

Australian Journal of **DementiaCare**

For all who work with people with dementia

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- Steps to a dementia-friendly society
- A caring community
- Intergenerational living
- Home theatre debut
- Dementia cafes

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'Care that is safe and right for me'

By **Janet Anderson**, Commissioner, Aged Care Quality and Safety Commission

People living with dementia represent a growing number of older Australians, and a growing proportion of older Australians accessing aged care. This twin observation – now almost commonplace – is one of the reasons for the closer attention now being paid to whether and to what extent aged care services (residential and in-home care) are meeting the needs, goals and preferences of individual consumers living with dementia.



Careful consideration of the responsiveness and tailoring of services to individual care needs has received additional impetus through the introduction, from 1 July 2019, of the new Aged Care Quality Standards (Standards) and the single Charter of Aged Care Rights. The new Standards apply to all aged care services, and were developed after extensive consultation with consumers, service providers, aged care experts and the wider community.

The defining characteristic of the new Standards is their focus on the consumer and what will work best for them; they put the consumer at the centre of the picture. Each of the eight Standards starts with an outcome statement expressed from the consumer's perspective. The title of this article – 'Care that is safe and right for me' – is from the consumer outcome for Standard 3: Personal care and clinical care. Each Standard also includes an organisation statement and a set of requirements which the organisation must demonstrate in order to comply with the Standard.

Because the expectation of consumer-centred, safe, quality care animates the entire set of Standards and is not delimited by diagnostic labels or categories of need, it can readily be argued that all eight Standards are applicable to the care of people living with dementia. At the same time, the Standards that focus most closely on support for these individuals are:

- Standard 1 - Consumer dignity and choice, requires that aged care consumers are treated with dignity and respect, and are supported to exercise choice and independence;
- Standard 3 - Personal care and clinical care, requires that each consumer receives safe and effective personal and /or clinical care that is in line with best practice, tailored to their needs and optimises their health and wellbeing;
- Standard 4 - Services and supports for daily living, requires that each aged care consumer receives safe and effective services and supports that meet their needs, goals and preferences and optimise their independence, health, wellbeing and quality of life; and
- Standard 8 - Organisational governance, requires effective risk management systems and practices for managing high-impact or high-prevalence risks and supporting consumers to live the best life they can.

Aged care providers' performance against the Standards and their ongoing compliance with the Standards is assessed and monitored by the Aged Care Quality and Safety Commission (Commission). Established on 1 January 2019, the Commission has a statutory responsibility to protect and enhance the safety, health, wellbeing and quality of life of aged care consumers, and to promote the provision of quality care and services by approved providers of aged care. It fulfils this responsibility through its consumer engagement, complaints, regulatory and education functions.

In its first six months the Commission prepared for the introduction of the new Standards and Charter. This entailed promoting the guidance available to the aged care sector and providing education and support for transition, as well as ensuring that Commission staff were ready to perform their functions in the context of the new Standards.

The Commission began assessing and monitoring aged care providers against the new Standards on 1 July 2019. While it is too early to comment on how the sector is responding to the new Standards, the Commission is already hearing from its Quality Assessors about the value of a different kind of conversation with staff, providers and people accessing aged care services. These conversations, which include people living with dementia who may be experiencing cognitive impairment, are focusing on how care and services are meeting their individual needs, goals and preferences.

Implementation of the new Standards and Charter by aged care providers represents an inflection point for our aged care sector, and for current and future aged care consumers. The new provisions put a spotlight on the importance of consumers (and their representatives) participating in decisions about their care and services, and through this process, optimising their experiences and outcomes of care.

While there are further reforms to pursue and work is already underway on these, the new Standards are a vital and significant step to enhance the safety, health and wellbeing of people living with dementia, and provide an unprecedented opportunity that can and should be seized by aged care consumers and providers.

For more on the Standards and resources, visit agedcarequality.gov.au. ■

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Cover image: Phil Hazell, who has younger onset dementia, and Occupational Therapy lecturer Catherine Andrew, with Phil's assistance dog Sara, at a recent conference where they were both presenting. They have been working on research together for the past three years. See their article on p32.

Affirmation for MOOC

A new study conducted by the University of Tasmania has attempted to measure the learning outcomes from the Wicking Dementia Research and Education Centre's Understanding Dementia Massive Open Online Course (MOOC) – to establish whether the course is an effective knowledge enhancement strategy.

Its key finding – that regardless of previous education and prior experience of dementia, all MOOC participants had greatly increased their knowledge of dementia in areas relevant to the provision of high-quality dementia care – affirms the course's value as a tool for knowledge acquisition.

The study was based on the use of the Wicking Centre's recently developed dementia knowledge tool, the Dementia Knowledge Assessment Scale (DKAS) and involved 4894 MOOC participants from courses conducted in 2016 and 2017.

Wicking Centre researcher Dr Claire Eccleston said the study was a response to research which showed significant deficits in the knowledge of important aspects of dementia in family carers, aged care support workers, nurses and other health professionals.

"This research shows that MOOC approaches may provide accessible opportunities to obtain this knowledge, potentially at the scale necessary to make a systemic difference to how we consider and support people with dementia," Dr Eccleston said.

The study's findings were published in the journal *npj Science of Learning*, a Nature Publishing Group publication. The Understanding Dementia MOOC was introduced by the Wicking Centre in 2013 and has had more than 190,000 enrolments internationally.

Government reforms put into action

Senator Richard Colbeck, Minister for Aged Care and Senior Australians, has hailed the introduction of a raft of new reforms which came into effect on 1 July 2019.

He said the comprehensive reforms are designed to protect and improve the lives of senior Australians in care, and demonstrate the Government's commitment to continue to improve the aged care system while the Royal Commission proceeds.

The reforms include the new Charter of Aged Care Rights, the new national Aged Care Quality Standards, the Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019 (Cth) (2019 Principles), and compulsory compliance with the National Aged Care Mandatory Quality Indicator Program by government-funded aged care homes.

The new Standards and single charter cover all aged care services including residential services, home care, short-term restorative care, the Commonwealth Home Support Program and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program. The Aged Care Quality and Safety Commission began monitoring and assessing provider performance against the Aged Care Quality Standards from 1 July 2019.

Aged Care Quality and Safety Commissioner Janet Anderson said she was impressed by the commitment shown by aged care providers in their preparation for the introduction of the new standards.

The Commission has developed a range of resources to support the implementation of the various reforms. The

most recent additions are:

- *Open Disclosure – Framework And Guidance*: a resource to support continuous improvement of communication with consumers when things go wrong.
- A self-assessment tool for recording consumers receiving psychotropic medications.
- The latest Regulatory Bulletin which outlines how the Commission will respond to identified areas for improvement and non-compliance with the Standards from 1 July 2019.
- The new single Charter of Aged Care Rights Template For Signing for aged care service providers and their consumers is now available in 18 translated languages.

All the resources are available to download from the Commission's website, www.agedcarequality.gov.au.



Connecting over coffee: Lifeview Residential Care launched its first community dementia cafe, Rosemary & Time, in July at ConXion Cafe, within its Lifeview Willow Wood home in Cranbourne, Victoria (pictured). Lifeview is planning to open more of the free dementia cafes in other areas where it has homes. The Rosemary & Time Cafe is for people with dementia living in the community and their carers, family and friends, to enjoy time together over refreshments and entertainment, in the company of people in a similar situation to themselves. "Going to a cafe is a great, non-threatening way to begin to access services, to meet people and to share experiences," Lifeview Chief Executive Officer Madeline Gall said. "Having seen the success of dementia cafes in other areas and seeing a need for services such as this locally, Lifeview is pleased to be able to bring this community-based service to the local residents of Cranbourne." The cafe is held on the second Tuesday of every month with guest speakers, dementia specialists, activities and music. It's free, bookings are essential and can be made by calling Kelly on (03) 9572 9600.

See pages 21-25 for more articles on creating dementia cafes and dementia-friendly communities.

Dementia Care Navigators

Two new Dementia Care Navigator services – one in Perth (WA) and one in Dubbo (NSW) – are now seeking participants to make use of the program and then be involved in its evaluation. The Dementia Care Navigator service aims to provide tailored information to identify and connect clients with appropriate support and services. It is being delivered in both locations by Dementia Australia.

These two services are the only dementia-specific ones being offered under the Federal Government's larger Aged Care Navigators Trial, which is led by COTA Australia, and funded until June 30, 2020. A list of all trial locations across Australia is now available on COTA's website (www.cota.org.au).

To access the Dementia Care Navigator service, call the National Dementia Helpline on 1800 100 500.

ISLAND Project launched

The Wicking Dementia Research and Education Centre at the University of Tasmania has launched a major research project designed to help prevent dementia through empowering people to self-manage significant modifiable dementia risk factors.

The ISLAND (Island Study Linking Ageing and Neurodegenerative Disease) Project will be the largest dementia study of its kind in the world, involving 10,000 community participants aged 50 and over across Tasmania, and the first to target a whole population through a public health and educational campaign, according to Wicking Dementia Centre Director Professor James Vickers.

The project aims to develop a toolbox to assist participants in monitoring dementia risk factors and behaviours, and will establish a state-wide registry to track the incidence

of dementia. Participants will complete the Centre's Preventing Dementia MOOC (Massive Open Online Course) (see story, p4), along with a variety of community co-developed and led programs, to empower and educate the community about modifiable factors that could potentially lower the risk of dementia. Participants will also be invited to engage in a range of related research studies to identify those at most risk of dementia through a combination of like factors, for example resilience, genetics, biomarkers, health data surveys and clinic activity studies.

Specific components of the ISLAND Project have been initially funded by the Medical Research Future Fund and the National Health and Medical Research Council.

More information about the project can be found at <https://islandproject.utas.edu.au/>



Dementia-friendly pharmacies in Qld: A total of 165 community pharmacies across Queensland have received specialist training to become dementia-friendly pharmacies. The pharmacies were recruited as part of the Dementia Friendly Pharmacy Program, an initiative of The Pharmacy Guild of Australia, Queensland Branch as part of the Queensland Government's Advancing Queensland: An Age-Friendly Community Grants Program. The program enabled pharmacy staff (including at Toowoomba's Southtown Pharmacy, pictured) to gain more awareness and understanding of dementia, to help them create a supportive environment to assist people with dementia and their carers. The Pharmacy Guild of Australia Queensland Branch President, Professor Trent Twomey, said each pharmacy received staff training and resources to become dementia friendly. "As a part of the training, pharmacists and pharmacy assistants received fully subsidised resources. This included access to self-paced online training modules, a pharmacy-specific dementia-friendly checklist, a resource kit with local dementia support groups, a promotional pack to help with in-store marketing and external advertising support through the Guild," Professor Twomey said. The full list of the dementia-friendly pharmacies is available at www.guild.org.au/qld-dementia-friendly.

News in brief

Asia Pacific Eldercare Innovation Awards

NSW-based aged care provider McLean Care® and Deakin University have won two awards at the 7th Asia Pacific Eldercare Innovation Awards in Singapore: one for Best Solution to Support Ageing in Place – Wellness, and the Innovation of the Year – Technology category. Both awards relate to the organisations' work to develop and implement 'Hector VR' – the driving simulator for older drivers, which helps them monitor and maintain their driving skills in a safe environment, and ultimately help with decision making about safe driving. Uniting Residential and Health Care was a finalist for the Best Dementia Care Program award, for its Abrina Atrium Installation Project – a memory support program to engage and enable rehabilitation and happiness for older people with dementia at Uniting Abrina aged care facility in Sydney.

Dementia Action Week

Discrimination experienced by people living with dementia, their families and carers will be the focus of this year's national Dementia Action Week, which runs from 16-22 September. Dementia Australia CEO, Maree McCabe, said the annual national awareness campaign will include a national survey to inform and increase understanding of the experiences and perspectives around discrimination, and what can be done to bring about positive change. Dementia Australia will also recognise and participate in World Alzheimer's Day on 21 September with activities aimed at raising community-wide awareness and support for people living with dementia.

Voluntary Assisted Dying in Victoria

The Victorian Parliament's Voluntary Assisted Dying Act 2017 came into effect on 19 June 2019. Now, Victorians at the end of life who are suffering and who meet strict eligibility criteria are able to request access to voluntary assisted dying. A person diagnosed with dementia may be eligible if they meet all of the conditions, including having decision-making ability throughout the entire process. The law has allowed for an 18-month implementation period to give health services time to plan and prepare for voluntary assisted dying. The law came about following a parliamentary inquiry into end of life care in 2015. More information and related implementation resources are available at www2.health.vic.gov.au

\$21 million for dementia research

The Australian Government will provide \$21 million to 13 research projects focusing on risk reduction, prevention and tracking of dementia. This brings the total investment under the NHMRC's Boosting Dementia Research Grant scheme to \$200 million. The initiatives include two projects at the new National Centre for Healthy Ageing at Peninsula Health-Monash University in Victoria. One of those projects will be the first in Australia to use electronic record data to develop ways of monitoring the prevalence of dementia. The full list of research projects can be found at <https://bit.ly/2Y9FXW5>

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.

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

Royal Commission latest hearings

The Royal Commission has continued its work, with its fourth and fifth hearings held in Western Australia in June taking evidence from more than 45 witnesses.

The Broome hearing (17-19 June) examined various models of care in remote areas, the unique care needs of Indigenous Australians and issues of access and inclusion. The main focus of the hearing was on the vital importance of cultural safety, and the factors that support or hinder this in practice for Aboriginal and Torres Strait Islander elders.

The Perth hearing (24-28 June) focused on the nature of person-centred care, advanced care planning and palliative care services. After hearing from 30 witnesses, Peter Rozen QC, Counsel Assisting, concluded that the key themes from the hearing had been how social attitudes inform the delivery of aged care, the importance of relationships in delivering person-centred care,

and the importance of organisational leadership.

Once again some devastating personal testimony was heard, with witnesses involved in two case studies appearing before the Commissioners. Both raised serious concerns about quality of care, leadership and complaints handling within the sector. Some positive direct experience of aged care was also shared by witnesses, and a panel of front-line staff (two nurses, a care worker and physiotherapist) spoke of the challenges they face in delivering person-centred care.

The Commissioners also heard about innovative practice from several organisations, including Wintringham, The Whiddon Group, Silver Chain and Alzheimer's WA. Jason Burton of Alzheimer's WA told the Royal Commission that at the heart of person-centred care is culture. Chris Mamarelis, CEO of The Whiddon Group, spoke about implementing consistent

staffing as part of its relationship-centred care approach, and goal-setting for residents.

The next round of hearings, in Darwin from 8-12 July and in Cairns from 15-17 July, focused on aspects of care in residential home and flexible aged care programs (including access and availability, wound, medication and pain management, nutrition and hydration, continence care, mobility and social supports); rural and regional issues; and quality of life for people receiving aged care.

In Darwin, the Commissioners heard that a lack of residential aged care services in rural and remote Northern Territory was forcing older Australians to relocate away from their family and community. Senior Counsel Assisting, Peter Gray, said that limited aged care services, cultural factors and the vast distances people had to travel had culminated in unmet

needs in the Territory.

The Cairns hearing was told about the urgent need to improve nutrition in aged care. Nutritionist and researcher Dr Sandra Iuliano said more needed to be done to ensure that residents had adequate levels of nourishment, and that there should be a national mandatory minimum education level to work with food in aged care.

The Office of the Royal Commission has prepared a further background paper, published in June, on *Advance Care Planning in Australia*. It gives a brief overview of the different practices across Australia's states and territories, and looks at the benefits, uptake, and improving of advance care planning in Australia.

The background paper, and details about upcoming hearings, are on the Commission's website at <https://agedcare.royalcommission.gov.au>

NEW REPORTS AND GUIDELINES

Global inaction



A new report has been published by Alzheimer's Disease International (ADI) to mark the second anniversary of the adoption of the World Health Organization (WHO) *Global Plan On The Public Health Response To Dementia 2017-2025*. The new report, *From Plan to Impact II: The Urgent Need For Action*, was launched at a side event to the 72nd World Health Assembly on 21 May 2019, featuring a panel of high-level governmental and industry representatives, including experts from Japan, Qatar, WHO and Dementia Alliance International.

The report reports on progress towards meeting target one of the Global plan, which calls for 146 WHO Member States to develop plans, policies or other frameworks on dementia by 2025, and features case studies on plans adopted and in development around the world.

ADI remains concerned that at the current rate the 2025 target will not be reached. Only 32 national plans currently exist, including just 27 WHO Member States. Up to 34 are in development. In the last two years only three countries (Chile, Qatar and Canada) have created plans, meaning at the current rate the 2025 target will not be reached.

ADI's CEO Paola Barbarino said: "Two years on from the commitment made by 194 Member States at the World Health Assembly, the pace of progress is still too slow. World governments must recognise the crisis we're facing now and proactively work to ensure they're prepared for the dementia emergency at a national level."

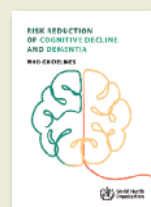
Canadian dementia strategy

The Canadian Government has become the 32nd in the world to adopt a national plan on dementia, with the publication of *A Dementia Strategy for Canada: Together We Aspire* in June. The plan includes key targets for

improving awareness, access to care, support and treatment, research and risk reduction of dementia by 2025, and is backed up by a budget of \$3 million (CAD) in fiscal year 2019 and \$12 million in each of the following four years. Over half a million people are estimated to be living with dementia in Canada, with that number projected to increase by 66% by 2031. Alzheimer's Disease International says that national dementia plans remain the single most powerful tool to transform dementia care and support people living with dementia and their care partners.



WHO risk reduction guidelines



People can reduce their risk of dementia by getting regular exercise, not smoking, avoiding harmful use of alcohol, controlling their weight, eating a healthy diet, and maintaining healthy blood pressure, cholesterol and blood sugar levels, according to new guidelines issued by the World Health Organization (WHO) in May.

The guidelines were developed by a group of 19 international experts, including Professor Kaarin Anstey from the University of NSW. The group reviewed evidence and made recommendations across a wide range of interventions to reduce dementia risk: physical activity, tobacco cessation, nutrition, alcohol use, cognitive interventions, social activity, weight management, hypertension, diabetes, dyslipidaemia, depression, and hearing loss.

WHO says the guidelines – titled *Risk Reduction Of Cognitive Decline And Dementia* – provide the knowledge base for professionals to advise people on what they can do to help prevent cognitive decline and dementia, and that they will also be useful for governments, policy-makers and planning authorities when developing policy and designing programs that encourage healthy lifestyles.

Professor Richard Fleming retires from DTA

After three years leading Dementia Training Australia (DTA), Professor Richard Fleming (pictured) has stepped down as Executive Director to pursue other interests, including environmental design consultancy work and research.

Professor Fleming is an environmental design expert and psychologist and has been involved in the development of services for people with dementia for almost 40 years. He began his clinical career in England's first Community Psychology Service. In the 1980s he played a major role in the deinstitutionalisation of psychiatric services in NSW, before establishing the HammondCare Dementia Services Development Centre, helping pioneer new approaches in development and delivery of residential services for people living with dementia.

He was appointed a Professorial Fellow in the Faculty of Science, Medicine and Health at the University of Wollongong (UOW) in 2010 and was Executive Director of the NSW / ACT Dementia Training Study Centre (DTSC) from 2010-2016, during which time he established the *Australian Journal of Dementia Care* with the then publishers of the UK *Journal of Dementia Care*. Professor Fleming was Executive Director of DTA from its establishment in 2016 until the end of June 2019.

"My decision to retire from DTA wasn't easy, but I'm looking forward to spending the next few months investigating the rumour that there are things to do outside of work and considering how

best to continue making a contribution," Professor Fleming said.

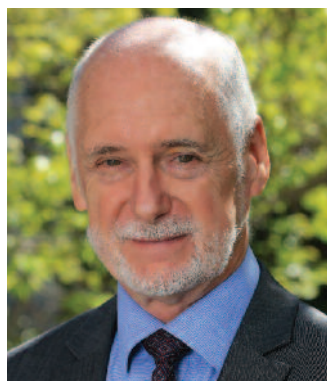
He said his departure was made easier by knowing that DTA is now in the capable care of new Executive Director Professor Belinda Goodenough, who worked with him on the development of the NSW / ACT DTSC and DTA (see story next page).

Professor Fleming said he was pleased to have the opportunity to continue his research in environmental design within UOW as an Honorary Professorial Fellow, as well as his work with the Safe and Just Futures for People Living with Dementia in Residential Aged Care research project, alongside Dr Linda Steele, Dr Lyn Phillipson and Kate Swaffer. The project is investigating the impact of restrictive design in residential facilities on the quality of life of people with dementia.

Rewarding challenge

Professor Fleming said the work of establishing and building DTA had been an immense but rewarding challenge and he wanted to acknowledge the dedication, enthusiasm and expertise of the DTA teams who had achieved so much, in such a short time. "It has been an absolute privilege to have worked with such talented and passionate people," he said.

DTA is a consortium of four universities (UOW, QUT, University of WA, La Trobe University) and Dementia Australia, that develops evidence-based training content for the dementia care workforce.



DPD success

Professor Fleming said a highlight of his career was his work in environmental design and developing DTA's Designing for People with Dementia (DPD) Environmental Design Education Service, which was recognised with an Older Person's Mental Health Award in 2016. Professor Fleming and architect Kirsty Bennett created the service within the former NSW / ACT DTSC before it became a major activity of DTA.

"The DPD service has led to real improvements in understanding how the environment can be used as a tool for enhancing the quality of life and minimising the responsive behaviours of people with dementia," Professor Fleming said.

He was extremely proud of the fact that the DPD's *Environmental Design Resource Handbook* has been listed as the primary reference for Standard 5 in the new Aged Care Quality Standards. The handbook describes the application of 10 key design principles in environments for people living with dementia, which were developed by Professor Fleming and Ms Bennett.

Positive signs

Professor Fleming said the introduction of the new Standards was just one of many positive things happening in Australia's aged care industry at the moment. "The new Aged Care Quality Standards will really demand a new approach from the aged care sector in the way in which care is delivered. Then there's the Aged Care Royal Commission and the recent Aged Care Workforce Taskforce. There are clear signs that many good things are happening and that there are many good operators and good staff who are striving to do their best.

"However, we have to continue to ask ourselves some hard questions – are we still valuing older people as much as we should, are we putting the resources they need into services? Above all, we must continue to promote positive experiences, meaning and a sense of belonging as an essential part of the experience of living with dementia," Professor Fleming said.

"Providing opportunities to find meaning is where the work we can do with people with dementia can be most profound. Change is possible when we are willing to see beyond risk and problems to focus on finding moments of happiness, hope and wellbeing.

"People experience a meaningful life when they feel valued, when they look forward to getting up in the morning and getting on with things, and when they can put their lives into a broader context or see it as part of a bigger picture."

Post-election ministerial moves

A post-election reshuffle by Prime Minister Scott Morrison has seen Greg Hunt return as Minister for Health, and the appointment of a new Minister for Aged Care and Senior Australians, Senator Richard Colbeck. Senator Colbeck replaces the former Minister for Aged Care, Ken Wyatt, who held the position since January 2017. Mr Wyatt is now Minister for Indigenous Australians. Labor's Julie Collins has been returned as Shadow Minister for Ageing and Seniors.

Telstra Business Woman of the Year

Residential aged care pioneer Natasha Chadwick, Founder and Chief Executive Officer of NewDirection Care at Bellmere in Queensland, is the 2019 Telstra Business Woman of the Year. Ms Chadwick won the category of Medium and Large Business Award as well as being named the overall winner. The award acknowledges her work developing the microtown™ residential community model, which supports older people, including people with dementia, to live in small group homes.

DTA 'national peak body' for workforce dementia training

In a short space of time, Dementia Training Australia (DTA) has established itself as the credible 'go to' provider for quality education and professional development for the health professional and carer workforce who are supporting people living with dementia, according to DTA's new Executive Director Professor Belinda Goodenough.

"Funded by the Australian Government (Department of Health) since its launch in 2016, DTA* has succeeded in providing a national approach to addressing training needs across rural and metropolitan regions around the country", said Professor Goodenough, who has taken the reins from Professor Richard Fleming who retired as DTA Executive Director at the end of June (see previous page). She has been with DTA since its establishment in 2016, in the role of Knowledge Translation Manager.

Providing a range of face-to-face training opportunities nationally has been an important core aspect to the work of DTA responding to the continued strong demand for this training. In addition, Professor Goodenough said one of DTA's key achievements has been the launch of an online training portal, offering a broad range of resources and courses – all accessible with free membership. The design and build of the portal was led by DTA Information Systems Manager, Michael Moriarty, and in the first two years of operation it has delivered nearly 20,000 occasions of training.

The widespread use of mobile devices amongst the dementia care workforce has proven to be a key facilitator of DTA's success. "We have seen



A meeting of minds in Sydney (from left) Professor Elizabeth Beattie (QUT), Dr Andrew Stafford (UWA), Professor Belinda Goodenough (UOW), Robyn Bilston (DOH), Jennifer Lindon (DOH), Dr Margaret Winbolt (LTU) and Dr David Sykes (DA). Photo: Michelle Rankin, DTA

exciting growth in the numbers of people accessing DTA courses and resources using a mobile device," said Mr Moriarty. "This has shaped the DTA priority to provide practical materials for a time-poor 'learn while you earn' workforce."

When asked about other secrets behind DTA's success, Professor Goodenough said, "I see DTA as a team of teams. Supporting people with dementia to live the best life possible takes a team approach. In the same way, effective workforce training needs to bring together a range of diverse and expert teams."

"DTA develops training content with a collaboration of clinical experts who know the latest evidence in medication management, environmental design, and speciality areas like pain, sleep, and behavioural support," she said.

One of the key teams for DTA is based in the Department of Health's (DOH) Dementia and Diversity Programs Section. "Working with our colleagues in the policy space is crucial to establishing priority directions to meet workforce training needs," said Professor Goodenough.

In her first week in the role of Executive Director, Professor Goodenough brought together senior representatives from the DOH's Dementia and Diversity Programs Section, and the DTA Executive Group, representing DTA's clinical, education, and policy portfolios (see photo). DTA Director Dr Andrew Stafford (University of Western Australia) demonstrated how virtual reality technology can help learners understand the world for the person with dementia, including some of the experience of being given psychotropic medication. Director Dr Margaret Winbolt (La Trobe University) spoke about how DTA was responding to the needs of a time-poor workforce, including busy professionals like GPs. Director Dr David Sykes (Dementia Australia) talked about a new online format for the popular Dementia Essentials course, scheduled for roll out in 2019. Strategies for providing more face-to-face training, and how to support staff in rural areas, were presented by DTA Director Professor Elizabeth Beattie (Queensland University of Technology). Together, the teams discussed a new knowledge-to-action pathway

for workforce training.

"DTA has benefited from excellent foundation work from our retiring directors, Professor Andrew Robinson (UTAS) and Professor Richard Fleming (UOW, Executive Director 2016-19)," said Professor Goodenough. "As the peak body for dementia training, we are working with the Australian Government to support a workforce experiencing a lot of change and challenges – I encourage teams interested in providing optimal quality care and support to people living with dementia to join us on the journey."

To learn more about how DTA can support you and your team with funded educational resources, visit dta.com.au

*** Dementia Training Australia is a consortium of four universities (University of Wollongong – Consortium Lead, Queensland University of Technology, University of Western Australia, La Trobe University) and the peak body Dementia Australia. In developing evidence-based training content, DTA works with key partners including the Wicking Dementia Research and Education Centre (University of Tasmania) and the Dementia Centres for Research Collaboration.**

New roadmap for research

The Australian Dementia Forum 2019 opened with the launch of a new roadmap for dementia research and brought together researchers, people with dementia and family carers to consider how best to make a difference, writes **Bojana Kos**

The NHMRC National Institute for Dementia Research (NNIDR) held its fourth annual Australian Dementia Forum in Hobart on 13-14 June 2019. This year's theme, *Shining a Light on the Impact of Dementia Research*, brought together over 430 delegates, and 200 community members, comprising researchers, health service delivery leaders, policy makers and people living with dementia, their carers and families.

The 2019 forum addressed the impact of dementia research and the need to maximise the positive benefit for people of all ages, living with all types of dementia, their families, and carers.

The forum's opening session included the launch of NNIDR's new Strategic Roadmap for Dementia Research and Translation, by Federal Minister for Aged Care and Senior Australians Senator Richard Colbeck. The Roadmap sets out the future strategic direction of Australian dementia research.

After five years of significant investment through the \$200 million Boosting Dementia Research Initiative, NNIDR has sharpened its focus for future dementia research efforts, with high priorities including introducing new and less invasive methods for early diagnosis into clinics across Australia, and tackling the challenge of dementia within Aboriginal and Torres Strait Islander communities.

Other priorities include improving quality of life and provision of care; research to explore new technologies, targets and drug candidates; and retaining and building dementia research capacity.

An accompanying Outcomes

Statement outlines goals for the dementia research sector in adopting Roadmap recommendations. The Roadmap is available to view on the NNIDR website, at bit.ly/2019DementiaRoadmap

Keynote speakers

This year, the forum's keynote speakers discussed prevention, cure and care. Professor Carol Brayne, from the University of Cambridge, spoke on the epidemiology of dementia in contemporary populations and identified areas for future focus. Dr Jeff Williamson, from Wake Forest Baptist Health in the US, presented his research on SPRINT MIND, a clinical trial which evaluates the effect of standard and intensive blood pressure control on the risk of dementia.

Margaret Dudley, Lecturer in Psychology at the University of Auckland, shared her unique experiences tackling the challenge of dementia in New Zealand's Maori community. Australian keynote speaker, Professor Lizzie Coulson from the Queensland Brain Institute, shared her findings on sleep apnoea as a risk factor for Alzheimer's disease.

Dementia journeys

Presentations from people living with dementia and carers included Kevyn Morris, supported by wife and care partner Leanne, who opened the forum and shared his story of diagnosis and living with dementia, his subsequent involvement in research, and his vital contributions to research strategy through the NHMRC NNIDR Research Community and Consumer Reference Group.

John Quinn and care partner Glenys Petrie spoke about their journey to living well after a



L-R: Senator Richard Colbeck, Professor Kaarin Anstey and Tara Quirke

dementia diagnosis. Theresa Flavin shared her experiences as a participant in the development of the Cognitive Decline Partnership Centre's (CDPC) guidelines on *Supported Decision Making in Aged Care*. Living with dementia advocate Bobby Redman called for more hands-on involvement for people living with dementia who participate in research.

Eileen Taylor and care partner Dubghlas spoke about the impact of involving people with dementia in clinical trials and offered insights on improving this experience. Former carer and Bachelor of Dementia Care student, Val Fell, considered the future of respite options within the aged and disability care systems. Phil Hazell shared his experiences as a research participant in advocating for the extension of workforce participation of people living with dementia. (See Phil's article on p32 of this issue of *AJDC*). Former carers Tara Quirke and Harry Douglas presented their research experiences with the CDPC and on the Good Spirit, Good Life research program, respectively.

Looking to the future

Dementia Australia Ambassador Ita Buttrose AC OBE, Alzheimer's Disease International Chair Glenn Rees, NNIDR Board Chair Graeme Samuel and Dementia Australia CEO Maree McCabe considered the future of dementia research and the impact of the Boosting

Dementia Research Initiative.

The academic debate: *APOE gene status – to know or not to know?* was a highlight of the forum, with Professor Kaarin Anstey (Neuroscience Research Australia), Dr Jo Burke (Tasmanian Clinical Genetics Service), Professor Ralph Martins (Edith Cowan University) and Dr Tony Cook (University of Tasmania) considering the ethics and practical implications of one of the biggest questions in dementia research. The Public Information Session, chaired by Professor James Vickers (Wicking Dementia Research and Education Centre, University of Tasmania), was an opportunity for researchers to engage with community members and share the latest dementia research findings in a meaningful and accessible way. A first for the forum, it proved to be a highly successful outreach activity which will be included in future forum programs.

The 2020 Australian Dementia Forum will be held in Adelaide and will include the State of the Science of Care Summit. Registrations and a call for abstracts open later this year. Visit nnidr.gov.au for details. ■

The Australian Dementia Forum Abstracts is included with this issue of the *AJDC* and also available as a PDF at bit.ly/ADF19Abstracts

■ Bojana Kos is from the NHMRC National Institute for Dementia Research

All the home is a stage

In what's believed to be an Australian-first, a musical theatre show involving people with dementia on stage and behind the scenes will be performed for the public in an aged care home during Dementia Awareness Month in September. **Althea Gordon** reports

Mind the Change Inc is an Australian not-for-profit arts association committed to providing high-quality arts based self-development workshops for people working with, caring for and living with dementia. Using 'applied theatre' drama techniques, in conjunction with laughter therapy, we aim to support the wellbeing of people living with dementia and memory loss by providing opportunities for sensory engagement, positive interaction and to overcome isolation. (Applied theatre is drama or theatre that is used in an educational, therapeutic or community context to provide social awareness or change.)

The inspiration

In 2018, inspired by the likes of US-based artist Anne Basting (Time Slips and The Penelope Project), Mind The Change Inc came up with the idea of producing a community-based musical theatre show including people living with dementia in every aspect of the production – on stage and behind the scenes.

Initial discussions were held with Mercy Place Mandurah aged care home in Mandurah, south of Perth, WA in mid-2018, and a working group consisting of residents, family members and staff was established.

Our aim was to use the performance to raise awareness of dementia in the Mandurah community, build a sense of community around the Mercy Place home by collaborating with local groups and schools, and showcase the ability of not only those living with dementia, but also older adults in the community, and their desire to still be included in community events and activities.

As the Artistic Director of



Cast members rehearsing at Mercy Place Mandurah. The decision to use the care home as the venue for rehearsals and the performances means that all residents can participate in the production, no matter what their physical or cognitive ability. All photos courtesy Mercy Place Mandurah

Mind The Change Inc, the group worked with me to select the show we would perform, decide what the production would look like, what was required and the associated risks. We needed something that wasn't too serious, something with music and something that children and the residents could relate to, as both would be involved in the production.

We chose the musical *A Year With Frog And Toad* (the shorter Theatre for Young Audiences (TYA) version), as it ticked all those boxes. It is based on the *Frog And Toad* children's books by Arnold Lobel, has a jazz-style musical score and is light and humorous. It follows the adventures of two friends, the cheerful, popular Frog and the rather grumpy, anxious Toad, along with their companions, as they celebrate and rejoice in the differences that make them unique and special.

Developing the concept

In January 2019 Mind The Change Inc began developing the concept with the working group and Mercy Place's lifestyle team. Auditions were held at Mercy Place soon after,

offering residents, particularly those living with dementia, the chance to be involved in the production in whatever capacity they chose. The home has 80-90 residents, with 20 people with dementia living in the memory support unit, and all are taking part in some way. If it's not on stage or in the chorus, it's helping to make props, the show poster or program. Some participants sit and give us feedback throughout our rehearsals, while others are involved more passively but will sit and make eye contact for an hour with a

big smile. Some of the more physically able residents have offered to be ushers during the performances.

Members from the local theatre community and schools also auditioned and there are five community members and three school children in the cast, as well as others from local schools, the Men's Shed and the community involved back stage assisting with sound, lighting, set and props, or front-of-house.

The performance

In what we believe is an Australian first, we will be performing the one-hour live situational musical theatre production in the Mercy Place Mandurah care home, rather than a theatre, with the shows open to the public throughout September as part of Dementia Awareness Month.

We don't know of anyone who has done this type of project in Australia, and definitely not in WA. People have put on shows *for* residents but not *with* the residents.

As 'situational theatre', the show is performed 'in situ' – meaning we are using the care home as our theatre and bringing the audience into the



Mercy Place residents and community members during a dance rehearsal for the show. The cast includes five people from local community groups and three school children

home. We also have five dedicated spaces within the home that have been set up as theatre spaces for the various scenes. At the end of each scene the audience moves on to the next space, where the actors for that scene are waiting. There will be a maximum of 20 audience members for each performance.

The decision to produce the show as a situational theatre piece, keeping the audience mobile and using Mercy Place Mandurah as the performance and rehearsal venue means any resident can participate, no matter what their physical or cognitive ability. To date, residents have been supported to design the marketing material for the show, make decisions about the staging, set and props for the performance and participate in audio, photography, dance and drama workshops during rehearsals. The staff and community members have also contributed and received advice and support on how to best nurture the budding thespians.

Positive impact

Rehearsals are held three times a week and the care home participants have become increasingly more engaged in the process at each rehearsal and look forward to every session. Residents who don't usually have success in



Residents have been supported to design and make the marketing material for the show, including the poster (pictured below) and program

attending group activities have been arriving 10-15 minutes before rehearsals even begin. When I leave, they always ask, "now when will you be back?" which is wonderful to hear.

The number of residents attending rehearsals varies from week to week; sometimes we have 20 people turn up, other times we have five. That is one of the challenges of working this way, but we are able to be flexible. The residents are supported by staff, students and our community actors, and we are also recording some songs and lines so they can speak along with their own recorded voice during the performances. We also put up large-print words so the residents can be guided to read if able. Humming along to the tunes is also a great addition to our chorus work. The positive

social and emotional impact on the mental wellbeing of those involved in our production of *A Year With Frog And Toad* has been extensive. Several participants living with dementia have learnt new songs from the show that they now recall from week to week. Staff describe how the project is positively influencing their interactions with the residents and, as one member of the working group who is living with dementia commented, "I feel like I've made a new set of friends here, it's really great, you feel connected".

The community actors and production team have also begun socialising and forming friendships with the residents and they notice and ask after them when they are missing from a rehearsal.

Sense of belonging

The sense of belonging to a group and having that responsibility or commitment has also seen a huge positive mental shift in some of the residents. Each time they contribute by rehearsing or taking part in an activity related to the production their

confidence grows. This repeated pattern over an extended period allows both the residents and the carers to build confidence and develop strategies in the 'safe' workshop / rehearsal environment that can be used to tackle everyday life challenges and stressful situations with renewed confidence and enthusiasm.

Our collaboration with local theatre groups, schools, businesses, Men's Sheds and the various teams within the care home has been instrumental in bringing this production to life. This process of creating a 'theatre family' also enables musical theatre to support the aged care sector in achieving key outcomes and actions within the National Guidelines for Spiritual Care in Aged Care (released in July 2018), namely Domain 5 of this document – 'Self-Expression'.

The challenge now is to continue to spread the good work in ways that challenge the status quo and offer yet more creative ways to care.

Tickets and dates

Tickets for *A Year With Frog And Toad* (TYA version) at Mercy Place Mandurah are available for performances from 19-22 September and 26-29 September through www.trybooking.com/506817a dmin@mindthechange.org or www.mindthechange.org

The production is sponsored by Healthway and presented by Act-Belong-Commit, which promotes awareness of the importance of being mentally healthy throughout life. For more ways to become involved in your community and maintain positive mental health visit www.actbelongcommit.org.au



Althea Gordon is Artistic Director of Mind The Change Inc. Her mother has been living with younger onset dementia for more than 13

years. Contact Althea at admin@mindthechange.org



PITCH perfect for home care workers

Training residential aged care staff and maximising dementia care capacity has improved care quality and clinical outcomes for people with dementia (Low *et al* 2015; Spector *et al* 2013). However, there is limited evidence about interventions to improve home care for people with dementia (Cooper *et al* 2017), despite the fact that people with dementia with high-level care needs increasingly remain in their homes. In Australia 70% of people with dementia live in the community and, of these, 84% may have severe or profound levels of disability (AIHW 2012).

Remaining at home enables older adults to stay independent and connected to family and community, has greater cost efficiencies compared to long-term residential care, and reduces the use of acute health care (McIntosh & Phillips 2003). While family carers often provide invaluable informal assistance, formal support, typically provided by home care workers, is also frequently needed as an

adjunct to maintain the health, independence and safety of the person with dementia, particularly as their symptoms progress (Lyberg *et al* 2013).

Providing home care is uniquely challenging as home care workers often work in isolation with little direct supervision, in varied environments, and in sometimes highly stressful situations, therefore needing higher levels of skills and situational adaptability (Delp *et al* 2010; Eggenberger *et al* 2012; Herber & Johnston 2013). As the quality of home care that people with dementia receive directly influences their quality of life and ability to remain independent (Rothera *et al* 2008), a well-trained and highly skilled dementia specialist home support workforce is needed.

The PITCH training program

There is a clear need for specialist dementia training programs for home care workers (Goh *et al* 2018). The NHMRC Boosting Dementia Research-funded PITCH Project – ‘Promoting

Independence Through quality dementia Care at Home’ – aims to improve outcomes for people with dementia and their paid and family carers by co-designing and testing an evidence-based dementia specialist training program for community care. The PITCH program aims to give home care workers the skills and confidence to deliver high-quality, person-centred services that promote independence, improve quality of life and reduce family carers’ stress.

Based on current adult learning principles, it is an experiential program that incorporates up-to-date information and knowledge on dementia with practical strategies to inform daily work, interactive role-playing and scenarios, and activities to promote reflection. It has at its core an appreciation of the lived experience of dementia and an understanding of the impact dementia may have on individuals and their family carers. Importantly, it also highlights the importance of the home care worker’s role

The PITCH project is developing and testing a training program to give home care workers the skills and confidence to deliver high-quality, person-centred services.

Briony Dow, Anita Goh and colleagues explain the co-design approach used to enable service providers, managers, home care workers, people with dementia and family carers to contribute meaningfully as true project partners

and their influence on the experiences of the person with dementia and family carers.

We will evaluate the PITCH program through a randomised controlled trial (RCT) in 2019-2020 with our partner home care providers. To date, these include Australian Unity, Royal Freemasons, Villa Maria Catholic Homes, and Benetas. The large-scale trial investigates the program’s impact on care recipient outcomes (independence, wellbeing, quality of life) and carer (both paid and unpaid) outcomes (burden of care, sense of competence, quality of life). The trial also includes health economic evaluations including outcomes for the service organisations.

Importance of partnerships

Recognising the importance of engaging a broad range of stakeholders, we used a co-design approach. In this participatory approach, people who use or are affected by a service participate in its design, implementation, review and/or delivery.

Our co-design partners included:

- A large research team from the National Ageing



Participants at one of the four PITCH co-design workshops held in 2018 for service providers, managers, home care workers, people with dementia and family carers

Research Institute (NARI), national and international research partners, and dementia education experts.

- People with dementia, family carers, home care workers, case managers and service managers.
- Service providers and industry partners.
- An involved project advisory group chaired by Anne Fairhall, a dementia advocate and family carer. The advisory group provides guidance and input into the design, development, and conduct of all stages of the project, including the implementation, policy and practice implications of the study.

How was the program co-designed?

We gathered in-depth information about how relevant stakeholders are currently experiencing home care, and how their experience could be improved. To do this, we asked participants to recommend the main elements that should be included in the PITCH program to effect a highly skilled, knowledgeable, and empathic workforce delivering home care support services. Their input was provided through:

- 43 interviews with people living with dementia, family carers, home care workers, case managers and service managers. The main themes identified through data analysis related to home care workers' understanding of dementia, person-centred care, communication and rapport, the need for mutual collaboration, and the influence of organisational constraints on continuity of care.
- Four co-design workshops involving all key groups in July 2018. In the first two workshops, 46 participants were asked for their views on the content, length, delivery and setting of the training program. In the second round of workshops,



Workshop participants said the co-design process made them feel like equal partners in the research

34 participants reviewed a prototype program. To promote the involvement of consumers and communities in research through meaningful partnerships, the workshops were facilitated using the World Café methodology (Brown & Isaacs 2005). In a World Café, all participants are regarded as experts of their own lived experience and experiential knowledge. This process prioritised the needs and voices of the participants with dementia. For example, we provided quiet break-out rooms and ample time for people with dementia to ask and respond to questions.

The overwhelmingly positive feedback received from all participants in our evaluation forms has supported our co-design approach. Participants' feedback indicated they felt the World Café method was appropriate, the workshops met expectations, covered important issues, and that the PITCH program will be helpful in improving community dementia care.

Importantly, they reported the co-design process allowed the opportunity to put forward their opinions and ideas, and that they felt like equal partners in the research. Feedback from co-design and prototype workshop participants included the following comments:

"I wanted to share how

wonderful the workshop was, and really felt it captured the gaps in current training and areas we can really make a difference" (service manager).

"It was great to be part of the workshops and have the opportunity to not only express my opinion, but also to hear and learn from the views of others" (family carer).

The research team then used all the information captured from the co-design methods to create the PITCH program. The program was piloted with both experienced home care workers from Alzheimer's WA in November 2018 and with a wider group in June 2019. This feedback helped further refine the program, alongside the assistance of a learning and design consultant.

Accessing PITCH

It is intended that the final co-designed PITCH program will be available to service providers free of charge at the conclusion of the RCT. If this program proves to be successful, people with dementia and their carers will be able to select care providers who have adopted PITCH, as an indication that they will receive appropriate high-quality dementia care. This will be a driver for improved home care services in an increasingly consumer-driven aged care sector. ■

For more information about the PITCH Project, contact the Project Manager Dr Anita Goh on (03) 8387 2377 or email a.goh@nari.edu.au

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References

Brown J, Isaacs D (2005) *The World Café: Shaping Our Futures Through Conversations That Matter*. California: Berrett-Koehler

Publishers.

Cooper C, Cenko B, Dow B, Rapaport P (2017) A Systematic Review Evaluating The Impact Of Paid Home Carer Training, Supervision, And Other Interventions On The Health And Wellbeing Of Older Home Care Clients. *International Psychogeriatrics* 29(4) 595-604.

Delp L, Wallace SP, Geiger-Brown J, Muntaner C (2010) Job Stress And Job Satisfaction: Home Care Workers In A Consumer-Directed Model Of Care. *Health Services Research* 45(4) 922-940.

Eggenberger E, Heimerl K, Bennett M (2012) Communication Skills Training In Dementia Care: A Systematic Review Of Effectiveness, Training Content, And Didactic Methods In Different Care Settings. *International Psychogeriatrics* 25(3) 345-358.

Goh AM, Gaffy E, Hallam B, Dow B (2018) An Update On Dementia Training Programmes In Home And Community Care. *Current Opinion in Psychiatry* 31 S103-S113.

Herber O, Johnston B (2013) The Role Of Healthcare Support Workers In Providing Palliative And End-Of-Life Care In The Community. A Systematic Literature Review. *Health and Social Care in the Community* 21(3) 225-235.

Low L-F, Fletcher J, Goodenough B, Jeon YH, Etherton-Beer C, MacAndrew M, Beattie E (2015) A Systematic Review Of Interventions To Change Staff Care Practices In Order To Improve Resident Outcomes In Nursing Homes. *PLoS One* 10(11) e0140711.

Lyberg A, Holm AL, Lassenius E, Berggren I, Severinsson E (2013) Older Persons' Experiences Of Depressive Ill-Health And Family Support. *Nursing Research and Practice* 2013:e837529.

McIntosh G, Phillips J (2003) 'Caring For The Elderly' – An Overview Of Aged Care Support And Services In Australia. Canberra: Parliament of Australia.

Rothera I, Jones R, Harwood R, Avery AJ, Fisher K, James V, Waite J (2008) An Evaluation Of A Specialist Multiagency Home Support Service For Older People With Dementia Using Qualitative Methods. *International Journal of Geriatric Psychiatry* 23(1) 65-72.

Spector A, Orrell M, Goyder J (2013) A Systematic Review Of Staff Training Interventions To Reduce The Behavioural And Psychological Symptoms Of Dementia. *Ageing Research Reviews* 12(1) 354-364.

Driving resources pass the test

Victoria Traynor and **HC (Rita) Chang** provide an update on the development and testing of two dementia and driving resources for consumers and practitioners, including GPs and nurses, in Australia and overseas

A dementia and driving decision aid and accompanying practitioner education module, developed by our research team at the University of Wollongong, provide evidence-based tools to support the complex decisions around driving retirement for people living with dementia.

Testing has found that both are culturally adaptable and acceptable to consumers and practitioners.

Currently there is no reliable test to assess driving risk for people with dementia and, while early discussions and planning for driving retirement are imperative, this is a challenge because of limited practitioner education on this topic (despite a desire by practitioners worldwide for further training and education), the absence of decisional support resources for drivers, and conflicting legislative requirements across regions.

The Dementia and Driving Education Module and Dementia and Driving Decision Aid (DDDA) booklet have been developed and evaluated by our team of aged care researchers (led by Professor Victoria Traynor) to address some of these challenges. Both resources are freely available from the Aged Dementia Health Education & Research (ADHERE) website at: <http://adhere.org.au/drivingdementia.html>

The Dementia and Driving Education Module

The practitioner-directed education module developed for GPs, practice nurses and allied health care professionals is designed to increase practitioner knowledge,

confidence and competence in supporting people living with early dementia with their decisions on driving retirement. The three-hour module is divided into three sections with seven learning activities incorporating six vignettes, five self-reflections and one case study. It can be completed as either a fully online module or as a blended course with the second section being delivered face-to-face. Both methods of delivery attract CPD points.

The impact of the online and face-to-face education on 240 Australian and 97 Taiwanese practitioners has been assessed using a survey developed by the research team. In pre-post test scores there were statistically significant improvements among participants in three areas of clinical practice: driving knowledge, and a sense of confidence and competence in supporting people living with dementia and their families in decisions on driver retirement (Veerhuis *et al* 2019).

The Dementia and Driving Decision Aid (DDDA)

The 32-page DDDA booklet is designed for use by people with early dementia to assist them to make informed decisions about driving retirement in partnership with their GPs, other practitioners, family members and carers, and to minimise stress associated with forced decision-making.

Content for the DDDA was developed from older people reviewing existing resources and an international industry expert development panel. The structure of the DDDA was informed by international guidelines on decision aids.

Consumer testing demonstrated that use of the DDDA reduced decisional conflict, improved consumer

knowledge and decision satisfaction (Carmody *et al* 2014).

Australian versions and translated adapted versions for New Zealand, the US and Taiwan are available. UK and Canadian versions will also be available on the ADHERE website by the end of 2019.

Training in Taiwan

Since 2017, we have been providing training workshops to clinical practitioners in Taiwan on the topic of dementia and driving, using the DDDA and the education module developed in Australia, tailored for local language and customs. This year we will continue to evaluate how these practitioners use the new skills to positively affect people with dementia and their family carers on the topic of driving cessation. ■

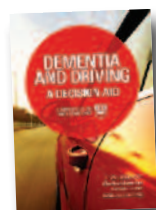


■ Professor Victoria Traynor (left) is with the School of Nursing at the University of Wollongong (UOW), NSW and Founding Director of Aged Dementia Health Education & Research (ADHERE). Dr HC (Rita) Chang is a lecturer in aged and dementia care in the School of Nursing at UOW. To follow up on this article, contact Rita at hchang@uow.edu.au

References

Carmody J, Potter J, Lewis K, Bhargava S, Traynor V, Iverson D (2014) Development And Pilot Testing Of A Decision Aid For Drivers With Dementia. *BMC Medical Informatics and Decision Making* 14(1) 1-7.

Veerhuis N, Chang HC (R), Traynor V (2019) *Driving With Dementia: A Shared Decision Approach To Planning For Driving Retirement*. University of Wollongong: Unpublished report.



Gold Soul companionship

Sanetta du Toit, Lok Yi Cheung, Kylie Angelou, Colin McDonnell and Lee-Fay Low describe an intergenerational program at Scalabrini Bexley which sees young people and older adults sharing a home

Everyone in residential care needs to have a sense of security, continuity, belonging, purpose, achievement and significance. Relationship-focused care is a way of empowering people living and working in aged care (Nolan *et al* 2006). Relationship focused-care emphasises seeing the aged care facility as a community where older people, staff, family and friends are valued. It contributes to improved quality of life for residents, their families and staff by strengthening communication between these key groups. Building positive relationships is a vital part of improving life in these facilities.

Intergenerational programs

Studies globally have found that students, particularly in health professions, have a negative attitude towards older people (Lovell 2006). Research investigating intergenerational programs that promote interaction between youth and residents living in aged care, as well as student placements within aged care services, highlighted the positive response between participants (Chung 2009; Kim & Lee 2018; Lokon *et al* 2017). These projects report promoting a sense of value and belonging for the older adults, whilst the young people expressed greater respect and appreciation for the residents, as well as developing confidence in interaction and communication (Annear *et al* 2017; Kim & Lee 2018; Lokon *et al* 2017). Of concern is that when intergenerational visits stop, the residents' health is negatively impacted (Schulz & Hanusa 1978).

One example of an ongoing



Founders of the Gold Soul Companionship program (from left) Associate Professor Lee-Fay Low (University of Sydney), Colin McDonnell (Scalabrini Villages), Sanetta du Toit (University of Sydney) and Sister Maria (Scalabrini Villages)

intergenerational program is to have university students living on-site in residential aged care facilities and spending time with residents. There are anecdotal examples of this model for intergenerational programs (see box p17).

The Gold Soul program

The Gold Soul Companionship Program is introducing increased opportunity for social and occupational engagement of residents in the Scalabrini Bexley care home in Sydney, NSW by enabling undergraduate students from the Faculty of Health Sciences at the University of Sydney to live-in at the facility. Since the program began in July 2018 students have been volunteering 30 hours per month in exchange for free accommodation.

Sister Maria, from Scalabrini Villages, named the program.

This is the meaning behind the name:

- Gold: being generous and giving, compassionate and loving, sharing wisdom and knowledge.
- Soul: the principle of life, feeling, thought and action in human beings.
- Companionship: the enjoyment of spending time with another person.

Up to four students are involved in the program at any one time. Their agreement with Scalabrini head office usually lasts between a year and 18 months. During this time the live-in students are each allocated a 'house' where they volunteer. They spend most of their time with specific residents, many living with dementia, but they also run and contribute to group activities. At the moment the activities that live-in students and residents share include:

- Joining residents on weekly bus trips to explore the city.
- Games and everyday group activities with residents who do not often leave the premises, eg bowling, joining them for religious rituals and events, participating in meal times, accompanying them to musical events, hosting high tea for residents and their relatives.
- Individual activities, including going for walks, watering the garden, picking flowers, or just providing companionship when someone feels lonely. There are also opportunities to share music as part of the Alive Inside program, or to enjoy playing with the in-house pet rabbit. ➤

Scalabrini Bexley

- Houses 160 residents who are living across three buildings (houses): Toscana is home to residents with high-care needs; Milano provides for residents with advanced care needs; and Sorrento is a purpose-built dementia-specific building.
- Employs 203 staff.
- Has two cafés onsite, Café Roma in Milano and Café Sienna in Toscana. Both are meeting places for residents and their families.
- Has a chapel in Milano house which holds a mass on Saturdays. The pastoral care program has three nuns residing on site and a daily Rosary is offered to each resident.

Loki and Angelo

Lok Yi Cheung (Loki) was among the first group of three students to join the Gold Soul Companionship Program at Scalabrini Bexley. In building a relationship with Angelo, one of the residents living with dementia, Loki had the opportunity to understand Angelo as a person, to get to know his history, personality and needs. Loki developed a personal interest in dementia after her first hospital placement and wanted to gain more exposure and insight into how this condition impacts the ageing population. These are her reflections, written before Angelo's death in June this year:

"Angelo had his 86th birthday in Sorrento house last October [2018]. Staff at Scalabrini love him, and even posted a comment in the home's monthly newsletter, *In The Loop*, which states: "everyone wants to spend time with Angelo, he is one of the most polite and respectful true gentlemen that I have ever met". His birthday party was attended by kitchen and catering staff, nurses, residents, and even the contractor renovating part of the premises. Through this program, I was lucky enough to get to know Angelo as the person he is now, and also had an opportunity to understand his past.

"Angelo was born in Santa Marina, a small town in Italy. He was part of a big family of 10, and came to Sydney as a young man, where he met his wife, Nina. They got married in 1972 and soon after they had their son. He was devoted to his beloved wife



and son. Unfortunately, his son passed away at the age of 20. Today Angelo still thinks of his wife, his son, and his dog, Bobby, and gets tearful when we mention them.

Angelo as a young man



Live-in volunteer Loki with Angelo at Christmas, 2018

"Angelo moved into Scalabrini Bexley in 2016. I have been exploring his hobbies and activities that give him joy and a sense of accomplishment. These include gardening, walking and dancing. At Scalabrini we have accommodated his needs with a raised garden bed. I have also involved Angelo in group activities with other residents. Bowling, especially, has encouraged him to interact with other residents and created opportunities for shared fun and joy. These rewarding experiences will benefit me in my future career as a physiotherapist."

*In loving memory of Angelo Zambon
(15 October 1932 – 15 June 2019).*

was really inspiring seeing Tanveer join the Gold Soul program and hit the ground running. In less than two months she was able to build an amazing connection with...a non-English speaking resident from a Russian background. Tanveer has brought back some quality of life for this lovely lady despite all the language barriers."

Relatives are also appreciating this new addition to the services at Scalabrini. Wellness Coordinator Tracey Gill received an email from a family member who stated: "I am contacting you at my mother's request. She has greatly enjoyed the company of one of the live-in trainee/volunteers there, called Gabrielle. Gabrielle visited her in the past and took her outside around the garden...being wheelchair-bound it was a highlight of her day."

Staff are delighted by what they see, especially for those residents who do not recognise people they know. One lady living with dementia does not interact with people, but a care manager shared that when Hannah, the live-in student who spends time with her on regular basis, approaches her, "she seems to recognise...her. Which is good. She actually lights up and smiles, which is great!"

Conclusion

Creating collective living communities that include younger adults could contribute to maintaining and/or expanding meaningful engagement of older residents, especially those who are living with dementia. It is low cost and potentially sustainable.

This pilot program is currently being evaluated by the project team. An oral presentation on preliminary findings was delivered at the Australian Occupational Therapy Conference (Angelou *et al* 2019). We hope that other organisations might offer similar opportunities to create connections between young people and residents. ■

The program's impact

Our students say that they love living and volunteering at Scalabrini Bexley. Living side-by-side with frail and vulnerable people is exposing the students to real-life realities and challenges faced by older adults, especially those living with dementia, on a daily basis. Live-in students also value the range of training they can engage in (eg person-centred dementia care training; a virtual dementia tour; and a 'Seated and Safe or Active and Engaged' workshop).

Living in an aged care

facility was quite daunting for the students at first and some found the initial couple of months quite overwhelming. They observed frequent ambulance visits and residents going in and out of hospital during the day and night. Regular supervision by on-site staff and University of Sydney mentors was introduced to support students from the outset and during their journey.

Staff report that the Gold Soul Companionship program benefits all those living and working at the facility. The students are supplementing

the paid workforce by spending more one-on-one time with residents and running activities on weekends. As one care manager said: "It's good that the girls can spend extra time with the residents themselves and get to know more [about their] background... They have the time to build special relationships".

Scalabrini Bexley Village Manager Joseph Massih is very impressed with the commitment of the live-in students. He commented specifically on Tanveer, the latest addition to the team: "It



Current live-in volunteers at Scalabrini Bexley (from left) Hannah, Loki, Tanveer and Gabrielle ready to serve food on Mother's Day

■ Sanetta du Toit is a Senior Lecturer in the Faculty of Health Sciences, Discipline of Occupational Therapy, University of Sydney (USYD); Lok Yi Cheung (Loki) is an undergraduate student in the Faculty of Health Sciences, Discipline of Physiotherapy, USYD; Kylie Angelou is an Honours student in the Faculty of Health Sciences, Discipline of Occupational Therapy at USYD; at the time of writing, Colin McDonnell was Dementia Excellence Practice Lead at Scalabrini Villages; and Lee-Fay Low is Associate Professor in Ageing and Health, in the Faculty of Health Sciences, USYD. To follow

up on this article, contact Sanetta at sanet.dutoit@sydney.edu.au

References

Angelou, K, Low LF, Du Toit SHJ (2019) *Promoting Meaningful Engagement For Residents With Dementia Through Intergenerational Programs: A Case Study Approach*. The Australian Occupational Therapy Conference, Sydney, July 2019.
 Annear MJ, Elliott KJ, Tierney LT, Lea EJ, Robinson A (2017) Bringing The Outside World In: Enriching Social Connection Through Health Student Placements In A Teaching Aged Care Facility. *Health Expectations* 20(5) 1154-1162.

Examples of intergenerational living programs

Intergenerational Living An Affordable Housing Model: <https://intergenerationalhousing.wordpress.com/>

The Nursing Home That's Also a Dorm: <https://bit.ly/2uZcoXD>

Intergenerational Living: <http://globalageing.org/intergenerational-living/>

Dutch Nursing Home Lets Students Live Free: <https://ab.co/1BP5nBg>

Dutch Retirement Home Breaks Boundaries And Age Divide: <https://bit.ly/2qmSDaB>

Chung JC (2009) An Intergenerational Reminiscence Programme For Older Adults With Early Dementia And Youth Volunteers: Values And Challenges. *Scandinavian Journal of Caring Sciences* 23(2) 259-264.
 Kim J, Lee J (2018) Intergenerational Program for Nursing Home Residents and Adolescents in Korea. *Journal of Gerontological Nursing* 44(1) 32-41.
 Lokon E, Li Y, Parajuli J (2017) Using Art In An Intergenerational Program To Improve Students' Attitudes Toward People With Dementia. *Gerontology & Geriatrics Education* 38(4) 407-424.

Lovell M (2006) Caring For The Elderly: Changing Perceptions And Attitudes. *Journal Of Vascular Nursing* 24(1) 22-26.
 Nolan MR, Brown J, Davies S, Nolan J, Keady J (2006) The Senses Framework: Improving Care For Older People Through A Relationship-Centred Approach. *Getting Research into Practice (GRiP) Report No 2*.
 Schulz R, Hanusa BH (1978) Long-term Effects Of Control And Predictability-Enhancing Interventions: Findings And Ethical Issues. *Journal of Personality and Social Psychology* 36(11) 1194-1201.

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Dance as medicine

"Much more of the brain is devoted to movement than to language. Language is only a little thing sitting on top of this huge ocean of movement"

– Dr Oliver Sacks

Dementia Hero: Dance As Medicine is a dementia-friendly program promoting communication through movement and dance, designed collaboratively with people living with dementia, and running in Sandgate, Queensland.

Connection, communication

Dementia Hero is about connection and communication. When verbal communication becomes difficult, people living with dementia require verbal communicators to learn a language they can connect with. Dementia Hero offers training for support people to help a person living with dementia to feel safe, connected and engaged with the world.

Christine Bryden, who was diagnosed with younger onset dementia in 1995, was one of the people I worked with to develop the program. She believes the inclusive nature of the Dementia Hero training program has the potential to benefit not just people living with dementia, but also those who have language dysfunction after a stroke or head injury, or who are living with Parkinson's disease.

"People living with dementia often become isolated in their communities, as well as within their families, due to being unable to express themselves verbally and to keep up with the flow of conversations around them," Christine said. It was important, therefore, "to discover non-verbal ways of communicating with people with dementia in order to overcome these feelings, which can often lead to significant depression. It is vital people



Beverley Anne Jansen is supporting her father William Hill, who lives with dementia. Both are Dementia Hero ambassadors

living with language dysfunction due to a range of conditions are included and supported within Australian society. This is their human right, as people living with a disability".

Movement language

The Dementia Hero program is based on non-verbal 'conversation' through improvised dance movement, and includes socialisation as well as moderate physical exercise. The 'movement language' in the dance workshops is generated by the participants, who are either living with dementia or support someone living with dementia. In this process there can be no wrong way because the thoughts and feelings communicated through movement are as unique as the individuals involved.

A trained facilitator guides the two-hour Dementia Hero workshop using movement, tactile and musical or sound stimuli, with participants invited to respond to a theme, such as 'nature', 'chocolate' or 'sport', for example. A theme inspires a movement response – they are 'talking' with their bodies. As participants explore a theme (like trees), they may move like trees, branches reaching out or leaves blowing

in the wind. The physical response often prompts memories. Seeing people's faces, especially their eyes, come alive when these movement ideas are embraced is a joy to watch.

The workshop also includes a half-hour break for refreshment, cooling down and socialisation. We aim for a class size of six people living with dementia and six enablers, plus volunteers who assist as needed.

Dementia Hero philosophy

The goal of Dementia Hero is for Australians with diverse communication styles to feel more included in Australian society and for Australians to gain a better understanding of how to communicate with non-verbal communicators. Body memory, the healing power of wellbeing dance and non-verbal communication are empowering abilities for an inclusive society.

Facilitator training

A Dementia Hero training program is available for allied health professionals and 'body aware' professionals such as dance practitioners, massage therapists, yoga instructors or Auslan (Australian Sign Language) signers. The training is designed to develop the

Tiina Alinen

introduces a new dementia-friendly program that encourages communication through movement and dance

participants' skills to facilitate Dementia Hero workshops in their own facilities or communities and to use the communication tool set on a one-to-one basis. Participants are taught to use The Listening Eyes Technique. This is a set of 'tools' or strategies that support perceptive conversation (active listening and being aware of subtle language) and relationship-building, and help a person with dementia to feel safe, connected and engaged. The technique was developed over my 35 years of professional practice.

Practitioners interested in registering for Dementia Hero training workshops can contact me via email tiinaalinen@gmail.com or phone 0400 731 624.

Workshops

With funding from Brisbane City Council, we are offering Dementia Hero workshops for people living with dementia and their support person in 2019 in the Brisbane suburb of Sandgate. The next Dementia Hero workshops will be held on 10, 17 and 24 August and the 2, 9 and 16 November at Sandbag Community Centre, Sandgate. To register interest, call Belinda on (07) 3869 3244. ■

For more information about Dementia Hero visit www.dementiahero.com.au



■ Tiina Alinen is a communication awareness consultant and a graduate of the Australian Ballet School. She began working with people with diverse abilities as a freelance dance artist in the 1980s

A community of care

Cath Bush explains the strategies used by Koonambil Aged Care to protect the freedom and culture of its residents. This includes supporting residents with dementia to come and go from the home on their own whenever they wish

Koonambil Aged Care Ltd is a community-owned organisation that operates a residential aged care facility in Coonamble, in north-west NSW. Koonambil has 30 bed licenses that allow ageing in place and respite, and also operates eight independent living units in a separate facility called Koonambil Village. Currently 70% of those living in the aged care facility have dementia.

The town of Coonamble has about 3000 residents, with a large Aboriginal population. The 2016 Census identified 30% of the Coonamble population as Indigenous, with another 15% choosing not to identify as either Indigenous or non-Indigenous. We offer an individualised approach to care that ensures the culture of our residents is respected. This article describes some of the ways that we achieve this within Koonambil's residential aged care facility (Koonambil).

An integrated community

We describe Koonambil as an 'integrated community' because we don't have a dementia-specific unit and residents with dementia are not segregated. They are cared for as individuals rather than groups of people or as a group of people with dementia.

We manage the needs of the residents with dementia through astute care planning for each person, in the same way we manage any other need. This means caring for the person, rather than approaching it as care for their dementia. We've found that this keeps all residents, dementia diagnosis or not, very much connected with their (and our) community. It has created a culture where everyone looks out for each other, as they would in the wider community.

Individual care agreements

We are very lucky to have excellent volunteers and staff who support our attentive philosophy to meet all resident needs. We are also lucky to live where we do. Coonamble is a small town where people know each other and keep an eye out for each other. This is what supports Koonambil to have such individualised



All Koonambil residents who are physically able can leave the care home on their own, subject to a risk assessment. Photos courtesy Koonambil Aged Care

care agreements with residents and their families.

Every person who comes into our care has an individual care plan completed, with significant input from their family or nominated representative, which contains the specifics of their personalised care. This is formulated with as much detail as is required to ensure that we can respect the culture of the person. We talk to each resident and their family members individually. Arrangements, including the resident being able to leave the facility on their own, are documented in their care plan and also communicated verbally to all care staff and the resident's family or representative. Subject to a risk assessment, all Koonambil residents who are physically able can leave the facility on their own. This is always promoted and encouraged to happen where possible. Families have told us that they have chosen Koonambil because they know residents won't be 'locked up'.

Enabling choice

Aboriginality and a diagnosis of dementia are just two factors to be considered when we are determining how to care for a resident in a way that protects their freedom to make choices, even if there is risk involved.

We engaged a consultancy firm, specialising in culturally directed care and policies, to create a 'Choice and Dignity of

Risk' assessment tool specifically for Koonambil. We use the assessment tool to weigh up the risk associated with a resident exercising their right to choose a course of action (such as leaving the facility on their own), but where the decision carries inherent risk. If the risk is considered too great (eg, the person has no sense of road safety) this wouldn't be an option. As residents can't always make these decisions for themselves, the choice and dignity of risk tool allows us to make that agreement with their family or representative. We can adapt our care plans to take into consideration cultural and personal preferences, and community support.

For Koonambil, consumer directed care means listening to residents and their families. Together, we agree on a care plan that supports every resident and keeps family members involved. Information about personal and clinical care is passed on to staff in structured meetings, but our individualised approach isn't just for residents. Staff have morning and afternoon tea together and use a communication diary that encourages them to support residents as they go about their day-to-day lives. All staff write in the diary, which gives each team member a sense of ownership for the care of residents.

We find the communication diary is particularly useful logistically (keeping

track of who is where and when) but also great to support continued individualised care – it keeps all staff up to date with personal details and information about individual residents, and allows them to maintain a consistent approach to the care of each person.

Respecting cultural practices

All residents have individual needs. For example, for one resident with a passion for flying, we've hung planes along the hall to guide him to his room. For Aboriginal residents who are living with dementia there are particular things we do to create an environment that respects cultural choices. Examples of cultural practices that are important to our Aboriginal residents and which we respect include:

- Being able to walk to and from where they are living to wherever they want to go without having to request permission or provide notice, for the period of time they choose.
- This concept of being able to come and go as they please without having to explain or seek permission is assumed.
- The importance of land and an individual's connection to land plays a significant role in their need to have access to that land.

The procedures we use to manage these cultural expectations include:

- A formal agreement between the resident, their family and Koonambil about the resident's ability and freedom to walk from the facility alone to visit their relatives or previous home without any restriction. After making an assessment using the choice and dignity of risk tool, the resident's family then signs the agreement to say they are happy for their family member to leave.
- The communication diary.
- The number of staff rostered on at any one time is structured to ensure they can keep residents safe. Koonambil uses a Vitalcare nurse call system which can provide data on call response times. We analyse this information and other influencing factors (such as individual resident needs) to allocate an appropriate number of staff for each shift.
- As Koonambil is an integrated care community, the residents can tell staff where other residents are.
- The main way for residents to leave the home is past the main office and via the front door, which means that staff are often immediately aware of residents leaving or returning to Koonambil.

Following are examples of how these procedures work in practice.

One of our residents with dementia was



The Koonambil Aged Care home in the town of Coonamble, NSW

a well-known local Aboriginal Elder. His son lived a two-hour bus trip from Koonambil. Without notifying staff, the resident left Coonamble and caught the bus to visit his son. Because of the agreement we had in place with his family, within half an hour of his leaving all parties knew that he was safe and arrangements had been made for his return. Community members who recognised the man when he boarded the bus contacted Koonambil and his family almost immediately, and we worked together to manage his travel appropriately. His son said his father would stay with him overnight and he would send him home to Koonambil on the bus the next day. Another family member was organised to meet him at the bus stop when he returned and bring him back to Koonambil. The resident was happy to return and all involved were pleased that he could visit his son.

This man would leave Koonambil independently every day to visit family and friends locally. This routine was well known and helped the community to identify his bus trip as unusual. Because we had good relationships with his family (immediate and extended) and the wider community, who counted him as an integral member, as well as an individualised care plan in place, this man was able to travel on the bus independently, stay overnight with his son and return safely to Koonambil without incident. He was used to visiting his son whenever he wanted, so the agreement was as simple as allowing him to continue to be as independent as he chose. This worked because it was well known by the Koonambil and wider community that he could leave to visit his son.

Even with an agreement in place with a resident's family, we will still get phone calls from up to half a dozen people in the town to let us know if they have seen a resident who is outside the grounds of Koonambil. This communication is open and welcome. It provides reassurance to us and the community, but ultimately it's the

agreement with a resident and their family that guides how Koonambil provides care. We're lucky we can do this in a small community.

We've had one such agreement with the family of an Aboriginal woman living with dementia who was very well known in the community. She would regularly walk about 2km 'home' to her previous address where her relatives still lived. Without fail, we'd get phone calls from members of the community to let us know they had seen her on her way. We would reassure whoever rang that she was able to walk to her old home. We'd then ring her family to let them know she was on her way and her family would let us know when she'd arrived. After she'd spent time with them they would drive her back to Koonambil. She was always happy to return to Koonambil and it was always her choice to return, in the same way it was her choice to leave for these visits to her previous home.

Individual approach

Our individualised approach can support residents in many ways. Responding to nomadic tendencies is just one example. Another is in relation to possessions. The Western notion of possessions is contradictory to traditional Aboriginal culture which saw material things shared, and continues to be an influence in this community.

One female Aboriginal Elder became a resident at Koonambil after being financially abused in the community. She had only two family members, neither of whom lived in the community. We were able to work with them to care for and protect this resident in a way they hadn't been able to do without our support. When she died she had a very small amount of money and a few of her own possessions – more than she'd ever owned before. In gratitude for the care that we had been able to provide, her family members bequeathed all her possessions to Koonambil.

Conclusion

Koonambil acknowledges the important role that members of our town's community play in caring for people with dementia. As long as we can do this, culture will be respected in a way that is inclusive for the community and provides the most supportive environment for the residents. ■



■ Cath Bush is CEO of Koonambil Aged Care Ltd, in Coonamble NSW. Contact her at ceo@koonambil.com.au

Making communities more dementia-friendly

Caroline Grogan highlights the four key elements necessary for the development of a dementia-friendly community

Dementia Friendly Communities (DFC) have been defined as friendly environments which enable people living with dementia the independence to live with choice and control over their lives (Wiersma & Denton 2016). This is a flexible approach, given 'friendly' is a personal consideration. The framework of person-centred care can fit within an individualised, friendly approach (Rahman 2017; Vernooij-Dassen & Moniz-Cook 2016). A tension arises when this is transferred into policy and evaluation measures. What is considered 'friendly' for one person can be a barrier for another person.

Furthermore, key principles of meaning, purpose and value for people living with dementia are highlighted in a dementia-friendly community, yet how these are implemented alongside strategies to elicit voices from people living with dementia in the process are often overlooked (Alzheimer's Australia 2014).

As part of my PhD research I am exploring 'Experiences of Implementing Dementia-Friendly Communities Principles and Processes in Local-Based Initiatives in South East Queensland'. This article highlights the four key themes to emerge from my review of national and international dementia-friendly community initiatives as being an integral part of the development of DFCs. The themes to have emerged from current global DFC movements are: raising awareness; people living with dementia having a valued role; care and support (formal and informal); and the physical friendliness of an environment.

Raising awareness

Negative misunderstanding of dementia by communities has been seen as a central area to address when investing in DFC activities (Lindsay *et al* 2012; Nay *et al* 2015; Nomura *et al* 2009; Smith *et al* 2016). In a UK study, people living with dementia highlighted that their primary concern was the want for more



Dementia Friends is a dementia-friendly movement that creates public resources and arranges events hosted by local organisations or governments to nurture friendships between people living with dementia and the wider community. Stock image: Rawpixel.com / www.freepik.com

interactions in the community to be positive; namely, people being helpful, supportive and having non-stigmatising attitudes and/or behaviours (Crampton & Eley 2013).

To raise community awareness of dementia, a number of activities were suggested in the literature, for instance the education of people in the community to create 'Dementia Friends' (Hayashi 2017), intergenerational activities and the establishment of welcoming shops/spaces for people living with dementia (Downs & Bowers 2008; Gronemeyer & Rothe 2015) and communities hosting events to raise awareness of dementia (Turner & Morken 2016).

An Australian study sought to raise awareness and change community attitudes through contact with the stigmatised group (people living with dementia) (Phillipson *et al* 2018). It gave participants the opportunity to co-facilitate education sessions to raise community awareness about dementia. Through this training, community members left with more of an understanding of the lived experience and the person 'behind the dementia', creating more empathy and understanding (Phillipson *et al* 2018).

This has been stated as the best way to break down stigma, by showing what people living with dementia are capable of (Phillipson *et al* 2018). The "most powerful means of reducing stigma and correcting the common misconceptions surrounding dementia is for those who have the disease to be *seen and heard more*" (World Alzheimer's Report 2012 p55).

Awareness also needs to be raised among professionals about how best to communicate with people living with dementia in delivering the diagnosis and in the journey after diagnostic disclosure (Carpenter & Dave 2004).

Dementia Friends

Dementia Friends is a DFC activity which educates people from the wider community (either online or in face-to-face groups) about dementia and how to support someone living with the condition. In Japan, Dementia Friends is a dementia-friendly activity that creates public resources and arranges events hosted by local organisations or governments to nurture friendships between people living with dementia and the wider community (Alzheimer's Australia & Alzheimer's Disease International (ADI) 2015; Alzheimer's

Disease International n.d.; Chalk & Page 2016; Nomura *et al* 2009; Smith *et al* 2016).

Japan's campaign to train Dementia Friends aimed to improve the everyday lives of people living with dementia through nurturing one million friendships across society. This project has become globally recognised for its efforts in raising awareness, deepening empathy and decreasing stigma relating to people living with dementia in society.

In Germany, police, shop owners and sports clubs are receiving dementia-friendly 'community training' to help with further inclusion for people living with dementia in their local communities (Downs & Bowers 2014).

Although there has been notable investment and progress in developing the Dementia Friends campaign and community training, the training of participants and the involvement of people living with dementia still leaves much to be desired (Hayashi 2017). For example, in Japan, the initial training template of Dementia Friends came under critical review as people living with dementia believed it was too deficit- and medical-focused (Hayashi 2017). This reinforced the power imbalance between organisations and people living with dementia. This also raises the concern of developing well-meaning 'dementia friendly' projects while limiting the active collaboration of people living with dementia in the development process.

Having a valued role

The second theme which emerges from examining international DFC activities concerns people living with dementia having a valued role in their community, especially in the development and realisation of DFC projects. This aligns with a prominent theme in research with people living with dementia which highlighted the need to maintain involvement in meaningful activities (Han *et al* 2016; Phinney *et al* 2007; Young *et al* 2016).

Upon diagnosis people often experience changes in social relations and meaningful engagement (Kuosa *et al* 2015; Smith *et al* 2017). This change can see people going from active participants in society (work, leisure) to becoming increasingly passive and overlooked (Innes *et al* 2016; Kuosa *et al* 2015; Swaffer 2016). Two ways that people living with dementia can participate in meaningful activities to have a valued role are being involved in research and volunteering (Roach & Drummond 2014; Tanner 2012).

When people living with dementia are involved in research, participants can



To make a public space dementia friendly, people living with dementia should be involved in the development process.

Stock image: www.freepik.com

experience benefits from the engagement (Stenhouse *et al* 2013; Tanner 2012). Furthermore, "involvement in research can challenge the marginalisation of older people with dementia and promote their social inclusion" (Tanner 2012 p297). Outcomes from studies can serve to also enhance wider community knowledge through the creation of digital stories (Stenhouse *et al* 2013), poems and art (Meyer 2017; Miller 2018). These align with DFC principles and can serve as a way to operationalise them locally.

Volunteering can also be seen as a meaningful activity supporting people living with dementia to have a valued role in the community (Roach & Drummond 2014; Roach *et al* 2016). This has been shown to increase social engagement and the possibility of people with dementia staying in their own homes (Roach & Drummond 2014).

In the Netherlands, the 'DemenTalent' project, launched in 2012, provided people living with dementia the opportunity to decide where they would like to volunteer in the community and build upon their talents (Alzheimer's Disease International n.d.). Some examples included opportunities to engage with a nursery, football club and local radio station. This replaced the widely used deficit model of care.

In Japan, people living with dementia were part of a program teaching younger people how to cook (Hayashi 2017). In Germany, projects advocated for greater involvement of people living with dementia because activities were often led by professionals (Gronemeyer & Rothe 2015).

Furthermore, when people living with dementia have the opportunity to serve and share skills, their self-esteem and enthusiasm is increased, along with staff empathy (Nomura *et al* 2009). This aligns with the objective frames of destigmatising dementia through recognising and empowering the rights

and abilities of people living with dementia (Reese 2015).

However, people living with dementia still remain underrepresented in steering committees or developmental consultation in Dementia Friendly initiatives. Notably, a North Wales study developed several projects to raise Dementia Friendly awareness, yet was criticised for not involving any people living with dementia in the development process (Chalk & Page 2016). "Reports of how researchers have *involved* people with dementia across the research process remain scarce" (McKeown 2017 p3).

This could be due to various reasons, including people with dementia being devalued and not seen as able to participate or partner with, given negative narratives around dementia (Nay *et al* 2015; Rivett 2017; Tanner 2012). Stringent university research ethics or government funding processes can deter the involvement of people living with dementia in the research or development process, with impaired cognition and informed consent proving delicate. This highlights the interplay between theory and social culture in shaping or hindering the level of active participation by people living with dementia.

Care and support

The third theme found in DFC literature was the need to improve formal and informal care and support for people living with dementia. This could include reducing barriers to accessing support, offering flexible and appropriate care and shifting the focus of care to person-centred or co-created. Practice guidelines have been implemented in various agencies, prioritising person-centred care (Downs & Bowers 2008). This shifts the focus away from the diagnosis to appreciate the person 'behind the disease', to destigmatise and empower people living with dementia (Chalk & Page 2016).

Memory Cafes

A major project highlighting care and support for people living with dementia is the creation of 'Memory Cafes' (McFadden & McFadden 2011; Plunger *et al* 2016). Memory Cafes, originally referred to as Alzheimer Cafes, are becoming a global trend and seek to raise awareness about dementia while fostering caring and supportive communal relationships (Mather 2006). The first Alzheimer Cafe was launched in 1997 in the Netherlands as an informal support network for people living with dementia, carers and stakeholders (Alzheimer's Disease International n.d.;

McFadden & McFadden 2011). The cafes offer informal socialisation, flexible support and care for people living with dementia and carers. (See p24 for more on this topic).

Participants highlighted their experiences of fellowship, friendship and access to advice relating to support services. This also aligns with the intrinsic need for people to engage and connect within a community. It is important when considering a dementia-friendly environment not to dismiss the social environment (Brannelly *et al* 2017). Accessibility also refers to information sharing, decision-making and social integration into mainstream society (Zychlinski *et al* 2016).

This initiative has grown to include 230 Alzheimer/Memory Cafes in the Netherlands, run by volunteers, providing a public social haven with care and support for people living with dementia (Alzheimer's Disease International n.d). However, there remains limited peer reviewed publications showing the direct link between an Alzheimer/Memory Cafe and the influence on people's wellbeing through engagement (Mcfadden *et al* 2014).

Physical friendliness of an environment

The fourth theme to consider when developing DFCs is the physical environment. In the UK it was defined as; "place: including scale, welcome, clarity and familiarity" (Crampton & Eley 2013; Hare 2016). It is advocated that when building a new infrastructure such as a

library, shopping centre, store or toilets, these things should be taken into consideration. This also saves economically as there is no need to make the environment more dementia friendly or age-inclusive at a later stage when public demand requires it. However, to make a public space dementia friendly, people living with dementia should be involved in the development process. In a DFC, people living with dementia must be encouraged to discuss their lived experience and hopes for their social engagement and environment (ADI 2016).

The most comprehensive study regarding design (outdoor, neighbourhood environments), has been by Mitchell & Burton (2010, 2006). Six design principles were raised in accordance with the needs of people living with dementia. These include: familiarity, legibility, distinctiveness, accessibility, comfort and safety (Burton & Mitchell 2006; Mitchell & Burton 2010). Outcomes from the study showed how people living with dementia could lose their way in complex street layouts, were intimidated in formal spaces (historic squares) and preferred vibrant cafes (Mitchell & Burton 2010).

Evaluation tools have been developed to guide organisations, communities and governments to audit environments to see where improvements can be made (Duffin 2014; Fleming *et al* 2017). These guidelines build upon the aforementioned principles and address appropriate lighting, footpaths, floors and signage (Duffin 2014; Fleming *et al* 2017).

Summary of the DFC themes

This article has highlighted the four key themes to emerge in national and international DFC initiatives as integral to the development of DFCs. Projects looking to develop DFC activities will need to appreciate: the challenge of raising awareness about dementia; supporting people living with dementia to have a valued role within the community; nurturing formal and informal support and care for people living with dementia and carers; and reducing barriers in the physical environment to create dementia-friendly spaces.

All of these areas need input and direction from people living with dementia. This is important to note because well-meaning activities can still neglect their voice or involvement. Further, while DFC activities are widely seen to be beneficial, more detailed evaluation and feedback is required to academically substantiate outcomes and guide other planning teams towards preferred outcomes.

Conclusion

The movement of DFC initiatives globally and nationally can offer a framework of support for and with people living with dementia and their families. It offers a socially inclusive framework to empower and build upon hope and community rather than discrimination through segregation. Every person should be valued for their inherent worth and dignity. When people living with dementia are not treated as participating citizens in society it is fundamentally a human rights issue. I believe "how society treats its members with dementia is the crucial test of its humanity" (McCurry & Drossel 2011 p153). Hopefully, as further DFC developments unfold, the abilities, voices and human rights of people living with dementia can be further realised. ■

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References

The reference list for this article is available on the *AJDC* website at www.journalofdementia.com/dfc-references

Dementia-friendly community resources

Guidelines For The Development of Dementia-Friendly Communities: this guide from Alzheimer's WA is a practical model for local governments, civic services and community organisations. It's free to download at: <https://bit.ly/32sSQtu>



Memory Cafes in WA: Alzheimer's WA (AWA) has partnered with local government and businesses to bring the Memory Cafe concept to WA. It now runs monthly Memory Cafes in a select number of cafes across Perth and in regional areas. Dates for 2019 are on the AWA website at: <https://bit.ly/2KEpwtN>

Memory Café Guidelines: Alzheimer's WA has also produced this free guide to support local governments, shopping centres, cafe owners and other interested organisations in setting up Memory Cafes in their local communities. It's available to download at: <https://bit.ly/2NQFW5d>



Community Café Toolkit: this resource from Dementia Australia includes a manual with instructions on how to establish and run a community café in your region, as well as checklists, templates and other resources to assist in getting started and in the day-to-day running of the café. For details and to request a copy, visit: <https://bit.ly/2XL7SHC>

Full steam ahead for D Caf

D Caf is a new dementia cafe program launched in Sydney earlier this year by a group of dedicated volunteers. They're aiming to have 20 D Cafs in place around Australia by the end of 2020, offering a friendly space and peer support for people with dementia and carers. **Annie Kenyon** explains

Getting together over a cuppa – it's how we bond, how we unwind and share our thoughts and ideas.

Having a chat while downing a mug of warm brew is an integral part of the day for so many people.

But for some, this essential part of their life disappears when dementia comes into the family. Isolation becomes the norm because it's simply too hard to hold a conversation with others and so, at a time when they need the most support, people stop going out, push others away and friends stop visiting.

This may seem a bit dramatic, but for those who have had a diagnosis of dementia, for themselves or a family member, all too often this is their reality.

Building a team

Enter Tim England – a passionate man who calls himself 'The Dementia Champion' (see *A Tale From A Dementia Champion*, in *AJDC* 7(1) 2018). Tim is a dementia care specialist and educator, with a Bachelor of Dementia Care from the University of Tasmania, who is dedicated to helping people with dementia and educating the public about the condition.

In 2017 he began presenting free public dementia education programs in his local community of Ku-ring-gai, in Sydney's north. It is his intention to make every community in Australia dementia friendly. That's no mean feat for a team of one. So far, he's done pretty well at spreading the word, even attracting one of the world's leading authorities on Alzheimer's disease, Ralph Martins, Professor of Neurobiology at Macquarie University and Foundation Chair in Ageing and Alzheimer's Disease at Edith Cowan University, to his cause as a guest speaker and dementia education advisor.

But Tim recognised that he was limited with what he could achieve alone and set out to build a team of like-minded people to work with him. And so the Hornsby Ku-ring-gai Dementia Alliance (HKDA) was born.

This group of dedicated volunteers met for the first time in September 2018 in Tim's living room. They came with



People with dementia and carers socialise at a D Caf dementia cafe in Sydney. Photos courtesy Hornsby Ku-ring-gai Dementia Alliance



little thought of what they were getting themselves into, just a commitment to Tim's cause and a willingness to help others. Each has brought their own unique skill set to the mix.

Dr Miranda Say is a Clinical Neuropsychologist with a special interest in dementia diagnosis and care, born while working in London at the Institute of Neurology. Through her work she brings her technical know-how and her unique perspective on how dementia is being treated in British and European communities.

Fiona Jenkins is a counsellor with a strong community commitment and a flair for spreadsheets and keen organisation. After witnessing her good friends' struggle with dementia and seeing how their entire relationship changed after he was diagnosed, she jumped at the chance to be on the HKDA team.

For retired Registered Nurse Anne Hunter, dementia was close to her heart after caring for her mother until she had to go into care. Through her career in dementia education, particularly in aged

care, she brings a unique insight to the group.

Michele Bell's expertise was as CEO of the Ku-ring-gai Neighbourhood Centre, an amazing group that supports people with dementia to remain living independently at home.

And finally, there is me – Annie Kenyon. I have a family member living with dementia and also bring to the group my expertise as a media and communication professional, having worked as a TV producer, writer and marketing specialist.

The Alliance members recognise that we are all cut from different cloth, yet we are all made from the same fabric and we share a commitment to help people with dementia and their carers live the best quality of life possible.

Making it happen

Right from our first meeting we talked about dementia cafes and Miranda told us what was happening in the UK and in various locations in Europe where they were common. We identified that this was something achievable that our group could do in Australia, so we put together a plan, came up with a name (D Caf) and set about using our individual talents to make it happen.

A month later we had a pilot six-week D Caf dementia cafe program up and running and the first regular D Caf officially opened in February 2019 at the PCYC Waitara in Sydney.

D Caf is such a simple idea. It's a place where people with dementia, and their carers, who are still living in the community can go once a week to socialise with others. It's not a formal care service and doesn't provide personal care. What it does provide is peer support, friendship

and social contact with others who are having similar experiences. It's a safe environment for people with dementia where there is no judgment. It's a place for family carers to talk with others who are in a similar position, and find out they're not alone. I am so proud that we, the Hornsby Ku-ring-gai Dementia Alliance, have made this a reality.

D Caf is held at the PCYC Waitara every Thursday from 10am-noon during school terms. Between eight and 10 people with dementia and their carers attend, along with six volunteers. The volunteers all receive individualised dementia education from the Alliance's professional health consultants. At this stage D Caf is run entirely by volunteers and is funded through donations (via our GoFundMe page at <https://au.gofundme.com/Dementia-Cafe>) and local grants.

During the two hours we provide food and activities, run a 15-minute exercise session and feature a special guest who leads an educational session which is usually hands-on. The subjects covered to date have included gardening, music, history, pets and art.

Support network

During the short time D Caf has been up and running we have seen participants forming strong friendships. They have created their own network of support within the group, something that has happened much more quickly than we anticipated.

One of the carers explained that D Caf is a place where she can truly relax because she knows her husband is happy, but just as importantly she is finding peace too because she can talk with people who understand what she is going through.

Expanding the program

We intend to open 10 more D Cafs in the Hornsby/Ku-ring-gai area by the end of 2019 and to have 20 D Cafs in place around Australia before the end of 2020. Our hope is that one day every town in Australia will proudly have its own D Caf – a safe, inclusive place that will benefit so many vulnerable people.

D Caf is designed to be duplicated and we provide face-to-face training so other organisers can use our system and maintain the program's high quality. Suitable venues include existing cafes or restaurants, church halls, community centres – anywhere there is adequate parking or public transport, good access and coffee and tea making facilities.

We are currently fielding inquiries from people in Sydney and other capital cities and are excited that our next D Caf opening is just around the corner.

How to start a D Caf

For more information about setting up a D Caf program in your area, or inquiries about the Hornsby Ku-ring-gai Dementia Alliance, contact Alliance Chairman Tim England on 0406 764 340, email dementiacaf@gmail.com or visit the Facebook page <https://www.facebook.com/dcaf.dementiacafe> ■



Annie Kenyon and Tim England

Dementia a key challenge for Sydney

By Catherine Ross, AJDC Contributing Editor

Dementia is one of the key challenges facing Sydney's older people now and into the future, according to a new report from the Committee for Sydney.

The independent think tank has worked with Baptistcare and Stockland to investigate how to achieve a more inclusive and liveable city for the older population. Its conclusion is that the key areas for action are housing, transport, planning, healthy and active ageing, social connection and mental health – and dementia.

Dignity And Choice: An Inclusive Future For Our Ageing Population reports on an Ipsos survey of 1000 Sydneysiders, asking them about their attitudes to ageing and retirement. It found that in some areas of Sydney, over half of residents approaching retirement are considering leaving their suburb due to lack of facilities for older people. One third said they were not confident they would be able to support themselves in retirement.

The report goes on to consider a wide range of policy areas and

how these will have to respond to the needs of older people, including the forecasted increase in the number of people living with dementia in Sydney in the future. It says local councils need to prepare for this and should follow the examples of Kiama and Hornsby in making their communities more dementia-friendly.

The report provides a series of policy recommendations. Some dementia-specific recommendations include that the Australian Government:

- support the development of dementia education programs specifically targeted at retirement village operators and staff
- provide funds to promote dementia awareness, risk reduction messages and healthy ageing in retirement villages
- prioritise allocations of home care packages which provide service integrated housing in retirement villages for people with dementia.

It also recommends that local councils develop strategies to manage the forecast growth in residents living with dementia, and that council-led social events should be accessible and welcoming for people living with dementia.

Implementing Adaptive Interaction in everyday care

Adaptive Interaction (AI) is a non-verbal communication tool for interacting with people with dementia who can no longer speak. **Maggie Ellis** and **Arlene Astell** share their experience of implementing AI into daily care

Adaptive Interaction (AI) is based on non-verbal channels of communication including eye gaze, facial expressions, movements, and touch. The initial stage of AI involves connecting with the individual who cannot speak, followed by uncovering their unique non-verbal communication repertoire, on which future interactions are based (Ellis & Astell 2019b).

Building on our initial case study (Ellis & Astell 2008) and later small group study (Ellis & Astell 2017), we developed a program to equip caregivers with AI skills. Our first feasibility study in a long-term care home (Astell & Ellis 2011) with a small group of staff and residents with dementia allowed us to explore practical and organisational issues in implementing AI. From this experience and subsequent research we have developed a range of approaches to equip caregivers with AI skills, available to family and formal caregivers in care homes, hospitals and community settings.

To inform dementia care, this brief summary of our work with caregivers and people with dementia who cannot speak is illustrated with quotations from caregivers and family members.

Groundwork

Whilst non-verbal behaviour makes up about 55% of any face-to-face communication, with words only accounting for 7% (Mehrabian 1971), often people do not feel comfortable being asked to communicate only non-verbally. It is therefore important to provide clear explanations about the purpose of AI, the rationale for this approach and illustrations of how it works. We do this before training starts and it is an integral component of AI training.

Once people start to understand AI, we are often asked if interacting non-verbally with an adult might be infantilising. Infantilisation – patronising and speaking down to an individual, such as calling a person with dementia ‘a naughty boy’ – is

In a previous article, published in the April/May 2019 issue of *AJDC*, Maggie Ellis and Arlene Astell described the genesis of Adaptive Interaction, its development over a number of years and their hopes for the future (Ellis & Astell 2019a). Access that issue at www.journalofdementiacare.com/aprilmay-2019/



Author Maggie Ellis (right) connects with Nancy using Adaptive Interaction

one of Kitwood's (1990) Personal Detractors. We are acutely aware of the negative impact of Personal Detractors on people with dementia, particularly those who can no longer speak, and we address these concerns directly. Our response is that people with dementia are attempting to maintain their place in the social world, using the communication means available to them. In this way AI builds on Kitwood's own observations that:

"In the course of dementia, a person will try to use whatever resources he or she still has available. If some of the more sophisticated means of action have dwindled away, it may be necessary to fall back on ways that are more basic, and more deeply learned; some of these were learned in early childhood" (1997 p75).

In our training we contextualise this by exploring and explaining the role of non-

verbal behaviour in communication across the life course (Ellis & Astell 2018).

Facilitators of AI

Delivering training in long-term care and specialist hospital care settings has highlighted to us a number of facilitators for incorporating AI principles into everyday practice.

Contents and experience

The first major facilitator is the contents and experience of AI training itself. Feedback from staff highlights the impact of the hands-on process whereby participants practice each aspect of AI as it is introduced to them:

"I found that Adaptive Interaction brought something out of the clients that was hidden. Even if it was only blinking an eye, it was



Maggie and Jim: AI in action

blinking an eye in response to something that we had done. Before, we wouldn't recognise it but with the training we realised that it was a response to us" (activities coordinator).

It is important to emphasise that whilst AI is based on the non-verbal fundamentals of communication, it is not as simple as just instructing caregivers to interact non-verbally. We use video-recording to empower caregivers to review their non-verbal interactions and reflect both on what works and what doesn't, but also on how they feel during the interactions. Early on we had an experience where a staff member had missed a training session but wanted to complete the homework of a short video recording of them interacting with their partner with dementia. Based on their colleagues mentioning imitation, the staff member proceeded to record an interaction which veered very close to mimicry, which is of course another Personal Detractor (Kitwood 1997) and definitely not part of AI.

In their reflection on AI, one member of staff pointed out:

"We take communication for granted and even though some of the residents can't communicate verbally we take for granted that they understand (speech). When we use non-verbal communication, we can see that they pay more attention and the focus is on you and them. It makes you think a bit more when you're communicating. It's beneficial for ourselves and the clients" (Registered Nurse).

Seeing is believing

The second major facilitator is staff witnessing the impact of using AI (ie, 'seeing is believing'). Before embarking on AI training many staff are sceptical about

non-verbal communication and about the potential of communicating with people with dementia who cannot speak. This is quickly dispelled once they start practicing AI skills:

"Taking a step back and watching the residents' body language – I couldn't believe the difference it made!" (care assistant).

Reaction of families

The third major facilitator is the reaction of families to AI being implemented in the care routine. Families of people with dementia who can no longer speak have particular concerns that their relatives are not ignored and that care staff can connect with them. The introduction of AI provides reassurance to them and validation to staff that they are doing something valuable and worthwhile:

"Even when the family members came in, he responded to them. I'd been telling them what I'd been doing so they were doing the same and they were getting a response. The family members saw something in their loved one that they hadn't seen for many years" (activities coordinator).

Challenges to AI

Although the training is well-received and staff see the benefits once they start using it, there are a number of environmental and organisational factors that influence the passage of AI into everyday care.

Leadership

Unsurprisingly, leadership is critical. Staff who receive AI skills training need the support of their managers to implement these into care routines and establish reflective practice. This support is important for reinforcing the value of AI

but also for combatting scepticism and negative perceptions of non-verbal communication held by untrained members of staff who might query the importance of AI in their caregiving role. In response we require that at least one senior member of staff participates in AI training to facilitate planning and implementation in their care settings.

Time

There is also the perennial issue of time, with staff expressing the view that they do not have time to use AI. This reflects a perception that AI is a specific activity to be undertaken once other tasks have been completed. We therefore emphasise throughout that AI is a means of communication to be used in *all* interactions with non-verbal individuals, in the same way that sign language is used with people who cannot hear.

Potential of AI

AI is both a mindset and a toolkit for any caregivers, including family members, wishing to interact with people with dementia who can no longer speak. Being non-verbal, AI cuts across language and cultural barriers to enable caregivers to connect with people who had previously spoken different languages (Zhivka *et al* 2017). We have also found impact with individuals with visual impairment alongside cognitive impairment, even when there is residual speech, as non-verbal means may provide more control for the individual. For example, we worked with a blind man with dementia who was able to use sound and touch to engage in AI.

We are always happy to respond to queries and specific communication challenges that individual caregivers or organisations are facing. Alongside our training courses, we have produced a book, *Adaptive Interaction For Dementia: How To Communicate Without Speech* (Jessica Kingsley Publishers 2018) which explains the history of AI and the steps involved in carrying it out, illustrated with representative cases. Additionally, videos of AI in action can be found on our website, Astellis: <https://www.astellis.co.uk>.

We find it fitting to end this article with a quote from a family member, as they are the ones who can benefit hugely from using AI when visiting their loved ones. The following quote is taken from an email to Maggie after a woman tried AI for the first time with her mother:

"If you asked me to describe the approach I would liken it to fishing. You watch for bubbles to come to the surface and then when you see them you cast your line and reel your fish in. I think I would have missed the signs if you

hadn't told me that they might be very subtle. The first was just a gentle rubbing together of her finger and thumb, then we moved on to head rubbing, finishing with a bit of lip licking! But once I was able to connect with her it was like she couldn't communicate enough. One afternoon she was yawning her head off whilst maintaining eye contact and squeezing my hand. It really was like she didn't want it to end. At one point I leant in and gave her a big hug. She put her arm up and hugged me back as well as kissed my cheek". ■

References

- Astell AJ, Ellis MP (2011) The Challenges Of Equipping Care Home Staff With Psychosocial Skills: Reflections From Developing A Novel Approach To Communication. *PSIGE Newsletter* 117 26-32.
- Ellis MP, Astell AJ (2008) A Case Study Of Adaptive Interaction: A New Approach To Communication With People With Advanced Dementia. In: Zeedyk S (Ed) *Techniques For Promoting Social Engagement In Individuals With Communicative Impairments*. London, UK: Jessica Kingsley Publishers.
- Ellis MP, Astell AJ (2017) Communicating With People With Dementia Who Are Non-verbal: The Creation Of Adaptive Interaction. *PLOS ONE* 12(8) e0180395, published online August 2017.
- Ellis MP, Astell AJ (2018) *Adaptive Interaction for Dementia: How To Communicate Without Speech*. London: Jessica Kingsley Publishers.
- Ellis MP, Astell AJ (2019a) Communicating Without Speech. *Australian Journal of Dementia Care* 8(2) 30-32.
- Ellis MP, Astell AJ (2019b) Adaptive Interaction: Facilitating Connection In Advanced Dementia. In: James I, Gibbons L (Eds) *Communication Skills for Effective Dementia Care*. London: Jessica Kingsley Publishers.
- Kitwood T (1990) The Dialectics Of Dementia: With Particular References To Alzheimer's Disease. *Ageing and Society* 10 177-196.
- Kitwood T (1997) *Dementia Reconsidered: The Person Comes First*. Buckinghamshire: Open University Press.
- Mehrabian A (1971) *Silent Messages* (1st Edition). Belmont, CA: Wadsworth.
- Zhivka T, Ellis M, Tisheva T, Astell AJ (2017) *Crossing Cultures In Dementia Care: The Bulgaria: UK Experience*. 32nd International Conference of Alzheimer's Disease International, Kyoto, Japan, 28 April 2017.



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A changed model of care, supported by a partnership with Dementia Training Australia, has helped Ananda Aged Care transition to the new Aged Care Quality Standards and improve the confidence of its staff to provide best practice dementia care. In this, the first of two articles, **Michael Page, Karen Daniels** and **Pooja Newman** explain the process. In Part 2, to be published in the October/November issue of *AJDC*, they will highlight the significant benefits achieved

All aged care providers began the transition to new Aged Care Quality Standards ('The Standards') from 1 July 2018 and were expected to comply from 1 July 2019.

While the first new Standards since 1997 were long overdue, providers felt high levels of anxiety around how this was to be achieved with limited resources in a relatively short time frame. Guidance materials and training were provided by the Aged Care Quality and Safety Commission, though how the standards would be audited was open to interpretation.

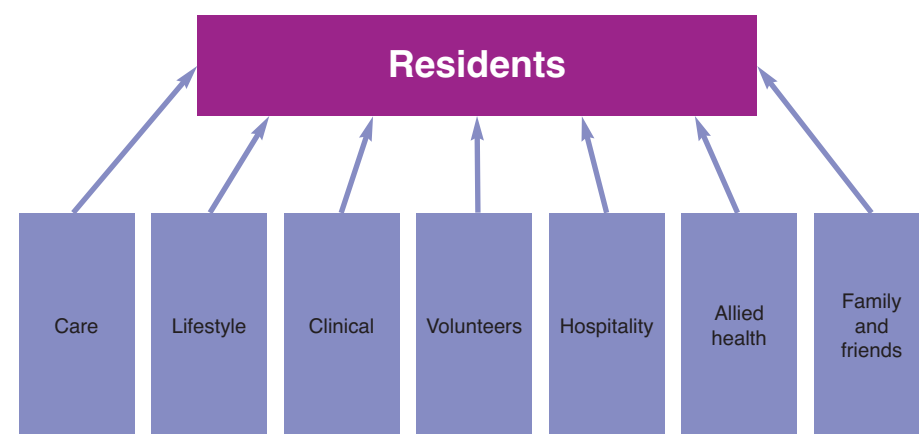
Ananda Aged Care embraced the opportunity and created a new role of Resident Focused Care Advocate to engage and consult with residents, families and staff and to advise management of priorities for the transition.

Ananda (a Hindu name meaning 'bliss') has two homes in Adelaide, South Australia. It is a family-owned organisation which promotes an inclusive, family-style environment for residents and staff. Ananda's 67-bed Findon home was upgraded extensively during 2014. Findon's Rose Wing is an eight-bed, female-only, Memory Support Unit (MSU) which, until December 2018, was a closed unit.

Ananda Hope Valley, purpose built in 2004, is a one-level 137-bed home with several gardens and outside courtyard spaces. Its 19-bed Derwent Wing MSU was a closed unit until February 2019. Following environmental assessment, occupancy was reduced to 17, with one double room used as a quiet space/sensory room. Derwent benefited from substantial refurbishment in 2018 using a vineyard theme, which tied in with the nearby Adelaide Hills viticulture community.

Both homes have a large number of Culturally and Linguistically Diverse residents (CALD), predominantly Italian and Greek. The Ananda workforce is also highly diverse with around 40 nationalities employed across the sites. Ananda had an impeccable accreditation record under the previous Standards and saw the transition to the new Standards as an opportunity to consolidate its values of compassion, comfort and care.

Michael Page (co-author here) was recruited to the newly created role of Ananda's Resident Focused Care Advocate in October 2018. As a healthcare change-management specialist with a strong nursing and dementia education background, Michael's first job was to advise the Ananda board on how to best prioritise



The traditional silo approach to aged care

A new standard of care

the numerous continuous improvement programs already underway, and to help prioritise an approach to meeting the new Standards. The project was led by Ananda's Clinical Director, Dr Pooja Newman, and Director of Nursing, Karen Daniels (co-authors here).

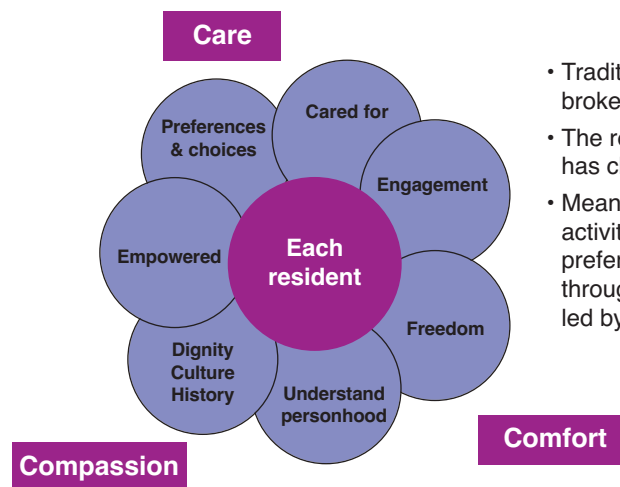
The nomenclature of the Resident Focused Care Advocate (RFCA) role was significant. While the new Standards refer to 'consumer directed care', Ananda residents were clear they did not wish to be called 'consumers' and that 'residents' was the appropriate term. Also, during a change management process it was considered vital that the RFCA was seen as someone with influence, though not 'wedded' to the board or management, and so could listen to and advocate for residents and staff with the aim of delivering resident-focused care.

After a period of consultation, engagement and observations of staff and resident interaction, the priorities for action were defined as:

- Changing the model of care from a traditional task-oriented approach to a resident-focused care model.
- Improving staff skills, knowledge and attitude towards residents with dementia, initially focusing on the MSUs and then rolling out key learnings to all areas. This was seen as a journey rather than a quick-fix solution and would need to be underpinned by significant investment in education and training.
- Improving the dining experience.



Making bread before lunch to stimulate the senses. All photos courtesy of Ananda Aged Care



The Ananda Resident Focused Care Model

Resident-focused care model

A task-oriented approach to service and care delivery has been used in aged care for years. However, the new Standards demand a truly person-centred approach, with each and every resident being at the centre of care, and dementia best practice has supported this for some time. Issues for providers have been that the care workforce currently receives little theoretical or practical training, and almost none in dementia care.

A task-oriented approach was pragmatic in terms of resource management, yet for residents it meant fitting into the routines of a home, rather than truly feeling it was *their* home and that they had agency or genuine control over their lives. Staff became very comfortable with this model, so disentangling the notion that speed and efficiency were the prized assets of a carer would have to be done respectfully and tactfully, without blaming the system or staff.

The Ananda Resident Focused Care Model (see diagram above) was underpinned by an ongoing conversation with staff that residents do not live in our workplace, we are visitors to their homes, with one purpose: to support them achieve the best life. It also encouraged staff to consider that residents value relationships over tasks, and while 'stuff still needed to get done', the prime value of each staff member was in their engagement with residents.

This approach maps neatly to Dementia Training Australia's (DTA) salutogenic approach (www.dta.com.au/

- Traditional roles and silos are broken down
- The resident is at the centre and has choice
- Meaningful engagement, activity (solo and group) and preferences are supported throughout the day/night and are led by the individual resident



dta-salutogenic-approach), which is about focusing on factors that support health and wellbeing rather than risk and problems, and finding opportunities for people with dementia to live as full a life as possible.

Workshops were held for staff across different shifts and at weekends, with over 60% of staff across both sites attending between October 2018 and April 2019. The workshop material then became an online course on Ananda's newly created in-house Learning Management System called 'Ananda Academy'.

Removing the silos

It quickly became evident that staff roles were operating in silos (see diagram p28) and needed to intersect to improve teamwork and care. The traditional Leisure and Lifestyle (L&L) approach, especially at Hope Valley, was restructured to move away from a 'cruise ship entertainment' feel, where a relatively small group of residents decided on activities and attended them enthusiastically, while others perhaps did not fit so neatly into this plan. The L&L team was merged with the clinical and care team to allow improved communication and sharing of residents' life story information so that a holistic approach could be adopted. While this took a couple of months for staff to understand, it began to show rewards.

An engagement shift was created to role model a new care/lifestyle hybrid and to role model and support resident-focused care. This included: carrying out daily



Ananda Aged Care's Matt Denny (lifestyle/carer) (left) and Michael Page (Resident Focused Care Advocate) receiving their DTA training certificates

environmental scans to ensure doors to gardens and all areas of the home were open and the ambient temperature and noise levels were comfortable for residents; setting up group activities; supporting carers with personal care tasks where needed; assisting the dining room set-up to provide a restaurant-standard front-of-house service; and, around these duties, providing one-on-one meaningful engagement for residents who either did not wish to join group activities or who had communication deficits that restricted this.

At Findon a Quality Ambassador/Staff Trainer role was created to support communication between teams of carers, clinicians and lifestyle staff and this has proved popular and supportive

Tailored training

DTA's Tailored Training Packages (TTPs) start with the understanding that staff need the right skills, knowledge and attitudes, and a built environment that supports them to provide high-quality care. TTPs are designed to bring about sustainable improvements in these areas to increase the wellbeing of people living with dementia and the staff who care for them (Fleming *et al* 2018).

Discussions between Ananda and DTA were ongoing through November and December 2018. During that time Built Environment Assessment Tool – Dementia (BEAT-D) assessments and staff training needs analyses were carried out with DTA. The formal TTP partnership agreement between DTA and Ananda was signed in late January 2019 and the one-year TTP began in March. The contracted objectives are:

- A reduction in incidents of responsive behaviour among residents.
- A reduction in use of antipsychotic medication.

- An increase in staff confidence in dementia care.

BEAT-D assessment

DTA's BEAT-D App was used in December 2018 to assess the environmental strengths and weaknesses of our MSUs. We answered structured questionnaires and uploaded photographs of aspects of the building that illustrate important features of its design, both good and bad. These were built into a comprehensive report that helped us see at a glance the areas that require improvement and begin planning how to do so.

The report was structured around 10 principles of design that have been found to be important in the reduction of confusion, agitation and depression while improving wayfinding, social interaction and engagement with life for people living with dementia (Fleming & Bennett 2017; Fleming *et al* 2016).

These principles are:

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

Following assessments in December 2018 we began implementing small and simple changes to our environments. Longer-term alterations to building design will be incorporated into the continuous improvement plan. Improvements had already been made in the past year, including the theming of both units (vineyard at Derwent and beachside at Rose) with attractive murals used to good effect. Changes made following the BEAT-D assessment included:

- Improved wayfinding signs, especially for toilets. We made more visual signs with yellow background and black writing in the main languages of residents: English, Italian, Greek and German. A photograph of a toilet was added. Use of signs to direct people to the dining areas were also used and visual clues were optimised.
- Replacement of all white toilet seats with black, contrasting with white toilets, in Derwent.
- Introduction of a large outdoor

umbrella in Derwent garden to make better use of the patio area.

- Introduction of a quiet room in Derwent and a reduction in the number of residents in the wing from 19 to 17.
- Introduction of improved mealtime ambience and sensory items. Better use of contrast colours, eg burgundy place mats on white tablecloths. Table-runners, plants, calm music.
- Change of layout in Rose Wing and use of homely / era-appropriate furniture to enable residents to find their way to quiet areas to be alone or with others.
- Improved layout of tables and chairs to make the wings more homely.
- Use of interactive animals (cats, dogs, birds) as sensory / reminiscence aids.
- Staff training on reducing unhelpful stimulation and providing quiet times, eg around meals or bedtime.
- Opening the doors to the MSUs and providing opportunities for residents to be involved in activities in other areas of the home, eg the Mediterranean Club run by an Italian volunteer at Findon.
- Refurbishment of Findon's Friendship Club (large day room), following DTA's principles of design, began in July 2019.

The BEAT-D assessment will be carried out again towards the end of the project to evaluate progress.

'Ananda Academy' and DTA online

'Ananda Academy' was launched in March 2019 and provides online mandatory dementia training for staff as well as courses like *The Ananda Resident Focused Care Model*, a clinical skills library for nurses and a link to our DTA training.

DTA has provided an Ananda-branded website which offers all staff access to



A mural has been used to disguise an exit in Ananda Findon's Rose Wing Memory Support Unit (MSU)

about eight hours of high-quality dementia training including: *The View From Here* (Graham *et al* 2018), *Bedtime To Breakfast* (Muldoon 2018) and *LGBTI and Dementia* (DTA). Many staff have taken up this opportunity so far and we encourage all new staff and those working in the MSUs to complete it.

Responsive behaviours consultancy

Each of the initiatives discussed were supported by a Responsive Behaviours Consultancy with DTA (Beattie 2017), where nine staff (five from Findon and four from Hope Valley) from various roles took part in an eight-week, one-hour video conference with DTA as part of a 'lead and learn' program. DTA consultants helped staff explore attitudes towards and experiences of responsive behaviours and offered tools and strategies to enable the knowledge from this group to cascade to the broader workforce.

This helped create a sustainable capacity-building education framework for addressing and reducing dementia-related responsive behaviour and created a small group of care champions for Ananda. Throughout the program the champions were closely mentored by DTA staff and supported to develop as leaders in responsive behaviour care.

Following the consultancy, which ran from March to June 2019, the two groups formulated and agreed on action plans with DTA, which included:

- Adoption of the Antecedent Behaviour Consequence (ABC) model to contextualise responsive behaviours.
- Implementation of assessment tools to help staff identify behaviours and individualise care planning.
- Commitment to extending the door opening at Derwent wing.
- An action team to consult on how best to use the quiet/sensory room in Derwent.
- Implementation of the Top 5 program (see *The View From Here*), memory boxes and 'Who am I' prompt cards.
- Refurbishment of Findon's 'Friendship Club' (large day room) to better meet the needs of residents with dementia.
- Cascading key learnings to care staff in the MSUs.

As part of the TTP, clinical staff began a Medication Consultancy from August 2019 with the aim of reducing use of antipsychotic medication and minimising chemical restraint.

Staffing, 'no uniform' policies

Greenwood (2018) explains the many benefits of consistent staffing, including familiarity with the people providing



Ananda has improved the dining experience for residents by clearing away clutter, using homely table settings and playing relaxing music

personal care tasks. This was a key early objective to help us develop dementia champions and to focus our training, workforce development and knowledge translation strategies. Rosters were assigned with the level of experience, training and confidence of staff to care for residents in an MSU. We also consulted staff on a 'no uniform' policy and most were very comfortable with this idea.

We translated knowledge on minimising unhelpful stimuli such as handovers, competing media (TVs, radios etc) and limited use of the Public Address (PA) system to emergencies only in the MSUs.

We are currently discussing the use of night attire for night staff as per the DTA course *Bedtime To Breakfast* (Muldoon 2018).

The dining experience

Research by The Lantern Project (Hugo 2018) found that stimulating the five senses is a key to mealtime enjoyment and can improve nutritional intake. As a part of Ananda's Resident Focused Care Model the ambience of the dining experience at each home was seen as sub-optimal and efforts were made to protect mealtimes from extraneous stimuli such as competing noises, other activities, staff walking through dining areas unnecessarily and use of the PA system.

At each home we installed a large umbrella and extra benches outside so that residents could dine on the patio and move around the garden in good weather. We also provided white

tablecloths with burgundy-coloured serviettes and placemats in keeping with the vineyard theme at Derwent, table-runners, plants as table decoration and cleared away clutter during meal service. Soft, relaxing music was encouraged and carers wore aprons to suggest a café/restaurant feel. Staff and residents used a bread maker to make their own bread and stimulate olfactory senses.

A bain-marie system was introduced at both homes by our Hospitality Manager and has transformed the quality of food and the ambience of the meal services and provided a homely environment for residents with and without dementia. ■

The second part of this article, *Opening The Doors*, will be published in the October/November 2019 issue of *AJDC*. In Part 2, the authors will discuss the results of Ananda's decision to open the doors to its dementia-specific units, and the benefits for residents and staff of the new model of care and tailored training program.

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The authors are grateful for all Ananda staff who have championed this change process. We would also like to thank Dementia Training Australia and all staff involved in the TTP for their continued guidance and support.

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References

- Beattie M (2017) Building Capacity To Provide Responsive Care. *Australian Journal of Dementia Care* 6(6) 10-11.
- Fleming R *et al* (2018) Going Beyond 'Tick The Box' Training. *Australian Journal of Dementia Care* 7(2) 11-12.
- Fleming R, Bennett KA (2017) Applying the Key Design Principles in Environments for People with Dementia. *Environmental Design Resources*. Available at: <https://bit.ly/2LKRoN9>.
- Flourish R, Goodenough B, Low L-F, Chenoweth L, Brodaty H (2016) The Relationship Between The Quality Of The Built Environment And The Quality Of Life Of People With Dementia In Residential Care. *Dementia* 15(4) 663-680.
- Golmbiewski J (2019) A Salutogenic Retrofit. *Australian Journal of Dementia Care* 8(2) 15-19.
- Graham F *et al* (2018) The View From Here. *Australian Journal of Dementia Care* 7(1) 13-17.
- Greenwood D (2018) Consistent Staffing Models: Sharing The Learning. *Australian Journal of Dementia Care* 7(5) 25-28.
- Hugo C (2018) The Lantern Project: Shining A Light On Food In Aged Care. *Australian Journal of Dementia Care* 7(2) 23-27.
- Muldoon D (2018) Bedtime To Breakfast And Beyond. *Australian Journal of Dementia Care* 7(1) 21-24.

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.

Catherine

I remember the first dementia conference I attended in 2008. I was just beginning my Master's degree, looking into the important topic of supporting decision making about the timing of driving retirement for people with dementia. It was the person with dementia who gave the plenary address at the conference who became the inspiration for me to focus my research on seeking opinions from people with experiences of living with dementia.

However, back then, obtaining ethics approval and recruiting people with dementia was more difficult than I first imagined. Fortunately, things have changed. Fast forward 10 years and there is now acknowledgment that when researching issues 'about' people living with dementia, those with lived experiences need to be involved to achieve better care outcomes (NHMRC 2018). Ethics committees are becoming more familiar with protocols that include people with dementia as participants. Those living with dementia also want to be involved in identifying the important research topics that are relevant to them (Flavin 2019; Redman 2019). But bearing in mind the motto of Dementia Alliance International, 'Nothing about us without us', can the research world do even better? The answer is yes. There is now a shift in conceptualising the role of people with dementia beyond roles as research participants to research partners, involved in research design,

Beyond the role of research participant

Catherine Andrew and **Phil Hazell** have been working on research together for three years. Initially, Phil, who is living with dementia, volunteered as a participant for Catherine's PhD project. More recently they have teamed up to present Phil's story of his lived experience of transitioning from work to retirement and beyond. This year they presented their work at the Australian Dementia Forum in Hobart in June and the National Occupational Therapy Conference in Sydney in July. In this article, they explain the importance of research collaboration with people with dementia and share advice about what they have learnt along the way

implementation and dissemination (Andrew *et al* 2019; Taylor & Liddle 2019).

Phil

I was diagnosed with younger onset dementia whilst still working as a consultant for a national company. Early after diagnosis, Sara, my assistance dog, became an important part of my life. With the support of Sara, my employer, my colleagues and clients, I was able to continue working for as long as possible (see <http://bit.ly/Sarah-one-of-team>). Before retiring from paid work I linked up with Dementia Australia, became a dementia advocate and I am now the chair of the Dementia Australia Advisory Committee. The work I do in the advocacy and research space keeps me very busy and gives me a sense of purpose that otherwise may have been

hard to find once I retired from paid work.

I initially became involved in research through my younger onset dementia key worker who told me that Catherine was recruiting participants for her project. I am now involved in several projects with different researchers, both as a participant and also as a co-researcher. To achieve better care outcomes, meaningful representation from those living well with dementia in research, on committees and in advocacy forums is essential.

Research design

Depending on the research question being addressed, researchers will adopt a quantitative, qualitative or mixed methods approach to their research design (DePoy & Gitlin 2011). Quantitative research methods typically use large sample sizes to obtain

data that can be statistically analysed. Qualitative research methods usually involve a smaller number of participants. Volunteers may be asked to participate in in-depth interviews, as the researcher seeks to understand people's lived experiences of an issue or phenomenon. Mixed methods research applies a combination of both quantitative and qualitative methods to collect and analyse participant data.

Regardless of the method adopted by researchers, research design follows common steps of gaining ethics approval, recruiting participants, collecting and analysing the data, and disseminating the findings. The lessons we have learnt from our work together, as well as from others involved in dementia research, are discussed below. The strategies

that supported our collaborative data collection and analysis and dissemination of findings are outlined in Table 1 (see p34).

Ethics

Gaining ethics approval for involving people with dementia in research can be a challenge for researchers. Ethics committees need to ensure that 'vulnerable' participants are safeguarded against harm (Australian Government 2014). When it comes to obtaining consent from people with dementia there may be a stereotypical response that assumes those living with a diagnosis of dementia are unable to give consent and that consent by a third party or guardian is required (Bond & Corner 2001; Bryden 2002; Dewing 2007). Dementia involves a progressive set of symptoms, however having a dementia diagnosis does not mean a person does not have capacity to give consent.

Those researchers wishing to involve people with dementia in research can learn lessons from researchers and those with dementia who have already blazed the trail for inclusion (Cridland *et al* 2016; Phillipson & Hammond 2018).

People with dementia believe the opportunity to be involved in research is critical, therefore the extra steps the researcher may be required to take to gain support from ethics committees and obtain ethics approval is appreciated. We hope that as researchers gain ethics approval to include people with dementia, and move from involving people with dementia as participants to inclusion as co-researchers, new benchmarks will be set to facilitate inclusive research partnerships.

Recruitment

Once researchers obtain ethics approval, the next step of the research process is finding volunteers. During the recruitment phase the researcher is usually seeking volunteers with a particular set



Phil Hazell and Catherine Andrew, with Phil's assistance dog Sara, at the recent National Occupational Therapy Conference in Sydney where they were both presenting

of characteristics that are relevant to the issue being investigated. Linking researchers with potential participants has proved to be problematic in the past. In reviewing the outcomes of a research project, critics may question why the opinions of more people living with dementia were not sought. Difficulties experienced by researchers in recruiting volunteers can lead to participant numbers reflected in the data being lower than ideal.

The reasons for difficulty in recruiting are varied. People with dementia may not be aware of how to access the digital platforms researchers use to promote their research. Public notices in the media may be overlooked. In our

experience the most effective method of recruitment has been word of mouth. This is termed 'snowballing' in the academic arena and involves a system of sharing information amongst communities about the researcher's call-out for participants (DePoy & Gitlin 2011).

More recently, a new service called StepUp for Dementia Research (Jeon 2019) has been launched in Australia that links researchers and interested participants using an online platform (www.stepupfordementiaresearch.org.au/). People with dementia and researchers alike hope that this register will streamline recruitment. Working together, research outcomes that positively influence health policy and

care practices for people living with dementia will be achieved. We encourage you to check out the website and to spread the word amongst your research and advocacy networks.

Voluntary participation

Researchers benefit from engaging people living with dementia in their research projects and consumer insights are essential for improving health outcomes. However, it is important to consider the purpose of participation from the point of view of the participants. Participating in research requires time and commitment. It usually involves delving into thoughts and feelings associated with the unique experiences of living with a dementia. This can be emotionally and physically demanding.

On the flip side, volunteering to be involved in research can be rewarding, providing a sense of purpose. Participation has the capacity to change community perceptions and raise awareness about living well with dementia. Dementia is not a mental health diagnosis; it is a cognitive decline. Making a meaningful contribution toward finding ways to reverse the impact of dementia on the lived experience is important.

Representation as a participant broadens the understanding of researchers, health professionals and policy makers about: (i) how dementia impacts on people in different ways; (ii) the importance of knowing the individual; and (iii) what living well with dementia looks like (Hazell & Andrew 2019).

Data collection

In the same way that obtaining ethics approval and recruiting participants needs to be adapted, several aspects associated with data collection should be managed on a practical level to support inclusive participation in research. Researchers need to

Table 1: Collaborative research – lessons learnt

Research design	<p>Avoid making assumptions about:</p> <ul style="list-style-type: none"> • what people living with dementia can and cannot do in terms of level of collaboration and participation. • topics the researcher considers important without seeking the opinions of people with dementia in the planning phase. <p>Too much information in 'correspondence' in narrative form can be hard to follow.</p>
Ethical considerations	<p>Persist with gaining ethics approval to involve people with dementia in all phases of research, regardless of preconceived perceptions about their capacity to give informed consent to actively participate in research.</p>
Recruitment	<ul style="list-style-type: none"> • Some recruitment platforms used by researchers are not readily accessible to those volunteers being sought for the research project. • 'Snowballing' or word-of-mouth can achieve good results. • For those who want to participate in research, let people know you want to be involved, don't wait to be asked. • Register on the new StepUp for Dementia Research website.
Data collection	<ul style="list-style-type: none"> • Meeting times and locations should accommodate the expressed preferences of the participant where possible. • We time-limited sessions to minimise risk of fatigue. A series of shorter interviews may be preferable to one long interview. • A conversational and informal interview format worked well for qualitative data collection rather than asking a series of set questions. • We allowed time during the interview to recall, reflect on, and clarify issues raised. • Several sessions over time allowed for 'work to retirement' transition updates.
Data analysis	<ul style="list-style-type: none"> • We scheduled regular 'virtual' meetings via 'Zoom' to keep the momentum going. • We used the same 'recurring' Zoom Room link for each meeting. • We kept our mobile phones handy in case of Zoom connection difficulties. • It was understood that it was okay for the person with dementia to postpone, cancel or reschedule meetings at short notice if required. • We used an online calendar to diarise our appointments well in advance. • A reminder email was sent the day before scheduled meetings containing an outline of topics to be covered and the Zoom link. • We allowed time to explore a topic; clarify things; and re-connect to ideas that may have floated away mid-sentence. • Follow-up emails outlining key dot points that summarised meeting outcomes and 'what next' were sent after each meeting.
Disseminating results	<ul style="list-style-type: none"> • Early planning and practice for presentations was essential. • We used 'screen-share' during Zoom meetings to collaboratively draft and edit presentation content in real time. • Presentation slides were colour-coded and annotated to signpost who was presenting which slides. • Together, we made realistic decisions about co-presenting, based on the amount of time allocated to the paper we were presenting.

consider issues such as the timing and location of data collection, presence of a care partner if required, costs of participation, and strategies to manage potential distress or fatigue. The best way to facilitate consumer

participation is to acknowledge individual preferences rather than assume what type of support people with dementia need. Everyone is different. We have described some of the practical strategies we adopted here:

- Interviews were conducted in the mornings and time limited to about 40 minutes to manage potential fatigue.
- Each interview was digitally recorded and then transcribed for analysis.
- The initial round of

interviews was conducted at the person's home.

- Later, for the in-depth single case study with Phil, frequency of contact was increased to weekly or fortnightly online meetings to keep the momentum going.
- There was flexibility about topics discussed.
- All meeting invites were diarised using Microsoft Outlook.
- We (Phil and Catherine) chose to use the 'Zoom Room' online meeting platform and included a recurring meeting link in each invite.
- We kept our mobile phones handy in case one of us had problems with logging in.

Data analysis

Data analysis in quantitative research involves 'number crunching', whilst in qualitative research analysis involves reviewing the data and using thematic analysis to 'make meaning' (DePoy & Gitlin 2011). In the data analysis phase of our collaborative research we spent 'Zoom' time together reflecting on the storied data we had collected with the purpose of unpacking topics to identify emergent patterns and themes. We employed a form of 'member checking' – that is, seeking respondent validation, to ensure the findings were an authentic representation of Phil's experiences (Depoy & Gitlin 2011).

Analysing the data required time and sensitivity to work together to review the important concepts identified and reflect on the meaning of these experiences. On a practical level, we allowed time to explore a topic, clarify concepts, and re-connect to ideas that might have floated away mid-sentence. Once we had analysed the data, we then had to decide how to share our findings.

Dissemination of findings

Undertaking research is important, however, beyond

collection and analysis of the data, it is essential that findings are shared and research can be translated into practice in a timely manner. Dissemination of findings can occur in a variety of formats including conference presentations and published papers. We believe that including the person with dementia in the co-researcher and co-presenter roles can give weight to the story of living well and working with dementia.

Our goal was to share our findings from our collaborative research, challenge community perceptions and potentially facilitate better outcomes for others. We took the opportunity to submit abstracts to two national conferences. We hoped disseminating our findings this way would contribute to the evolving knowledge base about living well with dementia.

The voice of the person with dementia can be a strong one. Being included as participants in research is essential. However, being involved in the dissemination of findings is also a powerful way to: (i) increase health practitioners' awareness of the impact of dementia; and (ii) inspire other people living with dementia to participate in advocacy and research.

When our papers were accepted, we started preparing early for our conference presentations. We shared drafts back and forth via email, however the most successful approach was doing real time preparation together. Via Zoom, we wrote and edited our content and slides using the 'screen share' function. We made to-do lists and completed tasks together 'on the spot' rather than leaving them to be followed up after the meeting.

When it comes to delivering papers at conferences, the time allocated to each presentation is very limited. This is something that has the potential to cause unnecessary distress. The time slot allocated to each of our conference presentations



With the support of his assistance dog Sara, his employer, colleagues and clients, Phil Hazell was able to continue working for as long as possible after his dementia diagnosis

impacted our final decisions about what would be delivered collaboratively and what would not. From our experience, a five-minute joint presentation is unlikely to honour the contributions of the presenter with dementia. We found that 10-minute sessions or longer would be more conducive to inclusive dissemination practices.

We recommend that conference organisers who want to include the voices of people living with dementia in authentic research dissemination make realistic decisions about allocating sufficient time to facilitate meaningful representation.

Conclusion

Our article highlights the importance of including people living with dementia as co-researchers, collaborating on the design, implementation and dissemination of findings. We have briefly outlined the strategies we adopted to support research participation, and more importantly co-researcher collaboration. We are not alone in this push to recognise the value of including people with dementia in all stages of the research process. Authentic research into the future will value collaborative approaches where academics and people with dementia work together in the research space. ■

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References

- Andrew C, Hazell P, Phillipson L, Sheridan L (2019) Consumer Perspectives: How Younger Onset Dementia Impacts On Workforce Participation During Onset And Progression Of Symptoms. *Australian Dementia Forum 2019 Abstracts*. Canberra, ACT: NHMRC National Institute for Dementia Research.
- Australian College of Behavioural Optometrists (ACBO) News, Views & FAQs: *Sara Is One Of The CR Team*. Available at: <https://bit.ly/2G6ar0S>
- Australian Government (2014) *National Statement on Ethical Conduct in Human Research* (2007). Updated May 2015. Canberra, ACT: NHMRC.
- Bond J, Corner L (2001) Researching Dementia: Are There Unique Methodological Challenges For Health Services Research? *Ageing & Society* 21(1) 95-116.
- Bryden C (2002) A Person-Centred Approach To Counselling, Psychotherapy And Rehabilitation Of People Diagnosed With Dementia In The Early Stages. *Dementia* 1(2) 141-146.
- Cridland EK, Phillipson L, Brennan-Horle C, Swaffer K (2016) Reflections and Recommendations for Conducting In-depth Interviews With People With Dementia. *Qualitative Health Research* 26(13) 1774-1786.
- DePoy E, Gitlin L (2011) *Introduction To Research: Understanding And Applying Multiple Strategies*. St Louis: Mosby.
- Dewing J (2007) Participatory Research: A Method For Process Consent With Persons Who Have Dementia. *Dementia: The International Journal of Social Research and Practice* 6(1) 11-25.
- Flavin T (2019) Effective Involvement Of People Living With A Dementia In Research – Supported Participation. *Australian Dementia Forum 2019 Abstracts*. Canberra, ACT: NHMRC National Institute for Dementia Research.
- Hazell P, Andrew C (2019) Beyond The Role Of Research Participant: Collaborative Consumer Involvement As A Member Of The Research Team. *Australian Dementia Forum 2019 Abstracts*. Canberra, ACT: NHMRC National Institute for Dementia Research.
- Jeon Y-H (2019) StepUp for Dementia Research. *Australian Journal of Dementia Care* 8(3) 17-18.
- NHMRC National Institute for Dementia Research (2018) *Dementia Care Forum: Involving Consumers In Research Towards Better Care Outcomes*. *Communique 2018*. Available at: https://www.nnir.gov.au/sites/default/files/files/Communique_Involving%20consumers%20in%20research.PDF
- Phillipson L, Hammond A (2018) More Than Talking: A Scoping Review Of Innovative Approaches To Qualitative Research Involving People With Dementia. *International Journal of Qualitative Methods* 17(1) 1-13.
- Redman B (2019) Involving Those With The Lived Experience In Dementia Research Means We All Win. *Australian Dementia Forum 2019 Abstracts*. Canberra, ACT: NHMRC National Institute for Dementia Research.
- Taylor E, Liddle J (2019) Technology Teams: Bringing The Experts Together To Make Technology Work For People. *Australian Dementia Forum 2019 Abstracts*. Canberra, ACT: NHMRC National Institute for Dementia Research.

RESEARCH NEWS



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

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Cognitive rehab for early-stage Alzheimer's

Researchers from the UK conducted a randomised controlled trial to determine whether or not cognitive rehabilitation was a clinically effective and cost-effective program for people with mild to moderate dementia.

The cognitive rehabilitation consisted of 10 therapy sessions over three months, followed by four maintenance sessions over the following six months. Therapy sessions were administered by occupational therapists and nurses in the person with dementia's home.

A community sample of 475 people was randomly assigned to receive cognitive rehabilitation or treatment as usual and followed up at three

and nine months post-randomisation.

At the three- and nine-months follow up, cognitive rehabilitation was shown to be clinically effective in enabling people with early-stage dementia to improve their everyday functioning in relation to their individual goals targeted in the therapy sessions. There were no changes in quality of life, mood, self-efficacy or cognitive performance for people with dementia. There were no changes in the carers' stress, health status or quality of life.

A cost-utility analysis found that the cognitive rehabilitation program was not cost-effective in terms of

improving quality-adjusted life-years of the person with dementia or their carer but the program was cost-effective from a broader health and social care perspective.

Study limitations include use of observational outcome measures, not including a general measure of functional ability and the exclusion of people with dementia who do not have a carer. Future work is required to extend this cognitive rehabilitation program to people with rarer forms of dementia.

Clare L, Kudlicka A, Oyeboode JR *et al* (2019) Goal-Oriented Cognitive Rehabilitation For Early-Stage Alzheimer's And Related Dementias: The GREAT RCT. *Health Technology Assessment* 23(10) 1-242.

Anti-dementia medication use

Researchers from Macquarie University have investigated the prevalence, duration, and time of initiation of anti-dementia medication (cholinesterase inhibitors or memantine) among Australians with dementia in residential aged care facilities, and evaluated resident and facility factors associated with use.

The retrospective cohort study reviewed data on 5354 people with dementia in 68 residential aged care facilities during 2014 to 2017, using electronic health record and medication administration data.

The study found that use of anti-dementia medication fell two percentage points from 2014 to 2017. It also varied by factors that were not clinically relevant – such as country of birth (higher use for Australian-born), marital status (less for single and divorced residents) and where people lived (lower in regional areas).

The use of anti-dementia medication was lower among people with concurrent diagnoses (myocardial infarction, cerebrovascular disease, heart failure, respiratory disease and diabetes).

The level of usage was lower in Australia than in other countries, including the US, UK and Denmark. The researchers noted that this study suggests factors for underuse also involved the Pharmaceutical Benefits Scheme (PBS) policy, people not getting their medications carefully monitored and updated when in aged care, and trouble accessing specialist care to get a diagnosis.

Lind KE, Gray LC, Raban MZ, Georgiou A, Westbrook JI (2019) Anti-dementia Medication Use By Aged Care Facility Residents With Dementia. *International Journal of Geriatric Psychiatry* 34(7) 1029-1040.

Dementia program adherence

Finnish and French researchers examined factors associated with adherence to two multi-domain programs which aim to prevent dementia by targeting multiple risk factors simultaneously.

The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) included 1260 people aged 60 to 77 who had a 'Cardiovascular Risk Factors, Aging, and Incidence of Dementia' risk score of six or more and a cognitive functioning score lower than expected for their age. These individuals received a two-year lifestyle program, incorporating physical training, cognitive training, nutritional counselling and cardiovascular monitoring.

In the FINGER study, 39% adhered to all intervention components, with adherence highest for cardiovascular monitoring (95%) and lowest for cognitive training (47%). Baseline predictors of poor adherence were older age (OR 0.91) and current smoking (OR 0.32), whereas an intermediate level of education was associated with better adherence (OR 2.05).

The Multi-domain Alzheimer Preventive Trial (MAPT) included 1680 people aged 70 years or

above with a Mini-Mental Status Examination score of 24 or more and who had reported a subjective memory complaint. Individuals in this study received a three-year program, which included cognitive training, physical activity counselling and nutritional counselling, with or without omega-3 supplementation.

In MAPT, 72% adhered to omega-3 supplementation, 54% adhered to the program and 51% adhered to both the supplementation and program. Depressive symptoms (OR 0.47) and current smoking (OR 0.37) were associated with poorer adherence, and no baseline measures predicted high levels of adherence.

The researchers conclude that multi-domain programs can be burdensome and are not universally suitable. Adherence, and in turn effectiveness, of these programs depends on participant characteristics. Future research should consider ways to reduce participant burden and increase adherence.

Coley N, Ngandu T, Lehtisalo J *et al* (2019) Adherence To Multidomain Interventions For Dementia Prevention: Data From FINGER And MAPT Trials. *Alzheimer's & Dementia* 15 729-741.

Reduced daily-life activity highlighted

Australian researchers assessed differences in daily-life activity levels and walking characteristics between older people with mild to moderate dementia living in the community and cognitively healthy older people.

Forty-five people with dementia and 90 cognitively healthy people, aged 81 years on average, were involved in the study. People with and without dementia wore a tri-axial accelerometer on their lower back for seven days and were assessed on physical performance.

People with dementia had

reduced daily-life activity compared to cognitively healthy older people – they took fewer steps per day, fewer and shorter walking bouts and had lower daily walk time. People with dementia also had reduced walking intensity, with reduced speed and stride length. They also had less regular walking patterns, with greater variability in stride time.

Among the people with dementia, higher daily-life activity levels were related to better executive functioning. People with dementia who had experienced falls in the past

year had reduced daily-life activity and walking speed when compared to people with dementia who hadn't experienced a fall.

These findings highlight opportunities for targeted programs to address low levels of daily-life activity among people with dementia.

Taylor ME, Brodie MA, van Schooten KS *et al* (2019) Older People With Dementia Have Reduced Daily-Life Activity And Impaired Daily-Life Gait When Compared To Age-Sex Matched Controls. *Journal of Alzheimer's Disease* 1-11. Epub ahead of print doi: 10.3233/JAD-181174.

What motivates informal carers

UK researchers reviewed the qualitative literature to determine what motivates people to care for someone with dementia.

Six electronic databases were searched without date restrictions. In total, 26 studies were identified. Most studies came from the US or Europe, with the remainder from Asia, South America, Africa and Australia. A total of 761 carers participated in the studies, most of whom were spouses and adult children.

Caring was generally described as a reflection of long-standing family relationships between carers and the person with dementia. Commonly offered motivations included love, reciprocity, respect, duty and obligation. A portion of carers emphasised feelings of obligation to take on the role while others felt societal, cultural or family obligations to do so. Providing care within the family was seen as superior to professional care.

In the minority of studies that examined ethnicity and culture, motivations for caring were largely similar across groups, with love, reciprocity and marital commitment frequently highlighted. Motivations were mostly consistent across genders, although caring was sometimes explicitly linked to the general female caring role within the family.

A limitation of this review was that most studies were cross-sectional, meaning the researchers were unable to determine whether motivations for starting to care for someone with dementia were similar or different to motivations for continuing to care.

Greenwood N, Smith R (2019) Motivations For Being Informal Carers Of People Living With Dementia: A Systematic Review Of Qualitative Literature. *BMC Geriatrics* 19 169.

Aboriginal community understanding of dementia

Researchers from the University of Tasmania set out to investigate Aboriginal community understandings of dementia and their responses to dementia care.

A total of 50 Aboriginal people who were aged over 18 years from rural Tasmania completed the Dementia Knowledge Assessment Scale. Twelve people also shared their dementia care experiences in individual interviews.

There were low overall levels of dementia knowledge. On average 51% of questions were answered correctly. The limited understandings of dementia reduced family members' capacity to provide quality care to people with dementia.

The main themes to emerge from the interviews were the cultural obligation to care for family members living with dementia, and the desire to maintain ongoing connections to home and community

among people with dementia.

The study has resulted in important initiatives including a community-based dementia education program to ensure Aboriginal people impacted by dementia are provided with effective and culturally appropriate care.

Cox T, Hoang H, Goldberg LR, Baldock D (2019) Aboriginal Community Understandings Of Dementia And Responses To Dementia Care. *Public Health* 172 15-21.

Research priorities of practitioners

In 2016, La Trobe University researchers conducted a postal survey of the 754 residential aged care services in Victoria, asking them to list their three most important research priorities.

A total of 162 services responded to the survey (21.5%). The three most important research priorities identified were workforce issues, strategies to manage residents with dementia (in particular responsive behaviours), and lack of funding to the sector. Workforce issues indicated were staffing numbers and mix, in particular nurse-to-resident ratios. The researchers say that, given some of the priorities are already well researched, it suggests staff have little time and/or limited access to research evidence to inform their work.

Rayner J-A, Fetherstonhaugh D, Cowen S (2019) Research Priorities in Residential Aged Care Services: A Statewide Survey. *Australasian Journal on Ageing*. Epub <https://doi.org/10.1111/ajag.12653>

Cannabinoids in treatment

Australian researchers undertook a systematic review to investigate cannabinoid use in treating

neuropsychiatric symptoms in dementia.

A comprehensive search was conducted in 27 online databases. Studies assessing the safety and/or effectiveness of cannabinoids in treating neuropsychiatric symptoms in people with dementia over the age of 65 years were included.

Twelve studies met the inclusion criteria. Dronabinol (three studies) and THC (one study) were associated with significant improvements in a range of neuropsychiatric scores. The most common adverse drug event reported was sedation.

The quality in studies ranged, with a high risk of bias in eight studies. The highest quality trial found no significant improvement in symptoms or difference in adverse drug event rate between treatment conditions.

Overall, observational studies showed promising results, however the efficacy of cannabinoids has not been proven in robust randomised controlled trials.

Hillen JB, Soulsby N, Alderman C, Caughey GE (2019) Safety And Effectiveness Of Cannabinoids For The Treatment Of Neuropsychiatric Symptoms In Dementia: A Systematic Review. *Therapeutic Advances in Drug Safety* 10 1-23.

Dementia Training Australia (DTA) has published **Guiding Occupational Therapy Practice for People Living with Dementia in the Community**, written by senior Occupational Therapists Vera Riley and Anne Pressley. The resource is an updated version of the 2011 publication, *Dementia: Osborne Park Hospital Guide for Occupational Therapists in Clinical Practice*, written by Louise Phyland (now deceased). The 128-page guide begins with 'Understanding dementia', looks at the links between dementia and delirium, depression and responsive behaviours, and then sets out short introductions to the wide range of tools and tests available to Occupational Therapists when assessing the needs of people with dementia. The bulk of the resource is given over to listing practical strategies that can be tried when supporting people with dementia – with communication, and both basic and instrumental activities of daily living. The free resource is available to download from the DTA website; go to <https://bit.ly/2XExcQf>



Professor Dawn Brooker is the editor of a second edition of Tom Kitwood's seminal text, *Dementia Reconsidered: The Person Comes First*, published in 1997. **Dementia Reconsidered, Revisited: The Person Still Comes First** reproduces the original chapters but presents new content from subject experts alongside each chapter, to

Since 2014, HammondCare's Dementia Centre has been working on **Intervene**, a project that focuses on pain management in residential aged care. Phase 2 of the project (2016-2018) was funded by the Cognitive Decline Partnership Centre and involved The Dementia Centre working with four care sites in Australia to co-create strategies for improved pain management. Several resources arising from the project are now available to download for free from The Dementia Centre's website.

The first is a 36-page resource titled **A Multidisciplinary Team Pain Management Model for Residential Aged Care**, which introduces the model, and describes its implementation and evaluation. The resource is intended to be used as a roadmap for aged care facilities wanting to foster a culture of care which is vigilant about pain management. It includes a 'Pain Management Protocol': a single page flowchart which guides staff through the process of recognising, assessing, treating and monitoring pain.

A series of three short films is another key output from the project. The films, developed in consultation with health care professionals working in the aged care sector to provide pain management education for frontline staff, have been endorsed by Pain Australia. The films are titled **Dementia and Pain**, **Assessment and Monitoring of Pain**, and **Reassessment and Monitoring of Pain** and are each 4-5 minutes in length.

The Intervene project's **Final Report** has also been published by HammondCare. This sets out the project's methodology, findings and recommendations. The report authors recommend that direct care staff should be recognised as central to the success of pain management, and that training on pain management should be accessible and focus on using formal pain assessment tools.

All the resources can be accessed at www.dementiacentre.com/programs/intervene



update the book in light of new thinking and progress since 1997. Some of the contributors include Jan Dewing, Steven Sabat, Julian Hughes, Bob Woods, Keith Oliver, John Keady and Claire Surr. Two key Australian contributors to the book are Christine Bryden who wrote the foreword and Kate Swaffer who wrote the afterword. The book is available from online booksellers in Australia, including Amazon (\$56.80).

Dementia UK, the charity supporting the work of Admiral Nurses (dementia specialist nurses) in the UK, has produced a further six short **advice videos**. The films cover topics such as understanding delirium, what to do when a person with dementia is restless or trying to leave the house, what to do when a person with dementia is distressed, incontinence, good habits for bedtime and calming techniques. The films are each roughly three minutes in length and are presented by Admiral Nurses and Dementia UK staff. They are free to view at www.dementiauk.org (search under 'Get support' for 'Advice videos').

Voice and Aged-Based Perspectives On Dementia, Social Disadvantage And Public Health Campaigning is the title of the final report from the three-year **Dementia in the Public Domain** project. It was written by Professor Simon Biggs, Dr Irja Haapala and Ashley Carr and published by the University of Melbourne. The national project examined current perceptions of dementia from a range of perspectives to inform future public dialogue, with funding from the National Health and Medical Research Council via the Cognitive Decline Partnership Centre (CDPC) at the University of Sydney. The project involved capturing the distinctive viewpoints of people with dementia, carers and professionals in health, social work and in everyday service industries, and then examining overlaps and differences between these perspectives and their connection to local and national campaigning. A key finding is that people with dementia want to live normally in their neighbourhoods and communities, and not to have to deal with stigma, while others want to know how to communicate with people with dementia. The recommendations

include ensuring that future campaigns focus on specific forms of disadvantage and exclusion arising from the experience of dementia. A related resource, **A Guide To Voice, Age And Campaigning**, is an abridged version of the final report. Both are available to download from the CDPC website; go to <https://bit.ly/2NdRWof>

New Australian technology start-up, Umps Healthcare, is promoting its range of **smart plugs** as a way of monitoring regular activities within a person's home – including possible changes in day-to-day living as a result of dementia. The home system is made up of five smart plugs which are plugged into any regular electronic wall socket, and track the use of the appliance that's plugged into them (eg, bedside lamp, kettle or refrigerator), with any substantial changes in useage patterns being reported to nominated family members or a care provider for them to take appropriate action. The plugs don't need a WiFi connection within the house to work, as Umps Healthcare has its own internet connection. An optional app is available which presents

the information captured in full detail. The system costs \$40 per month. For more information, go to www.umpshealth.com

CogTale (or Cognitive Treatments Article Library and Evaluation) is a new website still in development which aims to help researchers, clinicians, and members of the general public to be able to navigate the complex area of research into cognitive interventions in older age. CogTale is a comprehensive database of methodological features and summary results from all relevant trials of cognitive interventions in the field of cognitive ageing. For each article in the database, CogTale uses algorithms to produce several study quality scores, as well as a range of effect sizes (which tells how

effective a treatment was). Registered researchers may even enter their own trial results into the database. Project Director for CogTale is Alex Bahar-Fuchs from the University of Melbourne, and he is supported by team members from many countries around the world. To search CogTale go to <https://cogtale.org/>

Researchers from the University of Bristol (UK) have worked with three co-researchers who are living with dementia to create a series of five training videos that address common issues in communication with people with dementia. The videos are the result of a research project called **Getting Things Changed** which involved filming and analysing conversations with a large number of people with

dementia – and then reviewing what worked and didn't work so well alongside the co-researchers with dementia. The video titles are: 'An introduction to getting good support', 'Talking about the past', 'Quizzes for people with dementia', 'Talking in the here and now', and 'Messages from three people living with dementia'. The videos include 'pause points' where the viewer is asked to consider questions or to do a task based on the interaction, and reflecting on tricky situations where the communication could have been better. There are also discussion points and suggestions from co-researchers living with dementia. The films are aimed at anyone with an interest in communicating better with people with dementia. The

videos can be found on the University of Bristol website: go to <https://bit.ly/2KH7qqX>

The NHMRC's National Institute for Dementia Research (NNIDR) held its second National Public Lecture Tour in March 2019. The theme for the tour was 'Applying the latest dementia care research', and it explored dementia care and how the latest research can help people living with dementia live longer, and well, at home and in their local community. The 50-minute keynote presentation in Melbourne and Sydney was delivered by Dr Vincent Mor from Brown University in the US and was entitled **Designing And Disseminating The Next Generation Of Interventions For Persons With Dementia**. This presentation is now available to view on the NNIDR website at www.nnidr.gov.au/events/national-public-lecture-tour

The NSW Government's Family and Community Services (FACS) has funded an update of the **MedicineWise app** – enabling family carers and professional carers who look after one or more people to keep details of everyone they care for in the one app, and people who have more than one carer to share their medicine details with multiple people. The app's core functions include storing lists of medicines, scheduling reminders, and tracking when medicines are taken. The free MedicineWise app can be downloaded onto a smartphone from a user's preferred app store.

Illawarra's Italian Social Welfare Organisation (ITSOWEL) and Mindful Generations (creators of activity kits and scarves for people with dementia) have teamed up to develop new resources aimed at older Italian people living with dementia. The resources include a book called **Le Stagioni Della Mia Vita** (or **The Seasons Of My Life**). The book features photos only, with images relating to important Italian themes, such as breakfast coffee, gardening, food markets in Italy, herbs, olives, Italian scenery and food, traditions and music. The book also includes some historical photos of the Italian community living in the Illawarra. An audio sound button of someone speaking in Italian, and naming the items in the photos, also correlates with the book.

The other resource is a small **sensory suitcase** (pictured), which offers a range of items to touch, smell and look at (such as a coffee cup with coffee beans in it, an embroidered olive branch on linen, a photo of a margarita pizza with a felt pizza slice, and a pasta bowl with handmade crocheted penne pasta with cherry tomatoes and basil).

The resources may be used together or separately to support conversation, reminiscence and engagement with people with dementia. The package (which includes book, sound button and suitcase with sensory resources) costs \$150. If purchased separately, the cost is: book \$40, sound button \$20, suitcase and sensory resources \$100. To access the resources, contact ITSOWEL on (02) 4228 8222 or email info@itsowel.com.au



Events

■ 26-29 August 2019 – NSW

Quality in Aged Care Conference

Benchmarking against the new Quality Standards, updates on the Aged Care Royal Commission. Presented by COTA + ACSA, in Sydney. Details: <http://bit.ly/2SapD1K>

■ 28 August 2019 – National

Using Measures Of Adaptive Behaviour To Assess Adult Independent Living Skills

Free webinar: 12.30pm-1.30pm (AEST). This webinar for clinicians, hosted by Pearson, will explore two questionnaire-based instruments – The *Vineland Adaptive Behavior Scales* and the *Adaptive Behavior Assessment System* – which help guide decision-making around whether someone is safe to live alone and what support is required to enable independent living. For use when task-based assessments are not practical

or possible. Can't attend the live event? Register and receive a link to view the webinar recording in your own time. Details and registration: <http://bit.ly/2G7TIE8>

■ 20 September 2019 – National

DriveSafe DriveAware (DSDA) Research Round-up

Free webinar: 12.30pm-1.30pm (AEST). This webinar, hosted by Pearson, looks at some of the research that has used the *DriveSafe DriveAware* screening app that accurately predicts the driving ability of older people or those with cognitive impairments. Can't attend the live event? Register and receive a link to view the webinar recording in your own time. Details and registration: <http://bit.ly/2XFGFuS>

Details of more events at www.journalofdementiacare.com

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