but it also presented opportunities to review the delivery of DTA's Environments education across Australia. Online resources will continue to be offered in 2021, but we are also looking forward to re-introducing face-to-face environments education.

Limited places are still available in our Environments Consultancy service, which now offers a multimodal approach to education. The team will continue to support staff onsite to consider the environments from the perspective of the person living with dementia, but the consultancy program now also includes online learning opportunities, incorporating the suite of new resources. ■

If you would like more information about any of the DTA Environments services and resources, to express interest in the workshop series, or to be added to the Environments mailing list and to join our virtual community, email dta-environments@uow.edu.au. The resources described in this article can all be accessed via DTA's website at www.dta.com.au

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Rethinking rural dementia care

Marita Chisholm, Kaye Knight, Catherine Ramsdale, Jo Martin and Wendy James describe how a big effort by their small Victorian health service to do things differently during two COVID-19 lockdowns helped people with dementia living in the community and residential aged care

2020 saw the unprecedented impact of the coronavirus pandemic on the healthcare industry worldwide. One of the biggest impacts for Australia was the restricted access to health care facilities as well as the limited provision of services in the community.

For many, this isolation and restricted social interaction from family was a new experience, however, for rural communities, adversity, the tyranny of distance and isolation comes with the territory. Rural communities and people are known for their resilience and innovation when faced with challenges to everyday life caused by events beyond their control. So how did a small rural Victorian health service address this challenge?

This brief article outlines some of the ways Rural Northwest Health supported consumers with dementia or cognitive impairment, along with their carers, living in the community and in residential aged care during an extended period of lockdown and restricted interactions with the outside world during COVID-19.

Our community

Rural Northwest Health (RNH) is a small rural Victorian health service with campuses in Warracknabeal, Beulah and Hopetoun. It is located about 400km north-west of Melbourne. The organisation offers a range of services to the Yarriambiack Shire and broader Wimmera Mallee Region, including: acute care, palliative care, urgent care, aged care (including a 15-bed memory support unit), respite care, community-based memory support and carer support services, volunteer programs, and an extensive range of community health and allied health services. One such service, the Wellbeing Team including a Memory Support Nurse, provides support directly to community members to access and navigate the health service.

The Mallee region is known for its harsh climate and the hardships that come with this. People who forge a living here are tough. Yarriambiack Shire has one of the highest percentages of people over 80



Co-author Catherine Ramsdale, Rural Northwest Health's Wellbeing Coordinator and community Memory Support Nurse, with one of the wellbeing packs distributed to community-based consumers during the COVID-19 lockdowns. Each pack included information and activities based on the person's specific interests

years of age in Victoria and is a high-risk community for COVID-19.

Connecting in residential care

Within our residential aged care facilities, we implemented a broad range of measures to enable connection between our residential care consumers and their significant others, and to maintain consumer engagement with the wider world without residents needing to leave their care home. These included the introduction of CareApp, a communication platform for aged care providers to share photos, messages between consumers and families as well as providing a Live Chat function; letters from surrounding schools; setting up an email specific for families to send photos, letters etc. to be shared with their loved one; FaceTime, phone calls and a drive-by visit where residents from the Hopetoun and Warracknabeal aged care facilities sat in the car park while family and friends drove past to say hello. To manage all the different options to help keep families connected, Rural Northwest

Health developed a 'Keeping In Touch (KIT)' coordinator role at both residential aged care campuses.

Connecting in the community

The people living with dementia or cognitive impairment in our community and their carers were not forgotten either. A newly established Living Well Program designed to engage people in positive, purpose-driven activities while providing carer respite had only just commenced onsite when the first COVID-19 lockdown occurred in Victoria in March 2020. The comprehensive day program located at the Warracknabeal campus provides a home-like environment, integrating wellness and reablement approaches to assist people living with dementia or cognitive impairment to maintain essential life skills including: cooking, shopping, gentle exercise sessions, art and craft activities, gardening, and interactive programs. Faced with suspension of the program's onsite activities and the prospect of participants and their carers being isolated



Residents (above and below) from Rural Northwest Health's Hopetoun and Warracknabeal aged care facilities were able to say hello to family and friends from a COVID-safe distance during a drive-by visit. Photos courtesy Rural Northwest Health

at home without support or respite, the team had to quickly adapt and innovate.

A benefit of providing health services in a small rural community is the connection with, and knowledge of, individuals and their extended family/support base. Relationships are built on trust and first-hand understanding of the community. Rural people are stoic and often won't reach out for help. These trust-based relationships meant our community-based consumers readily accepted the home-based supports offered during COVID-19 in place of the onsite day program. These home supports were tailored to each person's abilities, capabilities and background – the core focus of the Living Well Program.

Person-centred COVID packs were developed by the Wellbeing Team and Memory Support Nurse and distributed to community-based consumers. Each pack included information and activities based on the person's specific interests (eg, seedlings to plant, reading material of interest, puzzles, games and treats).

The Wellbeing Team also offered 'COVID walks' where one team member

visited the person living with dementia or cognitive impairment and walked with them on a route of their choice (eg, to get the newspaper). Another COVID-safe strategy has been to sit and chat with the person living with dementia or cognitive impairment outside their house chatting. This allowed family members to have time to attend to tasks including leaving the house to get groceries and other supplies. We also provided information to assist carers.



Uninterrupted support

Feedback from the community was that this support was invaluable. When the second lockdown occurred in June 2020, we were prepared because we had already found a new way of delivering services and support during the first lockdown. The significance of finding new ways of doing things from the beginning of COVID-19 could not be underestimated; it allowed us to provide ongoing support without interruption for people living with dementia or cognitive impairment in the community and their carers.

Conclusion

Now that we are on the other side of the second lockdown, our onsite Living Well day program has recommenced with memory support continuing to be offered in the community. While to date our community has been spared a COVID outbreak, we continue to implement the same level of safety measures as health services across Australia to ensure our community is protected. And, as is so often the case, the connectedness and trust within our small community has proven one of the greatest assets when supporting for people living with dementia or cognitive impairment and their carers during extraordinary times. ■



■ From left: Dr Marita Chisholm is Innovation and Projects Manager Older Persons Health, Rural Northwest Health, Warracknabeal, Victoria, and an AJDC Editorial Advisor; Dr Kaye Knight is Executive Manager, People and Culture, Catherine Ramsdale is Wellbeing Coordinator, Jo Martin is Executive Manager Community Health, and Wendy James is Executive Manager Clinical Services, all at Rural Northwest Health. To follow up on this article, contact Marita at Marita.Chisholm@rnw.net.au

Community links key to pandemic support

An estimated two out of five people living with dementia live in rural or remote towns or communities in Australia (IGPA 2017). Dementia Support Australia is a free service funded by the Australian Government to deliver programs across Australia to support people with dementia where behaviours impact their care.

People living in rural and remote communities face many challenges including access to primary and specialist health care. It is Dementia Support Australia's (DSA) commitment to provide the same standard of access to support programs for all Australians, no matter where they are located.

DSA's work

Since its inception in 2016, access and referrals to DSA services has significantly increased with Dementia Consultants based in 35 locations across Australia. As a borderless service, teams respond to referrals from anywhere in the country within 48 hours to a week, depending on

the individual case.

Advice and recommendations provided by DSA Consultants are tailored for each person, their situation and environment. Consultants work with the family members, care staff and associated health services to understand the person and build knowledge to support people with dementia in the future.

DSA's COVID-19 response

To ensure continued support during the COVID-19 pandemic, in April 2020, DSA implemented a Pandemic Response Plan to let aged care services know that DSA was fully operational during COVID-19. This included more than 1000 cold calls to aged care providers to offer phone support and provide any COVID-19 related advice, 3100 resource packages which were delivered across Australia to aged care homes, and live chat functions and more video conferencing assessments.

As a result of these initiatives there was

Andrew Haszard explains how Dementia Support Australia and its team of Dementia

Consultants have supported people with dementia and care services in rural and remote areas of Australia before and during the COVID-19 pandemic and the specific challenges faced by people in those communities

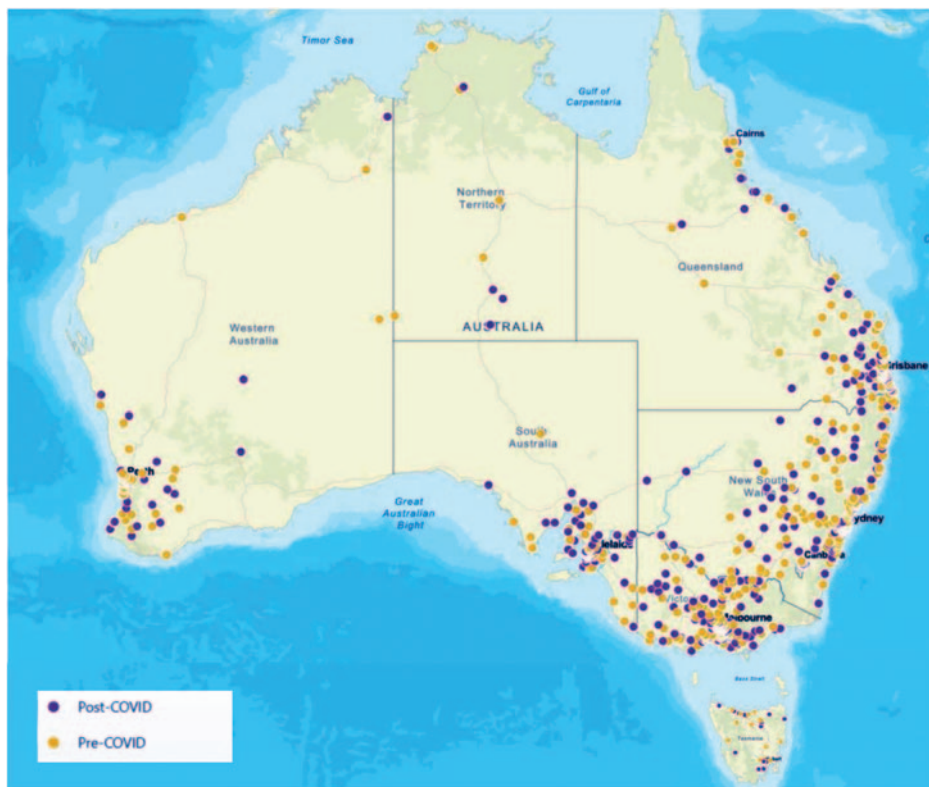
little to no interruption to DSA services, including across rural and remote Australia. DSA received more referrals in April and May 2020 than in any other period. For instance, the number of referrals received in May 2020 was 65% greater than referrals received in May in 2018, and 44% greater than referrals observed in May in 2019.

Among the reasons for this rise in referrals was a greater use of casual or agency staff who required more support, care staff who were impacted by travel restrictions or quarantine, and more fearful family members worried about things such as what would happen if the care home went into lockdown. Rural and remote regions were slightly more insulated than metropolitan areas which experienced more outbreaks and had more restrictions.

However, one impact the service observed during this time was a 55% increase in the provision of 1:1 support (March/April 2020 compared to March/April 2019). COVID-19 placed enormous pressure on residential aged care staff due to additional tasks involved in maintaining infection control. As part of DSA's standard practice, consultants broker items or services to support the person with dementia or carers. This ability to offer additional services such as nursing or carer support has meant that busy care staff can still support the person with dementia in need.

As an example, DSA provided funding for an additional care worker to spend one-on-one time with a resident to gather further information about their life story, trial initial strategies outlined by the DSA Consultant, and prevent the resident being admitted to hospital while medication changes, recommended by a DSA Clinical Associate, were implemented.

Another resident responded positively when the care home's cat visited, so DSA funded the purchase of a simulated cat



Areas visited by Dementia Support Australia Dementia Consultants in the six months pre-COVID-19 lockdowns and the six months post-COVID-19 lockdowns. Images and photos courtesy DSA

Cultural resources

As part of its continuing commitment to build internal cultural capacity and knowledge when supporting Aboriginal and Torres Strait Islander (ATSI) people, DSA has developed resources to support its consultants when visiting these communities and to raise awareness of our services. DSA commissioned the Balarinji Aboriginal-owned strategy and design agency to create the design for these resources. The result is based on the artworks *Spring Journey* (pictured) and *Spirit Ancestors*. You can learn more about the resources at: www.dementia.com.au/resources/cultural-resources



and included recommendations on how to introduce it to the resident. The care home was very happy with the result, reporting:

"The resident has been quite settled and loves the cat very much. She interacts very well with the cat and it brings her much joy."

During the pandemic lockdowns, some communities were completely closed off with no services going in. In addition to being unable to reach clients in these remote communities, DSA consultants were unable to visit care homes due to restrictions and quarantine requirements. As a result, the number of video consultations increased by over 100% in March / April 2020 compared to the same period in 2019.

Working together

Australia is a large and geographically dispersed country. Due to the sheer distances required to travel and the remoteness of many communities, DSA's approach to service delivery has been tailored to regional and remote Australia.

DSA ensures resources are available so that support can be delivered anywhere in Australia. Risk due to weather, such as floods and heat, are continually assessed. At times, consultants will travel with other services for support and to reduce the risk, travelling with those who know the land and have relationships with the communities they visit. For example, in a remote Indigenous community DSA consultants might travel with another service that has an existing or 'vouched' relationship with the community. These relationships are crucial to gain trust, knowledge and understanding. DSA consultants would rarely visit a remote Indigenous community on their own, but work alongside the local health network,

Aged Care Assessment Team assessors, families, allied health, and other services and clinics.

"In the remote communities, if you have those relationships with services that are known to those communities you can sit and have a yarn and exchange stories," says Steph who is a DSA Dementia Consultant providing services across the Top End.

"It is important for an Aboriginal person that you put your face into a story. This takes time. Building those relationships and trust is needed so you understand what is causing the behaviour."

A DSA Dementia Consultant based in the Northern Territory has adopted the Malparara Way – the strength of working

together, side by side on the journey. Malparara Way is a cross-cultural practice model developed in the early 1990s. It recognises and values the knowledge, skills and resources of the local people while assisting them in gaining access to services which are delivered in a culturally appropriate and effective way.

In this spirit of working together they link with other health services, align calendars and marry up a trip and travel in convoy.

In addition to the on-the-ground team, DSA Dementia Consultants will liaise with clinical experts about individual cases and with DSA medical specialists, such as geriatricians or aged psychiatry, who can provide medication reviews and recommendations via telephone, fax, or email.

Follow up on each client is generally with phone calls at least once a week, to discuss how the person with dementia is responding to the recommendations and whether additional support is required. In rural and remote areas it is optimal to provide follow-up support to someone who has an existing relationship with the person with dementia who is being supported.

Community-based approach

Providing services to regional and remote communities in Australia requires a different approach to those in urban areas. In Aboriginal and Torres Strait Islander communities people primarily are referred to DSA because the community needs additional support in



Providing services to regional and remote communities in Australia requires a different approach to those in urban areas. In Aboriginal and Torres Strait Islander communities the majority of DSA recommendations involve a community-based approach



People living in rural and remote communities face many challenges, including access to primary and specialist health care

looking after the person with dementia.

In the majority of these cases, DSA recommendations involve a community-based approach. Unlike DSA support services in other locations in Australia, support may not be specifically around the person and who the person is, but rather about where they are living, who is looking after them and what people can do to support that person.

A key outcome for DSA is to work with the community to keep people in the environment they are familiar with, rather than sending them into an unfamiliar environment such as an aged care home or hospital.

As an example, DSA was asked to support an Indigenous woman who liked to go walkabout. This is something she had always done, however because of her dementia she got the seasons mixed up and went out in the wet season, which was a risk to her health and wellbeing.

DSA recommendations to the woman's family members included talking to the community, the local shopkeeper, and health clinic about keeping an eye out for her. With consent, we also used an electronic tracker pendant (GPS), which enabled her to still go out walking and allowed her family to know where she was and prevented her from having to remain inside.

Overall, the aim was to keep this woman in her community, moving around, not confined to her house and to avoid her being transferred to Darwin and into aged care, where she would be 'off country' and have to adjust to a new environment.

In another case, the person would go walking at night and was at risk of being

hit by a car. The DSA Dementia Consultant purchased a reflective workman's vest so the man could be easily seen, and members of his community were enlisted to help get him home.

DSA works with members of these small communities to be able to support the person or people living with dementia, providing strategies and advice on how to enable them to stay and live in the environment that they know and are comfortable with.

Consistency of care

While there are barriers to providing support in remote community locations, primarily due to distance and environmental factors, support for people with dementia who are living in aged care homes in rural and remote Australia can be more challenging.

Without a doubt COVID-19 impacted care homes across Australia. DSA's Dementia Consultants were unable to enter some care homes, families were not able to visit, and clients were unable to leave. Even when restrictions eased, many care homes in the Northern Territory remained closed to site visits.

As with the remote communities, relationships built on trust over time are critical. In order to achieve this, face-to-face consultations are necessary, and this has been more challenging during this period. The use of technology such as video chat and phone calls increased during COVID-19 to support aged care organisations when face-to-face visits were not possible due to lockdowns. However, due to the complexity that exists within aged care there were

challenges with staff providing continuity of care due to the cultural diversity of clients and care staff, provider expectations, and the involvement of multiple services.

In addition, in regional and remote Australia, care homes, as with many organisations in these areas, have problems with recruitment and retention of staff. Continuity of care is critical when supporting a person with dementia.

Regional and remote locations could benefit from having a dementia lead to establish and implement a value-based approach to supporting residents living with dementia in such a culturally diverse and challenging social and geographic demographic.

Sometimes it's easier in an outback community health service where the DSA Dementia Consultant will have a relationship with one or two people that they can speak to every week to find out how the implementation of the recommendations are going. With a changing aged care workforce this makes it difficult.

DSA's Regional and Remote Outreach Strategy was put on hold at the beginning of 2020 due to COVID-19. The aim of the project was to target key areas within each state, promoting DSA service offerings, expanding community outreach programs, building relationships with key stakeholders within aged care and the community, and increasing the skills and knowledge of care staff in supporting people living with dementia.

During COVID-19 the service pivoted to provide telehealth services via videoconferencing and was able to maintain its level of support to aged care organisations. DSA is now working to reinstate the strategy to provide specialised outreach consultant teams, travelling to regional and remote locations. ■

For more information about Dementia Support Australia services and referral process, visit www.dementia.com.au/ or phone 1800 699 799.



■ Andrew Haszard is Head of Dementia Support Australia and Operations, The Dementia Centre, HammondCare. To follow up on this article, contact dsanews@dementia.com.au

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Australian Journal of DementiaCare Research Focus

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.

Lack of dementia services may contribute to retrievals

Fergus Gardiner, Noel Collins, Mathew Coleman and Frank Quinlan report on a cross-sectional review of data for patients with dementia requiring aeromedical retrieval by the Royal Flying Doctor Service of Australia

Overall, the Australian population enjoys relatively good health. However, rates of potentially avoidable morbidity and mortality increase with remoteness, to more than 2.5-fold higher in populations living in very remote areas compared to those living in major cities (Gardiner *et al* 2018a). The causes of lower life expectancies in rural and remote populations are multifactorial (van Gaans & Dent 2018), however in part appear to be associated with reduced access to essential services, such as healthcare (Gardiner *et al* 2018a). Whilst rurality is associated with lower life expectancy, rural and remote populations are likely to experience growing rates of dementia, due to high comorbidity rates and an ageing population.

While the exact number of people living with dementia in Australia is unknown, it is estimated that in the year 2020 400,000-459,000 Australians have dementia, with Alzheimer's disease making up the majority (up to 70%) of cases (AIHW 2020). This figure is expected to grow, due to the



Herb, a Royal Flying Doctor Service (RFDS) patient in Tilpa, far west NSW. As well as providing aeromedical emergency services to country Australia, the RFDS is also the GP for hundreds of communities in the bush. Photos courtesy RFDS

ageing Australian population, with median age increasing in rural and remote populations due to many younger people leaving for work and study (Bauer *et al* 2019).

Dementia is also likely to grow at a faster rate in rural and remote areas, as compared to major city areas, due to the higher rates of modifiable risk factors in rural and remote

areas, including (although not limited to) smoking, type two diabetes, hypertension, and obesity (AIHW 2020).

Additional risk factors that may be more prevalent in rural settings include lower levels of education, depression, excessive alcohol consumption, geographical isolation and infrequent social contact (Livingston *et al* 2020).

There is no cure for dementia which remains the leading cause of dependency and disability among older people (Morgan, Innes & Kosteniuk 2011), which is worrying given the ageing rural and remote population (Gardiner *et al* 2018b), coupled with high rates of vascular disease (Gardiner *et al* 2019a). While dementia can affect younger people, it is

mainly associated with advancing age occurring in those aged 65, or 55 years old if Aboriginal and Torres Strait Islander (hereafter referred to as Indigenous) (Gardiner *et al* 2019b).

Review of patient data

While there has been some research concerning older people's health and access to services in rural and remote Australia (Gardiner *et al* 2019b), there has been little research aimed at determining the characteristics of patients with dementia requiring aeromedical retrieval to inner-regional and major city areas for ongoing care.

We undertook a cross-sectional review of prospectively collected routine patient data for patients retrieved for dementia by the Royal Flying Doctor Service (RFDS) from anywhere in Australia between 1 July 2016 and 31 June 2020 (four years). Patient diagnostic data was coded to the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) (WHO 2020).

During the study period, the RFDS conducted 449 patient episodes of care for people experiencing a dementia, as



A RFDS primary health consultation in Tasmania. RFDS provides regular fly-in-fly-out GP, nursing and allied health clinics

highlighted in Table 1 (see below). This included 272 (60.6%) males and 177 (39.4%) females, with the median age being 71 years old (interquartile range (IQR) 52.75-79.0). The majority of patients were non-Indigenous (n=347; 77.3%), however there was an overrepresentation of Indigenous patients (n=102; 23.0%). Indigenous patients were significantly younger, with a median age of 53.0 (IQR 30.5- 67.0), as compared to non-Indigenous patients, with a median age of 74.0 years

(IQR 62.0-80.0).

Reasons for retrieval

The leading retrieval reasons were for delirium (n=134; 29.8%), unspecified dementia (n=93; 20.7%), and unspecified organic or symptomatic mental disorder (n=60; 13.4%) (see Table 1 which details patient aeromedical retrieval characteristics).

Discussion

It is unclear from this inflight clinical coding what the exact reasons for retrieval were. However, if retrieval is

assumed to be a proxy for the need for acute medical treatment, then studies looking at the reasons for acute hospital admission for people with dementia may provide some clues.

People with dementia are often admitted for co-morbid medical problems such as pneumonia, UTI or dehydration, consistent with the finding that 30% of retrievals were in response to delirium (Natalwala *et al* 2008). Other research reports suggest that the presence of responsive behaviours such as agitation, aggression as well as increasing functional dependency also increase the risk of acute admission (Toot *et al* 2013). Given that responsive behaviours significantly increase carer burden in home, residential care and medical settings (Sampson *et al* 2014), this is likely to contribute to local care or placement failure and a subsequent request for medical escalation and retrieval.

In rural and remote areas there is a shortage of local dementia services and due to geographical and social isolation many patients are required to travel long distances to access services (Bauer *et al* 2019). This puts

| (ICD-10 code) In-flight working diagnosis | Male (%) | Female (%) | Total (%) | Median age (IQR) |
|---|------------|------------|------------|------------------------|
| F00 Dementia in Alzheimer disease | 14 (5.1) | 13 (7.3) | 27 (6.0) | 74 (71-78.5) |
| F01 Vascular dementia | 16 (5.9) | 4 (2.3) | 20 (4.5) | 75 (67.75-80.0) |
| F02 Dementia in other diseases classified elsewhere | 11 (4.0) | 4 (2.3) | 15 (3.3) | 75 (62.5-78.5) |
| F03 Unspecified dementia | 58 (21.3) | 35 (19.8) | 93 (20.7) | 77 (73.0-85.0) |
| F04 Organic amnesic syndrome, not induced by alcohol and other psychoactive substances | 1 (0.4) | 2 (1.1) | 3 (0.7) | 71 (71.0-76.0) |
| F05 Delirium, not induced by alcohol and other psychoactive substances | 77 (28.3) | 57 (32.2) | 134 (29.8) | 68.5 (54.5-78.0) |
| F06 Other mental disorders due to brain damage and dysfunction and to physical disease | 22 (8.1) | 8 (4.5) | 30 (6.7) | 51 (34.75-64.0) |
| F07 Personality and behavioural disorders due to brain disease, damage and dysfunction | 10 (3.7) | 7 (4.0) | 17 (3.8) | 57 (49.0-67.0) |
| F09 Unspecified organic or symptomatic mental disorder | 36 (13.2) | 24 (13.6) | 60 (13.4) | 43.5 (28.0-68.0) |
| G30 Alzheimer disease | 7 (2.6) | 10 (5.6) | 17 (3.8) | 75.5 (71.25-77.0) |
| G31 Other degenerative diseases of nervous system (such as circumscribed brain atrophy; senile degeneration; degeneration due to alcohol) | 20 (7.4) | 13 (7.3) | 33 (7.3) | 68 (59.0-76.0) |
| Total | 272 | 177 | 449 | 71 (52.75-79.0) |

Table 1: Characteristics of patients who received an aeromedical retrieval for dementia, from the years 2016 to 2020, throughout rural and remote Australia

much pressure on friends, family and carers of people with dementia (Papastavrou *et al* 2015), who are required to escort loved ones, often due to the person with dementia not being able to, or allowed to, drive; or due to the inaccessibility of suitable public transport. Other obstacles to local care include fewer local specialist providers (and culturally appropriate services), limited clinical dementia training for local health care workers, and limited geriatric and diagnostic service (Kendig & Phillipson 2014; Morgan *et al* 2015).

The lack of commissioned memory assessment pathways and models of care in rural settings make post-diagnostic care and signposting to local non-government support organisations such as Dementia Australia difficult. Splits between the national funding of aged and geriatric care, primary care, social care and state-based older adult mental health or neurological services further complicates the provision of integrated care (Chase *et al* 2020).

Furthermore, many of the patients are from small towns, where the stigma of having dementia can be experienced, with carers avoiding accessing support services for fear of being ostracised (Phillipson *et al* 2015). Combined with the additional challenges of navigating complex health and social care systems, these challenges may result in people waiting until a crisis point before seeking any help. As such, sustained policy initiatives that support the commissioning and investment in local integrated dementia diagnostic and support services are likely to reduce the need for sudden escalation and aeromedical retrieval.

Improving the capacity and capabilities of local hospitals to detect and manage delirium, as well as specialist support to manage responsive behaviours in local care settings are also likely to reduce the dependency on RFDS services

by people living with dementia. ■

Acknowledgments

We would like to thank the supporters of the Royal Flying Doctor Service (RFDS) who make our service possible. We would also like to thank Professor Jane Farmer for commenting on the article before publication.

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■ (Pictured from left) Dr Fergus W Gardiner is Director Public Health and Research, Royal Flying Doctor Service of Australia (RFDS); Dr Noel Collins is Clinical Senior Lecturer at The Rural Clinical School of Western Australia, The University of Western Australia; Associate Professor Mathew Coleman is Chair of Practice in Rural Mental Health and Psychiatry Coach at The Rural Clinical School of Western Australia, The University of Western Australia; and Frank Quinlan is Federation Executive Director of the RFDS. To follow up on this article contact Dr Fergus Gardiner at Fergus.Gardiner@rfd.s.au



A patient is transferred on to an RFDS aircraft for transport to hospital

Training dental practitioners

Undiagnosed pain due to unmet oral care needs is often a significant cause of distress and agitation among aged care residents, particularly those living with dementia. However, as well as the difficulty of residents accessing dental care, many dental practitioners are not well equipped to provide dental care for people with dementia. **Archana Pradhan** (left) and **Ratilal Laloo** evaluated an

Australian-first online learning program for dentists on providing oral health care for people with dementia



People with dementia account for 52% of all residents in residential aged care facilities (RACFs) (NATSEM 2017). Oral health is challenging in RACFs with a lower priority over the demands of supporting residents with eating and with going to the toilet perpetuating the cycle of oral neglect. Residents' reliance on carers for daily oral care like tooth brushing, denture cleaning etc, and transport to dental facilities increases their vulnerability to oral disease which tends to be cumulative and more complex with time (Ettinger 2015).

Importance of oral care

The high prevalence of untreated dental decay in aged care residents with and without dementia (Hopcraft *et al* 2012; Silva *et al* 2014; Chalmers *et al* 2005) and periodontal/soft tissue lesions (Stubbs *et al* 2002) make oral care important for RACF residents. Residents with decayed teeth have reduced ability to chew and greater nutritional problems (Walls *et al* 2000) with consequent malnutrition correlating with declined activities of daily living (Furuta *et al* 2013). Pain and infection from poor oral health may go unnoticed, especially among people with cognitive impairment who are poor reporters of pain. Undiagnosed pain due to unmet oral care needs is often a significant cause of distress/agitation amongst residents particularly those with dementia (Sampson *et al* 2015). Furthermore, plaque accumulation and deteriorated periodontal status linked to aspiration pneumonia is a cause of death among frail elderly,

especially with advanced dementia (van der Maarel-Wierink *et al* 2013).

The elderly and people with dementia need complex oral health care, but they/their carers have difficulty accessing dental care. Although Geriatric Dentistry is covered within specialist disciplines (Special Needs Dentistry (SND)/Oral Medicine), integrated programs focusing on managing oral health complexities of the elderly is lacking and many dental practitioners (DPs) are not comfortable providing dental care for people with dementia (Slack-Smith *et al* 2015). Though the 2004-2013 and 2015-24 Australian National Oral Health Plans identify older people as priority populations for dental care, the recommendations have not been implemented (Pradhan *et al* 2019).

Increasing interprofessional (carers/dental/other health practitioners) engagement in oral care training in aged care (Hopcraft *et al* 2011) has prompted several models of training across various education programs (Samson *et al* 2010), including an online program developed by Dementia Australia and The Australian Dental Association (ADA), called 'Dentists and Dementia', which is the subject of this article.

Dementia Australia's consumer-driven National Quality Dementia Care Initiative had identified oral health as a problem among people with dementia that needs to be addressed. In response, it approached the ADA in 2015 to form a joint project to address limitations in the dental

workforce in providing appropriate and timely dental care for people with dementia.

Online learning

Collaborating with an intersectorial committee of specialists (SND), experienced dentists (aged care), geriatricians, people with dementia and their carers/advocates, the project group developed Australia's first online learning program for dentists on providing oral health care for people with dementia. 'Dentists and Dementia' (now called 'Partnership in Practising Care') was launched in August 2016. The six modules incorporating 19 videos (two-13 minutes, totalling about two hours) covers: 'What is Dementia?', 'Dentistry and Ageing', 'Dementia and Your Practice', 'Consent', 'Treatment Planning' (now called Treatment Planning and Delivery of Care') and 'Delivery of Domiciliary Care' (now called 'Domiciliary Care'), with typical case-scenarios/interviews with people with dementia, dentists and geriatricians working with people with dementia and their carers. Links to additional dental/medical care resources are also provided.

With the original intent for dentists to access and gain practical knowledge regarding the provision of oral health care for people with dementia in their day-to-day clinical practice, the online training modules were initially available only to ADA members via the ADA portal. When the modules were made publicly available on the Dementia Australia website in 2017 (www.dementia.org.au/resources/education-modules-for-dental-practitioners) they became a

useful resource for all DPs (dentists, oral health therapists, dental hygienists, dental prosthetists) to provide care for older adults, with or without dementia.

Evaluating the training

Between 2016-2018, through the University of Queensland (UQ), we evaluated the 'Dentists and Dementia' program, using a combination of the online training modules and a face-to-face post-training discussion. The aim was to improve DPs' self-reported knowledge, skills and confidence in providing appropriate oral care to the ageing population; assess if a post-training face-to-face clinical discussion is of added learning value; collect feedback on the online training modules (appropriateness of content; improvements needed); assist in continuing professional development (CPD) activities for DPs, and integration into primary/specialist dental curricula.

Methods

All 22,987 DPs registered during 2016-2018 (Dental Board of Australia 2019) were approached as participants for this evaluation. Participation in a pre-training online questionnaire was promoted via the ADA News Bulletin/emails, dental conferences/meetings, and the Facebook pages of the following dental associations: Australian Society of Special Care in Dentistry, Australian Dental and Oral Health Therapist Association, Dental Hygienists Association of Australia, Dental Prosthetics Australia.

The pre-training questionnaire was available through the UQ software Checkbox. Respondents were given the option to provide their personal emails to participate in the post-training questionnaire and face-to-face clinical case discussion. After completing the pre-training questionnaire, participants received the link to the online training modules.

Responses to the pre-training questionnaire were logged monthly (August 2016–2017). At six months, those who provided their personal emails were sent a link to participate in the post-training questionnaire, via the UQ Checkbox, and asked to provide feedback/suggestions for improvement. Another invitation (February 2018) to participate in the online training and follow-up face-to-face clinical case discussion was promoted via the Dental Hygienists Association of South Australia. A follow-up face-to-face clinical case discussion was organised (April 2018) for the interested participants in Adelaide, who were asked to complete a post-discussion questionnaire, the same as the post-training questionnaire.

The data from Checkbox were exported to SPSS for analysis. The characteristics of participating DPs were described using descriptive statistics. Responses to statements on knowledge, skills, and confidence were recorded on a 5-point Likert Scale (strongly disagree = 1, disagree = 2, neutral = 3, agree = 4, and strongly agree = 5).

Results

Forty-four dentists, 17 dental hygienists/oral health therapists and three dental prosthetists participated in the pre-training questionnaire. There were more female (59.4%) than male participants and nearly two-thirds (64.3%) had over 10 years' clinical experience. Almost half (49.2%) were 40–59 years of age. The majority worked in private practice (60.7%). Only 24 (39.3%) had received training in aged care, of whom two dentists and six dental hygienists had received both theoretical and

clinical training in their basic primary degree.

Forty DPs (62.5%) had provided dental care to some aged care residents in the past 12 months prior to undertaking the online training modules. Just over half (52.5%) had managed five or less patients independently, and only six (15.0%) had provided care for over 100 patients in the past 12 months. Referrals were generally made to other general dentists (26.6%), specialists (SND) (21.9%), oral maxillofacial surgeons (14.0%) and other specialists (9.3%): oral medicine specialists, oral pathologists and prosthodontists. The majority of the DPs (57.8%) consulted family/carers. Some consulted other dental professionals (29.7%) and non-dental professionals (26.6%) (GP, medical specialist, dietician, psychologist, speech therapist, nurse, or patients themselves).

Of the 64 DPs, 41 provided their emails to be contacted for the post-training questionnaire and/or practical training. After two reminder emails a week apart, only 21 participants responded at six months follow-up. No comparisons were able to be made for dental practice patterns pre- and post-training.

Reasons for participation

The most common reasons for online training participation were for knowledge, further skills and confidence in aged and dementia care. A few mentioned “lack of training” in geriatric dentistry. For some, personal reasons included family members or patients with dementia, or working in aged care. Few of the participants were recommended to participate in the online training by their colleagues. Other reasons were to provide holistic treatment; communicate better with patients and their carers; familiarise with oral needs as dementia progresses; handle ‘difficult’ patients and provide palliative care.

Feedback

Feedback regarding the online training was mostly positive for most participants who found

the online training logical, practical, easy, raised awareness, improved confidence and exceeded expectation. For a few, the online training was too long, whilst other participants wanted more practical clinical-related components. Suggestions included fewer but longer videos, and fewer modules (so a shorter time to complete the online training).

Some encouraging comments included:

- “Great that you are covering this much-needed area of dentistry – very challenging but needed and necessary.”
- “Well done – a difficult area but really needs to be tackled.”

The 12 participants reported the face-to-face discussion as insightful, informative, valuable, efficient, practical, helpful and hopeful. More clinical scenarios and opportunities for practical demonstrations were proposed.

A common theme for improvements for both the online training modules and face-to-face discussion was to involve carers and dental hygienists/oral health therapists, especially in the preventative regime and behavioural management.

Following online training, the percentage of DPs who ‘Agreed/Strongly Agreed’ increased for ‘adequate theoretical knowledge’ (by 13.2%), ‘how to maintain a friendly dental environment’ (by 14.2%), ‘understanding consent issues’ (by 12.4%), ‘effective communication’ (by 11.7%), ‘plan dental care’ (by 16.3%), ‘know who to consult in complex cases’ (by 16.0%), and ‘confident in working with other health professionals’ (by 7.7%). However, the percentage of DPs who ‘Agreed/Strongly Agreed’ decreased for the statements ‘can provide a thorough oral examination for aged care residents in dental surgery’, ‘out of dental surgery’, and ‘providing holistic care to aged care residents’ by 6.3%, 3.1%, and 1.7%, respectively, following online training (see Table 1, p40).

Following the subsequent

face-to-face clinical discussion, the percentage of DPs who ‘Agreed/Strongly Agreed’ further increased for ‘adequate theoretical knowledge’ (by 27.4%), ‘how to maintain a friendly dental environment’ (by 8.3%), ‘understanding consent issues’ (by 3.6%), ‘effective communication’ (by 8.3%), ‘plan dental care’ (by 22.6%), ‘know who to consult in complex cases’ (by 13.1%), and ‘confident in working with other health professionals’ (by 8.3%). The percentage of the DPs who ‘Agreed/Strongly Agreed’ also increased for ‘can provide a thorough oral examination for aged care residents in dental surgery’ (by 29.8%), ‘out of dental surgery’ (by 46.4%), and ‘providing holistic care to aged care residents’ (by 22.6%) as well. Due to the low response, translation into clinical practice following the online training and face-to-face clinical discussions could not be determined.

Discussion

According to previous research, many DPs lack confidence in providing dental care to RACF residents, especially those with dementia, due to inadequate training and experience; and fear treating geriatric problems (MacEntee *et al* 1992; Antoun *et al* 2008; Slack-Smith *et al* 2015; Bots-VantSpijker *et al* 2017). However, our study showed that DPs did not take advantage of the online training made available/accessible to them. This indicates DPs are still not interested/not willing to treat older people, probably due to other issues like lack of financial incentives (Bots-VantSpijker *et al* 2017) and problems obtaining informed consent.

With only 18 registered SND specialists in Australia (Dental Board of Australia 2019), the poor participation rate in the education program, despite reminder emails, confirms that the inadequate training in aged care for the aged care dental workforce will continue to be a concern into the future.

Responses from the few participants indicate that online training is an effective medium

| Pre-training, Post-training and Post-discussion on providing dental care for aged care residents | | | Disagree/Strongly Disagree (%) | Neutral (%) | Agree/Strongly Agree(%) |
|--|--|--------------------|--------------------------------|-------------|-------------------------|
| 1 | I have adequate theoretical knowledge on managing aged care residents | Pre [†] | 44.3 | 21.3 | 34.4 |
| | | Post1 [‡] | 19.0 | 33.3 | 47.6 |
| | | Post2 [§] | 25.0 | 0 | 75.0 |
| 2 | I know how to maintain a friendly environment in my dental surgery | Pre [†] | 26.2 | 21.3 | 52.5 |
| | | Post1 [‡] | 28.6 | 4.8 | 66.7 |
| | | Post2 [§] | 25.0 | 0 | 75.0 |
| 3 | I understand consent issues for aged care residents | Pre [†] | 24.6 | 16.4 | 59.0 |
| | | Post1 [‡] | 19.0 | 9.5 | 71.4 |
| | | Post2 [§] | 25.0 | 0 | 75.0 |
| 4 | I can communicate effectively with aged care residents and their carers | Pre [†] | 23.3 | 21.7 | 55.0 |
| | | Post1 [‡] | 23.8 | 9.5 | 66.7 |
| | | Post2 [§] | 25.0 | 0 | 75.0 |
| 5 | I can provide a thorough oral examination in my dental surgery for aged care residents | Pre [†] | 18.0 | 32.8 | 49.2 |
| | | Post1 [‡] | 23.8 | 33.3 | 42.9 |
| | | Post2 [§] | 27.3 | 0 | 72.7 |
| 6 | I can provide a thorough oral assessment outside my dental surgery for aged care residents (e.g. in an aged care facility) | Pre [†] | 36.7 | 31.7 | 31.7 |
| | | Post1 [‡] | 33.3 | 38.1 | 28.6 |
| | | Post2 [§] | 25.0 | | 75.0 |
| 7 | I have adequate knowledge and clinical skills to plan dental care for aged care residents | Pre [†] | 23.0 | 41.0 | 36.1 |
| | | Post1 [‡] | 33.3 | 14.3 | 52.4 |
| | | Post2 [§] | 16.7 | 8.3 | 75.0 |
| 8 | I know who to consult in complex cases when managing aged care residents | Pre [†] | 36.1 | 18.0 | 45.9 |
| | | Post1 [‡] | 19.0 | 19.0 | 61.9 |
| | | Post2 [§] | 25.0 | | 75.0 |
| 9 | When managing aged care residents I am confident in working with other health professionals | Pre [†] | 19.7 | 21.3 | 59.0 |
| | | Post1 [‡] | 23.8 | 9.5 | 66.7 |
| | | Post2 [§] | 25.0 | | 75.0 |
| 10 | When managing aged care residents I am confident in providing holistic care | Pre [†] | 21.3 | 24.6 | 54.1 |
| | | Post1 [‡] | 23.8 | 23.8 | 52.4 |
| | | Post2 [§] | 25.0 | 0 | 75.0 |

Table 1. Dental practice patterns in Aged Care

Pre[†] N = 61, Post1[‡] N = 21, Post2[§] N = 12

for educating DPs in theoretical aspects of providing care for the elderly and that face-to-face clinical discussions are of added learning value. Participants also provided valuable insight into how the training modules and face-to-face discussions could be improved to ensure delivery of efficient and appropriate oral health care in aged care.

As the study included all DPs, a dental treatment plan in providing care for aged care residents would differ by each category of DP, and hence, the level of knowledge and confidence gained after

participating in this study could also vary accordingly. However, low participation did not allow for stratification by the different categories of DPs.

A lack of training in aged care for DPs (Slack-Smith *et al* 2015; Bots-VantSpijker *et al* 2017; Hopcraft *et al* 2008) was confirmed by the 40% of participants who did not receive any training, and only eight DPs received both theoretical and clinical training during their formal education. Only about a third of the DPs 'Agreed/Strongly Agreed' to having adequate theoretical

knowledge in providing dental care for aged care residents, and less than a third to being able to provide a thorough oral assessment outside the dental surgery.

Following the online training there was further reduction in agreement among the DPs in the practical aspects like ability to provide a thorough oral examination for aged care residents in and outside a dental surgery, and in providing holistic care to aged care residents. This was probably due to the increase in their theoretical knowledge and

greater understanding of consent issues, and therefore, acknowledgment of the complexities involved.

The online training did increase the number of DPs who 'Agreed/Strongly Agreed' in maintaining a friendly dental environment, communicating effectively with care residents and their carers, treatment planning, knowing appropriate referral pathways, and inter-professional collaboration in providing care for older adults. This is similar to several studies where increased knowledge was the most common outcome with

online information delivery followed by perception of increased confidence in symptom management and communication (Sullivan 2017; Berndt *et al* 2018; Lawn *et al* 2017).

Education with a face-to-face interactive element was better regarded by the recipients because of the opportunity to discuss their learning, exchange ideas, and reflect among peers (Wolff *et al* 2014; Shah 2010; Lawn *et al* 2017). Interactive face-to-face methods of delivery, compared to lectures alone, enhanced participant activity and provided the opportunity to practice skills which can efficiently and effectively change professional practice and health care outcomes (Sullivan 2017). Whilst the online medium is a growing modern teaching method effective in educating and providing new acquired knowledge as a CPD activity, online education alone cannot replace face-to-face contact (Wolff *et al* 2014; Shah 2010; Sullivan 2017; Berndt *et al* 2017; Lawn *et al* 2017) and does not allow full collaborative learning (Berndt *et al* 2017).

As anticipated, the face-to-face clinical discussions increased the number of DPs who 'Agreed/Strongly Agreed' for all components including providing a thorough oral examination for aged care residents in and out of dental surgery, and providing holistic care to aged care residents. This possibly implies that these competency areas where DPs felt they were lacking initially post-training, were resolved post-discussion. Hence, online training with subsequent face-to-face discussion, reflection and practice is critical to reinforce skills acquired from the learning activity (Lawn *et al* 2017).

Considering the positive feedback from the face-to-face discussions and participant requests for more opportunities for practical demonstrations and clinical scenarios, more focus on practical training is recommended in the future, with the online training modules as an adjunct to the practical component of the

training to increase knowledge, skills and confidence of the DPs.

Further research involving more participants in a larger face-to-face component and follow-up is required to assess if the training will translate into clinical practice. This exploratory study has potential implications for the primary and specialist dental curricula, as well as in CPD courses, and to open opportunities to establish medical-dental-consumer collaborations between Special Needs Dentistry, geriatric medicine and aged care to achieve the shared goal of the health and aged care sectors in improving quality of life of the elderly and people living with dementia. ■

Education tools

The online learning program for dentists described in this article is now called 'Partnership in Practising Care' and is available from the Dementia Australia website at www.dementia.org.au/resources/education-modules-for-dental-practitioners. The Continuing Professional Development series is designed to support dentists treating people living with dementia. The modules focus on preventative methods and have a strong emphasis on quality of life.

Royal Commission

The 2019 Joint Submission to the Royal Commission into Aged Care Quality and Safety by The Australian and New Zealand Academy of Special Needs Dentistry and The Australian Society of Special Care in Dentistry, co-authored by Dr Archana Pradhan, Dr Kerrie Punshon and Associate Professor Mina Borromeo, contains a range of evidence-based recommendations for access to appropriate and timely dental care at RACFs to improve the oral health and quality of life for older people, including people with dementia. It's available to download at: <https://bit.ly/3oo4dgu>

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■ Dr Archana Pradhan is a dental specialist in Special Needs Dentistry at the Metro North Oral Health Service, Brisbane, and Honorary Senior Lecturer at The University of Queensland and The University of Tasmania. She was also a member of the Dentists and Dementia project steering group and is an active member of the Australia and New Zealand Academy of Special Needs Dentistry (ANZASND) and Australian Society of Special care in Dentistry (ASSCID); Associate Professor Ratilal Lalloo is Discipline Lead, Dental Public Health at The University of Queensland. To follow up on this article, contact Dr Archana Pradhan at a.pradhan@uq.edu.au

RESEARCH NEWS

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



Carers and sleep quality

Researchers from Edith Cowan University in Western Australia have concluded that sleep problems are very common among dementia caregivers, after asking family caregivers of people living with dementia to self-report their sleep patterns via a survey.

While 104 adult, primary, informal caregivers of people with dementia participated in the study by completing a questionnaire on demographic characteristics (this included questions on pre-existing medical history, caregiving history and use of respite), only 71 participants completed the full set of questionnaires (which included the Depression, Anxiety and Stress Scale (DASS-21) and the Pittsburgh Sleep Quality Index (PSQI)) and were therefore included in statistical analyses. The majority of participants were female (76%) and 44% of participants had two or more co-morbidities.

The study found that 94% were poor sleepers; 84% had difficulty initiating sleep, and 72% said they had difficulty maintaining sleep. Psychological distress was common, with high levels of moderate to severe depression, anxiety and stress. Stress was found to be a significant predictor of overall sleep quality. Overnight respite was only used by 8% of participants.

The lead researcher, Dr Aisling Smyth, is now working on developing a cognitive behavioural therapy program to promote better sleep for family carers of people with dementia.

Smyth A, Whitehead L, Quigley E *et al* (2020) Disrupted Sleep And Associated Factors In Australian Dementia Caregivers: A Cross-Sectional Study. *BMC Geriatrics* 20(312) doi: 10.1186/s12877-020-01726-1

Dementia-friendly communities in practice

A group of UK researchers has investigated the question of whether dementia-friendly communities (DFCs) are actually having an impact on people living with dementia within those communities.

The study involved a survey of people living with dementia who reside in six DFCs in England, but who were not directly involved in the running or planning of their DFC. The study sites varied in size, but all were recognised as DFCs by the UK's Alzheimer's Society.

In total, 240 people living with dementia completed the survey. Around half (48%) said they were aware they were living in a DFC. Being aware of living in a DFC was positively associated with a range of activities and involvement, such as taking part in leisure activities, community centre attendance, being involved in organised activities or groups, feeling understood, and feeling valued for their own contributions to the community.

When asked "What would most help you to live well with dementia in [site]?", participants were invited to select pre-specified options or

'other'; 102 people said that 'more public understanding of what it is like to live with dementia' would help them to live well in their community, 52 selected 'extra support in public spaces', 49 selected 'larger choice of enjoyable activities' and 22 selected 'better public transport'; 42 participants made their own suggestions as to what would improve their experience of living with dementia.

The researchers say that the study has illustrated the contribution that surveys can make in facilitating the expression of views and experiences of people living with dementia. They do, however, note the challenges that need to be overcome to ensure that the voices of those with advanced dementia are heard in studies like this; only 10.8% of participants had advanced dementia, and 78% of participants completed the survey with support from another person.

Darlington N, Arthur A, Woodward M *et al* (2020) A Survey Of The Experience Of Living With Dementia In A Dementia-Friendly Community. *Dementia*. First published online 8 October 2020 1-12: doi: 10.1177/1471301220965552

Confinement of people with dementia

An interdisciplinary team of researchers involved in the Australian project 'Safe and Just Futures for People Living with Dementia in Residential Aged Care', has published a paper reporting on findings from a recent study which explored the topic of confinement of people living with dementia in care homes through a series of interviews and focus groups.

The paper reviews some existing research on the confinement of people living with dementia in care homes, and goes on to report on the findings from the interviews and focus groups, which involved 45 participants (five people living with dementia, 19 care partners, 12 care home professionals, and nine lawyers and advocates).

Participants were asked a series of questions in both the interviews and focus groups

on their awareness and experience of community access and freedom of movement in relation to aged care homes and their views on human rights. A review of the data led the researchers to identify a series of interrelated factors that contribute to human rights breaches relating to confinement:

immobilisation and neglect; limited and segregated activities; apprehending community exclusion; duty of care, risk, and liability; and pathologisation and subversion of resistance.

The researchers conclude that, "microlevel interrelated and compounding factors contribute to human rights abuses of people living with dementia related to limits on freedom of movement and community access of people living with dementia, at times irrespective of the use of

restrictive practices".

The paper presents recommendations for human rights scholars and practitioners, but notes these are also relevant to aged care and health policy workers who might be able to affect the legal, policy, and service delivery frameworks that directly shape the conditions in aged care.

The research team included dementia advocate Kate Swaffer and was guided by an advisory group that included people living with dementia, care partners, care home professionals, and lawyers and advocates for people living with dementia.

Steele L, Carr R, Swaffer K, Phillipson L, Fleming R (2020) Human Rights And The Confinement Of People Living With Dementia In Care Homes. *Health and Human Rights Journal* 22(1). Available at: <https://bit.ly/3q2tkY6>

Partnerships in care homes

This study was conducted by the same Maastricht University researchers involved in the systematic review on interventions to foster family inclusion (see right, centre), and it explores similar territory, but on this occasion the researchers chose to ask family carers of residents living with dementia directly for their views on collaboration with nursing home staff.

The researchers conducted semi-structured interviews with 30 family carers of nursing home residents living with dementia. The carers were recruited from five nursing home wards within three psychogeriatric care organisations in the south of The Netherlands, based on convenience sampling.

The carers were asked about their experiences of collaboration with nursing home staff, including the things that hinder or facilitate it. From the data, three themes emerged of critical elements for shaping collaboration with staff from the families' perspective: 'communication', 'trust and dependency', and 'involvement'.

The researchers conclude that good communication appeared to be a requisite condition for having trust in staff and quality of involvement in residents' life. Good communication included having informal contact with staff, allowing family and staff to build a personal connection. They say that increasing informal contact and building a personal connection should be a priority for staff in order to improve collaboration and to create partnerships with families.

Hoek LJM, van Haastregt JCM, de Vries E, Backhaus R, Hamers JPH, Verbeek H (2020) Partnerships In Nursing Homes: How Do Family Caregivers Of Residents With Dementia Perceive Collaboration With Staff? *Dementia* 17(175) doi: 10.1177/1471301220962235

Pain and behavioural changes in aged care homes

Australian research led by HammondCare has investigated the prevalence and intensity of pain in people living in aged care homes who are showing responsive behaviours (or behavioural and psychological symptoms of dementia, BPSD).

The one-year retrospective study involved analysis of BPSD and the presence of pain in people referred to Dementia Support Australia (DSA), using the Neuropsychiatric Inventory and PainChek®, the pain assessment app developed in Australia. Referrals were categorised into

two groups: 'pain' group and 'no pain' group.

Two-thirds (65.6%) of the 479 referrals had pain identified, with almost half (48.4%) of these experiencing moderate to severe pain. Pain was highly prevalent (54.6-78.6%) in all subtypes of dementia, and people with pain had 25.3% more neuropsychiatric behaviours compared with the 'no pain' group. There was a high prevalence of aggressive or agitated behaviours across the entire group, but the 'pain' group was 3.8 times more likely to experience these behaviours than people

referred who were not in pain.

The researchers conclude that there is a strong need to consider the possibility of pain as a contributor to behavioural changes in aged care residents living with dementia.

HammondCare says the study is the largest of its kind, and the first to use an artificial intelligence-based, dementia-specific pain assessment tool.

Atee M, Morris T, et al. (2020) Pain In Dementia: Prevalence and Association With Neuropsychiatric Behaviours. *Journal of Pain and Symptom Management*. Published online 14 October 2020: doi 10.1016/j.jpainsymman.2020.10.011

Interventions to foster family inclusion

Researchers from Maastricht University in The Netherlands have conducted a systematic review to identify interventions to foster family inclusion in nursing homes for people with dementia – and concluded that very few interventions exist that try to enhance equal family-staff partnerships in nursing homes.

The systematic review opens with a literature review that explores issues, barriers and previous systematic reviews in this area. This review identified 29 studies in total; from this pool, the researchers identified 25 studies in which 21 different specific interventions for fostering family inclusion in family-staff interactions were tested. These 21 interventions were aimed at creating family-staff partnerships (2), including family members in formal decisions (9), enabling them to make better

informed decisions and/or participate more actively in future interactions with staff (7), and providing psychoeducation for family members (3). The review gives brief information about the approach used within these identified interventions.

The researchers say more effective research is needed – few studies evaluated whether or not the intervention led to an increase in family inclusion within the nursing home. They say future interventions should pay specific attention to mutual exchange and reciprocity between family and staff.

Backhaus R, Hoek LJM, de Vries E, van Haastregt JCM, Hamers JPH, Verbeek H (2020) Interventions To Foster Family Inclusion In Nursing Homes For People With Dementia: A Systematic Review. *BMC Geriatrics* 20(434) doi: 10.1186/s12877-020-01836-w

Systematic review of diversity and dementia services

Researchers from King's College London in the UK have conducted a systematic review to examine whether minority ethnic groups across the world have longer delays before accessing dementia or memory services, higher use of acute care and crisis services and lower use of routine care services, based on current literature. They also examined whether minority ethnic groups presented to memory services with more advanced dementia or lower cognition.

The review identified 20

studies, in total involving nearly 100,000 older adults with dementia or mild cognitive impairment; most of the studies were from the US (13), the UK (4), Australia (1), Belgium (1) and The Netherlands (1).

The researchers concluded that there was little evidence that minority ethnic groups in any country accessed routine care at different rates than comparison groups, although there was strong evidence that African American/Black groups had higher use of hospital inpatient services

versus US comparison groups. Less was known about primary care and emergency services.

They say the study quality was mixed, with a large amount of variability in the way ethnicity and service use outcomes were ascertained and defined.

Co M, Couch E, Gao Q et al (2020) Access To Health Services In Older Minority Ethnic Groups With Dementia: A Systematic Review. *Journal of the American Geriatrics Society*. First published 24 November 2020: doi: 10.1111/jgs.16929

COVID-19 resources

The Centre for Health Services Research at the University of Queensland has led on the publication of resources to support the delivery of quality of care for people with cognitive impairment in hospital in Australia during the COVID-19 pandemic. The key resource is titled **Going To Hospital During The COVID-19 Pandemic: Guidance For Adults With Dementia Or Other Cognitive Impairments, Their Care Partners And Families**, and an accompanying background document for health care professionals. A two-page poster is also available with a flow chart setting out COVID-19 clinical strategies for people with cognitive impairment. A number of organisations were involved in the development of the resources, including the Australian Commission on Safety and Quality in Health Care and the Dementia Australia Advisory Committee. Available at <https://bit.ly/2VrSn8P>

The website for NSW's Agency for Clinical Innovation hosts a hub of resources developed by the **Pandemic Kindness Movement** – a resource created by clinicians across Australia, working together to support all health workers during the COVID-19 pandemic. The hub brings together evidence-informed resources and links to valuable services to support the wellbeing of the health workforce – and presented within sections based on an adaption of Maslow's hierarchy of needs (basic needs, safety, love, belonging and so on). The resources are intended to be shared with health workers who need support and can be accessed digitally or printed. To access, go to <https://aci.health.nsw.gov.au/covid-19/kindness>

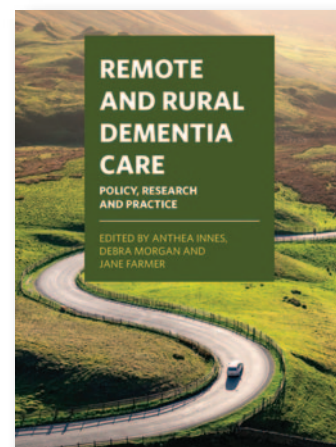
Dementia Australia released four Help Sheets in response to the COVID-19 pandemic – and these have now been translated into 38 languages. The four help sheets include **Tips For People Living With Dementia** which outlines the coronavirus symptoms, hygiene tips, the importance of having a good support network, ideas to remain active and engaged while in self-isolation, and where to go for help; **Tips For Carers, Families And Friends Of People Living With Dementia** which outlines the coronavirus symptoms, hygiene tips, helpful tips for primary carers, as well as for family, friends or neighbours, ideas for remaining active and engaged while in self-isolation, and where to go for help; **Tips For Residential Care Providers** which outlines the impacts coronavirus may have on residents, tips on alternative activities and how to support continued engagement with families and carers; and **Tips For Home Care Providers** which outlines the impacts coronavirus may have on a person living with dementia, tips to reduce heightened anxiety and where to go for help. To access the resources, go to

www.dementia.org.au/languages and search according to the relevant language.

Saying Goodbye: A Resource For Care Homes is a new publication from NAPA, the National Activity Providers Association in the UK. The 22-page resource brings together a collection of information sheets and aims to support care staff and teams to acknowledge the losses experienced by those living and working in residential aged care during the COVID-19 pandemic. Topics covered include: 'How to say goodbye', 'Supporting loss and saying 'goodbye'', 'Supporting people living with dementia in care homes to respond to loss and grief', 'Loss and grief in the care home', 'Acknowledgment of the death of a resident', and 'Showing respect after death'. The content has been developed by a range of organisations and individuals, including the Association of Dementia Studies at the University of Worcester, dementia consultant Danuta Lipinska, and staff from St Christopher's Hospice in London. Access the resource at <https://bit.ly/3fsPU71>

Researchers from University College London have worked with family carers of people living with dementia to develop a decision aid titled **Supporting You To Make Decisions While Caring For Someone Living With Dementia During Coronavirus (COVID-19) and Beyond**. The 19-page guide is aimed at carers who may be forced to make rapid and difficult decisions regarding a person living with dementia who becomes unwell due to suspected or confirmed COVID-19. It includes sections on wishes and preferences, advance care plans, managing care at home, supporting someone in a care home, hospital care, and care for the carer. The document is set out with space to enter responses, ideas and decisions. Although much of the information is UK-specific, the key decision-making steps are helpfully explained with clear suggestions for issues to consider, which will be relevant to anyone leading on the care of a person with dementia who has COVID-19. The guide is available at <https://bit.ly/3l3IKs8>

The Social Care Institute for Excellence (SCIE) has published online a collection of resources to support care homes emerging from COVID-19 lockdown, titled **Care Homes And Supported Living: Learning And Sharing Following The COVID-19 Lockdown**. The resources are grouped into three learning areas: 'Staff wellbeing', 'Balancing infection control with wellbeing', and 'Opening up care homes and supported housing', and include examples from a range of care homes, some of which support people living with dementia. The resource highlights key learning from the examples and provides links to related helpful resources. Access the resource at <https://bit.ly/3l1R5vq>



Policy Press is the publisher of a new book entitled **Remote and Rural Dementia Care: Policy, Research and Practice**, edited by Anthea Innes, Debra Morgan and Jane Farmer (Swinburne University of Technology; see p2 of this issue). One of the chapters focuses on Australia: 'Addressing Dementia Needs in Australia' and was contributed by Irene Blackberry (a co-author in this issue of *AJDC*), Clare Wilding, Michael Bauer, Margaret Winbolt and Hilary Davis. Other chapters consider the experience of people with dementia living in rural areas in other countries, including Norway, Ireland, Austria, Canada and Scotland.

Distributor NewSouth Books is offering *AJDC* readers a 30% discount when purchasing this book. To order, email ads@alliancedist.com.au with your name, delivery address (excluding PO boxes), quantity required, book title and ISBN (9781447344957). The price for *AJDC* readers is \$69.99 (normally \$99.99, hardback) plus \$12.50 delivery. Free delivery for 3+ copies.

The Australian Association of Gerontology (AAG) has published a position paper titled **Wellness & Reablement For All Australians Receiving Home, Community & Residential Aged Care Services**. The paper presents 10 core principles to ensure that the needs, strengths and preferences of older people are met through wellness and reablement approaches across aged care. Principle 2 refers to the need to include support to address the impact of cognitive disability on day-to-day

functioning (including health, mental health and emotional wellbeing). The AAG says the purpose of the paper is to provide clear direction to the Australian Government, policymakers and service providers on the core principles of wellness and reablement in aged care. Available at: www.aag.asn.au/documents/item/3692

Academic Press (under Elsevier) has published a new 288-page book, **Dementia Rehabilitation: Evidence-based Interventions And Clinical Recommendations**, co-edited by Lee-Fay Low and Kate Laver. The book opens with a chapter from dementia advocate Kate Swaffer, writing on 'Rehabilitation: a human right for everyone'. The book's 13 chapters cover broad terrain, including communication, cognitive treatments, maintaining physical functioning, leisure activities, driving, employment and buildings and design. Each chapter presents the research evidence followed by practical information on clinical assessment and delivery of therapies. The book is aimed at health and social care professionals, service planners, policy makers and academics, and costs \$A211.99. To find out more, go to www.elsevier.com/

BBC Music has launched a 'Music and dementia' initiative, working with over 100 organisations in the UK to help bring music to people living with dementia. A key part of the initiative is **BBC Music Memories**, which features nearly 3000 free, 30-second music clips, with links to full-length tracks on Spotify and Apple Music, to stimulate memory through music. The BBC hopes that families, friends and carers will work alongside people living with dementia to identify personally meaningful music and create playlists. Find the resource here: <https://music.memories.bbcrewind.co.uk/>

The Cochrane Library is the name given to the collection of databases that contain different types of high-quality, independent

Tips for dementia-friendly Zoom meetings

Members of the Dementia Australia Advisory Committee (DAAC) – all people living with dementia – have developed a range of new resources to support the use of video conferencing, in particular using the Zoom video conferencing platform.

DAAC members had spoken about the challenges of using Zoom, and DAAC member and AJDC Editorial Advisor Dennis Frost suggested the group develop some resources to support people living with dementia to navigate Zoom video conferencing, particularly given how reliant most people are on this platform since the pandemic.

The result is a group of resources – two guides and three help sheets – that include practical step-by-step instructions on how to use the technology, and helpful tips on how to get the best out of the online experience, including preparing written signs to use during the meeting such as 'I want to speak' or 'I agree'.

There are also tips on how to hold a dementia-friendly meeting, including taking a five-minute break every 30-45 minutes or when needed, ensuring everyone's name is clearly displayed on screen, and making sure any meeting papers are emailed rather than in a link.

Members of the Advisory Committee developed the resources, and then sought feedback from others living with dementia and staff from Dementia Australia.

The two guides are titled **Using Zoom: Guidelines For Meetings** and **Using Zoom: Participating In Meetings**, and the four help sheets are titled **Zoom Tips: How To Join A Meeting; Zoom Tips – How To Get The Best Out Of The Experience; Zoom Tips: On Holding A Dementia-Friendly Meeting; And Zoom Tips: Tools And Examples**. The free, online resources are available at <https://bit.ly/2IWCOMZ>

evidence to inform healthcare decision-making – the most well-known of which is the Cochrane Database of Systematic Reviews. From time to time, the Cochrane Library curates a Special Collection which brings together all its reviews on a particular topic as a way of making the research more accessible to a wider audience, including clinicians and policy makers. In September, the Cochrane Library published online an updated version of its **Special Collection On Diagnosing dementia** (originally published in 2019) which brings together all the reviews focusing on test accuracy of cognitive screening tests and questionnaires, including the Mini-Mental State Examination (MMSE), Mini-Cog, the Montreal Cognitive Assessment (MoCA), the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE), and AD-8. A brief introduction is given for each review, setting out the aim of the research inquiry. Access at <https://bit.ly/3nRyDHW>

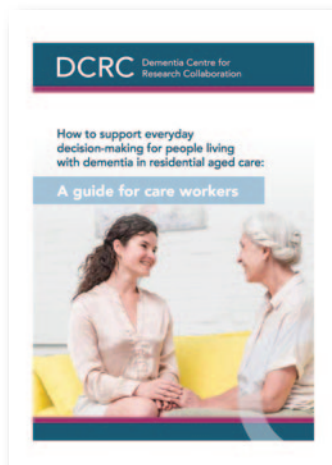
Dementia Australia's Centre for Dementia Learning has developed three online interactive education sessions for aged care workers working in residential and community care: 'Engaging and connecting with people living with dementia through COVID-19', 'Supporting behaviour changes during COVID-19

restrictions' and 'Understanding dementia'. The sessions – being badged as **Virtual Classrooms** – can be delivered to groups of up to 25 staff, who can be in different locations. The cost for a group of 25 staff is \$985; the cost for an individual is \$55. The Centre for Dementia Learning says a person-centred approach is the focus for the courses, with staff encouraged to get to know the person – to understand their needs, to learn about their abilities and to be flexible in their approach. Find out more at <https://bit.ly/3pUp3FV>

The Association for Dementia Studies at the University of Worcester has published **All Those Who Wander Are Not Lost: Walking With Purpose In Extra Care, Retirement And Domestic Housing**, a 20-page report summarising recent research conducted with UK housing provider Housing 21. The study's aim was to explore and understand walking with purpose among people living with dementia in extra care, retirement and domestic housing settings, along with the perceptions and responses of staff and family carers, in order to develop good practice guidelines (in development). The study consisted of a scoping literature review, an online survey

distributed to housing providers, and case studies involving interviews with key staff and family members. The researchers concluded that, although residents who walk with purpose constitute a minority of people living in retirement and extra care housing schemes, managing walking with purpose can be a challenge for management and staff and can occupy a disproportionate amount of their time. The report presents about 20 recommendations across various aspects: the resident who engages in walking with purpose; care culture, management and staff; other residents; family and other stakeholders; and design and assistive technology. The report can be found here: <https://bit.ly/3ft0pax>





Latrobe University researchers Dr Jo-Anne Rayner, Dr Deirdre Fetherstonhaugh and Dr Michael Bauer have written a new accessible guide for residential aged care staff, with the Dementia Centre for Research Collaboration. The 11-page guide, **How To Support Everyday Decision-Making For People Living With Dementia In Residential Aged Care: A Guide For Care Workers**, begins by exploring some key questions: 'Why people with dementia should be supported with everyday decision-making and have choices', 'How do you know that a person with dementia can make decisions?', and 'How can you support residents with making everyday decisions and making choices?'. It goes on to explore how to assist decision-making in a range of practical situations, for example, about clothing and personal appearance, when and what to eat, who to spend time with, participation in lifestyle activities, showering or bathing, and going to bed and getting up. The guide is available at <https://bit.ly/3l0kl5G>

A Singapore-based philanthropic organisation called the Lien Foundation has commissioned and published a creative design guide to better support people living with dementia. The 240-page online resource, called **Hack Care: Tips And Tricks For A Dementia-Friendly Home**, has the appearance of an IKEA catalogue, and although the

book is not affiliated with IKEA, many of the 50+ ideas in the resource involve an adaption (hence the word 'hack') of a familiar IKEA product – adjusted to better support the needs of a person living with dementia. The resource is the work of Lekker Architects and industrial designers Lanzavecchia + Wai. The Lien Foundation says the aim of the resource is to bridge the gap between design principles and practice by using IKEA items that are accessible and easy to use. The highly visual and colourful catalogue has two key sections: 'Microworlds' (focusing on specific items such as the chair) and 'Daily rituals' (focusing on topics such as mealtimes), alongside reflective contributions. The resource can be accessed at <https://hackcare.sg/>

DEEP – the UK's Dementia Engagement and Empowerment Project – supports a growing network of over 100 peer support and advocacy groups for people living with dementia. Four DEEP groups (Ashford Phoenix, Pathways in Bradford, the peer support group at Beth Johnson Foundation and SUNshiners) have now worked with film-makers Biggerhouse to make 22 films which, together, are called **DEEP Moments**. The films were all co-produced by the DEEP group members, working on a range of tasks including planning, script writing and sound recording, and according to DEEP "are the films that people with dementia wanted to make" – about what it's like to live with dementia, and what life with dementia feels like. The first film in the series (4.5 minutes long) acts as an introduction to the series. To access the films, go to www.dementiavoices.org.uk/deepmoments/

HammondCare's Dementia Centre has published a two-page position paper on **The Use Of Floor-Mounted Wayfinding Signage For People With Dementia Living In Residential Care**.

The paper considers whether two propositions are true or false ('The best way to help people with dementia find their way is with signage' and 'Floor stickers help people with dementia and vision impairment find their way'), and presents arguments and evidence in response. It includes a series of recommendations, the first of which is that signage should be used minimally in a residential care home environment, and only when other strategies for improving wayfinding have been implemented.

HammondCare concludes that the physical layout of a space or building is the most critical factor for how effectively a person with dementia will be able to navigate – rather than the signage. The resource is available to download from The Dementia Centre's website at <https://bit.ly/2OYzrLH>

The World Dementia Council (WDC) has published two short reports drawing on its 2019 work exploring the evidence base for dementia-friendly initiatives. This work involved a year-long consultation to gather international evidence on the design and delivery of dementia-friendly initiatives and involved a literature review, field survey and a number of consultation events, including one in Sydney in September 2019. Due to COVID-19, the WDC has decided not to publish one major report as a result of this work – but instead to release a series of papers, the first two of which have now been released. The first, **Defining Dementia Friendly Initiatives**, examines the context for the development of 'dementia friendliness' and summarises the three main types of dementia-friendly initiatives (raising awareness, enabling participation, and providing support). The second paper, **Methodology and Bibliography**, reports on the project's methodology and presents key references for the work. Both are accessible from <https://worlddementiacouncil.org/DFIs>



Hear Our Voice! Guidelines For Involving People With Dementia In Policy, Advisory, Consultation And Conference Activities is a new 24-page resource co-produced by The Centre for Economic and Social Research on Dementia (National University of Ireland), The Irish Dementia Working Group and The Alzheimer Society of Ireland. The resource aims to provide guidance for individuals and organisations that wish to involve people with dementia in their work or to gain their views in a formal way. The guidance begins with general principles and goes on to cover a wide range of practical matters: interaction; communication; providing information; venue; travel; consent; support; recognition and acknowledgment; payment/expenses; and general guidance on all types of involvement. The resource can be accessed at <https://bit.ly/3JSLb0z>

The Life Changes Trust has published **Loud And Clear: Exploring Two Decades Of Involvement, Voice And Activism By People With Dementia In Scotland**, written by Philly Hare. The book tells the story of how people with dementia in Scotland have campaigned for social change over the past 20 years, in particular the work of the Scottish Dementia Working Group (SDWG) continuing through to the work of various DEEP (Dementia Engagement and Empowerment Project) groups in Scotland. The book chronicles the involvement of

people with dementia in all sorts of activism, including research, collaborations with artists, and the influence of Scottish dementia advocacy in the wider world, for example on Japan and Australia. Some key individuals feature prominently – such as James McKillop and Agnes Houston – but many others' voices are included too. The book features case studies (demonstrating the impact of dementia activism), an easy-read accessible, three-page summary (which can also be downloaded separately), and an appendix with practical tips for newer activists. The book is available on the DEEP website, at <https://bit.ly/3f0Ldj6>

Dementia – A Whole Life

Approach is the title of a boxset of resources launched by the Life Changes Trust in Scotland. The Trust was established in 2013 with a substantial lottery endowment, half of which (\$A45 million) was allocated to the Trust's Dementia Program of work. This boxset presents much of the learning from work completed from 2015-2019, with contributions from a wide range of organisations and individuals involved with the program. The five volumes of the resource are: 'Human rights and dementia', 'Community and dementia', 'Independence, confidence and support', 'Peer support and dementia', and 'Information, awareness and training'. The resource is worth exploring due to the sheer size and breadth of this work program, shaped from the outset by the involvement of people with dementia, although much of the information is Scotland-specific. The boxset can be accessed on the Life Changes Trust website at <https://bit.ly/2P35lkl>

Good Practice In Young Onset Dementia: Improving Diagnosis And Support For Younger People With Dementia

is the title of a new resource from YoungDementia UK, which reports on results from The Angela Project, a three-

year study on younger onset dementia, and the largest ever conducted in the UK. The resource aims to present the study's findings and recommendations in an easy-read, summarised form, supported by quotes and images. The study involved gathering views of professionals and over 230 people living with or caring for someone with younger onset dementia, through interviews and a survey, as well as auditing 500 sets of case notes. Key recommendations relate to diagnostic accuracy, the individual's experience, care plans, and service design and development. The research was funded by the Alzheimer's Society and carried out by the universities of Bradford, Northampton, Surrey and UCL in partnership with Dementia UK and YoungDementia UK. The resource is available on the YoungDementia UK website at <https://bit.ly/30ZI27E>

The Australian Commission on Safety and Quality in Health Care has published a new guide, titled **My Healthcare Rights: A Guide For People With Cognitive Impairment**, which explains the rights all people have to safe and high-quality care, informed consent and open disclosure. The guide covers topics such as 'What do I need to know?', 'What can I do?', 'What can I expect?', and 'What if things don't go to plan?', as well as links to further resources. An easy-read version



of the guide (**About Healthcare Rights For People With Cognitive Impairment**) is also available. Access the guide here: <https://bit.ly/2Z1OZ6B>

The *Journal of the American Medical Directors Association* has published a new article, **Medication Management in Frail Older People: Consensus Principles for Clinical Practice, Research, and Education**, based on the work of the Optimizing Geriatric Pharmacotherapy Through Pharmacoevidence Network, which includes several researchers from Australia's Monash University's Centre for Medicine Use and Safety (CMUS). The consensus position includes seven principles for clinical practice, six principles for research, and four principles for education. The authors say that these principles can be used in conjunction with existing best practice guidelines to help achieve optimal health outcomes for this vulnerable population, and that implementation will require multidisciplinary collaboration between healthcare professionals, researchers, educators, organisational leaders and policymakers. Access the full article here at <https://bit.ly/2R66NZT>

The Dementia Centre for Research Collaboration (DCRC) has published a set of 20 **LGBTI Fact Sheets** within its collection of BPSD Resources, arising from the DCRC's BPSD research project. The DCRC says that the aim of the fact sheets is to provide background information on the lived experiences of LGBTI peoples which can influence the presentation of behaviours and the additional considerations relevant to their care. The fact sheets are aimed at care staff and health professionals working in all care settings, and vary in length. Topics covered include for example fact sheets on 'Personal history and lived experience', 'Disclosure and identity', 'Mental and physical

health', 'Young onset dementia' and many others. Access the resources here: <https://dementiaresearch.org.au/resources/lgbti-factsheets/>

The Young Dementia Network in the UK has published a leaflet intended to help a person to be aware of the most common signs and symptoms of younger onset dementia, and to record changes and symptoms they may be experiencing. The leaflet includes a checklist with 20 questions, such as 'Are you feeling less mentally 'sharp' than in the past?', 'Have you developed problems with reading, managing money, figures or other mental skills?', and 'Are you finding it harder to keep up with work demands than you used to?'. The idea is that the checklist is used as a prompt for a conversation with a GP or health professional – it is not intended to be a diagnostic tool. In November 2020, Young Dementia UK (the organisation behind the resource) merged with Dementia UK, and both organisations will now use the title of Dementia UK. The checklist can be found at www.youngdementiauk.org/young-dementia-network

The European Journal of Neurology has published **A European Academy of Neurology Guidelines On Medical Management Issues In Dementia**. The guidelines have been in development for some time and are based on a systematic review of literature and the Grading of Recommendations, Assessment, Development and Evaluations (GRADE) framework. The guidelines' recommendations for clinicians cover five key areas: systematic medical follow-up for patients with dementia, management of vascular risk factors in dementia, management of pain in dementia, management of agitation/aggression in dementia, and management of epilepsy in dementia. The full guidelines can be found here: <https://bit.ly/33ci959>

Dementia care event listings are available on the **AJDC** website at www.journalofdementiacare.com

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