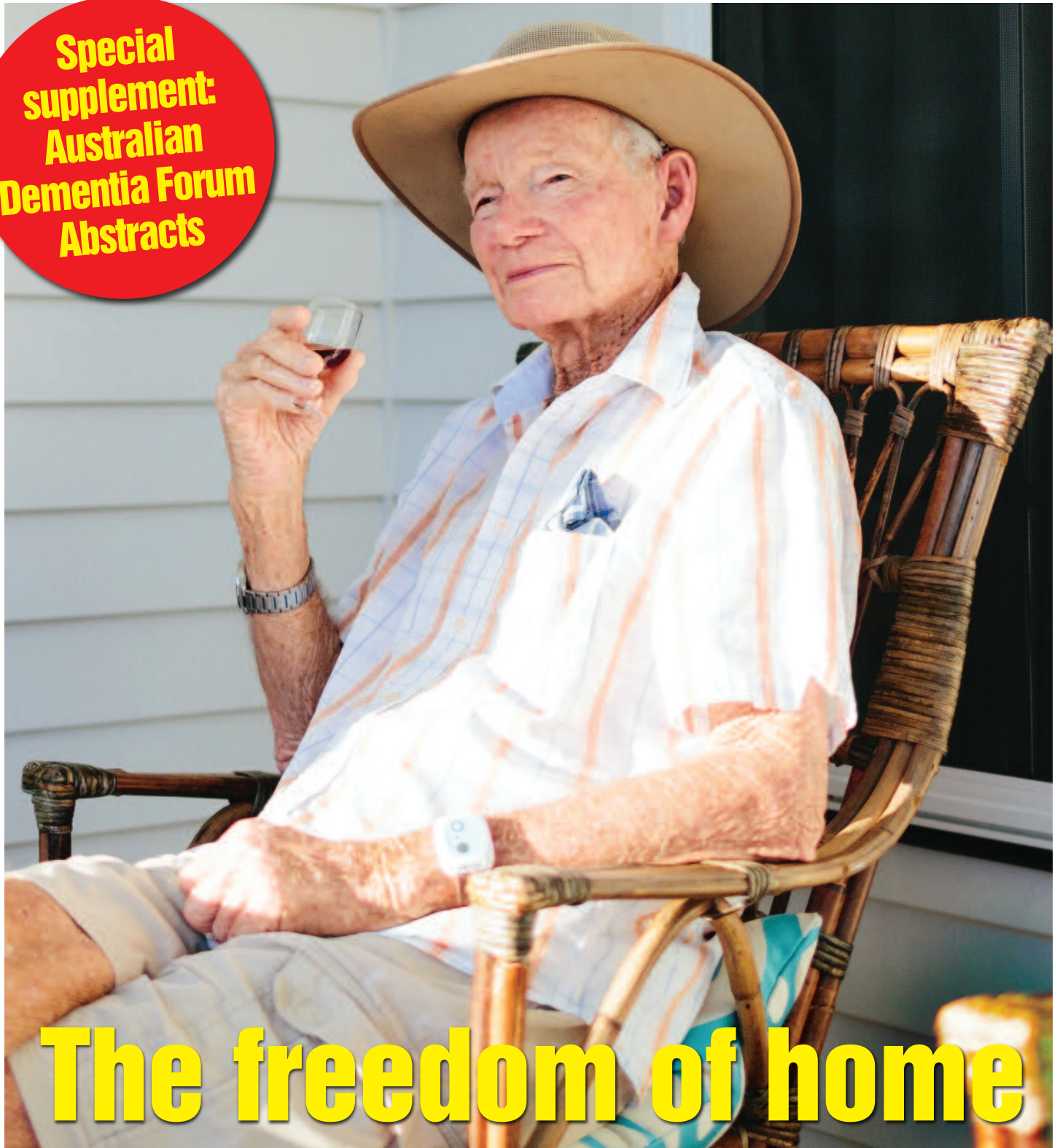


Australian Journal of **DementiaCare**

For all who work with people with dementia

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**Special
supplement:
Australian
Dementia Forum
Abstracts**



The freedom of home

**Also inside
this issue:**

- CARE for nurses ■ Implementing consistent staffing
- Facilitating artistic success ■ Why smaller is better

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Maximising impact of research

By **Janice Besch**, Director NHMRC National Institute for
Dementia Research (NNIDR)



As a key element of the Australian Government's \$200 million effort to tackle the challenge of dementia through research, the NHMRC National Institute for Dementia Research (NNIDR) has a simple vision – to identify and coordinate high-quality, high-impact research and translation initiatives in Australia and support the translation of research into policy and practice.

Like any other bold and innovative undertaking, we're dedicated to maximising the positive impact of this endeavour. To this end, the NNIDR is currently reviewing its Strategic Roadmap for Dementia Research and Translation (www.nnidr.gov.au/about-institute/strategic-roadmap) to ensure the investment made through the Boosting Dementia Research Initiative positively affects people living with dementia, their families, carers, and the broader community.

The consultative review of this strategy with researchers, industry representatives and people living with dementia has highlighted the key to maximising impact: the translation of research into practice.

In carrying out its mission, the NNIDR fosters partnerships between researchers, industry and philanthropic organisations to embed dementia research into the health system, and stimulate the translation of research findings into policy and practice. Indeed, the translation of research into practice which has a positive impact for people living with dementia, their families and carers, is the 'why' of the NNIDR's existence.

We all have a role to play in maximising impact. Government is an essential contributor in the translation of research to practical outcomes that make a difference. Clinicians are vital partners in research, by ensuring the discovery of new models of care for rapid introduction. Care practitioners are essential to the effort to translate research into care practice. Finally, and perhaps most importantly – advocacy groups and members of the public prepared to involve themselves in research play a key role in deciding what impact is most important to those living with dementia, their families and carers, and how it's delivered.

It's critical that we follow through on the findings of research and fully commit to the translation of research into practice. Throughout our consultations, many contributors shared the same concerns – that funding research without implementation costs enthusiasm, engagement and public opinion.

Dementia research brings its own unique challenges. While the value of translating research into practice in the area of care is understood, a large part of the dementia research effort internationally is necessarily dedicated to basic science. It's vital that we understand the molecular basis of dementia, and the opportunities to translate such research into practice are critically important but also long term. There is also so much we can do to discover and implement treatments and healthcare practices that make a real difference to the quality of life of people with dementia, their families and carers, right now.

I am pleased to report that the NNIDR is collaborating with research partners to develop methods to identify evidence ready for translation, ensure this evidence reaches people who can implement it, and measure the success of implementation efforts. A systematic approach will ensure delivery of a real and positive impact for those people in need.

Our review of the Strategic Roadmap has also confirmed the need for a holistic view. Often, the different elements of the industry are aware of what needs to be done in their area and we need to ensure each solution contributes to the larger whole. Our partners in research tell us that we must understand that our ultimate goal is to improve care, as well as provide for human health.

It's a monumental task in a context where we have no cure and there is so much work to be done, but practices like the review of the Strategic Roadmap show that researchers, universities, practitioners, health services providers, industry, as well as state, territory and federal governments will not be deterred. Every new discovery leads to another, and together we strengthen our ability to treat, diagnose, prevent, and care for those living with dementia.

The NNIDR team sincerely thanks the many people who have contributed to our strategic review. Our work to revise the Roadmap seeks to comprehensively respond to the voices of our stakeholders. ■

Abstracts from the NNIDR Australian Dementia Forum 2018: Collaboration, Cooperation and International Connections are included as a special supplement with this edition of *AJDC*.

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*. Contact Richard Fleming at rfleming@uow.edu.au

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.

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An Australian study has found that a small-scale, home-like model of residential care delivers better outcomes for residents with cognitive impairment and dementia, without any increase in facility running costs. Suzanne Dyer, Wendy Shulver, Stephanie Harrison and Maria Crotty report



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Cover image: A resident at NewDirection Care Bellmere Microtown in Queensland relaxes on the verandah of his home. The town is designed for people with a range of care needs, including advanced dementia, to share a house based on values and lifestyle, not diagnosis. See article p17. Photo courtesy NewDirection Care

News in brief

Oakden Committee report

South Australia needs more capacity to offer specialist residential care for people with dementia, according to the Oakden Oversight Committee, the body charged with implementing the recommendations outlined in Dr Aaron Groves' original Oakden Report, published in 2017. The Committee says 144 beds are needed across the state: 24 beds for people with dementia experiencing extreme or severe responsive behaviours, and 120 beds for people with significant responsive behaviours. The recommendation was presented in the Committee's final report, published in July this year, which details the work undertaken by six expert working groups to implement the Oakden Report recommendations. In July, Northgate House, the facility that replaced the Oakden Older Persons Mental Health Service, was awarded accreditation for three years. SA's Health and Wellbeing Minister Stephen Wade said the Oakden Oversight Committee report and SA Health's response will help to ensure the systematic failings exposed at Oakden will never be repeated. The facility was shut last year in the wake of Dr Groves' damning report which uncovered abuse and neglect of residents dating back 10 years.

Human rights in secure units

New Zealand's Human Rights Commission has published a new report, *This is not my home*, which raises concerns about the legal and human rights safeguards for an estimated 5000 older New Zealanders living in secure dementia units and psychogeriatric facilities, in particular where care is provided without the person's consent. The report – a collection of essays from lawyers, doctors, academics and a District Court Judge – identifies serious issues with the current legislative frameworks and associated policy and practices, such as a lack of legal safeguards protecting the rights of people placed in care. Acting Chief Human Rights Commissioner Paula Tesoriero said, "The report is concerning to read. Very few of these people have formally consented to being held in these locked facilities, so it is critical that appropriate safeguards are in place to ensure everyone's rights and preferences are respected to the greatest extent possible." The report's editors are calling for a formal Law Commission review with a view to legal safeguards being strengthened, and for the aged care workforce to have education and training to address the issue.

Better Practice win for Montefiore program

NSW care provider Montefiore has won a Better Practice Commendation Award for its Integrated Cognitive and Sensory Program aimed at people living with dementia in its Sydney residential aged care homes. Winners of the Australian Aged Care Quality Agency Better Practice awards were announced at the Future National Conference held in Sydney in August. Three organisations were awarded National Innovation and Excellence in Aged Care Awards: the City of Boroondara (for creating an age-friendly community), Fresh Fields Aged Care Pty Ltd (for its 'Back to Country' program), and The Whiddon Group (for embedding relationship-based care). Seven organisations (including Montefiore) won Commendation Awards.

Home care data

In August the Federal Department of Health released the latest data on home care packages, for the quarter up to the end of March 2018. The figures show an increase in the number of people waiting for home care packages around Australia: 108,456 in total, up 3.7% from the previous quarter (this includes those on interim packages who are waiting for their required level of care). People are currently waiting 12 months or more for high-level packages, and three- to nine months for a level 1 or 2 package. The figures also reveal an increase in the number of people receiving home care packages – 77,918 in December 2017, a 5% increase from September 2017. Dementia Australia welcomed the increase in home care packages, but called for more transparency in the data, wanting to know how many people waiting for home care are living with dementia. *Community Care Review* reports that Minister Ken Wyatt said about 12% of people currently approved for home care were living with dementia, based on Dementia Cognition Supplement figures.

Landmark reforms to aged care sector

Minister for Health Greg Hunt and Minister for Senior Australians and Aged Care, Ken Wyatt have made a joint announcement that the aged care sector is to receive a \$106 million boost to support better facilities, care and standards.

The funding will be directed to the following areas:

- \$16 million to the new Aged Care Safety and Quality Commission
- \$40 million to support aged care services in regional, rural and remote locations to improve, maintain and expand their infrastructure
- \$50 million towards supporting residential aged care providers and their staff improve quality and standards of care.

This will support 2700 aged care homes and 366,000 staff in new training as they transition to the new Aged Care Quality Standards, to be enforced from 1 July 2019.

The Federal Parliament gave its final approval for the new Standards by passing the Aged Care (Single Quality Framework) Reform Bill 2018 on 11 September – replacing standards that were 20 years old.

The standards covered are: client dignity and choice; ongoing assessment and planning of client personal and clinical care; services and supports for daily living; the provider's service environment; feedback and complaints; human resources; and governance.

"These new single quality standards have a single focus – to protect the rights of senior Australians. Under the draft new regulations, aged care providers' governing bodies and boards will be legally accountable for safety and quality," Mr Wyatt said.

Workforce strategy

Mr Wyatt also officially launched *A matter of care – Australia's aged care workforce strategy* on 13 September.

It identifies 14 strategic actions to help the aged care industry, which it says, "give the industry tools to prepare the workforce for the future and improve the quality of aged care for all".

Recommendations include the creation of a social change campaign to reframe caring and promote the workforce, a voluntary industry code of practice, reframing the qualification and skills framework, defining new career pathways including accreditation, and developing cultures of feedback and continuous improvement.

It also calls for a new standard approach to workforce planning and skills mix modelling, new attraction and retention strategies for the workforce, a revised workforce relations framework, strengthening the interface between aged care and primary / acute care and improved training and recruitment practices for the Australian Government aged care workforce.

In a busy first week back in Parliament, the Government also introduced legislation to the Parliament to establish the Aged Care Safety and Quality Commission, which comes into force on 1 January 2019. The new commission will bring together the Aged Care Complaints Commission, the Australian Aged Care Quality Agency and the aged care regulatory functions currently operating within the Department of Health.

COTA Australia Chief Executive Ian Yates described the new Standards and the Quality and Safety Commission as "a landmark advance for consumer rights in aged care".

Federal funding for Dementia Australia tech development

Dementia Australia will be the first organisation to benefit from the Federal Government's May budget commitment to invest \$5.3 million in dementia innovation.

Minister for Senior Australians and Aged Care, Ken Wyatt, announced that Dementia Australia will receive initial funding of \$1 million in 2018-19 to work with existing technology providers. The remaining \$4.3 million will be allocated through a grants process as part of the redesigned National Dementia Support Program.

Mr Wyatt said there was a critical need to continue exploring more effective ways to use technology to support people with dementia, as well as their families and carers.

"This latest commitment will fund the trialling of

technology to improve the quality of life for Australians already living with dementia, from sustaining their independence and enabling them to live in their own homes for longer, to helping families and carers to better understand dementia. It will also extend the capacity of the health and aged care sectors to respond to increased rates of dementia," he said.

Dementia Australia CEO Maree McCabe said the funding would enable the peak body to build on the success of its award-winning technologies.

"It is crucial we continue to explore new and innovative ways to improve dementia care through technological solutions, and ensure that people living with dementia are supported and empowered to live in their own homes and communities for longer," she said.

'Hug' nominated in national dementia care awards

In the August/September 2018 issue of the *AJDC* we reported on the LAUGH Project, an international collaboration between Cardiff Metropolitan University, Wales, Coventry City University, England, and the University of Technology Sydney. The three-year design research project explored how to make playful objects for people living with advanced dementia.

Eight objects were created as a result of the participatory design process and one, 'Hug' (pictured), was recently nominated for the 'Outstanding Dementia Care Product' in the UK National Dementia Care Awards. 'Hug' is a soft cushion-like object with long arms and legs that can be wrapped around the body, with embedded electronics that play personalised music and an electronic heartbeat. LAUGH Project lead researcher Professor Cathy Treadaway has now secured funding from SMARTExpertise Welsh Assembly Government to collaborate with the NHS and Sunrise Senior Living to produce multiple versions of 'Hug' and carry out a quantitative evaluation, to be undertaken by NHS staff at Llandough Hospital in Wales and Stroke Hub Wales. The LAUGH project ended in April this year with exhibitions in London and Sydney.



News in brief

Swaffer in '100 Women of Influence'

Chair and CEO of Dementia Alliance International, Kate Swaffer, has been named as a finalist in the *Australian Financial Review's* '100 Women of Influence 2018'. Swaffer has been nominated within the 'Global' category – one of 10 categories for the awards. Winners for each category and the overall winner will be announced at a gala dinner in Sydney on October 17. The list was chosen from 850 entries and includes women working across a range of industries.

Music project announced

NSW aged care provider Fresh Hope Care has announced that it will be working with I'm Soul Inc and Western Sydney University to offer residents with dementia the opportunity to engage in making music. The project will involve teaching residents to learn how to make music, using I'm Soul Inc's innovative technology and programs. The 12-month project will be conducted at Fresh Home Care's Pendle Hill site, Ashwood Residential Care Service, and will involve research input from Western Sydney University to evaluate the project.

ACSA Awards

NSW aged care provider Warrigal was named Provider of the Year in the 2018 Aged & Community Services Australia (ACSA) National Awards. The award recognises Warrigal's "outstanding leadership, management, workforce culture, innovation, communication and general excellence to the aged care sector". Winners of the other five award categories recognising outstanding achievement in the community this year were: Amana Living WA (Innovation in Service or Design) for its dedicated staffing model; Gilbert Hicks, Astely Care Inc WA (Volunteer of the Year); Jennie Hewitt, Feros Care NSW (Lifetime Achievement Award); Joyce Ashworth, Juniper WA (Employee of the Year); and Evan Cox, Rise Network WA (Trainee of the Year).

Funding for OPAN

The Federal Government has announced it is to give \$2 million to the Older Persons Advocacy Network (OPAN) to support its work, following the release of figures for the Network's first year of operation. Minister for Senior Australians and Aged Care, Ken Wyatt, said the funding would allow OPAN to continue and expand its vital work to support people experiencing elder abuse, whether in the community or in aged care and to advocate for their rights and protection. One of OPAN's key projects is to create a national decision-making system to support older people, especially those living with dementia.

Aged Care Rights charter

A draft single charter outlining the rights of aged care consumers, regardless of their subsidised care type, is open for public consultation until 10 October 2018. Minister for Senior Australians and Aged Care Ken Wyatt said the Government wanted input from aged care recipients, families, carers, service providers, consumer organisations, advocacy groups and anyone else with an interest in aged care rights. The charter is expected to come into effect from 1 July 2019 and is designed to be signed by both the aged care provider and the person entering their program. Mr Wyatt said it was part of the Government's commitment to strengthening the regulation of the aged care system to better protect consumers.

Aged Care Employee Day

The Whiddon Group launched Australia's inaugural Aged Care Employee Day on 7 August, which it describes as "a new day to celebrate and thank the hundreds of thousands of incredible people who work in #agedcare and make a huge difference to the lives of older people every day". Several other aged care providers joined in and used the day to acknowledge the efforts of their employees. Aged Care Minister Ken Wyatt applauded Whiddon Group for the initiative and thanked staff "right across the aged care sector".

News in brief

Knowledge of treatments is 'poor'

A study reported in the journal *Gerontology and Geriatric Medicine* has concluded that knowledge of treatments for dementia among Australians is poor, and that there is a need to better educate the public about effective treatments to improve their uptake and use. In 2017, 1001 participants completed an online survey on this topic, and of these nearly two-thirds (63.5%) could not spontaneously name any treatments that improved outcomes for people with dementia. Asked about the efficacy of treatments, nearly half (49.4%) thought "brain training" was "very likely" to be effective, followed by "education for caregivers" (46.2%) and "healthy diet" (43.4%). The researchers say that of the treatments frequently evaluated in research trials, fewer than half of the participants considered these very likely to be effective. Exercise, for example, was initially only nominated by 7% of respondents as an effective method to improve outcomes for people with dementia.

Desert Rose shipped to Dubai



Desert Rose – the dementia-friendly, net-zero energy house (pictured) designed and built by students from the University of Wollongong (UOW) and TAFE NSW – has been completed and shipped to Dubai where it will be reassembled for the Solar Decathlon Middle East 2018. The international design and construction competition focuses on sustainability and will be held from 14-29 November 2018. The team behind the house has worked with Dementia Training Australia (DTA), local care providers, community groups and people with dementia to design the house. The planning phase began close to two years ago and construction took about eight months, including prototyping and testing new products.

A Roast To Remember

A campaign by not-for-profit Community Vision is encouraging family and friends to get together for 'A Roast to Remember' this spring to help raise \$250,000 to purchase and run a community dementia bus in WA. Community Vision CEO Michelle Jenkins said the dementia bus would focus on people in the community who don't have immediate access to local dementia services to trial some new innovations such as virtual reality and therapy techniques for supporting people with dementia. As well as giving a respite break to carers, those staffing the bus would also be able to provide advice to carers and education to schools, workers and those living with dementia across regional and metro locations in Perth. "A Roast to Remember is all about the community coming together, sharing food, lifting spirits and making a difference," Ms Jenkins said. "It's simply a matter of inviting friends and/or family to a meal, serving a roast and raising funds. And if you are not a meat eater, roast a whole fish or simply enjoy a plate of your favourite roast veggies and gravy." A recipe book will also be sold to raise further funds to get the dementia bus up and running. For details and to register visit www.aroasttoremember.com.au

AAIC conference highlights

The prevalence of dementia among the LGBTI community, dementia survival times, and an e-learning program for aged care staff were among the many topics addressed at the annual US Alzheimer's Association International Conference, held this year in Chicago in July.

Researchers from the University of California and the Kaiser Permanente Division of Research found an overall prevalence of dementia of 7.4% among a population of 3718 lesbian, gay and bisexual adults aged 60 and above. Dementia diagnoses were collected from medical records, over nine years of follow-up.

Hanneke Rhodius-Meester of VU University Medical Centre in Amsterdam and colleagues examined survival time of 4495 people with dementia, and found that the median survival time was six years, regardless of age of onset. There was variation based on dementia type: 6.4 years in frontotemporal dementia; 6.2 years

in Alzheimer's disease; 5.7 years in vascular dementia; 5.1 years in dementia with Lewy bodies; and 3.6 years for rarer causes of dementia. Survival time hardly differed when comparing younger patients (age 65 or younger) to those older than 65.

A presentation was also made on the Improving Staff Attitudes and Care for People with Dementia e-Learning (tEACH) study, conducted by the University of Exeter and King's College London in partnership with the Social Care Institute for Excellence (SCIE), which involved 280 residents and care staff in 24 care homes over nine months. Care staff took part in an e-learning program, with or without Skype supervision, and researchers compared outcomes to usual care, finding that both approaches improved resident wellbeing and staff attitudes to person-centred care.

Abstracts from the conference can be found at www.alz.org/aaic/overview.asp

Qld Police join forces with Dementia Friends

The Queensland Police Service (QPS) is the first police service in Australia to announce that it is supporting Dementia Australia's Dementia Friends program.

The announcement was made on 4 September at the Brisbane 'Small actions Big difference' Roadshow event organised by Dementia Australia for Dementia Awareness Month. Over 50 police attended, including Acting Deputy Commissioner Alistair Dawson who participated in a panel discussion. The roadshow was the first of a series of events held around Australia to mark Dementia Awareness Month in September.

Dementia Australia CEO Maree McCabe said, "We are thrilled the Queensland Police Service has wholeheartedly supported and participated in our Dementia Friends program, which is a national program that aims to transform the way our nation thinks, acts and talks about dementia."

Acting Deputy Commissioner Dawson said the partnership would build organisational capacity to understand and assist people with dementia, their families and carers and improve policing responses.



Pictured at Dementia Australia's 'Small actions Big difference Roadshow' (from left) dementia advocates Dubhglas and Eileen Taylor, Maree McCabe, CEO Dementia Australia, Lisa and Jessica Origliasso and dementia advocate Danijela Hlis. Photo: Glenn Hunt

The event also featured Dementia Australia Ambassadors Jessica and Lisa Origliasso from The Veronicas, Professor Jürgen Götz, Foundation Chair Dementia Research and Director of the Clem Jones Centre for Ageing Dementia Research at UQ's Queensland Brain Institute, and Dementia advocates Danijela Hlis and Eileen and Dubhglas Taylor.

Throughout Dementia Awareness Month Dementia Australia asked the community to pledge support for people with dementia by becoming a Dementia Friend. To find out more, go to www.dementiafriendly.org.au

Consensus on approach to responsive behaviours

An International Delphi consensus process has been used to prioritise existing and emerging treatments for responsive behaviours in Alzheimer's disease overall, as well as specifically for agitation and psychosis. Lead author, Dr Helen Kales, says the paper advocates for a "significant shift in current practice", away from drug treatments to non-pharmacological interventions.

The research, published in *International Psychogeriatrics* in August, was led by researchers from the University of Michigan, the University of Exeter and John Hopkins University, and undertaken as an International Psychogeriatric Association taskforce.

The consensus concluded that, for responsive behaviours overall in Alzheimer's disease and for agitation, caregiver training, environmental adaptations, person-centered care and tailored activities should be the first-line approaches used prior to any pharmacological treatments.

If pharmacologic strategies were needed, citalopram and pain relief medication were prioritised ahead of antipsychotics. The researchers concluded that pharmacologic options, and in particular, risperidone, should be prioritised for psychosis following the assessment of underlying causes.

As a result of the study, the researchers have recommended

refinement of current treatment criteria and prioritisation of emerging therapies.

Clive Ballard, Professor of Age-Related Diseases at the University of Exeter Medical School, said: "Symptoms such as psychosis and agitation can be particularly distressing and challenging for people with dementia, their carers and their families. Many commonly prescribed medications can cause harm, in some cases significantly increasing risk of stroke or death. We now know that non-drug approaches are the best starting points and can prove effective. This research provides more specific and targeted guidance to support clinicians to give the best possible treatment options."

Music & Memory

Melanie Karajas (pictured) has been appointed as the new Australian Director of Music & Memory, the international program formerly offered in Australia by the Arts Health Institute. Music & Memory has now certified over 5000 aged and health care services in 11 countries to provide its personalised music playlist program – and over 120 of these services are in Australia. Ms Karajas says Music & Memory has invested significantly in its online support platform, the Care Community, which offers a range of training, implementation and promotional resources related to the program, and that Australian organisations will now benefit from reduced certification costs and annual renewal fees as well as a new 'multiple site' discount. To find out more, go to <https://musicandmemory.org.au>.



International award for RedUSE: The RedUSE (Reducing Use of Sedatives) project, led by Dr Juanita Westbury from the Wicking Dementia Research and Education Centre at the University of Tasmania, has won an Australian and New Zealand Mental Health Services Learning Network (MHSLN) award for Education, Training and Workforce Development. The RedUSE project – reported on in the August/September 2018 issue of *AJDC* – was aimed at reducing the use of psychotropic medications (mainly antipsychotic and benzodiazepine medications) in aged care facilities. Dr Westbury said it was an honour to receive the award for the project which made a significant difference to residents and staff in aged care facilities around Australia. Former Australian Prime Minister Julia Gillard (centre) presented the award to Dr Westbury (left), pictured with the project's pharmacist Sue Edwards, in Adelaide on 29 August.



ADI CONFERENCE HIGHLIGHTS

#Every3Seconds

Alzheimer's Disease International (ADI) used its 33rd International Conference in Chicago in late July to launch a new global dementia awareness raising campaign called #Every3Seconds – and the work of two Australian organisations features in a film that accompanies the campaign.

The campaign and film title highlight the fact that every three seconds someone in the world is diagnosed with dementia. The film has the format of a current affairs program, featuring 23 different news-style stories from dementia organisations around the world. It was produced by ITN Productions in partnership with ADI.

Dementia Australia's work with virtual reality technology,

interactive 3D games and apps features – showing how technology can be used to build empathy in carers, increase understanding about dementia and explain the significance of environment.

Dementia Training Australia's (DTA) work with Scalabrini Village as part of a Tailored Training Package (TTP) also features in the film. #Every3Seconds shows how the built environment at Scalabrini Village, based on DTA environmental design principles, creates familiarity for residents living with dementia, and allows them independence and freedom to make choices. Staff at Scalabrini Village have received DTA support and training through a TTP.

The segment on Dementia

Australia's work can be viewed on Dementia Australia's website, while the DTA work with Scalabrini can be viewed at <https://vimeo.com/281749787>

Innovation Index Launch

The ADI and the Global Coalition on Aging (GCOA) also used the 33rd International Conference to launch the 2018 *Dementia Innovation Readiness Index* – a report analysing the readiness of five specific countries to incorporate dementia innovation in their healthcare, policy and social frameworks.

The 2018 Index evaluated innovation readiness in Argentina, Brazil, China, India and Saudi Arabia across 10 categories and identified specific opportunities and

challenges to promote innovation. China scored the highest in terms of innovation readiness (6.1 out of 10), while Brazil scored the lowest (5).

The Index found that, although Argentina, Brazil, China, India, and Saudi Arabia have younger populations than G7 countries, they face many of the same barriers to dementia innovation, including limited public leadership and funding, uneven access to high-quality care, and difficulty with early, accurate diagnosis. However, because of their relative youth, these countries lack focus on – and even recognition of – issues related to dementia. Further, the barriers to innovation are exacerbated by resource limitations including, in some cases, extreme poverty.

Dementia Care Illawarra: our journey

Sharing a common bond and a strong desire to make a difference, young NSW high school students **Mackinly Zecevic, Daniel Micheltmore, Lucy Koder** and **Annabel Hickling-Smith** created an intergenerational dementia care project that has received international recognition

As students of The Illawarra Grammar School (TIGS) in Wollongong we are encouraged to find ways to involve ourselves in the local community. In 2017 our group of four Year 8 students quickly found our way together as we discovered we all have grandparents or relatives who are affected by dementia. We shared a passion and a desire to do something about this debilitating condition at a local community level.

Problem solving

This led us to accept the opportunity to take part in the Community Problem Solving Competition (CmPS) that provides students with an opportunity to learn and solve problems in a step-by-step process to better their local community. The CmPS is part of Future Problem Solving Program International (FPSP), which involves thousands of students each year from around the world and teaches critical and creative thinking, problem solving and decision making. The top CmPS projects are invited to the annual FPSP International Conference in June.

To initiate our project, we surveyed over 100 students



Dementia Care Illawarra project member Lucy Koder with Coral, a resident at Estia Health, during one of the team's weekly visits



Dementia Care team members (from left) Annabel Hickling-Smith, Mackinly Zecevic, Lucy Koder and Daniel Micheltmore, presenting their project at the Future Problem Solving Program International Conference in the US

from our school to find out the impact of dementia; we found that 32 had relatives with dementia. Most of the students we spoke to admitted often feeling despondent and unable to help. Having relatives with dementia, we understood that this harmful stereotype was untrue.

Consequently, we believed in altering the portrayed image of dementia from a child's point of view, empowering students to feel capable and confident with interactions between people with dementia and themselves.

Many people with dementia experience loneliness and lack of contact with young people when in a nursing home. This loneliness can cause harmful feelings of isolation and neglect. Our goal was to initiate relationships between youth and people with dementia to reduce loneliness and stigma.

Memory books

Our project, which we called Dementia Care Illawarra, included 80 students from our school visiting people with dementia living at IRT William Beach Gardens aged care home in Kanahooka twice a term. We gave each student visiting the home a prompt sheet which encouraged them to ask questions about the resident's life – their family, meals, former occupation, favourite activities and hobbies. The conversation was dependent on the person with dementia. The discussion could be anything from a favourite colour to the flowers on the table top. Students talked individually or in pairs with the residents for 1½ hours while staff from IRT supervised.

The students returned to the home a week later, after they had created a memory book for their resident that replicated the

different stories and answers that the students and residents had discussed. We created 35 memory books and the students presented the books to the residents, who were appreciative. The books incorporated word processed personalised text and colourful, relevant artwork.

The experience was beneficial for both the students and the residents, who learnt more about each other as well as themselves. For some students it was challenging to interact with the residents because of the negative stigma surrounding dementia, which caused some students to be nervous or uncomfortable. By preparing the students beforehand and providing them with a scaffold of questions they were more comfortable with the interaction.

Another obstacle we encountered was getting some of the residents to engage with the students, however we overcame this by experimenting with different techniques for different people. For some residents we used music from the 1940s and '50s to generate a conversation; others were more intrigued by our lives and through the conversation we would eventually turn it back to theirs. As such, all students were able to have productive dialogue with residents.

This project has now been introduced into our school's community service program and will continue for the years to come.

A winning project

We presented the project to CmPS judges and members of the visiting public at the National CmPS Competition in Sydney in October 2017. Our team, Dementia Care, won first place. This qualified us to take part in the Future Problem



The TIGS team, including students, parents and teachers, in the audience at the Future Problem Solving Program International Conference in the US in June

Solving Program International Conference in June 2018 at the University of Wisconsin-La Crosse in the US, where we would present our project and compete with other students from across the world.

Extending the project

After winning the National CmPS Competition, we extended our dementia care project to Estia Health aged care home in Figtree, Wollongong, where we orchestrated smaller, weekly visits with just our team of four (Mackinly, Daniel, Lucy and Annabel), hoping we could build relations with some of the residents with dementia and engage in activities for enjoyment.

During weekly visits in the term we would bring in therapeutic colouring books or simple games like Connect Four. Sometimes we would read books, or just simply sit and chat. Two of our team members play the violin and clarinet so we found and practised popular songs and jingles from the 1940s, '50s and '60s. We gave fortnightly concerts for residents, which were always a bit of fun enjoyed by residents, staff and ourselves.

Alongside this we created song books filled with these songs to disperse within the nursing home. These books were valuable to the staff who helped us convert the concerts

into an enjoyable singalong.

This year our team also learnt about the Art Gallery of NSW's Art Access Program For People Living With Dementia that involves viewing two to three artworks and then later creating art in various forms for some stimulation and fun. We attended and participated in one of these programs at the gallery and were amazed by the level of engagement shown by those with dementia and how they became less withdrawn whilst experiencing art.

Inspired, we contacted the gallery's program leader, Danielle Gullotta, and were invited to the art gallery to speak at a conference called Arts Engagement For Liveable Communities, in April this year. We spoke for 10 minutes on our project.

Our team was given the opportunity to be trained to run a program like Art Access within our local Wollongong Art Gallery. Our training with the Art Gallery of NSW is due to start very soon and we are looking forward to it.

International recognition

In June 2018 our team of four, and one other team from TIGS, travelled to the University of Wisconsin-La Crosse where we presented our Dementia Care Illawarra project to the Future Problem Solving Program International Conference. This



Daniel, Annabel and Lucy during one of their weekly visits to Estia Health

involved us being interviewed by a panel of judges and sending in a report summary and video of our project. We also presented our project to the other competitors and their families from all over the globe. It was an honour to speak alongside people from projects produced by 72 teams from all over the world, including about 30 teams in our Middle Division. (There was also a Junior and a Senior Division). It was a great experience to meet people of different ethnicities and with amazing, inspirational projects.

At the conclusion of the event the presentation ceremony saw us awarded second place in the

world in our division. We were thrilled.

Our wish for the future

Since returning home we've decided to continue our involvement with dementia care. As a team we can say we have been inspired by the beautiful people we have met through this program. We have personally gained knowledge on the developing issue of dementia and wish we could spread this among all school students in the world. It is a very important area of understanding that impacts so many in the world today.

We are proud of our journey and what we have learnt and hope we can continue it into the future. We strongly believe that youth have the capabilities to help and make a difference even in the face of such an immense issue as dementia. ■

■ Mackinly Zecevic, Daniel Micheltmore, Lucy Koder and Annabel Hickling-Smith are Year 9 students at The Illawarra Grammar School (TIGS), Wollongong, NSW. For further information about the Dementia Care Illawarra project, email TIGS English teacher and the school's FPSP coach Jean Burton at jburton@tigs.nsw.edu.au

See p29 for an evaluation of another intergenerational program for high school students and people living with dementia, this one based on music and reminiscence



Dementia Care team members (from left) Annabel, Daniel and Lucy celebrating second place in their Middle Division at the Future Problem Solving Program International Conference in June, along with fellow TIGS students Rubey Williams and Samuel Hobson, Year 12 students from Team BASE (Building Adolescent Self Esteem), who placed third in the Senior Division

CARE improves nurses' dementia knowledge

In Australia, 10% of people over 65 years of age and 30% of people over 85 years of age have dementia (Dementia Australia 2018). Many people living with dementia present to hospital due to mismanagement of, or acute changes in, symptoms associated with the condition. Along with this, 30% or more of older people will either present with or develop delirium during their hospital admission. This can increase to as high as 50% or more in intensive care units, regardless of patient age (ACSQHC 2016).

Within our service – the Flinders Medical Centre, a major public hospital and part of the Southern Adelaide Local Health Network – 65% of admissions to the Division of Medicine are people over 65 years of age. This is not surprising considering Australia has an ageing population, with South Australia having the largest population over 65 years of age in Australia: one in six (South Australia's Health Care Plan 2007-2016; SA Strategic Plan 2011). It is imperative that the care we provide our older patients with cognitive impairment is at the forefront of our nursing direction. Despite this, a gap analysis in early 2017 revealed that the care of patients with cognitive impairment was not the focus of any education program within the hospital. While these findings were unexpected, it provided the opportunity to address the issue.

Improving outcomes

The Australian Commission on Safety and Quality in Healthcare (ACSQHC 2016) states that education about dementia can improve both



Graduate nurses from the Division of Medicine, Cardiac and Critical Care at Flinders Medical Centre take part in a CARE Program activity designed to highlight the effect of stimulation overload on hospital patients with dementia, carers and staff

knowledge and confidence in caring for and interacting with this patient group. Moyle *et al* (2008) also found that knowledge about dementia can positively influence the outcomes of this patient group in the acute setting.

As mentioned, delirium can affect large numbers of patients within acute care, however, regardless of type, it is still not being recognised by nursing staff (Hussein *et al* 2014). A survey completed in NSW of clinical staff across five hospitals showed a nursing staff confidence rate of delirium recognition of 37% (NSW Agency for Clinical Innovation 2015) with 85% of staff indicating that they had "no training in managing confusion in hospitalised older people" (NSW Agency for Clinical Innovation 2015, p26).

Gesin *et al*'s 2012 study on educating staff on delirium (cited in Hussein *et al* 2014) showed an improvement in delirium knowledge and recognition among participating nurses. The development of a delirium in hospital leads to poorer outcomes (Hussein *et al* 2014; Moyle *et al* 2008) and an increased risk of adverse events (ACSQHC 2016) such

as an increase in falls rates, higher rates of mortality (Travers *et al* 2013), enhanced decline in cognition (Hasemann *et al* 2015) and an inferior recovery rate (Marcantonio *et al* 2003, cited in Schofield *et al* 2011).

Surr *et al* (2016) showed the importance of increasing knowledge among acute care nursing staff through education on dementia and delirium. It was clear that we needed to focus on dementia and delirium in our older patient cohort, along with identification and delirium prevention (Schofield *et al* 2011).

Program design

The CARE (caring for older people with cognitive impairment) Program was designed and written by Flinders Medical Centre Nurse Consultants within the Division of Medicine, Cardiac and Critical Care with oversight from the Older Persons Expert Working Group. We wanted to ensure we gave attention to the Southern Adelaide Local Health Network Older Person's Service Plan (SALN 2017), the ACSQHC Delirium Clinical Care Standard (2016)

After identifying a gap in dementia and delirium education for nurses, a team from Flinders Medical Centre in South Australia set about introducing and evaluating a program to address these issues.

Amanda Tuck, Jayne Harris and Elaine Swift describe the program and outcomes from the pilot study

and the Cognitive Decline Partnership Centre's (CDPC) Clinical Practice Guidelines and Principles of Care for People with Dementia (2016), including essential elements of partnering with consumers.

The objectives of the CARE Program included improving nursing staff knowledge on caring for patients with cognitive impairment, understanding the difference between dementia and delirium, the importance of early screening and identification, identification of risk factors, improving management of care, supportive care requirements, communication process and involving the patient, their family and/or carers throughout their admission.

After our gap analysis showed a deficit in nursing education on dementia and delirium it was important to ensure we were able to evaluate and adapt a program to address these deficits. To achieve this we started with a pilot program which included a knowledge survey pre-education, post-education and at six weeks post-completion, along with a content survey.

Our organisation recognises that the rights of consumers

The 4AT Assessment Test For Delirium and Cognitive Impairment

and carers should be included in decisions and choices about their care, and an active acknowledgment that their contribution is unique, due to their lived experience (Hospital Organisation Annual Report 2015-16). A component of our program was to include the 10 principles of dignity in care from the Clinical Practice Guidelines and Principles of Care for People with Dementia (CDPC 2016), along with gaining information from carers and patients to personalise care through rolling out the TOP 5 (see CCLHD 2018 and www.cec.health.nsw.gov.au) and Pieces of Me* tools (pictured on this page). Engaging in effective communication with the patient and their carer and family is recognised as being of high importance to assist in

managing and preventing dementia symptoms such as changes in behaviour (CDPC 2016).

The pilot

The CARE Program pilot started in 2017 with a group of graduate nursing staff. This group was chosen to decrease disruption to the rostering of any particular ward. It also offered us the chance to start with our potential future workforce.

Information was gathered on attendees' baseline knowledge and understanding of caring for patients with cognitive impairment through a pre-survey. They were provided with a rostered professional development day which included competency assessments and a post-education knowledge survey.

Six weeks after completing the CARE Program we asked the graduate nurses to repeat the knowledge-based survey to ascertain information on knowledge acquisition over time. Data from survey evaluation enabled us to review success and areas for improvement of the project, ensure there was evidence of improvement in nursing staff knowledge, and that we were able to realise the benefits (PMBOK® Guide 2013) before progressing with a broader program and rollout. Better outcomes for patients, families and carers and the organisation could not be investigated at this phase of the project. However, this is

The TOP 5 tool is used to record up to five personal tips from carers to improve communication and promote personalised care

something that we will be looking at once the majority of staff has completed the CARE Program.

The program was delivered over a one-day study day which was repeated twice to capture all the graduate nurses who were rotating through the Division of Medicine, Cardiac and Critical Care for their second placement: 42 graduate nursing staff attended.

Course content

The program began by educating staff on the importance of the program, global and Australian statistics, along with specific information on our Aboriginal and Torres Strait Islander population, culturally and linguistically diverse populations, and relevant data from our Division of Medicine, intensive care units and emergency department.

It included group work, and a variety of teaching styles such as reflection and discussion after watching patient experience videos. During the session dementia is defined and changes within the brain, effects on memory, progression and types of dementia, risk factors, assessment and symptom development are all discussed. The session includes a practical activity, simulating some of the deficits that people with dementia can experience, and screening of two videos from Dementia

Australia: What should people know about dementia? and What annoys you most about living with dementia?

During the session on delirium attendees are introduced to a fictional patient, 'Mr Smith', a case scenario that we follow throughout the program. This session covers the definition and types of delirium, delirium statistics, adverse events, predisposing and precipitating risk factors (also provided to staff on a quick guide lanyard card) and recognition of symptoms, which are linked back to 'Mr Smith'. Pathophysiology and assessment is included, along with the introduction of the 4AT rapid assessment for delirium and cognitive impairment (www.the4at.com/) (pictured top left), with links made to the national Delirium Clinical Care Standard (ACSQHC 2016).

The session concludes with a practical activity covering stimulation overload and the effects this can have on patients, carers and staff. Participants stand in a circle and bounce a ball to the person beside them. The ball must keep moving around the circle. We explain that this ball is their patient and if they drop it or stop bouncing it to the next person, something has happened to their patient. We then slowly add more and more tasks for participants to do and pass on. Eventually, there are so many tasks that someone makes a mistake. We then talk about the effects that stimulation overload can have on their patients, as well as themselves. Care and management of patients with dementia and with delirium, and the introduction of the TOP 5 strategies to support care and communication and Pieces of Me* tools complete the day.

Course measures

Our outcome measures for the pilot group included: early identification of delirium and the development of management strategies; ability

* The **Pieces of Me** tool was developed by Elaine Swift, Flinders Medical Centre Aged Care Clinical Practice Nurse Consultant within the Division of Medicine (and co-author of this article). The tool is used to gather important information about patients with dementia and delirium to provide the best person-centred care approach available. The one-page Pieces of Me sheet can be completed by the patient, the patient's family or carer, hospital volunteers or any member of the health care team. Information recorded includes details of the client's family, pets, friends, interests, worries and fears, what makes them feel safe, and preferences around sleep, communication, personal care and food. For a copy, email Amanda Tuck at amanda.tuck@sa.gov.au

to perform a risk assessment; implementation of reduction strategies; increased partnering with consumer engagement; and improved knowledge and awareness of methods of caring for older people with cognitive impairment (dementia and delirium). These were evaluated using a post-education survey completed six weeks after the program.

Our process key performance indicators for the pilot group were: completing, in partnership with consumers, and using the Pieces of Me and TOP 5 tools, and an increased knowledge of care requirements and risk assessment.

Quality measures for the pilot group were to improve knowledge and awareness of caring for older people with cognitive impairment, dementia and delirium.

Staff completed a survey, developed within the organisation, at the beginning and end of the education day and then again six weeks later so we could evaluate the level of knowledge gained from the training. There are 27 questions relating to the staff members' understanding of dementia and 19 questions that ask them about their experience and statistical knowledge of dementia and delirium presentations in acute care.

To receive a certificate at the end of the program participants were required to attend the full study day, and

complete a content evaluation, the pre-, post- and six-week post knowledge surveys and a competency assessment booklet.

Course evaluation

Results of the content evaluation were very favourable, with all attendees scoring the CARE Program as very relevant to their nursing practice for content (94%) and delivery (98%). Knowledge acquisition was also positive with the lowest score obtained pre-education being 23%, increasing to 70% post-education, showing a 47% increase in the lowest score. The mean knowledge score increased by 23% from 63% pre-education to 86% post-education and remained at 84% six weeks post-education survey (see Figure 1 below). The survey showed some areas that need to be improved within the program; these are detailed below. Verbal feedback was particularly positive, with participants suggesting that the program be rolled out for all staff.

74% of attendees believe that they were supported by their unit to work effectively with older people with, or at risk of developing, delirium and/or cognitive impairment. This increased to 91% in the six-week post-education survey.

Understanding previous experience of our staff is important when evaluating results of the surveys. 57% of

staff indicated that they have worked in acute or community aged care for more than six months (the longest being 11 years).

15% of attendees had previously completed a formal dementia education course or workshop, with 13.6% stating on their six-week post-education survey that they completed a formal dementia course or workshop after the CARE Program.

Evaluation of survey results has enabled clear identification of where adjustments and/or clarification of some topics needed to be built into the next CARE Program.

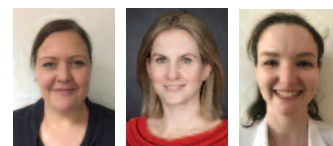
Attendees indicated that they have started to use the tools implemented during the CARE Program to enhance individualised care, with 54.5% indicating that they are using the TOP 5 tool. This result is greater than expected due to the fact that the division-wide rollout had not yet begun at this stage. 100% of attendees have indicated that the CARE Program has the ability to improve the care for older people in hospital.

Future activity

In the post-survey attendees were asked if they believe the CARE Program could be improved and if there have been barriers to implementing the CARE Program strategies. All suggestions are reviewed as part of our program evaluation.

Our challenges and considerations for further rollout included the return rate for the competency booklet at the six-week post-program completion: the return rate was 80% in group one, 78% in group two and 50% for group three. Commencing the program earlier in the staff members' six-month rotation could potentially improve these outcomes.

With the pilot program successfully completed, divisional rollout began early in 2018, with the aim to introduce the CARE Program



From left: Amanda Tuck, Jayne Harris and Elaine Swift

■ The authors are with Flinders Medical Centre, South Australia, where Amanda Tuck is Clinical Practice Consultant, Jayne Harris is Nursing Director Operations, and Elaine Swift is Aged Care Clinical Practice Nurse Consultant. To follow up on this article contact Amanda at amanda.tuck@sa.gov.au

to all nursing staff within the Division of Medicine, Cardiac and Critical Care in order to reduce the knowledge and practice gap in caring for older adults with cognitive impairment. We are running two CARE Program education days per month for staff from the wards, Emergency Department and Intensive and Critical Care Unit within the Division of Medicine. At the time of publication 172 staff had completed the program post-pilot. We've seen similar results to the pilot group in terms of improved staff knowledge around caring for people with cognitive impairment. Once more staff have completed the program we will be able to evaluate the outcomes for patients. ■

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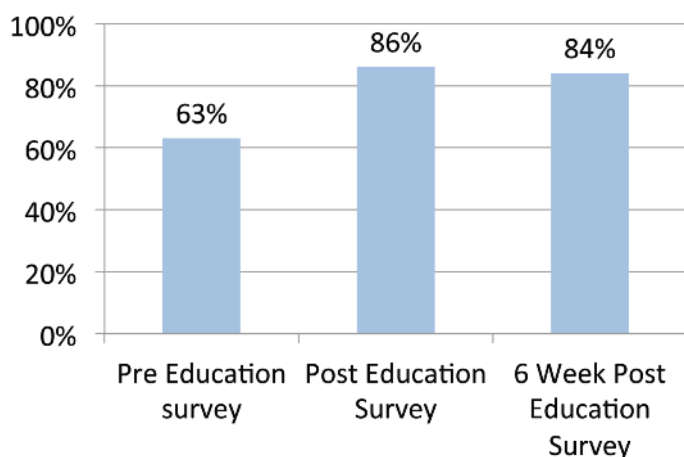


Figure 1: CARE Program knowledge acquisition

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Dementia Australia's one-hour workshop 'Enabling EDIE Acute', for health professionals working in a hospital setting, is now available nationally after successful delivery in Victoria over the past 12 months.

The workshop is provided in the workplace by trained staff from Dementia Australia's (DA's) Centre for Dementia Learning. It uses DA's award-winning* Educational Dementia Immersive Experience (Enabling EDIE) to give participants knowledge of a supportive approach to dementia care and empathy for the impact of stress and excess disability the person may be experiencing in an acute care setting.

EDIE is an innovative educational program that uses virtual reality technology (VRT) to create a 360-degree immersive experience enabling participants to see the world through the eyes of EDIE, a person with dementia, as he undertakes some simple activities of daily life. Using Samsung Gear VR headsets, Enabling EDIE Acute participants explore what it may feel like to experience dementia, including changes in visual perception, hearing and understanding.

The recent changes to the National Safety and Quality Health Service Standards to include cognitive impairment have seen an increasing focus on better addressing the needs of hospital patients with dementia. The Enabling EDIE Acute program promotes communication approaches and environmental strategies that can be used in a hospital environment to reduce stress, minimise the risk of excess disability, encourage and optimise wellbeing and support greater independence in

* Enabling EDIE program awards: 2017 Simulation Australasia Project Innovation Award for projects less than \$2.5 million; 2017 Information Technology in Aged Care Best Aged Care Software Development and/or Deployment; 2017 Victorian Training Award Small Training Provider of the Year.

EDIE Acute an exercise in empathy



Participants in the EDIE education program wearing virtual reality (VR) headsets that create a 360-degree immersive experience, enabling them to see the world through the eyes of EDIE, a person with dementia

patients with dementia. Environmental strategies include reducing noise and high stimulus, providing cues to orientation, ensuring the environment is well lit and that there is access to natural light.

Useful ways for hospital staff to support communication include:

- Identifying themselves to the patient as many times as needed.
- Minimising distractions and ensuring the environment supports optimal communication.
- Gaining the person's attention.
- Being inclusive in the conversation, friendly but respectful.
- Speaking slowly and clearly and keeping sentences short and simple.
- Providing choice but not overwhelming the person with too many options.
- Allowing time (at least 30 seconds) for the person to respond.

Gaining knowledge of this supportive approach has been shown to have benefits in

dementia care. Evaluation by Swinburne University on the impact of EDIE has shown that immersive technology can increase empathy and understanding twofold compared to a standard workshop experience. Research shows that the Enabling EDIE workshop provides participants with deep insight into the experience of dementia. Anecdotal evidence suggests that it is also changing clinical practice, improving the treatment of people with dementia and reducing the inappropriate use of antipsychotic medications and aggressive incidents (Dementia Australia 2017).

Completion of the Enabling EDIE Acute workshop also encourages participants to influence the practice standard of colleagues in the workplace.

Dementia Australia's Centre for Dementia Learning provides health professionals with access to an extensive suite of evidence-based learning and consultancy services designed to improve the support and care provided to people living with dementia. ■

For more information on Enabling EDIE Acute and Enabling EDIE workshops, including costs and bookings, visit dementialearning.org.au or call the National Dementia Helpline on 1800 100 500.

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Dr David Sykes, Director, Centre for Dementia Learning, Dementia Australia and Director of Dementia Training Australia

New dementia training for General Practice

With the right skills, GPs and Primary Health Care Nurses can play a vital role in recognising, diagnosing and managing dementia in their patients. **Marita Long** and **Margaret Winbolt** explain how they can access the latest advice

There are many complexities and difficulties that General Practitioners (GPs) may experience in recognising, diagnosing and managing dementia in their patients. Dementia is unlike most other diseases in that it does not have a straightforward test that health professionals can use to make a diagnosis. A diagnosis is made through a comprehensive history, usually provided by a close family member as a person living with dementia may not be able to provide a full history themselves due to the nature of the condition. This history accounts for 80% of a diagnosis, with investigation and examination each comprising 10%.

Dementia is also complex and nuanced, presenting in different ways in different individuals. No two cases are ever the same, and some of the subtle signs of the condition can be easily missed.

For people living with dementia in the community a stigma still exists and, for that reason alone, those people and their families may delay seeking medical advice, putting symptoms of dementia down to the usual ageing process.

Perhaps as a result of these difficulties and complexities it's estimated that more than 50% of people living with dementia in the community remain undiagnosed, resulting in missed opportunities for the person with dementia and their families and carers. This



includes family support and education, strategies to slow the progression of disease and prevent less-than-ideal outcomes (ie car accidents, loss of money, poor decision making), and future care planning.

Up-to-date advice

Prioritising the importance of a timely dementia diagnosis in primary care is one of the learning outcomes of a new Dementia Training Australia (DTA) course. The free online course, *Recognising, Diagnosing and Managing Dementia in General Practice*, provides GPs and Primary Health Care Nurses with the most up-to-date advice on dementia in the General Practice setting. Based on a

face-to-face workshop developed by the Wicking Dementia Research and Education Centre at the University of Tasmania and delivered across Australia, the course sets out a structured approach to recognising, diagnosing and managing dementia.

Throughout the four-hour course, GPs, a neuroscientist, a psychiatric geriatrician, nursing professionals and carers all share their knowledge, experience and insights in dementia research, education and care.

Upon completion of the course, learners will be able to:

- Identify the different types of dementia commonly seen in General Practice.
- Recognise barriers to

diagnosis of dementia, including time pressures, fear of making the wrong diagnosis, and subtlety of symptoms that can emerge over time.

- Identify the medical and social impact of dementia on the individual, family and wider community.
- Differentiate early warning signs of dementia from other medical presentations.
- Apply a framework for making a diagnosis of dementia.
- Apply inclusion and exclusion criteria for dementia diagnosis; for example, inclusion criteria includes gradual and progressive onset of memory problems, and impaired function (eg, someone who previously loved to cook is muddled in the kitchen).
- Use validated screening tools to help make a dementia diagnosis.
- Demonstrate giving a diagnosis of dementia to a patient and / or family member.

Partnerships with educators

DTA also offers other online training for GPs through *The Timely Diagnosis and Improved Management of Dementia in Primary Care*, a Royal Australian College of General Practitioners (RACGP) accredited course on the assessment and investigation of a person who presents with cognitive impairment, hosted at thinkgp.com.au.

Both online courses are part of a larger body of work, led by the DTA teams at the Wicking Dementia Research and Education Centre and La Trobe University, to upskill GPs in recognising, diagnosing and managing dementia. DTA works in partnership with the organisations that GPs turn to for their education, for example RACGP, to develop GP-relevant content and to link into extensive GP networks that enable the training.

These collaborations have led to the following training activities:

- A partnership with General Practice Supervisors Australia (GPSA) to develop GP Supervisors' teaching plans. The Diagnosing Dementia and Understanding Dementia teaching plans will be used by GP supervisors to teach trainee GPs (Registrars) in the practice setting to better understand and diagnose dementia. These will be used by the 4000 GPSA members as well as GP Registrars who

access them for their own learning at gpsupervisorsaustralia.org.au.

- The Identifying Patients With Dementia online short course, developed by DTA and RACGP, and available to RACGP members at racgp.org.au.

Delivering the diagnosis

An important part of all these GP training activities is providing guidance on how to appropriately explain dementia to patients. As a guide, the Recognising, Diagnosing and Managing Dementia in General Practice course includes a video of a GP delivering the diagnosis to a person living with dementia and their carer.

Increasing knowledge and awareness of how to have these conversations can help build the confidence of a GP in making a diagnosis. Because a diagnosis is not something that people will want to hear, there are many factors to consider, including the importance of adhering to the rules of breaking bad news, finding out what the person

with dementia and their carer already know about dementia, thinking about who needs to be present, and what information needs to be shared.

Important role

With the increasing prevalence of dementia in Australia, GPs will need to become ever more skilled in diagnosis, and that is why this training is so important. GPs are well-placed to diagnose and manage dementia because they know their patients and families best. Dementia care is largely managed in primary care and GPs will have developed strong therapeutic relationships with their patients. GPs can connect people with dementia to the right services and help them navigate the aged care system. GPs can really make a difference here, and we want to inspire them to take ownership, with the confidence of being equipped with the right skills. ■

The new online course Recognising, Diagnosing and

Managing Dementia in General Practice can be accessed via the DTA website dta.com.au

Acknowledgments

Recognising, Diagnosing and Managing Dementia in General Practice was developed for DTA by a team led by the University of Tasmania: Professor Andrew Robinson, Professor Dmitry Pond, Dr Marita Long, Dr Hilton Koppe, Dr Margaret Winbolt and Helen Douglas. The contributions of various GPs, a neuroscientist, a psychiatric geriatrician, nursing professional and carers who have shared their knowledge, experience and insights in dementia research, education and care are acknowledged and appreciated.



■ Dr Marita Long (left) is a Tasmanian-based GP and medical educator; Dr Margaret Winbolt is a Director of Dementia Training Australia (DTA), based at La Trobe University, Melbourne

To read more on this topic, see *Communicating a dementia diagnosis and What is a timely diagnosis?* in Research News on p37

Office-based assessment of cognitive impairment

The September 2018 issue of the *Australian Journal of General Practice*, the RACGP's peer-reviewed journal, features a freely available review of what GPs can do to assess cognitive impairment in a General Practice setting.

Professor Dmitry Pond, Head of the Discipline of General Practice at the University of Newcastle, discusses office-based tests for cognitive impairment in light of the fact that GPs are now taking a bigger role in diagnosing dementia.

Office-based assessment of cognitive impairment aims to identify cognitive problems in those at moderate risk of dementia and then distinguish dementia from other common causes of cognitive impairment – the three 'Ds': delirium, depression and drug (medication) effects.

The article briefly explains why an assessment for cognitive impairment may be helpful, who to assess, what assessments are required and what to tell the patient. The article is available at: <https://bit.ly/2p1v4ST>

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The freedom of home

Natasha Chadwick and **Alasdair A MacDonald** report on a new, award-winning inclusive model of residential aged care that doesn't segregate people by physical or cognitive diagnosis. Instead, residents with a range of care needs, including advanced dementia, and with similar values and lifestyle preferences, share a home together



Residents are free to pursue lives that are as independent as possible and choose their own daily routine

The number of people living with dementia continues to increase each year, including those with a younger onset diagnosis (Dementia Australia 2018). Paradoxically, much of the aged care industry continues to provide products and services that are not in line with the Aged Care Roadmap (Aged Care Sector Committee 2016).

In essence, the Roadmap talks of greater consumer choice, which is nothing new to the industry; government, peak bodies, providers and consumers all have spoken (and continue to) about moving away from the traditional institutional models of residential aged care. No longer will the consumer accept a blanket one-size-fits-all approach – nor should they.

However, when it comes to dementia-specific residential aged care, unfortunately there has been little or no change in what is being delivered. Terms such as 'dementia-specific unit', 'locked unit', 'secure unit', 'the dementia wing', 'the dementia section', 'high-care and low-care dementia floors', to name just a few, are sadly familiar to us all.

In 2012, after more than 20 years working in aged care, Natasha set out to develop an alternative to traditional residential aged care that wasn't institutional, segregated and task-driven. A global search for best practice, looking at models of residential care in the US, the UK and Europe, including the Hogeweyk dementia village in The

Netherlands, consistently brought us to the same conclusion: the model would need to be customised to suit the Australian market, and there would be no separate units or areas for people with dementia; instead, they would be integrated with residents living without dementia.

In late 2017, after almost six years of research and development, we opened the NewDirection Care Bellmere Microtown™ in Queensland – a new model of residential aged and dementia care that we believe will revolutionise the sector. At the end of the day the solution was pretty simple – enabling residents the freedom of home, access to outdoor spaces and the wider community, and no longer segregating residents based on their physical or cognitive diagnosis.



The NewDirection Care Bellmere Microtown in Queensland has 17 homes on six streets for 120 residents

Trialling the concept

Before building the Bellmere Microtown we trialled this idea of inclusive, 'small-scale living' with a pilot program in 2014 in Wynyard, Tasmania. Two small houses were built, each with seven bedrooms, a working kitchen, laundry and living room, enabling seven residents with and without dementia to live together in a regular house and take part in day-to-day activities such as cooking and cleaning. There were no longer routines, but instead residents started to experience a sense of normality, greater freedom and empowerment. They reported a significantly positive experience and improvements in their quality of life.

Key findings and outcomes from the program, which is still running in Tasmania, included:

- It was clear that residents do not need to be segregated by diagnosis, but instead grouped according to their lifestyle and values. This led to the development of our proprietary Lifestyle Survey (explained in more detail later in the article).
- Residents were supported and encouraged to do day-to-day household tasks such as cleaning, laundry, cooking, gardening, etc, as much as possible.
- The optimum resident-to-staff ratio, which changes as the care needs of each house changes (eg, a maximum of two



Feeding the chickens and helping to clean out their pen is a daily ritual for many of the Bellmere residents

staff per shift in homes while the care needs of residents are high and a minimum of one otherwise.

- The development of the House Companion™ role, including a customised training program.
- House Companions being able to assist with medication administration, resulting in the removal of medication trolleys.
- A customised food safety program specific to the model.
- Introduction of non-chemical cleaning.
- Removal of certain routines such as waking all the residents at the same time.
- Reduced incidents of 'sundowning', responsive behaviours and improved sleep among residents.
- Increased appetite and participation in menu planning and cooking.
- Creation of a resident community garden and use of produce in cooking.
- Full compliance with the accreditation standards.
- Costs per resident were shown to be in line with those in traditional models of residential care.

The Bellmere Microtown

The success of the model in Tasmania led to the development of NewDirection Care Bellmere, which opened in September 2017. The \$30 million residential aged care facility is a world-first Microtown, located between Brisbane and the Sunshine Coast. It has 17 individually styled homes located on six streets over 2ha and is home to 120 residents. The Microtown recreates life in a small Australian town and is designed for people of all care needs, including those with advanced dementia and younger onset dementia, to live together. Sixteen of the houses have seven people

living in each and one home has eight residents. They live together based on their values and lifestyle; they are not segregated according to their diagnosis, nor are residents with dementia isolated in a secure location. Houses closer to the town square are defined as 'urban' or 'modern' and designed for residents who have come from a city environment or lived in an apartment, while those further down the street and closer to the community gardens and chook pen are very traditional and more suited to residents from country areas or a farming community.

Unlike traditional institutional care environments, where many areas are restricted or out-of-bounds, there are no locked secure dementia units, no corridors lined with rows of bedrooms and large common areas, nor industrial-sized laundries, or a central commercial kitchen preparing generic, canteen-style food served at fixed times by dining staff in a large and loud dining hall. Neither are there nursing assistants or personal carers helping residents with eating and personal care at fixed times, or Registered Nurses (RNs) running around with medication trolleys.

Instead, the Bellmere Microtown looks exactly like any other Australian



Residents are supported and encouraged to do household tasks including laundry

suburban community – the houses all have picket fences, mailboxes, garden hoses, a barbecue, clothes line, and front- and backyards, positioned on wide, landscaped streets, each with their own name and house number.

Each resident has their own private ensuite bedroom (some with double or queen beds so couples can live together) and share the home's domestic-style kitchen, laundry, dining room and sitting rooms as a family unit. They decide their daily routine, right down to the menu and are free to explore as much as they wish throughout the Microtown.

As with any other suburb, the Microtown has a town centre or shopping precinct with a cinema, corner shop, café, beauty salon, barber, GP, dentist, and a wellness centre for residents and team members. Families and the wider external community also have access to those same shops and services as they are open six to seven days a week. We also have created partnerships with community support groups who provide volunteer services such as local churches offering spiritual support, local schools for intergenerational programs, and some Indigenous groups to provide connections for residents' specific cultural needs.

The community garden, tended by residents and an onsite gardener, provides seasonal produce for their own use. Residents also tend to the chickens, feeding them and cleaning the pen. Pets are welcome if the other residents in the house all agree as a 'family unit'. The animal is assessed for suitability by a vet, a support plan is completed, and an agreement is put in place between the resident/family and NewDirection Care. At present one of the houses has a pet dog and another has a bird that are looked after by residents and House Companions, providing company, love and a sense of community for all.

Profiling tool

While there are no dedicated dementia units, nursing home or hostel units at



The community garden provides seasonal produce for the town's residents

Some of the homes have double or queen beds so couples can live together



NewDirection Care our residents' needs cover the typical broad spectrum that you would expect in any residential aged care facility. Our inclusive approach means that seven or eight like-minded residents are assigned to a house because they share similar core values, interests, hobbies and lifestyles. The Lifestyle Survey profiling tool which we developed, based on findings from the Tasmanian pilot, draws out an individual's social world view and personality traits, with a particular focus on factors that influence living and interacting with others. The questions cover topics including religion, attitude to money, politics, how the person likes to socialise and even when they like to eat their main meal of the day.

House Companions

Each house is autonomous, has its own budget, and is just like a regular home. Residents are able to personalise their bedrooms and bathrooms with additional furniture, photos and ornaments, and add some personal items in common areas. Meals are prepared in the kitchen, residents eat dinner family-style, and laundry is done in the home's laundry room and hung on the backyard clothesline. Complaints about food are nil as residents assist with all menu planning (and shopping if they're able to), based on what each person wants to eat.

Residents are supported by what we call a House Companion™, a unique 24/7 rostered role that has been specifically designed and validated by NewDirection Care and is a world first in residential aged care. What makes the role unique is that it's covered by its own Enterprise Agreement, in recognition of the differences between this role and an AIN/Personal Carer under the current Aged Care Award; it's supported by a unique training program that we have

customised to our needs, in partnership with various training organisations; and staff working in this role have responsibilities for a home's budget, menu planning and laundry, not just personal care, cleaning and cooking.

We created this staffing model after successfully trialling the role in Tasmania. House Companions are recruited through a detailed assessment process based on NewDirection Care's values of 'individuality, community, relationships, respect and empathy' and undergo intensive training and a five-week induction program. This covers dementia care, medication administration, manual handling, first aid, personal care, palliation, nutrition, cooking, food safety cleaning, laundry and customer service.

House Companions form part of each home's 'family' unit, providing assistance as needed with daily activities such as cooking, cleaning, personal care and medication. They wear everyday clothes, not uniforms, and form strong personal bonds with residents and their families. We roster the same staff in each house where possible and eventually would like to implement consistent staff assignment. House Companions help each resident determine their day-to-day routines, menus, activities and outings. There are no shower lists or regimented wake-up and meal times. Instead, residents get up in the morning when they want, eat what and when they want to, receive guests, visit friends in the other houses, and their loved ones can spend the night – just as they've done throughout their lives.

There are a maximum of two House Companions in each house from 7am to 9.30pm daily, depending on care needs. They are backed by a team including RNs, dementia support, physiotherapist and other allied health services. When the doors to each house are locked at



Residents have full freedom of movement and independence throughout the 2ha site

9.30pm an overnight team, including an RN and several House Companions, are stationed onsite in the administration building to assist residents if necessary.

Safety, freedom of movement

As previously mentioned, there are no locked or secure dementia units. Residents are encouraged to walk, explore and integrate as they wish throughout the Microtown. The 2ha site is fenced and there is one entrance/exit through the front reception area. Residents' house doors are locked only at night. There are no 'hourly checks' during the night or the night team coming in and out of their houses.

Residents have full freedom of movement and independence without compromising their safety through our proprietary mobile monitoring technology. The system encompasses a telephone system, CCTV and movement sensors (including bed sensors), and a hands-free team communication platform, all captured on a simple computer dashboard which will alert the team when a resident requires assistance or guidance. Residents also have the option of wearing a GPS location device if they wish.

Through the use of this technology residents are free to pursue lives that are as fulfilling and as independent as possible. Free and safe access to outdoor



The town centre includes a store and cafe for residents, team members, family and the wider community



Inside the town's corner store where residents and House Companions shop for their households



Residents are supported by House Companions who are part of each home's 'family' unit

spaces provides opportunities for socialising with fellow residents, team members and the broader external community. For those people living with dementia this freedom provides the right prompts to experience normal life, and they are typically more involved in their daily routine and decision making.

Positive outcomes

In the 12 months since NewDirection Care Bellmere opened its doors the benefits at this early stage, based on resident, family and staff feedback, internal assessments and quantifiable data, include:

- Autonomy, with the freedom of home, as residents, including those with dementia, have full access to all parts of the Microtown.
- Residents are able to live and die in their home. To date, five residents have passed away and all but one (who died in hospital) were able to palliate and die in their bed in the same house that they joined when they entered. Our model also supports loved ones to be onsite 24/7 during such times, with access to a night room.
- Little or no 'sundowning' among residents with dementia. We believe this is due to a range of factors such as residents not being woken at set times, and always being on the go, whether doing household tasks, in the gym, gardening, tending to the chooks or socialising with others at the shops and café.
- Minimal nocturnal activity which, again, we believe is due to the fact that residents rise and sleep when they want. If we do see residents up during the

night it's typically during their initial settling-in period as they get used to their new environment.

- Preliminary studies and key clinical data has seen a reduction, and in some cases cessation, of residents being prescribed certain medications (eg antidepressants and antipsychotics). Some residents have also had their sleep medications reduced, stopped or substituted with alternatives such as melatonin. However, we believe the improved sleeping patterns are because residents can rise and sleep when they want (see point above).
- Increased appetite with healthy weight gain reported. As such, our clinical indicators look at weight variance rather than weight loss (the industry benchmark). We believe residents' increased appetite is because they are involved in cooking, be it helping to cook or simply being in the house and smelling and hearing the food being prepared. The use of meal substitutes or thickened fluids are limited unless clinically prescribed.
- More engagement with the wider community which is pivotal, in particular for those residents living with dementia. They can stroll to the shops, café and other services where they meet visitors just as they would in the community.

For residents living with dementia who have transferred to NewDirection Care from traditional residential aged care facilities (where they were in secure dementia units with reported severe behaviours, non-engagement, 'aimless wandering' and 'exit-seeking'), we have enabled them to 'deinstitutionalise'. Normal things such as opening the front door, going for a walk, helping with gardening or cooking are all encouraged and supported. Much of this is obviously possible due to the non-segregation of residents, the ability to safely and freely move throughout the community and of course access to the wide outdoor space. This provides the opportunity for residents to meet and interact with others, make choices and transactions at the onsite shops, and visit neighbouring houses for a cuppa – all of which supports social interaction.

There is a sense of normality and people create friendships just as they would in the community. When people are assigned to a house that is appropriate for their lifestyle and values the probability of everyone getting on is much higher, regardless of their diagnosis. There have been challenges, with some residents who do not have dementia struggling to

understand the condition, so we provide them with education and ongoing support, which helps. Since Bellmere opened we've had only two people change households.

International recognition

During a visit earlier this year, Jannette Spiering and Eloy van Hal, founders of the Hogeweyk dementia village in The Netherlands said that NewDirection Care's Microtown "can be seen as further development in Australia of the world-renowned De Hogeweyk model. We recognised all of the important elements that are needed to continue your life: living according to your lifestyle, in a fantastic house, staying part of a vibrant society and meeting friends and relatives every day. And of course, support from dedicated and specifically trained staff on hand nearby when needed" (NewDirection Care 2018). Jannette and Eloy were particularly interested in the two main differences between their model and ours: the integration of all residents at Bellmere compared with their community which is for residents with advanced dementia only; and our House Companion model which is significantly different to their staffing model.

NewDirection Care Bellmere was named Facility of the Year – Independent Seniors Living, at the 5th Asia Pacific Eldercare Innovation Awards 2017 and our House Companion Model won the 2018 Innovation of the Year – Care Model at the Eldercare Innovation Awards 2018 (www.ageingasia.com).

What's next?

NewDirection Care is now working to expand the Microtown concept in a more urban setting. With land at a premium we won't have the luxury of building on such a large site. Instead, a vertical Microtown with apartments will be developed. We expect the urban setting will attract potential residents who have lived in a city, rather than the current Bellmere site which is located in a more regional area. ■

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■ Natasha Chadwick is Founder and CEO of NewDirection Care; Dr Alasdair A MacDonald is Chief Operating Officer at NewDirection Care. To follow up on this article, email natasha@newdirectioncare.com.au

Small-scale, home-like residential care delivers better outcomes for people with dementia. See article p32 in this issue.

Scaffolding to facilitate artistic success

Producing works of art can be fulfilling in its own right for people with dementia, regardless of therapeutic outcomes. **Alexandra Ramsey** and colleagues show how people can be supported to use their ‘retained skills’ in painting and drawing

Arts interventions have been shown to be beneficial for people with dementia, especially when they are person-centred and built on the assumption that these are individuals with human needs rather than patients with symptoms to be treated.

Observational measures have shown improvements in task interest, sustained attention, self-esteem, sadness, pleasure and verbal expression of feeling normal compared to non-art interventions (Kinney & Rentz 2005). Benefits can also be cumulative if participation is maintained over time (Rusted *et al* 2006).

Beard (2012) distinguishes art activity and art therapy for people with dementia. While both are beneficial, art therapy seeks to create some measurable outcome in symptoms or behaviour, which may benefit carers as well. Previous literature tends to focus on the therapeutic aspect, homing in on disease and behaviour-related outcomes such as depression scores or reductions in undesirable behaviours. It relies heavily on the reports of caregivers and observation rather than the opinions and feelings of the people participating in the activities.

This focus violates two important needs, both noted by Tom Kitwood (1997), namely the need for identity (positive perception of the individual by the self and others) and the need for inclusion (to be a legitimate player in social groups, culture and wider

society). In this case, identity is violated by positioning the art participants as patients or subjects, while inclusion is violated by excluding the voices of people with dementia from research.

By contrast, anyone can participate and experience the benefits of art activity and they do so for improvements in wellbeing, emotional expression and creative occupation (Beard 2012). If we consider art production in dementia as an *activity* rather than a *therapy*, then investigations can go beyond disease-based therapeutic outcomes and consider person-centred care-based outcomes such as art quality and individual wellbeing.

As the art produced by people with dementia is often considered to be of low quality (Gretton & ffytche 2014; Kirk & Kertesz 1991; Seifert & Baker 2003; Seifert *et al* 2001), engaging them in art activities has typically been focused on achieving a therapeutic outcome. We will argue, however, that this emphasis demonstrates a failure to recognise and facilitate retained art skills, rather than an absence of them.

An activity such as drawing can be considered as a production line, requiring the individual to contribute several different skills to achieving a desirable outcome (see Figure 1 below). Someone may have many intact cognitive skills, such as procedural memory and composition perception, but cognitive skills such as task sequencing, perception and explicit memory may be impaired

■ Alexandra Ramsey is a psychology graduate from the University of St Andrews, Susan Webb is a Dementia Ambassador and founder of the Independent Care Activity Network, Joanne Robinson is the founder and CEO of the Little Art School, and Maggie Ellis is lecturer in the School of Psychology and Neuroscience at the University of St Andrews.

This article first appeared in UK JDC 26(4) 20-23

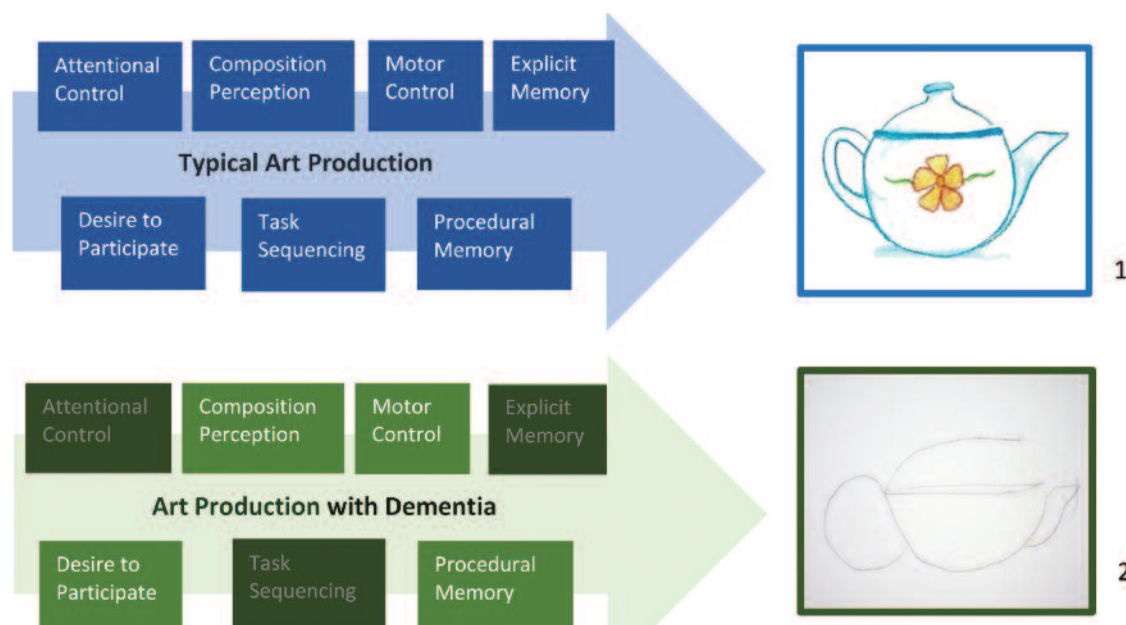


Figure 1: Specific skills needed for art production can be lost in dementia. Drawing (1) is by a person without dementia, while (2) was produced in ‘unscaffolded’ conditions by someone with dementia

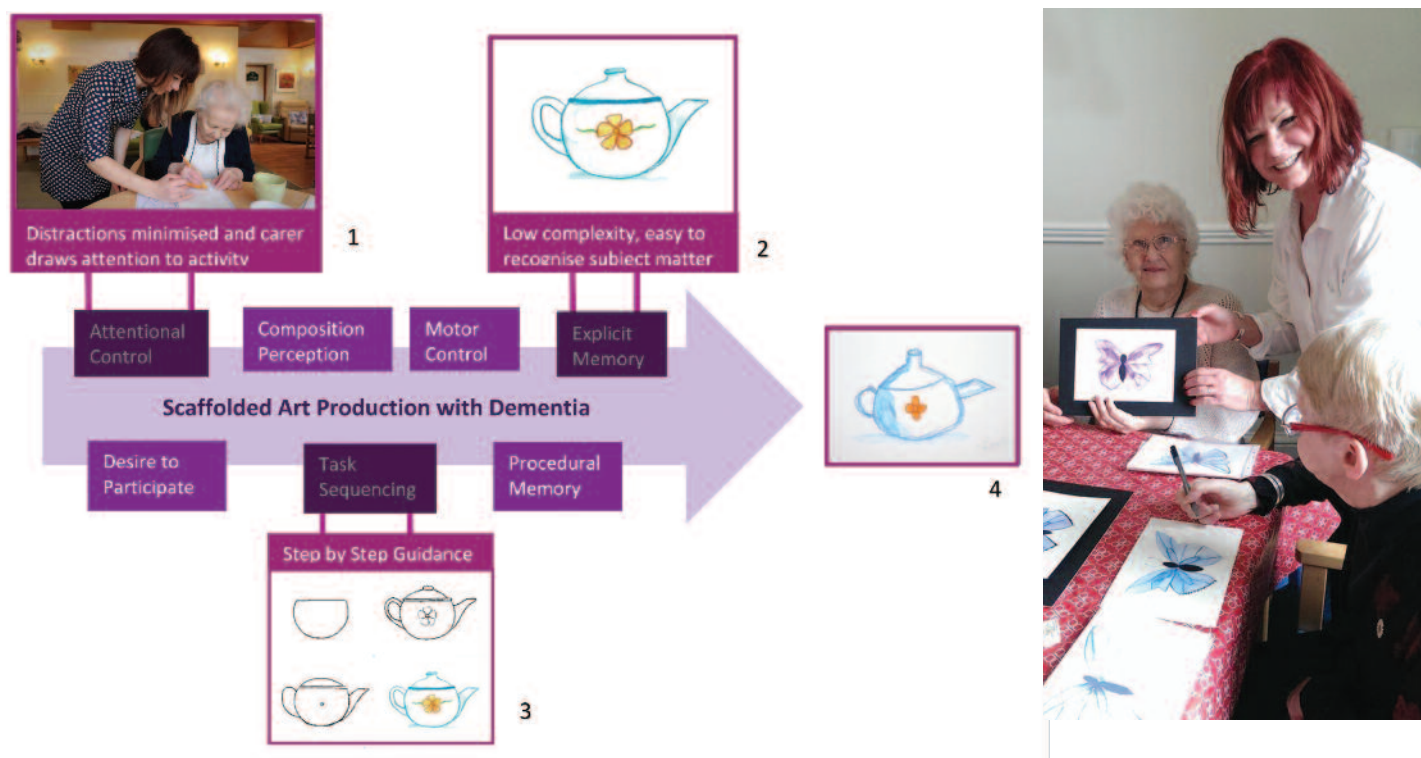


Figure 2: (above left) Targeted 'scaffolds' can compensate for specific skill deficits. (1) shows a Little Art School (LAS) teacher working with a person with dementia, (2) is an example of the subject matter used for drawings, (3) is a step-by-step guide from LAS classes, and (4) is a scaffolded drawing by someone with dementia

Above right: drawing class in the Little Art School

and result in a reduced outcome (see Drawing 2 in Figure 1) (Gretton & ffytche 2013, Kirk & Kertesz 1991, Seifert & Baker 2003, Seifert *et al* 2001). An observer perceives the reduced outcome as indicating a lack of ability to complete the activity (as in previous research), but we think art skills are retained in dementia and aim to demonstrate this using a technique known as 'scaffolding'.

Scaffolding art

Originally an early-years educational theory, scaffolding is a naturally occurring process between people with dementia and their carers in which an individual who lacks some cognitive, physical or linguistic ability is guided to participate in an activity that they would struggle with on their own (Cavanaugh *et al* 1989; Cicourel 2012; Hyden 2011, 2014, Vygotsky 1987). Vygotsky's theory concerns three areas: what can be achieved alone, what can be achieved with support and what cannot be achieved at all. The 'zone of proximal development' (ZPD) represents the space between what can be achieved alone and what cannot be achieved at all (Vygotsky 1987). Scaffolding bridges this gap, taking people to the best they can achieve.

For people with dementia, scaffolding provides an opportunity to employ retained skills to maximise the success of an activity. This facilitation can cultivate a sense of identity and demonstrate that the person's deficits do not define them (Anbäcken *et al* 2015). Our investigation is the first to propose the use of dementia-tailored scaffolding for art activity sessions to mitigate the effect of common deficits, allowing people to use their retained skills in painting and drawing.

It has been suggested that the most accurate assessment of the skill set of people with dementia can be gained by observing them in collaboration with other people. These partnerships highlight the fact that they can and do demonstrate their retained

skills when given the opportunity (Kindell *et al* 2016). So observing them drawing under scaffolded conditions may provide a more accurate representation of their artistic skills than has been demonstrated in previous research. Scaffolding techniques may also improve wellbeing and visuospatial skills in participants, maximising the positive effects of art interventions seen in research before now. Finally, facilitating the use of retained skills in visual art production could help to tackle negative perceptions of people with dementia through the display of scaffolded art.

Little Art School

The Little Art School Trust (LAST) is a registered Scottish charity offering art classes to people with dementia in Ayrshire and East Renfrewshire through their 'Art in a Suitcase' project. All participants are living in residential care. The project is a real-world example of naturally developed scaffolding in which structured (but flexible) art classes help people to maximise their drawing performance and be proud of the work they produce.

Scaffolding different tasks is complex, as techniques for one activity may not be appropriate for another, so the LAST program involves a new modality of scaffolding yet to be investigated. While their methods are not explicitly referred to in terms of scaffolding, LAST's aim of maximising benefit to clients by supporting an engaging activity bear a close resemblance to its principles. The program gains an understanding of its clients' strengths and deficits and integrates it into drawing and painting activities.

Using a set of targeted scaffolds for those cognitive deficits identified as inhibiting art production, LAST aims to bridge the ZPD (see Figure 2). While explicit memory does not interfere with basic drawing activity, it could cause distress ➤

➤ or confusion if individuals do not know where they are or why they are there. This is tackled by starting each class with ‘warm ups’ where participants have a chance to doodle freely. The warm up gives them a chance to exercise the motor skills they require for the art task and ground themselves in the present activity before they are asked to engage with the step-by-step scaffolds in the lesson. In addition, easily recognisable subject matter helps clients to recognise what they are drawing, with ‘templates’ showing bold, recognisable objects, such as a teapot, on display throughout the lesson (see Figure 3).

Impaired task sequencing commonly interferes with planning and carrying out activities in dementia (Baum & Edwards 1993). In response, LAST created the step-by-step templates to break drawing down into manageable steps and provide a reference for individuals to assess their skills. It was also noted that clients with dementia were struggling to reach for art materials in the correct order (picking up a paintbrush when they wanted a pencil), so art facilitators now present each person with the tools they need as and when they need them. Unnecessary debris is cleared away to avoid confusion.

Attentional deficits also interfere with task success, so materials are provided in such a way that attention is not distracted from the task in hand (Parasuraman *et al* 1992). Noise is minimised and, if participants become distracted from their art, their attention is gently brought back to it. Step-by-step provision of art materials helps ensure attention is not diverted from the task by clutter, while print-outs of previous drawings aim to prevent the urge to interact with objects rather than draw them (eg eating an apple intended as a still life).

Art facilitators encourage and praise clients for their drawings to maintain motivation, avoiding boredom and frustration by offering more complex drawing options to more skilled clients. The program is tailored to individual requirements. Clients are encouraged to sign their work so visitors can see that it is theirs and the framed drawings can often be found on display in their care homes.

LAST was keen to investigate how far its structured sessions improved clients’ visuospatial skills. Previous research has not looked at whether scaffolding in art activities can facilitate cognitive improvement in people with dementia.

Investigation: part 1

The first stage of our investigation aimed to test whether the scaffolded LAST art activity would result in improvements in visuospatial ability compared

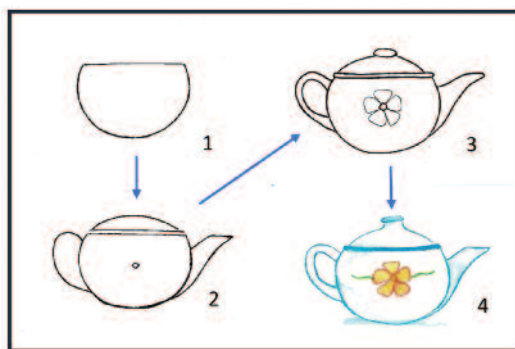


Figure 3: Step-by-step template for scaffolding of task sequencing used in the structured art sessions

with an unscaffolded art activity. This was done by organising two art activity sessions. The first followed the normal structure of LAST sessions, but the second was a completely unstructured session completed at least a week later. In the unstructured session, participants were asked to do their own drawing using only the final teapot image on the template (number 4 in figure 3) to guide them, while facilitators were instructed to give only minimal facilitation. Both activity sessions followed administration of wellbeing and visuospatial measures.

Wellbeing was tested with the dementia quality of life scale (DemQOL), a self-report measure, because we did not want to exclude the voices of people with dementia by relying on carer reports or observational measures. Higher levels of wellbeing following the structured session compared to the unstructured would demonstrate that scaffolding provided greater positive effects.

Visuospatial ability was measured using an extract from the Addenbrooke’s Cognitive Examination (ACE III) (clock drawing, letter identification and infinity pattern). If scaffolded sessions yielded higher visuospatial scores than unscaffolded sessions, this would demonstrate that scaffolding could improve cognitive skills and more so than in the absence of scaffolding.

Eight people with diagnoses of dementia or cognitive impairment living in three residential care homes in Ayrshire were recruited as volunteers to participate in the investigation (see Table 1 below). All participants undertook the scaffolded session having completed the wellbeing and visuospatial measures, although two of them did not then go on to attend the unscaffolded session. A further three did not wish to complete the measures after the unscaffolded session, but still completed drawings.

Part 1 results

The mean DemQOL score was higher in the structured session than the unstructured, but the difference was not statistically significant. So scaffolded art activity does not increase wellbeing when compared with unscaffolded activity. It should be remembered, however, that three out of the eight participants in the unstructured session did not wish to complete the measures after the session.

Structured sessions were bright and full of chatter and this mood appeared to last for hours following the activity. But the unstructured activity was quiet and some participants appeared to become strained and confused about the aims of the drawing task.

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Table 1: Information about participants

Gender	Age	Diagnosis
1 Female	87	Probable Alzheimer’s Disease
2 Female	92	Probable Alzheimer’s Disease
3 Female	81	Vascular Dementia
4 Male	83	Mixed (probable AD & Vascular)
5 Female	94	Mild Cognitive Impairment
6 Female	76	Probable Alzheimer’s Disease
7 Female	85	Probable Alzheimer’s Disease
8 Female	85	Stroke

Kinney JM, Rentz CA (2005) Observed well-being among individuals with dementia: Memories in the Making, an art program, versus other structured activity. *American Journal of Alzheimer's Disease & Other Dementias* 20(4) 220-227.

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Seifert LS, Baker MK (2003) Art and Alzheimer-type dementia: A longitudinal study. *Clinical gerontologist* 26(1-2) 3-15.

Seifert LS, Drennan BM, Baker MK (2001) Compositional elements in the art of individuals with Alzheimer's-type dementia. *Activities, Adaptation & Aging* 25(3-4) 95-106.

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They appeared withdrawn and declined to participate in testing.

This leads us to speculate that the scaffolded task did yield benefits to wellbeing, although these could not be properly compared with the unstructured task because a low-key atmosphere meant that some participants were in no mood to take part in the post-session measures. The same effect may have been at work when we found no significant difference in visuospatial ability improvement between the two tasks.

Investigation: part 2

In the first part of the experiment, 11 structured and nine unstructured drawings were collected. A cursory look by the researchers suggested that the art completed under scaffolded conditions was of a higher quality than the unscaffolded (see drawings above). To discover whether this observation was significant – and if scaffolding really did facilitate the use of retained drawing skills – we asked people unaware of the purpose of the study to rate the drawings. People were selected on a random, opportunistic basis by asking people in the School of Psychology and in local businesses. Twenty people without professional art expertise rated the success of the drawings in achieving a likeness to the teapot on a simple 0-10 scale. Each drawing was presented for rating beside the target teapot image (see Figure 4), then we divided up the ratings between the structured (n=218) and unstructured (n=162) categories in order to compare the two sets of ratings.

Part 2 results

The mean rating for structured drawings (5.00 out of 10) was found to be significantly higher than that for unstructured drawings (2.12 out of 10), which is evidence of a recognisable effect when art production by people with dementia is scaffolded. The data suggest that that the scaffolding programme designed by LAST increased drawing success.

By compensating with scaffolding for the damaging impact of dementia deficits (relating to, for example, explicit memory, task sequencing and attentional control), facilitators enabled participants to reveal a retained ability to create art by achieving a likeness to a given object (eg the teapot). The

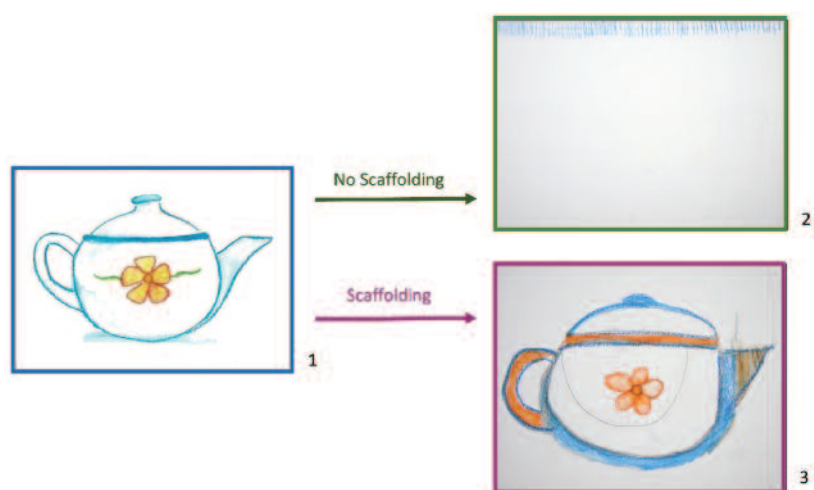


Figure 5: Comparison of drawings achieved by one participant



Two 'scaffolded' drawings (on the right, above) compared with 'unscaffolded' drawings on the left

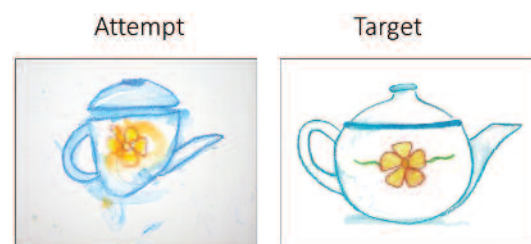


Figure 4: Drawings were rated by comparing each one with a 'target' drawing

results demonstrate that there is an art-specific ZPD in dementia and that, by the use of scaffolding to bridge the gap, participants were able to draw more competently than they could on their own.

Discussion

While our research did not replicate the wellbeing improvement of structured art activity shown in previous studies, it has provided support for the practice of scaffolding in art activity for people with dementia. The present findings contradict previous research suggesting that dementia art is of poor quality and that the only reason to facilitate it in such cases would be for its therapeutic benefits (such as reduced depression or anxiety) (Gretton & ffytche 2014, Kirk & Kertesz 1991, Seifert & Baker 2003).

In contrast, we have shown that drawing a likeness of subject matter such as a teapot is possible with retained skills, indicating that structured scaffolding is an important factor in optimising the success of art activities in dementia. It can be an activity for personal fulfilment and artistic expression rather than a therapy (Beard 2012). Our study also supports the idea that scaffolding could be applied more broadly to activities such as cooking or personal care.

The effect of scaffolding in maximising the utilisation of retained skills was apparent to the lay raters who were invited to assess the drawings against the target image. The scaffolded drawings suggest that, even if we cannot see retained skills in dementia under normal conditions, it does not follow that those skills are absent.

Attitudes toward dementia still focus on deficits and what people *cannot* do. Scaffolded art presents a visual example of what people with dementia *can* do (see Figure 5). It has the potential to engage people with different levels of expertise, education, age and language in finding an outlet for retained skills that all too often go unnoticed. ■

Consistent staffing models: sharing the learning



Daniella Greenwood puts the case for consistent staff assignment, arguing it is the most powerful operational approach to support the rights of people with dementia and to promote staff retention

The traditional model of staffing in residential aged care is 'rotating assignment' (Farrell *et al* 2006). With this approach, personal support staff regularly work with a range of different residents (or clients in a home care context). Rotating assignments make it difficult for personal support staff to develop relationships and familiarity with the people they support, so it is not difficult to see why they are a key operational barrier to recognising and honouring the existing and emerging preferences, passions and strengths of people living with dementia.

The rotating assignment approach is another way of ensuring that staff do not get 'too close' to the residents they support. Research indicates that relationships are the primary source of job satisfaction for staff (Ball *et al* 2009; Gittell *et al* 2008), and a key source of satisfaction and wellbeing for residents/clients in a consumer-directed industry (Belardi 2015). Despite this, the deeply embedded concept of 'professional distance' has a strong hold in both residential and home care settings.

At the same time, personal support staff are trained and instructed to provide 'person-centred care', which involves them having a deep understanding of each person that they support. Some residential aged care homes have up to 200 residents – how could it be possible to develop relationships with this many people?

What is consistent assignment?

The alternate approach is consistent staff assignment (also known as dedicated, primary or permanent staff assignment). With consistent assignment, clinical, cleaning and catering staff work consistently in the same area, and personal support staff support the same small group of people – whether in a residential or home care context. For personal support staff, consistent assignment is specifically designed for



All the photos on these pages show residents and staff from some of the organisations that the author has worked with or is currently working with to develop and implement consistent assignment. This includes Schlegel Villages (above) and the Research Institute for Aging, Ontario, Canada where she is developing, implementing and evaluating consistent assignment (Dedicated Support). The trial begins in October 2018

moments of intimate personal bodily care. All other duties, interactions and assistance outside of personal bodily care are provided by the consistent team. Consistency in the delivery of personal care and support offers many benefits to residents/clients and staff. Castle (2011) investigated care outcomes for 3939 long-term care homes in the US and found that care outcomes were significantly improved in homes using consistent staff assignment ($p < .01$). In a later study, Castle (2013) found that consistent assignment led to reduced staff turnover and unplanned leave.

Rights, decision-making, dignity

Australia's new Aged Care Quality Standards call upon providers to uphold the right of residents/clients to be self-determining. This includes ensuring that systems and processes are put in place that are specifically aimed at maximising the ability of residents/clients to make decisions about their own lives and about the way that care and support are provided.

The key to recognising and supporting the choices of people living with dementia – particularly those who no longer use words to communicate their preferences – is to surround them with people who know them well. People living with dementia rely on the

empathetic attunement of consistent personal support staff in order to have their emerging and embodied preferences and strengths recognised and honoured. This is vital if we are committed to protecting their ongoing rights to self-determination and participation as the level of dependency on others increases. Consistent assignment represents an important operational enabler in supporting the rights of people living with dementia.

The development of familiarity and trust between a professional support worker and the person receiving assistance is also the key to maintaining dignity throughout personal bodily care routines. Receiving assistance with personal bodily care remains an excruciatingly vulnerable process for the person being assisted, and it can lead to feelings of loss, shame, sorrow, fear and helplessness. Even when people are no longer mobile, or use words to communicate, they tend to do their best to move their bodies and limbs to cover private areas that are exposed.

Personal bodily care is where the rubber meets the road in terms of supporting dignity. How many *different* people would *you* want having access to your naked body?

Other key benefits of consistent staff assignment include:



In September 2018, Mercy Health opened a state-of-the-art, purpose-built, Small Household Living Centre in Ballarat, Victoria. Consistent assignment is an integral component of the Mercy Way approach, where multi-skilled Care Companions work consistently with eight residents in small households

- Personal support staff are able to get to know and support what is unique *about*, and uniquely important *to*, the people they support.
- Personal support staff can get to know the little things about a person, the things that matter, and also be more aware of subtle changes in mood and health.
- People living with dementia see familiar faces and feel the familiar touch of their bodies.
- People living with dementia are able to experience a sense of purpose in the reciprocal nature of the developing relationship.
- Personal support staff can bring their humanness, tacit knowing, intuitions, strengths, and life skills to their relationships at work.
- Personal support staff are offered the opportunity to connect deeply and truly get something back from their relationships with the people they support.
- Families are able to develop close and trusting relationships with consistent staff members.
- Families no longer experience the exhaustion of dealing with lots of different strangers. It is worth their while now to share more, connect more deeply, and have deeper levels of trust in the organisation and in the personal support staff directly providing the day-to-day support.
- The circle of close and consistent relationships in the lives of people living with dementia is extended beyond family care partners. This provides another layer of protection,

accountability and advocacy in terms of ensuring that the rights of the person are being upheld.

Why isn't everyone doing it?

Why is rotating staff assignment still so common in both residential and home care services? Having worked internationally with a range of service providers – for-profit, not-for-profit, church and government owned, including six years implementing consistent assignment with organisations and individuals – I have heard common themes and ‘reasons’ to explain why consistent assignment is not adopted. Below, I outline and briefly address some of the most common barriers cited by staff and service providers.

Resistance: difficulty getting ‘buy-in’ from employees

It is vital to engage with all stakeholders when embarking on any change or improvement initiative. This means that engaging residents, clients, staff at all levels, volunteers and family needs to be the *first step*. Finding out what matters most to residents/clients, family and staff is the key – this is the step that organisations most often skip. *Key learning #1: top-down solutions and ideas do not work – no matter how good they are. Everyone needs to be involved in finding the answers, and everyone is called upon to contribute.*

It is too difficult to implement

Moving to consistent assignment takes time, resources and organisation-wide

commitment. In my experience, a good implementation plan would allow three months from the initial engagement of multiple stakeholders to day one of the new roster and allocations. The move to consistent assignment needs to be part of a larger shift from a medicalised and institutionalised culture to a more relational one.

Although the process will be unique to each organisation there are some key implementation steps that are important:

- Engage all stakeholders in the process, including presenting the beneficial outcomes and links to deeper values, meanings and callings.
- Outline what consistent assignment is, and what it is not (see earlier section ‘What is consistent assignment’).
- Choose one area or service in which to carry out a trial to fine-tune the model and processes.
- Determine the preferences of residents/clients in terms of existing relationships, language and gender (eg, some may only feel comfortable being supported by a female or male).
- Determine the preferences of personal support staff in terms of existing relationships, preferred days, shifts and work areas.
- Gather information around indicators such as job satisfaction; sick leave; turnover; complaints; clinical indicators; and extensive feedback from residents/clients and family. This will help build a case for organisation-wide implementation.
- Hold interactive workshops with all staff.
- Implement a three- to six-month trial and gather regular feedback from all stakeholders; continue to adjust the model as required.
- Evaluate the trial using the indicators mentioned above to obtain the ‘before’ and ‘after’ outcomes. Personal stories and feedback are a vital component of the evaluation. Publish outcomes internally.
- Introduce all departments within the organisation to the initiative and processes developed during the trial. Ask each to consider how it might contribute to and support the implementation and maintenance of consistent assignment.
- Develop a working or advisory group to oversee the ongoing implementation and maintenance of consistent assignment.
- The next steps are focused on maximising the *benefits* of consistency. With the accountability that consistency provides comes the ability to increase flexibility to further support the day-to-day choices of residents/clients.

Key learning #2: there are key steps and minimal operating expectations for consistent assignment, but unique processes and systems will need to be developed by all stakeholders in each organisation. It is vital that all departments contribute.

Professional distance

Moving beyond the idea that personal support staff need to keep their *professional distance* is a keystone in successfully implementing consistent assignment.

Empowering, two-way relationships between people living with dementia and personal support staff are characterised by mutuality, solidarity, commitment, love and empathy. This is the antithesis of a relationship characterised by 'professional distance', where employees are cut off from their own humanness, including their invaluable intuitions, passions and tacit knowing.

Personal support staff are also sisters, brothers, mothers, lovers, neighbours and best friends to others; others who think that they are amazing. The key focus for service providers and management needs to be on encouraging personal support staff to bring their 'amazingness' to work with them, not to leave it at the front door and replace it with professional distance. We need to let go of the idea of professional distance because it remains a powerful barrier to upholding the rights of people living with dementia to communicate their choices; to understand, and to be understood.

Key learning #3: in addressing and alleviating organisational or individual concerns around professional distance it is vital to hear the voices of everyone. Gather staff together to unpack why this might be a problem. What are their fears? What are the supposed worst-case scenarios? What might be the benefits of closer relationships?

Leave management

Personal support staff are not robots; they get sick, take leave, move to a new house, get promoted and take up new employment opportunities. Systems need to be in place to ensure that every effort is made to fill leave shifts with consistent staff members. Expectations need to be managed in terms of everyone understanding how this will be handled. The personal support staff filling shifts during leave need to be introduced to the people they will be supporting.

Key learning #4: systems and processes need to be in place to address leave management, with a priority on consistency and transparency when replacing shifts.

Staffing changes

Concerns that staff might leave the service, or be promoted, largely centre on protecting residents or clients from the pain of losing an important relationship. This is no different from any one of us insisting that we will never again have a relationship in our lives for fear of being hurt. In attempts to protect a person, to sanitise life, the right to experience close relationships and the benefits of consistency are denied altogether. This represents its own kind of paternalism.

Staffing changes can be handled sensitively, with rituals developed around saying goodbye and beginning new relationships.

Key learning #5: potential pain and loss are not good enough reasons to deny access to close relationships and consistent support.

Workload and burnout

In many cases I have found that issues around 'workload' fairness equate to a misunderstanding of what consistent assignment is, and what it isn't. The issue primarily arises because one small group of people that a personal support worker consistently supports may constitute a heavier workload than another support worker's group. The workload in different sections changes frequently because of changing resident needs.

Much effort can be made to ensure that each section is initially balanced in terms of workload, but the balance soon changes, and allocations will need to be adapted again and again. The answer lies in looking at the other duties that do not involve intimate personal care. There are many non-personal care duties, such as making beds, serving tea and coffee, emptying linen skips etc. These are the areas that need to be reallocated to better balance the changing workloads.

Some resist consistent assignment because it is thought that personal support staff need 'variety' to avoid 'burnout'. This approach may be beneficial in a factory, or even in sales or hospitality; but it does not accurately reflect the real-world experiences of



Gallipoli Home, Auburn, NSW opened in July 2018. It supports Islamic faith practices through a unique Ageing in Community Approach which actively engages family and the local community. A key part of its model is consistent assignment (Permanent Rahma Partners), which ensures that residents' gender preferences can be guaranteed, and dignity maximised

personal support staff – and the non-financial benefits they get from this work; what it means to them personally.

However, there are situations and people that present an ongoing challenge to personal support workers. Consistent assignment shines a light on these individual issues and calls for them to be addressed in a positive way, rather than to ‘rotate’ personal support staff to avoid having to deal with them effectively. For example, it is common for well-meaning families to present an ongoing challenge to staff by overriding the day-to-day choices of residents/clients. I have often heard from staff that they wake up residents when they are happily asleep or take them to activities that they do not enjoy because they are genuinely afraid that the family will confront them.

Another example is when a resident or client is experiencing distress, often during personal care routines. When consistency is in place, personal support workers are more committed to finding out how best to approach and support the person, rather than to pathologise the ‘behaviour’ as merely a ‘symptom’ of dementia. These challenges are common and can go unaddressed in a rotating assignment model. In a consistent assignment model however, these conflicts stand out and need to be addressed immediately.

Key learning # 6: workloads can continually be adjusted through rotating duties that do not involve acts of intimate personal bodily care. Individual challenges and issues need to be dealt with effectively as they emerge. Understanding what brings meaning to the work and lives of personal support staff is important.

‘That’s not my resident/client’: teamwork

When looking at the day-to-day duties of personal support staff, a relatively small proportion of their time is spent assisting with personal bodily care. As stated earlier, consistent assignment is specifically for the intimate acts of personal care and support. Outside of that, everyone is called upon to support all residents.

Key learning # 7: training is the key to ensure that everyone works together as a team outside of the personal bodily care provided.

‘We are already doing it’

A major barrier to implementing a strictly consistent assignment model is the belief that it is already in place. Having a ‘consistent team’, or ‘consistent team leaders’, or only keeping allocations consistent for set lengths of time does not represent a true consistent assignment approach.

Key learning # 8: staff need to be consistently assigned across all roles and all shifts – permanently.

Death and dying

One of the strongest reasons presented for avoiding consistency and close relationships is to avoid staff grief when someone they are supporting declines in health or dies. However, I have seen funerals held at a residential care home so that personal support staff can be present; I have seen people refuse to go to hospital for palliative care because they want to die “at home” and “with loved ones” in a residential care home; and I have seen a substantial increase in consistent personal support staff taking part in eulogies and in supporting families long after the death of a loved one. Here, a son shares his experience:

“The dedicated staff over the last few weeks with mum and me made all the difference. It was a real close community, it felt like something of days of old, where you would have community and family and people around you who really cared for me, the son, but also for mum. It made the whole passing experience so special, and such an achievement for mum... it was a blessing to be a part of” (Neal Bethune, son of Dulcie Bethune).

His mother’s funeral was held at the residential home so that the consistent staff could all be involved.

Personal support staff have shared with me their stories about the benefits they have experienced in terms of gaining a deeper understanding of humanness and finitude. They take great pride in being with the person and their family, and then lovingly preparing and presenting the body of the person they have worked with. In doing so, they have unwittingly created their own meaningful rituals for the occasion. In a society that tends to hide and sanitise death and dying this is a precious gift for staff.

Key learning # 9: the death of a resident or client can be a gift for professionals providing care and support.

Conclusion

With a newly focused lens on rights, self-determination, customer/consumer choice and workforce strategy it is clear that changes to aged and dementia care in Australia are rapidly accelerating. In the real world of day-to-day service delivery, a commitment to consistent staff assignment draws on the strengths of what is currently working well, and on what is most important to key stakeholders. Consistency is a powerful operational approach to promote staff retention and to support the rights of our most vulnerable citizens to be included and to be self-determining. ■



The author worked with Arcare Aged Care from 2012-2018 developing and implementing an internationally recognised best practice consistent staff assignment model across the organisation (called dedicated assignment). Photo: Cathy Greenblat

■ Daniella Greenwood is a consultant, speaker, published author and activist. She works internationally alongside aged care organisations in a range of culture change initiatives such as implementing consistent staffing models; maximising resident self-determination and freedom; non-hierarchical leadership approaches and improving professional attitudes and beliefs about people living with dementia. Daniella is part of the global #BanBPSD campaign group. Contact her at Daniella Greenwood & Associates, daniellagreenwood@mac.com

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'The music that I love and remember'

Rachael Ho, Jiang Weiting, and Melison See

investigate the impact of personalised music and intergenerational bonding on people living with dementia



Left to right: Rachael Ho, Jiang Weiting, and Melison See

Fumiko, aged 80, sits in her wheelchair in one of the homes in Apex Harmony Lodge (AHL), a residential care home in Singapore purpose-built for people with dementia. She stares into space with little expressed pleasure. "She hardly speaks," the nurses say. Even during activities Fumiko's expression remains neutral. However, last November during a Music with Reminiscence (MwR) session, there was a breakthrough: upon hearing *Aijin*, a Japanese song performed by Teresa Deng, Fumiko's eyes widened and she broke into song, swaying her body. The nurse nearby was so surprised she immediately took out her phone to film the scene.

Also present was 17-year-old Ana, a volunteer from the United World College Southeast Asia (UWCSEA) who had been paired with Fumiko to enjoy listening to music on an iPod once a week during the MwR sessions. Although Ana is Filipino and cannot speak Japanese, music has overcome barriers and enabled them to connect as they beat the tambourine and hold each other's hands while the music plays.

Music with Reminiscence

MwR is a collaborative intergenerational initiative started in January 2016 by AHL and UWCSEA, an independent international school in Singapore for students from kindergarten to Year 12. This initiative is part of AHL's Intergenerational Bonding Strand, integrating the therapeutic benefits of music with the social benefits of intergenerational bonding. The aim is to improve residents' psychosocial wellbeing, leading to the appreciation of each generation as a gift to one another.

The main objectives of MwR are threefold: to improve quality of life through enhancement of positive emotions and amelioration of negative emotions in residents with moderate-stage dementia; to enhance students' understanding of people with dementia

and their appreciation of intergenerational experiences; and to enhance person-centred care (Kitwood 1997) for residents by gaining a better understanding of their interests.

Planned as a three-year project, the initiative was inspired by the Music & Memory program developed by Dan Cohen in the US. The Music & Memory program engages people with varying stages of dementia through the use of personalised music playlists, delivered on iPods and other digital devices. People with dementia are able to reconnect with their environment, are observed to be happier, and rely less on antipsychotic medications (Music & Memory Inc 2018). Familiar music also taps into deep memories not lost to dementia, enabling participants "to feel like themselves again" (Music & Memory Inc 2018).

Research has also shown that intergenerational interaction improves cognitive functioning, and enhances social and emotional wellbeing in people with dementia (Park 2014). Simultaneously, such interactions result in the amelioration of social stigma related to dementia among the young. In Park's study, youth volunteers were reportedly more empathetic and showed an increased cultural understanding.

Structure of MwR

Selection criteria

Residents must show an inclination to engage via music and one-to-one interactions. Before each session, a list of residents is reviewed by the program facilitator, who also checks with the nurses if residents are physically and emotionally able to participate. If the resident is not in the mood to participate, their decision is respected.

Participants

The program initially involved residents from two care homes in AHL from early 2016 to mid-2017. Currently, MwR has been extended to include two more AHL homes.

Program duration

Each program lasts for eight to 12 sessions.

Intergenerational interactions

Every week each volunteer (aged between 16 and 18) from UWCSEA is paired with the same resident to listen to their personalised music playlist on the iPods. The music is curated based on each resident's demographic profile and preferences. A typical session includes volunteers reminiscing with residents

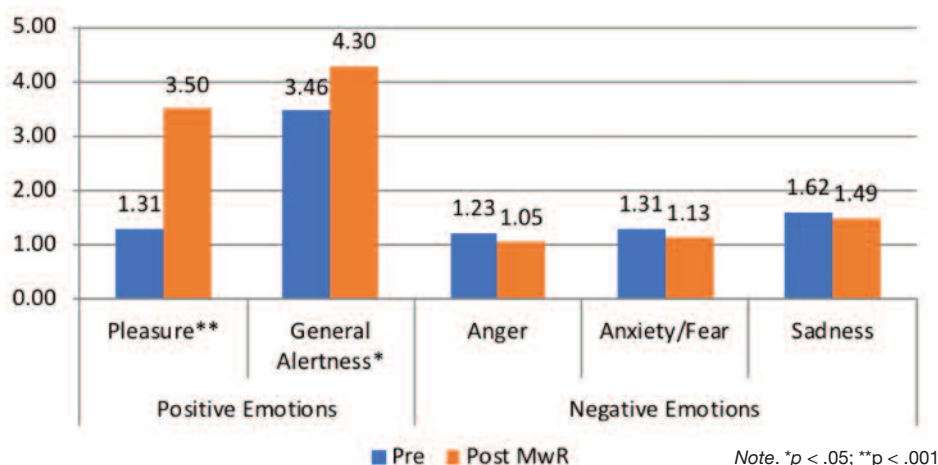


Figure 1: Average OERS scores of the 13 residents for baseline and post MwR scores

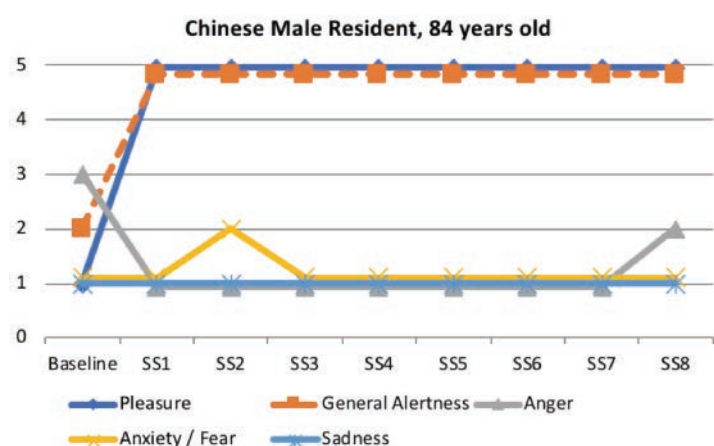


Figure 2: 84-year-old Chinese male resident Koh's OERS baseline and subsequent eight sessions' scores

through singing, playing instruments and providing a listening ear.

Song Observation List

After each session, the volunteers complete this qualitative assessment. It identifies each resident's musical predilection, observed cognitive and behavioral responses, and intergenerational interactions, such as sharing stories engendered by the music.

Method

From November 2017 to February 2018 nine volunteers from UWCSEA were engaged in the program over eight sessions with the residents. Each session typically paired one volunteer with one resident.

A mixed methods approach was adopted. Firstly, quantitative data was collected on the participating residents by the volunteers using the Observed Emotion Rating Scale (OERS) (Lawton 1999), which measures the affect elicited during sessions based on observable



Age and cultural differences fade away to the sound of music as Apex Harmony Lodge resident Ho (left) and a student volunteer, who are more than 65 years apart in age, listen to music together

expressions in people with dementia. It consists of five items, each representing five emotions – pleasure, anger, anxiety / fear, sadness, and general alertness – on a five-point scale ranging from 1 (*Never*), 2 (*Less than 16 seconds*), 3 (*16-59 seconds*), 4 (*1-5 minutes*), to 5 (*More than 5 minutes*). Participating residents had their baseline score recorded before the program commenced, and their score recorded at the end of every session. The scores for the eight sessions were then averaged to produce the post MwR evaluation scores.

Additionally, qualitative feedback was gathered from volunteers through reflection forms to understand their key learning points. Observations of staff and family members were gathered to add depth to this analysis.

Results

Prior to data analysis, the OERS data was cleaned, and six residents' data were removed as they did not have either baseline data or any data for at least one of the sessions. Hence, a total of 13 residents' data were analysed. There were six males and seven females aged 52 to 87 years old ($M = 76.38$, $SD = 9.59$) with moderate stage dementia; 69.2% of them were Chinese ($N = 9$), 23% were Malay ($N = 3$), while 7.69% ($N = 1$) were Japanese.

Paired-samples t-tests were performed to evaluate the impact of the MwR program on residents' OERS scores. The results were encouraging: there were statistically significant increases in the scores of positive emotions from baseline to the post MwR score.

Firstly, in the Pleasure score, there was a significant increase from baseline ($M = 1.31$, $SD = 0.63$) to post MwR score ($M = 3.50$, $SD = 1.09$), $t(12) = 5.92$, $p < .001$ (two-tailed). The average increase in the Pleasure score was 2.19 with a 95% confidence interval ranging from 1.39 to 3.00. The eta squared statistic (.74)

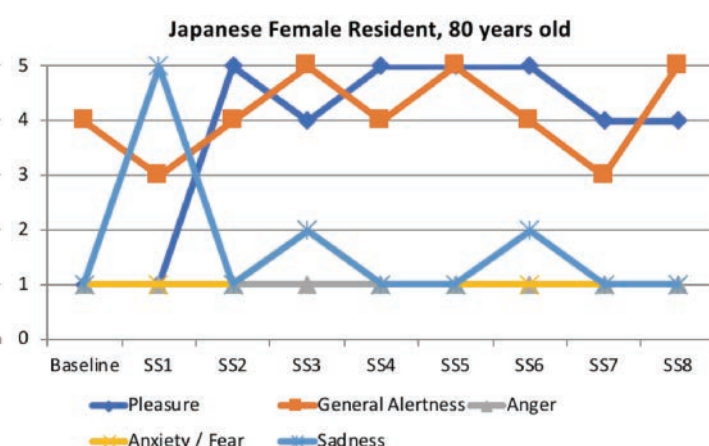


Figure 3: 80-year-old Japanese female resident Fumiko's OERS baseline and subsequent eight sessions' scores

indicated a large effect size.

Secondly, in the General Alertness score, there was also a significant increase from baseline ($M = 3.46$, $SD = 1.05$) to post MwR score ($M = 4.30$, $SD = 0.81$), $t(12) = 2.38$, $p < .05$ (two-tailed). The mean increase in General Alertness score was 0.83 with a 95% confidence interval ranging from 0.07 to 1.60. The eta squared statistic (.32) indicated a large effect size too.

However, no statistically significant differences between baseline and the post MwR score were observed for all three negative emotions. Having said this, it is notable that the average OERS scores for all negative emotions have decreased slightly from baseline to the post MwR scores, implying improvement in residents' wellbeing. More studies are therefore required to explore the impact or relationship that programs similar to MwR have on the negative emotions in people with dementia.

The bar graph on p29 shows the average scores of the 13 residents for baseline and the post MwR scores for each emotion.

For residents who have data across all eight sessions, their results reveal a notable decrease in negative emotions and an increase in positive emotions between baseline and subsequent sessions. For example, in the Anger score, Koh, an 84-year-old Chinese male resident showed a decrease from baseline (3) to subsequent sessions (1), and this was maintained until session 7 (see Figure 2).

Additionally, there was also an increase in positive emotions, most particularly Pleasure, experienced by Fumiko, the 80-year-old female Japanese resident referred to at the start of this article, from baseline (1) to subsequent sessions ('5' in Sessions 2, 4, 5, and 6) (see Figure 3).

Overall, residents in MwR have shown an increase in quality of life, with a significant increase in positive emotions, especially pleasure, and decrease in

negative emotions, most notably anger. However, as there are limitations in the small sample size and inconsistency of residents' participation, a larger sample size is needed to validate the optimal benefits of the program.

Thematic analysis

Volunteers' reflections provided consistent qualitative themes that showed positive perceptions and a deeper understanding of people with dementia. Staff and family members' observations also showed an increase in residents' wellbeing. The highlighted themes included:

Empathy

From the time volunteers embarked on this program, their understanding and acceptance of people with dementia has deepened through their personal interactions. A common desire expressed was to "make a difference" and improve the residents' well-being.

"I am learning about how dementia affects [the residents], but they are still very human," said Ana.

Connection

As the same resident and volunteer are paired weekly, a strong emotional connection was forged over the course of the program, leading to spontaneous activities such as creating new art pieces together, dancing to the music and playing the xylophone. Some residents even recognised the volunteers each week.

"I remember her," exclaimed Carol as soon as she saw her volunteer at the start of a session.

"I may be mistaken but the first time I saw that he may have recognised me was very touching. He saw me, smiled and waved, I knew he had remembered me when he acted like he had headphones on," wrote Arushi, another volunteer.

Personal growth

MwR was shown to cultivate positive character traits, such as patience, in the volunteers, as well as skills like listening and using body language to overcome language barriers.

From feeling unqualified and hesitant at the start of MwR, the volunteers' confidence grew throughout the program as they became more attuned to the residents' emotions, taking more initiative to engage them in conversation, and even breaking into song and dance with them.

Increased positive affect

"...we have observed that my mother is able to come out of down times. She is also more blissful," shared Lynette, Fumiko's daughter.

Discovery

Another common theme shared was the new discoveries made about the residents. For example, there were significant moments where residents started reminiscing and sharing. Mid-way into the program, Ong started opening up to volunteer Adel while listening to an Elvis Presley song. "She had a friend in this nursing home who passed away and she still remembers how she was feeding her with a spoon because she was bed-bound," shared Adel.

In the case of another resident, no one knew which instrument he had played when he was in a band. Then one day he revealed to his student volunteer that he had played the drums and double bass. This was a new discovery and helped care staff better cater to his interests.

Another common finding was the unlocking of forgotten selves through music. When Fumiko burst into song, a nurse commented, "Wa Fumiko is singing! She is usually so quiet." This was a new discovery for staff and the student as, for the first time, they saw Fumiko come alive.

Learnings

Some of the salient learning points from the MwR study are:

- Ensure residents' wellbeing throughout the sessions by having staff close by to intervene if residents need assistance.
- Journey with the volunteers. As it may be the first time many of the students have interacted with people with dementia it is critical to conduct pre-session briefings, and mid-session and post-session reflections so the students can express how they are processing their experience. We have realised that such platforms aid learning at both ends.
- Pair volunteers with the same resident to deepen their relationships.

Some preliminary ideas to improve the initiative include:

- Sharing personalised playlists with nurses to promote continuation of wellbeing as residents listen to their favourite songs.
- Including value-adding learnings, such as personal enhancers (any interaction that has a positive experience on the person and their wellbeing) from Dementia Care Mapping, for students to improve their interactions.

Conclusion

Music with Reminiscence is a transformative program that brings new life to residents with dementia, providing



Ana, a student volunteer, visits Chia every week and although they don't exchange any words, it is one of the rare times when Chia becomes animated. Together they sway to the music, beat the tambourine and enjoy her favourite songs

a glimpse of their rarely-expressed emotions. Combined with the benefits of intergenerational bonds formed with student volunteers, this initiative has proved to be an effective non-pharmacological approach in enhancing residents' wellbeing.

A moment to remember

It is the end of the session. Fumiko looks at Ana as she gently removes her headphones. Just before Ana stands up, Fumiko places her hands over Ana's, her lips curled into a smile. Perhaps the beauty of Music with Reminiscence lies in this: where words may fail, the heart still feels. ■

The authors' colleague at Apex Harmony Lodge, Associate Psychologist Chng Jiayun, shared the MwR initiative at an oral presentation during the Arts and Dementia session at the Alzheimer's Disease International (ADI) 33rd Conference in the US in July this year.

Acknowledgments

The authors would like to thank UWCSEA for their partnership in this intergenerational initiative. The students have made a difference in the lives of the residents.

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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.

What makes a real home for people with dementia?

An Australian study has found that a small-scale, home-like model of residential care delivers better outcomes for residents with cognitive impairment and dementia, without any increase in facility running costs. **Suzanne Dyer, Wendy Shulver, Stephanie Harrison and Maria Crotty** report

The average size of aged care homes in Australia has increased over time and 77% now have more than 60 places (up from 45% in 2011) (AIHW 2012, 2017).

Internationally, there is a move towards providing residential aged care in more home-like (normalised) settings. These models are usually provided in small-scale settings and aim to maximise the independence of residents and deliver person-centred care (Ausserhofer *et al* 2016).

In the Netherlands, there is greater availability of nursing home care provided in group living and in 2011 25% of residents with dementia in homes lived in small-scale environments. The Green House model in the US offers small houses and aims for the residents to have meaningful lives (Afendulis *et al* 2016). Green House models of care are now available in 32 US states and have been shown to offer a preferred model of care without impacting clinical measures of care quality (Span 2017). In Nova Scotia, Canada, new and replacement

government-owned facilities must be built to a set of physical design and staffing standards that meet a 'household' model of care (Keefe *et al* 2017).

The World Health Organisation has stated that newer models of residential aged care "offer promise for older people, family members and volunteers who provide care and support" (World Health Organisation 2015).

Some studies have shown improved outcomes with these alternative models of care in terms of medical measures of quality of care and less consistently in quality of life, changed behaviours and activities of daily living (Afendulis *et al* 2016; Ausserhofer *et al* 2016). Other studies have demonstrated improved quality of life with smaller-scale changes to the physical environment (Chenoweth *et al* 2014). However, evidence to support these models of care internationally is still fairly sparse and there is very little information on the associated costs of care.

A research group at Flinders



Independent access to outdoors is an important component of home-like residential aged care

University, as part of the NHMRC Cognitive Decline Partnership Centre (CDPC), undertook a cross-sectional study examining alternative models of residential care for people living with cognitive impairment and dementia to address this evidence gap in the Australian setting. The NHMRC Cognitive Decline Partnership Centre is a partnership between Dementia Australia, three aged care provider organisations (Helping Hand, Brightwater and HammondCare), 10 universities and other

healthcare organisations. Whilst the aged care organisations did not provide funding for this study, the partnership allows aged care providers to have input into research priorities.

The Investigating Services Provided in the Residential care Environment for Dementia (INSPIRED) study enrolled more than 541 residents and their family members where necessary, from 17 aged care homes across four Australian states. Twelve months of retrospective data from Commonwealth and State data

custodians on medication (through the Pharmaceutical Benefits Scheme and pharmacy records), health service (through the Medical Benefits Schedule) and hospital use (through state data custodians) were obtained, with data collected between January 2015 and February 2016.

This is the first study internationally to comprehensively compare the costs and resident outcomes (including quality of life, consumer-rated quality of care, hospitalisations, medication use) of home-like domestic models of care and more standard Australian models of care.

By examining the costs of providing care, the project also gives aged care organisations and health decision makers in Australia a measure of the cost of delivering quality care to people with dementia, enabling them to plan services and shape policy more effectively and efficiently.

The INSPIRED study provides the first estimate of the 'whole-of-system' costs of providing health and residential care for people living in residential aged care in Australia using individual level health and social care data. This approach to estimating costs indicates that previous, more limited cost perspectives underestimate the costs associated with caring for people living with dementia in permanent residential care.

The INSPIRED study has shown that the cost of providing residential aged care in Australia is higher for people living with dementia compared to those without (approximately \$82,000 for people living with dementia and \$73,000 for those without dementia) (Gnanamanickam *et al* 2018).

Consent for participants

A total of 1323 people were assessed for eligibility. Residents were eligible to participate in the study if:

- They had been a permanent resident in the aged care home for more than 12 months.
- They were not in immediate palliative care.
- They had no complex medical

How can we measure good quality residential aged care?

Previous measures of the quality of aged care homes have focused on the perspectives of staff or independent assessors with little focus on the perspectives of residents themselves.

Within the INSPIRED study, residents, including people with dementia, and their family members identified characteristics of residential care which are most important to them for good quality care. From these findings we developed an evidence-based instrument to measure the quality of care from the consumer perspective: the Consumer Choice Index – 6 Dimension instrument (CCI-6D). The CCI-6D has been validated and correlates as expected with other measures of resident quality of life and quality of care (Milte *et al* 2017).

The CCI-6D can be used by aged care organisations to properly evaluate the success of innovations to improve care from their consumers' perspectives. This simple questionnaire can be completed by residents or their family members to rate the quality of care of a facility, based on the six dimensions of: care time (time spent attending to individual needs); shared spaces (do they make you or your family member feel 'at home'); own room (does it make you feel 'at home'); outside and gardens (is there access); meaningful activities (how often does the facility offer me things to do that make me feel valued); and care flexibility (how flexible is the aged care home with the care routines). Their responses can be used to get a preference-rated summary score ranging from 0 to 1, with higher scores indicating better quality of care.

The tool, in conjunction with the standard, more objective quality of care measures aims to:

- Enable residents, their family members and informal carers to provide input into assessment of the quality of care.
- Enable assessment of quality of care in a manner that reflects the quality of life of the residents.

If incorporated into routine monitoring or evaluation of aged care facilities nationally it may enable earlier detection of failures of care.

For more information and to access the CCI-6D User Guide visit: <https://bit.ly/2PA25AY>.

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Milte R, Ratcliffe J, Bradley C *et al* (2017) Evaluating the quality of care received in long-term care facilities from a consumer perspective: development and construct validity of the Consumer Choice Index-Q2 Six Dimension instrument. *Ageing & Society* 1-23.

or family issues which would impede their participation.

- They had a family member available and willing to participate on their behalf (if the resident themselves was cognitively impaired).

Of the assessed residents, 901 were eligible to participate. Of these 541 individuals (61%) consented to involvement in the study (24% self-consent, 76% proxy consent), and 84% of participants had likely dementia (a medical diagnosis of dementia or cognitive impairment indicated by a cognitive assessment with the Psychogeriatric Assessment Scales Cognitive Impairment Scale (PAS-Cog) score of five or more). Given that there was no direct incentive for participation, the average consent rate of 61% is considered high, and compares favourably with consent rates for internal facility surveys and

other dementia research (Goodman *et al* 2011).

The input of facility staff in participant enrolment was invaluable, with care staff providing advice on eligibility of individual residents, particularly with regard to medical or family issues and cognitive ability to consent (in conjunction with facility records and cognitive assessment scores). For residents with moderate or severe impairment, or where a researcher had any doubts about the ability of a resident to self-consent (regardless of their recorded cognitive status), proxy consent from a family member was sought. The concept of 'continuous consent' was used, whereby if the resident or family member at any time indicated through verbal or non-verbal means that they no longer wished to participate, the investigator terminated their participation.

Models of care

The INSPIRED study compared outcomes for residents living in a home-like (normalised), clustered domestic model of care to those of residents in more standard residential aged care homes. The home-like settings were defined as those that met at least five of the following six criteria: smaller size (up to 15 residents in a living unit), outdoor areas with independent access for residents, continuity in care staff, meals cooked in the living units, meals available for self-service or residents can assist with meal preparation. This model of care aims to provide a home-like environment which looks and feels more like a domestic home.

Four-aged care homes (with 120 participants in the study) operated by one organisation provided this home-like model of care. All were dementia-specific homes. Homes that met four or fewer of these criteria

were defined as providing a standard model of care; none of the standard Australian aged care homes met more than two of these criteria. There were 13 homes (with 421 study participants) that were considered standard Australian aged care homes, operated by four different providers. Other differences observed between the facility types were higher investment in staff training and greater direct care hours in the home-like settings. The individual providers are not identified to protect the anonymity of the study participants.

Participants

The homes participating in the study were all not-for-profit providers and were considered to provide a high quality of care. The ambulatory-care sensitive hospital admissions (considered potentially preventable) from residents in the study over 12 months were below the national target of 8.5%. Two hundred and forty-seven residents (or their proxies) of the participating standard care facilities rated their social care-related quality of life with the Adult Social Care Outcomes Toolkit (ASCOT). More than 74% of the residents indicated that they felt as safe as they wanted, found the room as clean and comfortable as they wanted, always felt clean and presentable and had all the food and drink they like when they wanted.

The mean facility size was 83 beds and four of the 17 facilities were located outside of major cities. Fourteen of the facilities had a dementia-specific unit or wing.

The participants in the INSPIRED study were an average of 85 years old and 75% were women. On average they had 3.6 comorbidities (including dementia). The residents of the home-like models were slightly, but statistically significantly younger (83.3 years vs 86.1 years in standard care), had less comorbidities (average of 3.2 home-like vs 3.8 standard) and all had a medical diagnosis of dementia or a PAS-Cog of five or more. Fewer residents of the



In home-like models of care residents participate in domestic activities

home-like models also had weekly interactions with close social ties (56% home-like vs 75% standard).

Outcomes for residents

The residents living in a home-like model of care had dementia and were more likely to have changed behaviours (Dyer *et al* 2018; Harrison *et al* 2018a). After adjustments for differences in the characteristics of the residents and aged care homes, living in a home-like model of care was associated with:

- Better quality of life for the residents, as rated by the residents and their family members (as measured on the EQ-5D-5L health-related quality of life scale).
- Better quality of care, from the consumer perspective, as measured by the Consumer Choice Index – 6 Dimension instrument (CCI-6D) (see box p33 for details). Residents and their proxies rated the overall quality of care higher; in particular they rated being able to get outside whenever they wanted and the flexibility of the care routines higher (Gnanamanickam *et al* 2018).
- A 68% lower rate of being admitted to hospital. Hospitalisations are associated with both poor outcomes for residents and higher costs to government. Reasons for the lower hospitalisation rates in the domestic-style homes are not known. It may be due to differences in advanced care planning or within facility out-of-hospital healthcare services.
- A 73% lower chance of an emergency department presentation, and
- A 52% lower chance of being prescribed a potentially inappropriate medication (medications where the

potential harm may outweigh the potential benefit) (Harrison *et al* 2018b). In particular, they were less likely to be prescribed psychotropic medications, including antipsychotics, antidepressants and benzodiazepines (Harrison *et al* 2018a).

Total running costs for the aged care homes were similar, but after adjustment for differences in the participants (such as their cognitive abilities and mobility) and location etc of the homes it was estimated that caring for the residents living in the home-like settings in a standard aged care home would have cost approximately \$13,000 more per person per year (Dyer *et al* 2018). This, however, does not capture any additional capital costs of the build, so further work is needed to investigate alternative financing options and the potential economic impact of this.

Conclusion

The INSPIRED study found that providing a home-like clustered domestic model of care which encourages independence for residents in Australia was associated with better quality of life, fewer hospitalisations and less exposure to potentially inappropriate medications, without any increase in facility running costs. In particular, these models of care were also rated as providing a higher consumer-rated quality of care, indicating that it is a preferred model by residents and their families.

The findings of fewer hospitalisations and emergency presentations with the home-like model of care in our study are consistent with reports of lower hospital readmissions and lower spending on Medicare per resident with the Green House small-home model of residential aged care in the US (Grabowski *et al* 2016).

However, the INSPIRED study involved a single provider for the home-like model of care and whether these benefits can be maintained consistently across other providers and in longitudinal studies requires

further work. Nevertheless, the promising results seen in this Australian study indicate further investigation into funding arrangements that reward providers of models of care that deliver benefits for residents is warranted.

The Flinders University team is currently conducting a Cochrane Collaboration systematic review to examine the body of evidence that currently exists on the impact of the physical environmental design of residential aged care homes on resident quality of life (Harrison *et al* 2017). Further research aiming to make evidence-based choices about ways to improve the quality of life of people living with dementia in residential care should be a priority and involving those living with dementia in this research is critical. However, the current system creates significant barriers to the conduct of such research and systems need to be streamlined to facilitate further research to better inform optimal models of care for people living with dementia in residential care homes. ■

The study, *Cluster models of residential aged care are associated with fewer hospitalisations and better quality of life: an Australian cross-sectional study*, was published in the *MJA* (4 June, 2018): <https://bit.ly/2MLHkVZ>

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Challenges with gaining ethics approval

We found the challenges of conducting this research were considerable. Summarised by the phrase ‘nothing about us without us’, people living with dementia emphasise the importance of meaningful involvement in research. This enriches research with the perspective and experience of people living with dementia every day (Alzheimer’s Australia 2010). The World Health Organisation has stated that mechanisms that assist people with dementia, families and carers to participate in dementia research should be in place (World Health Organisation 2017).

However, the hurdles to be overcome in achieving this in our research were considerable. Progress of the INSPIRED study required 13 separate ethics approvals from seven different ethics committees. In addition, governance approvals were required from data custodians in each state and each aged care organisation participating in the study. To obtain data on participant hospitalisations, approval was required from both the relevant state Department of Health and the relevant data custodians.

In recent years significant progress has been made towards harmonisation of ethics approvals for much research across jurisdictions. The National Health and Medical Research Council has established a national approach to recognition of a single ethics and scientific review of multi-centre human research across Australian jurisdictions. All states and territory health departments (except the Northern Territory) have now agreed to National Mutual Acceptance (NMA) of ethics and scientific review of research conducted in public health organisations. Originally covering clinical trials only, the scope of NMA now includes all human research.

This study however was not eligible for single ethical review as it was not within the scope of NMA. Moreover, jurisdiction-specific

laws that impose consent and proxy decision-making rules must still be followed despite NMA (Ries *et al* 2017). Therefore, despite being much less invasive than a randomised trial involving clinical intervention, requiring only completion of questionnaires and access to participant records, it was necessary to submit multiple ethics applications across multiple jurisdictions.

In Australia, different states and territories have their own laws governing personal and substitute decision making for people with cognitive impairment. These laws vary between jurisdictions, and can be more stringent than the requirements of the National Statement on Ethical Conduct in Human Research (Ries *et al* 2017). The interpretation of legislation by different ethics committees added further complexity and multiple responses, legal advice and re-submissions were required for all applications.

Inconsistent legal frameworks across Australia can create a barrier which may discourage or even prevent further national-level dementia-related research, and inappropriately prevent people with dementia from participating. Such research is critical if we are to have evidence-based approaches to improve the quality of care and outcomes for people living with dementia.

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Members of the INSPIRED study research group at Flinders University (clockwise from back left) Professor Julie Ratcliffe, Professor Maria Crotty (AJDC co-author), Dr Stephanie Harrison (co-author), Dr Emmanuel Gnanamanickam, Dr Rachel Milte, Dr Suzanne Dyer (co-author), and (inset) co-author Dr Wendy Shulver

RESEARCH NEWS



Briana Lees reports on the latest published dementia research from Australia and around the world

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Optimal temperature in residential care

Australian researchers undertook a study of thermal comfort in aged care homes to determine what temperature variations residents were living with and what their temperature perceptions and preferences were. Prior to this study there has been very little research into how residents of aged care facilities perceive their thermal environment and a lack of guidelines for thermal conditions for the aged care sector.

Data was collected for this study from five residential care homes in NSW during the warm spring-summer season as well as during the cold autumn-winter season. Staff members, volunteers, residents and visitors of the five homes were included in the study. A total of 509 participants, including 322 residents, completed a questionnaire which included questions about their awareness of the temperature in the home, their preferences and any behavioural adjustments they made to improve thermal

comfort.

The researchers concluded that a comfort band between 20°C and 26.2°C would appear to be appropriate and desirable for residents living in aged care facilities. However indoor air temperatures in the participating facilities were found to range between 17.2°C and 31.6°C. During the warm season, 53% of residents and 40% of non-residents were exposed to temperatures colder than those recommended by usual thermal comfort standards for summer clothing.

In the warm season, residents were most comfortable at 22.9°C and non-residents were most comfortable at 22.0°C. In the cold season, non-residents were most comfortable at 21.2°C.

Linear regression analyses indicated that during the warm season, 23.2°C was the preferred temperature for residents and 21.7°C was the preferred temperature for non-residents. In the cold season, 21.5°C was the preferred temperature for non-residents.

Data were not available to calculate the most comfortable temperature or preferred temperature for residents during the cold season.

Behavioural adjustments were found to be effective at improving thermal comfort. These included layering clothing and changing indoor air velocity by opening windows or using fans.

This study provides temperature recommendations for residential care homes in the warm and cold seasons and offers strong evidence that these facilities should be designed and operated to provide appropriate indoor thermal environments that ensure occupants are not exposed to colder or hotter temperatures than those recommended. Staff members should be trained to provide good thermal care to residents.

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'Wandering' in the community

This narrative review reported on wandering* among people with dementia who are cared for in the community. The Australian researchers reviewed nonpharmacological intervention studies that reported outcome measures of wandering characteristics (eg frequent ambulation, pacing and boundary transgression) or those deemed to be at risk of outcomes associated with wandering behaviour (eg weight loss, injury from falls or becoming lost).

Eleven studies were included. The interventions focused on engaging the person in an activity, improving safety with environmental modifications and technology to improve navigation or monitor movement.

Engaging activities that are meaningful to the person were found to reduce the intensity of wandering. Massage and aromatherapy did not impact restlessness, pacing or walking.

Visual barriers that disguised doorways appeared to reduce entry into out-of-bound areas, while visual grids on the floor, to minimise entry, were not effective. There was some evidence that smart home technology may reduce night-time walking and injury from falls.

The review identified promising interventions but further investigation is needed using larger samples.

MacAndrew M, Brooks D, Beattie E (2018) Nonpharmacological interventions for managing wandering in the community: a narrative review of the evidence base. *Health And Social Care In The Community* 1-14.

*** Editor's Note:** While the *AJDC* acknowledges there is ongoing debate over the use of terms such as 'wandering' (along with others such as 'managing behaviour' and BPSD or 'behavioural and psychological symptoms of dementia') in relation to people with dementia, our current editorial policy is to continue publishing articles that include these terms when it is clear they are used in the context of the research or practice being described and the author's intent is to promote person-centred care.

Risk and the impact of dementia-related behaviours

UK researchers explored how residential care home staff manage dementia-related behaviours, interviewing 40 care home staff and completing 384 hours of participant observation.

The authors found that some people with dementia experience behaviours which can create risks for themselves and other residents or staff members. These behaviours included aggression, agitation, anxiety, wandering*, calling out and sexual disinhibition.

To manage the risk and impact of these behaviours, staff

employed multiple strategies such as person-centred care and individualised interventions, which are endorsed as effective approaches by the current research evidence base. However, other strategies were also used, including surveillance, restrictions, resident placement and forced care, which can negatively affect the human rights of people with dementia.

The authors conclude that balancing care practices between safeguarding and liberty is difficult in communal settings where there is a duty of

care for all residents. A limitation of this study is that it did not assess the effect of these practices on the residents who were experiencing the behaviours or others in the residential care home. Additional strategies, guidance and training, and staff assistance for risk mitigation is an area of research requiring immediate attention.

Backhouse T, Penhale B, Gray R, Killeit A (2018) Questionable practices despite good intentions: coping with risk and impact from dementia-related behaviours in care homes. *Ageing & Society* 38(9) 1993-1958.

Communicating a dementia diagnosis

This Australian study reviewed practices and attitudes towards communicating a diagnosis of dementia. A total of 24 quantitative and 21 qualitative studies were included in the review.

Pooled analyses showed that 34% of General Practitioners (GPs) and 48% of specialists routinely told the person with dementia their diagnosis and 89% of GPs and 97% of specialists routinely told the family the diagnosis.

The practitioner's decision to diagnose and communicate the diagnosis of dementia to the person and their family

was influenced by:

- Their own beliefs regarding dementia and treatment efficacy.
- Their confidence in the diagnosis and their ability to communicate the diagnosis.
- Patient circumstances, including the patient's level of awareness, the severity of their symptoms and level of family support.
- Access and availability of services and specialists for the patient.
- Cultural norms in relation to dementia including stigma and common clinical practice.

The authors conclude that to improve practitioners' confidence in communicating dementia diagnoses, interventions should be developed that include guideline development, practitioner education, anti-stigma public health campaigns, support and sufficient practitioner reimbursement for time spent managing patients with dementia.

Low L-F, McGrath M, Swaffer K, Brodaty H (2018) Communicating a diagnosis of dementia: a systematic mixed studies review of attitudes and practices of health practitioners. *Dementia* 0(0) 1-50.

Recognition and carer health: Researchers in Italy evaluated the impact of the perception of being recognised by a person with Alzheimer's disease on a carer's psychophysical health. They also examined the level of burden reported in these caregivers.

A total of 31 caregivers and people with Alzheimer's disease were interviewed for this study. The Caregiver Burden Inventory (CB), the Short-Form Health Survey and a visual analogue scale were given to caregivers. People with Alzheimer's disease completed the Mini-Mental State Examination (MMSE).

Increased perception of being recognised was associated with decreased total burden and

objective burden among caregivers. It was also associated with higher MMSE scores in people with Alzheimer's disease.

Linear regression models revealed that the perception of not being recognised by the person with Alzheimer's disease predicted a higher level of objective burden in the caregiver, while the level of cognitive impairment in the person with Alzheimer's disease did not predict the level of objective burden in the caregiver.

Lai C, Cipriani M, Renzi A, Luciani M, Lombardo L, Aceto P (2018) The effects of the perception of being recognised by patients with Alzheimer disease on a caregiver's burden and psychophysical health. *American Journal of Hospice & Palliative Medicine* 35(9) 1188-1194.

What is a 'timely' diagnosis?

This Australian study explored the preferences of consumers regarding when a diagnosis of dementia should be communicated.

A cross-sectional survey was conducted using an iPad with adults in the waiting room of an outpatient clinic in an Australian hospital. The survey included questions about socio-demographic status and their experience with dementia.

Eligible participants for this study were people aged over 18 years who had attended an outpatient appointment as a patient or person accompanying a patient and they spoke sufficient English to complete the online survey.

A total of 446 participants completed the survey. Immediate disclosure of a personal dementia diagnosis was preferred by 92% of people. Similarly, 88% of people preferred immediate disclosure of their spouse or partner's dementia diagnosis. There was very high correlation (0.91) between preferences for self and preferences for their spouse. Overall, preferences were not associated with socio-demographic characteristics or previous dementia experience.

Given the sample was recruited from a regional hospital and only English-speaking participants were included, the views of consumers from culturally and linguistically diverse backgrounds may not be well represented in this study.

These findings provide guidance to health care providers about preferences for disclosure of a dementia diagnosis and may help to overcome potential barriers to timely diagnosis.

Watson R, Bryant J, Sanson-Fisher R, Mansfield E, Evans T-J (2018) What is a 'timely' diagnosis? Exploring the preferences of Australian health service consumers regarding when a diagnosis of dementia should be discussed. *BMC Health Services Research* 18 612.

Family dynamics and distress

Australian researchers examined the specific ways that family dynamics contribute to adult primary caregivers' distress in the context of caring for a parent with dementia.

Semi-structured interviews were conducted with 17 adult primary caregivers for a mother or mother-in-law with dementia who was living in the community. Caregivers ranged in age from 36 to 70 years.

Interviews were analysed using thematic analysis. Four themes were identified that represented areas of particular concern and distress for the caregivers:

The role of primary caregiver was often given to the person in the family who was perceived

to have the greatest amount of time, closest proximity and highest capacity for care-giving duties. The care-giving role often caused feelings of obligation, distress and resentment towards their family.

Some caregivers felt that a major challenge of their role was related to other family members' inability to accept the diagnosis of dementia. Denial and differential understandings of dementia among family members contributed to caregiver distress because they often resulted in conflict and tension.

Caregivers found that other family members often had different views and approaches

on how the parent with dementia should be cared for and this would cause conflict and distress for the caregiver.

Many caregivers felt that miscommunication between family members regarding the care for the parent with dementia caused additional stress for them.

Further research into the development of interventions to support adult caregivers is required.

Tatangelo G, McCabe M, Macleod A, Konis A (2018) I just can't please them all and stay sane: adult child caregivers' experiences of family dynamics in care-giving for a parent with dementia in Australia. *Health and Social Care in the Community* 26(3) e370-e377.

Online

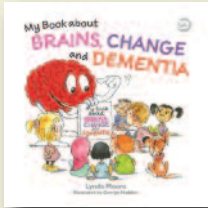


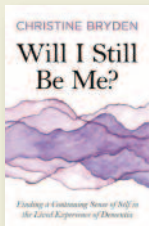
Dementia Australia has published a 24-page guide, **LGBTI and dementia**, to increase awareness about what information and support is available to people living with dementia who are lesbian, gay, bisexual, transgender or intersex (LGBTI). The guide sets out what sort of help is available and how to access it, via NDIS or My Aged Care. It is structured as a series of basic questions (such as 'What do I look for when choosing an LGBTI inclusive service provider?', 'How is the privacy and confidentiality of people who are LGBTI protected?', and 'How are the rights of people who are LGBTI protected?') with the answers set out below each question. The suggestions included in the resource are based on research conducted by Dementia Australia and feedback from people who are LGBTI. The free guide is available to download from the Dementia Australia website.

Do I see what you see? is a new animated film about Posterior Cortical Atrophy (PCA) directed by Simon Ball in partnership with the Alzheimer's Society (UK). The eight-minute film features contributions from six people living with PCA and their partners. It's an output from the interdisciplinary Created Out of Mind project, which has been based at the Wellcome Collection in London since October 2016. The contributors explain how everyday tasks such as making a cup of tea, reading, driving and walking down stairs

Books

My book about brains, change and dementia aims to explain dementia to children who are aged four and above. The new 48-page book is written by Lynda Moore and colourfully illustrated by George Haddon. It explains what happens to the brain when a person has dementia and how to help if someone we know has dementia, drawing on age-appropriate language and a diverse collection of characters to do so. The book emphasises that anyone can be touched by dementia, and that it's important to be open and honest when talking about the challenges raised. It's published by Jessica Kingsley Publishers and available in Australia from Footprint Books for \$22.99 plus postage (go to www.footprint.com.au).





Australia's Christine Bryden has written a new book, **Will I still be me?**, subtitled 'Finding a continuing sense of self in the lived experience of dementia', and published in August 2018 by Jessica Kingsley Publishers. Bryden shares her experience of living with dementia and argues that a continuing sense of self is possible after diagnosis and as the condition develops. The book considers what it means to be an embodied self with feelings and emotions, how individuals can relate to others despite cognitive changes and challenges to communication, and what this means for the inclusion of people with dementia in society. It is available to purchase in Australia via Footprint Books for \$27.99 plus postage (www.footprint.com.au).

are fraught with challenges for people living with PCA. The film drew on extensive input from Created Out of Mind Director and UCL neuropsychologist Sebastian Crutch. It's available to view on the project's website, www.createdoutofmind.org

My faith matters is a new 14-page resource to support the spiritual journey of people living with dementia. It is intended to be used by churches as they support people with dementia who identify as having a faith, as well as those who do not. The resource sets out 11 items that can be completed with the person with dementia (such as 'About me', 'My daily routine', and 'Things that bring me peace and hope'), as well as short lists of suggested questions that can be used to prompt conversation about each of the items. The booklet includes thoughtful tips and ideas for putting the resource to good use. It has been produced by the UK charity Livability, and is available to download for free from its website: www.livability.org.uk

Dementia Australia has expanded its range of help sheets available in other languages. Its popular '**Tips for visiting**' and '**Tips for friends**' help sheets give suggestions for

supporting social engagement, are aimed at relatives and friends of people living with dementia, and have now been translated into Cantonese, Hindi, Japanese, Khmer, Mandarin, Nepalese, Punjabi, Tagalog, Arabic and Thai. The resources are available on Dementia Australia's website at www.dementia.org.au/languages

The Cognitive Decline Partnership Centre (CDPC) at the University of Sydney has been working on a project investigating **supported decision-making for people living with dementia**. During August 2018 the project team hosted three hour-long webinars on this topic – the first two are available to view online now. Webinar 1 was on **human rights, dementia and supported decision-making**. Webinar 2 was on **supporting decision-making for people with dementia**. The final Webinar 3 was on **supported decision-making for aged care providers**. For more information, look on the CDPC website at <http://sydney.edu.au/medicine/cdpc/>

The Race Equality Foundation in the UK has published a 12-page briefing paper on **Dementia and minority ethnic carers**,

summarising what is known about the issues facing minority ethnic carers of people living with dementia. The paper looks at specific issues for these carers – assumptions about caring roles, the nature of family care, barriers to support for carers, carer coping strategies, and the negative impact of caregiving – and also considers the implications of these findings for policy and practice. The paper can be found on the foundation's website.

Exercise for seniors is a new four-minute video from Home Instead Senior Care aimed at showing people over 65 how to move, mobilise and maintain fitness. The film shows personal trainer Michelle Bridges explaining and demonstrating how to do a series of simple exercises. It's available to view for free on Home Instead's website.

Dementia Alliance International (DAI) used World Alzheimer's Month (WAM) in September to share the stories of DAI members around the world. The DAI website features the series of blogs, called **#Hello my name is**. Each day a different DAI member shared their story of living with dementia, with some posts including public

presentations made by the DAI member. Available at: www.dementiaallianceinternational.org

The Centre for Cultural Diversity in Ageing has launched two new directories to benefit consumers and staff in the aged care sector. The **Bilingual staff directory** allows consumers to search for aged care services employing bilingual staff, and a **Bilingual agency staff directory** lists agencies with bilingual staff who can be engaged by aged care providers to help match languages spoken by their consumers. Both directories are available on the centre's website: www.culturaldiversity.com.au

Researchers at the University of Nottingham have worked with cartoonist Tony Husband to produce **Winston's world**, a colourful and engaging training resource on dementia for home care workers. The 90-page book is set out in five chapters, with each chapter telling an everyday story of life with dementia, featuring a cast of fictional characters, including Winston the cat, two women living with dementia (Janet and Freda) and Daisy, a home care worker. Every scenario has been developed to offer a focus for reflection and discussion, with prompt questions to stimulate individual reflection or small-



group discussion. **Winston's world** is based on a study called Broadening Our Understanding of Good Homecare (BOUGH), which was managed at the University of Nottingham in the UK in 2016/17 by Justine Schneider. The drawings are the work of Husband in response to a narrative written by Schneider. A PDF of the resource can be viewed at <https://idea.nottingham.ac.uk/resources/winstons-world> and downloaded for free. The resource is also available to purchase as a printed document – for details see above link.

Education and training provider **Kaplan Professional** has teamed up with Dementia Australia to develop education resources on dementia aimed at financial advisers. The resources will be available on Kaplan Professional's online professional development platform, Ontrack, and are designed to help financial advisers understand the impact of dementia on the person living with the condition and their wider family.

Global estimates of informal care, a new report from Alzheimer's Disease International (ADI) and the Karolinska Institutet in Sweden, shows that women continue to be disproportionately affected by dementia, as they provide 71% of informal dementia care hours globally. The ADI report estimates that the annual global number of informal care hours provided to people with dementia living at home is about 82 billion hours, equating to 2089 hours per year or six hours per day. This is the equivalent of more than 40 million full-time workers, a figure that will increase to 65 million full-time workers by 2030. The ADI report concludes that employers and labour laws need to adapt to the increasing numbers of employees with a caregiving role as the number of people living with dementia increases globally. The report's findings are based on analysis of extracts from the database that were used in the 2010 and 2015 World Alzheimer Reports. The report is available to download from the ADI website.

The Organisation for Economic Cooperation and Development (OECD) has published a report entitled **Care needed: improving the lives of people with dementia** which presents new data on the quality of

dementia care in the 36 OECD member countries. The 161-page report presents a detailed look at how OECD countries currently care for people with dementia, from when they receive a diagnosis through to the end of their lives. The report concludes that most countries remain poorly equipped to identify dementia, initiatives to make communities inclusive and safe for people with dementia are fragmented, and that the quality of care for people with advanced dementia is often poor and can result in worse health outcomes. It found that most health systems have very poor data on dementia care, and recommends that countries work to strengthen the measurement of quality and outcomes of dementia care. The report is available to read on the OECD website.

Cancer and dementia: a guide for carers is an information leaflet from Admiral Nurse charity Dementia UK that explains the basics of each condition and then looks at topics including the benefits and disadvantages of treatment, issues of consent and capacity, helpful tips for attending GP and hospital appointments, Advance Care planning and care options. It's free to download at: <https://bit.ly/2OkF19i>

Events

■ 9-10 October 2018 – VIC

Embolden

A conference for service providers and older people: respecting elders; challenging ageism, preventing elder abuse; building an age-friendly world. Presented by Celebrate Ageing, in Melbourne. Details: www.celebrateageing.com/embolden.html

■ 28-30 October 2018 – SA

LASA National Congress 2018

Australia's largest aged service industry event, presented by Leading Age Services Australia, in Adelaide. Details: www.lasacongress.asn.au

■ 11-14 November 2018 – NSW

11th International Conference on Frontotemporal Dementias

In Sydney. Details: www.icftd2018.org.au

■ 21-22 November 2018 – NSW

Building A Quality Aged Care Workforce

Presented by COTA, in Sydney. Details: <https://bit.ly/2M73FYX>

■ 21-23 November 2018 – VIC

51st AAG Conference: Advancing Not Retiring

Hosted by the Australian Association of Gerontology (AAG), in Melbourne. Details: <https://bit.ly/2oMJuGs>

■ 27-29 November 2018 – NSW

4th Dementia Care Delivery Summit: Transforming Dementia Care For Quality of Life

Presented by Akolade, in Sydney. Details: <https://bit.ly/2oMXnUZ>

■ 27-29 November 2018 – NSW

3rd Australian Future of Aged Care Summit: The Next Wave in Consumer Care Innovation

Presented by Akolade, in Sydney. Details: <https://bit.ly/2wWGkEr>

■ 22-23 February 2019 – QLD

Occupational Therapy Australia National Aged Care Symposium: Respect: Relate: Renew

Presented by Occupational Therapy Australia, in Brisbane. Details: www.otausevents.com.au/agedcare2019

■ 28-29 March 2019 – NSW

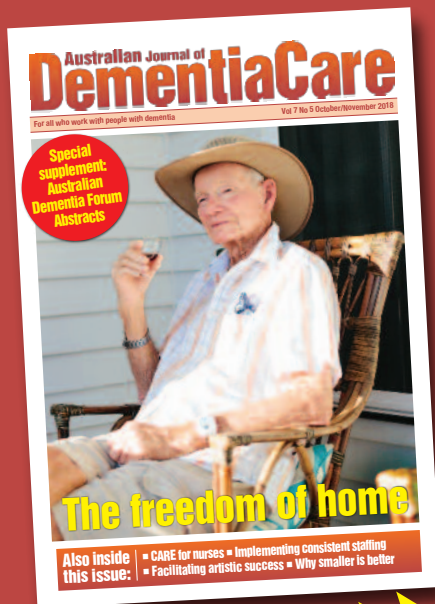
The RED Conference: A Regional Experience in Practical Dementia Care

Presented by Omnicare, in Port Macquarie. Details: www.red.omnicare.org.au

Details of more events at www.journalofdementiacare.com

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