Australian Journal of
DementiaCare

For all who work with people with dementia
Vol 9 No 4 October/November/December 2020

Workforce training & education

44-page special issue

Also inside this issue:

- Dementia care during COVID-19
- Speech pathology and reablement
- Resources to support staff wellbeing
- Excellence in palliative care

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Thinking big

By **Professor Belinda Goodenough**,
Australian Journal of Dementia Care Co-Editor and Executive Director, Dementia Training Australia

Australians have a long-standing affection for building big structures and sculptures. The start of this phenomenon is credited to the Big Banana in Coffs Harbour NSW, which began life in 1964 as an advertisement for a banana stall. There are now at least 150 larger-than-life cultural icons dotting the nation, and even a Wikipedia entry listing Australia's Big Things (Wikipedia 2020). It is possible to use Google Maps to plot a Big Things road trip, and share stories with fellow travellers via a dedicated Facebook page.

Overall, 2020 has been a year for contemplating the big issues (both good and bad) in dementia care, and associated workforce training. For aged care, recent research has suggested that Australia needs a minimum 37% increase in staff hours to improve care quality (Eagar *et al* 2019). As a flow-on effect, any increase in the size of the aged care workforce (for whom dementia is arguably core business), will necessarily require relevant increases in national capacity to train and educate those staff.

The focus in this issue of *AJDC* on workforce training and education is therefore timely. Supporting quality dementia care will require a huge collaborative effort involving many players, including Dementia Training Australia (DTA). Some of DTA's major training initiatives are profiled in this issue, along with others from Dementia Support Australia and Dementia Australia.

Each of these organisations has certainly stepped up in a big way during 2020 to ensure the workforce continues to have access to quality education initiatives, using virtual and remote delivery. At first, these approaches were devised as interim solutions to the COVID-19 restrictions, but the big prediction is that these changes to training delivery may endure beyond the pandemic, as people have become more comfortable with remote learning. Indeed the name 'Zoom' has now become a household word.

Of course, this special 44-page issue of *AJDC* is also the first for the new editorial team since the big news of the transfer of the journal to a new home at the University of Wollongong, and managed by DTA. To celebrate the next *AJDC* chapter, the new team is exploring exciting ideas for the journal to augment its potential to support workforce capacity-building in dementia knowledge and understanding, based on feedback from our 2018 readership survey (see article pp4-5).

The *AJDC* team looks forward to helping the journal take its place in the big picture – and showcasing, among other things, the efforts of the aged care sector to embrace creative and evidence-based approaches to workforce training to improve the lives of people living with dementia.

Optimism that Australia's aged and dementia care workforce can continue to rise to the task is shown in the amazing efforts of staff on the frontline during the pandemic. They have continued to provide care and support whilst also protecting our most vulnerable citizens, especially in Victoria; to our workforce – the rest of Australia says the biggest thank you. ■

References

Eagar K, Westera A, Snoek M, Kobel C, Loggie C, Gordon R (2019) *How Australian Residential Aged Care Staffing Levels Compare With International And National Benchmarks*. University of Wollongong: Centre for Health Service Development, Australian Health Services Research Institute. Available at: http://bit.ly/RC-research-paper-1.

Wikipedia (2020) *Australia's Big Things*. Available at: https://bit.ly/2REDXjy.

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Details: https://journalofdementiacare.com/submissions/

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 Journal of DementiaCare
For all who work with people with dementia Vol 9 No 4 October/November/December 2020

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This special 44-page issue of *AJDC* focuses on training and education for the dementia care workforce, highlighting quality initiatives from Dementia Training Australia (DTA), Dementia Support Australia and Dementia Australia. It also features five pages on dementia care during COVID-19, including resources to support the wellbeing of care staff as they navigate these challenging times.

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Cover image: this issue of *AJDC* puts Australia's aged and dementia care workforce firmly in the picture, focusing on evidence-based approaches to workforce training and education to improve the lives of people living with dementia. See articles pp16-29.
Photo: iStock

AJDC: the next chapter

Co-Editors **Belinda Goodenough, Lyn Phillipson** and **Louisa Smith** introduce the next chapter for the *Australian Journal of Dementia Care*

In 2018, the *Australian Journal of Dementia Care (AJDC)* conducted its first readership survey since the journal's launch in 2012. In total, 159 readers responded, sharing insights on everything from how they used the journal through to a wishlist of suggestions for future content and format.

We are pleased to advise that the future has arrived.

Building on the solid foundation laid for the journal by the outgoing editorial board and senior staff (see previous issue of the *AJDC*), the journal's new owner and publisher, the University of Wollongong, along with the incoming team (see box next page) are exploring a range of new *AJDC* features – inspired by the 2018 readership survey (available at https://bit.ly/ajdc-reader-survey).

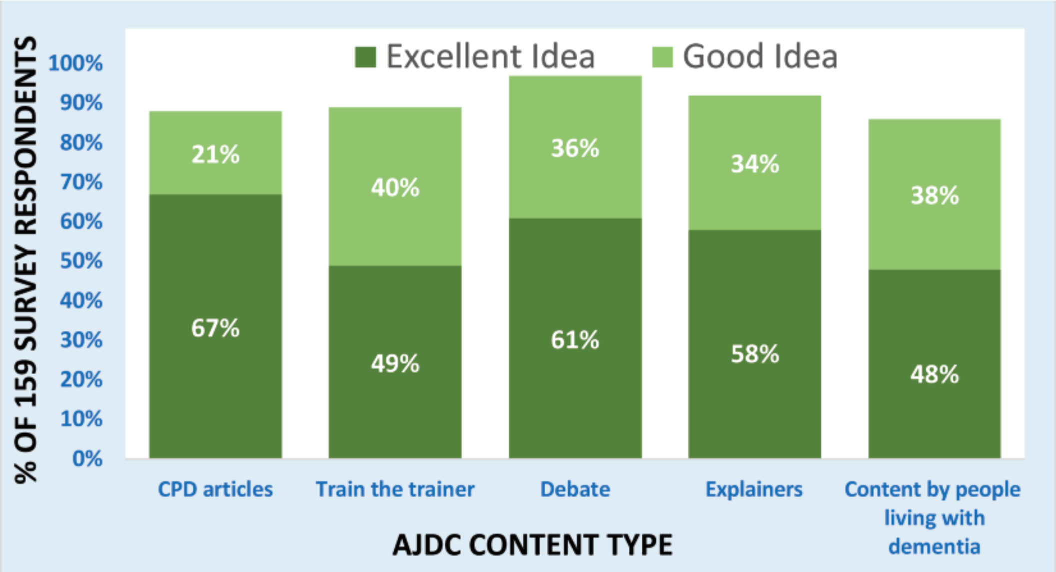


Figure 1: Rating of future *AJDC* content ideas (scale: Excellent, Good, Poor, No opinion)
Source: 2018 AJDC readership survey (https://bit.ly/ajdc-reader-survey)

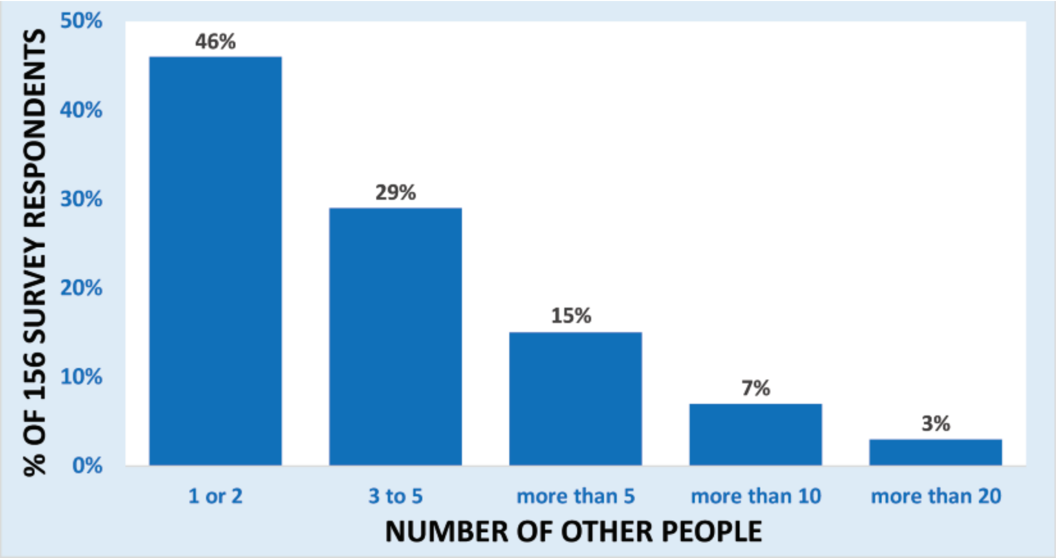


Figure 2. How many other people read your copy of *AJDC*?
Source: 2018 AJDC readership survey (https://bit.ly/ajdc-reader-survey)

Training and explaining

The survey confirmed that the *AJDC* is considered to be a go-to resource for educating and training the workforce about dementia. More than 80% of survey respondents endorsed ideas (as Excellent or Good) for more *AJDC* content that was useful for continuous professional development (CPD) and for training in-house educators (see Figure 1, this page). There were similarly high levels of enthusiasm for more *AJDC* content on debates and controversies, as well as topical explainers (including leading change).

In response to this feedback, *AJDC* is developing a new series of micro-courses in partnership with Dementia Training Australia (DTA). The short online courses will focus on selected *AJDC* articles and feature quiz questions to check understanding. Successful completion will be acknowledged with a certificate from DTA, which can be added to an evidence portfolio for CPD (see the article on p16 in this issue for more information about CPD).

Access to quality content

The *AJDC* will also welcome and commission more content that explains key topics in dementia, with attention to some of the debates that benefit from multiple points of view. We also want to be more inclusive of the lived experience of dementia, in content planning, reviewing and writing. For the first time in the journal's history, we are pleased that the editorial team now includes representation for people living with dementia.

The 2018 readership survey asked respondents to estimate how many other people would typically read through their copy of the *AJDC*. The results indicated that *AJDC* issues are well travelled. Almost half of the readers indicated that their copy of the journal was read by at least one other person – sometimes more than 20 (see Figure 2, above). In addition, when asked about where the

Along with their roles as *AJDC* Co-Editors, Professor Belinda Goodenough (top) is Executive Director of Dementia Training Australia, University of Wollongong (UOW); Associate Professor Lyn Phillipson (middle) is Principal Research Fellow in the Faculty of Social Sciences, UOW; and Dr Louisa Smith (above) is a Research Fellow in the Faculty of Social Sciences, UOW

AJDC was stored, 58% indicated that they put their copy of the journal in a public place for others to use. Only 3% threw it away!

After doing the arithmetic, we conservatively estimated that each printed copy of the *AJDC* was reaching at least four people (the recipient plus 3.6 others). This pass-it-on reach was also complemented by high levels of feedback encouraging the *AJDC* to grow its online presence. In fact, a third of respondents were keen to see the journal go fully online, which matched the preferences of another third who wanted to access the *AJDC* in print format only.

Given that 93% of respondents also indicated that they were likely to use an online article archive, the *AJDC* is planning to develop its digital offerings. We are now exploring ways to provide easier access to individual articles via the *AJDC* website, as well as develop the article submission portal to support a catalogue of more peer-reviewed content submissions, to be accessible online.

The new editorial team is looking forward to writing the next *AJDC* chapter. Do you have an idea for an article? If so, we would love to hear from you: please get in touch with the team via the Submissions page on the *AJDC* website, at https://journalofdementiacare.com/submissions/. ■

Introducing the *AJDC* team

The *Australian Journal of Dementia Care* (*AJDC*) has a new editorial team, based at the University of Wollongong, via the offices of Dementia Training Australia. You can read more about the backgrounds of the people in the new team on the *AJDC* website (www.journalofdementiacare.com/about-ajdc) – and notice the commitment to supporting early career researchers. We are keen to help the next generation of dementia researchers build their skills in bringing the best available evidence into contact with the experience of people living with dementia and those who provide support and care. We asked some of the editorial team to nominate an aspect of *AJDC* they would like to see develop, and present their responses below:

Dr Marita Chisholm, Innovation and Projects Manager, Older Persons Health, Rural Northwest Health	Dementia care in rural and regional Australia across a range of care settings (with an interest in the Aged Care Quality Standards).
Mr Dennis Frost, person living with dementia and dementia advocate; Chair of the Southern Dementia Advisory Group	Interested in research news, with the experience of the project participant, and promoting the active involvement of people living with dementia in all aspects of research, from concept to implementation, including the co-design and development of assistive technologies.
Professor Belinda Goodenough, Co-Editor *AJDC*; Executive Director Dementia Training Australia	More of the 'big picture' lens, to help practitioners and service managers understand the vision in national policy developments.
Ms Lynda Henderson, carer for a person living with dementia; member Southern Dementia Advisory Group	Co-designing research and practice innovations with people living with dementia, including the use of accessible assistive technology.
Dr Claire O'Connor, Research Fellow, HammondCare; Conjoint Lecturer, School of Population Health, UNSW	Translating research and evidence-based developments in dementia practice for people with lived experience of dementia.
Associate Professor Lezanne Ooi, Principal Research Fellow, University of Wollongong and the Illawarra Health and Medical Research Institute	Involving people living with dementia, carers and consumers in research design and research finding discussions.
Associate Professor Lyn Phillipson, Co-Editor, *AJDC*; Principal Research Fellow, University of Wollongong	Increasing the focus on life and care for people with dementia in community settings.
Ms Catherine Ross, Contributing Editor, *AJDC*	Growing a sense of community among *AJDC* readership through greater online engagement.
Ms Kerry Schelks, Managing Editor, *AJDC*	Increasing the range and depth of topics and opinions featured in the *AJDC* – making it even more relevant and useful to all those with an interest in dementia.
Dr Louisa Smith, Co-Editor, *AJDC*; Research Fellow, University of Wollongong, AHSRI, BAL	Supporting the inclusion of the voices of people with dementia and including these voices in debates about dementia care.
Dr Chris While, Training Consultant, Dementia Training Australia; Research Fellow, La Trobe University and the Australian Centre for Evidence Based Aged Care	Supporting dementia care leaders to mobilise new knowledge and create a learning environment that supports innovation.

News in brief

Korongee Village opening

Glenview CEO Lucy O'Flaherty (right) with the Governor of Tasmania, Kate Warner, at the Korongee Village launch

Korongee Village, a purpose-built development for people living with dementia, officially opened in Glenorchy, Tasmania on 14 July 2020. Korongee is a partnership between not-for-profit aged care provider Glenview Community Services, health sector superannuation fund HESTA and Social Ventures Australia (SVA). SVA manages HESTA's Social Impact Investment Trust which contributed $19 million to the development. The village, in Hobart's northern suburbs, features 12 houses in four cul-de-sacs, a community centre, gardens, hair salon, general store, café and wellness centre, and has been informed by extensive research on best practice models of dementia care. Glenview CEO Lucy O'Flaherty said Korongee was a "game-changer in addressing the big social challenges of dementia".

Aged Care Employee Day

#ThanksforCaring was the theme for this year's Aged Care Employee Day on 7 August, which held particular significance because of the current circumstances facing aged care workers. The annual day was initiated by aged care provider Whiddon in 2018 and is now led by Leading Age Services Australia (LASA). "Aged care employees are on the frontline every day working to provide care for Australians, including those living with dementia," Dementia Australia CEO Maree McCabe said. "On Aged Care Employee Day, and every day, we acknowledge aged care staff for their professionalism, compassion, empathy, dignity and the care they provide," she said.

Postgraduate scholarships

The Dementia Centre for Research Collaboration (DCRC) and the National Health and Medical Research Council (NHMRC) are inviting applicants to apply for the 2021 DCRC Postgraduate Research Scholarships for Dementia Research. Three PhD scholarships are on offer at $30,000 per annum for up to three years starting in 2021. DCRC says that candidates undertaking research into dementia care and prevention will be prioritised for funding. Applications close on 2 December 2020. For more information and full details regarding eligibility, go to https://bit.ly/329dGjz or email DCRCgrants@unsw.edu.au.

DEMON Network launch

An international network for applying data science and artificial intelligence (AI) to dementia research has launched – known as the Deep Dementia Phenotyping (DEMON) Network. The new network brings together academics, clinicians and other partners and now has over 500 members from across the world. It is led by DEMON's Director Professor David Llewellyn at the University of Exeter with support from Alzheimer's Research UK, the Alan Turing Institute, Dementias Platform UK and Dementia Research Institute (DRI). The network intends to offer a range of training, networking opportunities, seminars and workshops, as well as coordinated engagement with industry. To find out more about the network, go to http://demondementia.com/.

Dementia Action Week

A new survey conducted by Dementia Australia has revealed that people living with dementia continue to feel isolated and excluded – with as many as three out of four people with dementia surveyed saying that people don't keep in touch like they used to, and 65% saying people they know have avoided or excluded them.

The survey findings were released at the start of Dementia Action Week – which ran from 21-27 September. The week's theme – "Dementia. A little support makes a lot of difference" – and the campaign associated with it were developed in consultation with people living with dementia, many of whom shared their story as part of the week's events.

Dementia Australia says the findings reveal just how big an issue discrimination is and the impacts it has for people living with dementia, their families and carers.

Dementia Australia CEO Maree McCabe said while the survey findings are distressing for people living with dementia, it would not take much to turn those findings around.

"A little bit of support can make a really big difference to someone with dementia," she said.

Lancet Commission revisits risk factors

'Be ambitious about prevention' is a key message from The Lancet Commission's 2020 report, *Dementia Prevention, Intervention And Care* – in which it revisits its 2017 report findings on this topic, and adds a further three modifiable risk factors for dementia: excessive alcohol consumption, traumatic brain injury and air pollution.

The 2020 publication reports on the growing body of evidence for the nine potentially modifiable risk factors for dementia first put forward by the Commission in 2017: less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, and low social contact. It says new reviews and meta-analyses conducted by the international team behind the Commission have only confirmed the evidence for these nine factors.

It also says "newer, convincing" evidence now exists to support the conclusion that excessive alcohol consumption, traumatic brain injury and air pollution should be added to this list.

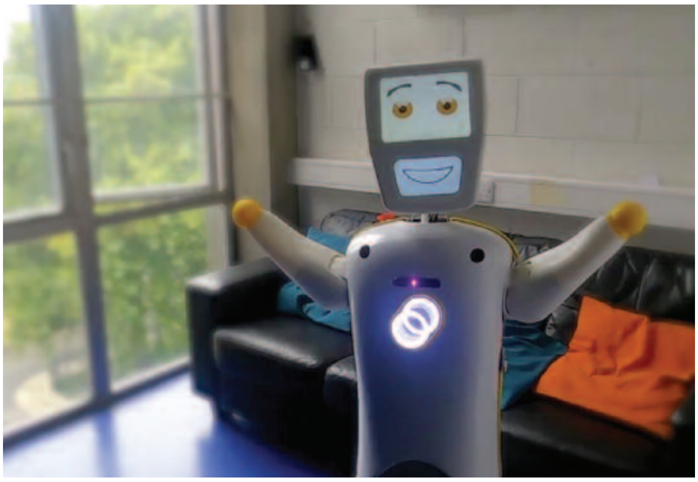
The Commission says that together the 12 modifiable risk factors account for around 40% of worldwide dementias, which theoretically could be prevented or delayed, and that the potential for prevention might even be higher in low- and middle-income countries where more dementias occur. It refers to its model as a "life-course model" of dementia prevention and urges action on the part of both individuals and policy makers to realise the significance of these findings.

The report recommends some specific actions for risk factors across the life course, such as aiming to maintain systolic blood pressure of 130mm Hg or less in midlife from around age 40 years and encouraging use of hearing aids for hearing loss. It goes further to make recommendations aimed at supporting people who are already living with dementia: provide holistic post-diagnostic care, manage neuropsychiatric symptoms, and care for family carers.

The report was launched at the Alzheimer's Association International Conference in July 2020. It is available to read in full in *The Lancet* at https://bit.ly/3hd2CGm.

Stevie the Robot takes centre stage

A robot who featured on the front cover of *Time* magazine has taken centre stage at the HammondCare International Dementia Conference, held on 21-22 September 2020, introducing a session on the role of technology and Artificial Intelligence (AI) in dementia and aged care.



Stevie (pictured), who stands about 1.4m tall, weighs about 60kg and has two stubby arms, made a guest appearance at the conference via video link from his Trinity College Dublin Department of Mechanical and Manufacturing Engineering workshop, where work continues on his sensors and software.

HammondCare describes Stevie as "the world's most advanced social robot". They say he has been designed to live and work in retirement communities, augmenting rather than replacing the role of carers, freeing them up to focus more on person-centric tasks and so improving care outcomes for residents.

According to HammondCare, plans are underway for Stevie to be involved in a research trial in an aged care home in Australia next year following on from other pilots in Ireland, the US and most recently in a UK dementia care facility in Cornwall.

Assistant Professor Connor McGinn, who is leading the research group that created Stevie at Trinity College Dublin, discussed the latest progress in the robotics project during the session at the HammondCare conference.

Associate Professor McGinn told the conference that Stevie can potentially carry out everyday tasks in aged care, such as make video calls to loved ones and control lights, but his real value is emerging in how he can provide social interaction – or fun.

Watch a short video of Stevie here: https://vimeo.com/455776099/051d291881.

CALL-OUTS FOR RESEARCH PARTICIPANTS

The AJDC website now includes a section which lists Australian dementia and aged care research studies currently recruiting for participants to take part or complete surveys. AJDC provides these listings as a free service for Australian researchers wishing to invite people to participate in their research, and members of the public who are interested in participating or being involved. Here are two studies which are currently recruiting for participants. For more information, go to AJDC's home page (https://journalofdementiacare.com/) and click on 'Research: get involved'.

Transport technology and dementia

People living with dementia and their care partners are being invited to contribute to a new two-year study which will explore how new transport technologies – such as app-based ride-sharing services and driverless buses – could help people living with dementia improve their quality of life and levels of independence. The cross-disciplinary study will gather information about current and future transport technologies, identify possible issues from the perspective of people living with dementia and their carers, as well as other stakeholders, and will also develop key considerations for future transport technology development and research. The study is being supported by the Dementia Australia Research Foundation and the Dementia Centre for Research Collaboration. To find out more about the contactless research activities involved in the initial stages of the study, contact Dr Jacki Liddle on j.liddle@uq.edu.au.

Aged Care Data Compare project

Researchers at the University of Queensland's Centre for Health Services Research (CHSR) are seeking aged care providers, software vendors, geriatricians, health services researchers and developers to be involved in Aged Care Data Compare, a new project launched in July. The aim of the two-year project is to find out how assessment data routinely collected in residential aged care can be put to better use – to improve care, for greater efficiency and transparency, and to make it easier for organisations to report to government. The project is funded by the Digital Health Cooperate Research Centre, the Bupa Health Foundation and the Australian Department of Health. The project team, led by CHSR Director Professor Len Gray, aims to resolve technical challenges around the standardisation and sharing of valuable data, and ultimately to construct a prototype 'data hub' to support a quality benchmarking platform. The researchers are intending to set up clinical and technical working groups. To find out more and to register interest in the project, go to https://chsr.centre.uq.edu.au/aged-care-data-compare.

ADI report launch

Drastically improved dementia design in the built environment is needed across the world, according to Alzheimer's Disease International (ADI), which is calling on governments and multilateral bodies to overtly recognise dementia as a disability.

The call comes with the launch of ADI's latest *World Alzheimer Report*, titled *Design, Dignity, Dementia; Dementia-Related Design And The Built Environment*, on Monday 21 September – World Alzheimer's Day.

According to ADI, "most countries are woefully behind" in terms of making the built environment accessible for those living with dementia.

"We need to apply design guidelines and principles for people living with dementia in the same way as design guidelines are provided for people living with a physical disability," says ADI's Chief Executive, Paola Barbarino.

Co-author of the report, Professor Richard Fleming (pictured), says that dementia design is needed urgently, and our knowledge of how to do it has grown over the years.

"The rising number of people living with dementia requires that their needs are considered at the beginning of every building project that is likely to be used by elderly people. Dementia design should never be an afterthought," he said.

Recognising dementia as a disability is one of several recommendations from the *World Alzheimer Report 2020*, alongside the recommendation to incorporate dementia-related design into national dementia plans.

For more information on this report, go to the Resources section in this issue, on p43.

News in brief

Poor progress on dementia plans

Alzheimer's Disease International (ADI) is concerned that globally only 31 national dementia plans exist and that progress to develop plans is "far too slow". The comments come on the back of a new ADI report, *From Plan To Impact III: Maintaining Dementia As A Priority In Unprecedented Times*, which provides an overview of the current national responses to dementia around the world – with particular reference to the challenges and opportunities provided by the COVID-19 pandemic and how these relate to the care of people with dementia. The report takes as its starting point the World Health Organization's 'Global action plan on the public health response to dementia 2017-25', which includes the target that by 2025, 146 of the 194 Member States will have a national plan. The report includes a substantial number of case studies across all the action areas as well as contributions from key individuals. ADI is calling on all governments to dedicate a minimum of 1% of the societal cost of dementia to research.

UOW features in UK summer school

A team of researchers from the University of Wollongong (UOW), led by Associate Professor Lyn Phillipson, participated in a summer school being run by TEDI-London, a new design-led engineering school. Associate Professor Phillipson is lead investigator of the UOW's 'Connections for Life with Dementia' research program. The researchers shared their knowledge via webinars and online masterclasses with almost 150 students from across the world who were taking part in the program in the UK. As part of the process, students collaborated with people with dementia and their carers to create products and services that work for them. The Dean and CEO of TEDI-London, Professor Judy Raper, said, "We invited the UOW 'Connections for Life with Dementia' team to be part of the summer session due to its unique program of research supporting the creation of dementia-friendly communities."

Alliance's shared principles

Dementia Australia is one of a new alliance of aged care consumer and carer groups which have come together to share their vision for aged care – through the promotion of 10 shared principles, announced on 23 September.

The alliance includes Carers Australia, COTA Australia, the Federation of Ethnic Communities Council of Australia, National Seniors Australia and the Older Persons Advocacy Network.

The alliance says the 10 shared principles will help all older Australians get the support they choose, when and where they need it and be treated with dignity and respect, by an aged care workforce that is trained and equipped to provide the standard of care older Australians and their families expect and deserve.

The 10 principles are being summarised as:

- A better Aged Care Act.
- A simple system where care is guaranteed within 30 days.
- Full transparency and easy-to-understand indicators to help inform consumer choice.
- A trained, registered and qualified workforce.
- Proper recognition and support for the role of unpaid family/friend carers.
- Easy-to-understand information and local solutions.
- A strongly resourced regulator that takes robust action to ensure consumer protections.
- Services that are inclusive, culturally safe and sensitive.
- A funding model that ensures sufficient taxpayer funding, control by consumers over their funding, independent pricing and transparency in how funds are spent.
- Better integration of other health and wellbeing services with aged care.

The full statement is available to view on Dementia Australia's website at https://bit.ly/3iXRnmJ.

Cycling Without Age

HammondCare Strathearn, an aged care residential home in Scone in regional NSW, has taken ownership of two trishaw bikes – offering residents the chance to get out and about in the fresh air, with the assistance of volunteer cyclists who 'pilot' the bikes.

The trishaws, known as Triobike Taxis, are promoted by Cycling Without Age (CWA), the global, not-for-profit organisation founded in Denmark in 2012 that seeks to support older people to get out on bicycles.

CWA has now spread to 42 countries all over the world, including Australia.

Scone Chamber of Commerce President Stephen Guihot and local doctor Richard Abbott now volunteer to pilot the trishaws regularly.

Stephen said: "It's so motivating for the residents to be able to get out for a ride around town. They love it. They are lining up to have a go."

The purchase of the trishaws was made possible through a donation to the HammondCare Foundation courtesy of the local Paradice Foundation.

Strathearn Residential Care Manager Sarah Pearce said HammondCare was delighted to be able to make the trishaw trips available for residents.

"We appreciate the donation that made this possible and the local volunteers who are willing to give their time to take our residents for a ride," Sarah said.

To find out more about Cycling Without Age, go to https://cyclingwithoutage.org.au/.

Trishaw pilot Dr Richard Abbott with HammondCare Strathearn residents Daphne and Martin Eveleigh

Dementia Australia launches Action Plan

Leadership and culture change that supports dementia, building workforce capacity, and a commitment to continuous improvement, are the three fundamental components of a new Action Plan released in August by Dementia Australia, as part of its Quality Care Initiative.

Dementia Australia CEO Maree McCabe says the Action Plan represents a consensus view of thought leaders across the aged care sector.

"The Action Plan was developed by Dementia Australia in consultation with key decision makers within the aged care sector, including representatives from government, regulators, workforce and industry," Ms McCabe said.

The Action Plan is the next step in making the 2019 communique, 'Our Solution: Quality care for people living with dementia', translate into practical actions. Dementia Australia followed up the publication of the communique by leading stakeholder roundtable discussions in November 2019, which focused on how to embed quality dementia care consistently across the aged care system.

"Participants agreed that making dementia core business in the aged care sector requires a leadership choice, backed by organisational capability," she said.

The three key components of the Action Plan are:

- leadership and culture change that consistently supports dementia
- building workforce capacity to understand and support people with dementia
- a commitment to continuous improvement that embeds quality dementia care.

The Action Plan sets out specific actions that will be taken by all stakeholders – Dementia Australia, aged care providers, industry, the Government, and regulators – to deliver on these three elements.

The Action Plan was released as part of the online Dementia Australia National Symposium Series 2020, which included presentations from a range of local and international speakers, such as Professor John Pollaers and Professor Dawn Brooker.

Australian trio join DSDC: The University of Stirling's Dementia Services Development Centre (DSDC) in the UK has appointed Australia's Kirsty Bennett (pictured centre), Debbie De Fiddes (far left) and Terri Preece (far right) as Design Associates within its DSDC Design Team – a multi-disciplinary team of architects, engineers and designers specialising in dementia design.

The appointment of the trio, through the Evoke Collective Australasia, follows a successful number of years of DSDC working in Australia. As DSDC Design Associates, the Australian team will offer clients a full audit service which leads to the DSDC's independent Dementia Design Audit Certificate.

Ms Bennett is an architect and author specialising in designing for people living with dementia and co-author of the *World Alzheimer's Report 2020* on the built environment. Ms Preece is experienced in aged care sector management, operational design and policy. Ms De Fiddes is an interior designer with a focus on environments for older people and people living with dementia.

For more information, email Ms Preece at info@evokecollectiveaustralasia.com or visit https://bit.ly/36kywif.

AUSTRALIAN DEMENTIA NETWORK NEWS

Dementia Clinical Quality Registry

The Australian Dementia Network (ADNeT) has announced that the roll-out of the ADNeT Dementia Clinical Quality Registry is gathering momentum, despite delays related to the pandemic.

Five sites have now joined the network, after completing training: the Queen Elizabeth Hospital, Adelaide, Procognition on the NSW Central Coast, The Prince of Wales Hospital in Sydney, the SpARC Memory Clinic in SA, and Murrumbidgee Local Health District Aged Care Service.

ADNeT says the purpose of the registry is to become an effective tool for quality improvement in the diagnosis and care of dementia in Australia by identifying variations in clinical practice, benchmarking service providers and monitoring the effectiveness of treatments and care.

ADNeT expects to have 15 pilot sites providing data by the end of 2020. It says once the pilot is completed, it aims to have over 50 memory clinics and then wider community participation in the registry.

For more information, visit the ADNeT website (www.australiandementianetwork.org.au/) or contact the ADNeT Registry Program Manager on email ADNeT.Registry@monash.edu.

Memory clinics list

ADNeT is currently developing the first national list of memory clinics, with a view to offering a postcode search tool that will help primary care clinicians and people with cognitive impairment, as well as their family carers, to locate specialised assessment services in their area. Clinicians who offer a specialised assessment service for the assessment of cognitive decline and dementia (memory clinic or other private or public specialised service) and who would like to be listed should contact ADNeT via adnet.mc@unsw.edu.au.

Peer support program

ADNeT is also setting up a peer support program (for example offering webinars on specific topics to clinicians in memory clinics) and is currently obtaining expressions of interest from memory clinics clinicians (for more information email adnet.mc@unsw.edu.au).

Baird addresses International Dementia Conference as CEO

HammondCare's new CEO, Mike Baird (pictured), has given his first public address since becoming CEO. He was speaking at HammondCare's International Dementia Conference, held online on 21-22 September, and involving up to 6000 online participants.

In his speech, Mr Baird reflected on his personal experience of supporting his mother.

"I have a mum with multisystem dystrophy, and it has been a very difficult few years. And it was through my mum that I engaged with the aged care sector," he said.

"This is an incredibly important time for the aged care sector, not just here [Australia], but across the world," Mr Baird said.

HammondCare launched a range of new resources at the International Dementia Conference: for more information, see Resources, p42.

Royal Commission update

The Royal Commission into Aged Care Quality and Safety continues its work, with five hearings conducted in July, August and September in Melbourne and Sydney – though with no public access, due to COVID-19 restrictions – and the publication of a substantial body of research reports since July (see below).

By 31 July 2020 – the final date for general submissions – the Royal Commission had received 9301 submissions.

COVID-19 has also influenced the schedule for the Royal Commission, with the Prime Minister Scott Morrison extending the Royal Commission's reporting period for a further 3½ months. The Commission will now deliver its final report by 26 February, 2021.

The hearings

The five hearings conducted during July to September explored multiple issues:

- In Melbourne, from 15-17 July 2020: to examine the provision of mental health care, oral health care and allied health care to people receiving aged care services.
- Two hearings in Sydney from 10-14 August 2020: the first, to inquire into the response to the coronavirus (COVID-19) pandemic in aged care and, the second, to inquire into aged care accommodation.
- A virtual hearing from 31 August to 2 September 2020 to examine requirements for the delivery of high-quality and safe care to older people in their homes and in the community.
- In Sydney, from 14-22 September: on the financing and sustainability of future improvements to the aged care system, the appropriate funding model or models to support the delivery of aged care services, and the prudential regulation of aged care providers.

What the Royal Commission research says

Since July 2020, the Royal Commission into Aged Care Quality and Safety has published nine research reports, exploring a range of broad future-facing issues such as Australians' views on aged care, models for aged care, and future cost implications of aged care reform. These reports will play an important part in informing the findings and recommendations presented in the Commissioners' final report in 2021.

Research Paper 4, What Australians Think Of Ageing And Aged Care: Roy Morgan report sharing findings from a survey of 10,000 people seeking their views on ageing and aged care.

Paper 5, They Look After You, You Look After Them: Ipsos report sharing the findings of 35 focus groups and 30 in-depth interviews conducted during July-September 2019 about attitudes to ageing and aged care.

Paper 6, Australia's Aged Care System: Assessing The Views And Preferences Of The General Public For Quality Of Care And Future Funding: This Flinders University research showed that Australians strongly support increased funding to ensure universal access to high-quality aged care services in the future.

Paper 7, Models Of Integrated Care, Health And Housing: This paper prepared by the National Ageing Research Institute (NARI) provides an overview and analysis of integrated models of care for older people as they relate to health care, social care, and housing or accommodation in Australia.

Paper 8, International and National Quality and Safety Indicators for Aged Care: The new research from South Australian Health and Medical Research Institute examines practices in 11 countries and 305 care quality indicators. Countries examined include Australia, New Zealand, the US, Canada, the UK, The Netherlands, Germany, Denmark, Finland, Sweden, and Iceland.

Paper 9, Cost Of Residential Aged Care: The University of Queensland conducted this research using detailed financial data, a comprehensive set of care quality indicators for aged care homes, and a measure of relative care needs, which was developed by the University of Wollongong in Research Paper 10.

Paper 10, Technical Mapping Between ACFI and AN-ACC: The University of Wollongong conducted its research in collaboration with the University of Queensland. Their work provides a measure of relative care needs to assist with supplying data and care quality indicators.

Paper 11, Aged Care Reform: Projecting Future Impacts: This report from Deloitte Access Economics examines key aged care funding reforms the Royal Commission is considering. The modelling indicates reform would need new funding equivalent to a 1 percentage point increase in income tax rates.

Paper 12, Report On The Profitability And Viability Of The Australian Aged Care Industry: In this report, global professional services firm BDO analyses data supplied by aged care providers to the Australian Department of Health – and concludes that there is not enough transparency in the way this information is handled in Australia.

Guidelines on psychotropic medicines

Professor Simon Bell (pictured), Director of the Centre for Medicine Use and Safety at Monash University, will lead a multidisciplinary team to develop guidelines for the appropriate use of psychotropic medicines for people living with dementia – thanks to a grant of $200,000 from the Dementia Centre for Research Collaboration (DCRC).

The guidelines will consider clinical, social and legal dimensions of medication use, as well as non-pharmacological alternatives to psychotropic medications including person-centred approaches. DCRC says that implementation planning and regular stakeholder engagement will take place throughout the guideline development process.

"We propose to adopt, adapt, update and develop guidelines on psychotropic medications to incorporate best available evidence, including for Aboriginal and Torres State Islander peoples, people with intellectual disability and people from culturally and linguistically diverse backgrounds," said Professor Bell. "Our goal is to improve care for people living with dementia," he said.

Professor Henry Brodaty (UNSW Sydney and a Director of the DCRC) said that the DCRC had funded the guideline development in response to the high use of psychotropic medications in residential aged care facilities and the recommendation from the Royal Commission into Aged Care to avoid chemical restraints.

The guidelines are due to be finalised in April 2021.

International report on COVID-19 impact

The London School of Economics and University College London is leading an international collaborative effort to report on the impact and mortality of COVID-19 on people living with dementia across the world.

So far the team has collected data from nine countries: the United Kingdom (UK), Spain, Ireland, Italy, Australia, the US, India, Kenya and Brazil.

The 'living' publication, *Impact and Mortality of COVID-19 On People Living With Dementia: Cross-Country Report*, will be updated in coming months, but reported in August that people with dementia account for:

- 25% of all COVID-19 related deaths in England and Wales
- 31% in Scotland
- 19% in Italy.

Nation-level data has not been available for the rest of the countries.

The report authors conclude that the high rates of deaths in people living with dementia are linked to death rates in care homes, where many residents have dementia. They are concerned that in many places the basic human rights of people with dementia may have been compromised during the pandemic, and that guidelines and tools to support institutions and practitioners to respond better to the needs of people with dementia during the pandemic are required as a matter of urgency.

Alzheimer's Disease International (ADI) responded to the report by saying the global community must come together to form an action plan to protect people with dementia from the worst ravages of COVID-19, and that further data on dementia-COVID mortality is urgently needed.

Alzheimer's Disease International CEO Paola Barbarino

"We need transparency. Governments must incorporate dementia into COVID response plans to protect the millions of people impacted by dementia globally," says ADI CEO Paola Barbarino. "They deserve dignity, and we need justice for those who have sadly died," she said.

ADI is calling on governments to collect, analyse and publish key data, including mortality data and disruption to diagnosis, disaggregated by age, gender and the presence of pre-existing conditions, to help find critical solutions to mitigate risks and find solutions to a return to support for people living with dementia.

The report is available to download at https://bit.ly/3hbPdyg. The publication also reports on the impacts internationally of COVID-19 in terms of access to healthcare for people living with dementia; impacts on people living with dementia in the community; impacts on people with dementia living in care homes, and presents an overview of international policy and practice measures to mitigate the impact of COVID-19.

Federal aged care funding boost

The Minister for Health Greg Hunt and Minister for Aged Care Senator Richard Colbeck announced in late August that the Australian Government will provide an additional $563.3 million to extend support for the aged care sector's response to COVID-19.

The announcement came shortly after the Prime Minister's announcement that an additional $171 million would go to the sector, and earlier announcements in June and March.

The late August funding boost takes the Government's spending commitments to aged care to over $1.5 billion since the pandemic began.

The latest round includes a $245 million injection of the COVID-19 Support Payment provided to all residential aged care providers; a 30% increase in the viability supplement and the residential care homeless supplement for a further six months; and an extension of the Supporting Aged Care Workers in COVID-19 Grant, to help providers cover the costs of implementing single site workforce arrangements in the hotspots of Greater Melbourne and the Mitchell Shire.

Greg Hunt and Richard Colbeck

The Government will also provide a third Workforce Retention Payment based on employment at 30 November 2020, costing $154.5 million and will expand support for older Australians who temporarily relocate from residential aged care facilities to the community to live with their family due to concerns about COVID-19, with an additional $71.4 million for the Commonwealth Home Support Program.

Royal Commission on COVID-19

In a damning indictment of the aged care sector, the Royal Commission into Aged Care Quality and Safety's Senior Counsel Peter Rozen QC has concluded that "none of the problems that have been associated with the response of the aged care sector to COVID-19 was unforeseeable".

Mr Rozen made his remarks in the final session of the Royal Commission's hearing into the response of the aged care sector to the pandemic (held 10-13 August in Sydney). The particular challenges of COVID-19 restrictions for people with dementia came up repeatedly.

Mr Rozen said the sector was not well prepared for the pandemic, that the lessons from the early outbreaks at Dorothy Henderson Lodge and Newmarch House had not been properly conveyed to the sector, and further that the sector "is not properly prepared now".

By the final day of the hearing (13 August) there had been 220 deaths of residents in aged care due to COVID-19 – representing 70% of all the country's COVID-19 deaths. "On this measure," he said, "we're one of the worst performing countries in the world."

Mr Rozen called for a national aged care plan for COVID-19 to be put in place, overseen by a national coordinating body, with workforce challenges addressed as integral to the plan – given problems such as the casualised workforce in aged care, and the urgent need for clinical skills during an outbreak. At the time of going to press, the Commission was due to issue a special report on 30 September on the COVID-19 pandemic in aged care, with specific recommendations on measures to protect older Australians.

Review of care in time of COVID at International Dementia Conference

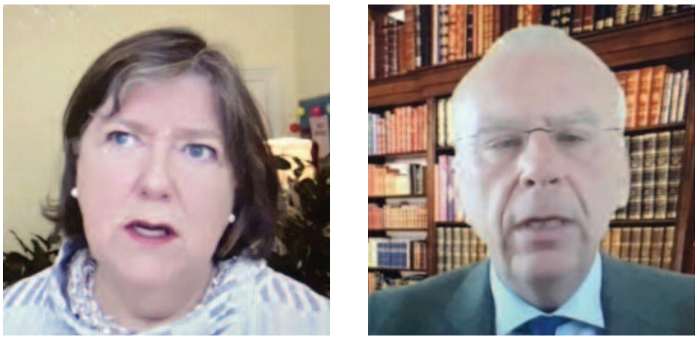
A panel of aged care experts representing the UK, The Netherlands and Australia has agreed that lessons from the pandemic must be integrated into the continuing and future pandemic response.

The discussion took place during a session titled ‘Care in the time of COVID’ at HammondCare’s virtual, interactive International Dementia Conference, held on 21 September.

Australia’s Professor Chris Poulos, Head of Research and Positive Ageing at HammondCare, said that, while the response overall in Australia has been “generally quite good”, the sector could have been more proactive about some of the measures to prevent the virus getting into aged care homes.

“We should have known earlier that we should have been restricting staff working across more than one care home – we were a bit late to the game with that,” he said.

He cautioned against blaming governments or providers though, saying, “This is about lessons learned and moving forwards.”



Professor June Andrews and Professor Wilco Achterberg, speaking during the virtual ‘Care in the time of COVID’ panel discussion during HammondCare’s International Dementia Conference

Professor Wilco Achterberg, a physician from The Netherlands, said that in the early part of the pandemic, aged care homes were not seen as an important part of the health care system and so missed out on vital planning and resourcing.

“The pandemic exposed an existing issue that our care home network, while providing very good care, was not taken seriously by the wider health sector,” Professor Achterberg said.

Professor June Andrews said one of the biggest challenges in the UK had been the number of older people in hospitals, waiting for a move to aged care, when the pandemic hit.

“In the UK, there was rushed response to suddenly move older people from hospitals into aged care, often without the normal transition processes,” Professor Andrews said.

Architect David Hughes, recent Chair and CEO of Pozzoni Architects, Manchester and London, said a key learning from the pandemic was that the small household model for aged and dementia care had proved effective for infection control.

Data in aged care

On 12 September 2020 the Australian Government began publishing a weekly ‘data snapshot’ of residential aged care facilities which have recorded COVID-19 infections – with a view to providing greater transparency for residents and their families around the situation in aged care facilities.

The data includes all aged care facilities where there has been more than one case in either a staff member or resident. It shows that of the 2706 aged care facilities in Australia, 213 (or 8%), have had cases of COVID-19, and of these, 115 facilities have had two or more cases (with 110 of these in Victoria).

The report says the death rate in aged care across Australia as a proportion of total aged care residents is around 0.32% (3.2 in 1000) compared to 5.3% in the UK.

It also shows that 32,398 aged care residents died between 1 January and 31 July 2020 compared to 33,383 residents for the same period in 2019. The report says the reduction this year is likely to be due to increased influenza immunisation rates and increased infection control protocols introduced during the pandemic.

Latest news from the ACQSC

The Aged Care Quality and Safety Commission (ACQSC) has confirmed that it is working with State and Territory governments and local health authorities across Australia to monitor and test preparedness of aged care residential services to further outbreaks of COVID-19.

It says it is drawing on lessons learnt from outbreaks in NSW and Victoria to ensure that all services nationally have well-tested plans, adequate training and infection control practices to minimise infection risks and to respond immediately, decisively and effectively if a positive case is identified in their service.

Unannounced spot checks conducted by the ACQSC initially in Victoria and NSW are being extended to all jurisdictions to observe infection control practices, and ensure that staff, management and visitors are adhering to safe personal protective equipment (PPE) protocols, and safe infection control arrangements.

The ACQSC says it modified its regulatory program in March 2020 to focus additional effort where it is needed most to ensure that providers are doing everything possible to keep aged care consumers safe.

Senate censure of Colbeck

The Senate has formally censured the Minister for Aged Care and Senior Australians, Senator Richard Colbeck, on a number of matters in relation to his handling of his portfolio during the pandemic.

Senator Penny Wong, the Leader of the Opposition in the Senate, put forward the motion to censure the Minister on 3 September on these grounds: (i) failing to recall the most basic and tragic facts about aged care residents (pertaining to his inability to recall basic information requested in a recent Senate committee hearing) (ii) describing his management of aged care as a “high water mark” (iii) dismissing deaths as a “function of aged care”, and (iv) failing to take responsibility for the devastating crisis in the aged care sector, which has caused death, grief, and untold trauma for vulnerable Australians and their families.

The motion was passed 25 to 21.

While Labor called on the Minister to resign, Senator Mathias Cormann backed the Minister by telling the Senate: “We stand with our colleague Senator Colbeck who is doing a very good job in a very challenging area in a very difficult context.”

Coordinated action needed to save lives

More must be done to safeguard and support people living with dementia through the pandemic and beyond, writes Dementia Australia CEO **Maree McCabe** (pictured, right)

Immediate and sustained coordinated action is needed to prevent neglect and premature deaths, and ensure appropriate support and care of people living with dementia in residential aged care homes during the COVID-19 pandemic.

The impact of the second wave of COVID-19, on Victorian residential aged care services in particular, has exacerbated existing challenges in the aged care system, including the capacity and availability of the workforce, clinical governance and the challenge of balancing the individual care and wellbeing needs of residents with the safety of all living or working in the service.

Dementia prevalence in residential aged care is significant: recent data suggests that just over two thirds of all people living in residential aged care have moderate to severe cognitive impairment (Royal Commission into Aged Care Quality and Safety 2020). With this high prevalence, anyone being deployed and trained to provide care must not only be trained in infection control, but also in the basics of dementia care.

To date, there have been multiple failings in the aged care system for people living with dementia, their families and carers – both at the individual provider and systemic level.

The lack of a specific and consistent focus on dementia within legislative, regulatory, policy, funding and service delivery contexts means that the needs and preferences of people living with dementia, their families and carers are not currently being adequately addressed.

Photo courtesy Dementia Australia

Right now, we are seeing the effect of these systemic failings in full force. We must do more to safeguard and support people living with dementia through this pandemic and beyond.

People living with dementia are some of the most vulnerable people in the community right now. Depending on their symptoms and the level of their abilities, they will have varying levels of understanding of the changing situation with COVID-19.

Ramping up the focus on engagement and communication at this time of restricted physical contact is vital for all of us, but especially for people living with dementia. If stimulus is reduced for people living with dementia the loss of cognitive function can escalate. Over time these are losses that most people will not be able to regain.

Effective communication and engagement are paramount at this time. People living with dementia might have trouble recognising people wearing personal protective equipment (PPE) or more difficulty understanding them.

Introductions by name, using a reassuring tone and pitch, and repeating important key messages are imperative to communicate effectively, as is focusing on person-centred care.

Engaging with the family wherever possible, even if they

Resources to support carers

Dementia Australia recognises the challenging situation that governments and aged care providers are dealing with during the COVID-19 pandemic – especially in Victoria – and is available to assist all staff with strategies, further information and resources to support quality dementia care.

If you are caring for someone with dementia in your professional role, or as a family member or primary carer, and have any concerns, questions, or would like more information, call the National Dementia Helpline on 1800 100 500 or visit dementia.org.au for web chat, resources and information in other languages.

- Help Sheet: Tips For Carers, Families And Friends Of People Living With Dementia: https://bit.ly/2ZPin0f.
- For COVID-19 information and support for senior Australians, their families and carers, contact the Older Persons COVID-19 Support Line on 1800 171 866.
- For support for people with dementia who are experiencing changes in behaviour that impact their care or the carer, contact Dementia Behaviour Management Advisory Service (DBMAS) on 1800 699 799.
- For the most up-to-date Federal Government information about COVID-10 visit the Department of Health website at: https://bit.ly/2ZQzHlw.

are unable to be on site, will help aged care workers in their role. The familiar voice of a loved one on a phone call may help to calm someone who seems distressed.

Family members may be able to share the person's story with staff that will help them to better understand what the person in their care might be experiencing or how they are responding. They will appreciate being included and the more you know about the person, the more you can plan and be prepared to communicate in a way that is best for them.

Dementia Australia knows from broad consultation with people living with dementia, their families and carers, that if we get quality dementia care right then there will be quality care for all.

For the sector to deliver quality dementia care as a consistent and integral part of aged care, we must ensure a competent and confident aged care workforce that is well supported and led.

Staff education and training are paramount to improving the deficiencies in the current system, eliminating the misuse of physical and chemical restraint, and treating people with the respect, dignity and care they deserve.

Dementia Australia has long called for increased dementia training and qualifications, as well as a governance framework to support these initiatives. Now more than ever, dementia-specific education needs to be extended to hospitals, ambulance, emergency services, and logistics teams.

Educating the workforce has been the focus of the Centre for Dementia Learning at Dementia Australia for a number of years, through programs such as consultancy and providing a comprehensive suite of education programs including the award-winning Educational Dementia Immersive Experience (EDIE™) workshop; and also through the delivery of the Dementia Essentials program as part of Dementia Training Australia.

The Royal Commission into Aged Care Quality and Safety will release its anticipated recommendations in February 2021. A response to these recommendations will take time, yet urgent action is needed now to ensure quality care for the almost half a million Australians living with dementia.

We must ensure the sector is well supported to provide quality dementia care as an integral part of aged care if we are to see a consistent improvement in the quality of support and care provided to people living with dementia. ■

References

Royal Commission into Aged Care Quality and Safety (2020) *International and National Quality and Safety Indicators for Aged Care, Research Paper 8.* Available at: https://bit.ly/3ceiF66.

COVID-19 resources

Alzheimer's Disease International (ADI) has run a series of four **webinars on dementia and COVID-19** as a way of sharing valuable experiences from around the world of supporting people with dementia in a range of settings. The four sessions are: 'Supporting people with dementia during COVID-19: experiences and advice from around the world'; 'Future gazing: COVID-19 and dementia'; 'The hidden casualties of COVID-19: revealing the emergency in care homes and the lessons learnt in day care'; and 'Innovating for the new normal: Experiences from around the world'. A varied line-up of speakers include representatives from Alzheimer's associations from around the world as well as researchers and ADI staff. All four are available to view online at ADI's website at www.alz.co.uk/content/adi-webinars-on-dementia-and-covid-19.


www.freepik.com

The Older Persons Advocacy Network (OPAN) hosted a webinar in July which is now freely available to view on **Caring For Older People Living With Dementia During COVID-19 Restrictions**. The one-hour session was conducted in partnership with Dementia Australia and covers a range of issues, including what it's like for a person living with dementia during COVID-19, strategies for caring for a person with dementia during COVID-19, the risks of chemical restraint, and an open question and answer segment. The panellists include OPAN's CEO, Craig Gear, Maree McCabe (Dementia Australia CEO), Dr Melanie Wroth (Senior Staff Specialist in Geriatric Medicine at Royal Prince Alfred Hospital and Chief Clinical Advisor for the Australian Care Quality and Safety Commission) and Wendy Henderson (Consultant with the Centre for Dementia Learning at Dementia Australia). Access the webinar via this link: https://bit.ly/2QQZc1q.

Dementia-specialist nurses' charity, Dementia UK, has published a news post on its website on the topic of **Advice For People With Dementia Around Face Coverings**. The online information looks at questions such as 'Why might my relative with dementia be struggling with wearing a face covering?' and 'What to do if I can't get my relative with dementia to wear a covering?' and suggests practical solutions to try. The information is available at www.dementiauk.org/advice-about-face-coverings/.

YoungDementia UK has published two short films: **Keeping Well In Tough Times Parts 1 and 2**. Via a series of video calls, YoungDementia UK has collated hints and tips from younger people living with dementia who have shared their ideas for keeping well during the coronavirus pandemic. The films are both one minute long and include simple suggestions such as keeping your mind active, and exercising regularly, alongside practical tips for how to put this into practice by people living with younger onset dementia. The films are available on the YoungDementia UK website at www.youngdementiauk.org/young-onset-dementia-films.

The Australia Government's **Department of Health website** continues to publish a range of resources to support aged care services during COVID-19, such as guidelines for infection prevention and control in residential aged care, information on emergency leave, and emergency funding for Commonwealth Home Support program providers. All the resources are available at https://bit.ly/2AqPSwB.

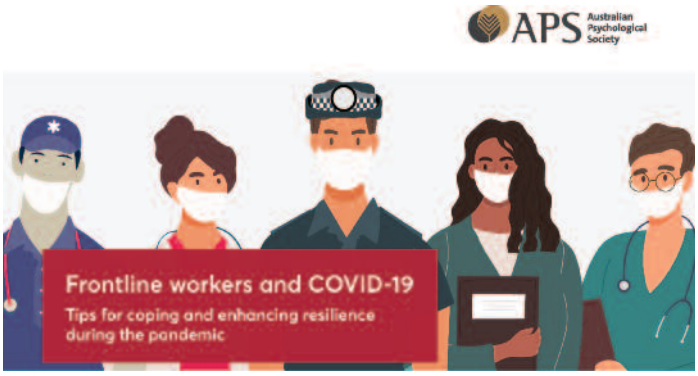
The **Aged Care Quality and Safety Commission website** also continues to publish a range of resources related to COVID-19 aimed at aged care providers, including from August a range of video and print resources translated into 15 languages. All the resources are available at www.agedcarequality.gov.au/resource-library.

Resources to support workforce wellbeing

There is widespread recognition that the global pandemic has placed great pressure on the dementia care workforce. Here is a selection of resources to guide and support staff as they navigate these challenges

The Australian Government Department of Health website includes a substantial webpage on **Mental Health For The Health Workforce During COVID-19**. The resource presents information and ideas on why mental health is important for health workers; getting urgent help; how health workers might be feeling; keeping mentally healthy; support contacts; staying informed; resources; and mental health for patients and carers. To access the resource, go to https://bit.ly/3gTiJZI.

Dementia Training Australia's (DTA) collection of free online resources now includes a webinar titled **Improve Resilience And Wellbeing In The Dementia Care Workplace During COVID-19**. The 45-minute session is led by Samuel Eddy, a workplace wellbeing educator and executive coach, and was conducted in April 2020. Eddy's presentation explores normal stress versus problematic stress, resilience, and what is known about workplace stress for the dementia care workforce. Eddy introduces participants to three practical tools (one to check your 'stress temperature', one exploring the 'change curve' during COVID-19, and one exploring wellbeing 'anchors' and the importance of daily structure) and also conducts a mindfulness meditation. The session is aimed at anyone working in the dementia care workforce. It is available to access on the DTA website via https://dta.com.au/download-type/video/.



The Australian Psychological Society has published a four-page information sheet on **Frontline Workers And COVID-19: Tips For Coping And Enhancing Resilience During The Pandemic** (pictured above). The resource is aimed at frontline police, healthcare and social support workers. It presents information on stress and burnout, suggests strategies for boosting resilience and coping, and also offers tips for some specific situations (such as where frontline workers have a pre-existing mental health or physical health issue, or situations in states and territories where restrictions have eased). The resource includes links to other organisations offering services that may assist frontline workers. Access the resource via this link: https://bit.ly/3bttLDJ.

Phoenix Australia (Centre for Posttraumatic Mental Health) and the Canadian Centre of Excellence in PTSD have collaborated to publish a 28-page resource titled **Moral Stress Amongst Healthcare Workers During COVID-19: A Guide to Moral Injury**. This resource is aimed at healthcare workers and organisations with the view to helping them to understand better the range of complex emotions arising from the COVID-19 pandemic. The resource explains the meaning of the terms 'moral emotions', 'moral injury' and 'moral stressors', and discusses how these have been key challenges for the healthcare workforce during the pandemic. It considers positive emotions arising too, and presents practical and emotional strategies for individuals, team leaders and organisations when responding to workplace stress during the pandemic. A range of tip sheets are also available on the Phoenix Australia website aimed at supporting healthcare workers during COVID-19, for example on sleep and self-care. To access the guide and the tip sheets, go to www.phoenixaustralia.org/ and click on 'COVID-19'.

ACSA and LASA's new shared initiative, the **Aged Care Support Hub**, has been developed to support aged care providers and their staff in Metropolitan Melbourne and the Mitchell Shire who have opted into the *Guiding Principles for Residential Aged Care – Keeping Victorian Residents and Workers Safe*. A section on Frequently Asked Questions gives detailed information on a broad range of COVID-19-related topics such as grants and funding, eligibility for payments, compliancy and guidelines, general questions and a list of case studies. The Support Hub can be accessed at: supporthub.agedservicesworkforce.com.au.

In late August, the Victorian Government's Health and Human Services Department published a nine-page report, **Protecting Our Healthcare Workers**, which sets out the actions taken by the Victorian Government to track and respond to the coronavirus outbreak among healthcare workers across hospitals and aged care facilities in Victoria – with the hope that other parts of Australia and the world may be able to learn from this experience. The four key actions include: sharing of data, support for infection prevention control, improving COVIDSafe workplaces, and promotion of financial incentives to limit worker mobility. The report summarises key findings about how and where healthcare workers acquired coronavirus, separating out data by occupation and workplace. The report is at: https://bit.ly/31SNR79.

The Black Dog Institute, the research centre affiliated with UNSW Sydney, produces a wide range of resources in relation to mental health – including an app aimed at supporting health professionals during the pandemic, known as **TEN: The Essential Network**, developed with Federal Government funding announced in May. The app is a one-stop-shop for a wide range of resources to support health professionals, accessed via a screening tool designed to recommend relevant resources and online tools, including links to access professional help. More information is available at www.blackdoginstitute.org.au/ten/. As part of the TEN initiative, the institute's website now includes a section on **Coronavirus Resources For Health Professionals**, which contains over a dozen fact sheets on mental health issues related to working in health and aged care during the pandemic, such as **Financial Stress And Health Care Workers During COVID-19**; **Managing Health Anxiety During COVID-19**; and **Sleep, Fatigue And Stress In Health Care Workers During COVID-19**. Access all these resources via this link: https://bit.ly/3hWCj8x.

Medication management: care teams take action

Melissa Morley and **Bronwen Wright** report on Dementia Training Australia's work to support two residential aged care facilities through a quality improvement process to tackle the issue of antipsychotic medication for people living with dementia

There is growing concern regarding potential overuse – and inappropriate use – of psychotropic medications, such as antipsychotics and other sedatives, in older people, especially those living with dementia who are at increased risk of injury and death when prescribed these.

Dementia Training Australia (DTA) offers a Medication Management Consultancy (MMC) service which is consultant-led and evidence-based. It aims to embed knowledge and processes to reduce and/or optimise the use of antipsychotic medication if prescribed for people living with dementia in a residential aged care facility who may be experiencing responsive behaviours.

In this article, we report on DTA's recent involvement delivering an MMC service within two residential aged care facilities operated by Ananda Aged Care. They were the first MMCs to be completed in South Australia and resulted in considerable beneficial changes for both residents and staff.

Ananda Aged Care offers general and dementia-specific care within two aged care sites, Findon and Hope Valley, both in Adelaide. Both sites undertook the MMC during mid-2019 and successfully completed the service by June 2020. This longer than average MMC completion time (most are completed within six months) stemmed from Ananda Aged Care's dedication to continue the MMC, even during the global COVID-19 pandemic.

As part of the Medication Management Consultancy, staff receive a comprehensive antipsychotic resources suite which includes an antipsychotic poster (pictured left), summarising suggested steps to support a person with new responsive behaviour, and quick reference cards (right)

About DTA's consultancy

The MMC is a quality improvement service which offers organisations the following benefits:

1. Support
Each DTA consultant is a highly experienced health professional, working in dementia care. They support staff through this change process, providing continuity throughout the course of the consultancy. DTA consultants guide staff through a process which involves care teams reviewing how their procedures and policies shape the way their team is currently managing antipsychotic medications. They support teams to develop evidence-based mechanisms that can ensure sustainability and align with best practice changes, for example through medication management policy and procedure improvements.

2. Benchmarking
This is conducted at the beginning and end of the consultancy, and involves measuring staff knowledge about recommended use of antipsychotic medications for responsive behaviours, and the number of residents prescribed antipsychotic medications for responsive behaviours.

3. Provision of resources to support appropriate use of antipsychotic medications for responsive behaviours, which include:

- A 1-1.5 hour interactive online staff education training course: by completing this course, staff will have gained a greater awareness of the limited role antipsychotic medications have in supporting a person living with dementia, and enhanced their knowledge of alternative strategies to use instead of antipsychotics.
- Education delivered to staff on how to use the DTA resources, including how to implement evidence-based processes within a facility, through regular video conferencing with the DTA consultant.
- Other resources provided as a complimentary package mailed to the facility, including fact sheets for consumers about antipsychotic medication use for responsive behaviours from Dementia Australia, DTA antipsychotic review reminder stickers, reference cards and posters.

Over the past three years, 15 residential aged care facilities have completed an MMC with DTA. It is a popular national service, with another 17 MMCs currently in progress at different facilities around Australia. Key contributors to the success of the MMC service include regular support and facilitation offered by the DTA consultants, coupled with a collaborative relationship with the nominated Action Group at the facility. Ultimately, this presents a unique opportunity for an organisation to reduce the number of antipsychotic medications used to support people with responsive

New medication guidelines

The Pharmaceutical Society of Australia (PSA), the national peak body for pharmacists in Australia, produces standards and guidelines governing the professional practice of pharmacists in Australia. Two new guidelines from PSA will be of interest to those working with people with dementia, particularly those in residential aged care.

Guidelines for Quality Use of Medicines (QUM) services provides guidance to pharmacists on professional issues relating to the various activities undertaken within the scope of Quality Use of Medicines (QUM) services. QUM services are a key strategy to optimise medication management within residential aged care facilities (RACFs). They support RACFs to safely manage medicines and improve medicine management practices and procedures. QUM services involve three types of activities: education and training; clinical governance; and resident-level activities, which are implemented following the development of a QUM plan, as part of a cohesive quality improvement process.

Guidelines for Comprehensive Medication Management Reviews focuses on comprehensive medication management reviews which aim to identify, resolve and prevent medication-related problems and optimise medicines use in partnership with medical practitioners and patients, regardless of practice setting. The guideline sets out clear information about patients' rights, confidentiality and consent; professional collaboration and communication; clinical and quality governance; and focuses in detail on the comprehensive medication management review cycle of care which can now involve up to two follow-up reviews of care.

PSA has also partnered with the **Department of Health** to publish a range of **practice resources** to support pharmacists conducting medication reviews via telehealth, given the widespread use of telehealth in the current COVID-19 pandemic. The resources include two-page fact sheets on the following topics: Use of visual and audio technology in telehealth medication review consultations; Assessment of safe storage and disposal of medicines during a telehealth medication review consultation; How to prepare for, and what to expect from a telehealth medication review consultation (consumer resource), and Use of digital resources to support the medication review consultation.

To access these resources go to: https://bit.ly/30LEDcs.

behaviours and / or ensure best practice recommendations are followed if prescribed.

The Action Group

A key contributor to achieving the MMC outcomes included the nomination by Ananda Aged Care of a diverse team, known as the Action Group, to work cohesively and meet regularly via video conference with their dedicated DTA consultant. The Action Group participants at both sites included a mix of clinical nurse specialists and managers, registered and enrolled nurses, medication-competent careworkers and a development workplace manager. Each had their own experience, knowledge, unique skill set, role and responsibilities. The meetings formed a safe and comfortable, non-judgemental opportunity for participants to reflect on their practice and interactions with residents, and brainstorm site processes and procedure enhancements, assessing these from the perspective of different staff roles.

The MMC service aims to develop the Action Group into a confident and knowledgeable team regarding antipsychotic medication management with emphasis placed on aligning recommendations for best practice care. One of the strengths of the Action Group is that it provides other internal and external staff with a point of reference to guide, foster and contribute opportunities to raise awareness about alternative strategies in preference to antipsychotics, and help reduce and / or ensure best practice recommendations are followed, if these medicines are prescribed.

What did the Action Group do?

During the MMC, the Action Group trialled and adopted different strategies in order to develop their own antipsychotic management procedure. For example, DTA antipsychotic review reminder stickers were trialled in a dedicated paper-based documentation system. Staff at Hope Valley found this particularly useful as a simple way to communicate to the rest of the multidisciplinary team as to when prescriber reviews were planned, if actions were undertaken and what the outcome was. Meanwhile, staff at Findon added antipsychotic review alerts to an electronic system to improve monitoring of prescriber reviews within the Memory Support Unit (MSU).

Additionally, the Action Groups at both sites worked cohesively to ensure accurate documentation of antipsychotic usage, including recording behaviours and tracking trends over time, reviewing for effectiveness, monitoring for any side-effects, and managing titration plans. Communicating key information to prescribers in a concise, confident manner and continuing to practise Ananda Aged Care's approach to providing holistic care also helped the teams to successfully titrate and cease antipsychotics as per recommended best practice.

The results

Two key measures relating to antipsychotic use at Ananda Aged Care included:

- staff knowledge regarding psychotropic medication measured using a validated tool in the form of an anonymous quiz (Brown *et al* 2016) followed by,
- the number of residents prescribed antipsychotic medications for responsive behaviours assessed by clinical audit.

Staff knowledge

Across both sites, 49 respondents completed the quiz. Upon completion of the MMC, the average number of correct responses improved by 23%.

Antipsychotic use

Findon achieved an average 26% reduction in antipsychotic use following the MMC process. Specifically, cessations occurred for all 'when required' antipsychotic medications by the end of the consultancy. Furthermore, six residents within the MSU had their antipsychotic doses reduced by 50% to align with recommended best practice.

In comparison, Hope Valley increased their antipsychotic usage by an average 31% at the end of the consultancy. A contributing factor to increased usage was an influx of new residents to the facility who were already prescribed antipsychotic medication. However, while the overall usage increased, at least 12 residents had their antipsychotic medication reduced to minimum doses with further plans for cessation. Furthermore, the MMC service has provided staff with robust processes to support new residents and ensure further optimal medication management in relation to antipsychotic use.

Anecdotal reporting from staff provides additional insight into the various benefits offered during the MMC service including:

- More meaningful interactions and engagement from residents with staff.
- Significant reductions in incidences of drowsiness, improved night-time sleep quality, increased mobility, fewer falls, increased appetite and enjoyment from food when residents' antipsychotic medication doses were reduced and/or ceased.
- Strengthening of existing non-pharmacological interventions, developing and documenting a comprehensive review process when an antipsychotic medication is prescribed, and monitoring for signs of ineffectiveness and adverse effects.
- Seeing value in developing a tailored and new antipsychotic procedure with a sustainability plan to ensure the processes continue to be implemented after the consultancy ends.

Lessons from the work

DTA knows that there is a greater acceptance for any changes to practice when all key stakeholders, including senior management, are involved in the MMC process. At Ananda Aged Care, the Action Group included staff in senior roles, which provided organisational support to drive and lead onsite quality improvement and practice change.

A major quality improvement outcome achieved for Ananda Care included the development of site-specific antipsychotic management procedures. These ensured a systematic process was in place that aligned to the evidence-based, best-practice recommendations and included collaborative development to represent the thoughts and ideas from a diverse range of participants within the Action Group. Learnings from Ananda Aged Care's success has influenced DTA's recommendations regarding selection of Action Group participants and will further shape future improvements in the way DTA supports organisations through sustainable change processes.

Conclusion

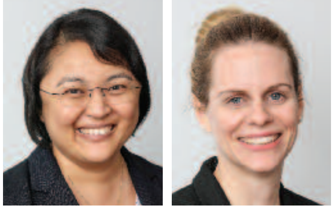
Supporting Ananda Aged Care throughout the MMC process has led to benefits for both staff and residents. The MMC process has demonstrated improved staff knowledge of antipsychotic use, as well as reduction in prescribed antipsychotics for residents. We congratulate the organisation on its ongoing dedication in delivering what matters most to people living with dementia and its success at making such a difference at these facilities. ■

Reference

Brown D, Westbury J (2016) Assessing Health Practitioner Knowledge of Appropriate Psychotropic Medication Use in Nursing Homes: Validation of the Older Age Psychotropic Quiz. *Journal of Gerontological Nursing*. 42(9) 21-27.

More information

Dementia Training Australia offers the Medication Management Consultancy Service alongside a range of other consultancies and educational services through Tailored Training Packages (TTPs), which are designed to bring about sustainable change within organisations to improve the wellbeing of people living with dementia and the staff who care for them. For more information about improving the use of antipsychotic medications used to support people living with dementia, visit the DTA website www.dta.com.au or phone (02) 4221 5555 to request a call-back from a DTA consultant.



■ Melissa Morley and Bronwen Wright are both Medication Management Consultants with DTA

Kavita Saini, Clinical Nurse at Ananda Aged Care, Findon, reflects on the benefits of the DTA Medication Management Consultancy

Action Group Findon members, Workforce Development Manager Michael Page (far left), Kavita Saini (at back), Daniel Sim (far right), Huong Thi Diem Nguyen (kneeling) and Pradeep Chandran Ramachandran Nair (inset)

Ananda Aged Care partnered with Dementia Training Australia (DTA) from March 2019 until June 2020 to receive expert training via a Tailored Training Package (TTP) for its staff. One part of the TTP was a Medication Management Consultancy (MMC), which started in August 2019 and ran to June 2020. The main objective for Ananda was to understand the use of antipsychotic medication in the context of responsive behaviours due to unmet needs in our residents living with dementia.

Champions for change

Two separate groups of four staff at each site (known as the Action Group) were involved as champions for change. I was a member of Findon's Action Group, along with another clinical nurse, a registered nurse and a personal care worker who had been a pharmacist in India and was an asset to the team for his knowledge and ability to communicate learnings to the care team. We met with the DTA consultants via regular Zoom meetings to discuss our plan of management and the outcomes. DTA also provided helpful resources, including quick reference cards and posters for each home.

Prior to the program, Ananda was using various strategies to support people with responsive behaviours, including our own approach called 'Follow the Five' which asks staff to first check whether any of five unmet needs (pain, under/over stimulation, continence needs, hunger/thirst, and repositioning) could be prompting the behaviour. Following this, staff consult with the resident's representatives, the GP, then the on-call manager prior to administering any pro re nata (PRN, as required) antipsychotic medications. We also involve Dementia Support Australia (DSA) for additional support and review if required.

The Ananda angle

Positive results

Before 2018 (when Ananda invested significantly in dementia education and training for staff) it was not uncommon for care staff to ask nurses to use medication to 'manage' residents with dementia, especially if a person was agitated or vocally disruptive. On reflection, following the DTA-led change management process, we feel we have had great success: now at Findon we have no residents with PRN antipsychotic medication prescribed.

Working together with GPs and residents' representatives we have also reduced the use of regular antipsychotic medication among residents. One example involves a situation where we advocated with a GP. Initially the GP was not willing to review his client's antipsychotic medication, but after we put into practice some strategies to aid communication within the multidisciplinary team, the GP agreed with the benefit of reducing the medication dosage. He said later that he was very impressed with the amount of work our facility was doing with the MMC.

During the COVID-19 pandemic concern has been that care home residents may be more likely to be prescribed antipsychotic medication in response to increased emotional distress due to social isolation and lockdowns. However, our experience has been that we have managed to further reduce antipsychotic medication use during COVID-19 with no adverse effects or increased incidents of responsive behaviour.

Assessing pain

In January 2020, we introduced PainChek® artificial intelligence app technology to help assess pain in residents unable to verbalise this to staff. We consulted with GPs and commenced regular PainChek® assessments for residents with cognitive impairment: three times a day in fact. PainChek® is a validated assessment tool which is best used post-movement and, in our experience, is superior to standard pain assessment charts. It gives us more opportunities to assess a person's pain very precisely, especially with its ability to detect pain by scanning a resident's face. In July 2020 our staff carried out almost 1600 pain assessments using PainChek®.

The daughter-in-law of one resident is a pharmacist and was very satisfied to know that her mother-in-law has been de-prescribed antipsychotic drugs successfully. The resident had a history of calling out – she also used to do this when she was living at home. We sought advice from Dementia Support Australia (DSA) who provided a series of recommendations. Staff introduced a range of strategies and the resident's vocally disruptive behaviours reduced significantly, allowing de-prescription. Now, in retrospect, it seems likely that this woman had been experiencing hallucinations as a result of medication side-effects.

Conclusion

The MMC did not just benefit nursing staff: care staff are also now more aware of the importance of non-pharmacological interventions to give quality care to our residents with responsive behaviour. They proactively look for signs of unmet needs and respond accordingly, using an individualised plan of care.

The MMC was a very rewarding and helpful process. Yet the MMC and overall TTP is not a one-off project – it is an ongoing work in progress, especially when new residents arrive with an antipsychotic prescription in place. The MMC has equipped us with the skills and knowledge to continue to review our residents for optimal medication management in order to improve the quality of care we deliver. ■

Acknowledgments

All staff at Ananda Aged Care who have taken part in this process, especially Action Group Findon: Kavita Saini, Daniel Sim, Huong Thi Diem Nguyen, Pradeep Chandran Ramachandran Nair; and Action Group Hope Valley: Karen Steer, Taffy Nyanhemwa, Karamjit Sekhon, Belinda Cavaioulo.

Ananda Aged Care and the DTA TTP

Ananda Aged Care is a family-run organisation of two homes in Adelaide, South Australia. Ananda Findon is a 67-bed home which includes Rose Wing, an eight-bed Memory Support Unit (MSU) for female residents. Ananda Hope Valley, purpose-built in 2004, is a one-level 137-bed home with several attractive gardens and outside courtyard spaces. It has a 19-bed capacity MSU, Derwent Wing, which was substantially refurbished in 2018.

Both the MSUs were locked units until December 2018. Since then, their doors are now open during the daytime and shut at 5pm to promote a quiet environment until breakfast time.

Both homes attract a high proportion of residents from Culturally and Linguistically Diverse (CALD) communities, in particular the Italian and Greek communities.

Following the appointment of Michael Page as Ananda's Resident Focused Care Advocate, the organisation partnered with DTA to carry out a one-year Tailored Training Package (TTP) for staff. Due to the COVID-19 pandemic, the consultancy extended from March 2019 to June 2020 and in that time Ananda benefited from expert advice and training which included:

- Access to a suite of online dementia education for all staff chosen by Ananda management.
- Access to materials for Michael Page to use for workshop training for six one-hour units.
- A Responsive Behaviours Consultancy which ran for eight weeks (March to June 2019) for one hour via video conference with DTA as part of a 'lead and learn' program. Outcomes included: improved confidence of staff in supporting responsive behaviours; continuous improvements reflecting best practice dementia care at both homes; and a reduction in antipsychotic use and other forms of restraint.
- Access to and use of the DTA's assessment tool to assist cost-effective improvements to the environment (known as BEAT-D).
- The Medication Management Consultancy which ran from August 2019 until June 2020 at both sites.

The TTP has previously been reported on in two *AJDC* articles (*A New Standard of Care*, *AJDC* 8(4), Aug/Sept 209 and *Opening the Doors on a New Standard of Care* (*AJDC* 8(5), Oct/Nov 2019.

Supporting the frontline workforce during COVID-19

Ellie Newman describes a successful partnership between DTA and NurseWest, developed in response to the COVID-19 pandemic, to equip newly qualified nurses with dementia and delirium training

The Western Australia (WA) Department of Health (WA Health) has run its own nursing and midwifery temporary staff pool, known as NurseWest, since 2003.

NurseWest offers nurses, midwives and assistants in nursing casual shifts and short-term placements in all public metropolitan hospitals and community health services across the state, including rural and remote hospitals and health services.

NurseWest also plays an important role in WA Health's Disaster Management Plan, assisting with the placement and movement of temporary nursing and midwifery staff.

NurseWest runs a program called QuickStart, developed with the goal to onboard newly qualified registered nurses to the WA Health workforce. The current QuickStart program was timed to facilitate the employment of nurses before the predictable annual increase in staffing requirements due to the flu season. This year, however, NurseWest had a greater response from health services for participants due to the COVID-19 pandemic. The current QuickStart group has 34 participants, many of whom are working on medical, geriatric, psychogeriatric and rehabilitation wards in hospitals across Perth.

As part of its work on being recognised as a 'Working Towards Dementia-Friendly Organisation' by Dementia Australia, the East Metropolitan Health Service (EMHS) in WA has been delivering workshops on dementia and delirium at NurseWest for some time. However, due to COVID-19, the EMHS staff delivering the training were required back on the wards to support patient care. When EMHS was approached to assist with the QuickStart program, in order to preserve continuity, the health service reached out to Dementia Training Australia (DTA) to see if and how DTA could assist with this.

Workforce readiness

As a result of that link-up, and following strict social distancing and hygiene guidelines, DTA delivered face-to-face training in Perth on 'Caring for patients with dementia and delirium in hospitals' over several sessions throughout April to all 34 newly qualified registered nurses. At a time when all other face-to-face training had paused, the continuation of this QuickStart training was significant, ensuring the new nurses' readiness to join the workforce.

This was a great opportunity to demonstrate collaboration between the health services (WA Health/NurseWest and EMHS) and DTA, and to offer support for their initiatives and COVID-19 workforce response plans.

Aligning the fundamentals in this training with actual activities occurring in the local hospitals to support patients with dementia and delirium received really positive feedback from the participants.

The author, Ellie Newman, delivering a DTA training session to newly qualified registered nurses in Perth in April on 'Caring for patients with dementia and delirium in hospitals' – with strict adherence to social distancing requirements being observed

One of the participants said, "It provided context and hope that something was actually happening to support not only the patients but staff in their assessments and care delivery". Another said that the course was "fabulous" and suggested that universities should teach this "…before first practical placement – would be such a help instead of being thrown in the deep end".

New knowledge

Of those participants who completed the evaluation, all strongly agreed that the training had provided new knowledge or information about how to care for people living with dementia and all said their confidence in caring for a person with dementia had increased.

All participants said that, as a result of the training, they would support someone else to change the way they care for or support a person with dementia; that they would try a new procedure or technique shared during the training; and would do further education or training.

This new partnership between DTA and NurseWest has been a great success, and as a result DTA will undertake two more, longer training sessions later this year with NurseWest. ■

Accessing the training

If you are interested in receiving training in dementia and delirium care in hospitals, contact Ellie Newman at ellie.newman@dta.org.au.

■ Ellie Newman is Director, Dementia Training Australia, University of Western Australia and, at the time of writing, Clinical Specialist for Dementia and Delirium within the Royal Perth Bentley Group, which is part of the EMHS

New tool to improve acute care environments

All sorts of environments can be improved to better support people living with dementia – including hospitals. **Ash Osborne** and **Kirsty Bennett** introduce a new DTA resource that can help facilitate this change process within acute settings

Hospitals are challenging places for many people, due to the busy, unfamiliar and stressful nature of the environment. Photo: © Cathy Greenblat 2013

Hospitals are challenging places for many people, due to the busy, unfamiliar and stressful nature of the environment (Alzheimer's Australia 2014). Living with a disability, cognitive impairment or the physical, sensory or cognitive impacts of old age can make this experience even more difficult (AIHW 2013). There is an increasing awareness, supported by research, that the environment has an important role to play in improving the hospital experience for people living with dementia and age-related disabilities – and for family and friends who visit, and hospital staff too.

Dementia Training Australia's (DTA) Environments Team has developed a new assessment tool to address the specific needs of an acute inpatient ward environment and to support the implementation of environmental changes within an acute health care setting. The new tool – known as EAT-Acute Care – is based on the evidence-based principles of designing for people living with dementia that are at the heart of the DTA Environment Team's work. The EAT-Acute Care tool sits within a larger new resource called the *EAT-Acute Care Handbook* (see image next page), both of which are now available to download from DTA's website (go to www.dta.com.au).

This article provides some background to the needs of people living with dementia in a hospital environment and reports on the work involved in the development, trial and launch of this new, evidence-based assessment tool. The DTA Environments Team is looking forward to working with hospitals around Australia to put the tool into practice as part of the consultancy service offered by the team.

Hospital admissions

In 2016-17, around one in seven (14%) Australians were aged 65 and over, however, they accounted for 42% (2.8 million) of same-day hospitalisations and 41% (1.8 million) of overnight hospitalisations (AIHW 2018). Approximately 10% of these hospitalised older Australians would be living with dementia (Brown *et al* 2016).

People living with dementia are twice as likely to be admitted to hospital, and two to three times more likely to have an adverse event in hospital (for example falls, delirium and sepsis) than people the same age who do not have dementia (Panayiotou 2018) and potentially poorer health outcomes due to delays in recovery and extended lengths of stay (AIHW 2013). According to the Australian Institute of Health and Welfare (2019) people living with dementia had an average hospital length of stay of 13 days in 2016-17. This is compared to an average stay of 2.7 days for people who did not have a diagnosis of dementia (Alzheimer's Australia 2014).

Hospital admissions were mostly for acute care (72%), followed by geriatric evaluation and management (8%), maintenance care (7%) and rehabilitation care (6%), and commonly began with a new admission from the community (70%) (Alzheimer's Australia 2014).

In 2016-17, almost all (97%) hospitalisations of people with a diagnosis of dementia were assigned to the highest or second highest categories for clinical complexity. Further, the majority (71%) of dementia

Key design principles

1. Unobtrusively reduce risks
2. Provide a human scale
3. Allow people to see and be seen
4. Manage levels of stimulation – reduce unhelpful stimulation
5. Manage levels of stimulation – optimise helpful stimulation
6. Support movement and engagement
7. Create a familiar place
8. Provide a variety of places to be alone or with others – in the unit
9. Provide a variety of places to be alone or with others – in the community
10. Design in response to vision for way of life

Reference: Fleming & Bennett (2014); Fleming & Bennett (2017)

hospitalisations were of the highest clinical complexity, compared with 16% of hospitalisations of people without a diagnosis of dementia (AIHW 2019). In addition, the average costs of care for people with dementia was almost 2.7 times more than for a person without dementia (AIHW 2013).

The acute care environment

There has been a substantial amount of research on the effects of aspects of the built environment on people living with dementia, particularly for people living in residential aged care. Fleming and Bowles initially published a set of design principles in 1987 (Fleming & Bowles 1987), and these were further developed by Fleming, Forbes and Bennett (2003), and Fleming and Bennett in the following decades (Fleming & Bennett 2014; Fleming & Bennett 2017). The Fleming-Bennett key design principles are:

- Unobtrusively reduce risks
- Provide a human scale
- Allow people to see and be seen
- Manage levels of stimulation – Reduce unhelpful stimulation
- Manage levels of stimulation – Optimise helpful stimulation
- Support movement and engagement
- Create a familiar place
- Provide a variety of places to be alone or with others – in the unit (or in the ward)
- Provide a variety of places to be alone or with others – in the community
- Design in response to vision for way of life

More detailed information about the design principles can be found on DTA's website (see www.dta.com.au/resources/environmental-design-resources-introduction/).

A review of the literature with a focus on the acute care environment (Fleming & Bennett 2014) showed that there is sufficient support for these evidence-based design principles to be used in an acute setting. The principles allow for a structured understanding of the effects that the built environment of a hospital ward will have on people living with dementia.

These principles have been adopted across a number of key health care standards and guidelines including The Australian Commission on Safety and Quality in Health Care's guidance *A Better Way to Care* (ACSQHC 2014) and *National Safety and Quality Health Service Standards: Guide for Hospitals* (ACSQHC 2017) and the *Australasian Health Facility Guidelines* (AHIA 2020).

EAT-Acute Care tool

DTA has already developed a number of environmental assessment tools – these focus on residential aged care, Indigenous older people, and dementia-friendly communities. The DTA Environments Team recognised that there was a need to develop a tool that could support the application of the evidence-based design principles in an acute care inpatient ward environment – that is, inpatient wards with a short length of stay (a maximum of seven days).

This new assessment tool, the EAT-Acute Care, has been developed to address the specific needs of people living with dementia who are being cared for in this type of acute setting. The tool is not intended for use in other hospital areas, such as emergency departments and clinics, or in places where patients have a longer stay, such as rehabilitation wards or older person's mental health units.

How is the EAT-Acute Care organised?

The assessment tool has been developed around the 10 design principles referred to earlier to create comprehensible, manageable and meaningful environments for people living with dementia (Fleming & Bennett 2014). These principles are the basis of all the assessment tools in the DTA's Environmental Design resources.

When developing the EAT-Acute Care, each of the key design principles was reviewed. Questions were then drafted using the existing Environmental Assessment Tool-Higher Care (EAT-HC) (this is aimed at facilities providing care for less mobile people with dementia), the available literature and the extensive practice experience of the authors.

Additional questions were added to reflect the most pressing issues in acute settings. Lighting design, for example, is an area that can cause great distress to a patient living with dementia when they are spending time in bed and being observed and tested regularly, as is often the case in acute settings. When lights shine directly into a patient's eyes, they can cause unnecessary distress. Lighting solutions need to avoid this while providing staff with the levels of lighting they require to provide care. Reflections, glare and high levels of contrast due to shadows also need to be avoided.

The unfamiliar environment is another issue for people with dementia in acute settings. While wards need to accommodate a range of complex clinical needs, the placement and use of equipment must be managed so that it does not create confusion and make the environment difficult to interpret. Fixtures and fittings need to be easily recognisable and therefore useable. If a patient cannot recognise a basin or tap, they will not be able to use it. Finishes need to provide warmth, rather than simply focusing on creating a clinical ambience. Consideration needs to be given to personalising the bedspace to assist a patient to know it is theirs. Destinations, such as a place to sit, a staff base or outdoor space, need to be easily found, and wayfinding in corridors should be a priority.

Initial development

Following the development of a draft EAT-Acute Care in mid-2018, DTA sought feedback from acute care clinicians and design professionals, including architects and interior designers. The resource was also introduced to attendees at the Alzheimer's WA Acute Care Forum and participants at two design consultation forums in Perth, including architects and designers with acute care design expertise and senior specialist dementia and cognitive impairment clinicians. An early draft of tool was used in four different acute environments and was reviewed and discussed with staff in these settings. Input was also sought from experts working across design, facility management and operations before commencing formal in-hospital trialling of the tool.

Trial of the tool

During May 2019, DTA Senior Design Consultants Ash Osborne and Terri Preece trialled an updated draft tool in 30 wards across four tertiary hospitals in Western Australia. Wards were assessed independently following clarification of key information with the ward manager, such as number of beds, ward boundaries and access to outdoor areas and places to sit. The assessment focused on the physical environment and aspects of the use of the space. The types of wards visited included:

- general medical
- general surgical
- acute frailty units
- oncology
- orthopaedics
- medical assessment units
- haematology
- neurology

As a result of this trial, a final version of the tool was developed. The final tool only includes those questions which obtained a high degree of inter-rater reliability (the extent to which two or more evaluators agree) during formal evaluation of the trial data at the University of Wollongong.

EAT-Acute Care Handbook

The EAT-Acute Care is a principles-based assessment tool which specifically recognises the needs of people living with dementia when they become patients in short-stay wards. Questions are organised around each of the key design principles.

The EAT-Acute Care enables information about a ward environment and use of spaces to be collected and used to inform a systematic conversation about the strengths and weaknesses of the environment. This data also enables areas of the ward which have the greatest and the least room for improvement to be identified.

The EAT-Acute Care sits within the new *EAT-Acute Care Handbook* which includes a range of resources:

- Part 1: 'Key Design Principles' contains a description of the 10 key design principles (Fleming & Bennett 2014).
- Part 2: 'An Acute Health Care Literature Review' describes the evidence that informs the principles.
- Part 3: The 'Environmental Assessment Tool-Acute Care' introduces the tool and provides directions for its use.
- Part 4: 'Using the spreadsheet' contains a guide to scoring the EAT-Acute Care and showing the results graphically. It includes a template to assist with planning for change.
- Part 5**:** 'Applying the principles' provides information about the questions contained in the EAT-Acute Care and outlines design considerations for each of the questions.
- Appendix 1: EAT-Acute Care Tool
- Appendix 2: EAT-Acute Care Planning Template

As with DTA's other EAT tools, the EAT-Acute Care has been designed for use by staff who have not been specifically trained in its use or in environmental design. Familiarity with the evidence base supporting the design principles is, however, essential if the tools are to be used confidently and to best effect. See https://dta.com.au/dementia-environments/ for more information.

Conclusion

The EAT-Acute Care recognises that an acute hospital ward is a challenging environment for a person living with dementia. This new tool provides a basis for a systematic and informed conversation about the ways in which a ward environment can support a person living with dementia and provide a path to change. ■

Access the EAT-Acute Care via the larger suite of resources, the *EAT-Acute Care Handbook*, which is available to download from DTA's website at www.dta.com.au. For further information on supporting resources, webinars and DTA's Environments Team consultancy service, email dta-environments@uow.edu.au.

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Creating supportive environments

Nick Seemann introduces a new DTA online course which aims to inspire learners to rethink the possibilities of physical environments, with a primary focus on care homes

In September 2020, Dementia Training Australia (DTA) launched a new free online course, titled *Creating Supportive Environments for People Living With Dementia*, which explores why physical environments matter for people living with dementia. The course introduces learners to basic ideas about how the design, configuration and set-up of buildings and gardens can support or curtail the independence, social engagement and daily activity of those who use or live in that building.

Architect and DTA's Lead Environments Consultant Nick Seemann

While the content is applicable to a range of settings, the course focuses on improving care homes. It is aimed at care staff, management, building and design professionals, and emphasises the application of design theory to practice. The course has been prepared for a broad audience in recognition that environmental changes require the involvement of a multidisciplinary team: management, design professionals and care staff. While management may be gatekeepers to a project, care staff have a fundamental role in the daily activities that realise the changes in practice.

Mentoring program

The course is available for individuals to complete for their own professional development. It will also feature in a new mentoring program led by DTA's Environments consultancy, where DTA will work with a team of people within a facility to audit the existing environment, diagnose problems and then plan change.

To begin, the facility's multidisciplinary team will complete the online Creating Supportive Environments course together to create a shared foundation to the project development work that follows. The project work may be an operational change (such as the removal of clutter or greater support to enable residents to access gardens), a small refurbishment (such as the creation of a more usable kitchen) or a larger renovation.

Positive examples

The course format was inspired by Damon Gameau's documentary *2040*, which uses positive examples of environmental initiatives to

Examples of well-designed environments for people living with dementia. Top: Peninsula Villages Tearoom refurbishment, Woy Woy; above left: a shaded courtyard in an aged care facility; above right, a corridor refurbishment design developed by Constructive Dialogue Architects encourage people to embrace climate solutions that already exist. Similarly, this DTA course is heavily based on interviews with architects and facility managers, who each explain how their care homes support resident independence, comfort and safety. Much of the material has been developed through online video interviews conducted during the pandemic lockdown.

Three modules

The course has three modules, each requiring about an hour to complete. The first module, *Why Environments Matter*, explains the negative effects of clutter, noise and busyness on people living with dementia and shows how a building can support mobility, orientation and engagement in an active life.

The second module, *Exploring Good Places to Live*, showcases good practice examples from around the world and encourages participants to look for features that are applicable to their own work situation.

The final module (*Transforming Buildings and the Organisations That Run Them*) focuses on what the learner can do to bring about change in the built environment where they work.

Conclusion

While care homes can sometimes be disempowering and disabling places to live, this is not inevitable. There are many examples of care facilities that support people with dementia to retain independence and stay active. Our hope is that the course will help both individual learners and organisations to plan improvements and work to create better buildings and more usable gardens. ■

To access the course, *Creating Supportive Environments for People Living With Dementia*, visit: www.dta.com.au/online-courses/creating-supportive-environments/.

■ Nick Seemann is an architect and Lead Environments Consultant with DTA's Environments Consultancy team. To follow up on this article, email the DTA Environments Team on dta-environments@uow.edu.au

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Learning at all levels

University of Wollongong undergraduate students **Roy Letton**, **Mikayla Mennilli**, **Sarah Reardon** and **Laurence Karacsony** report on an innovative joint project in which the students worked with Dementia Training Australia to develop an online course on nutrition and dementia aimed at care staff working in residential aged care settings

We are a group of fourth year and recently graduated students in various Bachelor degrees (Science, Nutrition Science, Medical and Health Science, and Commerce) who signed up to complete a subject called CRLP200: Career Ready Learning and Practice in the first semester of 2020. The course offers students the chance to take on an internship or team-based consultancy role as a way of becoming workforce-ready.

We chose to work with Dementia Training Australia (DTA) on a team-based project to develop an online course on nutrition and dementia (see 'The DTA Angle' below) aimed at care workers in residential aged care settings, under the guidance of DTA staff. In this article we'd like to share with you some of the learning from this process, and how it has shaped our thinking about our working futures.

The team's final presentation to DTA at the conclusion of the project, conducted online due to the pandemic

The process

To begin, we had a meeting with the DTA team, allowing us to get to know each other and to discuss the project brief. The goal of this project was to create a storyboard of content that would lead to the development of an online nutrition course that could be used by DTA. Initially, we agreed the course might cover issues such as, but not limited to, various aspects of nutrition, the role of the context of eating in aged care facilities for people living with dementia, and nutritional requirements as people age.

Our next task was to learn more about dementia: the physiological aspects, but more importantly what it means for a person to live with dementia, and for their family and friends too. We focused our research on the importance of diet and nutrition for people with dementia, the role and priorities

The DTA angle

By Jacqui Watts

Dementia Training Australia (DTA) is a consortium funded by the Australian Government to provide nationwide education and training on the care of people living with dementia. Although there are many training resources available in Australia that focus on different aspects of dementia support, there are very few that address the specific challenges of eating and nutrition. This is especially true in relation to easily accessible, practical training for front-line aged care staff.

To address this gap, DTA collaborated with Careers Central at the University of Wollongong (UOW) to involve students completing the Career Ready Learning and Practice (CRLP200) module of their degree, in the development of an online course on eating and nutrition.

The primary aim of the project was to end up with a straightforward online product that would provide practical training to aged care workers with varying levels of experience. The secondary aim of the project was to broaden the students' understanding of the experiences faced by people living with dementia, and challenges faced by those who work to support them.

DTA is now looking at how it might develop the students' work into an online course offering.

Jacqui Watts is a Research Fellow with Dementia Training Australia and DTA coordinator for the project of care staff, and how to create an effective eating environment.

We held further meetings with the DTA team, using their guidance to steer our learning, as well as reviewing DTA's existing online courses. The DTA team directed us to consider a few things we did not think of initially, such as: the uniqueness of each individual, their background and their relationship with certain foods, drinks and environments. For example, some people may find it difficult to eat in a noisy environment, while others may have a history of alcohol abuse, which is another prevalent issue seen by care staff.

Within our team we divided up the workload, enabling us to cover more ground and give each other feedback on what to expand on or improve upon. This was a great strategy for us. It meant we could be constructive, while also learning how the information we conveyed could be perceived by another person. This was a helpful process given that we needed to be mindful that a proportion of our audience (care staff) may have limited dementia knowledge and speak English as a second language.


Understanding Dementia

It's very important that care workers practice patience to develop trust with individuals with dementia.

Dementia is a degenerative and progressive disease that effects the individual in many ways.

It can be really difficult for all people involved. As a care worker, it is important to understand that people with Dementia can perceive things which may or may not be the reality of any given situation.

Nutrition and hydration are important to maintain a healthy lifestyle, and is a large component of care work.

Helping them eat at eye level is an effective way to build confidence for them, as it shows you have time to share.

Each individual is different. You may even build wonderful friendships with some people with dementia. Your patience, care and efforts are appreciated.

DEMENTIA: THE INDIVIDUALS YOU CARE FOR

Understand the effects of dementia on the brain and the effects on the individual

Engage with the individual in a way that is accomodating and familiar

Be reassuring, vigilant and patient

Lend a hand and smile. Your role as a care-worker requires care

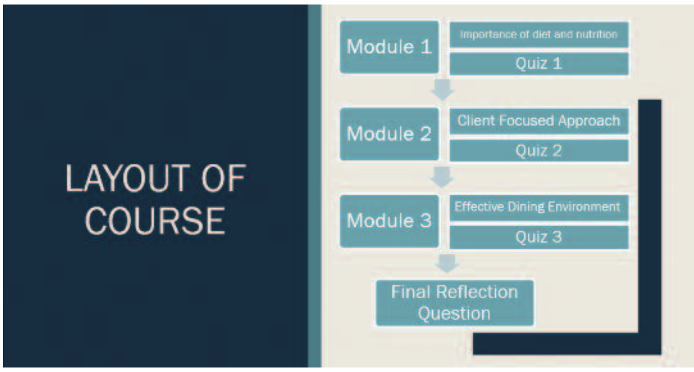
Two storyboards developed as part of the students' project with DTA (above), and the course layout (below)

The final product

We developed three modules for our short course on nutrition and dementia in aged care settings:

Module 1 explored how nutrient requirements change with age, the causes and signs of malnutrition, and why those living with dementia are at a high risk of malnutrition, along with the role of supplements in malnutrition prevention.

Module 2 concentrated on the client-focused approach: the role of valuing the life history of the person, the need for communication between residents, families and registered nursing staff, as well as the importance of personalised care.



Module 3 focused on supporting residents to be ready for mealtimes, the physical and social aspects of the dining environment, and tips on how to enhance energy intake. We looked at practical ways of involving people with dementia in activities before meals, for example by setting the table.

Learning about dementia

It was interesting for us to learn about the variety of diseases that come under the classification of 'dementia'. Before this we didn't really understand what differentiated the types of dementia and were unaware of the sorts of challenges faced by people living with dementia.

We also learnt about the importance of a client-focused approach when supporting people living with dementia. Each person living with dementia is unique, has their own life history, personality, likes and dislikes. It is important to learn about, and respect, these differences when working in dementia care.

We learnt a lot about the importance of a tailored eating environment: how the use of visual cues, reducing distracting noise and decluttering can all help a person with dementia to understand their surroundings and focus on eating. We also came to appreciate that care staff have a complex role and so we tried to share possible

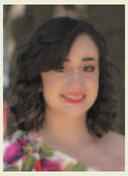
In their own words


I thoroughly enjoyed researching the importance of nutrition for older people with dementia. Before this project my future career goal was to work in clinical health care, however this project has made me open to working in aged care as this experience highlighted the diversity of people you can encounter working in aged care.

Sarah Reardon, Bachelor of Nutrition Science


I feel I've benefited greatly from the experience of organising and completing such a large project. Throughout the course of the project I've developed a greater understanding of the challenges that people living with dementia face, along with an appreciation for the work that care workers do as it improves the quality of life of many people.

Roy Letton, Bachelor of Science


Completing this project showed me the importance of working in a nurturing environment. The people we collaborated with from DTA were incredibly supportive; they encouraged our ideas and showed faith in the new perspective we would bring to nutrition and dementia. This experience has also presented different possible career paths that I had not previously considered and illustrated how vital this area is.

Mikayla Mennilli, Bachelor of Medical and Health Sciences


Aside from the subject material, the process and research involved in creating a storyboard/educational tool surrounding a focused aspect of an already complex issue (dementia care) opened my eyes to how something like this can be achieved through diligent work and team effort.

Laurence Karacsony, Bachelor of Commerce strategies that could help in practice.

Review and challenges

Our course – about one hour in length – was a bit too long to be an ideal short course. It could easily be expanded upon to create three full short courses. The focus of the course could have been less on the specifics of nutrition, with more focus on the priorities of care workers and how to create an effective dining experience.

Due to the global pandemic and the restrictions in place, we were not able to visit any aged care facilities. This meant we were unable to engage with aged care workers and discuss their knowledge of nutrition and malnutrition prevention. Instead, we heavily relied on peer-reviewed journal articles as well as the input from the DTA team.

Conclusion

We all learnt a lot from having this opportunity to engage in a real-world challenge with DTA: to develop learning materials that can support a workforce to deliver quality care for people living with dementia. Throughout the process of creating the online course we learnt a lot about dementia and had our eyes opened to many aspects of dementia care we were not previously aware of.

Working with DTA to achieve a completed course has been an extremely valuable experience that will shape our future endeavours. We would certainly recommend the experience to other students who may be keen to learn more about the dementia field. ■

■ Roy Letton has now completed a Bachelor of Science at the University of Wollongong (UOW); Mikayla Mennilli has completed a Bachelor of Medical and Health Sciences at UOW and intends to go on to study a Masters of Speech Pathology; Sarah Reardon has completed a Bachelor of Nutrition Science at UOW and works as a dietitian assistant; Laurence Karacsony is currently studying a Bachelor of Commerce at UOW, majoring in Business Law

Skills to improve the mealtime experience

Food, nutrition and the mealtime experience: What skills and education are needed by the aged care workforce?

The Aged Services Industry Reference Committee (ASIRC) – part of the Australian Industry and Skills Committee – is currently investigating this exact question: what skills and education are needed by the aged care workforce to enable them to better support people living in residential aged care when it comes to food, nutrition and the mealtime experience?

Earlier this year the ASIRC published a discussion paper on this topic, seeking input from aged care stakeholders on its contents.

The ASIRC wanted to know what sorts of training products might address the clear skills gaps in this area and to identify how these skills would be implemented in the workforce.

Dementia Australia has contributed to the paper by posing some specific questions that relate to people living with dementia, for consultation. It says that aged care workers need the skills to recognise and understand the reasons why people with dementia might not want to eat.

The consultation on the discussion paper concluded in late September, but the report, *Improving The Food, Nutrition and Mealtime Experience in Aged Care* is available to view on the SkillsIQ website at https://bit.ly/2FeVgoW.

Building capacity for quality dementia care

Blue Care's **Nerida Pankhurst** shares what she has learnt from a six-month intensive dementia care training program, developed by HammondCare and Dementia Support Australia, and how she's implemented the principles in her work

Blue Care was one of only three organisations chosen for the Intensive Industry Partner (IP) Consultant Program pilot in October 2018 and I was thrilled to be asked to participate. Since completing the initial foundation-level course, I have been re-accredited to 'expert' level, graduating as a Dementia Consultant in November 2019 in Cairns.

Upskilling the workforce

With industry collaboration at the heart of this course, the IP Program is designed to support aged care providers and the people they care for by upskilling and educating the aged care workforce, embedding high-level dementia care knowledge within organisations and building capacity within the sector to improve the lives of people living with dementia across Australia.

The six-month intensive training program provides DSA accreditation (foundation, proficient and expert levels) and involves dementia education and information sharing, along with practical hands-on experience working alongside consultants from Dementia Support Australia (DSA) for four days each month. DSA consultants provide advice to people who care for someone with dementia where behaviours are impacting their care (see box this page).

IP Program participants are involved in all stages of the DSA service – first referral and triage, then first contact and introduction of the service, followed by the assessment visit to the aged care facility, learning and recording the person's life story, identification of contributing factors and then developing a recommendation report and finally follow-up to see how effective the recommendations have been for each client.

The program promotes using evidence-based therapeutic interventions like music therapy, reminiscence therapy and child representation therapy, along with effective pain management and identification of delirium.

Holistic assessment

I have worked at Blue Care for almost 22 years, caring for residents through all stages of dementia, from early onset to palliative care. Coming from a lifestyle background, I found the training enabled me to be on the same page with clinical staff, helping to build relationships and therefore better outcomes for people living with dementia.

For me, dementia care is always about finding the most effective response for each individual client. Each person living with dementia is one person living with dementia – experiencing dementia in their own way and affected by their own wellness or un-wellness, their own past life experiences and the impact of the environment and people around them.

The IP Program training supports this philosophy, teaching participants to conduct a holistic assessment, exploring both clinical wellness and appropriate lifestyle interventions.

The information was all evidence-based and gave me further knowledge and skills in supporting people living with dementia.

At the end of the initial program, I gained a 'foundation' level qualification as an Industry Partner Consultant and then took this knowledge back to Blue Care to build upon my learning.

Dementia Support Australia

Dementia Support Australia (DSA) is a national service led by HammondCare and funded by the Australian Government under the Dementia and Aged Care Services Fund. It incorporates: the Dementia Behaviour Management Advisory Service (DBMAS); Severe Behaviour Response Teams (SBRT); and the Needs Based Assessment Program, which determines eligibility to a Specialist Dementia Care Program (SDCP).

DSA consultants provide advice to people who care for someone with dementia where behaviours are impacting their care. DBMAS supports staff and carers with information and assessment, while the SBRT are a mobile workforce of multidisciplinary healthcare professionals who provide a rapid, on-the-ground response to support people with dementia living in residential aged care. When aged care providers request assistance, the DSA consultants will identify cases of residents who are experiencing 'severe behaviours' and escalate them to SBRT support.

SDCP Assessors determine eligibility for people with very severe dementia for admission into the Specialist Dementia Care Program. This is a Government initiative that provides specialist accommodation, management and support for those people living with dementia who are unable to be cared for by mainstream aged care services. The program aims to help people return to less intensive care settings through specialised, transitional residential support.

For more information about DSA, visit https://dementia.com.au/.

Better equipped

The training has equipped me with stronger skills in comprehensive analysis, identifying the contributing factors to responsive behaviour and improving my report writing so I can better advise our services on positive strategies to support people living with dementia.

The knowledge I gained from the program continues to have a flow-on effect – building more capacity within Blue Care to better review and respond to people living with dementia in both residential aged care and community contexts.

It has not only helped me support staff with strategies for clients experiencing responsive behaviours, it has also assisted the Blue Care team to facilitate improvements in our clients' living environments to support them to live better *in* their dementia. Some of these changes include adding wayfinding signage and familiar items in rooms, repositioning photos for reminicense, and improving the outdoor areas to encourage more engagement for and between residents.

During the IP Program, we worked alongside DSA consultants during their visits to aged care facilities, watching them in action. At the end of each visit, we wrote a reflective report which was peer reviewed. (I attended at least six visits during the six-month program). Once confident, we were able to lead visits, with DSA consultant support.

The IP training teaches participants how to obtain information from each aged care service prior to a visit from the DSA consultant, enabling them to review the person's needs and situation in advance and provide advice as an interim measure before the first visit.

Improving practice

Peer reviews and reflective practice were a big part of the program, teaching me how to improve practice. Getting feedback on reports and thinking about how your day or week has gone and what you can celebrate or improve upon is really powerful.

I was also trained as a consultant for the DSA 24-hour telephone service which supports care staff and family carers on the ground.

This helped me better understand the experience of the family carer and their need for strong support as they experience what the person living with dementia is experiencing.

Information sharing

One of the highlights of the IP Program was attending the 2018 International Dementia Conference, hosted by HammondCare. This was a great experience and the information sharing was invaluable.

I particularly liked the session presented by John Quinn on 'Masculinity and Dementia'. His presentation really highlighted for me who the expert is, and that is the person living with dementia – all we need to do is listen and we will gain so much. This topic formed part of my discussions with Blue Care staff for many weeks.

Conclusion

I continue to support people living with dementia at eight Blue Care homes and three community services, helping them to have a better life experience and encouraging staff to better understand their clients and to be person-centred in their approach.

I also chair Blue Care's Memory Support Advisory Group (which now has rural, remote and indigenous representatives along with consumer representatives), and, along with my team, have created Coopers Café, a café for people living with dementia and their families. I am also gathering evidence to seek re-accreditation with the IP Program as a Dementia Consultant in 2021. ■

■ Nerida Pankhurst is Care Co-ordinator at Coopers Plains Memory Support, Blue Care SEQ South

For more information about the HammondCare/DSA Intensive Industry Partner (IP) Consultant Program, email dsa@dementia.com.au. The IP program hasn't been active in 2020 due to COVID-19 and the increased demand on DSA services. However, DSA expects to re-activate it in 2021 in a new format.

The Nightingale Program: excellence in palliative care

Jayne Littledike and **Alison Davis** describe a palliative model of care, provided by specialist nurses, that offers strategies and advice to support people living with dementia, their families and care providers during all stages of diagnosis


Photo: Prostooleh/freepik.com

Dementia Australia's Nightingale Program, established in 2016, is a unique and innovative nurse-led model of care. It is the only specialist dementia palliative care program in Australia, providing dementia-specific education and clinical support to people living with dementia, their families and carers in South Australia.

The concept for the program was initiated following feedback from Dementia Australia clients, who experienced unmet needs in terms of accessibility and provision of palliative care services. This inequity is also evidenced throughout the literature (Dempsey *et al* 2016; Duane *et al* 2015; Hanson *et al* 2019). The program was developed to improve planning opportunities and early access to a palliative approach to care for people living with dementia, their families and carers.

The Nightingale Program team consists of three Clinical Nurse Consultants and a Consultant Geriatrician. The service provides specialist assessment, education and support within a dementia palliative model of care. To promote an interdisciplinary approach, the nightingale team collaborate with other specialists, primary health care providers, Adelaide palliative care services, aged and community care and other service providers in the sector.

In providing this overview of the Nightingale Program we aim to inspire other clinicians to implement similar approaches and to promote accessibility to palliative services so that all people living with dementia have a voice in their care, can live longer in their own homes and experience dignity at the end of their lives.

Dementia and palliative care

Dementia is the leading cause of death for females and the second leading cause of death overall in Australia. Furthermore, the Australian Bureau of Statistics (2018) identified that deaths due to dementia have increased by 68.6% since 2009. Despite this, many people, including health professionals, do not view dementia as life limiting and therefore do not seek out palliative care services (Hanson *et al* 2019).

Additionally, there is a lack of clinicians with expertise in both palliative and dementia care, which results in significant missed opportunities to identify the end-of-life stage, to work through future planning and to discuss the complexity of symptoms experienced in dementia.

Other factors affecting palliative outcomes for people living with dementia include a lack of documented future care directives, increased hospital admissions characterised by protracted length of stay, leading to a significantly higher risk of death, falls, delirium, and a likely loss of function, as well as premature entry to residential aged care (Hansen *et al* 2019).

The majority of people living with dementia have at least one carer and this person is often a spouse or family member. Carers of people living with dementia experience higher rates of physical, psychological and economic stress and higher rates of depression when compared to other carer groups (Brodaty *et al* 2003). In addition to these challenges, family carers often face ethical dilemmas as the person living with dementia is reliant on them as their substitute decision maker and advocate.

Palliative care

The World Health Organisation (2018) defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through treatment to prevent and relieve symptoms, to minimise physical, psychosocial and spiritual stress. Palliative dementia care goes beyond a biomedical approach and addresses the many cognitive, psychological and functional progressive changes experienced throughout the stages of dementia.

Too often, people living with dementia receive inadequate or inappropriate end-of-life care (Dempsy *et al* 2015). Given the lack of understanding of the progression of dementia, it is not surprising that clinicians are often unable to anticipate the needs and complications that arise during the end stages, including recognising the key indicators that indicate that the terminal stage is near and when to refer to palliative care services. (Dempsey *et al* 2015). People living in the advanced stages of dementia are at risk of multiple complications including recurrent infections, dual incontinence, dysphagia, pain, myoclonic jerks (quick, involuntary muscle jerks) and seizures. Additionally, it is estimated that approximately 90% of people living with dementia have multiple comorbidities such as heart and respiratory disease and diabetes (Moss *et al* 2002; Mitchell *et al* 2007 cited in Dempsey *et al* 2015).

The Nightingale Program

The Nightingale Program recognises the importance of the wellbeing and personhood of people with dementia within a model of palliative care. The service provides specialist nursing support to people living in the community, residential and acute care settings. There is no fee for this service and no impact on other services that the client may be receiving. A face-to-face service is provided throughout metropolitan South Australia, with phone support offered in regional areas of the state. Goals of the program include ensuring families have ongoing dementia-specific palliative care support, education, advanced planning and practical advice.

Referrals

Referrals are received through a variety of sources including Dementia Australia's National Dementia Helpline, medical, nursing and allied health professionals, Adelaide palliative care services, family and friends, residential aged care facilities and community service providers. With an emphasis on maintaining a timely response, Nightingale Program clients are clinically triaged and allocated to a nurse according to priority of need. Each nurse manages a case load of 20 to 30 clients which begins with assessment and consultation to ascertain the symptoms of concern, and needs and goals of the clients.

Assessments

The service is underpinned by continual, multifactorial nursing assessments, which are inclusive of family carer observation and based upon current best practice evidence. The aim of assessment is to help understand the individual's progression and staging of their symptoms, such as pain or depression. A wide range of assessment tools from both the dementia and palliative paradigms are applied.

It is beyond the scope of this overview to describe all of the assessment tools used, however two pivotal assessments frequently used in our clinical reporting are the Functional Assessment Staging Test (FAST) and the Abbey Pain Assessment.

The Nightingale Program team (from left) Toni Fewster, Jayne Littledike and Alison Davis, all Clinical Nurse Consultants

Identifying stage of dementia

Endsley and Main (2019) identified that determining the prognosis for a person living with dementia and planning future care begins with establishing the current stage of the syndrome. The Nightingale Program assessment process is built around this concept; by identifying the stage of dementia and the person's symptoms we are able to provide targeted and anticipatory advice, education and support. Dementia syndromes (the most common being Alzheimer's disease, vascular dementia, dementia with Lewy body, and frontotemporal dementia) are recognised as having seven distinct stages.

The FAST staging is a validated measure of the course of Alzheimer's disease in the published, scientific literature from a functional perspective (Scalan & Reisberg 1992). Primarily, the Nightingale Program supports people living in the advanced stages of dementia (stages 6 and 7), which can be summarised as progressing from improperly putting on clothing, to a loss of ability to hold up their head independently (Auer & Reisberg 1997; Scalan & Reisberg 1992). Through reflection, we have identified that people at a FAST stage 6 and 7 are the most underserved and most at risk of needing specialist palliative care.

Pain assessment

Pain is recognised as a common symptom in palliative care, regardless of the diagnosis (Endsley *et al* 2019; Hendricks *et al* 2015). In dementia, pain is often undiagnosed and therefore undertreated, which can affect quality of life, mood, cognition and responses to care (Dempsey *et al* 2016).

The Abbey Pain Scale is an instrument used to score pain symptoms for people who are no longer able to verbalise pain. It is a movement-based assessment that uses observations of vocalisation, facial grimacing and changes in body language and physiological and physical changes (Abbey *et al* 2004).

In the Nightingale Program, we commonly observe that once pain is managed, symptoms such as agitation, pacing, loss of appetite, impaired sleep and reluctance for care, improve. We acknowledge the subjectivity in pain assessment and our experience is that, through educating carers to recognise the symptoms of pain and identify the triggers, they are empowered to better understand, respond to and manage pain.

Nursing recommendations

Detailed nursing recommendations are provided to clients to manage the symptoms of dementia and co-morbidities, and address the goals of care. These can be provided as a written report or, in many cases, as a demonstration of better approaches to care. Modelling of care is pivotal in providing an individual approach and gives the carer confidence, as they see the immediate benefit.

Long-term support

The Nightingale Program has the ability to support people, care providers and families over an enduring period of time; this is not afforded to traditional palliative care services which can only support people in the last months of life. Given the complexities of the Australian health and aged care systems, having access to a single and reliable point of contact who has a thorough understanding of the client's needs and is skilled in navigating the systems is essential.

Ongoing support and evaluation is provided to the team at a weekly case conference with a Consultant Geriatrician. New and existing clients are individually presented for discussion regarding symptoms and medication management. A clinical report is developed which details current symptoms and stage of dementia and provides a plan for the pharmacological management of pain, agitation and depression if indicated. This report is shared with family, general practitioners, other treating specialists and health providers in order to optimise symptom control and foster a shared understanding.

Empowering families and carers

Through a flexible approach, we model best practice care interventions which upskill and empower families and carers. No two people or circumstances are the same; the approach to care needs to be flexible, dynamic and directed by the person living with dementia and their families, with respect to their goals, personal preferences and religious and spiritual beliefs.

Critical to the program's success is the ability to maximise service opportunities with other stakeholders, through shared care, collaboration and an interdisciplinary approach. Feedback from Nightingale Program clients and families has identified that specialist coordination of support is invaluable.

Conclusion

We understand the importance of supporting carers and recognise that, without their support and cooperative approach, our work would not be effective or sustainable. We remain with clients as their needs change, including if there are periods of hospitalisation or admission to residential care. The relationships we build with the person living with dementia and the carers and other stakeholders are vital in promoting ongoing assessment, evaluation and proactive responses that promote living well and dying with choice and dignity. To date, the service has proudly supported over 650 clients, families and carers.

Dementia Australia is keen to explore options for this service to be expanded in South Australia and for the model to be adopted in other Australian States and Territories.

In the meantime, other services that support people living with dementia can apply the program's principles to their current practice through:

- understanding the person living with dementia
- using dynamic, validated assessment tools
- implementing a planned approach to care – proactive versus reactive
- being flexible – think outside the biomedical model of care
- adopting an interdisciplinary approach
- providing family education and support.

Dying with dignity

Jayne Littledike and **Alison Davis** explain how the Nightingale Program supported Steve, and his wife Vicki, from his initial referral right through to his peaceful and dignified death at home

Steve (pictured at right) began as a client of the Nightingale Program at the beginning of December 2017, at the age of 63. He was a car enthusiast and retired business owner, living with his wife Vicki (pictured with Steve, far right).

Steve's care needs were related predominantly to his living with frontotemporal dementia. It affected his ability to communicate, with a loss of verbal language early in his diagnosis. He had poor impulse control. He lost the cognitive ability to process information, to assess his environment or sequence tasks.

Vicki initially sought advice from our service around Steve's increasing sleep disturbance, anxiety, vocalisations and urinary frequency and incontinence. He would become distressed and start to disrobe as he paced, increasing the risk of falls. Vicki had previously attempted toileting schedules and ruled out possible infections, however, at the time of referral, responses were as frequent as every few minutes.

An initial nursing assessment found that Steve had a Functional Assessment Staging Test (FAST) score of 6 (advanced dementia). Following a Nightingale team case conference, which included our consulting geriatrician, a clinical letter with medication recommendations was sent to Steve's GP. A follow-up case conference was also held with the GP to explain the rationale for the changes. Non-pharmacological strategies were also provided and over a relatively short period of time there was notable reduction in Steve's pacing and agitation.

Ongoing support for Steve and Vicki via phone calls and home visits from our team provided ongoing assessment, advice and strategies for the changing symptoms of dementia. This advice covered constipation, probable infections, sleep disturbance, pain, carer fatigue, medication management, changes in swallowing, diet, mobility and other clinical changes including myoclonic jerks and seizures.

Ongoing anticipatory planning from the start ensured that Vicki and Steve were supported in their choices. They were given information on the progression of the dementia and what type of care, equipment and environmental changes would be necessary to manage Steve's care at home. We also discussed when it was timely to stop prophylactic medications, what 'comfort care' involved and even funeral arrangements and what to do when Steve died at home.

Vicki and Steve were empowered to embrace the moment and took a trip interstate to see family, including a visit to the local pub, just weeks before Steve's death. The photo (above left), taken during that trip, says it all – embrace the good things.

By August 2018, Steve was no longer safe to stand and had progressed to a FAST scale of 7, with changes occurring rapidly: he was sleeping during the day; changes in his swallowing and appetite where noticeable; and he was experiencing more chest infections and urinary tract infections. By September, myoclonic jerks were increasing in frequency and Steve began to have seizures.

By October, he was in the end stages of the disease. Steve had a series of seizures in one day, after which he no longer had a safe swallow. Palliative care services were brought in during Steve's final weeks for a collaborative approach. In those last days we supported Vicki, reassuring her she was capable of the care required and listening to her stories of the man she loved, allowing her to grieve.

On October 31, 2018, Steve died at home, peacefully and with dignity, surrounded by his family, just as he had wished.

Our vision is a future where every person with a diagnosis of dementia can access the care and support of a nurse with specialist skills in dementia care and palliative care. This person-centred, holistic model of care would be available at a time that still enables choice and proactively supports the person with dementia and their families. ■

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Speech pathology and reablement

Speech pathologists can play a central role in the treatment of communication difficulties experienced by people with dementia and supporting existing skills across the course of the disease. **Erin Conway** explains

While difficulties with memory are one of the most recognisable features of dementia, a change in communication ability is also a common symptom. The changes experienced by people with dementia, such as changes in their ability to find the right words to say, understand the question being asked, or follow along with an everyday conversation (eg, Caramelli *et al* 1998) can have a significant impact on their social interactions, independence, relationships with family and friends, and quality of life (eg, Ritcher *et al* 1995; Potkins *et al* 2003).

Speech pathologists are allied health professionals who specialise in the identification and treatment of communication difficulties (as well as swallowing and mealtime difficulties) for people across their lifespan. Speech pathologists can therefore provide services for people with dementia, aimed at enhancing communication function through rehabilitating and/or compensating for the communication difficulties that the person is experiencing, supporting the maintenance of existing skills, and/or facilitating a supportive communicative environment (Speech Pathology Australia 2015). Speech pathologists should play a central role in the treatment of communication for people with dementia across the course of the disease (American Speech-Language-Hearing Association 2017; Royal College of Speech and Language Therapists 2014).

In the past decade there has been an increasing amount of research focused on speech pathology treatment for people with dementia. The following sections summarise some of the current evidence for the efficacy of speech pathology treatment in dementia, highlighting the contribution of Australian research teams.

Communication partner training

The *Clinical Practice Guidelines for Dementia in Australia* highlight that providing training to support effective communication between a person with dementia and their family or care-givers is a key recommendation for quality dementia care (Laver *et al* 2016). A number of communication skills training programs have been developed for use with people with dementia and their family, care-givers or aged care staff and have shown positive outcomes for quality of life and wellbeing for people with dementia, as well as improvement in communication skills and related knowledge for family or care staff (Eggenberger *et al* 2013).

MESSAGE training

One communication skills training program that has been developed and evaluated in Australia is the *MESSAGE Communication Skills Training for Caregivers of People with Dementia* (Smith *et al* 2011); available from www.youtube.com/UQDementiaCare (and see box p35 for more details). This program presents practical compensatory strategies, developed following a review of research evidence, that the caregiver can apply in everyday conversation to support the person with dementia's participation.

Evaluations of the MESSAGE training have found that it is able to significantly increase knowledge of communication support strategies for family carers, staff in residential aged care and in community aged care (Broughton *et al* 2011; Liddle *et al* 2012; Conway & Chenery 2016). Other positive outcomes involve improvements in aspects of the carer experience following training, including a measure of positive experience in caregiving and a measure of care staff preparedness to provide care (Conway & Chenery 2016).

Current research is continuing to

explore the outcomes of the MESSAGE training on direct changes to conversation behaviour by care staff, and exploring whether the use of the MESSAGE communication strategies can also reflect a person-centred communication style. A person-centred communication style can be defined using behaviour associated with four indicators of person-centred care (Kitwood 1997) that are most relevant to communication: facilitation (eg, initiating or maintaining a topic of conversation), recognition (eg, recognising the unique person through using their name), negotiation (eg, supporting choice), and validation (eg, affirming the persons emotions) (Savundranayagam 2014).

The MESSAGE strategies have also been applied as part of a training program for people with co-occurring dementia and hearing impairment. The Hear-Communicate-Remember program provided family members of people with dementia and hearing loss with: strategies to support using hearing aids, memory strategies applied to hearing aid use, and the MESSAGE communication strategies (Meyer *et al* 2019). This program was piloted with a small number of family carers and participants reported that they were satisfied with the program and the presentation of strategies in training videos, and were able to learn strategies applicable to their everyday life (Meyer *et al* 2019). Future research should further explore the functional impact of this training.

Overall, communication partner training programs offer the opportunity to create a more supportive communication environment to maximise the participation of people with dementia in everyday communication; there are also more direct rehabilitative approaches available that aim to support everyday communication.

Rehabilitation of word retrieval

Difficulties with word retrieval (finding or thinking of the right word) is common in many types of dementia and can have a significant impact on everyday communication abilities. This is a growing area of both research and clinical focus for speech pathologists (Speech Pathology Australia 2015). Treatment in this area can focus on compensation for difficulty, restorative rehabilitation, and/or maintenance of existing word knowledge and use.

A recent systematic review revealed that there is positive evidence to support treatment of word retrieval for people with Primary Progressive Aphasia (PPA) diagnoses, and people with an Alzheimer's disease diagnosis (Beales *et al* 2018). Beales and colleagues examined the results of 37 studies, the majority of which focused on treatment of people with PPA, and categorised the types of treatment approaches across studies. There were four types of treatment approach identified by Beales *et al*: re-learning, stimulation, reorganisation and cognitive-relay. The outcomes for each are summarised below.

Communication skills training programs have shown positive outcomes for quality of life and wellbeing for people living with dementia. **Photo: Tirachardz/freepik.com**

Re-learning

The most frequently reported treatment approaches were the re-learning approaches (22 studies); these treatments involved retraining the link between word meaning and word form often using semantic (meaning) and/or phonological (word/sound) cues (eg, Jokel & Anderson 2012). Improvement in direct treatment measures (eg, picture naming) was reported for most investigations (Beales *et al* 2018).

Stimulation

The stimulation approaches to word retrieval treatment usually involved repeated presentation of picture stimuli for the client to name, often with the name label presented simultaneously (written and/or spoken) (eg, Savage *et al* 2013). All 12 studies categorised as stimulation approaches reported improvement in their direct treatment outcome measures (eg, picture naming) (Beales *et al* 2018).

Reorganisation

The reorganisation investigations refer to neural reorganisation and involved approaches that promoted the use of different parts of the brain to take over for impaired functions. Three investigations were included in the review (Beales *et al* 2018). These investigations involved both behavioural (repeated naming) treatment, and behavioural and neural measures of change (functional MRI studies) (eg, Dressel *et al* 2010). Evidence of compensation by different areas of the brain following treatment were reported, for instance increased use of frontal and temporal areas in the right hemisphere after treatment (eg, Dressel *et al* 2010).

Cognitive-relay

Finally, the cognitive strategy approaches to word retrieval treatment took a more compensatory approach. These interventions involved training people to use an additional cognitive strategy to support their word retrieval; for instance, training participants to use a series of self-cues (self-generated meaning cue – let's say for the word 'pizza' – eg, type of food), autobiographical cue (eg, my favourite take-away food), sound (eg, starts with 'p') and written word (eg, pizza) cues to help think of the word needed (Beales *et al* 2016). Significant improvement in naming accuracy following treatment was reported for the two cognitive strategy studies included in the review, along with indications of increased confidence for participants in retrieving words (Beales *et al* 2018).

Rehabilitation beyond naming

In addition to outcomes related to improved naming, it is also important to consider the impact of treatment beyond the single-word level. Exploring the impact of improvement in word use in conversation, for instance, likely has a more functional impact on a person's every day communication. Five studies included in the Beales *et al* (2018) review investigated the impact of their treatment at the discourse level (for example in monologue storytelling tasks or picture descriptions; Beales *et al* 2016; Beeson *et al* 2011). Four of these studies reported some element of improvement in word use at the discourse level following treatment (Beales *et al* 2016; Beeson *et al* 2011; Croot *et al* 2015; Heredia *et al* 2009), suggesting that there is potential for benefit beyond the single-word level for some treatments.

NARNIA intervention

A recent West Australian study extended upon existing research to focus on treating word retrieval for people with dementia specifically at the discourse level (Whitworth *et al* 2018). Whitworth and colleagues investigated the effect of the Novel Approach to Real-Life Communication: Narrative Intervention in Aphasia (NARNIA) intervention (Whitworth *et al* 2015), originally designed for use with people with non-progressive aphasia related to stroke, for two people with PPA (one with semantic type and one with logopenic type). This intervention incorporated a range of discourse types, such as, expressing opinion, recounting events in a narrative and explaining procedures for tasks that focused on topics of interest or relevance for the person.

The NARNIA intervention focuses on multiple levels of word retrieval, from production of words, to sentences and then directly on the discourse level. Whitworth and colleagues (2018) found that the two participants showed significant improvement across the discourse elements being investigated, including amount of talk, use of nouns and verbs, and the structure of their discourse production.

Overall, there is growing positive evidence to support direct rehabilitation for people with PPA and/or Alzheimer's disease to improve word retrieval performance at the single-word level; and initial promising results for interventions focused beyond the single-word level to improve word retrieval in discourse. There remains the need for continued research with larger cohorts of participants and further consideration of everyday functional impacts, such as confidence in communication or performance in conversation, as well as a need to enhance the validity of interventions through the involvement and consultation with people with dementia and families in their design.

For moderate to advanced dementia

Much of the research discussed in the previous sections of this article has focused on outcomes for people with mild-to-moderate dementia, however, speech pathologists in clinical practice also require evidence-based approaches to support communication for people with moderate to advanced dementia.

The current available research related to communication treatments for people with moderate to advanced dementia that could be applied by a speech pathologist was explored in a recent systematic review by a group of clinicians and researchers from Queensland (Swan *et al* 2018). Eleven studies were included in the review, with 10 of these investigating direct treatment methods, across cognitive stimulation approaches (eg, reminiscence, social activity, or cognitive stimulation therapy), cognitive training approaches (eg, semantic naming treatment or spaced retrieval treatment), or compensatory approaches (eg, use of memory books); the one study using an indirect approach, ie not working with the person with dementia directly, involved communication partner training (see Swan *et al* 2018).

Swan and colleagues (2018) found that although there was significant variability between the interventions and methods of the included studies, there were a few commonalities that could represent potential areas for future research or clinical focus when working with people with moderate to advanced dementia.

The focus on conversation as the mechanism of treatment was a common feature across multiple studies, for instance group treatments that facilitated the participation of the person with dementia in conversation as part of the treatment activity (eg, reminiscence or social breakfast club and conversation group; Okumura *et al* 2008; Santo-Pietro & Boczko 1998), or individual treatments where conversation participation was supported through the use of memory aids (Bourgeois *et al* 1997).

The use of group treatments was also commonly seen in the included studies that reported positive outcomes, such as cognitive stimulation therapy (Spector *et al* 2010), reminiscence therapy (Okumura *et al* 2008), conversation therapy (Tappen *et al* 2002), and combined social interaction with procedural tasks around breakfast or 'breakfast club' (Santo-Pietro & Boczko 1998).

The other approach that shows potential for improving communication was the use of external aids, such as memory books, that provide compensatory support for people with dementia in conversation (eg, Bourgeois *et al* 1992). Despite these areas of commonality, the studies included in the review were relatively dated, and had variation in their approaches and outcome measures, with no two investigations the same. Interestingly, only six of the studies included treatments conducted with a speech pathologist, which highlights this as an area of growth for speech pathology research.

Reablement practice

People with dementia represent an important clinical population for speech pathologists, and in order for clinicians to provide best practice person-centred evidence-based care to individuals with dementia they need to be able to access current best evidence that is valid for the clinical population.

There is evidence that direct communication interventions for word retrieval in people with mild to moderate dementia (Beales *et al* 2018), as well as communication interventions for people with moderate-advanced dementia

Get the MESSAGE

What is MESSAGE, and how can you find out more about it?

MESSAGE is a mnemonic, with each letter acting as a reminder of the seven communication strategies within the MESSAGE communication skills program. 'M', for example, stands for 'Maximise attention' and 'S' stands for 'Support their conversation'.

Dementia Training Australia (DTA) has launched Dementia Discovery – a series of short, free online training modules offering introductory level education about dementia and aimed at those who are new to the aged and dementia care workforce.

One of the modules within the Dementia Discovery course, 'Communication Matters', introduces learners to the MESSAGE communication skills training program. The module includes two films: one which introduces care staff to the MESSAGE strategies (21 minutes), and the second one which shows the strategies being put into practice (13 minutes). Learners are then asked to respond to a series of questions to check their understanding of the films' content.

A Certificate of Completion is available for those who complete the course, along with help sheets from DTA consortium member Dementia Australia and links to external resources and websites. To access the course and for more information, visit www.dta.com.au/dementia-discovery.

(Swan *et al* 2018) may improve or protect communication function, and potentially improve wellbeing. There is also evidence to suggest that communication partner training can facilitate a quality communication environment to support participation of people with dementia both within the family and aged care contexts (eg, Eggenberger *et al* 2013).

There is therefore positive evidence for speech pathologists to focus on reablement and lessen the functional impact of dementia for people by maximising ability through compensatory and / or restorative treatment (Poulos *et al* 2017).

Looking to the future, there is a need for continued research work focused on evidence to support intervention in communication, the role of the speech pathologist in evidence-based dementia care and reablement and, importantly, exploring and incorporating the views of people with dementia in the design of research and interventions. ■

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Australian Journal of DementiaCare

Research Focus

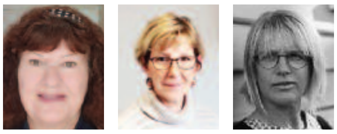
This section aims to provide a channel of two-way communication between researchers and practitioners in the expanding field of social, psychological and nursing research in dementia care, including all aspects of nursing and care practice, communication and the environment.

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.

Fostering community conversations around dementia

University of Tasmania researchers (pictured from left) **Susanne Becker**, **Helen Courtney-Pratt**, and **Pauline Marsh** report on a pilot project exploring how informal community cafés, where all are welcome, might reduce stigma and normalise discussion about dementia in everyday life



The impact of dementia on individuals, families and communities is far-ranging. Stigma and fear can contribute to isolation of those living with the impact of the condition, resulting in subsequent invisibility in the community.

Whilst significant work has been undertaken in the movement toward dementia-friendly communities, where inclusion and respect for the rights of all are central, there is still a way to go before people can comfortably and openly disclose a diagnosis and experience authentic respect for their personhood and rights. Indeed, one of the biggest challenges is to 'get the conversation going'. The pilot project described in this article drew on the example of 'death cafés' to explore how an informal conversation strategy might reduce stigma and normalise open discussion and consideration of dementia in everyday life.

Project aim

The aim of this study was to explore whether café-style conversations around dementia would be welcomed, supported by, and beneficial to a range of people.

Project background

About 70% of people with dementia live in the community (Alzheimer's Australia 2014) and, progressively, the proportion of people living with dementia within their communities will increase. Recent aged care reforms in Australia have sought to strengthen and extend services offered to older people to enable them to remain in their own home and communities (Department of Social Services 2015).

In addition to support for ageing-in-place, further initiatives such as age-friendly cities (World Health Organization 2007) and dementia-friendly communities (Chalk & Page 2016) have emerged (Turner & Morken 2016). Alongside these, there have been moves to decrease the stigma of dementia through education and improved citizenship rights for people living with the condition, nationally and internationally (ADI 2019; Kim *et al* 2019). There is, however, a long way to go.

There is an established recognition of the importance of supporting community conversations about dementia in order to decrease stigma, isolation of those living with the condition, and to understand how people living with the condition can be supported to live well in the community. Fostering conversations at a grassroots level can help to demystify dementia and facilitate those living with dementia to make ongoing contributions to the community (ADI 2019, 2018). Other suggested benefits include delayed entry to residential aged care, and greater support for ageing in place for all (Evans 2018).

The Wicking Dementia Research and Education Centre through its *Dementia friendly communities: prioritising action through community input* research stream (Courtney-Pratt *et al* 2018), discovered a strong need for informal information sessions with the capacity to reach a wide range of community members.

The notion of a community café pilot project was developed, based on the successful death café model. The death café model aims to decrease stigma and societal discomfort about discussing and planning for death (Baldwin 2017) and is an established, albeit grassroots, approach to demystifying often difficult topics in the general community. In the death café model anyone is welcome, sometimes to listen and socialise, but there are other benefits including linkages to information and service providers, and social support (Miles & Corr 2017).

Although dementia cafés have been operating in some communities, their primary purpose has generally been to provide networking and support groups for carers and/or people living with dementia (Dow *et al* 2011). In this pilot study, however, we extended the invitation to the general community and opened the conversations to include those worried about receiving a dementia diagnosis, wanting to seek further information, caring for those living with the impact of dementia, and importantly anyone with a diagnosis or current experience.

What we did

Four cafés were arranged late in 2018, with key community personnel and advertised through one local council's Positive Ageing Network, and posters placed in local shopping and community hubs. Morning tea was provided. Two café sessions partnered with existing community morning tea events at a neighbourhood house and a community garden.

Community members were advised that their normal morning event would host a dementia café instead of usual activities and other participants were invited via advertising through local networks. The other two cafes were standalone events – one in a community hall and the other in a community garden attached to a local school. Representatives who understood the current health provision framework, local community resources, and had knowledge of dementia attended all cafes.

Participants were asked to answer four questions via postcard at completion of the sessions (see images this page). Return of postcards implied consent and all responses were anonymous. Cards contained a small amount of demographic information (suburb, age and gender) and option for free text responses. Attendees were not asked to declare the presence of a dementia diagnosis or carer role, and although several individuals indicated through discussion they were living with dementia or were in a caring role, others may have chosen not to disclose a diagnosis.

Community feedback

Of the 78 people who attended the four cafés, 29 provided feedback via the postcard. Under half of those attending the pilot cafes provided written feedback and responses provide insights into why people attended, what they hoped to gain from a session, and what adaptations may be required to extend the café concept into the broader community. The average age of those providing feedback data was 57 years of age (range 31-83) and respondents were predominantly female (27 females and two males).

HAVE YOUR SAY ON CAFÉ CONVERSATIONS ABOUT DEMENTIA

Dr Susanne Becker
Wicking Dementia Research
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WE ARE INTERESTED IN HEARING VIEWS FROM EVERYONE WHO ATTENDED

Please complete the answers on reverse side and post back.

Tell us a little about why you came to the café today?

What did you hope to get out of coming today?

What did you get out of coming today?

What advice would you give us about holding future café conversations about dementia?

Answers to the questions will be used to inform the development of a toolbox that communities can use to enable conversations about dementia. Feedback will also be used in short reports or publications. For more info, please contact Susanne at: s.e.becker@utas.edu.au

AGE
GENDER
SUBURB

Participants were asked to answer four questions via postcard at completion of the sessions, covering the following: (1) Tell us a little about why you attended today?, (2) What did you expect from attendance?, (3) Has attendance met your expectations?, and (4) What feedback do you have to improve the running of future cafés?

Attendance and expectations

Overwhelmingly, feedback identified that people attended the café "*to find out more about dementia and learn" (1 Male)*, a comment reiterated by many participants. Other phrases captured a similar essence, including being "*interested in the subject" (3 Female)*, and *"for information" (25 F & 26 M)*. Other participants provided greater depth as to what type of information they sought, writing that they came *"more to find out about how to deal with or notice changes in people" (22 F)* or *"to learn more about dementia and to be able to tell when one has this disease" (27 F)*. Some individuals were worried about the possibility of their own dementia diagnosis and came because, for example, "*I have a few signs of memory loss that concern me" (19 F)*.

Participants also stated they attended to share experiences, to listen or to assist others. For example, one respondent wrote: *"to help others from my first-hand experience with dementia (mother)" (8 F)*, and *"to listen to other people and learn more about their experiences" (12 F)*. One person attended three of the four cafés as she was motivated to share her experiences and insights with others, writing *"my mum has dementia and she is now in a nursing home. I've done lots of courses about dementia and would like to help others"* (17 F).

A small number of participants came to support the initiative despite not having a connection to someone with dementia, or a specific dementia motivation. For example, a member of the local council's Positive Ageing Network said they wanted "*to learn more about dementia"* and "*add support to the initiative"* (15 F). Other participants had support roles in the community as volunteers or as allied health team members. One participant said they attended because, "*I coordinate volunteers, some of whom spend time with people who have dementia – diagnosed or undiagnosed"* (14 F) and another was a "*…local social worker supporting the local community"* (24 F).

What was helpful?

Most respondents (n = 26) stated that they gained information, which ranged from upcoming dementia education opportunities (three participants), understanding *"where to go or ring up if I have questions"* (5 Not Stated), and *"having general information about what is available in the community"* (6 F).

The opportunity to share stories and make connections with people in their own community was highlighted. One participant responded that *"helping others with advice is most rewarding"* (17 F), while another participant was able to recruit a volunteer for their local community activity (14 F). Attendance at the café provided an opportunity to meet others informally, with comments including: *"nice to talk to like-minded folk"* (2 F), *"pleasant and open conversation"* (19 F), and the *"value of connection and conversation"* (24 F), and a *"relaxing and enjoyable session"* (6 F).

Future café formats

Feedback was overwhelmingly positive with most respondents expressing a variant of "have as many as possible" (17 F) or having "regular meetings in the community" (21 F). The informal format of the sessions was supported with one woman, for example, describing the session as *"casual, informative, helpful, friendly – keep going with this format"* (28 F), and others saying the food and 'cuppa' were great additions (multiple participants).

It was suggested that more pamphlets with information to support verbal discussions would be helpful (11 F, 16 F and 19 F). Others suggested the addition of a "*person at each table to open the conversation about dementia and facilitate discussions and questions*" (14 F).

Increased community involvement could be a future aspiration: "*greater involvement of community members, including youth and intergenerational*" (15 F). Two participants commented on the Neighbourhood House as an ideal venue to have "*informal chats in a relaxed atmosphere*" (20 F), and to reach out to members of a community, for example, "*where people might not have access to doctors as easily*" (3 F).

Two participants felt the café style session was too loud and impacted on their capacity to participate and suggested providing seating away from the main gathering for those who were hard of hearing (9 F and 12 F).

What the feedback tells us

Our findings indicate that the café style is welcome and beneficial, a heartening response when communities are seeking opportunities to improve community awareness and understanding around dementia. Given the push by the *National Framework for Action on Dementia 2015-2019* (AHMAC 2015) to improve communities' understanding, such an 'open-invitation' café concept is a valid option for communities seeking such initiatives.

Information and understanding

All participants who completed feedback indicated they had gained information or understanding around dementia, findings consistent with other café concept studies (Dow *et al* 2011; Kiddle *et al* 2015; Merlo *et al* 2018). Diverging slightly from the more established Memory Lane Café (Dow *et al* 2011) and Alzheimer's or dementia café's concept (Greenwood *et al* 2017; Merlo *et al* 2018) that target people with dementia and their carers, our cafés successfully attracted interest from the wider community.

Decreasing stigma

Providing relaxed, café-style opportunities can decrease stigma, link individuals and improve awareness and create communities that are more inclusive and accepting of the person with dementia. Although stigma wasn't directly addressed in participants' comments, we suggest that informally sharing stories and listening to the stories of others attending the café may assist in decreasing the stigma associated with the media's often homogenous portrayal of those living with dementia (Kilduff 2014). As reported in the *World Alzheimer Report 2019* (p144): "Conversations can change lives. We know that sharing personal stories within communities is vital for ending stigma."

Choice of venue

From this small study it appears the site of the café may have an impact on attendance. It is not always clear whether similar café-style studies are reporting on cafés held in established café businesses or using a public or private space and making it into an improvised café (for example Dow *et al* 2011; Greenwood *et al* 2017). Other studies have used a mixture of established cafés and public places (eg Friedman *et al* 2016) or created a space within an Alzheimer's clinic (eg Merlo *et al* 2018). Kiddle and colleagues (2015) held their sessions in a local youth centre.

Choice and suitability of the venues was not discussed or evaluated further in these above studies.

Nevertheless, the greatest number of people in our study attended the café held in the local neighbourhood house where a fortnightly morning tea event was long established. Members of this community were familiar with the location, space and timetabling, which may have significantly impacted on attendance. Choosing a venue where people usually gather may assist with attendance. This aspect for future cafés demands attention and further evaluation, particularly given the 'all are welcome' concept.

Community partnerships

Working in partnership with key community personnel and a local council, and building on their experiences of holding events and implementing initiatives, assisted in advertising our pilot study's cafés through established avenues such as networks and community hubs.

Collaborating with agencies outside of the health sector, to increase the reach and provide initiatives such as café-style conversations in sites where community members already feel comfortable, may be one way of furthering community members' awareness and understanding of dementia.

Conducted in two local council areas, one of which has an established and active Positive Ageing Network, we were able to value-add onto an existing calendar of events. While this is a strength to build on in these communities, it is acknowledged that not all communities have this foundation and may require significant support to conduct similar sessions.

As a small pilot study, information collected about the café-style conversation approach will add to the toolbox of strategies to increase the awareness and understanding around dementia in the community. The café model successfully stimulated conversations around dementia on a range of topics and catered to the various interests and needs of the attendees.

Conclusion

Feedback from this pilot study suggests that a format based on the death café model of 'all are welcome' and an atmosphere that ignites conversations around dementia can be beneficial to community members.

Holding the cafés in local community hubs where people are already comfortable, such as neighbourhood houses and community gardens, may facilitate attendance. Participants were generous in sharing their own experiences, which others found aided their understanding.

This is a worthwhile and accessible model for communities to consider, to improve awareness and create communities that are more inclusive and accepting of the person with dementia.

There is a need to further evaluate and understand the impact of community-based interventions that intend to get community conversations started, to decrease stigma and promote the citizenship rights of people living with dementia. ■

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RESEARCH NEWS

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

Palliative care: barriers and facilitators

UK researchers from the University of Hertfordshire have conducted a systematic review to investigate the factors influencing the provision of palliative care services for people with advanced dementia. Despite increased awareness of the palliative care needs of people with advanced dementia, the evidence suggests many are still not able to access it.

In total, 34 studies were included – 25 qualitative studies, six quantitative studies and three mixed methods studies. The findings identified a range of barriers and facilitators to accessing palliative care, including organisational, healthcare professionals and patients-related factors.

Barriers included lack of staff skills and training opportunities on palliative care in dementia, lack of awareness that dementia is a terminal illness and a palliative condition, pain and symptoms assessment/management difficulties, discontinuity of care for people with dementia and lack of coordination across care settings, difficulty communicating with the person with dementia and the lack of advance care planning.

Mataqi M, Aslanpour Z (2020) Factors Influencing Palliative Care In Advanced Dementia: A Systematic Review. *BMJ Supportive and Palliative Care* 10(2) 145-156. Epub ahead of print doi: 10.1136/bmjspcare-2018-001692.

Practice nurses in primary dementia care

A systematic review on the role of the practice nurse in the care of people living with dementia or cognitive impairment and their support person(s) has concluded that it has the potential to increase early recognition of cognitive impairment and more appropriate primary care management of dementia. The study was conducted by researchers from the University of Newcastle in NSW.

A total of 13 studies were evaluated in the review, but they varied in purpose, design, practice context and scope of role, making it difficult for the authors to synthesise findings and draw conclusions. Some positive roles undertaken by nurses working in the general practice setting included patient accessibility to the practice nurse, early recognition and management of cognitive changes, care management and collaboration with the GP.

In some studies, the practice nurses' contribution was constrained by a lack of definition of the role, inadequate dementia-specific training, time constraints and poor communication with general practitioners.

Gibson C, Goeman D, Pond D (2020) What Is The Role Of The Practice Nurse In The Care Of People Living With Dementia, Or Cognitive Impairment, And Their Support Person(S)?: A Systematic Review. *BMC Family Practice* 21(141) doi: 10.1186/s12875-020-01177-y.

Evaluation of dementia education in schools

This Australian study reports on the quantitative evaluation of an education dementia program – with and without an intergenerational program – on attitudes to dementia among children in the short- and long-term, as well as a qualitative exploration of which elements of the education program facilitated change.

The research involved 81 children (35 boys aged around 9 years old, from Years 4 and 5) from three classes participating in an eight-week dementia education program; of these, 52 were also involved in an intergenerational experience with older adults.

The findings show a positive change in children's dementia knowledge and attitudes immediately after the program; this remained higher six months after the intervention. There were no differences between the groups who interacted with older adults and those who did not. Interviews with participants also identified positive changes in children's empathy and improved community awareness.

The researchers say that this is the first evidence that school-based dementia education improves knowledge of and attitudes toward people with dementia long-term.

The intergenerational dementia education program was called 'Forget Me Not' and was developed in partnership with the City of Unley, Unley Primary School, and aged care provider ECH in Adelaide, South Australia. It has been featured in *AJDC,* in the June/July 2019 edition (Vol 8 No 3, pp28-31).

Smith AE, Kamm GL, Lai S et al (2020) A RE-AIM Analysis Of An Intergenerational Dementia Education Program. *Frontiers In Public Health* 8(248) doi: 10.3389/fpubh.2020.00248.

Strategies and interventions to reduce refusal of care

Researchers at the University of East Anglia have conducted a systematic review on strategies and interventions to reduce or manage refusals in personal care in dementia. A total of 36 articles, relating to 30 studies, met the eligibility criteria; of these 28 were studies conducted in long-term care facilities, one in a psychogeriatric unit and one with people with dementia living in the community. Fourteen out of the 30 studies focused on general or mixed care activities, eight on bathing, four on mealtimes, two on medication administration, and two on mouth care.

Positive strategies identified included music interventions, interaction and communication style, caregiver approach, bathing techniques, abilities-focused approaches, distraction approaches, and video-simulated presence of a loved one. There was most evidence for music interventions and different bathing techniques, and interaction and communication styles were associated with reduced refusals. No evidence was found to show that slow-stroke massage (mixed care activities) or aromatherapy (mixed care activities and medication administration) reduced refusals of care.

The researchers conclude that some non-pharmacological interventions, such as playing music during care or communicating positively, can reduce but not eliminate refusals of care, and that more research evidence is needed to underpin strategies such as Namaste Care or distraction techniques. They say future research should address refusals of care in hospital settings and in community settings, and interactions involving family carers.

Backhouse T, Dudzinski E, Killett A, Mioshi E (2020) Strategies And Interventions To Reduce Or Manage Refusals In Personal Care In Dementia: A Systematic Review. *International Journal of Nursing Studies* doi: 10.1016/j.ijnurstu.2020.103640.

Medication management roles

Australian researchers have conducted a qualitative study to explore the roles of different stakeholders in medication management for people with dementia with a view to identifying the barriers and enablers for achieving those roles.

The researchers conducted nine focus groups with stakeholders from rural and metropolitan communities in two Australian states (55 participants in total, including consumers, general practitioners, nurses and pharmacists).

The sessions were transcribed and thematically analysed, with four major themes identified: supporting the role of the person with dementia, carer roles and challenges, health professional roles, and process and structure barriers to medication management.

Participants discussed the importance of advance care planning, and the potential benefits of early implementation of dose administration aids to support patients in self-managing their medication. While carers were seen as vital advocates for patients, carer burden and changes in the patient-carer roles acted as barriers to this role.

General practitioners were regarded as the main care coordinator for a person with dementia, but effective collaboration and communication with allied health professionals and specialists was also important for optimising medication use.

Barriers to medication management included a lack of evidence, guidelines and practitioner training to guide prescribing and deprescribing decisions in people with dementia.

The researchers concluded that future research should focus on improving the evidence base to guide prescribing, facilitating stakeholder communication and ensuring early documentation of patient wishes for the future.

Cross A, Etherton-Beer C, Clifford R, Potter K, Page A (2020) Exploring Stakeholder Roles In Medication Management For People Living With Dementia. *Research in Social and Administrative Pharmacy.* doi: 10.1016/j.sapharm.2020.06.006.

GP dementia program evaluation

The effectiveness of a nationwide Continuing Medical Education (CME) program to enhance dementia-related awareness, practice, knowledge and confidence of general practitioners (GPs) in Australia has been evaluated by a team of Australian researchers.

The program's educational content was based largely on Brodaty *et al's* (2013) *Dementia: 14 Essentials of Assessment and Care Planning* and *Dementia: 14 Essentials of Management* (2013).

Data sources included self-report surveys by GPs (who participated in an accredited CME program face-to-face or online), program evaluations from GPs, and process evaluations from workshop facilitators.

CME participants completed surveys one or more times between 2015 and 2017: 1303 GPs completed the survey before and 1017 GPs completed the survey after the program, and just 138 completed a survey at six-to-nine months follow-up.

Average scores increased between pre-CME and post-program for awareness, practice-related items, knowledge, and confidence, and significant increases were seen in all four outcomes for GPs who completed these surveys at both pre- and follow-up time-points – but the authors suggest cautious interpretation of the results given the low follow-up response rate.

Most respondents who completed program evaluations said the training was relevant to their practice, and suggestions for additional content included topics such as capacity and legal issues, locality-specific specialist and support services, case studies and videos to illustrate concepts.

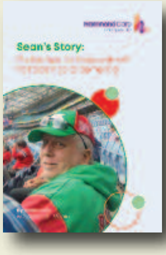
The authors conclude that dementia CME programs may contribute to improving capacity to provide timely dementia diagnosis and management in general practice.

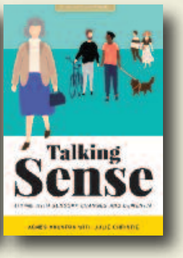
Casey A-N, Mofizul Islam M, Schütze H *et al* (2020) GP Awareness, Practice, Knowledge And Confidence: Evaluation Of The First Nation-Wide Dementia-Focused Continuing Medical Education Program In Australia. *BMC Family Practice* 21(104) doi: 10.1186/s12875-020-01178-x.

Australia's Heather Hill, author and consultant in dance and person-centred practice, will be in conversation with Mary Fridley from New York's East Side Institute as part of **Creating A New Performance of Memory Loss and Dementia**, an international online event exploring culture change, which will take place on Wednesday 28 October from 11am-12.30pm. Other panellists include Susan Massad, a retired physician educator (US), Nicola Pauling, Applied Improvisation facilitator and Artistic Director of Voice Arts (New Zealand) and Chuck McClatchey (US), who was diagnosed with younger onset dementia in 2016 and serves as a member of the Dementia Action Alliance Advisory Board. The cost is approximately $35. For more information, go to https://eastsideinstitute.org/events/.

Footprints Books – longstanding Australian distributor of books published by the UK's **Jessica Kingsley Publishers** (JKP), which specialises in books about dementia – ceased trading on 30 September 2020. JKP books can now be accessed instead via Woodslane, a NSW-based distributor of academic books. To find out more, go to www.woodslane.com.au

New HammondCare resources





HammondCare has launched two new substantial booklets (each 30-40 pages) on the topic of supporting people who are living with dementia and are deaf: one is aimed at family and friends, the other is aimed at care staff. The title for both booklets is **Deafness and Dementia: Interpreting Changes In Behaviour**, and both cover similar territory: introducing dementia, understanding behaviour, and communication and engagement. The resource for family and friends includes some simple approaches in response to behaviours, as well as communication strategies. The resource for care staff includes more detailed information about communication strategies that relate to supporting a person who is deaf/Deaf, and more on activities and engagement. The booklets provide information relevant to supporting both people who were born deaf (and may identify as being part of the Deaf community) as well as people who have lost their hearing completely later in life. The Deafness Foundation funded and reviewed the resources.

Sean's Story: My Five Tips For Living Well With Frontotemporal Dementia is a 16-page booklet in which Sean Kelly, who lives with frontotemporal dementia (FTD), shares his advice for others on living well with dementia. The new HammondCare resource is the result of conversations between Sean and Deborah Moore, a Dementia Consultant with the HammondCare Dementia Centre. The booklet covers 'What is FTD?', then goes on to present Sean's story and five tips (eg 'Chase the right diagnosis'). Inset boxes placed throughout the resource include a broader reflection on the significance of the 'tip' or issue for people with dementia more generally, and links to relevant resources.

The book, **Talking Sense: Living With Sensory Changes and Dementia**, was first published in 2018 by HammondCare – and now the book is available as an audiobook.

Talking Sense was written by long-time dementia advocate Agnes Houston, with Julie Christie, after Agnes found a dearth of information and support for people living with dementia who were experiencing sensory changes. The book covers the following areas: vision, hearing, touch, position sense and balance, and taste and smell. For each sense, the chapter begins with an introduction to the sense, and then explores the impact of ageing, and then the impact of dementia on that sense. The resource includes lots of practical suggestions, and information about who to go to for help, where support organisations can be located, and how to access services.

All the new HammondCare resources listed here are available to download for free from the Dementia Centre's website, at https://bit.ly/2HmJHwE.

UK-based charity Music for Dementia has launched its own internet radio station, **md4radio** (available at https://m4dradio.com/), as one way to deliver on its campaign to make music available to everyone living with dementia. The non-commercial radio station offers five different programs, each presenting music from different eras: the 1930s/'40s, 1950s, 1960s, 1970s, and a mixed program. Speaking is kept to a minimum, and the choice of music is linked with the time of day – from waking through to early evening, and then night-time. All are available 24 hours a day, seven days a week. Music for Dementia says the music has been chosen after careful focus group research, and it welcomes ongoing feedback as the station develops its programming.

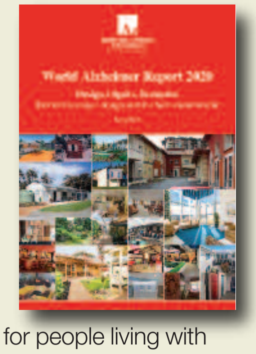
The Aged Care Quality and Safety Commission has published a 12-page rapid review on the evidence regarding interventions to improve the use of medications for older adults in residential aged care settings. **Better Use Of Medications In Aged Care** reports on what is being done at present on this issue, how interventions are having an impact, what supports interventions' effectiveness, and issues for the future. The review was conducted by Health Outcomes International (HOI) as part of its evaluation of the work funded by the Australian Government under the 2018-19 'Better use of medications in aged care' budget measure. The report can be accessed from here: www.agedcarequality.gov.au/media/88305.

The National Ageing Research Institute (NARI), Melbourne Health and the Academic Unit for the Psychiatry of Old Age, University of Melbourne jointly host a free weekly online **Seminars in Ageing** program – and dementia features regularly in the content presented. In September, for example, Dr Ross Bicknell gave a presentation on 'Identifying people with dementia at risk of dying in residential care' and Associate Professor Yen Ying Lim from Monash University spoke about 'The role of digital technology in driving understanding of brain-behaviour relationships in Alzheimer's disease'. Earlier presentations this year have examined cognitive interventions for people with dementia, dementia research in diverse communities, and reducing dementia risk through education among others. The seminars are all available to view after the event on the NARI website at www.nari.net.au/education/seminars-ageing.

3 Simple Checks To Support Your Residents is the title of a one-page A4 fact sheet aimed at personal care workers in residential aged care settings, published by the Commonwealth Department of Health, with a view to helping them better support residents living with dementia. The fact sheet begins by saying people with dementia often have changes in their behaviour, but that by doing three simple checks, it should be possible to manage the behaviour without medication. The three checks are: Check in with your resident; Check the care plan; and Check with your co-workers. Each ‘Check’ comes with suggestions for particular points to probe or consider. The fact sheet can be found at https://bit.ly/3fd25U4.

My Dementia Companion is a new online resource released in pilot stage, with an open invitation now out to people living with dementia and their family members to sign up to use the resource. **My Dementia Companion** is described as a ‘digital personal concierge’, guiding users to personal and practical support throughout the dementia journey, with all the relevant information and resources brought together in one place. The resource is a winner of the Decoding Dementia Innovation Challenge, supported by Dementia Australia, the Department of Health and Deloitte, and has been developed with input from a range of stakeholders. It is available for use on computers and smartphones. To find out more and sign up for the pilot, go to www.mydementiacompanion.com.au/.

PalliAGED, the online resource managed by CareSearch at Flinders University, has launched a new online resource about understanding and providing psychosocial care for older people approaching the end of their life – and throughout includes references to the particular needs of, or issues for, people with cognitive impairment. The new **Psychosocial Care Practice** page presents information within three questions: ‘What can I do?’ (practice suggestions, and links to recommended assessment tools); ‘What can I learn?’ (links to online resources, films, courses and academic papers from a wide range of sources); and ‘What can my organisation do?’ (organisation-wide strategies and resources to tap into). The online resource can be accessed via www.palliaged.com.au/tabid/6019/Default.aspx.



Alzheimer Disease International (ADI) has launched its two-volume World Alzheimer Report 2020 **Design, Dignity, Dementia: Dementia-Related Design And The Built Environment** on World Alzheimer Day (21 September 2020). The wide-ranging publication was written by Professor Richard Fleming, Dr John Zeisel and Kirsty Bennett along with a long list of contributors from around the world, and covers design progress to date, best practice, pioneers and innovators, design principles, designing for culture and context, the importance of including people with dementia in every stage of the design process, education and training, and the role of design during the pandemic and beyond.

The report compares against progress made in the physical disabilities movement and demands the same progress is now made in design solutions for people living with dementia. It calls for design solutions to be included in national governments’ responses to dementia, including in their national plans, recognising design as a vital, non-pharmacological intervention.

ADI has made a series of commitments in the report’s eight recommendations about actions it will take to drive forward this issue: for example, ADI will facilitate discussions on the development and adoption of a common set of design principles; it will work with other advocacy groups for the recognition of dementia as a disability, and call for more overt and considered inclusion of dementia-related design as a non-pharmacological intervention to be included in national dementia plans.

Volume 2 is entirely made up of case studies (84 in total) and includes examples from 27 countries, in a wide range of contexts, including home/domestic settings, day and residential care, hospitals and public buildings and spaces. ADI has also released a series of eight interviews – with innovators, pioneers, architects and researchers (such as Margaret Calkins) – each talking about designing spaces for and with people living with dementia (and also featured in the report).

The report is available to download, and the videos to view, on ADI’s website at www.alz.co.uk/research/world-report-2020.

New online courses from DTA

Dementia Training Australia (DTA) has launched a series of new free online courses, all of which can be accessed via the DTA website (go to https://dta.com.au/ and click on ‘For individuals’, and then ‘Online dementia courses’). Learners can complete individual modules as separate units and obtain a certificate of completion for CPD credit at the conclusion of each module.

Understanding Responsive Behaviours is aimed at people working in residential and community care settings. The course introduces learners to tools and frameworks to assist in understanding more about responsive behaviours, and to develop effective strategies to implement in their workplace.

Sleep Matters consists of three 30-minute modules: Understanding Sleep; Assessing Sleep; and Optimising Sleep. The course is aimed at health and care staff working in residential care. It explores sleeping issues faced by older people, the association between sleep and dementia, and how staff can optimise sleep for those living in aged care.

Too Much Of A Good Thing: Fundamentals Of Deprescribing course is aimed at anyone working with people living with dementia in any care setting, and includes case studies, interactive learning activities and recorded interviews with experts in the field. Both modules in this course take 30 minutes to work through, with module 1 covering polypharmacy and module 2 focusing on deprescribing.

Recognising and Acting On Pain In People Living With Dementia For Direct Care Workers is another three-module course, in total taking three hours to complete, and aimed at care workers working in residential care. The modules include: The Recognition Of Pain For Direct Care Workers; Assessing Pain For Direct Care Workers; and Pain Management Strategies For Direct Care Workers.

Creating Supportive Environments For People Living With Dementia aims to raise awareness of the impact of the built environment on people living with dementia. The three modules each take an hour to complete and include: Why Environments Matter; Exploring Good Places to Live; and Transforming Buildings (and the organisations that run them).

DTA workshop

Meaningful Spaces Workshops: Dementia Training Australia’s Virtuality Reality Nursing Home workshops will be held in February 2021 in Perth, Geraldton and Albany, WA. This immersive virtual reality experience for nursing, medical and allied health professionals will grow your understanding of the role of environmental design and medication management in supporting a person experiencing changed behaviour and psychological symptoms of dementia. Visit https://dta.com.au/events/meaningful-spaces/ for more information.

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

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