

Australian Journal of **DementiaCare**

For all who work with people with dementia

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Measuring the quality of care

**Also inside
this issue:**

- Supported decision-making
- The Tailored Activity Program
- Connecting rural carers
- Responding to 'dementia doubters'

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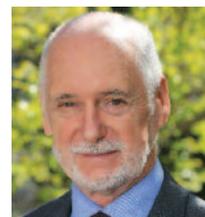
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Changing times

By **Professor Richard Fleming**, Executive
Editor, *Australian Journal of Dementia Care*



A lot of us are waiting...waiting to see what is going to happen in the aged care sector over the next 12 months. Almost everyone is, or has recently been, or soon will be, under some form of scrutiny. The NHMRC National Institute for Dementia Research, Dementia Training Australia (DTA) and the Dementia Behaviour Management Advisory Service (Dementia Support Australia) are all undergoing evaluation. The Dementia Centre for Research Collaboration has recently emerged from an evaluation of the three Dementia Collaborative Research Centres. There have been investigations into various issues in residential aged care, reviews of the aged care workforce and new aged care standards promoted. And, of course there is the Royal Commission into Aged Care Quality and Safety that will begin in early 2019.

It is hard to imagine that by the middle of 2019 there will be anyone in the aged care sector who will not have been involved in some form of evaluation of their service.

Is there a common thread to these evaluations, some common direction emerging from their concerns? In the case of services for people with dementia there are some common themes that are gaining strength. They have been around for a while but are now becoming dominant.

The most obvious is the strengthening of the voice of the people who are living with dementia. There is an insistence that their voice is heard in the selection of research topics and the design and implementation of research. It is occurring in the involvement of people living with dementia and their families in the evaluation of the effectiveness of training delivered by DTA. It can be seen in the conduct of the Australian Aged Care Quality Agency, which is now very interested in the views of residents on the care that they are receiving.

This is related to another theme, a move away from a problem-oriented approach towards a more holistic approach aimed at providing opportunities for people living with dementia to lead as full a life as possible.

A clear sign of the strength of these themes can be seen in the recognition of them in the world outside of dementia care. Kate Swaffer, probably the best-known advocate for people living with dementia in Australia and a person with a diagnosis of dementia, was recently included in the *Australian Financial Review's* list of 100 Women of Influence. Kate's advocacy is for the recognition of the rights of people living with dementia to enjoy the whole range of human rights available to every citizen; rights that include the opportunity to take risks and not to be indefinitely detained against their will.

These themes of listening to the 'consumer' (and acting on their views) and taking a broader view of the goals of our services seem to me to be central to the changes that have begun and are likely to be consolidated by the findings, recommendations and changes arising from these reviews and evaluations.

However, these changes will not come easily. The article by Kate Swaffer in this issue of the *AJDC* illustrates some of the problems that are being encountered in moving towards a system where the voices of people living with dementia are taken seriously.

There are also going to be practical problems. A lot of people are tired of being scrutinised, evaluated and continuously found wanting. The aged care workforce is itself ageing and many of the people in it are looking at the current round of evaluations and reviews and saying 'enough is enough'. They don't want to go through it all again and they are choosing to call it a day.

The question is, will this departure of the old guard clear the way for a more progressive paradigm or are we losing our most skilled people? We won't know the answer for some time yet, but what is quite clear is that we would stand a better chance of retaining the best people if their contribution was recognised by improvements in their status and conditions, some more attention to the good news stories and greater celebration of the high-quality care that can be found in Australia. ■

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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Cover image: Finding ways to measure and improve the quality of care and support that residents receive led The Whiddon Group to trial a new and innovative use of the ASCOT tool in care planning. See article pp31-35. Photo courtesy The Whiddon Group



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Inquiry reports on quality of residential aged care

Ensuring one registered nurse is on site at all times in residential aged care facilities, a review of the Aged Care Funding Instrument (ACFI), and a rating system for aged care facilities are just three of the 14 recommendations made by a Standing Committee following its Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia.

The Health, Aged Care and Sport Committee inquiry was set up at the request of Minister for Health Greg Hunt in December 2017 to examine the delivery and regulation of the current aged care system, the prevalence of mistreatment, and the adequacy of current consumer protection arrangements.

The inquiry received 123 submissions, involved seven public hearings and presented its final 173-page report on 22 October.

In his foreword, Committee Chair Trent Zimmerman MP said that some recurring issues raised during the inquiry were

the complexity of the current system, a reluctance or inability to raise concerns or make complaints regarding the quality of care, and an overall lack of consumer focus.

He said the inquiry had received submissions outlining “harrowing experiences” within aged care facilities and that, “This is simply not acceptable in a nation like Australia”.

Overall, the report concludes that there are “major deficiencies” within the aged care sector.

The report’s recommendations relate to a wide number of issues, including restrictive practices, transparency around complaints information, and access to advocacy.

Its final recommendation is that, “Australian Government agencies responsible for the delivery of aged care services commit to a more consumer-oriented focus, with greater, and more transparent, consumer involvement in the delivery of aged care services”.

Scrutiny on staffing ratios

The same Standing Committee on Health, Aged Care and Sport commenced an inquiry on 14 September into the Aged Care Amendment (Staffing Ratio Disclosure) Bill 2018.

The bill proposes quarterly reporting by aged care providers on the ratio of aged care recipients to aged care staff, including the breakdown of staff by category and level, and further reporting within 28 days if a 10% adjustment to these ratios occurs within

a quarter period.

The private member’s bill was introduced into the House of Representatives in August by Rebekha Sharkie MP, who has since been appointed as a supplementary member of the Committee for this Inquiry.

Submissions closed in October and have now been published on the inquiry’s web pages (www.aph.gov.au). Dementia Australia supports the bill, but a number of care providers expressed concerns.

Neck scan ‘could predict dementia risk’: A five-minute neck scan could offer a new way to predict cognitive decline before symptoms appear, say a team of international researchers led by University College London. They used ultrasound scanners to look at blood vessels in the necks of more than 3000 people in 2002 and monitored their memory and problem-solving ability over the next 15 years. Those with the most intense pulses at the start of the study were about 50% more likely to show accelerated cognitive decline over the next 10 years than other study participants. The researchers said the test could provide a new way to identify people at risk of developing dementia, leading to earlier treatments and lifestyle changes. The study was presented at the American Heart Association’s Scientific Sessions Conference in Chicago in November.

News in brief

Committee reviews workforce skills, standards

A new committee – the Aged Services Industry Reference Committee (IRC) – has been set up to review and develop national competency standards for Australia’s aged care services industry. Minister for Small and Family Business, Skills and Vocational Education, Senator Michaelia Cash, said workforce qualifications and standards were fundamental to quality aged care. “The IRC will work right across the vocational education and training (VET) and higher education sectors to meet the challenges of an ageing society,” Ms Cash said. The IRC, set up by the Australian Industry and Skills Committee (AISC), will progress key findings from the Aged Care Workforce Strategy Taskforce report, *A matter of care*, released by the Federal Government in September. Members of the IRC have now been named, and include consumer advocates, peak industry bodies and employer and employee representatives. The chair is Ian Hardy, CEO of Helping Hand, who is due to retire at the end of 2018. Nine specific interest advisory committees – including one on dementia – will be established to support the IRC’s work by providing strategic and policy advice. To register interest in participating in one of these committees and for more information on the IRC, visit the AISC website at www.aisc.net.au.

Global recognition for Swaffer

Kate Swaffer, Co-Founder, Chair and CEO of Dementia Alliance International (DAI), has won the ‘Global’ category in the *Australian Financial Review’s* ‘100 Women of Influence 2018’ awards, announced in Sydney on 17 October. In her role with DAI, Ms Swaffer, who is living with younger onset dementia, has worked with the World Health Organisation and the United Nations to create social change by demanding human rights and access to the Convention on the Rights of Persons with Disabilities (CRPD) for people with dementia and their families worldwide. Ms Swaffer is also an author, speaker and academic. She was one of 11 women to receive awards – one for each of 10 categories and one overall winner (Megan Davis, the UNSW Pro-Vice Chancellor). **See Kate Swaffer’s article on p21 of this issue of AJDC**

Grant applications open

Grant applications are now open to access \$18 million in funding for dementia research – the final tranche of funding within the \$200 million Boosting Dementia Research initiative, launched in 2015. \$15 million is to go towards Implementing Dementia Risk Reduction and Prevention Research projects (Priority Round 5), and \$3 million is for research on Improving Dementia Data and Methods (Priority Round 6). Applications for both rounds close on 19 December 2018. For more information, go to the NHMRC website.

New Muslim aged care facility

Gallipoli Home, which describes itself as the “first aged care home in Sydney dedicated to serving the needs of our Muslim and culturally diverse elders”, opened its doors to its first residents on 2 July and was formally opened on 14 October. The 102-bed residential facility is located next to the Gallipoli Mosque, and came about in response to needs identified by the Mosque and seven cultural associations in Sydney. The home plans to employ staff who speak Turkish, Arabic, Hindi, and Urdu to be able to cater for over 10 different cultural communities.

Dementia awareness

New survey findings from Dementia Australia suggest that although Australians are aware of dementia and its associated challenges, they are still unsure about how to support or communicate with someone living with the illness. The national online survey of over 1500 people found that 80% had heard of dementia and 66% were able to correctly describe at least one symptom of the disease. However, 44% said that they were unsure how to talk to someone with dementia and 25% indicated that they were uncomfortable around people with dementia. The survey report, *Inclusion and isolation: the contrasting community attitudes to dementia*, is available on the Dementia Australia website (www.dementia.org.au).

Royal Commission into Aged Care

The question of how to best deliver care to people living with dementia has been identified specifically in the Terms of Reference for the Royal Commission into Aged Care Quality and Safety. The Royal Commission was announced in September, the day before ABC aired the first of a two-part *Four Corners* investigation into the treatment of the elderly in aged care homes.

Prime Minister Scott Morrison announced the Terms of Reference after the Government convened four roundtables and received over 5100 submissions on the matter from consumers and family carers, care workers, health professionals and providers.

He also announced that Justice Joseph McGrath and Lynelle Briggs AO have been appointed as the Royal Commissioners. Justice McGrath is a judge of the Supreme Court of Western Australia. Ms Briggs is a former Australian Public Service Commissioner.

The Royal Commission's Terms of Reference include:

- Quality and safety including the extent of substandard care.
- How to best deliver care services to people with disabilities residing in aged care facilities, including younger people.
- How to best deliver care to the increasing number of Australians living with dementia.
- The future challenges and opportunities for delivering accessible, affordable and high-quality aged care services, including people's desire to remain living at home as they age, and aged care in rural, regional and remote Australia.
- What the Government, the aged care sector, Australian families and the wider community can do to strengthen care services to ensure quality and safety.

- How to allow people greater choice, control and independence and how to improve engagement with families and carers.
- How to best deliver sustainable aged care services through innovative care and investment in the aged care workforce and infrastructure.
- Any matters that the Commissioners believe are relevant to their inquiry.

Mr Morrison described the Royal Commission as "...a vital step for Australia to

determine the full extent of the problems in aged care and to understand how we can meet the challenges and the opportunities of delivering aged care services now and into the future. It is also about helping to build a national culture of respect for ageing and our senior Australians".

The Prime Minister stressed that the Royal Commission would be an additional undertaking from the Government – and would not replace the planned aged care reforms that are underway.

"As the Royal Commission

goes about its critical work, our rigorous policing and reform program will continue at full pace with the new Aged Care Quality and Safety Commission, upgraded Aged Care Quality Standards and record levels of funding support for older Australians. There will be absolutely no compromise on the safety and quality of aged care," he said.

The Royal Commission will be based in Adelaide. Its interim report is to be provided by 31 October 2019, and final report no later than 30 April 2020.

Sector reactions

Dementia Australia applauded the "elevated focus" on dementia and younger people in aged care within the Royal Commission's Terms of Reference. Dementia Australia CEO Maree McCabe said with 70% of people living with dementia residing in the community and around 50% of those in residential aged care with a diagnosis of dementia, the Terms of Reference highlight that dementia must be acknowledged as core business for aged care.



From left: Maree McCabe, Ian Yates and Pat Sparrow

"Whilst it is evident there are systemic deficiencies and challenges in aged care around staffing, education and the capacity to provide quality of care, it is encouraging that quality and safety are paramount in these Terms of Reference," Ms McCabe said.

The Australian and New Zealand Society for Geriatric Medicine (ANZSGM) welcomed the announcement of the Royal Commission, saying it would be arguing for a strong focus on an assessment of the adequacy and quality of medical care provided to older people living in residential aged care facilities.

ANZSGM President Associate Professor Edward Strivens said, "There is a high level of unnecessary use of psychotropic medicines, which include antipsychotics, to manage people with dementia."

COTA Australia Chief Executive Ian Yates warned that, "The Government must not sit on its hands and use it [the Royal Commission] as an excuse not to act on the most urgent reforms".

COTA Australia said the Royal Commission must investigate an appropriate range of penalties for neglect, excessive restraint and abuse in residential aged care and the need for more effective monitoring of staff, including the use of CCTV cameras.

Aged & Community Services Australia (ACSA) said the scope of the Royal Commission will encourage a wide-ranging and constructive national discussion on the future of quality services for Australia's ageing population.

ACSA CEO Pat Sparrow said, "It is pleasing to see the Terms of Reference acknowledge the need to look into all aspects of aged care; issues specific to remote, rural or regional areas; caring for those with chronic or complex health needs like dementia, as well as hearing from younger people with disabilities living in residential care."

More information is available on the Royal Commission into Aged Care's website at <https://agedcare.health.gov.au/royal-commission-into-aged-care-quality-and-safety>.

Anderson to lead new Quality Commission

Janet Anderson will lead the new Aged Care Quality and Safety Commission (ACQSA).

Ms Anderson comes with extensive management experience working across all levels of government, in particular in health policy, including her recent position as Deputy CEO of the NT Department of Health.

She will oversee the approval, accreditation, assessment, complaints resolution, monitoring and compliance of Commonwealth-funded aged care providers, reporting directly to Minister for Senior Australians and Aged Care Ken Wyatt.

The Minister has also released more detail on the workings of the new

commission, due to begin operations from 1 January 2019.

Mr Wyatt said the commission will have a budget of almost \$300 million over four years, and will employ “dozens of additional senior compliance officers”. Unannounced re-accreditation audits are set to increase from 263 this year to almost 900 in 2019, and unannounced inspections (targeting particular standards, identified risk factors and complaints) are expected to rise to more than 3000.

The Government is describing the new commission as a “one-stop shop” for aged care residents, their families and aged care providers on aged care quality and safety matters.

CHSP boost while waiting list worsens

A select number of targeted Commonwealth Home Support Program (CHSP) care providers are set to receive a share in \$100 million additional Federal Government funding over two years in order to offer more support to older Australians living independently in their own homes.

The new funding was announced in October and will be targeted at five CHSP services marked for growth: domestic assistance, meals, transport, home maintenance, and home modifications. First payments will be made to successful providers in January 2019.

The additional funds were welcomed by the aged care sector, although some organisations used the opportunity to draw attention to newly released data on Home Care Packages for the

final quarter of 2017/18, which found that waiting list numbers have continued to grow.

Maree McCabe, CEO Dementia Australia said, “This extra funding is much needed as the waiting list numbers for home care packages have increased to over 121,000 people in need of urgent support.”

Pat Sparrow, CEO of Aged and Community Services Australia (ACSA), said while it welcomed the new funding it was “alarmed” at the number of people on a waiting list for a Home Care Package.

ACSA and five not-for-profit aged care peak bodies responded to the funding announcement by releasing a statement urging immediate action on reforming home care, and making a number of recommendations for how to do this.

News in brief

New statistics on deaths from dementia

A new report from the Australian Bureau of Statistics – *Causes of death 2017 report* – says that the number of deaths from dementia has increased by 68% over the past decade, with the death rate increasing from 33.1 deaths per 100,000 people in 2008 to 41.6 in 2017. Dementia remains the second leading cause of death in 2017, accounting for 13,729 deaths. An additional 12,301 deaths had dementia recorded as an associated cause of death. The leading cause of death remains ischaemic heart disease, but the number of deaths from ischaemic heart disease has been steadily declining over the past decade.

Dementia in residential care

In 2015, almost half (49.9% or 93,400 people) of all people living in residential aged care had dementia, according to another new report from the Australian Bureau of Statistics, published in November. The proportion of people living in residential aged care with dementia increased with age, from almost one quarter of all men (24.4%) and women (24.2%) aged 50-64 years, to around half of those aged 85 years and over (49.8% of men and 53.6% of women). In addition, aged care residents with dementia were twice as likely as those without dementia to have nine or more impairments (53.4% compared with 23.9%). The findings are drawn from the 2015 ABS Survey of Disability, Ageing and Carers (SDAC) and appear in the ABS report titled *Australians living in residential aged care*.

Still time to cook A Roast To Remember

A campaign to raise \$250,000 to purchase and run a community dementia bus in WA has been extended until the end of December 2018. By early November about \$62,000 had been raised from A Roast To Remember, which encourages people to hold a fundraising roast dinner for friends and family. Community Vision, the charity behind the campaign, is also calling for fundraisers to submit their best roast recipes for a booklet to be launched in 2019 to raise further funds. Staff manning the bus will provide respite breaks and information to carers in the Perth community who don't have immediate access to local dementia services. Details: www.aroasttoremember.com.au

AFTDA to join forces with Dementia Australia

The Australian Frontotemporal Dementia Association (AFTDA) is to join forces with Dementia Australia, in a move that will see AFTDA's carer support groups expand nationally, now managed and delivered by Dementia Australia. AFTDA was established in 2012 and its main focus has been to set up carer support groups for people affected by frontotemporal dementia. AFTDA Chair Ian McRae said that, “Following the Federation of Alzheimer's Australia unifying and changing its name to Dementia Australia in October 2017, AFTDA viewed the change as a positive, inclusive step in broadening the public's understanding of dementia, especially to increase awareness of the less-well-known younger onset dementias, such as frontotemporal dementia.”

Dementia-friendly pharmacies

Priceline Pharmacy chose Dementia Awareness Month in September to announce that it is working to make its 334 pharmacies dementia-friendly – by training its pharmacists and making some physical adjustments to its stores. Black floor mats are to be removed (they may be perceived as a hole in the floor by some people with dementia), and quiet areas set up so that people with dementia can sit down and take a break if they are becoming anxious or disoriented. The changes were due to be completed during October.

Carer recruitment

CQUniversity's Caring for Carers team is working to make it easier for family carers to participate in its free six-week video conferencing support program, which is due to run on multiple occasions during 2018 and 2019. The program is aimed at regional and isolated family carers of people living with dementia. Participants can now simply register themselves online at www.cqu.edu.au/caringforthecarers without needing to scan and attach their ‘consent to contact’ form. Carers do not have to stop any other carer programs or services in which they are involved in order to participate in the program. Caring for Carers is being funded by the Department of Health to evaluate feasibility, acceptability and effectiveness of video conferencing to connect carers with other carers.

Village 'helps couples remain together'

Minister for Senior Australians and Aged Care Ken Wyatt and Aged Care Scalabrini's new state-of-the-art Sydney aged care facility, The Village,



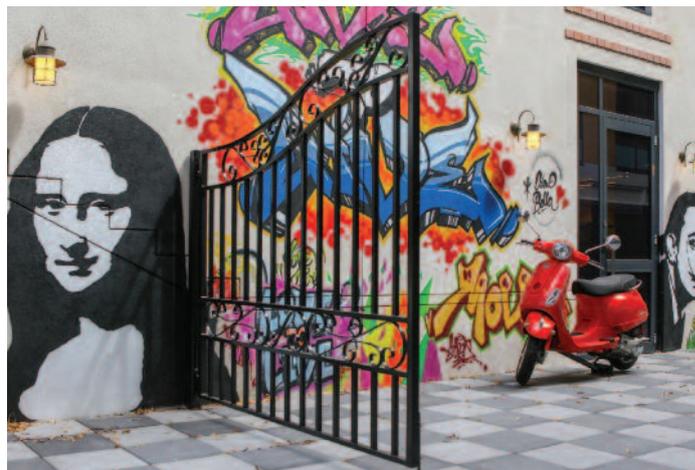
Cutting of the celebratory cake at the opening are (from left) Scalabrini Chairman Professor Leroy Certoma, CEO Elaine Griffin, Provincial Superior Father Delmar Silva, and (front) Pastoral Care Coordinator Sister Maria Elena Figueroa.
Photo: Scalabrini

at the end of September, praising the way it helps couples with dementia remain together.

The Village, in Drummoyne, opened to residents in February 2018, and is specifically designed to support people living with dementia or other complex health care needs. It includes 16 apartments for couples where one partner is living with dementia or has complex health care needs, or for single people with a care need.

"Too often, older couples can be separated when one partner needs higher care because they have dementia," Mr Wyatt said. "Scalabrini has designed an aged care home that is truly homely, helping couples remain together and age in comfort and with dignity."

The community's dementia-friendly design provides a sense of autonomy and familiarity within a safe



A mural in the courtyard at The Village by Scalabrini
Photo: Dementia Training Australia

environment. Residents maintain normal patterns of life, with groups of six to 14 living in individual houses and taking part in a range of activities that meet their interests. Families, friends and neighbours are encouraged to visit.

Mr Wyatt also praised the way The Village delivers aged care to senior Italian-Australians.

The Village by Scalabrini won the Best Aged Care Facility award in the 2018 Australian Healthcare Week Excellence Awards.

WHO's Australian age-friendly mentor

Dr Lyn Phillipson (pictured) from the University of Wollongong has been appointed as an Age-friendly Mentor by the World Health Organization (WHO) and the International Federation of Aging. The mentoring role is one of just 20 worldwide and forms part of the Age-friendly Environments Mentoring Program, established to foster leadership development in people working to make their communities more responsive to people of all ages. Dr Phillipson leads the university's Dementia Friendly Communities and Organisations project.

See p33 in this issue for more on Dr Phillipson's research work

innovAGEING call-out

Aged care innovation network, innovAGEING, is inviting aged care providers to share case studies of their efforts to innovate. The network was launched in 2017 by Leading Age Services Australia (LASA) and brings together progressive thinkers and practitioners in an online community of practice called innovAGEING Open Lab. innovAGEING's Principal Advisor, Merlin Kong, says the network is seeking case studies on initiatives that: used new concepts on ageing, and translated these into service design and delivery; have fostered new business models; and enabled providers to be more consumer-centric in their service delivery. "There are many positive stories about aged care and the time to tell these stories is now," he said. Contributions can be emailed to innovAGEING at info@innovageing.org.au. Participants will be emailed a brief questionnaire to complete.

PCA departure

Liz Callaghan has resigned from her role as CEO of Palliative Care Australia (PCA) to take up a new position at the Australian Department of Health. Ms Callaghan has led the PCA for the past four years. PCA Board Chair Dr Jane Fischer says Ms Callaghan leaves PCA in a very strong position for the future. "Liz has done a phenomenal job at leading PCA with her expertise in health policy, management and stakeholder engagement."



New intergenerational facility

Yackandandah Health has officially opened its new intergenerational facility in Yackandandah, in north-east Victoria.

The new double-storey building (pictured) has 16 rooms upstairs for aged care residents, including people with dementia, and 10 apartments for individuals or couples downstairs.

Yackandandah Health CEO Annette Nuck said, as part of the health service's progressive approach to aged care, known as the Yackandandah Model, the new building is one of several innovative projects it is undertaking to meet community health needs. Yackandandah Health is a community-owned, not-for-profit organisation.

"We are leading the way with a move to intergenerational care. The new building is the first step as the apartments are not specifically for older people. Someone who is younger and



looking for one-bedroom accommodation in Yackandandah can apply," Ms Nuck said.

"We are also working toward the opening of a new childcare centre on our site at the start of 2019 and recently received funding for a Care Sanctuary, which connects people to animals and the land. This will be for the whole community," she said.

Ms Nuck said they had started planning three years ago to meet the changing demands for aged and health care in the community.

"The demand for a variety of options to suit people's different needs as they age is just continuing to grow," she said.

'Universal' approach to dementia design

Dementia Training Australia Environmental Design (DTA ED) Education Service Manager Kirsty Bennett, ED Consultant Terri Preece, and DTA graphic designer Emma Paul created a poster for this year's Australian Universal Design Conference in Brisbane to illustrate the message that dementia-friendly design is good design for everyone.

Universal design (UD) is "the design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people regardless of their age, size, ability or disability..." according to The Centre for Excellence in Universal Design, based in Ireland.

"Universal design is about creating inclusion for everyone everywhere, including people living with dementia," said Ms Preece, who presented the poster at the conference.

"Our poster, '*Universal design means... designing for people with DEMENTIA*', highlighted the Dementia-Friendly Community – Environmental Assessment Tool (DFC-EAT), and associated key design principles, as a possible tool



Dr Jane Bringolf (left), Director of the Centre for Universal Design Australia, which hosted the conference, with DTA Environmental Design Consultant Terri Preece and the DTA poster

that could be used to enhance public and commercial environments so people with dementia can continue to live meaningful lives within their communities and ensure their inclusion within the universal design framework," Ms Preece said.

This year's Australian UD Conference, with the theme '*Home and away – creating inclusion everywhere*', aimed to broaden delegates' thinking about the many ways UD can be used and applied.

UD is now an international movement recognised by the World Health Organization, and the United Nations through the Convention on the Rights of

Persons with Disabilities as a way to create greater social and economic inclusion for everyone.

The Centre for Universal Design Australia, which co-hosted the Brisbane conference with COTA Queensland, says that with the roll-out of the National Disability Insurance Scheme and policy changes planned for older people, "everyone needs to be ready to embrace the principles of universal design in their daily work".

The DFC-EAT Assessment Tool and other resources are available on the DTA website at www.dta.com.au/resources/environmental-design-resources-introduction/

What works for carers?

The Productivity Commission has found limited evidence of positive interventions to support carers of people with dementia to prevent or delay entry into residential aged care.

The 'What works' review identified an initial pool of 44 randomised controlled trials (mostly from overseas), of which 26 were assessed as being high quality and suitable for analysis. Of the 26 interventions, just three were found to be effective: two involved counselling and the other case management. Even so, the report says that none of these are appropriate for Australia to adopt at this stage – if the purpose is to prevent or delay entry into residential aged care.

The report says these findings do not mean that dementia-related funding for carer services, resources and research should be reduced. There are gaps in the research (in particular, research on respite services), and that supporting carers of people with dementia may have important benefits beyond keeping the person with dementia at home. The report is available at: <https://bit.ly/2qFuBqB>.

A carer's view: see below

SHAREYOURVIEWS

AJDC welcomes Letters to the Editor on any subject related to dementia care. Letters can be emailed to Executive Editor Professor Richard Fleming at rflaming@uow.edu.au. Please include your full name, address and phone number for verification. Only your name and city will be published. Letters may be edited, with the writer's permission, before publication.

Review discounts carers

I am a carer for my partner, who is living with dementia. Among policies and programs concerned with dementia, I have a particular interest in services meant to support carers in their direct caring responsibilities, and beyond. Since beginning my own role as a carer, I have been struck by the extent of the disparities between informal carers' experiences and much of the thinking of those responsible for the design, management and evaluation

of services. The recent review by the Productivity Commission, *Interventions to support carers of people with dementia* (SCRGSP 2018), exemplifies this disparity. The review, released on 18 October, was to consider what works to support carers of older people with dementia to prevent or delay entry into residential aged care.

By its title, the Productivity Commission's investigation of the impact of programs designed to support carers of

people with dementia demands attention. Unfortunately, the study's central concern is just with discovery of evidence about how such interventions might offer cost savings for government by delaying or avoiding residential placement. But even with this restrictive goal, the study reveals very little.

Background and method
Interventions to support carers of people with dementia was

produced by the Steering Committee for the Review of Government Service Provision (SCRGSP), comprising about 18 officers from various federal, state and territory agencies. Actual authorship is unclear.

The review used a research scheme said to be timely and rigorous, and that is meant to be particularly suited to inform evidence-based policy and management. This 'Rapid Evidence Assessment' (REA) approach is claimed to reduce

risk of bias in findings that can occur “if researchers focus on studies that are easily accessible or that have results conforming to their hypothesis” (SCRGSP 2018 p7).

It was to complement ‘performance reporting’ on government services that the Steering Committee says it undertook this ‘what works’ type study. As such, it is the Productivity Commission’s first trial of “current global evidence on what works (or does not) to achieve particular outcomes for government services” (SCRGSP 2018 p9, p43).

Because the review team “did not have prior expertise in conducting REAs”, or even in the subject area, two (unidentified) consultants with relevant expertise to provide “advice and guidance” were engaged (SCRGSP 2018 p43). The team also acknowledged a lack of “expertise in searching databases”, helping explain that its search string yielded far too many studies – “given the time constraints”.

Consequently, the original plan that the Productivity Commission “assess interventions aimed at carers of all older people” was abandoned. Instead, the “scope was limited to carers of people with dementia, to ensure the task was manageable and the question being answered remained policy relevant” (SCRGSP 2018 p43). This mid-course shift assists in understanding the repeated tendency in the review to assume that the needs and preferences of older people in general and those with dementias are the same.

Bearing out the review’s persistent stress on empirical rigour, a third of the report proper is devoted to method and characteristics of the selected input data.

To find the international studies on which findings are based, the review examined three databases with a search string that included the terms ‘dementia or Alzheimer’, ‘caregiver or carer’, and ‘intervention or support’

(SCRGSP 2018 p9). Studies were selected for analysis only if they met the following criteria (SCRGSP 2018 p10):

- The carers studied were informal carers (who were mostly the recipients’ female spouses).
- The intervention programs were focused on assisting carers in their caring role.
- The study’s outcome measures included “prevention of, or delay in entry to long-term residential care”.
- Carers were randomly selected for the intervention, and there was a control group which did not receive the same support.

Other limitations

In addition, all studies had to be published in peer reviewed journals, so ‘grey literature’, such as books or government and other reports, were excluded. By this criterion, even the Productivity Commission’s own reports would be overlooked.

Though the review was of international literature, only English language sources were examined. In all, 48 journal articles, reporting on 44 interventions (including two studies of Australian programs) met these criteria. Twenty of these were identified as having “high overall risk of bias”, leaving 28 studies that “were focused on when analysing and discussing the results” (SCRGSP 2018 p19, p23).

These exclusions severely limited what intervention programs the review could rely on. The authors acknowledge that, for example, “evidence for some of the carer support services commonly provided in Australia was not available”. The two respite services studied were classed as of low quality and, therefore, counted as of little evidential value. “No studies were identified that tested the effectiveness of providing carers with financial support” (SCRGSP 2018 p41).

Because of the restrictive criteria, a quality study like

that of Jorgenson *et al* (2018), on risk of residential admission of 1116 older Australians receiving home care services for higher-level needs, could not be considered.

Findings

Unsurprisingly, given the extent of the review’s methodological constraints, its results are meagre. The ‘key findings’ are summarised as follows: “Interventions that support carers of older people with dementia show limited effectiveness in preventing or delaying older people’s entry into residential aged care. Of the 26 interventions rated at a relatively low risk of bias studies, only nine reported a positive effect and only three of these had a statistically significant effect” (SCRGSP 2018 p35).

Of the three interventions with effects counted as significant, one was a case management intervention in Hong Kong – where “there are relatively few residential facilities” (SCRGSP 2018 p36).

The other two programs with a significant effect (in delaying entry to residential care) were counselling interventions in the US. For these, the authors also note various failures in attempts at replication (SCRGSP 2018 p36).

The review’s authors make the rather bland observation on the need to explore “other options to prevent or delay the entry of older people with dementia into residential aged care need”, such as preventing or delaying the progression of dementia (SCRGSP 2018 p41).

A final critical point concerns the review’s foundational claim justifying its overall concern with keeping people with dementia living at home. This is that, along with this being cheaper for governments, the majority of older Australians prefer to “age in place” (SCRGSP 2018 p1, p6). This assumption is not unambiguously supported by the references cited. Moreover, it takes too little account of

costs other than those to government, and capacities for independent living of people with dementia. The review discounts fundamental variables like severity of dementia; gender; ethnicity; income and wealth; and residential care and service options and standards.

Conclusion

The review of interventions to support carers of people with dementia exemplifies the disparity between informal carers’ needs and the practices of organisations responsible for the design, management and evaluation of services for people living with dementia and carers. It was commissioned to help save government money and designed and conducted by a body admittedly lacking expertise in dementia care. Ironically for the Productivity Commission, the review seems to have been wasteful, and of little or no practical value.

Without direct connection or accountability to those directly affected by dementia, the review raises the question about how much better value might have accrued if relevant carers were engaged and better represented through peak organisations.

Unfortunately, the peak carer and dementia organisations tend to make it too easy for authorities to bypass carers who are critical of existing practices.

**Emeritus Professor Martin Mowbray
Melbourne, Victoria**

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Virtual dementia-friendly rural communities

Irene Blackberry and colleagues introduce the Verily Connect project, which is working to bring together family carers in rural communities across Australia – with the help of co-designed technology

Support for family carers is an area of dementia practice and research that is often overlooked. There are over 200,000 informal carers of people living with dementia in Australia (Dementia Australia). Carers play a critical role in sustaining quality of life of people living with dementia. This is particularly true in rural areas, where the availability of formal care may be minimal. Furthermore, people living in rural, regional, and remote areas of Australia may have trouble accessing services due to the need to travel long distances to be able to use the services (Umstätt Meyer *et al* 2014).

However, online technology provides opportunity for people to connect, interact and build meaningful relationships in the virtual environment and thus bridge geographical distance (Mason *et al* 2017). Analysis of data about internet usage and online access among Australians aged 65 years and over indicates that, although this group of people access the internet in lower numbers than their younger counterparts, an increasing percentage of older people are now getting online (researchacma 2016).

Introducing Verily Connect

Since 2015, our interdisciplinary team has worked closely with rural community members to undertake dementia research that supports family carers. We conducted four focus groups and a modified Delphi survey to identify and prioritise service and support needs of people living with dementia and their carers. Findings from this community consultation



(Bauer *et al* in press) identified the following themes:

- Difficulties with access to and information about services.
- Need for health professionals to have more training to help them better understand the experience of living with dementia and the importance of information sharing.
- Need for more support for carers and access to information about services.
- Need for local community members to better understand dementia and carers' experiences.

These findings were used to develop and pilot a prototype app (SENDER – Service Navigation and Networking for Dementia in Rural Communities) in 2016-2017 and a volunteer-led rural dementia project (HelpDem), which then led to the development of the Virtual Dementia Friendly Rural Communities (Verily Connect) project.

To the best of our knowledge, the Verily Connect project is a world-first trial to

determine the effectiveness of virtual dementia-friendly rural communities. The project uses a newly developed smartphone app, website and videoconferencing to connect carers of people living with dementia and engage whole rural communities, including people with dementia, to achieve the ultimate goal of improving life for people living with dementia locally and nationally.

A total of 12 rural communities across Victoria, South Australia and NSW are participating in the project, which runs from July 2017 to June 2019, with results to be presented by December 2019. La Trobe University in Victoria is leading the project, in partnership with Swinburne University, Flinders University, the University of Newcastle and the University of Saskatchewan, Canada.

We are using a co-design approach to create Verily Connect, drawing upon learnings from the community consultation, the pilot of the SENDER app, and the

HelpDem project. This approach continues as we engage iteratively with community members to develop implementation strategies and to provide us with feedback about Verily Connect technology solutions.

Verily Connect aims to create and trial innovative technology solutions to:

- Increase support for carers of people living with dementia and the rural communities in which people living with dementia age-in-place.
- Increase the capacity of the whole rural community to provide support for and care of local people living with dementia, and their friends and families.

There are three key features of Verily Connect (see Figure 1, next page):

- A purpose-built application (app) available as a website and for mobile devices that provides the opportunity for users to chat to other users and obtain targeted information about dementia, about keeping well, and about local services and supports.
- Peer support groups for carers are available via video-conference, thus enabling rural carers to bridge the geographical distances that divide them.
- In each community, there is a local technology support hub, which is staffed by trained volunteers who are available to provide face-to-face support to Verily Connect users.

Implementation

The Verily Connect Project is currently being implemented

What is a virtual dementia-friendly community?

Alzheimer's Disease International (ADI) defines a dementia-friendly community as "a place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights and recognise their full potential" (ADI no date p10).

Key principles of dementia-friendly communities include that people living with dementia need to be supported by people, communities, organisations and partnerships (ADI no date p10).

The various forms of dementia-friendly communities worldwide highlight that this concept is heterogeneous and tailored to each individual community (Williamson 2016). There are resources available for how to create a dementia-friendly community, for example by Dementia Australia (Alzheimer's Australia Vic 2016).

Although there is established understanding about dementia-friendly communities, the concept of a *virtual* dementia-friendly community is new.

In our view, a virtual dementia-friendly community adheres to the key principles of dementia-friendly communities, but it adds a virtual dimension. That is, not only is there face-to-face interaction with environments, people, communities, organisations and partnerships, there is also an interaction in the virtual space of the internet.

We propose that sharing information and facilitating communication online is another way in which the goals of "reducing stigma and increasing understanding of dementia and empowering people with dementia" (ADI no date p10) can be achieved.

across 12 rural communities in Victoria, NSW and South Australia. We will evaluate the project using a stepped wedge cluster randomised controlled trial. (In this type of trial, each of the 12 communities is classified as a 'cluster', and the time that each community starts using Verily Connect strategies is staggered. At each 'step', three communities have access to the online technologies. Each step is eight weeks' long. Effects of Verily Connect are compared for each community according to when they are waiting for Verily Connect to start in their community and when they are actively using the online technologies.) Our primary outcome is an increased level of support among rural carers as measured by the Medical Outcomes Study (MOS) Social Support Survey (Sherbourne & Stewart 1991).

At the end of the project, a toolkit will be developed to share learnings from the project and to assist in the development of a global network of virtual dementia-friendly communities.

A virtual network gap

A review of models of dementia-friendly communities was recently published (Blood *et al* & Innovations in Dementia 2017). However, current

evidence for the effectiveness and cost effectiveness of dementia-friendly communities is lacking, as the evaluation primarily used qualitative methods (Lin 2017). In addition, the role of digital technology in supporting dementia-friendly communities is not well understood. Although digital technology may be used as part of the implementation of a dementia-friendly community, to date there have been no attempts to set up a virtual network of dementia-friendly communities.

Linking carers and services

Verily Connect is an adjunct to existing services; it does not replace current services. Through providing clear and accessible information about services, we anticipate that Verily Connect will assist members of the public to identify and more readily approach service providers. Over time, users of Verily Connect might also provide each other with user-friendly advice and tips about which services are most helpful in particular situations, for example, where it is best to go to receive emergency respite care.

Users of the Verily Connect app might also help service users identify a wider range of services that are available, but

which may be unknown to all carers.

Likewise, our community consultation also revealed that many rural service providers do not have comprehensive knowledge of the services available for people living with dementia and for family carers (Bauer *et al* in press). It is widely acknowledged that rural services experience high staff turnover and have a high proportion of overseas-trained staff, both of which may limit understanding of local services and access to specialist services. The Verily Connect app enables rural service providers to promote their service to people living with dementia, family carers and other service providers.

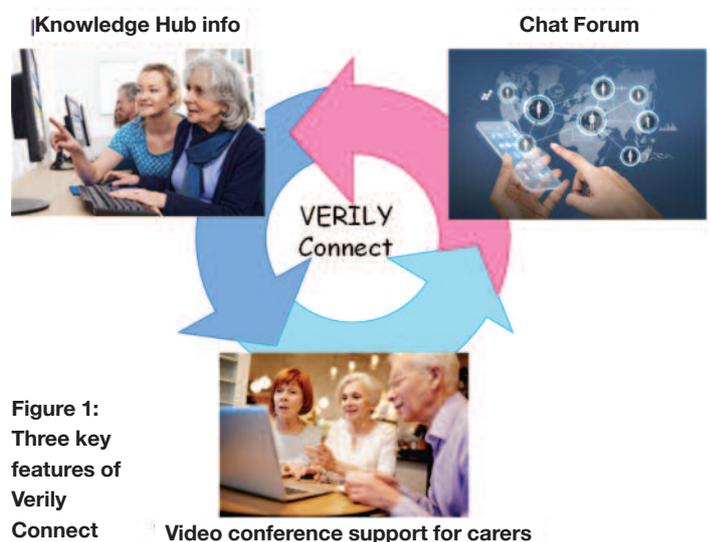
How will it help?

Social isolation in rural areas is a significant problem (ReachOut 2018). Through using technology, our project aims to reduce social isolation among carers of people living with dementia. Technology offers carers the opportunity to be connected to a wider network of carers and service providers. The use of technology may also alleviate stigma and privacy issues that can occur in small rural communities. The Verily Connect Project will examine how tailored use of technology may increase support among carers and lessen the more stressful impacts of caring.

How to get involved

Recruitment for the Verily Connect project is well underway in all our participating communities: Victoria (Koo Wee Rup, Mansfield, Warracknabeal, Horsham, Kyneton, Robinvale, Heathcote, Edenhope), NSW (Molong, Nyngan) and South Australia (Victor Harbor, Riverland).

We encourage carers, volunteers, service providers and all community members of our participating communities to be involved and help their community become more dementia friendly. Please visit www.verilyconnect.org.au or call (03) 5444 7676 for further information. We welcome all feedback to help us further support carers in rural communities. ■



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Supported decision-making: human rights and emerging practice

Craig Sinclair shares current thinking about the importance of supported decision-making for people with dementia – and introduces new resources to support practice in this area

Supported decision-making is an emerging area of practice that is grounded in an increasingly prominent disability rights movement. The Convention on the Rights of Persons with Disabilities (CRPD) establishes an equal right to legal capacity for people living with disabilities (United Nations 2006). The CRPD provides a human rights framework, which calls on governments around the world to ensure that people living with disabilities are recognised by the law on an equal basis with others, and that they have access to support in making

decisions and exercising their 'legal capacity'.

The voices of dementia advocates, in particular people with lived experience of dementia, have been critical in drawing global attention to the relevance of the CRPD for people with cognitive disabilities such as dementia (World Health Organization 2015; Swaffer 2018), and the need for governments and the community to provide supports that enable people to live well with dementia.

This article explores national and international developments on the topic of supported decision-making, and explores

recent research findings with implications for how this emerging practice might be implemented in dementia care.

What is supported decision-making?

Supported decision-making has been defined as "the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters" (United Nations Office of the High Commissioner on Human Rights 2009 p15). Supported decision-making is more than just 'helping someone to make a decision'. In the context of

disability rights theory, it means understanding that a person's impairments (eg in the case of dementia perhaps a cognitive, language and/or memory impairment) are not the sole cause of the person's experience of disability. Instead, disability is seen as an interaction between a person's impairment, and the community's collective ability to accommodate that impairment, in order to ensure their full and effective inclusion and participation (Shakespeare *et al* 2017).

Thus just as hearing aids or wheelchair ramps can accommodate the needs of

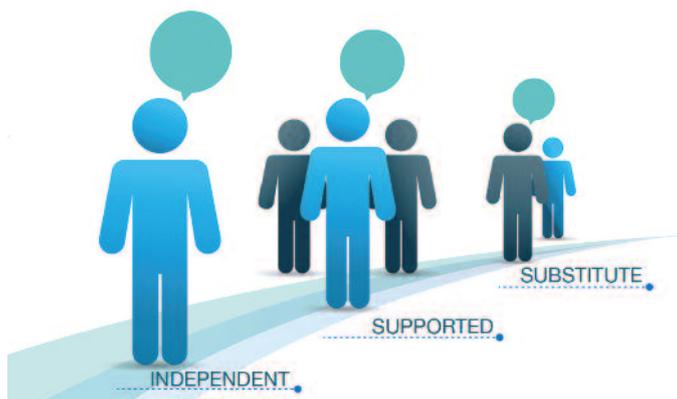


Figure 1: A spectrum of decision-making styles, as described by research participants. Source: Cognitive Decline Partnership Centre

people with sensory or physical impairments, supported decision-making includes (but is not limited to) the range of practical steps that can accommodate a person's impairments and enable them in making decisions about their lives.

The supported decision-making approach directly challenges the view that a person with a disability is 'incompetent', or should be excluded 'for their own protection or wellbeing'. Instead it acknowledges that each person has unique decision-making abilities, and unique needs for support, in order to exercise their right to legal capacity on an equal basis with others. Having signed and ratified the CRPD and its accompanying 'Optional Protocol', Australia is obliged to ensure that legal systems and frameworks are in place to ensure that these rights are observed.

This is an interesting challenge in a federated system like Australia, where different laws relating to decision-making and guardianship are in place across the different states and territories. However, a United Nations Committee, in its assessment of the current situation, determined that Australia's Government should "...take immediate steps to replace substitute decision-making with supported decision-making..." (United Nations Committee on the Rights of Persons with Disabilities 2013). The Australian Law Reform

Commission's (2014) report made a number of recommendations for changes in domestic laws, to begin the process of implementing supported decision-making. A small number of pilot programs have commenced, and Victoria has introduced a formal framework for supported decision-making, through provision of a 'supportive attorney' for financial decisions and a 'medical support person' for healthcare decisions (Victorian Office of the Public Advocate 2018).

Supported decision-making and dementia

Supported decision-making has been more widely used, over a longer period of time, in the context of developmental disabilities, than for people living with dementia. However, this disparity is now

being addressed. A Cognitive Decline Partnership Centre funded team, including researchers and consumer representatives, has been investigating supported decision-making in the context of dementia, focusing particularly on healthcare and lifestyle decision-making. A number of studies are underway, investigating Australian laws, the policies of Australian aged care organisations, and interviewing people living with dementia, their family members and professionals involved in dementia care.

This research has illustrated that both people with dementia and their family members place a high value on maintaining involvement in decision-making. Maintaining involvement and being included by others (particularly close family members and friends) has been shown to relate not only to a person's individual sense of purpose, self-worth and identity, but also more broadly to their ongoing sense of belonging and 'relational' identities (eg as a partner, parent or friend) (Sinclair *et al* 2018).

Through these interviews, we have observed that 'supported decision-making' is already happening in the community, at least on an informal basis. Rather than

decision-making being solely 'independent', 'supported' or 'substituted', decision-making involvement was occurring on a spectrum (see Figure 1), and influenced by factors relating to the individuals involved, their relationships, the decision itself, and external factors relating to the environment. These factors were dependent on the context, and changed over time (both progressively and also fluctuating from day to day).

We have also observed the importance of people's trusted relationships, as the social context and 'engine room' in which meaningful decisions are made. This shows the importance of the social context in decision-making, in addition to other factors related to the dementia process. Given that many people living with dementia also experience declines in their social networks and an increased reliance on key relationships, this points to the importance of acting at a community and societal level to address stigma and discrimination, and ensure full and effective participation in the broader community wherever possible.

Practical strategies

People living with dementia and their supporters have described a range of practical

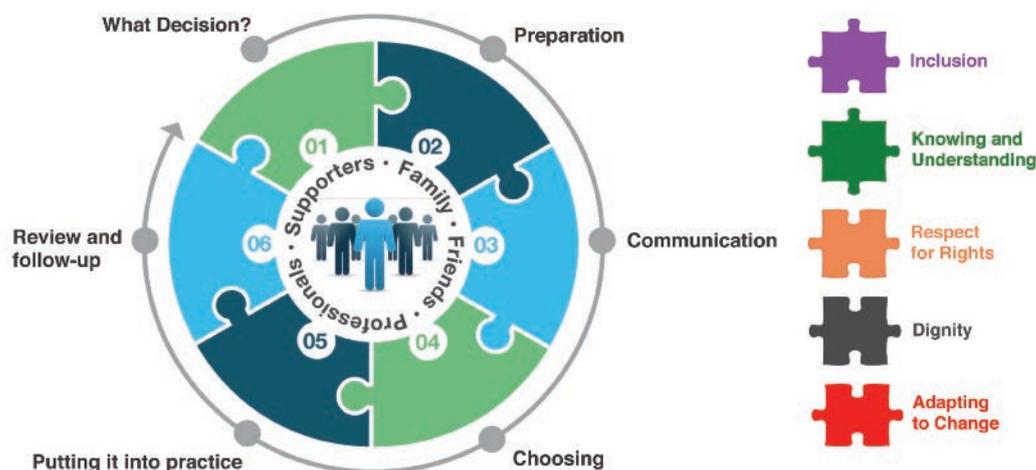


Figure 2: A process (left), and set of overarching values (right), to inform supported decision-making. Source: Cognitive Decline Partnership Centre

strategies they use to maximise involvement and participation, including things like:

- Prompting: identifying an opportunity for decision-making, or providing reminders about decisions that need to be made.
- Encouraging: help from other people to get motivated with making a decision.
- Providing ideas: providing suggestions or giving examples of the sorts of decisions made by other people.
- Interpreting: help to translate unfamiliar words or complex jargon into understandable language.
- Listening: listening to a person as they talk through their ideas, being a 'sounding board' and providing emotional support.
- Questioning: asking questions about a planned decision, to raise potential problems or another point of view.
- Affirming: providing reassurance about the decision and helping the person to put it into practice.

Based on these strategies, and what our participants told us they valued most, our team has developed a suite of resources that introduce a guiding model for a supported decision-making process, along with a set of key values, which underpin each stage of the process (see Figure 2). We suggest that this should be seen not as a strict, linear, or tick-box approach, but instead as a series of considerations to think about at each stage of the process. The overarching values of inclusion, knowing and understanding the person, respect for rights, dignity and adapting to change are important throughout the process.

Problems and pitfalls

While the developments around the CRPD and implementation of supported decision-making are

undoubtedly promising, and arguably better reflect the needs of people living with dementia, there are a range of potential issues that practitioners and the community need to be mindful of. These include:

- adequately resourcing decision-making support
- training care providers in supported decision-making strategies
- educating the community about supported decision-making
- safeguarding against potential undue influence from supporters
- inconsistent laws across Australia.

Practical resources

Through this research and the extensive input of advisory groups across three states in Australia (WA, SA, NSW), our team has produced a number of resources aimed at assisting practitioners and the community in understanding and implementing supported decision-making more formally in dementia care. These include:

- A policy guideline document for Australian aged care providers.
- A guidebook for people living with dementia, their family members and carers.
- A series of short videos describing lived experiences of supported decision-making and practical strategies.

A three-part webinar series aimed at understanding (i) the human rights and legal basis of supported decision-making, (ii) the practical principles and strategies for supported decision-making in the context of dementia, and (iii) the implications of supported decision-making in the aged care context.

All of these resources are freely available on the CDPC website, on our project resources webpage, which can be found at <http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php>

What next?

For any staff working in organisations providing care for people living with dementia, we recommend a review of your organisation's existing policies in the area of supported decision-making.

For those in aged care contexts (both community and residential), our research has generated a policy guideline document, which includes a self-assessment audit tool and framework for policy review and development. This guideline, *Supported decision-making in aged care: a policy development guideline for aged care providers in Australia*, has recently been promoted by the Australian Aged Care Quality Agency, and included in the resources relevant to incoming standards for aged care providers (Australian Aged Care Quality Agency 2018).

It is also important that similar processes of policy review are undertaken for organisations providing services in community settings, including those accessed by people with younger onset dementia.

Our ongoing efforts have included working with a range of partners and stakeholder organisations to convene a research and policy forum, held on 15 October. This forum aimed to generate consensus recommendations regarding the role of supported decision-making in the forthcoming National Plan to address elder abuse (Attorney-General for Australia 2018). The report and recommendations arising from the forum are available here: <http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php> ■

For further information on this work, visit the Cognitive Decline Partnership Centre website: <http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php>

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Tailored activity for responsive behaviours

Sally Bennett and colleagues introduce TAP-Australia – an innovative tailored activity program for people with dementia and their carers living at home



TAP coaches carers in how to engage a person with dementia in meaningful activities, such as food preparation, to help them reconnect with things they previously enjoyed doing. Photo: iStock

Our multidisciplinary research team*, led by The University of Queensland, has recently been awarded a three-year NHMRC grant (2018-2020) to implement the Tailored Activity Program in Australia.

The Tailored Activity Program (TAP) is an evidence-based program that has demonstrated effectiveness in reducing the occurrence of responsive behaviours in people living with dementia (including agitation, aggression, apathy and depression), as well as reducing carer stress and demand on carers (Gitlin, Winter *et al* 2008). Responsive behaviours are experienced by the majority of people with dementia, are often an expression of unmet needs (such as boredom or frustration) and can lead to distress for both the person with dementia and the carer (Cerejeira *et al* 2012). They can be some of the most challenging issues for family caregivers to understand and to manage.

TAP coaches carers in how to engage a person with dementia in *meaningful activities* – that is, any activity that is important or personally meaningful to the person with

dementia (Gitlin, Winter *et al* 2008). This engagement in activity (such as food preparation, sorting nuts and bolts or fabrics, or doing some form of gardening) can help people reconnect with things that they previously enjoyed doing, which in turn helps promote their sense of identity and connection with others.

TAP is delivered by occupational therapists in up to eight home visits, which occur over three-four months. The occupational therapist assesses the person's capabilities and strengths, and trains carers to tailor and adapt meaningful activities, use effective communication strategies, generalise these skills to other activities of daily living, understand environmental triggers for responsive behaviours, and to use stress reduction strategies for themselves.

TAP has also been shown to be cost-effective in the US (Gitlin, Hodgson *et al* 2010). However, it is not currently available in Australia. This is due to a number of factors. While occupational therapists are routinely involved in assessing people with dementia, they often only see them on a few occasions (Bennett *et al* 2011). This is

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partly due to therapist-specific factors, but also to the nature of referral requests, and organisational perceptions of occupational therapy scope of practice. There is also a general lack of awareness about potential reimbursement options (for example Medicare, Home Care Packages, Short-Term Restorative Care, Transition Care Programs) for interventions such as TAP. In addition, people living in regional and remote areas of Australia often have difficulty accessing occupational therapy services.

TAP-Australia: Phase 1

The University of Queensland research team aims to address these issues through the NHMRC grant and to explore how TAP can be effectively implemented in Australia to make this important service available to people with dementia and their informal carers. In Australia the program will be known as TAP-Australia, with the research into its implementation called *i*-TAP-Australia. To explore how TAP-Australia can be integrated into routine clinical care, the research team is conducting interviews with a wide range of stakeholders including people with dementia and their families, occupational therapists, and managers of healthcare organisations that refer people with dementia for support. The aim of the interviews in

Phase 1 is to understand:

- What are the barriers and enablers to implementing TAP in Australia?
- What funding mechanisms are available for reimbursing practitioners for delivering TAP-Australia?
- What are the most appropriate referral pathways for TAP-Australia?
- What is the best way to inform health care professionals and the public about TAP-Australia and its benefits?

Phase 1 of the project is running from July 2018 to January 2019.

Implementing TAP-Australia: Phase 2

Information gathered from the interviews in Phase 1 will inform Phase 2 of the project which will aim to understand how to implement TAP-Australia across Queensland in 2019 and 2020.

Partnerships are being established with organisations that employ occupational therapists, and referral pathways and funding mechanisms for TAP-Australia will be identified. A media and marketing campaign, running from early 2019 to early 2020, will help promote awareness of the program.

Seventy occupational therapists with previous experience working with people with dementia will be invited to participate in the implementation research, and

will receive free, comprehensive training to be certified to provide TAP-Australia, as well as more in-depth education about dementia. These occupational therapists will then each deliver TAP-Australia to between three and five people with dementia living in the community and their informal carer(s) with whom they live. The TAP-Australia program is expected to be delivered to people with dementia and their informal carers from around mid-2019.

The participating occupational therapists will be fully supported in providing TAP-Australia by the research team and through the development of a supportive network of practitioners. This is likely to be self-sustaining beyond the project's lifetime and contribute to the longer-term sustainability and uptake of TAP-Australia.

Anticipated benefits

Anticipated benefits of TAP-Australia for people with dementia include reduced responsive behaviours, increased involvement in activities and improved quality of life. Reduced carer stress, distress about behaviours, and improved quality of life are expected to be likely benefits for carers. Other outcomes include measures of TAP-Australia uptake (that is, how many people received TAP-Australia and in which geographical locations) and the feasibility

and acceptability of TAP-Australia. An economic analysis of TAP-Australia will also be undertaken.

In addition to providing an effective, much-needed intervention for family carers of people living with dementia, lessons from this project will inform the larger-scale adoption of TAP-Australia across Australia. ■

Participating in TAP-Australia

If you are an organisation that employs occupational therapists in the community, or you are an occupational therapist interested in participating in TAP-Australia in Queensland, or would like further information about the program, please contact Sally Bennett at sally.bennett@uq.edu.au

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Training to improve the hospital experience

A new training resource for staff working in acute care settings is now available from Dementia Australia, designed to improve the hospital experience for people living with dementia. **Kerry Schelks** reports

A new free experiential training package has been developed by Dementia Australia to further build the capacity of staff in hospitals and Multi-Purpose Services (MPS) to care for people living with dementia by increasing their understanding and empathy.

The self-guided *Insights into the hospital dementia experience* toolkit provides hospital and MPS staff with a training resource to improve their understanding of dementia in a hospital setting and the unique challenges that can arise for both the individual and support staff.

It is designed to be delivered in the workplace by two health facilitators experienced in providing education to hospital and MPS staff and who also have an in-depth knowledge of dementia and experience in group-based debriefing. The workshop can be delivered in either a two-hour or three-hour module, depending on the number of participants (up to a maximum of 20), and lesson plans are provided for both.

Given the toolkit is designed to be used by facilitators with an in-depth knowledge of dementia it focuses on the importance of person-centred care and understanding behavioural responses rather than providing detailed information about dementia, its causes, pathology or treatment. It gives participants the opportunity to experience what it might be like to have dementia and its impact in the hospital/MPS setting and aims to increase their empathy for people living with dementia.

The workshop includes group discussion, a simulation exercise and debriefing.

The training package

Dementia Australia's CEO Maree McCabe said the training package enables staff to put themselves into the shoes of a person living with dementia and provides greater understanding of how the condition might impact on their hospital experience.

"Through the use of simulation and debriefing exercises facilitators work with participants to adopt a practice that is more sensitive, informed and considered, leading to a better experience for the person living with dementia, their families and carers, as well as for the staff who work with them," she said.

The package contains all the necessary resources for trained facilitators to be able to deliver a session. This includes a facilitator guide, participant handbook and simulation resources that are free for facilitators from hospitals or MPS sites. The facilitator guide lists equipment and recommended 'props' for a 20-minute simulation exercise, most of which can be found in the hospital setting, or are provided in the workshop toolkit.

The simulation exercise

The simulation exercise involves the facilitators playing the roles of hospital staff while the participants are treated as patients. They're asked to undertake tasks designed to give them an idea of the



A facilitator, wearing a hospital gown, in the role of a staff member, with participants at the start of the simulation exercise. All wear masks to hide their individuality

frustration, confusion and anxiety that people with dementia may experience in an unfamiliar, confusing, noisy and busy hospital setting. The props include admission forms that are deliberately confusing, games without instructions, and a recording of a noisy hospital environment, designed to be played throughout the exercise.

Input from people living with dementia

With funding from the Department of Social Services Aged Care Service Improvement and Healthy Ageing Grants Program, the toolkit was developed by people living with dementia, dementia care specialists, members of the NSW Health Education and Training Institute and the Agency for Clinical Innovation. People living with dementia, their families and carers shared their own hospital experiences to ensure the training captured the realities of a hospital or MPS stay.

Pilot evaluation

The toolkit was tested during 18 pilot workshops across nine hospital and MPS sites in NSW in 2016, involving 211 participants including nursing,

allied health administration and catering and cleaning staff. An evaluation (Abbato 2017) demonstrated that staff's empathy and understanding of the triggers of behavioural responses in patients with dementia increased immediately after training compared to before, and the increased empathy was sustained eight weeks after training. A reported improvement in confidence to communicate with a person living with dementia among staff was also a positive sign.

Positive results were shown to impact others in addition to the patient with dementia, including: the staff member implementing the change; other staff in the workplace; and families of the patient (Abbato 2017).

Stories of change

The evaluation report includes 15 participant narratives as evidence of applied practice change, gleaned from 18 in-depth interviews conducted about 12 weeks after hospital and MPS staff from the nine sites participated in one of the pilot workshops. The quotes below are taken from those narratives (Abbato 2017):

"It was a really big wake-up

call for me to not take for granted that patients know what we are doing without us taking the time to explain, slow down and explain things to them... I was running around and getting jobs done without actually taking enough time to explain to them. They must be terrified. As nurses I think we are very task-oriented and we need to get everything done quick, quick, quick. But for people who have dementia, it is important to be more calm and take a slower pace."

"I can really put myself in their position because I feel like I have been there through the simulation activity. I now feel for the patients with dementia a lot more and I have become more tolerant..."

Accessing the training

Insights into the hospital dementia experience toolkit is freely available to educators from hospital or MPS sites by completing the application form at <https://bit.ly/2LTPiGg>. The workshop is relevant to anyone who provides care to a person with dementia who is spending time in a hospital or MPS. While most workshops have been delivered to clinical staff, several workshops have included administrative, catering, housekeeping and maintenance staff.

Other assistance to hospitals

For those hospitals seeking assistance with how to improve the patient experience for people living with dementia, the Centre for Dementia Learning offers a range of other programs including consultancy specifically for health care providers. For more information contact 1300 DEMENTIA or visit dementialearning.org.au ■

■ Kerry Schelks is Managing Editor of the *Australian Journal of Dementia Care*

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Changing medication management practice

Kate Fulford and **Andrew Stafford** describe a pharmacist-led, evidence-based service for staff working in residential aged care facilities that aims to embed knowledge and processes to optimise the use of antipsychotic medications for people with dementia experiencing responsive behaviours

Responsive behaviours are experienced by the majority of people living with dementia at some point throughout their journey with the condition. For decades, antipsychotic medications have been used in residential aged care to alleviate responsive behaviours. This is despite these medications being of limited effectiveness for most responsive behaviours, and concerns regarding an increased risk for injury and death for a person with dementia who is prescribed an antipsychotic (TGA 2015).

There is also an increasing body of evidence that addressing responsive behaviours with non-pharmaceutical (non-drug) approaches is at least as effective as using antipsychotic medications (TG Ltd 2016). Consequently, most clinical guidelines that address responsive behaviours recommend that antipsychotic medications should only be considered when all non-medication approaches have failed, and only for severe symptoms of aggression and agitation. However, many residential aged care sites report difficulties in adhering to these guidelines due to various barriers including a lack of knowledge, processes and commitment to change.

The Dementia Training Australia (DTA) Medication Management Consultancy (MMC) is a pharmacist-led, evidence-based service that aims to embed knowledge and processes to optimise the use of antipsychotic medications for responsive behaviours. The MMC is a three-tiered process



Staff at Baptistcare Dryandra aged care facility in Kellerberrin, WA. Dryandra successfully completed the first DTA Medication Management Consultancy in August this year

which benchmarks and then follows over time the number of residents prescribed antipsychotic medications for responsive behaviours and staff knowledge about the appropriate use of psychotropic medications for responsive behaviours within the residential aged care facility (RACF).

Supporting appropriate use

The consultancy also includes resources to support appropriate use of antipsychotic medications for responsive behaviours. All staff members at the facility are given access to a series of online DTA education programs from the *Management of antipsychotic medications for responsive behaviour in residential aged care* suite of eLearning. Using a case study format, these programs present evidence-based approaches to support a person experiencing responsive behaviours, both with and without antipsychotic medications.

In conjunction to the online

training, a multidisciplinary action group is formed, representing various providers of care within the RACF, including nurses, care workers and occupational therapists. The group meets regularly with the DTA consultant to develop and implement a facility-wide procedure for managing antipsychotic medications within the aged care home. The facility also receives a number of additional resources to assist with implementing the desired practice changes, including reminder stickers, reference cards, a reference poster and Dementia Australia fact sheets for relatives and family carers about antipsychotic medication use for responsive behaviours.

Sustainable approach

The MMC aims to create a sustainable approach to managing antipsychotic medications by strengthening ties to external resources by involving the community pharmacist/s and general practitioners throughout the consultancy service. The goal of the consultancy is to contribute to reducing the number of antipsychotic medications used to support people with responsive behaviours, ensuring that these medications are prescribed at the lowest possible dose for the shortest possible time, if they are used at all, and ultimately improve the wellbeing of people living with dementia in residential aged care.

Baptistcare Dryandra's experience

Baptistcare Dryandra aged care facility in Kellerberrin, a regional community in Western

Australia, successfully completed the first DTA MMC in August this year. At the conclusion of the 12-month MMC, there was a marked improvement in the alignment of care with the current principles of best practice in management of antipsychotic medications for those who participated.

The Dryandra consultancy was championed by Jun Wynn, the facility's clinical manager, who was integral to the development and implementation of the facility's new procedure for managing antipsychotic medication.

"The entire medication consultancy period changed not only my perception, but all care staff at Dryandra with regards to dealing with responsive behaviours," Jun said.

"There was some hesitation at first, but through an evidence-based and individualised approach, the staff, GP, and the local pharmacy eventually came on board as they could see the positive change in our residents' day-to-day living.

"The medication consultancy was not meant to eliminate or reduce behaviour incidents, but to enable our residents to engage more into various activities in the home, making their stay with us meaningful and worthwhile.

"The staff at Dryandra now understand that in every responsive behaviour, lies a 'cry' that needs to be heard and addressed."

The procedure developed at Dryandra during the MMC included individualised non-pharmacological approaches for residents experiencing a responsive behaviour tailored to their unmet needs. This included strategies such as giving residents access to enclosed outdoor areas and equipment to garden with, and documented review dates to assist staff in adhering to the recommended durations of therapy.

As part of the sustainability plan following the conclusion of the MMC a monthly antipsychotic usage audit and a weekly meeting of the existing

action group members was introduced to discuss the care plans of all residents currently prescribed antipsychotic medications. Importantly, this plan included the development and documentation of individualised antipsychotic withdrawal plans for each resident, as recommended by current guidelines (PrescQIPP 2014).

DTA's perspective

From DTA's perspective, it has been really rewarding working with Baptistcare Dryandra over the past months. It is the first residential aged care facility to commence a MMC, and the staff were very enthusiastic about improving their knowledge on the appropriate management of medications used to support people with dementia. Throughout the consultancy process it was inspiring to observe the nursing and care staff grow in their capacity to become integral parts of the monitoring process of antipsychotic therapy. Ultimately, this strengthened their adherence to best practice, which has likely improved the quality of care for their residents.

The MMC aims to strengthen inter-professional bonds to use the knowledge and skills from a wide range of people including care workers, nurses, pharmacists, general practitioners, diversional therapists, physiotherapists and other professionals associated with the individual RACF, a task at which the Dryandra staff excelled. Since the completion of the MMC, Baptistcare Dryandra has been nominated for a Better Practice award for its improvement in managing antipsychotic medications in responsive behaviours.

DTA and Baptistcare will continue to work closely together through the MMC at other Baptistcare sites, with a second Baptistcare site in Western Australia in the final stages of its MMC. It has been particularly impressive to see how willing staff members at each of the Baptistcare sites have been to engage with us to

ensure that if antipsychotic medications are used to support people with dementia it is done in the safest way possible.

Building capability

The MMC was designed to assist RACFs to build capability within the workforce with additional knowledge through benchmarking and review processes. DTA cannot do this work in isolation; there needs to be commitment from the organisations we work with to achieve positive outcomes. Our experience with Baptistcare has certainly demonstrated commitment, and DTA looks forward to seeing the organisation continue this work into the future.

Overcoming challenges

Over the 12-month consultancy, DTA has had a unique insight into the operations of Dryandra, resulting in a new understanding of some of barriers and enablers of undertaking a facility-wide consultancy of this calibre. In particular, we have an expanded appreciation of the dedication and passion of different staff members to embrace and embed changes in practice for the betterment of their residents, and how it is empowering for all staff members to access training, whether they are working in clinical or non-clinical roles.

We have learnt that the consultancy needs to be malleable to the demands of the facility and have realistic solutions to barriers such as turnover of staff and accreditation requirements to bring about a sustainable change. Furthermore, working with a facility located in rural Western Australia allowed us to further refine our communication strategies to ensure that the consultancy can be equitably delivered nationwide without requiring the regular presence of a DTA consultant on site.

Tailored training

DTA offers the Medication Management Consultancy along with a range of other

consultancies and educational services through Tailored Training Packages (TTPs) which are designed to bring about sustainable change within organisations to improve the wellbeing of people living with dementia and the staff who care for them. DTA offers a limited number of TTPs each year, and is currently engaged with about 288 facilities across Australia.

Medication management education

DTA's Medication Management educational services also include the Medication Management app (www.dta.com.au/resources/medication-management-app-for-ios-android-and-desktop) to assist residential aged care staff working with people living with dementia improve medication use; and a one-hour online course, *Management of antipsychotic medications for responsive behaviour in residential aged care*, for health care professionals including GPs, psychiatrists, psychogeriatricians, interns or resident doctors and nurses. ■

To access more information on TTPs, the Medication Management Consultancy or online learning programs visit the DTA website www.dta.com.au

■ Kate Fulford is a Medication Management Consultant and Project Pharmacist with Dementia Training Australia; Dr Andrew Stafford is a Director of Dementia Training Australia and an accredited consultant pharmacist

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The reliability and meaning of a dementia diagnosis

In this response to the ‘dementia doubters’ who claim public dementia advocates may, in fact, not have dementia, **Kate Swaffer** discusses the legitimacy of a diagnosis and the myth that dementia is a pathway that leads only to deficits and death

Although a multifaceted human being, retired nurse, current author, academic, and co-founder, Chair and CEO of Dementia Alliance International (DAI), I am mostly referred to only as a dementia advocate. Depleting the fullness of my lived experience and ever-changing identity, many refer to me as a victim* or sufferer* of dementia. Unfortunately, my diagnosis and that of others is doubted because I remain high functioning, albeit with disability support. This article discusses the impact of receiving a diagnosis, Prescribed Disengagement®, the ‘dementia doubters’, improving care and the embedded stigma and myths surrounding dementia.

Diagnosis

Historically, receiving a diagnosis of dementia was difficult at almost any age and, as a nurse in the 1970s, I learnt there were only two ‘types’; senile dementia or presenile dementia. There were no more definitive diagnoses. Today, whenever a person is told they have dementia, they have usually been through a large suite of tests, often spanning many years, before their physician tells them (and their family) they have a dementia of this or that type. Patients usually believe their physicians, and today very few physicians will see a patient without a family member or advocate present, when testing for, and when giving a diagnosis of dementia.

However, we know reliability of a diagnosis shows great fluctuation (Van



The author, Kate Swaffer (right), with Mdm Hui-Mei Su (Amy), a member of Dementia Alliance International and Taiwan’s first self advocate. Amy, an artist, was diagnosed with younger onset dementia in 2012, at the age of 62. Photo courtesy Taiwan Alzheimer’s Disease Association

Dyk *et al* 2015; Takayama *et al* 2016), and in some studies at autopsy a significant number of people who presented with symptoms of, and were diagnosed with, dementia showed no evidence of it in their brains, and there are many with no symptoms whose brains showed strong evidence of it at autopsy. As a result most physicians do not tell people they have dementia without being very confident of the diagnosis. In recent years, many people with dementia have been ‘downgraded’ from dementia to Mild Cognitive Impairment (MCI), and are advised this is because they have not ‘deteriorated as expected’. Many members of Dementia Alliance International (DAI) report this, and report that sometime later they have been advised their original diagnosis of dementia is again valid.

This is stressful, often leading people to feel as if they are frauds, rather than questioning the embedded misperception among physicians and others that people diagnosed progress along some predictable, relatively brief temporal trajectory. People find this especially difficult if they have disclosed their initial diagnosis, and although it is currently confounding for everyone, it

contributes significantly to the dementia doubters. Being publicly accused of faking dementia or doubting a diagnosis could be seen as unethical.

Globally, there has been a push in the academic and clinical community for a more timely diagnosis for all people with dementia, and in the UK in 2014 there was a financial incentive for general practitioners to diagnose dementia which, naturally, resulted in many false positives. The National Health Service in the UK states (2018): “*Living well with dementia*: ... People with dementia shouldn’t simply stop doing what they enjoy in life; instead, they should try to remain as independent as possible and continue to enjoy their usual activities.”

Alzheimer’s Disease International (ADI) and Bupa developed a Global Charter (2013), *I can live well with dementia*, yet there is little to no support to do so; worse, if we dare to, people doubt our diagnosis. Surviving and living well with cancer or another terminal illness is seen as positive. Living well with dementia, on the contrary, too frequently means the widespread doubting of our diagnosis. It seems that we are with dementia where we were with cancer in the mid-1970s; still prisoners of the stigma and ignorance.

The misguided under-estimations of our potential and the increase in false positives resulting from increased efforts to make early diagnosis continue to create oppressive and humiliating barriers to the full engagement in society of those who are correctly diagnosed. Perhaps the worst myth affecting us is that people diagnosed with younger onset dementia (YOD) will exhibit the same trajectory of increased dysfunction as do those diagnosed in their later years, or indeed, anyone diagnosed at a later stage of dementia. These myths are endemic and malignant.

Prescribed Disengagement®

Consistently, people diagnosed with dementia are, if suitable for their ‘type’ of

Footnote: * The words sufferer and victim are words I don’t normally use. They are used in this article to make a point about the negative effect of the tragic discourse of dementia, leading to misperceptions we cannot live well. It’s recommended not using these and other disabling and disrespectful terms. Dementia language guidelines are available from Dementia Australia: go to www.dementia.org.au/resources/dementia-language-guidelines and DEEP www.dementiavoices.org.uk/2014/10/dementia-words-matter/

dementia, prescribed one of the few drugs that may slow the progression. They are then mostly told there is nothing else 'we' can do, and to get their end of life affairs in order, to become acquainted with aged care, and give up our pre-diagnosis life. I have termed this Prescribed Disengagement® (Swaffer 2015; Swaffer 2016 pp157-163).

In a systematic review of the way physicians communicate a diagnosis of dementia, Low *et al* (2018) found little evidence in the literature of patients experiencing Prescribed Disengagement. However, anecdotal and other evidence suggests otherwise. For example, in a fundraising ride around Australia in 2017 Greg Kelly, who was diagnosed with dementia aged 59, said in an interview for WIN News Central Queensland: "The specialist just simply said, 'go away and get your affairs in order'" (WIN 2017). In a qualitative study Reed *et al* (2017) found there was surprisingly little discussion of the impact of dementia on personal functioning or abilities. Instead, participants mostly focused on poor interactions with physicians during and after the diagnosis process, as well as on the malignant stigma of dementia and the immediate change in the way they were treated by others in their everyday life following diagnosis.

Rehabilitation

The WHO (2017a) states "Dementia is one of the major causes of disability and dependency among older people worldwide." One must therefore question why the health care sector does not offer proactive disability assessment and support, including cognitive and physical rehabilitation, similar to what I would have been provided had I had a stroke at the age of 49, not dementia. Speech pathology to aid swallowing difficulties, near the end of life, is too late for a person with Primary Progressive Aphasia (PPA). As far back as 2005, Marshall demonstrates that rehabilitation does have positive outcomes for people with dementia in terms of quality of life and self-esteem.

There is an increasing acceptance of rehabilitation for dementia, although misconceptions abound. Families and health care professionals, including physicians, often don't support rehabilitation for dementia because they believe the person with dementia is only "going to get worse" (Hopper 2003), thereby subconsciously ignoring the value of improving quality of life. A few years ago, I advocated for the inclusion of rehabilitation in the Clinical Practice Guidelines for Dementia in Australia;

The stories of many other advocates who speak publicly indicate the dementia doubters are global. Even those who don't speak publicly as advocates are often told by family or friends that they 'don't look like they have dementia'

curiously, it was not included, in spite of my providing evidence for inclusion. Ironically, many who advocated against this are now teaching it. Poulos (2017) provides evidence that rehabilitation has an important contribution to make in the management of functional decline in people living with dementia.

The dementia community of health care professionals have been slow to follow the evidence. Associate Professor James McLoughlin, an academic neurophysiotherapist at Flinders University, in part-time clinical practice, now lectures about and provides rehabilitation for people with dementia. In a DAI Webinar, he not only talked about its impact and value to people with dementia, but how difficult it is to get health care professionals to accept it as best practice (McLoughlin & DAI 2016).

Since 2009 I've been actively advocating for rehabilitation and proactive disability support for people with dementia at the time of diagnosis. Now the WHO *Global Plan of Action on the Public Health Response to Dementia 2017-2025* (WHO 2017b) (Global Dementia Action Plan) has been adopted, human rights must be included in dementia services, support and national dementia plans, which means, therefore, rehabilitation and disability support.

There are many others factors that may lead to slowing the progression of dementia. Doidge (2010, 2015) provides strong evidence of the power of neuroplasticity and rewiring our brains. I believe advocacy, which involves a great deal of mental effort, has contributed positively to my own (and others')

slower than expected progression, alongside my continued tertiary studies and research. Seligman (2013) suggests resilience and flourishing are major factors in being positive about life, even with a terminal illness, and Walker (2012) provides numerous examples of holistic health options supporting terminal and chronic health conditions, which improve outcomes and quality of life. Lipton (2005) has shown that we can change our cells through the power of belief.

Bredesen (2014, Bredesen *et al* 2016, 2017) provides a growing body of evidence for slowing the progression of dementia, including reversing it, with his research into people with MCI or early Alzheimer's disease (AD). This, and other holistic and lifestyle approaches to dementia not only support the pathway many advocates have self-prescribed, it is the closest thing to hope currently available. Kostoff *et al* (2018) adds to this new way of managing dementia providing non-pharmacological treatment protocols for slowing the progression of, or reversing early AD and MCI. Interestingly, I presented at the ADI 2012 conference in London on my own successful non-pharmacological interventions for dementia, which at that time was not well received.

Not being believed

A friend and colleague Brian Le Blanc who lives in the US writes a regular blog, speaks publicly, and has published twice on this topic. After being accused by family and friends of faking dementia, he wrote in his first blog on the subject, *So...you think I'm faking my Alzheimer's disease, do you?* (Le Blanc 2017):

"Oh wait, I get it . . . I'm supposed to be curled up in a bed, not able to talk intelligently, not able to feed myself or go to the bathroom by myself, and not remember my wife and children. God forbid, should I be able to use a laptop to write blog posts that will hopefully bring awareness and education to people who don't understand the ins and outs of Living with Alzheimer's Disease that they only saw in their elderly parents and grandparents!"

Not being believed creates significant distress in those diagnosed and their families (Swaffer 2016 pp75-82). Bryden says about being 'undiagnosed' and not believed: "As if the initial diagnosis was not shocking enough, this is even more traumatic!" (2018).

An initial diagnosis for many people often occurs after many years of searching for a reason to explain their cognitive changes. When a diagnosis of

dementia is finally given, many choose to get a second, third and even a fourth one. It is not only a difficult diagnosis to make, it is a very distressing diagnosis to receive, one that our families and close friends receive as well, as without them or some type of external support, as the dementia progresses, we may not be able to live independently. In my case, every time the tests are repeated I am still hopeful it is not dementia and instead some other treatable condition is found to explain the cognitive decline I am experiencing.

The stories of many other advocates who speak publicly indicate the dementia doubters are global. Even those who don't speak publicly as advocates are often told by family or friends that they "don't look like they have dementia". A master class webinar hosted by DAI, "*But you don't look like you have dementia*" (DAI 2017), powerfully shares the stories of many who have faced this.

Adding to this discussion, at my last appointment with my neurologist I mentioned an article published last year in *The Lancet Psychiatry*, by Professor Robert Howard (2017), *Doubts about dementia diagnoses*. Howard shares his uncertainty about the diagnoses of many "dementia advocates", saying: "Although none of these individuals has been my patient, observing their performance at meetings or through their writing has led me to develop serious doubt about the diagnoses that they carry" (Howard 2017 p580).

My neurologist, who has been seeing me since 2004, immediately looked up the article and started reading it. He

seemed sincerely 'concerned' that a colleague would publicly question any physician's ability to diagnose. We both ultimately laughed, and he reminded me that over the past 10 years, I have been retested a number of times, had a second opinion from specialists at an interstate memory clinic and, although he could only confirm my diagnosis 100% at autopsy, he sincerely believes to the best of his medical knowledge that I have the semantic variant of Primary Progressive Aphasia (svPPA).

In a response to Howard's article in the same journal, titled *No doubts about dementia advocacy*, William Hu (2017) suggested:

"Dementia advocacy is a form of John Henryism (named after the American folklore figure who died victorious after showing his superior prowess over a machine), and the advocates' health can be made worse by the persistent curiosity of dementia professionals into their abilities, and that "cognitive assessment in public settings is not valid or accurate" (p830).

Unlike our close friends or family, dementia professionals and members of the public do not see the effort it may have taken a person with dementia to get dressed that day or the support required from others, nor the time and effort put in daily to continue to live a productive and meaningful life. I've referred to it as the 'Olympics of my life' (Swaffer 2013; 2016).

The dementia doubters

So what of the dementia doubters who claim public dementia advocates may in fact not have dementia? Their views may

be based on reductionist attitudes, and the misperception that we are all the same, without considering many are being diagnosed much earlier than older people, who often do not seek a diagnosis until a crisis, due to the still very pervasive stigma being experienced (Gove *et al* 2016; O'Connor *et al* 2018), if at all. The conclusion Gove and colleagues reached around stigma in their

own profession was that: "Measures to involve GPs in tackling stigma should include training and opportunities to explore how they perceive dementia, as well as support to address structural discrimination" (p391).

This view of dementia suggests we are all the same regardless of our age or stage at diagnosis and should present that way; it is based on the medicalised deficits-based approach, and end-stage view of dementia. Even the way a person reacts to their diagnosis of dementia will be shaped by external and individual factors, such as their personality and personal history, emotional intelligence and resilience. Indeed, Howard does admit that dementia advocates "...are not a bit like the people with dementia that I have diagnosed and treated".

Thus, Howard and others may be falling prey to a sampling problem and incorrectly generalising from small samples to a larger population who have been diagnosed but who do not act as expected. Additionally, those diagnosed with younger onset dementia are unwilling to accept Prescribed Disengagement and instead, are willing try everything, including lifestyle changes. Advocacy in itself assists in reducing isolation, and the evidence consistently indicates isolation is not only a risk factor for dementia; it can speed up the progression (Poey *et al* 2017). The Alzheimer's Society in the UK is also now saying that "taking regular gentle exercise, eating a healthy diet and doing cognitive exercises can help someone with dementia manage their symptoms more effectively" (BBC News 2018).

A significant shift

There has been a significant shift in the way some academics and clinicians view people with dementia in the last two decades. Sabat (2018 pp124-125) views dementia more subjectively than those who see it only through the medicalisation of the condition, and the medical model of care; he reviews the need for resilience, and sees stigma in a new way, helping redefine the roles that are key in changing practice and attitudes, and therefore reducing stigma. Advocacy increases resilience, also a factor for managing living more positively, with dementia or for managing any other critical period of a person's life, as found by Williamson & Paslawski (2016) and Seligman (2013).

The late Tom Kitwood (1997) is attributed as saying: "If you have met one person with dementia, you have met one person with dementia." We all react



Kate Swaffer, representing Dementia Alliance International, presenting at the 11th Session of the Convention Of State Parties (COSP) on the Rights of Persons with Disabilities (CRPD) in New York in June this year

and respond differently to the world, and to life, and these words therefore apply to every human being, experiencing any medical condition, as well as every reaction to a life event, illness or crisis. Howard and other dementia doubters seem not to take this uniqueness of all patients into account. Ironically, he and others with similar views are part of a system that is advocating for earlier diagnosis, but their attitudes and practices seem out-dated, and are potentially harmful to the very people being diagnosed earlier.

Dementia being managed as a chronic progressive disease, with lifestyle changes, is the way forward. Even if this approach is not a cure, it will enhance wellbeing and quality of life, may slow the progression, and will reduce the risk of other comorbidities and improve quality of life.

Being invited to tell our personal stories has increased the presence of people living with dementia at conferences and events, and invitations onto advisory or expert working groups. Most professionals suggest this is helpful, as it ensures outcomes are based on our genuine needs, not what others perceive them to be, and many say it has enhanced education. Ironically, it has also increased the number of dementia doubters, and the inexplicable occurrence of a 'public dementia diagnosis' whereby people feel they can diagnose, or doubt a person's diagnosis, after reading their book or blog, or listening to them present at a conference.

Conclusion

Before dementia, people have good and bad days; life with dementia is no different. It is possible to live a positive and productive life, some of the time, even with dementia, if supported well. I suggest, with a lot more proactive disability support from the day of diagnosis, and moving away from the out-dated dysfunctional and medicalised attitudes about dementia, many more will be living positively with dementia, for much longer, either confounding the experts even further, or teaching them it is possible.

With or without dementia, we are all born with a death sentence. There is no need for a diagnosis of dementia to be seen as the catalyst to give up living, and meekly go home and wait for that to happen. ■

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Supporting selfhood and individuation: a case study

Dodi Rose and **Steven R Sabat** examine how engaging in activity that connects with a person's valued, lifelong abilities can strengthen and support selfhood

People diagnosed with dementia frequently experience social isolation (Snyder 2009) that can have negative effects on their sense of self as well as on their ability to experience and express what psychologist Carl Jung called *individuation*: their ability to be someone distinct from all others, displaying their unique valued attributes in the social world and experiencing the accompanying fulfillment.

People diagnosed often become innocently restricted, in the eyes of others, to being 'dementia patients' and this unfortunately prevents them from being all they have been in their social lives and from expressing many of their intact and valued attributes as unique people. Furthermore, this situation often leads to people diagnosed feeling saddened and often depressed – both of which are not symptoms of dementia as much as they are appropriate reactions to the social circumstances they now experience. This, in turn, can have negative effects on their loved ones as well. So what can be done in non-pharmacological ways to help alleviate these situations?

Aspects of selfhood

We can begin by understanding that there are different aspects of our selfhood and this understanding can illuminate not only the problem we have just discussed, but possible solutions as well. According to social constructionist theory (see Sabat 2001), two aspects of selfhood are



Author Dodi Rose at the National Gallery of Victoria (NGV) in Melbourne, where she's been a voluntary guide since 2005 and coordinated the NGV's 'Art & Memory' and 'Gallery Visits You' programs from 2009-2015. Her work at the NGV with people living with dementia was inspired by co-author Steven Sabat's concept of the Self. Photo: National Gallery of Victoria

especially germane here: Self 2 (the self of our attributes) and Self 3 (the many different social relationships we create with others) (see box this page).

Self 2

Self 2 is comprised of one's physical and mental attributes, past and present, including one's interests, abilities, dysfunctions, foibles, beliefs (political,

social, moral, religious), and beliefs about one's attributes. One can take pride in some attributes and be embarrassed, saddened, or angered by others. Often, people diagnosed with dementia find that others focus increasingly on attributes related to their diagnosis, the very attributes about which they are saddened and embarrassed, while simultaneously paying less attention to the attributes in which they take pride (Sabat 2018). Imagine how you would feel if everyone around you began to see you principally in terms of the attributes you like least about yourself!

Self 3

Simultaneously, their Self 3, or their multiple social personae/identities (devoted friend, authoritative scholar, compelling teacher, loving parent, grandparent, and the like) are reduced increasingly to 'dysfunctional dementia

Aspects of selfhood

Self 1: Expressed via personal pronouns.

Self 2: Physical and mental attributes past and present, including beliefs about said attributes.

Self 3: Social personae (devoted spouse, loyal friend, demanding professional, dysfunctional patient) constructed with cooperation of at least one other person.

Reference: Sabat SR (2001) *The experience of Alzheimer's disease: life through a tangled veil*. Oxford: Blackwell Publishers



Dodi Rose, engaging people living with dementia in an Art & Memory tour at the NGV. The preferred tour is the slow tour, where everybody is happy to pause, reflect and enjoy the moment. Photo: National Gallery of Victoria

patient', because healthy others do not cooperate with the person so as to co-construct one of the healthy, valued social identities he or she has built with the help of others and taken delight in in the past. We cannot act as a devoted friend to someone if that someone does not recognise us as being his or her friend. Both of these rather innocently inflicted assaults can lead to sadness and grieving on the part of the person diagnosed that can increase his or her stress levels and undermine psychological wellbeing. Naturally, such effects can be harmful to loving care partners as well.

In the following case study we build upon and support previous research (Sabat 2001). We show that when people living with dementia feel safe to express themselves in spite of word-finding and memory difficulties, and are given the opportunity to engage in their social world in ways that connect with valued, lifelong abilities, (a) they can enjoy, as would any person, enlivening moments that engage their intact abilities and (b) provide them with opportunities to express themselves socially in ways that connect with their positive sense of self and proper pride and their unique, valued abilities.

Sara's story

Sara (not her real name), diagnosed with dementia, had worked for many years as a voluntary guide at the National Gallery of Victoria (NGV) in Melbourne. Her daughter accompanied her on fortnightly

Art & Memory program tours at the gallery. (The interactive Art & Memory program is designed specifically for people living with dementia and their carers, offering participants an opportunity to enhance their quality of life through mental stimulation, communication and social engagement during tours and discussions of the gallery's art works).

The first author of this article, Dodi Rose (DR), came to accompany Sara and her daughter on subsequent fortnightly visits to the NGV for over a year and witnessed in Sara a vibrance and clarity as soon as she entered the gallery.

Whatever fragmentation of cognitive abilities Sara may have experienced before the tours, on seeing and recognising DR she was able to gather herself and focus on the moment, stimulating aspects of her personality (Self 2 attributes) that were dormant before. It was especially helpful to give Sara time to find the words she wanted to use, whereby she could reflect on the various works of art on display. DR asked questions about her feelings and observations regarding the artworks. In slowing down and giving Sara time to reflect, feel and respond, it was a welcoming experience for her to know that the focus was on her perceptions, thoughts and feelings rather than on the dysfunctions connected with dementia.

The tours were always initiated on the premise that DR was to be instructed by

Sara on the skills of art appreciation: how to engage the public with the artworks. Thus, Sara was in what we might call a senior position to DR in that she was the one with knowledge and authority about the artwork, over and above that of DR. With her expertise valued and acknowledged by DR, Sara received the necessary cooperation she needed to construct the positive and valued Self 3, the social persona, of teacher, docent, or guide. The troubling Self 2 symptoms of dementia were not focused upon; rather the two women stayed attentive to and focused on Sara's enduring positive attributes, her special place within the gallery, her great ability to enliven children's curiosity and interest as she had done in the past. Sara was able to retrieve somatically and consciously her embodied and now emerging Self. Her enjoyment and love of the art collection and the treasures within the gallery enabled her to flourish in her role of teacher, docent, guide.

For Sara, in a very real sense, the gallery provided an experience of peace and safety, for she was in the company of people she trusted. As well, the gallery was a place where Sara could retrieve many stories about works of art and have her comments appreciated and respected. During one of the Art & Memory tours, Sara observed that the gallery played an important role in society as "a welcoming place where you can come to be a part of life...without having to be somebody, or say anything, without having to do anything – simply being. No one has to be alone, isolated; you simply step into the gallery to once more connect with the community, without anything being asked of you. You can engage on any level you desire... with everyone treating you with warmth... you never have to be alone again." This surely was a powerful and poignant observation as well as an indication of how Sara's sense of Self was being nourished and developed in this environment.

The very fact of being a person was honoured, independently of what one can do, of being asked things, that "everyone treating you with warmth" was clear and appreciated deeply by Sara. This is a clear statement about how a diagnosis of dementia does not prevent a person from appreciating the warmth and acceptance of others and the security of a place in which others will not focus on the attributes (the dysfunctions) that are so troubling and often embarrassing to people diagnosed.

Experiencing the gallery

Guanyin Bodhisattva

On one visit to the NGV's Asian

collection, Sara, DR and Sara's daughter approached the Chinese wooden sculpture of *Guanyin Bodhisattva* (Jin Dynasty 1115-1234), seated in a pose of 'royal ease', robed and jewelled. Sara immediately took up the same elegant pose, mirroring *Guanyin*, demonstrating with her body the figure's grace, power and regal stance. Sara spoke of "*Guanyin's* elegant, relaxed pose" and the gesture of her hand held with such delicacy yet displaying great strength. Sara was fully embodied. She explained, "You can see the way in which *Guanyin's* big toe is pointing upward and the little finger on her hand is also pointing upward, bringing the whole sculpture to life." She called attention to these seemingly insignificant but very potent details. As she spoke, Sara was able to draw on her previous knowledge, whilst also expressing new insights.

Bushido

Sara, her daughter, and DR also visited the *Bushido* exhibition in the NGV's Japanese collection. Sara's observations brought each element of the exhibition to life as she spoke of "the marvel of the craftsmanship, the intricate detail, with nature as the main inspiration, the complexity of the metals used and the beauty of the embroidered garments". "Were they done by women?" ... "Were they acknowledged?" Sara's thoughtful questioning opened up many insights worthy of exploration. In summing up her thoughts, Sara marvelled at "the human imagination and the innovation of the human being to be able to create such works of not only great skill but of great beauty!"

The Thinker

In the Salon gallery was the bronze sculpture of *The Thinker* (1884) by the French sculptor Auguste Rodin, believed to be the earliest version of the world-famous figure. Sara called attention to "the weight of his head on his hand – the pensive moment of thinking the thought, the weight of the twisted body with the other arm relaxed; the feet with toes stretched, arched, holding the tension of the twisted body." Sara spoke of how she loved to watch people viewing art: seeing the intensity of their gaze, and the personally meaningful relationship they formed with the collection.

Sara's daughter believed that her mother became empowered by her awareness that she could still enrich the lives of others with her incisive artistic perceptions and wisdom about life. In these and other experiences at the gallery, Sara became fully present, truly seeing

and participating in the world she loved and to which she still had much to offer.

Reconstruction of selfhood

Sara's demeanor was strikingly different at home as opposed to at the gallery. Her daughter noted that as her mother's illness progressed her self-esteem and personal confidence plummeted and she often became very frightened by the confusion that engulfed her. At home, her spirits were often low and she had trouble getting up in the morning. "What's the point?" she'd ask. "I'm no use to anyone anymore." Sara often resisted the idea of going to the gallery. Her daughter felt she may have been embarrassed and ashamed of her deteriorating memory and condition and was worried about meeting former colleagues.

However, as soon as she and her daughter stepped into the gallery, Sara's whole demeanor changed. She became visibly calmer and more self-possessed. She expressed excitement at being at the gallery, which she referred to with delight as "my old familiar haunts". Sara delighted at renewing her acquaintance with what she referred to as "my old friends" – iconic works in the gallery's permanent collection. It was a pleasure and a privilege to assist Sara in reaffirming her in-depth understanding and appreciation of the gallery's collection, and in particular her love of Asian art.

Sara's definitive statements about the gallery affirmed her love of this special place: "The gallery is a place you can be in and allow beauty to affect you, there is no rubbish here" ... "It is all quality, excellence, the artists using the very best materials and creating the finest works of art."

Through these experiences Sara was able to reaffirm her own wisdom and sense of self-worth. During the gallery visits Sara also met other people who knew her and with whom she had interacted when she worked at the gallery: curators, security guards and colleagues who had also been voluntary guides. She not only remembered moments in time, but was being remembered by others. During one of the Art & Memory tours, an NGV staff member recognised and greeted her, recalling, "You were a breath of fresh air!".

Sara glowed with renewed feelings of worth and self-respect during these interactions; her smile was radiant as she remembered how much she had valued her time in the gallery and how greatly she was valued.

In being celebrated and by focusing on

her positive, valued, attributes rather than aspects of her cognitive abilities that were diminished, Sara was visibly more and more confident. She embodied the dignified, happy, fulfilled person she had been.

Transformation

Sara's daughter observed that at the gallery her mother vibrated with individuation, with a dignity and sense of place in the world, which had become lost to her in her daily life. Her posture became upright and proud, her movements graceful and expressive. She displayed a sense of purpose, a sense of pride in her achievements and accomplishments, and a sense of joy in being alive.

There was a striking transformation in Sara's sense of herself when immersed in the world of the gallery where she could draw on her vast knowledge of art and where she could engage children. As she noted, "I loved encouraging their creative minds and making the gallery an interesting, vibrant place for them."

Conclusion

It is clear, then, that a person diagnosed with dementia can retain and express a great deal of their valued knowledge and attributes as well as the ability to be a person vastly different from a 'dementia patient' if only given the opportunity and support of patient, caring others. When we engage people with dementia as human beings who are fundamentally intact in the most important of ways, we help them to flourish and find meaning in the world and we do the same for ourselves. ■



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The power of collective action

Practice change programs are often seen as the way for care organisations to achieve person-centred care. **Sarah Cope** questions this approach and says instead, residents should be given more opportunities to support one another

In Australia it is well understood that people living with dementia in residential aged care facilities (RACFs) live within organisations that spend large amounts of money on practice change programs. The goal of achieving a person-centred culture for many RACFs is often elusive. All too often programs can become diluted by day-to-day care, leaving the rollout of person-focused practice approaches to revert back to time-focused routines. Therefore care then becomes once again dictated by the structure of the organisation rather than by the consumer.

This article highlights ideas for practice change in achieving a more collective person-centred approach from observations of interactions from a facility in the Pacific.

Confronting conditions

In 2017 I joined 12 undergraduate nursing students as an academic facilitator on a clinical placement to an island in the Pacific. During the placement students were required to spend time within a mental health unit at an island's hospital to gain clinical experience. The mental health unit catered for people in acute mental health crisis as well as providing permanent residential care for people living with dementia. The environmental conditions within the mental health unit were confronting and extremely impoverished.

The physical environment was set as an institution as Goffman (1961) established, located away from the main hospital and socially isolated from the island community. Overcrowding was an immediate issue with only 28 beds for 41 people. Many slept without mattresses or bedding, and resorted to sleeping on the ground with no linen. Strict rules were imposed by medical, nursing and security teams. Day-to-day care within the institution was rule-bound with layers of surveillance. The institution set the order of the day. Tasks were performed at the same time in the same manner and care work was controlled through the dominance of

tasks. Nursing staff wore white uniforms and security guards wore black with padded vests and carried batons. The staff instilled order with a regimented administration of set times for medications, meals and staff-to-resident interaction.

Sense of community

Initially, the impoverished environment and overall disciplined administration of care made me incensed. Seeing shared living spaces for people with dementia and those experiencing acute mental health issues brought to the fore ethical issues of risk and safety. After a few weeks however, I started to notice that those living within the unit created their own routine. A sense of community and home was formed by one another rather than the organisation. I started to consider this institution and care for people living with dementia differently.

Instead of holding on to my expectations of what best practice should be, I started to let go of my moral expectations. I began to deliberate about what was really going on between residents. I looked beyond what was immediately in front of me and started to think about, as Goffman (1959) espoused, "the definition of the situation". What was the driving force behind people living together as a collective group? How was this group of individuals creating a sense of self,

community and collaboration? What was really going on aside from the organisational structure and rigid rules?

Connections and negotiations

I began to focus on understanding interactions and collective action between individuals. Once considered in this light, as Meltzer and colleagues (1975) inform, I noticed connections and negotiations between individuals. What was evident behind the wire fence of this institution was the collectivism between the short-term patients and long-term residents.

This secure institution was a home for many, created by those living within, rather than by staff dictating and delivering a fixed organisation of care. To explain further, and to provide an example, within the institution was a man of 22. He was diagnosed with a mood disorder and had a complicated history of violence, abuse and drug dependence. This young man took it upon himself to support the residents living with dementia by helping them with personal care and meals. He would carry those that were unable to walk and covered in faeces on the floor to the shower block and gave essential personal care.

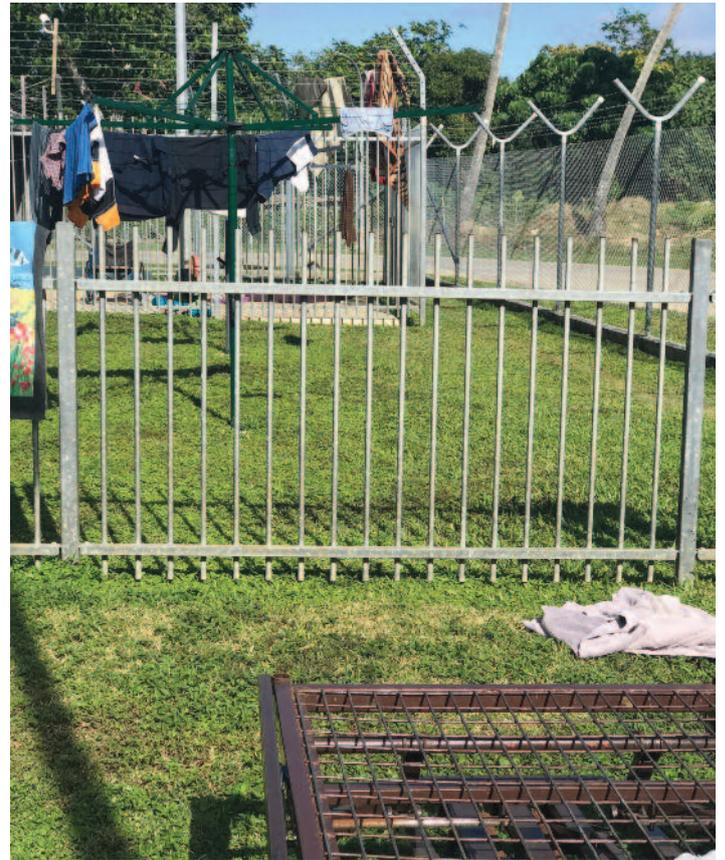
He was not the only one to do so; many would support those who were dependant on others for their care needs. Other people living in the unit created safe spaces inside the larger living area to initiate group discussions and memory support groups. If a person living with dementia had a fall or experienced incontinence, it was the fellow individuals within the institution that understood and delivered person-centred care.

It was at this point I recognised that it was the collective action of fellow residents towards the dependent care group that espoused a person-centred approach towards one another. This all occurred against squalid living conditions, an appalling impersonal environment and away from the hierarchy and bureaucracy of nursing teams and security guards.

The routine of enabling an



Above: The unit's communal outdoor area



Left: The entrance to the unit for people living with dementia, part of the Pacific island mental health unit. Within this confronting and extremely impoverished environment, it was the patients and residents who created a sense of community and home, rather than the organisation. Right: Overcrowding was an issue, with only 28 beds for 41 people. Many slept without mattresses or bedding, or on 'overflow' beds in this outdoor area

individualised, person-centred approach was created through flexibility in caring for one another through collective action.

Residents hold the key

Let's pause for a moment and consider the reality of care practice in Australian residential aged care facilities. We are bound by strict accreditation rules and hierarchical systems. What if, rather than imposing a person-centred approach through complicated practice change programs, residents were provided with more opportunity to support each other? As Kitwood (1997) states, giving is part of living.

In other words, those living within the facility hold the key to creating a collective and caring environment by supporting one another. Shared collective actions, as Gongaware (2012) affirms, sets identity-making against the structure of an organisation. This means, as Klandermand (2004) explains, collective action is created by everyone working together.

On the island, residents created their own sense of identity and a collective movement towards a more person-centred care approach. They were able to

find a sense of purpose and build a person-centred environment through their interactions, thus producing collective action to support others. Collectivism, as Melucci (1995, 1996) notes, symbolises unity. Hence those living within the unit negotiated care giving through collective action to produce their own definition of person-centredness. In this instance, against the harsh realities of living in an appalling institution, individuals overcame adversity to deliver care and understanding towards each other as was highlighted through their collective group action.

Take a step back?

At this point I would like to reiterate my proposed argument for further thought and consideration. If we focus on interactions and collective actions of groups within RACFs against the structure of the organisation, this may provide another way of thinking about achieving a person-centred approach. In other words, interactions within our facilities create the home and a sense of belonging, aside from the overlaying organisation.

It is at this point we need to stop and

look at the situation of what is really going on with the interactions and collective actions of residents. Currently, organisations promote a person-centred approach at every opportunity. Managerial hierarchies impose one-line mantras about person-centeredness as a model or a representation of practice that does not align with everyday care.

We know that person-centeredness is an approach rather than a model and need to ponder further on whether the millions of dollars being spent by care providers to impose culture change to create a more person-centred reality is really working.

Maybe the answer is already in front of us. What if we provided an opportunity for residents to create their own collective action? What if we, the care givers, managers, and organisational hierarchy, just take a step back and learn from those who have achieved this in the most undesirable circumstances? For example what if, as on the island, the concept of time was irrelevant and care came from a more organic paradigm? What if personal care, such as a shower, was delivered when the individual was ready; food was given by others when wanted; food



Can residents be given more opportunities to create a caring environment by supporting one another? Photo: Eberhard Grossgasteiger, Unsplash

preparation was a whole-of-facility operation?

Bound by the clock

In Australia care is bound by the clock. Time is the dominant force over when and how care is provided. Time and temporality (meaning past, present and future of how things are done) dictates. The dominance of time and routine is privileged over actual person-centeredness and collective action. The current situation of practice does not align with the needs of people living with dementia. I propose if we remove the dominance of when a task should be completed we may be able to recreate a more collective home environment.

What if we do not turn the lights on at 6.30am or 7am when the morning shift comes on for the day? What if we leave the lights off until people wake naturally; staff do a morning handover, then a quiet round to check who is awake and who is asleep. People wake when ready; breakfast is available on demand. Personal care is not dominated by time and is offered when the person is ready; medication delivery is prescribed at times to match the individual's unique cycle (within reason. Time is removed from the day.

Currently, in practice for most morning shifts, 11am is the golden hour for care staff discussions. This is the time that staff orientate and judge whether their work is 'falling behind' or not. Their work is time-based and removes opportunity for collective action. Time has become the socially bound representative over collective care actions. Of course, managers, those in

hierarchical positions and care staff alike reject that a preference for routine exists, but reality demonstrates the opposite.

I suggest that for a true person-centred approach to align with the person living with dementia we must remove time-based routines. We need to consider a move to a more collective and person-centred focus requiring a whole-of-organisation culture change movement. For example, a facility could focus on one wing of the RACF to trial changes to care.

Education sessions would be required to inform the residents living with dementia, their families and all staff and to explain, discuss and negotiate proposed temporal changes to care delivery: the morning shift staff would not routinely turn on lights, start medication rounds and bring people to the dining room for a communal breakfast. The kitchen would be affected due to variances in meal delivery and meal times. Cleaning staff would need to alter cleaning routines, and noisy cleaning activities would be moved to times that did not disturb others. Staff meal break times would change so they were available to provide individualised care as residents awoke during the morning.

Time for change?

Changes to care provision need to be gradual. As with all change, this can bring uncertainty and stress to all involved, so planning is vital. Of course these changes may not be suitable for all people living with dementia as some individuals require care routines because of their dependency on help with

personal care, toileting and nutrition.

This is just one suggestion to change care practice. This article suggests an alternate view and offers many avenues for further discussion.

Postscript

After my trip to the Pacific island I made a presentation to the Australian High Commission on the island to raise awareness about the impoverished environment and appalling living conditions within the mental health unit and the desperate need for improvement.

Since then, a recent report has identified some improvements for the residents with dementia: a new built environment has been proposed, to be paid for with international funding. At the time of writing the overcrowding issue had been resolved, with each person now having their own bed; people living with dementia and older adults are no longer admitted to the mental health unit and are now cared for in a designated ward within the main hospital. ■

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

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

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

Integrating ASCOT in care planning

Ann-Marie Towers, Karn Nelson, Nick Smith and Kamilla Razik report on a joint UK-Australian project which trialled a new and innovative use of the ASCOT tool in residential aged care planning to help staff initiate and hold conversations with residents, including those with dementia, about their emotional and social wellbeing

Australia's population is ageing and with 54% of aged care residents estimated to have dementia (AIHW 2012), finding ways to measure and improve the quality of the care and support they receive is becoming increasingly important. As providers face mounting pressure to be accountable for the quality of their services, being able to measure outcomes will also become even more imperative.

However, measuring the quality of care and the impact of aged care services on quality of life and wellbeing, consistently and systematically, is a challenge for many aged care providers. The clinical bias in care planning and reporting in Australian residential aged care is exacerbated by the (mainly) clinical base of the current Aged Care Funding Instrument (ACFI). This has resulted in a lack of focus on evaluating the impact of services on wellbeing.

The Adult Social Care Outcomes Toolkit (ASCOT),



Integrating the ASCOT in care planning gave Whiddon's staff a greater understanding of how they could better support residents' social and emotional needs with more tailored and personalised care. Photos: The Whiddon Group

developed by the Personal Social Services Research Unit (PSSRU) at the University of Kent in the UK, is one of the few tools able to measure the impact of care services on user wellbeing or Social Care Related Quality of Life (SCRQoL). It is internationally recognised as robust and can be used in a variety of settings and with people with any disability, including dementia.

ASCOT measures Social Care-Related Quality of Life

(SCRQoL) across eight domains (see Table 1, p32) and can also be used to estimate the impact a service is having on those outcomes. The eight domains of wellbeing cover four lower-order needs (accommodation, food, safety, personal care) and four higher-order needs (social interaction, occupation, control over daily life, dignity). The four lower domains are traditionally much easier to support, whereas the four higher

domains are more challenging for providers to support well.

Reliability of the ASCOT tool is well evidenced internationally. The measure has been used in research in the UK, Australia, Japan and Europe and its domains have been found to be relevant to providers, service users and their families and sensitive to the impact of services on users' quality of life (Malley, Towers *et al* 2012; Netten, Burge *et al* 2012). While widely used to assess and review community care programs and services in the UK and other countries, the ASCOT's use in Australia is less common.

In 2016, the ASCOT team at PSSRU and Australian aged care provider The Whiddon Group embarked on a project to explore how they might use the ASCOT to inform care planning conversations with residents, including those living with dementia, in their aged care services. Whiddon's review of its care planning practices had identified a gap around consistent evaluation, goal setting and structures in

the wellbeing area. Importantly, some Registered Nurses (RNs) said they were not confident initiating and conducting conversations with residents around their emotional and social needs

During 2016-2017 the PSSRU team and The Whiddon Group conducted a 15-month trial at four Whiddon aged care homes in NSW to test the feasibility and benefits of using the ASCOT in care planning in residential aged care, as well as the sustainability and effectiveness of the 'circle of care' interview methodology designed for the trial.

Although ASCOT has previously been used in 'assessment and review' (Johnstone & Page 2014) the integration of ASCOT into care planning, and the 'circle of care' approach that enabled people with dementia to participate, represented a new use of the ASCOT both in Australia and internationally, particularly in residential aged care.

This article provides an overview of the ASCOT pilot study in Australia, along with Whiddon's perspective on what was learnt through the trial in terms of value added to care planning and quality of care, relationship-based care and client and family empowerment, as well as the sustainability of the methodologies used.

The Whiddon trial

The University of Kent's ASCOT team helped design the trial and methodology, and provided webinar and online training tools for Whiddon's RNs, as well as ongoing support to the trial managers. Whiddon ran the trial, conducted mentoring and support sessions before and semi-structured interviews with RNs after each wave of the trial. The RNs conducted ASCOT conversations and collected data, which was submitted to, analysed and reported by the ASCOT team.

The main goals were to test the integration of the ASCOT in care planning. This included:

Box 1: Question and response options from the ASCOT 'control over daily life' domain

Which of the following statements best describes how much control you have over your daily life?

Interviewer prompt: By 'control over daily life' we mean having the choice to do things or have things done for you as you like and when you want. If needed, please prompt: When answering the question, think about your situation at the moment.

Please tick one box.

- I have as much control over my daily life as I want
- I have adequate control over my daily life
- I have some control over my daily life, but not enough
- I have no control over my daily life

- Its value to residents and improved quality of their care (including its alignment with Whiddon's MyLife model and relationship-based care approach).
- User-friendliness and effectiveness of the tool and 'circle of care' methodology for residents, families and RNs.
- Sustainability of conducting ASCOT conversations as part

of care planning in terms of additional RN time and burden to residents and families.

- The value to quality improvement of services at individual, service and system level.

Adapting ASCOT for care planning purposes

The ASCOT consists of a suite of measures for service users

(www.pssru.ac.uk/ascot/), including; self-completion questionnaires (SCT4 & SCT4-ER), face-to-face interviews (INT4) and a mixed-methods approach for measuring the outcomes of care home residents (CH3). Different tools are recommended for different settings and user groups.

For the Whiddon trial we used the ASCOT face-to-face interview tool (INT4) in care planning conversations in the four sites. As the ASCOT INT4 measure was not designed for people with cognitive impairment and/or difficulty communicating, we expected most aged care residents to struggle to complete it without help. To overcome this but still include clients in their care planning conversations, we needed a methodology where a rounded perspective was gathered for residents living with dementia and then used to complete the ASCOT interview tool (INT4). The ASCOT team proposed an innovative approach to completing the INT4 whereby trained RNs led care-planning

Table 1: ASCOT domains of social care-related quality of life

Domain	Definition
Control over daily life (choice)	The person can choose what to do and when to do it in his/her daily life.
Personal comfort and cleanliness	The person is personally clean, comfortable and is dressed and groomed in a way that reflects his/her personal preferences.
Food and drink	The person feels that s/he has a nutritious, varied and culturally-appropriate diet with enough food and drink that he/she enjoys when s/he wants it.
Accommodation comfort and cleanliness	The person feels their home environment, including all the rooms, is clean and comfortable.
Personal safety	The person feels safe and secure; not feeling worried about bullying or abuse, falling or other physical harm, or being attacked or robbed.
Social participation and involvement	The person is content with their social life; spending time with the people they like, including friends, family and people in the community.
Occupation (how you spend your time)	The person feels that they are able to spend their time during the day doing enjoyable and meaningful activities, which could include free time or leisure activities, housework, going to work, college, or volunteering.
Dignity	The psychological impact of support and care on the person's personal sense of significance; the person feels that s/he is treated nicely and kindly by paid support staff.

Easy Read ASCOT for people with dementia

Dr Lyn Phillipson, an NHMRC-ARC Dementia Fellow from the University of Wollongong (UOW), in NSW, has also been working on a collaborative research project with the University of Kent supported by her NHMRC Fellowship and an IRT Research Foundation/UOW partnership grant. This research has worked to adapt an Easy Read version of the ASCOT to engage older people with cognitive impairment in reporting on their social care related quality of life.

"I am really excited about the potential of Easy Read principles – that is the use of simple language and pictures – to improve the accessibility of survey tools and other research information," Dr Phillipson said.

"The ASCOT-ER had been rigorously developed by researchers from the University of Kent but only for use with younger people with intellectual disability and autism. We have now been able to

use the same cognitive interviewing methods to adapt it for older people with cognitive impairment and dementia and it has improved our ability to report on their Home Care Package outcomes," Dr Phillipson said.

"It is essential in a consumer directed care (CDC) model that we have tools that can help us assess client-related outcomes for all service using groups. We also want to understand the contribution their care and supports make to their quality of life.

"We know people with dementia have frequently been excluded from evaluation studies of CDC because the evaluation tools have not always been accessible. So the use of the new ASCOT-ER to assess SCRQoL in this population is really welcomed."

To find out more about this research, contact Dr Phillipson at lphillip@uow.edu.au

approach, measured in terms of additional RN time, were set as critical success factors for the trial.

All participating RNs at the four sites received online, webinar materials before baseline and had ongoing support from the ASCOT team throughout the trial.

ASCOT data were collected at baseline (T1), six months (T2) and 12 months (T3), along with data on participating residents' needs and characteristics and feedback from RNs, collected by Whiddon, about the 'circle of care' conversations.

This article focuses on the 12-month follow-up data and the feedback from qualitative interviews with RNs regarding their experience of using ASCOT in care planning.

conversations involving the resident, their family members and their dedicated care worker. We called this a 'circle of care'.

Together, the circle of care worked through the eight ASCOT domains, discussing the residents' quality of life in each. Ultimately, the aim was to indicate, by ticking one of four possible response options, whether the residents' needs were being met by the service in this area of their life and, where necessary, discuss how their experience might be improved. An example taken from the *control over daily life* domain can be found in Box 1 (see previous page).

For each ASCOT domain, there is one question regarding the person's current quality of life and four possible response options. Conceptually, these response options correspond to the following outcomes states:

- Ideal state (person's needs and preferences are met in this area of life).
- No needs (person has no or only temporary/trivial unmet needs).
- Some needs (sufficiently important or frequent to affect the person's quality of life).
- High needs (physical or

mental health implications if they are not met over a period of time).

For each ASCOT domain there is also a second question which asks the person (or their carer) to say what their expected quality of life would be if they were not in a care home and were living in the community with no additional support services. The responses help identify the gap

between the person's expected and current quality of life and the impact of care services.

Balancing the perspectives of clients, their family member(s) and the dedicated care worker and then using this information to choose a rating that accurately represents the resident's quality of life in each domain requires a skilled and considered approach. The reliability of the ratings, and the sustainability of the

Results

Residents' needs and characteristics

A total of 61 residents took part in the trial across the three waves. This summary focuses on the findings at wave three (12 month follow up), which had a sample size of 47 residents (ranging from 11 to 13 per site) with an average age of 86 years. The majority (62%) were women. Nineteen participants were diagnosed



The consistent and structured conversations and the insights gained around residents' social and emotional needs with the ASCOT tool supported the relationship-based care which underpins Whiddon's MyLife model

with dementia, but more (n=31) had short-term memory problems. On average, most residents had lived in the service for about 16 months and could manage about six activities of daily living (ADLs) on their own without help.

Residents' SCRQoL

As the ASCOT is preference-weighted for use in economic evaluations (Netten, Burge *et al* 2012), scores for SCRQoL range between 1 and -0.17. A score of 1.00 is achieved when each domain is rated as ideal state. A score of -0.17 is achieved when each domain is rated as high needs. A score of below 0 is equal to what the general population sees as a state worse than death.

The average SCRQoL score at the 12-month follow-up (T3) was 0.83 across all four sites (ranging from 0.76-0.87 per site). Although this is high compared to other studies of ASCOT use in the UK, in which the mean current SCRQoL score for care home residents was 0.71 (Netten, Trukeschitz *et al* 2012; Towers, Smith *et al* 2016), it is comparable with other work using the ASCOT in Australia (Kaambwa, Gill *et al* 2015; Cardona, Fine *et al* 2017).

The bar chart below summarises the distribution of responses in each domain. Services were very good at meeting residents' needs in the four basic domains (accommodation cleanliness and comfort, personal cleanliness and comfort, food and drink and personal safety) and dignity. In these domains, no residents were recorded as having high (unmet) needs, although a small proportion did have some unmet needs, meaning their quality of life was being affected. Following the pattern found in English care homes (Towers, Smith *et al* 2016), there is more evidence of unmet needs in the higher-order domains of social participation, occupation and control over daily life and also less evidence that people are in the 'ideal' state compared with



Photo: The Whiddon Group

personal safety, accommodation cleanliness and comfort and personal cleanliness and comfort.

Time taken to complete the interviews

Based on the RNs' estimations, the mean time to complete the ASCOT care planning conversations ranged from 19-28 minutes, with a mean of 25 minutes across all four sites. On average, RNs estimated that these interviews took only an additional two minutes, compared with usual care planning conversations, by wave three.

RNs' perspectives

Whiddon conducted semi-structured interviews with the RNs at six-monthly intervals. The majority of RNs reported that residents were feeling empowered, "at the centre of their world" as a result of having structured conversations around their wellbeing. "They feel that it gives them a safe place to talk about feelings, and that we

want to hear them. It doesn't feel like a whinge."

RNs reported learning things about new residents that would normally take much longer to 'come out' and that the structured conversations helped to facilitate good outcomes and solutions. For example, one lady with dementia, who came into care with her husband, who had been her primary carer, immediately confided in the RN that she was distressed that her husband had requested that she be excluded from the social and creative programs. The RN was able to discuss this openly, as part of an ASCOT conversation, with the woman's husband and a joint decision was made that his wife should participate in the painting program, which she did with enthusiasm. For his part, through these conversations, her husband was able to come to terms with being in residential aged care, and the benefits to his wife.

Residents and family feedback

Residents reported that having the structured conversations, and seeing issues followed up, made them feel that "the staff really care about me". Family members reported that they were learning things about their family member that they had not heard before, and they now felt more involved in their care, and able to follow up on things with the RN.

Feasibility of use in care planning conversations

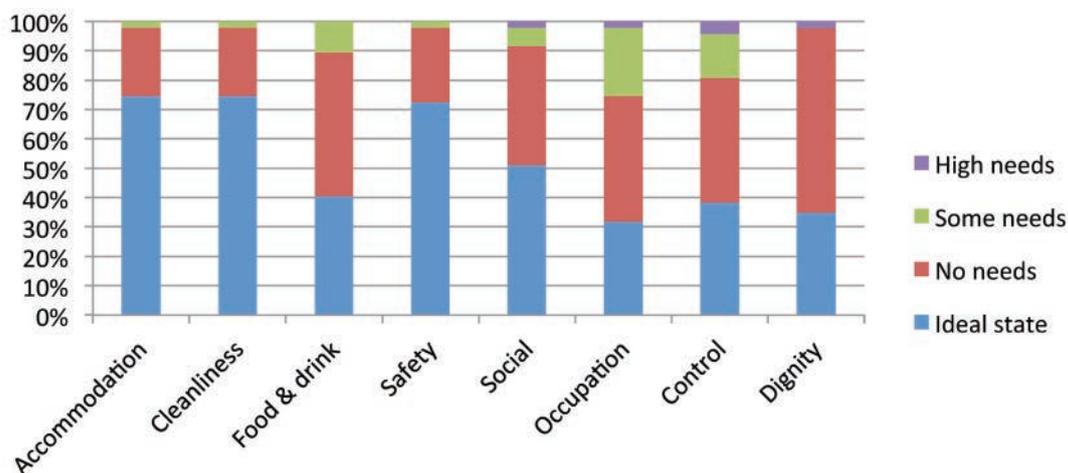
RNs reported that the ASCOT tool was easy to use and a good base for conversations. Some of the wording required explanation, reflecting cultural differences. This, coupled with the high average SCRQoL scores, which have also been reported in other Australian research using ASCOT, might indicate the need for future research to test and culturally adapt the wording for an Australian population.

There is also likely to be value in conducting a preference study to develop scoring weights specific to the Australian population.

The question about 'expected quality of life' if the person was not in a care home attracted criticism. It was deemed relevant to ask new residents, but not beyond three months when it had the effect of 'closing down' conversations with traumatic thoughts. Instead, it might be better for these estimations to be made by trained RNs instead of asking residents directly, which is more in line with the mixed-methods ASCOT toolkit used by researchers in care homes (Towers *et al* 2016).

The circle of care methodology, while effective for residents with dementia, required some amendment as the administrative burden of trying to hold one conversation with all

Current SCRQoL by domain



participants present proved too onerous.

Notwithstanding these areas for review, the value to care planning and the sustainability of integrating the ASCOT conversations in Whiddon's normal case conferencing and annual care planning cycle was clear for most of the RNs.

The consistent and structured conversations and the insights gained around residents' social and emotional needs is a good support to the relationship-based care which underpins Whiddon's model of care. This is illustrated by the following quote from a RN: "This gives us the time to stop and recognise that they are people too, like us, and the challenges they experience around accepting help".

Discussion: what we learnt

The data showed us that the homes in this pilot study were good at supporting residents across most of the lower-order domains and that staff deliver care in a way that makes residents either feel good about themselves or does not affect their self-image.

Food and drink was more challenging. Our relationship to food is complex and touches many emotional and social needs. Some residents were not happy with the modifications to their food following a dietician's prescription. One or two residents were not happy with the quantity they were receiving, and this trial was the first time that they had given this feedback. This information gave Whiddon staff the opportunity to make improvements and during the study they were able to work on all of these needs and saw improvement from waves 1 to 3.

The higher-order domains are relatively more difficult to support. The services were particularly good at supporting social participation but scores were relatively lower for control over daily life, suggesting further areas for focus.

Whiddon learnt that average

SCRQoL scores on their own are not a good indicator of service performance. They have to be seen in the context of the individual's care and functional needs and the care profile of the different services. As this was a pilot, there were not enough data to really understand this; with more time and data we should be able to better interpret trends.

Conclusion

Residents and their families responded well to the ASCOT domains and the questions opened up conversations about aspects of their lives that staff felt would otherwise have been missed. Indeed, in one site, a whole service issue around meals was identified because of the focus of the ASCOT questions. The care planning meetings lasted no longer than usual but successfully refocused the attention on wellbeing. Staff reported having a greater understanding of how they could better support residents' social and emotional needs with more tailored and personalised care.

Structured interviews around residents' emotional and social needs don't usually happen in residential aged care. The use of the ASCOT tool facilitates this process, providing a basis for conversations. It also has the benefit of being able to rate quality of life and measure outcomes over time.

The increased empowerment



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of residents and families and the underpinning of Whiddon's relationship-based care approach were two of the strongest factors in the organisation's decision to pursue full integration of ASCOT in its care planning processes and systems following the trial. Whiddon is currently working with the ASCOT team and its care planning systems provider to integrate the ASCOT tool. In the meantime the ASCOT is an integral part of evaluating and providing wellbeing goals for Whiddon's relationship-based care program.

ASCOT recognition

In June 2018, the Whiddon Group won the 2018 NSW/ACT Organisation Award in the inaugural Leading Age Services Australia (LASA) Excellence in Age Care Service Awards for the ASCOT work and was listed in the 2017 *Australian Financial Review's* Top 50 most innovative Australian and New Zealand companies, primarily for its integration of the ASCOT tool.

Authors Karn Nelson, Ann-Marie

Towers and Nick Smith, also spoke at the British Society of Gerontology conference in Manchester in July on different projects where the ASCOT tool was used to measure outcomes (www.britishgerontology.org/events-and-courses/past-conferences/2018-manchester). ■

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Accessing the ASCOT tool and training

Service providers or individuals in Australia and overseas can access the ASCOT by registering with the University of Kent PSSRU and obtaining a licence. The registration form can be downloaded from the ASCOT website at www.pssru.ac.uk/ascot/licensing/. The licence is free for not-for-profit use. For-profit use incurs a fee based on factors including type of use, number of participants and size of the study.

For more information and to access the tutorial videos on how to use the ASCOT, visit the website at www.pssru.ac.uk/ascot/tools/.

The PSSRU team is currently developing ASCOT online training modules and these are expected to be available in 2019.

RESEARCH NEWS



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

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Does staff education impact quality of life?

This systematic review examined the impact of nurse and care staff education on measures of functional ability and quality of life for older people with dementia living in residential care homes. The Australian researchers were also interested in identifying the components of successful education programs.

They included 13 studies in the review which were conducted in Australia, the UK, Europe, Asia and the US.

The educational interventions trialled varied across the studies. Most included education on responsive behaviours in dementia as well as behavioural management

skills. Other areas addressed were communication skills, promotion of positive values and strategies to promote self-care and emotion-oriented care.

Programs with greater success were run over multiple sessions and included multi-faceted components such as hands-on support, train-the-trainer and ongoing auditing.

Educating nurse and care staff was associated with a modest improvement in the ability of people with dementia to engage in daily living activities. However, the impact of nurse education on residents' agitation, anxiety, mood and quality of life was limited and inconsistent across studies.

This review revealed the low quality of research in this field. Similarities and differences in the clinical settings of the intervention and control groups were generally not reported, reducing the overall confidence that education programs were the primary factor leading to change. There is a need for well-designed studies testing interventions designed to be both efficacious and sustainable.

Bauer M, Fetherstonhaugh D, Haesler E, Beattie E, Hill KD, Poulos CJ (2018) The impact of nurse and care staff education on the functional ability and quality of life of people living with dementia in aged care: a systematic review. *Nurse Education Today* 67 27-45.

Comorbidity with dementia

This UK study investigated the presence of concurrent conditions (comorbidity) with dementia and examined the associations between severity of comorbidity and quality of life (QoL).

A total of 1547 people with dementia were included in the study. The researchers recorded the presence or absence of 23 chronic conditions in the participants using the Charlson Comorbidity Index.

Participants' QoL was assessed using two measures: the EQ-5D-3L, which measured mobility, self-care, their usual activities, pain level and anxiety / depression, and the QoL Alzheimer's Disease (QoL-AD) scale, which assessed QoL domains important in cognitively impaired older people, including mood, memory and general health.

The majority of the people with dementia were living with more than one chronic condition, ranging from 0 to nine. The most frequent comorbid conditions were: hypertension (39%), connective tissue disease (25%), depression (15%), diabetes (13%) and chronic pulmonary disease (13%).

The average QoL score on the EQ-5D-3L was 71.9 and on the QoL-AD was 36.8. People with dementia reported moderate to severe difficulties with mobility (42%), pain (40%), performance of usual activities (34%), anxiety or depression (34%) and self-care (17%).

A higher number of comorbid conditions was associated with lower QoL scores on the QoL-AD scale, and those with severe comorbidity (five or more conditions) showed the greatest impact on their wellbeing.

The researchers conclude that comorbidity is an important risk factor for poor QoL and health status in people with dementia. A multidisciplinary approach to care provision is recommended.

Nelis SM, Wu Y-T *et al* (2018) The impact of comorbidity on the quality of life of people with dementia: findings from the IDEAL study. *Age and Ageing* 0 1-7.

Systematic review of care home sleep studies

This systematic review of 54 studies examined non-pharmacological interventions that aimed to improve night-time sleep among long-term care residents, including those with dementia.

Of the interventions included in the review, 53% reported on residents with dementia. The interventions were categorised as environmental interventions, complementary health practices, social / physical stimulation, clinical care practices or mind-body practices.

There was no clear pattern of positive findings. Three interventions had the most promising results: increased daytime light exposure, night-time use of melatonin and acupressure. Three studies tested social and

cognitive activities on residents with dementia and one reported improved sleep, while the other two reported mixed findings.

The paper concludes that non-pharmacological interventions have the potential to improve sleep for residents living in care homes, including those with dementia. However further research is needed to standardise interventions and provide clear implementation guidelines using cost-effective practices.

Capezuti E, Zadeh RS, Pain K, Basara A, Jiang NZ, Krieger AC (2018) A systematic review of non-pharmacological interventions to improve nighttime sleep among residents of long-term care settings. *BMC Geriatrics* 18 143.

Nutritional care at home: A scoping review conducted by researchers in the UK has summarised studies on nutritional care for people living with dementia at home. A total of 61 studies were identified and many found that people living at home with dementia were vulnerable to malnutrition.

Using a content analysis approach during data extraction, the authors identified three overarching themes in this review:

- The importance of timely identification of nutritional risk for the person with dementia and subsequent regular monitoring of their nutritional status.
- The need for multi-component tailored interventions

to prevent nutritional decline.

- Considering the nutritional status of the family caregiver.

The review found that there was a lack of interventions available to address the increased risk of malnutrition among people living at home with dementia. Family carers require support to enable them to identify malnutrition risk and take action to prevent nutritional decline.

Mole L, Kent B, Abbott R, Wood C, Hickson M (2018) The nutritional care of people living with dementia at home: a scoping review. *Health & Social Care In The Community* 26:e 485-496.

Changes in intimate relationships

Researchers in the UK explored the changes in long-term intimate relationships where one partner had Parkinson's-related dementia and the other provided care to their partner.

Twelve female spouses whose partner had Parkinson's disease and mild cognitive impairment, Parkinson's disease dementia or dementia with Lewy bodies completed interviews with the researchers.

Couples' relationship satisfaction, intimacy and communication had reduced in the mild cognitive impact stage of Parkinson's disease.

However, the decline in these domains was markedly greater

with the emergence of dementia.

Increased spousal care responsibilities resulted in partners spending more time together but feeling more emotionally distanced. Some partners spoke of their role changing from spouse to caregiver and they reported feelings of frustration, resentment, anger, sadness and worry. They also reported decreases in their own health, independence and freedom.

Spouses reported that their partner's cognitive impairment was more difficult to accept, manage and cope with than the motor symptoms associated with Parkinson's disease.

Despite the difficulties in managing their partner's symptoms, spouses did not renounce their marital vows and exhibited acceptance and resilience towards the situation.

The authors acknowledge several limitations of this study, including only interviewing female spouses, recruiting a relatively small sample and not examining pre-morbid relationship satisfaction.

Vatter S, McDonald KR, Stanmore E, Clare L, McCormick SA, Leroi I (2018) A qualitative study of female caregiving spouses' experiences of intimate relationships as cognition declines in Parkinson's disease. *Age & Ageing* 47 604-610.

One-in-five residents are 'undiagnosed'

This Australian study examined the cognitive status of people living in residential aged care homes and whether or not a dementia diagnosis was recorded.

This study included 541 residents from 17 residential care homes across Australia. The researchers examined cognitive status using the Psychogeriatric Assessment Scale Cognitive Impairment Scale (PAS-Cog) and dementia diagnosis using medical records.

Overall, 65% of residents had a diagnosis of dementia in their medical records with a mean PAS-Cog score of 13.3, indicating moderate-to-severe cognitive impairment. In this study, 83% had a PAS-Cog score of 4 or more, which indicates a likely cognitive impairment. More than 20% of residents had a PAS-Cog score of 4 or more with no medical diagnosis of dementia in their records and 11% had a PAS-Cog score of 10 or higher without a diagnosis recorded.

The study indicates that up to one in five residents in Australian aged care homes may have dementia which has not been formally diagnosed. The authors conclude that care staff should pursue a formal diagnosis of dementia for residents with moderate or severe cognitive impairment because this is necessary for access to medications which may delay further functional decline.

Dyer SM, Gnanamanickam ES, Liu E, Whitehead C, Crotty M (2018) Diagnosis of dementia in residential aged care settings in Australia: an opportunity for improvements in quality of care? *Australasian Journal on Ageing*. Published online 6 September <https://doi.org/10.1111/ajag.12580> (Open access).

Increasing personal decision-making

Members of the Australian public provided their views on how to increase personal decision-making in residential care to ensure people with dementia have their needs and preferences met.

This study used a citizens' jury, where 12 members of the Australian public (the 'jurors') were provided with a question about personal decision-making ('charge') and information was presented to them by a range of dementia experts ('expert witnesses') over two days. Following this presentation, the jury deliberated on how to increase personal decision-making and delivered their verdict.

The jury believed that person-centred care should be the foundation of care for all older people. They recommended that funding for each resident should be split

between basic health, nutrition and hygiene needs.

It was agreed that people with dementia should have the ability to choose discretionary services which addressed their social, leisure, spiritual or other needs, and have choice in their clothing, meals (timing and nature) and the timing of activities.

Risk management strategies were recommended to ensure that residential care facilities have processes in place so that external service providers have undertaken necessary checks (eg police check) and to prevent 'sales people' from entering the facility.

The jury suggested that residential care homes should have care coordinators whose role would be to:

- Provide assistance in eliciting residents' preferences, values and choices.

- Implement risk management strategies.
- Support decision-making among people with dementia and their caregivers.

The researchers concluded that the jurors' recommendations were relatively conservative and were generally consistent with the views of stakeholders in other contexts. This broad consensus suggests that implementation of the recommendations would be regarded as a positive change in service delivery.

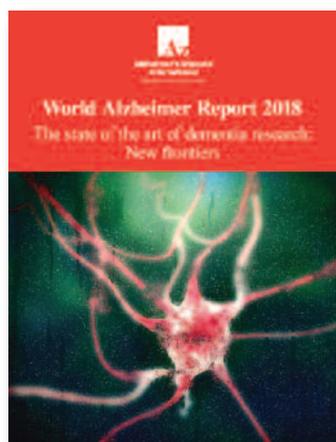
Laver K, Gnanamanickam E, Whitehead C, Kurrle S, Corlis M, Ratcliffe J, Shulver W, Crotty M (2018) Introducing consumer directed care in residential care settings for older people in Australia: views of a citizens' jury. *Journal Of Health Services Research & Policy* 23 176-184.

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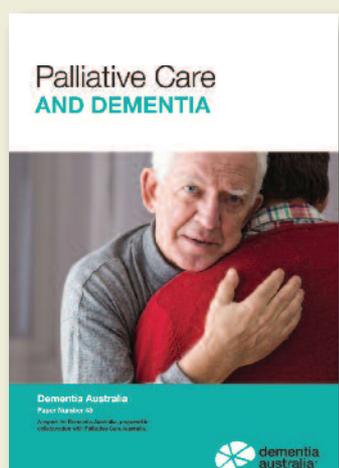
The Australian Aged Care Quality Agency (AACQA) has developed **Guidance and resources for providers**, a hub to access a range of resources to help aged care organisations transition to and implement the new Aged Care Quality Standards. Organisations must be compliant with the new standards from 1 July 2019. The hub includes sections on legislation, case studies, guidance and consumer resources, as well a glossary. The resources can be accessed via the AACQA website at www.aacqa.gov.au.

Dementia Training Australia (DTA) is offering a new free two-hour online learning course aimed at registered and enrolled nurses working in residential aged care, called **The Pain Puzzle**. The course has three modules and covers the recognition, assessment, treatment and management of pain. It also explores the organisational attributes which facilitate optimal pain management from the perspective of nurses as clinical leaders at the centre of the care team. The course provides two hours of professional education – a certificate of completion is issued after satisfactorily concluding the course (and passing an online knowledge quiz). Go to the DTA website to register: www.dta.com.au.

Alzheimer's Disease International (ADI) has published its World Alzheimer Report 2018. **The state of the art of dementia research** reports on what is known about



Deborah Parker, Joanne Lewis and Kelly Gourlay are the authors of this new discussion paper, prepared in collaboration with Palliative Care Australia for Dementia Australia on **Palliative care and dementia**. The 36-page resource provides guidance for health professionals about palliative and end-of-life care for people with dementia and those who support them. It covers topics such as prognosis, symptom management, advance care planning, personal comfort measures, recognising dying, and grief and bereavement support. It also considers the particular issues arising for family carers, people from culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander people, and lesbian, gay, bisexual, transgender and intersex people. The paper is available to download from the Dementia Australia website at www.dementia.org.au.



some key areas within dementia research, including cause, cure, diagnosis, risk reduction and care. While acknowledging that there has been no major breakthrough in dementia research for 20 years, the report also features stories of progress and innovation. It is based on interviews with 21 leading researchers from around the world, including Australia's Professor Henry Brodaty AO. ADI is arguing that the funding devoted to dementia research internationally is tiny. It says that the global ratio of publications on neurodegenerative disorders versus cancer is 1:12. Available at: www.alz.co.uk.

The Macular Disease Foundation Australia (MDFA) is arguing for urgent reform of vision care within the residential aged care system after a study conducted by MDFA found high rates of eye disease, often under-diagnosed and untreated, in residents of Australian aged care facilities. The MDFA report **Vision and eye healthcare study in residential aged care facilities** reveals that more than 70% of the nearly 200 residents who took part in the study had some form of eye

disease; almost 30% had untreated cataracts and more than 60% had some degree of age-related macular degeneration. The report says the use of vision aids – other than spectacles – was extremely low and identified barriers in access to ophthalmology services. The report is now available to download on the MDFA website at www.mdffoundation.com.au.

As a result of the report's findings, the Macular Disease Foundation Australia (MDFA) has developed a new collection of resources on **Managing eye health and vision loss in residential aged care facilities**. The resources include a seven-minute training video for care workers, a four-



page fact sheet on eye health aimed at care workers, a similar resource aimed at families and guardians, and a 12-page guide on eye health aimed at management and health professionals. The tools are designed to improve understanding of eye health and vision loss in aged care facilities. The resources are all available to download on the MDFA website (www.mdffoundation.com.au).

Gaynor Macdonald and Jane Mears are the editors of a new book from Routledge entitled **Dementia as social experience: valuing life and care**. The book's concern is the wider social context in which dementia care takes place. It brings together contributions from a range of academics and practitioners, and the 11 chapters are set out in three parts: challenging social constructions of ageing and dementia, autonomy and dignity, and persons in relationship – the dynamics of care. The hardback book is available to purchase from Routledge for \$193.60.

Music memories is a new website launched by the BBC in the UK which aims to promote the use of music to help people with dementia reconnect with their memories. The website was developed in collaboration with the dementia charity Playlist for Life and includes large amounts of music that will be familiar to Australian audiences. The site offers over 1800 pieces of music, grouped into three collections: 'Classical music', 'Popular music', and 'Theme tunes'. Tunes are free to access and can be saved into a playlist and listened to later. The website can be found at <http://musicmemories.bbcrewind.co.uk/>

In 2017 the NSW Nurses and Midwives' Association took the lead in developing a series of leaflets aimed at helping people who may be in the process of deciding about residential aged care options: the **10 questions**

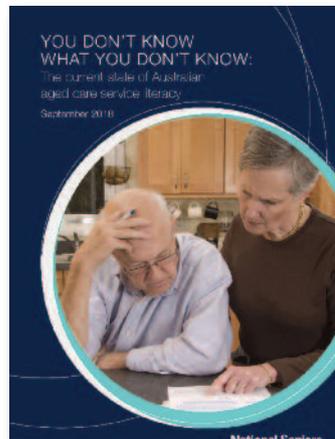
leaflets. One of the leaflets in the series of 15 is called **10 questions to ask about dementia care in residential aged care**. The two-page leaflet presents one-paragraph answers to 10 key questions covering topics such as activities, staffing levels, incontinence, medication and medical support, decision-making, and more. The leaflets and associated promotional materials are available to download for free from www.10questions.org.au.

Advance Care Planning Australia has continued to expand its range of free online courses, aimed at aged care workers, health professionals and the general public. The Austin Health initiative now hosts nine online learning modules on advance care planning, each lasting 30 minutes, and covering topics such as 'Advance care planning and dementia', 'Advance care planning aged care', and 'Advanced communication'. The courses can be accessed via <https://learning.advancecareplanning.org.au/>

Meaningful Ageing Australia has published a **Leader's guide to running an effective spiritual care volunteer program**. The free-to-access guide aims to give aged care organisations the necessary information to set up, manage and maintain a spiritual care volunteer program, and includes a large number of templates and forms. The guide had its origins in material created by BaptistCare NSW &

ACT, and has been shaped by Meaningful Ageing Australia's work establishing spiritual care volunteer programs. To access the resource, go to <https://meaningfulageing.org.au>

You don't know what you don't know is the title of a new publication from National Seniors Australia (NSA) which reports on a study into literacy or understanding of older Australians about the aged care sector, including access to My Aged Care, assessment services, consumer contributions, complaints processes, regulation and consumer rights. After analysing 5500 survey responses, the NSA researchers concluded that the majority of people have very limited aged care literacy, and they argue that there is a clear need to increase the aged care literacy of this cohort, to improve the usability of the My Aged Care website, and to educate older Australians about the need for adequate financial planning so that they can know what to expect to pay for their



aged care. The report includes a number of quotes and examples involving people with dementia. The report can be downloaded from the NSA website at www.nationalseniors.com.au.

Delirium in persons with dementia is the title of a new, one-hour webinar presented by Professor Donna Fick of Penn State Center for Geriatric Nursing Excellence as part of Dementia Training Australia's range of online learning opportunities. The webinar presents an overview on delirium and delirium superimposed on dementia, challenges to improve assessment for people with dementia and delirium, prevention and management of delirium, and components of age-friendly care. The webinar can be accessed through the DTA website or vimeo ([go to vimeo.com/293285597](https://vimeo.com/293285597)).

The Advance Project Toolkit is a new free, evidence-based toolkit and a training package designed for Australian GPs, general practice nurses, and practice managers, and published by HammondCare. The resources form the second stage of a major Department of Health-funded project called the Advance Project. The toolkit consists of a number of resources to help primary care clinicians to work as a team to initiate conversations about advance care planning, and to assess patients' and their carers' palliative and supportive care needs. Online training modules are available to explain how to use these resources in

everyday clinical practice. Tele-mentoring is also available from the Advance Project team to assist individual clinicians and general practices to implement the resources in clinical practice. For more information and to access the resources, go to www.theadvanceproject.com.au or contact the team on advanceproject@hammond.com.au

Dementia UK has published two new information leaflets, one on **Dementia and difficulty with sounds**, and the other, **Sex, intimacy and dementia**. The first leaflet looks at the additional difficulties that people with dementia may face with their hearing, aside from those traditionally related to ageing (for example, identifying what a sound is, or picking out one sound from another). The second leaflet looks at possible changes in relationships that may occur as a result of a partner living with dementia. Both leaflets are available to download from the Dementia UK website at www.dementiauk.org

UK charity ALIVE has developed a set of free **conversation cards** to support relatives, friends and care staff build social connections and engage in meaningful conversations with people with dementia. The resource contains illustrations and ideas to prompt conversations on specific interests such as gardening, travel and music. The cards are available to download at www.aliveactivities.org/resources/conversation-cards-for-dementia/

Events

■ 12-13 December 2018 – NSW

Dementia in Diverse Groups: two-day symposium

Six two-hour workshops, presented by Dementia Training Australia, in Wollongong. Includes: CALD, YOD, LGBTI, ATSI, veterans and the homeless. Details: www.dta.com.au

■ 1 February 2019 – WA

Introduction to the Hierarchic Dementia Scale-Revised (HDS-R) and the Possibility Oriented Approach to Care Planning

Workshop, presented by Dementia Training Australia and the WA Occupational Therapy Association. Details www.dta.com.au

■ 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

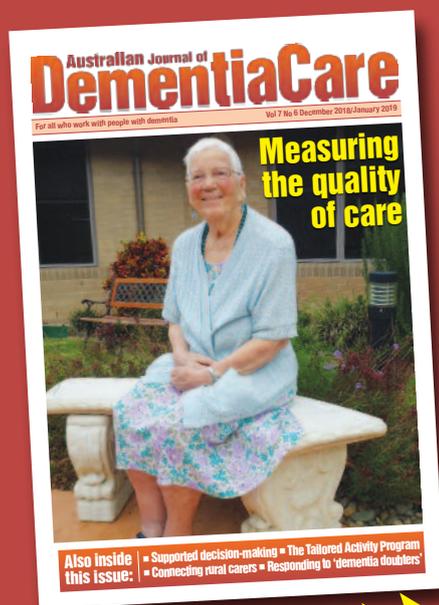
The RED Conference: A Regional Experience in Practical Dementia Care

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

Details of more events at www.journalofdementiacare.com

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