Australian Journal of

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For all who work with people with dementia

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Also inside this issue:

- Mooving and Grooving
- ‘Kinecting’ through digital games
- Eat Walk Engage
- Co-design for advanced dementia

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Collaborating with competitors

By **Professor Richard Fleming**, Executive Editor *Australian Journal of Dementia Care*, and Executive Director Dementia Training Australia

Professor John Pollaers heads up Australia's Aged Care Workforce Strategy Taskforce. His task is to steer the development of an industry-driven workforce strategy that will provide sustainably better care to older people delivered by committed, happy, high quality staff. His vision is not just to change the aged care sector but to shift society's attitudes to ageing and dying. This is captured in an eloquent statement from Professor Pollaers: "We exist to inspire people to **want to care**, enable people to **properly care** and **enhance life through** care. **Because how** we care for our ageing is a reflection of who we are as a nation."

He intends to do this through 15 strategic actions which are described on the Taskforce website (https://bit.ly/2KuPP1Z). Underpinning all of these actions is the idea of finding a common, unifying, industry-wide understanding of what the care of older people is about and how it should be delivered. This shared understanding should become a rallying point for those interested in delivering high-quality care. But how many will join the revolution?

The problem is competition. Let's take the example of training staff in the care of people living with dementia, a critical part of the development of the skilled workforce that Professor Pollaers and the Taskforce want to bring about.

There are many organisations that provide training and I am sure that there is a great deal of common ground in their understanding of what high-quality training is about. But is that enough to unite them into a force for positive change? It doesn't seem so. A cursory look at their websites will show that their efforts are directed at pointing out their differentiators not their common goal.

While some of the leaders in the field of dementia training are, by nature, competitive, I don't think it is their competitive nature that drives this particular competition. It is simply the drive to survive that is at the root of the competition.

Survival for these organisations depends on two things – continuation of their Government funding and the income they can generate from selling training to aged and health care organisations. The reality is that both of these sources of income must be won through competition. Even when these organisations wish to collaborate, and even when their major sponsor, the Government, wants them to collaborate, the threat to survival of losing a source of income results in competition.

This is clearly seen towards the end of Government funding rounds when organisations that have collaborated for a year or two are confronted with the possibility that collaborators may turn into competitors in the final year of funding.

If Professor Pollaers is right about the way to a better future being via greater unity, then we must find ways to minimise competition. This will be resisted by many who see competition as a spur to innovation and higher quality products and services but, leaving that objection aside, what conditions would help to bring this about?

The ideal way would be for organisations, and individuals, to follow Professor Pollaers' lead and to focus on the development of a coherent, unified system governed by self-regulation; to be selfless in the pursuit of the greater good.

If we cannot achieve that then, perhaps, the coherence and unification needs to be brought in from above. This could take the form of a clear National Action Plan on Dementia in which the roles and responsibilities of all Government-funded organisations were clearly defined and articulated with 'mission creep' being forbidden. The contracts would define collaboration and deter competitive behaviour.

This approach exists, in part, in contracts today but lacks a clear, overarching vision and allows influential players to position themselves to take over the activities of others, paradoxically spurring competition.

A third, and relatively easily achieved way, would be to increase the length of the funding cycle. If the cycle was five years rather than three, the duration of the collaborative stage would increase proportionally, improving the possibility of the emergence of a coherent and unified system that would become sustainable by proving its worth to consumers and providers alike.

Voluntarily collaborating with competitors has never been easy. The current moves away from multinational agreements, as exemplified by Brexit, show that despite massive efforts the result is usually unstable. I am not sure that we are going to be able to achieve it but I like to think we can. ■

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Cover image: A big smile from Alison at the Water Memories group, part of Dementia Canterbury's community-based program of activity groups for people with dementia, run in collaboration with local community services.
Photo courtesy Dementia Canterbury

News in brief

Design School for People Living with Dementia

Professor Colm Cunningham of HammondCare's Dementia Centre and dementia campaigner Agnes Houston MBE have hosted what is thought to be the first of its kind in the world, a Design School for People Living with Dementia, in Birmingham on 13 March. The event brought together a group of people with dementia to share their knowledge and experience, while also giving them the opportunity to learn more about design. The event is the first in a series of design schools, which it is hoped will result in a valuable body of knowledge for architects, planners, developers and service providers to build better places and spaces for people living with dementia.

Award for The Village

Aged care provider Scalabrini has received an award for its newest facility – The Village, which opened in Drummoyne, Sydney in February this year. This is the group's seventh care facility. The award, for Best Aged Care Facility, was presented at the 2018 Australian Healthcare Week Excellence Awards, held in conjunction with the annual conference and expo in March. Scalabrini CEO Elaine Griffin and The Village General Manager Fiona Kendall wrote about The Village in the April/May 2018 issue of *AJDC* (*A village for all*).

Driving simulator for people with dementia

NSW care provider McLean Care has announced that it is working with Deakin University to develop a virtual reality vehicle, thanks to a major grant from the Australian Government's Dementia and Aged Care Services (DACS) Fund. The simulator car will be housed at its Inverell aged care facility, and is set to benefit people with dementia who have lost their driving license and want to relive the experience of driving again, as well as older people still with their license who may need to practice driving or help with making an informed decision as to whether or not to continue to drive. McLean Care CEO Sue Thomson said that "by combining cutting-edge technologies such as sensors, virtual reality, and simulation training, we are leading the way in developing technology to support the seniors in their local areas to remain connected to their communities". The simulator will be able to produce reports and health metric data (for example on drivers' reaction times and heart rates) that can be used by health professionals to support decision-making around a person's suitability to continue driving.

$85m for carer support

The Federal Government has announced an additional $85.6 million in funding over four years for new services for carers. These will include digital services such as peer support, counselling, coaching and educational resources via the Carer Gateway website (from October 2018), and a new network of regional delivery partners to be established across Australia, giving carers access to new and improved local services (from September 2019). Both will form part of the Integrated Carer Support Service. The Department of Social Services (DSS) is leading on tendering, consultation and implementation for this work: look on the DSS website for further information.

New definition for Alzheimer's disease

The US National Institute on Aging and the Alzheimer's Association (NIA-AA) has developed and proposed a new strictly biological definition of Alzheimer's disease – as opposed to the current definition which is based on cognitive changes and behavioural symptoms. The new definition was published in the April 2018 issue of *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, and forms part of the NIA-AA's new research framework. In the new definition, the presence of neurodegeneration (nerve cell death) and neuropathology (specifically beta amyloid plaques and tau tangles) identified through cerebral spinal fluid or brain imaging confirms a diagnosis of Alzheimer's disease – even if the person is not symptomatic. According to lead author Dr Clifford Jack, once validated in diverse global populations, this new definition will create a powerful tool to speed and improve the development of disease-modifying treatments for Alzheimer's disease. The report authors however caution against the use of the definition in general practice, saying this would be "premature and inappropriate", and that they recognise the need to continue to support research not based on the biomarker-based framework. The new definition was developed as part of a 2017 review of diagnostic guidelines.

Home care and remote service needs

Most older people are positive about the care they receive at home – though they do have complaints about various issues, including lack of continuity of care for people with dementia, and poor training for dementia care. The findings come from a National Seniors Australia report entitled *Accentuating the positive: consumer experiences of aged care at home*, which was commissioned by the Aged Care Workforce Strategy Taskforce to inform the strategy.

National Seniors Australia surveyed providers and consumers on the issue, receiving over 4500 responses, as well as conducting interviews with clients and care providers, and inviting stories from consumers. Report author, National Seniors Australia Research Director Professor John McCallum, said it was important to listen to negative views to target areas for improvement.

The Aged Care Workforce Strategy Taskforce is due to present its strategy to the Federal Government by 30 June 2018. As part of its national consultations taskforce members have also met recently with representatives from remote and very remote aged care providers to examine aged care services in those regions.

"The taskforce has heard, loud and clear, that a tailored approach to the aged care workforce is required, especially in remote and very remote locations," said Taskforce Chair Professor John Pollaers, who convened the May meeting.

Professor Pollaers said an industry accord on the remote aged care workforce was detailing priorities, desired changes and recommended actions to underpin support for the remote workforce.

The Government established the taskforce in November 2017 to develop Australia's first workforce strategy, focused on supporting safe, quality aged care. Workforce requirements are predicted to increase from about 366,000 currently to almost one million by 2050.

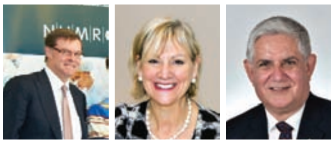
Bethanie Front Door project: WA aged care provider Bethanie has launched an initiative called The Front Door project which has seen 25 residents living with dementia at its Bethanie Fields aged care home receive a door motif on the front of their private room to assist with orientation and create a more homely environment. "Residents and families each chose their own unique door design, opting for motifs that may be similar, for example, to a house they lived in whilst growing up," said Bethanie occupational therapist Kristy Alexandratos. One of those residents is Elizabeth Bowron (pictured) who says she chose her door because she loves blue: "Blue like the open sky – it goes to wherever you want to go. I love it."

Technology focus in Budget dementia funding

An injection of $5.3 million funding to improve care for people living with dementia – with an emphasis on using innovative technology – is the key dementia-specific commitment announced in this year's Federal Government Budget, handed down on 8 May.

The Department of Health said dementia-focused care technology was a relatively new market with untapped potential to help people with dementia to live at home for longer. It said that the new dementia funding would enable further development of, and investment in, technological solutions that help people living with dementia, their families and carers to understand dementia, and develop skills and strategies for caring. The technology projects could be developed for use in the community, aged care, health and education sectors to improve dementia care.

The department said the new technologies would be showcased through programs such as the National Dementia Support Program and through community organisations providing services for people living with dementia.



From left: Dr Stephen Judd, Maree McCabe and Ken Wyatt

The dementia funding is part of the Government's overall Budget commitment to increase spending for aged care by $5 billion over five years. Some key elements are:

- $1.6 billion over four years to create 14,000 new high-level home care packages.
- $146 million to improve access to aged care services in rural and regional areas.
- $82.5 million for increased support for mental health services in residential aged care.
- $20 million over four years for a pilot project targeting loneliness and those at risk of isolation.
- $32.8 million over four years to deliver palliative care in residential aged care.

Funding has also been committed to support the establishment of the new Aged Care Quality and Safety Commission from 1 January 2019, and $50 million over two years from 2018-19 to support residential aged care providers to transition to the new quality standards framework.

The new Commission will bring together the functions of the current Australian Aged Care Quality Agency, the Aged Care Complaints Commissioner and the aged care regulatory functions of the Department of Health. A new Chief Clinical Advisor will advise the Commission, particularly on complex clinical matters.

The Minister for Aged Care, Ken Wyatt AM, said the Commission will provide a single point of contact for consumers when they need help in dealing with claims of sub-standard care.

Leading Age Services Australia (LASA) CEO Sean Rooney said the budget initiatives responded (in part) to the growing demands for age services in Australia and were welcomed by the aged care sector, but that LASA had hoped that the Budget would map out a plan to meet the longer-term needs of Australia's rapidly ageing population.

HammondCare Chief Executive Dr Stephen Judd said this year's Budget had delivered a mixed bag for aged care, with new initiatives welcome but systematic changes still needed in home care. He said that, while the new money for home care packages was welcome given the number of people still waiting for home care (in excess of 100,000 people), a superannuation-style solution was necessary to help more people access government-subsidised support.

Dementia Australia CEO Maree McCabe called for a focus on government better supporting vulnerable seniors such as people living with dementia across the country: "The gap in this budget is that dementia is not recognised as core business," she said.

Study reveals keys to quality of life

Good relationships, social engagement, better everyday functioning, good physical and mental health, and high-quality care are all linked to better quality of life (QoL) for people with dementia, according to a new study.

The study, led by the University of Exeter and published in the journal *Psychological Medicine* in May, has identified the factors that can be targeted to support people to live as well as possible with dementia.

Factors linked with better QoL include having good relationships with family and friends, being included and involved in social activities, being able to manage everyday activities, and having religious beliefs. Factors that are linked with poor quality of life include poor mental or physical health, difficulties such as agitation or apathy, and unmet needs.

The study stems from the IDEAL program in the UK, a major longitudinal cohort study of 1550 people with dementia and their family members or friends, which aims to understand what makes it easier or more difficult for people to live well with dementia.

The findings from the study will help to identify what can be done by individuals, communities, health and social care practitioners, care providers and policy-makers to improve the likelihood of living well with dementia. For more information, visit www.idealproject.org.uk

TBI and dementia link

Researchers from the University of Washington School of Medicine say they have established that having a traumatic brain injury (TBI) is associated with an increased risk of dementia – both compared with people without a history of TBI and with people with non-TBI trauma. The findings were reported in *The Lancet Psychiatry* in April, and come from a national population-based observational cohort study in Denmark, using information on citizens from national registries – in total a cohort of 2.8 million people.

The overall risk of dementia in individuals with a history of TBI was 24% higher than those without a history of TBI, after accounting for other risk factors for the disease. A single "severe" TBI increased the risk by 35%, while a single "mild" TBI or concussion increased the risk by 17%.

Lead author Professor Jesse Fann said, "What surprised us was that even a single mild TBI was associated with a significantly higher risk of dementia. And the relationship between the number of traumatic brain injuries and risk of dementia was very clear."

A similar study published in *JAMA Neurology* in May led by researchers at University of California (UCSF) has suggested that concussion, even without loss of consciousness, can increase a person's risk of dementia.

News in brief

Wicking MOOC boost

The JO and JR Wicking Trust has given a third round of funding – amounting to $3.7 million – to the Wicking Dementia Research and Education Centre, part of the University of Tasmania's College of Health and Medicine. The funding will be put towards maximising the reach of the Wicking Centre's Massive Open Online Courses (MOOCs) and establishing an evidence base for the impact of the courses, including knowledge evaluation. The two courses – 'Preventing Dementia' and 'Understanding Dementia' – have already been taken up by about 146,000 participants worldwide, but the Wicking Centre now hopes to reach 400,000 Australians and a further one million people globally through its online education over the next five years.

Inaugural Advance Care Planning Week

More than 100 events were held across Australia from 16-22 April to mark the inaugural Advance Care Planning Week and raise awareness of the importance of advance care planning. Aged Care Minister Ken Wyatt was present for the week, held in Victoria, and used the opportunity to launch a new resource, *Advance care planning in aged care*, aimed at care providers across community and residential settings. The guide, and various other resources (conversation starters, quizzes and activities to help get people talking) are available on the Advance Care Planning Australia website. Advance Care Planning Australia is an initiative from Austin Health, which has received $4.1 million from the Federal Government to run a three-year awareness program.

Scholarships for rural health professionals

Health professionals in rural and regional Australia are being encouraged to apply for financial support to help them build up their professional skills, via a new Federal Government scheme called the Health Workforce Scholarship Program. Minister for Rural Health, Bridget McKenzie, launched the new program in April, which will see $11 million being made available. The program will offer grants to postgraduate rural health professionals undertaking further study, as well as one-off bursary and support payments to cover the cost of attending training. Further information about the program is available on the Rural Workforce Agencies (RWA) websites (there is one RWA for each state).

Hospital admissions study recruitment

The Melbourne Ageing Research Collaboration (MARC), led by the National Ageing Research Institute, is conducting a study to understand the main reasons that people with dementia go to hospital emergency departments, identify how many of these could have been avoided, and develop resources to support people with dementia and their carers in making healthcare decisions. MARC is currently seeking various participants for the study, referred to as the Preventing Avoidable Hospital Admissions for People with Dementia (PAHA) study: carers of people with dementia (if you have been to a hospital emergency department with the person you care for in the past three months), GPs working in the Melbourne metropolitan area, and clinical staff working in hospitals. Participation will involve completing a survey and involvement in a focus group. For more information contact Dr Anita Panayiotou on (03) 8387 2662 or a.panayiotou@nari.edu.au

Moving Pictures

The National Ageing Research Institute has received an additional $132,000 in Federal Government funding towards its Moving Pictures program, a major project in which 15 short films are being developed, based on interviews with carers of people with dementia in Sydney, Melbourne and Perth, aimed at Chinese, Indian and Arab communities. The films will be available in five languages (Mandarin, Cantonese, Hindi, Tamil and Arabic) and will focus on dementia warning signs, seeking help and care. National Ageing Research Institute Social Gerontology Director Bianca Brijnath is the chief investigator for the project and is working with colleagues from Curtin University, the University of Technology Sydney and Peking University. The films will be made available online and via a free mobile and tablet app by June 2019. The extra funding was announced by Aged Care Minister Ken Wyatt following a meeting with Dr Brijnath and Chinese older people in Perth.

Funding boost for Aboriginal and Torres Strait Islander communities from NHMRC

Research into dementia in Aboriginal and Torres Strait Islander communities has received a major boost, with an announcement from the National Health and Medical Research Council (NHMRC) in April that $14 million of funding will go to five major projects across three states.

Aged Care Minister and Indigenous Health Minister Ken Wyatt said: "From physical fitness to brain training, we expect this research to generate information that will translate directly into improved health outcomes and a better quality of life for Aboriginal Australians with dementia." The funding comes from the Federal Government's $200 million Boosting Dementia Research Initiative.

The five research projects are:

- Let's CHAT: Community Health Approaches to Dementia in Indigenous Communities, led by Associate Professor Dina LoGiudice from the University of Melbourne.
- Addressing Health And Care Needs Of Aboriginal and Torres Strait Islander People Living With Dementia And Their Communities: A Cluster Randomised Controlled Trial, led by Professor Robert Sanson-Fisher from the University of Newcastle.
- Dementia Prevention And Risk Management Program For Aboriginal Australians (DAMPAA), led by Dr Kate Smith, from the University of Western Australia.
- Multifactorial, Multidisciplinary Nurse Led Aboriginal Dementia Prevention Through Cardio-Metabolic Risk Reduction, Behaviour Change And Other Strategies: A Pragmatic Randomised Controlled Trial, led by Professor Sandra Eades from the Baker Heart and Diabetes Institute.
- Our MOB (Mind Our Brain): Dementia Prevention Across The Life Course With Aboriginal Australians, led by Dr Kylie Radford from the University of NSW (Neuroscience Research Australia, NeuRA)


Dr Kylie Radford

Dr Radford said she was excited to see the recognition and support for groundbreaking research into dementia, with the combination of projects set to improve the lives of Aboriginal and Torres Strait Islander people living with brain disease.

"Our project will focus primarily on understanding the major causes and risk factors contributing to these higher rates of dementia in Aboriginal and Torres Straits Islander peoples, in order to develop effective prevention strategies across the life course," Dr Radford said.

Benefits to the community will include enhanced awareness and skills around dementia and healthy brain ageing, accessible active ageing support and a stronger evidence base to guide health policy and practice for an ageing Indigenous population.

Dementia-friendly activity

Community engagement grants for 21 projects

Kiama Municipal Council is one of 21 organisations from across Australia that have each been awarded a $15,000 Community Engagement Grant to develop dementia-friendly activity in their communities. The funding will support a third phase of work for the Dementia-Friendly Kiama Project, and include business and community education, and support the Kiama project's Dementia-friendly Kiama Advisory Group (DAGs) to become an incorporated organisation.

Some of the other projects to receive grant funding include a project in the Adelaide Hills to promote dementia-friendly tourism, the establishment of a native sensory garden within Woowookarung Regional Park in Ballarat, and the production of a community action plan to develop a dementia-friendly community within the Shoalhaven region of NSW.

More details on the successful grant applications are available on the www.dementiafriendly.org.au website. The grants are part of the Dementia-Friendly Communities initiative, managed by Dementia Australia with $3.9 million funding from the Federal Government.

Alzheimer's WA Chief Executive Rhonda Parker

WA's whole-of-town approach

Manjimup and York in Western Australia (WA) are pilot sites for a whole-of-town approach to a dementia-friendly communities, project managed by Alzheimer's WA.

Alzheimer's WA Chief Executive Rhonda Parker said: "We wanted to look at what would happen if we worked with a whole town. That means the retailers, community members, places like schools and hospitals, public transport."

The project, funded through the WA Country Health Service, is the culmination of four years' work aimed at making WA a dementia-friendly state. The initiative provides education, support and awareness to help break down the stigma associated with dementia.

Local workers receive training on how to identify and engage with people living with dementia and business owners are given tips on how to make the environment less perceptually confusing, such as using contrasting colours to highlight objects or reducing noise wherever possible.

Findings from the pilot phase, which concludes in June, will inform future Dementia Friendly Communities initiatives.

Bundaberg focuses on tourism experience

Researchers are seeking the views of anyone who works with passengers at the Bundaberg airport and railway station, or who works for local bus or taxi services, as part of a bigger project which began in 2016 to help the Queensland town achieve its aim of being a dementia-friendly tourist destination. Local transport workers are being invited to complete the survey (see below) which asks about their experiences of interacting with passengers who may have dementia or confusion.

Focus groups are also being held with people with dementia and family carers.

CQUniversity academic Dr Maria O'Reilly is leading the research project, working alongside colleagues Claudia Bielenberg and Professor Carolyn Unsworth from CQUniversity, as well as Professor Jill Franz (QUT) and Nicole Shepherd (UQ). The research team has already completed an environmental assessment of the airport and railway.

The survey is available via www.surveymonkey.com/r/dementiatravel

CarFreeMe trial in Queensland and the ACT

A program designed to provide practical and emotional support for those advised they should stop driving is being trialled in Queensland and the ACT.

Led by Dr Theresa Scott, NHMRC-ARC Research Development Fellow at The University of Queensland, CarFreeMe is an evidence-based approach that aims to support people living with dementia who are adjusting to life without driving.

"The transition to non-driving comes at significant personal cost, including increased risk of depression, anxiety, loneliness and isolation, identity loss, and grief," Dr Scott said.

"As symptoms of dementia progress, people lose insight into their driving ability and how it may affect others. Therefore, the ideal situation is for voluntary and gradual driving cessation."

Program participants collaborate with a trained health professional to develop tailored solutions to their individual needs based on their location and access to alternative forms of transport.

Dr Scott's team is also developing a telehealth resource for GPs, primary carers and health professionals in rural and remote areas.

She said the program aims to "help people realise they have a life outside of driving. It was developed with input from people who have experienced driving cessation and what they said they needed to adjust and remain active and connected to their community".

The study is open to people who have already stopped driving or are thinking about stopping in the future. Potential participants need to be aged 65 years or over with a diagnosis of dementia and have a family member or carer available to participate with them.

For Queensland inquiries, contact Sandra Smith or Donna Rooney on (07) 3443 2546 or email Sandra.smith@uq.edu.au or Donna.Rooney@uq.edu.au. For ACT inquiries, contact Amy Nussio on 0457 779 766 or email a.nussio@uq.edu.au

First festival of love and dementia

Perth hosted Australia's first festival of love and dementia, LoveFest, in May. The festival was an initiative of The Museum of Love, which develops, collects, preserves and displays items documenting the importance of love in the lives of people with dementia.

Museum curator, Melbourne-based researcher and educator Dr Catherine Barrett, said the aim of LoveFest is to bring the museum to local communities – to hear local stories and build local capacity for dementia-friendly families, communities and services.

LoveFest was launched in Perth with a photo exhibition of people with dementia kissing someone they love. The exhibition, by Lisa White – The Social Photographer, was installed in a vacant shop in Garden City Shopping Centre and attracted significant attention.

The LoveFest Perth presentations event involved people with dementia and their family members sharing stories about the importance of love in their lives. Photo: Lisa White – The Social Photographer

A presentations event in the City of Melville Community Hall involved 14 people with dementia and their families sharing their stories about the importance of love in their lives, the challenges dementia brings and their strategies to consolidate relationships and connection. Over 150 people attended the exhibition launch and LoveFest presentations event.

Images from The Kiss photographic exhibition at LoveFest Perth 2018. The portraits, of people with dementia kissing someone they love, seek to highlight the importance of human connection and love in the lives of people living with dementia. Photos: Lisa White – The Social Photographer

Dr Barrett said a resource developed from LoveFest Perth will enable the presentations, strategies, photographs and information about services to be shared with those unable to attend – particularly people living in rural WA. It will be freely available on the Museum of Love website at www.museumoflove.com.au/lovefest.html

"The evaluation of LoveFest shows it is making a difference and our vision is to roll this capacity building process out nationally," Dr Barrett said.

She is inviting individuals or organisations interested in hosting a LoveFest event in their town or city to email her at director@celebrateageing.com. More information is on the Museum of Love website.

LoveFest Perth was supported by the City of Melville, GRAI, Garden City Shopping Centre, Alzheimer's WA, Lisa White – The Social Photographer and Consultivation, as well as aged care service providers including The Care Side, Hall & Prior Health and Aged Care Group, Chorus, Southcare and Heart To Heart Connections.

Intervention reduces sedative use

A national intervention program has led to a significant reduction in the use of psychotropic medication in residential aged care facilities (RACFs) around Australia.

Results of the RedUSe (Reducing Use of Sedatives) intervention were published in the *Medical Journal of Australia* in May. The research, led by Dr Juanita Westbury from The University of Tasmania's Wicking Dementia Research and Education Centre, involved more than 12,000 residents in 150 Australian care homes.

"Under RedUSe approximately 40% of residents had their antipsychotic or benzodiazepine medication ceased completely or their dosage reduced," Dr Westbury said.

"Furthermore, substitution to sedating antidepressants did not occur and the issuing on an 'as needed' basis of antipsychotics and benzodiazepines declined significantly."

RedUSe aims to ensure that sedative medication is used appropriately and is reviewed frequently in the aged care setting through strategies including education of nursing staff, promotion of evidence-based guidelines, and drug audits of aged care home medication use.

The key recommendations of Dr Westbury's research included making RedUSe available to all Australian RACFs in the future and for the program to be offered as part of the Federal Government funded Quality Use of Medicines program for community pharmacists.

It also recommended national training for residential aged care staff in alternatives to medication for the treatment of responsive behaviours associated with dementia.

Dr Westbury said she had received an overwhelmingly positive response to the project from staff at RACFs around the country.

Report highlights seven risk factors

Almost half of dementia instances can be attributed to seven modifiable lifestyle factors, according to a new Australian research report, *Cognitive ageing and decline: insights from recent research*. The risk factors are physical inactivity, midlife obesity, midlife hypertension, smoking, diabetes, depression and low educational attainment, but the report says most people are unaware of the causes of dementia and what they can do to prevent them. The research was led by Professor Kaarin Anstey, ARC Centre of Excellence in Population Ageing Research (CEPAR) Chief Investigator and NHMRC Principal Research Fellow at Neuroscience Research Australia (NeuRA).

SHAREYOURVIEWS

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

Family carers need training too

By **Paul Williams**

I refer to the Dementia Training Australia (DTA) Directors' article, *Going beyond 'tick the box' training* (*AJDC* April/May 2018)*. I agree it is essential to provide best practice care training for the dementia care workforce.

The same criteria should also apply to family carers who are 'on the job' for several years, 24 hours a day, seven days a week. However, the following shows barriers exist to training family carers for long-term dementia care.

My wife was in moderate stage dementia when diagnosed with Alzheimer's disease. She was also losing language ability and becoming agitated. Her increasing agitation was a reflection of my not understanding how to validate her unmet needs.

Although Dementia Australia provides the excellent Living With Dementia program, it aims to help carers and people in early stage dementia. As a result, I used their help sheets to improve my communication skills. However, help sheets do not give practical demonstration of the nuances of eye contact, body language and tone of voice.

My lack of skills put great stress on our relationship and was the main reason my wife entered residential care. While there, I saw how trained formal carers used effective communication skills when caring for her personal needs.

Bit by bit I learnt the skills needed in dementia communication. Consequently, our relationship and quality of life significantly improved. Moreover, it confirmed my belief that family carers need the same skills as formal carers.

To return to the DTA Directors' article, I note that DTA has, or will have, online courses available to 25,000 professional and formal carers. I also assume the training modules will cover skills for all stages and types of dementia.

To reach the estimated 200,000 home carers (Brown *et al* 2017) I believe it would be cost-effective to adapt some courses to a home setting. The University of Tasmania's Wicking Centre MOOC, *Understanding dementia*, is a good example of what can be done to involve carers who are unable to attend classroom training.

But, there is a barrier. Policies set out in the National Frameworks for Action on Dementia seem to mandate that only health professionals and formal carers will receive care skills training. For example, the *National Framework for Action on Dementia 2013-2017*, (p10), states: "Health professionals have access to education and training based on best practice to enable them to provide the highest level of care"; and "People living with dementia, their family and carers, have access to a range of information through a variety of mediums to empower them to make informed decisions about their care."

Likewise, the *National Framework for Action on Dementia 2015-2019*, 3.2 Support for Carers, (p14), is almost dismissive of the family carer's need for training, stating:

"Carers should have access to support tailored to their needs in order to effectively respond to and manage the pressures associated with the physical, mental and emotional demands of their caring role. The provision of information and support services to carers may help to make the caring experience less stressful, and more rewarding."

These policies deny carers the very skills that would decrease their burden of care. They also contradict studies such as *Family caregivers of people with dementia* (Brodaty & Donkin 2009) that cite the following benefits of training family carers:

- Reduces the family carer's psychological stress and risk of burnout.
- Improvement in quality of life for the person with dementia and their carer.
- Effective training may delay entry to residential care by up to 1.5 years with cost savings for government funding and families.

But then, I found another barrier. The *Australian Clinical Practice Guidelines and Principles of Care for People with Dementia* (Guideline Adaptation Committee 2016, p4) states: "Carer(s) and family…should be offered education and training to enable them to develop skills in managing the symptoms of dementia."

However, under *Support for Carers* (p59), Item 102 negates the above proposition and rates the evidence base as EBR Low for "training in providing care and communicating most effectively with the person with dementia".

In closing, I know that policies and practice guidelines for health professionals and formal carers are necessary to protect the wellbeing of the people they care for.

Nevertheless, I bring these matters to the DTA Directors' attention in the hope that a fresh evaluation will be considered of the family carers' need for skills training in the later stages of dementia. It would do much to improve the wellbeing of carers and their loved ones. ■

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NB: The *National Framework for Action on Dementia 2013-2017* is archived and no longer available online.

*** The article, *Going beyond 'tick the box' training*, is available to read in full on the *AJDC* website at www.journalofdementiacare.com**

Writing for *AJDC*: Do you have a project or survey to report, or a change in practice organisation or structure which has worked well (or not), and would you like to share this experience with others? We welcome contributions of this kind, as well as bright ideas for improving the environment or well-being of people with dementia, and letters to the editor responding to articles in *AJDC*. Contact Richard Fleming at rfleming@uow.edu.au

The *Australian Journal of Dementia Care* is a multidisciplinary journal for all professional staff working with people with dementia, in hospitals, nursing and aged care homes, day units and the community. The journal is committed to improving the quality of care provided for people with dementia, by keeping readers abreast of news and views, research, developments, practice and training issues. The *Australian Journal of Dementia Care* is grounded firmly in practice and provides a lively forum for ideas and opinions.

Mooving and Grooving

Moove and Groove is a specialised silent disco experience for older people incorporating dance, music and exercise. After a successful trial with people with dementia, dementia-specific classes are now running in several aged care homes in NSW and a train-the-trainer program is being launched in June 2018. Founder **Alison Harrington** explains

The photos above and on the following pages show participants, instructors and care staff during Moove and Groove classes. The program has shown clear benefits for people living with dementia. Photos this page: Elizabeth Williams, Media and Communications, NSW Government. Photos over page courtesy discoDtours

The Moove and Groove program was borne out of a desire to improve the physical and mental health of older people by providing them with a fun and engaging activity to be involved with.

The idea came about after I founded a business called discoDtours in 2015 to run silent disco dancing tours for groups of people through the streets of Sydney as a fundraising activity for charities. Silent discos have been around since the early 1990s and involve people dancing to music broadcast via wireless headphones instead of speakers. Those without headphones don't hear any music, giving the effect of a group of people dancing in silence. While silent discos usually operate indoors with a DJ playing music, our idea saw groups of 10-30 people dancing around a defined outdoor circuit led by a dance guide.

When I first started the disco tours business I was completing postgraduate studies in social impact at UNSW and was required to complete a research project on an innovative program for aged care. In my discoDtours dance tours I saw that people were getting great exercise and were also on a natural high after dancing, and I wondered if the concept could also make people healthier and happier in aged care. After writing a research paper I applied for and received a NSW Liveable Communities Grant* (2015-16) to test the concept with active older residents. I worked with an exercise physiologist and a music therapist to put together the initial Moove and Groove pilot program at RSL LifeCare ANZAC Village Narrabeen, with the core concept being participants having fun. The 10-week pilot was well received and the care home has continued with regular classes for residents since then.

What is Moove and Groove?

A Moove and Groove class usually runs for 30 to 60 minutes and is led by a trained instructor. All participants listen to the same music and hear the instructor's voice through their headphones, which have adjustable volume. The instructor leads participants on a guided routine which can be chair-based, mobile inside and around the grounds of the care home, or a combination.

The Moove and Groove silent disco class consists of:

- An instructor giving guidance on dance/exercise moves, a commentary and motivation to participants.
- Specifically selected and edited music from eras which the participants relate to – normally the 1940s-1960s, but more recent songs are also included.
- Movement: specific exercise/dance movements to develop balance, strength, flexibility and coordination.
- Technology, which consists of Bluetooth-enabled silent disco headphones customised so the wearer can clearly hear both the music and the instructor's voice through the headphones, a wireless transmitter, microphone and music device (usually iPods)
- Props, such as pom poms, fans and colourful streamers for participants to wear and hold while dancing.

The dementia trial

Following the success of the initial pilot with active older people, I became intrigued

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* The NSW Government's Liveable Communities Grants Program offers $4 million in funding over four years for projects that improve the lives of older people living in NSW. The program is now in its third year. Details: www.facs.nsw.gov.au

about the potential benefits of this program for people with dementia, as there was so much research on the benefits of music for people living with dementia. I also was aware of the documentary *Alive inside: a story of music and memory* and the Music and Memory program (a one-on-one music therapy model in which care professionals are trained to set up personalised music playlists, delivered on iPods and other digital devices). What we had developed with Moove and Groove was a one-to-many model that also had the added benefit of providing exercise.

In 2017 I received a small amount of additional funding to run a second pilot program focused solely on people living with dementia. This was completed at the Huntingdon Gardens care home in Sydney, under the supervision of dementia consultant Rose Rowlison.

This pilot was conducted with 12 people with moderate to advanced dementia. The 45-minute sessions were run weekly for seven weeks. There were many things we wanted to test in those weeks, the most basic being whether participants would keep the headphones on. Each person was observed before, during and after the classes by two to three staff members and the dementia consultant. We were looking at measures including:

- mood and behaviour before and after the class
- eye contact with the instructor
- ability to follow instructions
- engagement with other participants and staff
- verbal engagement – such as talking or singing
- other observable signs of happiness or engagement (ie clapping, smiling)
- mood and behaviour (settled or unsettled) for up to six to eight hours after the class.

We found that:

- 94% of the cohort could tolerate the headphones on for the duration of the 45-minute class, even if not all were actively participating (ie moving their hands, engaging in eye contact, smiling).
- 65% of the cohort participated in the class and were able to follow the instructions.
- 62% demonstrated positive enjoyment of the class by smiling, moving their hands and legs, participating and being relatively settled. While we couldn't see any immediate observable signs of engagement in the remaining participants, this doesn't mean the music didn't stimulate or calm them in some way. There were only a few instances where participants indicated they did not want the headphones on. In such instances we did not persist, and instead offered to place the headphones on their lap so they could still hear the music.
- 55% had continual eye contact with the instructor during the class.
- Staff observed that there was a significant reduction in responsive behaviours, such as agitation, for the remainder of the day after the morning class.

The most surprising finding came when we ran the same class without the use of headphones. Instead, the music was played audibly in the room along with the instructor's commentary. There was a 50% reduction in all of our key measures: eye contact, participation and enjoyment. This suggests that it may be the immersive nature of the headphones that makes the experience special for participants, screening out distractions and enabling them to truly listen to the music and the instructor's voice.

The benefits of the program

Since the initial trial we have run many more classes with different groups of people with dementia and have observed clear benefits from the program, namely:

- Mental stimulation via the music: participants appear happier and more engaged during class. Staff have observed that many are more active – walking, talking and singing – during or after the class. One amazing story came from our Feros Village Byron Bay class where a participant who doesn't usually walk got up and started dancing when the song *New York, New York* came on and, at the end of the class, walked back to his room. The care staff thought this was quite extraordinary, given he hadn't walked in months.

- Physical exercise: as participants are engaged for longer periods of time they are more able to listen to instructions. Many are more likely to follow exercise instructions in these sessions than normal physiotherapist-led exercise sessions without headphones or music. Using Fitbits, we have tracked exercise activity in our more active classes and found that participants are burning 200-300 calories per class.
- Mood: we have observed that participants appear more settled, happier and content after the class. We would like to have more research data on how long this change is sustained and the benefits of doing classes more than once a week.
- Connection: The amazingly counterintuitive thing about the Moove and Groove program is that even though the disco is silent and people are 'in their own world' of music, they are experiencing the same activity together and this is very powerful. Participants are still being social – they're listening to the same music at the same time, watching each other and sharing that communal experience. There is always a special moment in a class when a good song comes on and everyone looks at each other and smiles.

An unexpected benefit of the program is the joy and happiness it brings not only to participants but to their families and the staff. We now have staff and many family members coming to join in the classes. For example one couple, Ray, who has moderate dementia, and his wife Kay are regular attendees in our Narrabeen class. Kay started coming by herself and then Ray came to watch. After three classes he put on a set of headphones and joined in. The classes are now a regular part of their weekly routine and Kay loves their time together and can see the change in her husband during class. "For that one hour it is like I have my old Ray back and it is such an enjoyable thing to do together," she says.

The future

The Moove and Groove program is currently running in Sydney and the NSW North Coast with 10 weekly classes for people with dementia in five aged care facilities and four drop-in classes aimed at more active older people in the community. On any given week we are currently putting a smile on the faces of over 170 participants.

We are finding that as participants become more familiar with the program, week on week we are getting much higher participation rates compared with the initial trial, with 98% of people in most of the groups engaged with headphones on.

We have received much interest in Moove and Groove from around Australia and in June this year we will launch a train-the-trainer program for aged care facilities and individuals. This will enable us to train Moove and Groove freelance instructors as well as aged care lifestyle and recreation staff to deliver the program in care homes and the community. The training package includes headphones, music, props and online access to more than 50 specially developed dance/exercise routines. We recently received a third round of funding under the NSW Government's Liveable Communities Grants Program to further develop the train-the-trainer program.

We are committed to measuring the benefits of this type of therapy. RSL LifeCare ANZAC Village Narrabeen is a major supporter of the program and over the next six months we will be working with the organisation to further evaluate the impact of Moove and Groove on a group of participants with dementia. This will consist of direct observation of their engagement, participation, and mood during class. We will also be using the care facility's records to track participants' ongoing behaviours and mood after the class. We will attempt to benchmark changes in behaviours over time as people participate weekly in the program throughout the year.

We are also working with several university students, including one from Charles Sturt University who is completing her Masters in Gerontology and will be writing her thesis on the Moove and Groove program.

We believe Moove and Groove really is a world first. We are not aware of any similar programs elsewhere and are excited about its potential to improve the lives of people with dementia, their carers and families worldwide. ■

Accessing the program

For more details on the train-the-trainer program or how to bring Moove and Groove to your aged care home or service, email discodtours@gmail.com, call our Program Director Sally Fuller on 0412 105 468, or visit our website at http://www.discodtours.com.au/moove-groove.php

A short video of the program is available to watch at: https://www.facebook.com/60SecDocs/videos/1545095865588534/

■ Alison Harrington is the founder of discoDtours and a former lawyer and technology entrepreneur with a passion for social change

Alison Harrington and Sally Fuller

Eat Walk Engage: delirium prevention for acute care

Margaret Cahill, Karen Lee-Steere, Alison Mudge and **Prue McRae** explain how clinicians in Queensland have created an evidence-based program to help prevent delirium and facilitate the speedy recovery of older patients in hospital

Delirium is a serious and common complication of acute illness and hospitalisation (Marcantonio 2017). It is much more common in people aged 65 and older, and especially in people with dementia and other causes of cognitive impairment. It is associated with higher mortality, longer hospital stays, a higher risk of discharge to residential care facilities, increases susceptibility to complications such as falls and pressure injuries, and increases future risk of dementia (Marcantonio 2017).

An estimated 20% of older inpatients in Australian hospitals have dementia and 10-30% have delirium (Travers *et al* 2013; Iseli *et al* 2007), and caring for patients with cognitive impairment in acute care is often a difficult and complex intervention for staff on busy wards with multiple competing demands (Grealish & Chaboyer 2015). Consequently, medical and nursing staff often under-recognise delirium, particularly the hypoactive form. Importantly, there is robust evidence that multi-component non-pharmacologic interventions can prevent delirium in more than 30% of all cases, but the implementation and sustainability of these strategies is challenging in busy acute care settings (Hshieh *et al* 2015).

Multidisciplinary approach

Eat Walk Engage is an evidence-based multidisciplinary delirium prevention program developed at Royal Brisbane and Women's Hospital.

Morning tea at Royal Brisbane and Women's Hospital is an opportunity for patients to socialise, whilst also promoting oral intake and mobility.
All photos: Clinical Multimedia, Royal Brisbane and Women's Hospital

Building on previous improvement projects for older inpatients (Mudge *et al* 2008; Mudge *et al* 2012; Young *et al* 2013) and the principles of established programs such as the Hospital Elder Life Program (www.hospitalelderlifeprogram.org), Eat Walk Engage focuses on working with local ward multidisciplinary teams to implement sustainable strategies to support the nutrition and hydration, early mobilisation, and meaningful cognitive engagement of older patients – all necessary for delirium prevention in this vulnerable population (Mudge *et al* 2015). The Eat Walk Engage program recognises that, although these interventions appear simple, they involve deliberate engagement and coordination of a wide range of health professionals, support staff, patients and families within a system that is not always older-person friendly (Queensland Health 2016).

Using the i-PARIHS implementation framework with a strong focus on enabling facilitation (Harvey & Kitson 2016), Eat Walk Engage develops and supports effective collaboration among local interdisciplinary teams to improve care processes, while embedding and sustaining changes in practices and associated processes of care, involving all levels of medical, allied health professional and nursing staff.

Working within each ward context, and incorporating each unique ward culture and patient cohort, a trained facilitator from a nursing or health professional background helps identify local needs for patient care recovery and any encountered barriers. Older patients actively contribute to the assessment of barriers, enablers and program impact through structured interviews that directly inform improvement efforts (Mudge *et al* 2015a).

Factoring in the complexity and busyness of the hospital environment, this program contends with challenges such as competing tasks (eg dressings removed for review just as breakfast is served), risk averse practices (eg discouraging patients at risk of falling from mobilising) and unclear ownership of roles and responsibilities (eg who should update the orientation boards or help set patients up for meals). However, encouraging staff to keep a patient-centred perspective, enabling team discussions and debates and advocating with decision makers helps resolve such barriers. The facilitator's role is then to support the team to develop and implement these iterative improvements to positively support patients in their recovery.

Evaluation

Over the past five years, Eat Walk Engage has been incrementally implemented in 10 wards across the Royal Brisbane and Women's Hospital, including medical, surgical and oncology units, caring for high numbers of older inpatients. The program has been evaluated through pilot pre-post studies (Mudge *et al* 2015a; Mudge *et al* 2015b), through the measurement of processes and outcomes of care on intervention wards, and most recently in a large cluster randomised controlled trial in four hospitals (Mudge *et al* 2017). The study collected data on more than 1000 older patients admitted to wards at Caboolture, The Prince Charles, Royal Brisbane and Women's and Nambour Hospitals, and compared outcomes on four wards implementing Eat Walk Engage and four control wards. The 2017 trial has demonstrated improvements in care processes such as mobility and mealtime assistance in the four participating wards, and will report outcome findings later this year. Several other hospitals are adopting Eat Walk Engage principles, and we plan to develop a collaborative for spreading the program within and beyond Queensland hospitals.

Sustainability

A significant emphasis of this program is on the sustainability of locally adapted process changes initiated by multidisciplinary staff into everyday practice, despite the challenges of staff turnover and competing priorities. For example:

- Several medical and surgical wards have implemented dining tables in four-bed bays to facilitate oral intake, social engagement and mobility in their older patients with cognitive impairment. It brings a new perspective for staff to see patients who may have appeared withdrawn and quiet actively engaging in conversations with other patients while eating their meals.
- Several wards have instituted weekly group activity sessions for older patients, including those with cognitive impairment, to participate in various arts and crafts sessions, exercise groups and meaningful activities related to current events (eg making poppies for ANZAC Day; joining in Irish songs for St Patrick's day).

Environmental improvements

Following input in late 2015 from the Designing for People with Dementia (DPD) environmental design education service (dta.com.au), concerning the environmental impact of hospitalisation on older patients, several wards made dementia-friendly environmental improvements. Such changes have included:

- A destination on each ward for patients to enjoy social interactions or to read the paper or a magazine.
- Adopting signage to facilitate way-finding for amenities or places to visit.
- Larger-sized clocks and orientation posters to support orientation.
- Additionally, each ward has established a cognitive kit or cupboard in order to support patients in their ward, providing access to meaningful activities such as crosswords, fiddle blankets, puzzles and DVDs.

Family involvement

Families are also encouraged to bring personal objects from home and participate in the provision of care. To facilitate communication between family members, the patient and the interdisciplinary team, goal-setting posters outlining patient-specific strategies such as walking to the window, attending a group morning tea, or sitting out of bed for each meal have also been instituted on several wards.

A Delta dog visiting a patient on the vascular ward

Patients and their family members or visitors are encouraged to attend weekly morning teas and 'happy hours' to facilitate a concept of 'normal life' while in hospital. This enables patients to leave the ward area, optimising their mobility and oral intake while enjoying fresh air and social engagement. The patients, and their family members, enjoy this opportunity with many commenting on how this has considerably improved patient morale.

These social, mobility and cognitive activities are supported by hospital volunteers and enabled by our specially trained and dedicated Eat Walk Engage allied health assistants. These assistants are integrated into the ward-based multidisciplinary teams and are trained to assist with the implementation of Eat Walk Engage strategies, delegated by all members of the team. They provide a visible face of the program.

Education and leadership

Although many of the program activities are tailored to the individual wards, the Eat Walk Engage program facilitators also contribute to organisational leadership in the care of older people through active advocacy, policy development, research and education. They have led a series of 'Better Way to Care' multidisciplinary one-day workshops attended by more than 100 staff in 2017. The workshops are specifically designed to enhance the care of older people, particularly those with cognitive impairment.

Members of the program team have also presented in grand rounds and workshops for a wide range of health care professional audiences within and outside of Royal Brisbane and Women's Hospital. They recently coordinated a whole-of-hospital delirium and cognitive impairment audit, using the new Australian Delirium Clinical Care Standard (www.safetyandquality.gov.au) and are involved in a range of quality improvement and research projects aiming to improve care of patients at risk of, or with, delirium.

Allied health assistant, Leon, supports a patient in the oncology ward to get up and about

Conclusion

With new hospital safety and quality standards recognising the need to improve care for patients with cognitive impairment, Eat Walk Engage is a timely example of how clinicians can create an evidence-based program to support staff in the delivery of high-quality care to prevent delirium and facilitate the speedy recovery of older patients in hospital. A strong evidence base, a multidisciplinary leadership team, engaged champions working effectively in teams, and listening to our older consumers have been critical factors for its success.

Acknowledgment

Thank you to the staff and patients of Royal Brisbane and Women's Hospital who continue to contribute, support and advocate strongly for improving care of older patients at our facility. ■

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A patient at the hospital enjoys some quiet time. Each ward has a place which feels 'a bit like home', where patients and their families can go to relax away from the bedside

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L-R: Margaret Cahill, Karen Lee-Steere, Alison Mudge and Prue McRae

Kinecting through group digital games

Digital technologies offer lots of opportunities for people with dementia to enjoy games and engaging activities. **Erica Dove** and **Arlene Astell** describe their research project and the findings so far

Participating in enjoyable activities is important for wellbeing (Pressman *et al* 2009). Generally speaking, people with dementia have fewer opportunities for such activities than those without, which can have a negative effect on their wellbeing (Chung 2004). Digital technologies can be a solution, offering lots of opportunities to play games and take part in other engaging activities. Furthermore, they can be used by people with dementia (Astell 2013).

Nintendo Wii and Xbox Kinect are mainstream technologies that are currently being used in dementia research and care (Dove & Astell 2017). This type of technology is called 'motion-based' since the player makes movements to produce actions on the screen. The movements are natural and familiar, such as raising an arm, so the technology is accessible to a wide population including people with dementia.

We are carrying out a study using the Xbox Kinect for people with dementia, which involves observing and running group digital activities in community-based adult day programs.

Displaying the bowling stance

Project background

To start we reviewed articles that had been published about people with dementia and motion-based technology (Dove & Astell 2017). While this confirmed that people with dementia can learn to use motion-based technology, we found that most studies did not mention how the technology was introduced to them or how they were taught and supported to use it. The technology delivered cognitive, physical and leisure activities, although we found that most studies used it mainly for cognitive and physical activities rather than leisure. Drop-out rates were low and participants enjoyed the experience, suggesting that people with dementia find motion-based technology to be a source of entertaining activities.

The Kinect Project has three research questions:

- How can people with dementia best be introduced, taught and supported to use motion-based technologies?
- What are the effects of

repeated practice on learning of skills during play?

- How does using Xbox Kinect in a group setting affect the activity?

Phase 1: Observing

As a first step to answering our research questions, we went to an adult day program to find out how people with dementia can be taught and supported to use motion-based technologies. This particular community-based program was chosen as it already owned an Xbox Kinect and members of the day centre regularly played on it. We observed staff teaching the 23 members (16 of whom had dementia) to play Xbox Kinect bowling one hour per week for 20 weeks. Field notes taken during observations were analysed to identify key themes in the training and playing (Astell *et al* 2016).

The findings revealed three main themes, namely the importance of a trained trainer, learning and mastery, and playing 'independently together'. First, the trainer.

People with dementia can learn to play Xbox Kinect bowling and enjoy doing so, but trainers must know how to introduce, teach and support them. The trainers ran the group digital activities using repeated instructions, spoken reminders, gesture modelling, and task breakdown to achieve these goals. They also offered physical support to people with mobility impairments, eg supporting them from behind, and gave praise and encouragement to everyone.

Second, as participants became more familiar with the technology and the game, they built on their learned skills to reach a level of mastery. This became apparent as players needed fewer instructions and reminders, learned to change aim and position to hit more pins, and began to teach others.

Celebrating after bowling

Finally, using the Xbox Kinect in a group setting increased the leisure effect of the activity. For example, participants supported each other by clapping, cheering and offering positive encouragement. While the goal of the activity was always focused on fun rather than winning or losing, participants began to engage in playful teasing and friendly competition. This created a positive group environment which encouraged unity and socialisation among day centre members.

Phase 2: Teaching

The second phase of the project aims to apply and build on the knowledge gained from the first phase. We have been running group Xbox Kinect bowling sessions in several community-based adult day programs for people with dementia, but this time we are taking the role of the teacher rather than the observer.

Group sessions lasting one hour are held with participants twice a week for 12 weeks using the teaching methods discovered in phase one, applying the lessons from the three themes.

We are using two video cameras which are placed at the front and back of the room. Video-recording was chosen as the optimal method of data collection as it allows us to capture all aspects of the group activity, including conversations between participants or between participants and the trainer, evidence of learning, body movements, facial expressions, and in-game/on-screen activity.

Preliminary findings from phase two support the themes identified in phase one. Teaching methods picked up from phase one (eg gesture modelling, verbal reminders, task breakdown) are being employed successfully in phase two to teach people with dementia to use motion-based technology, even if they have no prior experience with this type of technology. And it remains important that the trainer is properly trained for the task.

As seen in phase one, participants can build on learned skills to reach a level of mastery as is evident from a reduced need for instructions, improved performance (eg bowling more strikes), and teaching others. Participants also learn to self-correct movement errors, change the aim of the ball to hit more pins, and develop a bowling stance.

Once again, we have also found evidence that people play 'independently together'. While each person takes their turn, other members of the group clap, laugh and cheer, and make encouraging comments such as "way to go!" and "you can do it!". This creates an inclusive and supportive environment that promotes socialisation between day program members, staff and trainers.

Our findings so far provide supporting evidence for the abilities of people with dementia in using motion-based technology, the benefits to be derived from it, and the practicality of employing group motion-based activities in these kinds of community adult day programs.

Future directions

Our project adds to the body of knowledge about the use of technology to challenge negative opinions and low expectations of people with dementia (Astell *et al* 2017). Motion-based technology in a group setting enables people with dementia to learn new skills and engage in meaningful activities while socialising with others. It can be both practical and enjoyable.

To translate our research into practice, we have been training day centre staff to introduce day program members to Xbox Kinect, and to teach and support them to use it, and are creating a 'how-to' manual which explains both the technical aspects (eg how to install the technology) and the practical aspects (eg how to introduce the activity). These resources will support the adoption and use of these technologies in adult day programs once the research has ended.

We believe that this has the potential to improve the lives of people with dementia by providing accessible, meaningful group activities to increase their wellbeing. ■

■ Erica Dove is research assistant, Research and Academics, and Arlene J Astell is Ontario Shores Research Chair in Dementia, both at the Ontario Shores Centre for Mental Health Sciences in Canada.

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Australia launches world's largest music therapy trial

University of Melbourne researcher **Felicity Baker** reports on the world's largest music therapy trial for people with dementia. She explains why the project could be a game changer for music therapy, dementia care, and residential care

In April this year, supported by a $1 million National Health and Medical Research Council (NHMRC) research grant, The University of Melbourne launched the first large-scale cluster randomised control trial that studies the effectiveness of music therapy on people living with dementia in residential care.

Over three years, our University of Melbourne research team, in collaboration with international partners, will undertake the world's largest music therapy trial for people living with dementia, studying its impact on 500 participants across 40 residential aged care facilities in Australia. Our team secured the NHMRC grant based on pilot data and a long history of music therapy practice in the aged care sector in Australia. While music therapy has been practiced in aged care here for a very long time, there hasn't been this kind of large-scale, systematic study of its use in dementia care anywhere in the world.

Acknowledging the future challenges that lie ahead for an ageing Australia, the Government established the Boosting Dementia Grant Scheme through the NHMRC to fund research that targets depression and wellbeing in the lives of people with dementia and those caring for them. Primary aims of the scheme include the development and testing of cost-effective interventions targeting:

- Reductions in incidences of high levels of depression and suicide.
- Non-pharmacological management of neuropsychiatric symptoms and behaviours.
- Quality of life, social isolation, and participation in meaningful experiences.
- Residential care staff stress.

To address these aims, our research seeks to test existing practices of group music therapy and choral singing on the aforementioned target areas in a systematic way and thus gather evidence of effectiveness and inform health care planning and policy for an ageing Australian population.

The study, Music Interventions for Depression and Dementia in the Elderly (MIDDEL), will compare the impact of group music therapy, recreational choir singing, a combination of both and standard care on symptoms of depression and other wellbeing outcomes in people with dementia.

Further, we aim to examine whether dosage has an effect on depression and other outcomes, (two sessions per week versus one session per week), and whether the effects differ according to baseline levels of depression and dementia.

We will build a health economic analysis into our study, the first of its kind in music therapy, that focuses on dementia care. The analysis will enable us to determine the cost-benefit of both types of interventions on outcomes for people living with dementia in residential settings which we anticipate will inform future policy, funding, and dementia care practice.

University of Melbourne researchers, including the author (third right), during a group music therapy session for people with dementia. Photo: Giulia Giannini McGauran

As we hypothesise that group music therapy will reduce neuropsychiatric symptoms (eg agitation) that are distressing for both the person with dementia and care staff, we will also embed an analysis of staff wellbeing, collecting data such as number of days absent from work due to illness and measure their sense of burden in the workplace. This data will also be included in the cost-benefit analysis.

Group music therapy

The core principle of group music therapy (GMT) is affect regulation through active, reciprocal music making with the use of singing and musical instruments. This music making facilitates the relationship between the music therapist and the person living with dementia, and between participants in the group. The approach takes into account the level of dementia severity and symptoms that can vary from person to person and from session to session. The core intention of GMT is to meet the psychosocial needs of each person living with dementia, which in turn is thought to reduce depressive symptoms and anxiety and to stimulate overall social and emotional wellbeing.

GMT also aims to work in the 'here and now' by responding to participants' immediate emotional expressions, acknowledging them, and validating their emotions by transforming them into meaningful musical expressions for therapeutic gain. It features concepts of personhood (recognition, trust, respect). Its conceptual framework is grounded in McDermott and colleagues' (2014) psychosocial model of music in dementia.

In summary, the core aims of GMT are:

- To meet the psychosocial needs of people with dementia.
- To empower the person with dementia with resources that promote affect regulation and attunement.
- To foster empathic

A group music therapy session for people with dementia.
Photo: Giulia Giannini McGauran

relationships.

- To foster and improve verbal, non-verbal, and musical communications between the person with dementia and other group members.
- To reduce behavioural and psychological symptoms (agitation, apathy, depression etc) through regulation of emotions.
- Foster relationship-building through musical interactions.
- Target mental stimulation, mood enhancement, reciprocal interaction, and human connection.
- Support responses in the here and now.
- Flexibility to support participation.
- Support identity/history of the person.

Returning to the aforementioned aims of the NHMRC Boosting Dementia Grant Scheme, our project aims to be a game changer for music therapy, dementia care, and residential care. We hypothesise that engagement in group musical experiences will lead to reductions in levels of depression with a flow-on effect to a more positive quality of life, reduced social isolation, and less severe neuropsychiatric symptoms. A focus on residential care staff stress will also serve to generate knowledge about how music interventions can enhance the residential care home environments.

More information on the MIDDEL trial is available at: https://bit.ly/2rvHpQU. ■

Acknowledgments

The project team comprises: Professor Felicity Baker, The University of Melbourne; Professor Christian Gold, UniResearch, Bergen, Norway; Professor Hannah Mette Ridder, Aalborg University, Denmark; Dr Jeanette Tamplin, The University of Melbourne; Dr Imogen Clark, The University of Melbourne; Dr Claire Lee, The University of Melbourne. Industry partners are Bupa Aged Care, Regis Aged Care, BlueCross, and Royal Freemasons Homes.

■ Professor Felicity Baker is Head of Music Therapy, Co-Director of the National Music Therapy Research Unit and Co-Director of the Creative Arts Therapies Research Unit at The University of Melbourne. She is former Australia Research Council Future Fellow (2011-2015) in the area of music therapy. Contact her at: felicity.baker@unimelb.edu.au

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Music, Mind and Wellbeing

The University of Melbourne-based Music, Mind and Wellbeing (MMW) initiative links neuroscience with music and social wellbeing. In addition to the MIDDEL trial, the MMW Research Group has additional studies under way as part of its commitment to developing novel music therapy-informed interventions that aim to change the lives of people living with neurological disorders including dementia. They include:

Remini-Sing, an NHMRC-ARC funded research project led by Dr Jeanette Tamplin, is investigating the effect of weekly therapeutic singing groups on relationship quality and wellbeing between people living with dementia in the community and their family caregivers. Pilot feasibility research found that participants perceived intrapersonal, social, and cognitive benefits while sustaining healthy ratings for relationship quality, quality of life, depression and anxiety.

The next phase of this research, a randomised controlled trial, will compare outcomes for participants who attend 20 weekly Remini-Sing group intervention sessions with wait-listed control participants. Participants are now being recruited from metropolitan Melbourne, Bendigo and Hobart, and it will be possible for all participants to continue to attend these groups, if they wish, following the study period.

To register interest contact Carol Fountain at Uniting AgeWell on (03) 9251 5997 or CFountain@unitingagewell.org

The Group Songwriting study is funded by the Dementia Australia Hazel Hawke Dementia Fellowship 2018, awarded to Dr Imogen Clark. Designed for community-dwelling people living with dementia and their family caregivers this single-blinded random controlled trial is exploring the potential of group songwriting to improve participants' health, wellbeing and quality of life.

The 60 participants recruited to the study will be allocated to either an experimental condition with six weekly group songwriting sessions or usual care control group with the option of group songwriting following completion of the study if desired.

Based on pilot data, the research team anticipates that the intervention will support sustained healthy relationship quality for couples/dyads, improve social connectedness and quality of life, and reduce ratings of depression for both people living with dementia and their family caregivers. Songs written during the project will also be performed and recorded to increase public awareness and understanding about living with dementia.

Music and mood study

Mood Regulation Using Music: A Community Health Strategy for Improving Quality of Life in People with Mild Dementia is an NHMRC-ARC funded research project led by Dr Sandra Garrido from Western Sydney University. The project aims to improve quality of life by promoting effective self-management of mood via music. People with dementia and their carers or support person, whether living at home or in a care facility, are invited to participate. Participants will be provided with a set of guidelines for music selection, equipment for playing music and an iTunes gift card. The study will look at how useful the guidelines are to people caring for someone with dementia in using music to target particular symptoms such as depression, apathy or agitation.

In another study Dr Garrido and her colleagues in occupational therapy are looking at the power of music to help people with mild to moderate dementia who are experiencing difficulty in performing everyday tasks at home.

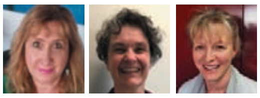
To inquire about participating in either of these studies, email Dr Garrido at s.garrido@westernsydney.edu.au or phone 0403 870 050.

From left: Dr Sandra Garrido, Dr Imogen Clarke and Dr Jeanette Tamplin

Something for everyone

A big smile in the pool at the Water Memories group

In New Zealand's South Island, Dementia Canterbury has trialled an alternative respite service model that provides a broad range of community-based activity groups to help people living with dementia enjoy meaningful activities in normal social settings, while also helping to support care partners. **Darral Campbell, Susan Gee,** and **Beverly Seabridge** explain



Left to right: Darral Campbell, Susan Gee, and Beverly Seabridge

For people with or without dementia, meaningful activities and meaningful relationships are at the heart of a positive and enjoyable life. While these universal needs do not change when living with dementia, the amount of support needed does, both at an individual and societal level. Alison Phinney and colleagues talked with people with dementia (Phinney *et al* 2007) and found that activities can be meaningful when they: provide pleasure and enjoyment; help maintain a sense of autonomy and personal identity and foster a sense of connection and belonging.

Dementia Canterbury, a registered charity affiliated with Dementia New Zealand, aims to support people to lead fulfilling lives after a dementia diagnosis and work towards a dementia-friendly and responsive community where people living with dementia feel safe and confident to participate in activities.

Between 2015 and 2017 Dementia Canterbury (DC) piloted and evaluated a community-based program of eight activity groups in collaboration with local community services to help people living with dementia continue to engage in meaningful activities in normal social settings. The groups were developed in response to the interests of local people diagnosed with dementia.

The program, which is still running, also aimed to improve the quality of life for the care partners and reduce the stress associated with their caring role. The activity program provides another respite option for carers whilst encouraging social involvement and connections.

An alternative model

The vision was not to replicate or compete with existing short-term respite (day care) services but to provide an alternative model, with a program that offers a broad range of activities in existing community environments, delivered in partnership with other community providers.

A DC coordinator works with staff and / or volunteers from DC and partner organisations to run the program. Around 30 trained DC volunteers are involved in the groups in a given month.

When the pilot was launched, DC already had three community groups in place: art gallery-based art appreciation (Artzeimers), library-based literary discussion (Next Chapter), and gardening (Christchurch Botanic Gardens group). A further five community groups were gradually introduced during the pilot and a formal review was held at the end of the trial to guide future planning. More than 50 people living with dementia took part in groups during the pilot period. Another five community-based activity groups have been introduced since the pilot ended. At the time of writing, over 70 people are taking part in the program, each participating in from one to seven different groups.

How the groups work

- DC staff have an initial discussion with the person with dementia and their support people to identify a portfolio of appealing activities.
- The groups are held at community venues.
- Groups are coordinated by a DC staff member, often alongside facilitators from community organisations. DC provides training for the staff and DC volunteers, supported by mentoring in the community group environment.
- The groups are limited in size, usually up to eight people.
- The focus is on a stimulating, enjoyable, meaningful activity and maximising opportunities to share opinions and reminiscences.
- Involvement in the group is open-ended, except for the six-week Life Stories group.
- The groups maintain a regular structure or rhythm to foster familiarity, usually including a social time with a 'cuppa' at the end.
- The majority of care partners use the groups as an opportunity for respite, but they can accompany the person living with dementia to the groups if they wish.

Feedback

Feedback was gathered from participants through structured observations of two activity groups (using the

McBakers Group members busy baking treats for children requiring hospital treatment and their families

A member of a Life Stories group with a precious photo

Outcomes-based Observation Tool (Kinney & Rentz 2005) and the Menorah Park Engagement Scale (Camp 2010), 'vox pop' interviews with participants at activities, a focus group with participants, surveys with volunteers, reflections from collaborative partners and DC staff, questionnaires for care partners and needs assessment questionnaires on entry and after six months.

The pilot group activities

Artzheimers

The Artzheimers' group meets fortnightly for an hour at the Christchurch Public Art Gallery. A volunteer guide talks about a specific artwork before encouraging discussion and reminiscence. One of the group's strengths is in encouraging people to express themselves.

Gardening

Two different gardening groups meet monthly: the original gardening group in partnership with the Christchurch Botanic Gardens and a second group initiated during the pilot period at the Opawa Community Gardens. Gardening activities are seasonal and involve a range of activities such as planting, watering, deadheading roses, raking leaves and general care. There is a sense of satisfaction at the visible difference achieved together. Several men and people with younger onset dementia attend the group as the physicality and job-like nature seems to appeal.

Next Chapter library groups

Librarians set a theme for the fortnightly group, such as 'communication', 'war time', 'seasons', or 'transport'. They provide literary readings, a range of audio, visual, and tactile resources and well-chosen questions to spark discussion and reminiscence.

Water Memories

Water Memories swimming clubs were developed in Australia and combine the benefits of a fun social activity that evokes happy memories with the positive benefits of physical exercise for people living with dementia (Neville *et al* 2013).

Collaborating with two aqua centres, each Water Memories group is offered monthly and includes options of water-based exercises with an instructor, lane swimming, and general fun.

McBakers

The McBakers group meets at Ronald McDonald House to cook and prepare baked goods for sick children and their families staying at the facility. One helper to every two to three clients ensures that people with all levels of baking ability can be accommodated within the group. During the pilot, participants spoke of the value of baking for the children and how much they enjoyed interacting with them. Some clients have regained confidence in their cooking ability and repeat the recipes at home.

Life Story group

Life Story work involves the person with dementia being supported to gather and document their personal life story to celebrate their life and reinforce and communicate their identity (Kindell *et al* 2014; Gridley 2016).

Life Story groups run for six weeks and meet at a local library, with each participant pairing up with a support person to help gather the stories. Group discussions at the beginning of each session introduce the life stage being covered, while those at the end encourage the sharing of stories. Stories and photos are added to a computer document in each session. At the end of the six weeks each participant is presented with a booklet illustrating their life story.

During the pilot, volunteers and family members also reported finding the process very rewarding: "*this is one of the most important things I've done with my mum…It's fabulous*".

Court Theatre group

The targeted theatre and storytelling group draws on the benefits of artistic stimulation, life story work, and intergenerational connections. The group attends theatre performances with support.

Participants also meet with the youth actors group and tell stories from their lives. The young actors, coached by Court Theatre staff, then re-enact these stories with the aid of imagery and music overlays. This proved to be a rich opportunity for intergenerational sharing: "*I felt proud to see them tell some of my stories, and for one of them to say 'wish you were one of my history teachers',*" explained one participant.

Impact on participants

Enjoyment and mood

During the pilot evaluation the participants talked about the enjoyment and laughter of the groups and loving the experience. Short structured observations found that the participants in every observation were actively engaged and showed 'in the moment' pleasure. In the feedback questionnaire 97% of carers thought the participant enjoyed the group, and 100% of the care partners said they noticed a difference in the participant and that the groups were good for the person with dementia.

Some care partners noted that the participants seemed "*more animated for a short time once home again*", while others felt that the groups helped with improved general mood.

Continuity

The groups helped participants to maintain familiar activities and interests and reconnect with the life they have lived: "*I felt connected to my time as a teenager going on to the stage*", said one. Participants talked about being able to do things they were "*already interested in*" and things they "*used to like and do*".

The participants talked about feeling "*comfortable*", and "*normal*" through doing "*normal things*" and to be able to "*talk to people in the same boat*".

Getting out

The activity groups offered the participants a way to expand their world and be out in the wider community. This expanded world was reflected in having something to talk about to care partners and the feeling of having "*something to look forward to*" (participant).

Social connection

The participants talked about "*meeting people*", of "*strangers becoming friends*", and "*not [feeling] isolated*".

Confidence

The activity groups also provided a boost to participants' self-esteem and confidence: "*I used to bake a lot. This is the only time I get to do it now. If I had a recipe I could do it at home now*" (participant). "*It's a place where he cannot fail*" (care partner).

Other benefits

Care partners valued the opportunity for exercise and keeping physically active that some of the groups provided participants. Two of the care partners said that they felt the activity groups helped the person living with dementia to stay in their own home for longer than they otherwise would have.

Impact for care partners

In the initial needs assessment over 80% of care partners reported feeling there was not enough time for themselves and that they felt stressed trying to meet other responsibilities. After six months' involvement 73% reported that the activity groups had reduced their stress. Care partners often appreciated the time during which the person living with dementia independently attended the group as "*a break*", when they could "*do their own thing"* and "*get things done*" while the person living with dementia was "in safe hands". For care partners who joined in activities, the groups offered quality time together and a chance to enjoy "normal" things alongside people who understood.

Impact for community partners

The volunteers felt that being involved in the groups deepened their understanding of living with dementia and helped develop empathy. They were strongly positive about the benefits of the groups for participants, which made it a rewarding experience to be involved in.

For community partner organisations, the collaboration with DC provided opportunities to enhance accessibility and for staff to expand their skills and empathy and "*heightened staff awareness and understanding of dementia considerably*".

In some instances the partner organisation's successful experiences of working with the client group have led them to find new ways to open up their environment and expand offerings for people living with dementia. For example, the art gallery is now also providing opportunities for people with dementia to make art; the city librarians not only encourage reminiscence in the Next Chapter groups but also facilitate the creation of more in-depth Life Story books. A new guided walk at the Botanic Gardens was suggested by the guide after the success of the gardening group.

Fun at the community garden

Moving beyond the pilot

Growth

Our evaluation found that the pilot activity program was enthusiastically received and was consistently seen as beneficial. These groups have become an invaluable component of DC's mission to support people living with dementia to lead fulfilling lives and break down barriers to enable them to participate in and enjoy activities in the community.

Our emphasis on partnership with the community to deliver normalised activities is going from strength to strength and we are seeing these organisations embracing the concept of 'dementia friendly'.

The range of activity groups and locations continues to expand, with the addition of:

- a guided walking group at the Christchurch Botanic Gardens
- a walking group that meets at a historic homestead and gardens owned by the city council
- a 'DIY' group in partnership with Bunnings and a local Menz Shed.
- another garden group, which is developing a community edible garden
- a 'creative making' group at the Christchurch Public Art Gallery.

Sustainability

We are now seeking long-term funding to further develop the program, offer more activities, more often, and ensure its sustainability.

An ongoing challenge is encouraging funders to broaden their understanding of what beneficial short-term respite care might look like, and to recognise the value of encouraging social engagement as a goal. It is also crucial to ensure that program expansion does not dilute the experience for participants. For example, the Life Stories group is not just about providing a template for a Life Story booklet. What is pivotal for participants is the relationship building and the joy of being empowered to share and celebrate their story with others.

Increasing access to transport

Providing transport (and reminder calls) is essential to ensure access for those clients who live alone or whose care partners are working or unable to drive. It also gives other care partners the option of having more respite time instead of driving. Beyond the contribution of our current volunteer drivers, and a van for transport, further funding will increase our ability to offer transport.

More groups more often

Participants and care partners expressed their enthusiasm for more groups, more often. Along with increasing the range of groups offered, we are aiming to offer new activities on a fortnightly basis. The group coordinators reported advantages for groups that met weekly or fortnightly, rather than monthly, in establishing routine, connections and familiarity.

Listening

If we can't accommodate clients' suggestions for a new activity we try to find other ways to support the interest within the group settings. We also listen to our clients' feedback about their experiences with the groups and make changes if required.

Conclusion

We are proud to share our positive experience of offering an activity program that concentrates on providing meaningful community-based activities for people living with dementia in normal social settings. The voices of people living with dementia, care partners and helpers speak powerfully of the impact of this activity program in making a positive difference to the lives of those involved. The program supports and is supported by a wider vision where receiving a diagnosis of dementia is seen not as the end of the road, but the start of a new part of the journey. ■

■ Darral Campbell is the Manager of Dementia Canterbury; Susan Gee is the lead researcher of the Canterbury District Health Board's Psychiatry of Old Age Academic Unit; Beverley Seabridge is Dementia Canterbury's Activities Coordinator. To follow up on this article contact Susan Gee at Susan.Gee@cdhb.health.nz

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LAUGH: co-design for people living with advanced dementia

Researchers in Australia and the UK have been working with people living with advanced dementia to develop a collection of sensory objects to engage, comfort and bring pleasure and fun to their lives. **Gail Kenning** tells the story behind the designs

While dementia impacts physical and cognitive functioning, emotional memory is retained and people living with dementia, even in the advanced stages, are still able feel joy, have fun, and laugh.

This article reports on a collaborative UK-Australian design research project, funded by the Arts and Humanities Research Council (AHRC grant AH/M005607/1) in the UK, to encourage people living with advanced dementia to engage playfully, have fun, and to promote social connection. The *LAUGH: Ludic Artefacts Using Gesture and Haptics* co-design project was led by Professor Cathy Treadaway of Cardiff Metropolitan University in Wales, in collaboration with Dr Jac Fennell, Aidan Tayler, Dr Amie Prior and Professor Andy Walters (Cardiff Metropolitan University), myself (Dr Gail Kenning, University of Technology Sydney, Australia), and Dr David Prytherch (Coventry University, England). The aim of the project was to research and design hand-held 'ludic artefacts' (playful objects), to encourage spontaneous fun and 'playful playing' – that is play that is not goal or outcome driven, but just feels good to do.

Objects, toolkit

The analysis and findings from a series of workshops held during the project, together with information from a review of existing projects and the input of people living with dementia, led to the development of a series of objects made for six people living with advanced dementia, and a toolkit to support designers. The toolkit, *Compassionate design: how to design for advanced dementia*, is freely available from the LAUGH website: www.laughproject.info/home-2/toolkit-for-designers/. In addition, a small number of hard copies are also available on request.

Play and wellbeing

In response to our ageing population, resources are increasingly being channelled into exploring how to support people to not only have a long life, but also a good quality of life. However, this is an area that's not supported well in relation to people living with advanced stages of dementia. Karn Nelson, Executive General Manager of Strategy at The Whiddon Group in Australia, recently commented "there are many projects for people at early and mid stages of dementia, but so little for people with advanced dementia".

'Hug' is a soft cushion-like object made for Thelma during the LAUGH project. When she was first given 'hug', Thelma remained in a state of quiet contentment, relaxed, but not smiling or engaging with others

Research is increasingly showing that quality of life can be improved for people living with dementia when they have opportunities for social engagement and to engage in meaningful activities. Activities that engage multiple senses are particularly effective for connecting with people living with advanced dementia and fun activities that include 'playful playing' can contribute to positive wellbeing. However, play is often associated with children and discouraged in adults, and may be viewed as infantilising of older people and people living with dementia. The LAUGH project shows that playful objects can be designed that promote dignity and respect, through personalisation, by offering sensory experiences, and by encouraging connection.

What is considered meaningful, fun or enjoyable is highly personal and varies from individual to individual. This is no less so for people living with advanced dementia. But understanding what they find meaningful, enjoyable and fun is complex because they may be non-verbal and unable to communicate needs, wants and desires. Asking family members for information may be unreliable as what a parent or spouse liked to do before having dementia may be no longer applicable or appropriate. Care staff may know the person through a care context and not necessarily have a holistic view of them or their life.

Another challenge in working with a personalised approach to design for playfulness is that people living with advanced dementia in care homes are part of a larger community that includes staff, family members and other residents. This can impact on what is made, why, and the response to the designs. For example, research shows that objects and activities that might be fun, comforting, occupy and entertain a person living with dementia may be perceived as infantilising by care staff, family members, or other residents. It is important to understand that what may be perceived as fun, playful or 'being silly' to one person (clowning, pulling faces, dressing up, or making up stories) may be considered childish or embarrassing to others. Similarly, while it may be accepted that an adult may take comfort in holding objects (ie clothing, jewellery) that belong(ed) to loved ones, taking comfort in dolls, blankets, or soft toys may be frowned upon. So, this raises questions with regards to how we can design to support personhood and enable individuals to experience a wide range of emotions, and be playful, and have fun, without undermining their dignity.

After having 'hug' for three months there was noticeable change in Thelma's condition

Multisensory engagement

The LAUGH project drew on research that shows the importance of multisensory engagement for people living with advanced dementia, particularly for those who may no longer be mobile or able to communicate through speech. At this stage people interact with the world through touch, and may be more responsive to objects and activities that are also accompanied by sound, highly contrasting colours or lights, and smell. Sensory materials can also generate playfulness, humour and pleasure and can relieve stress and tension.

Research showed that projects that explored fun and playfulness were, for the most part, performative; they used poetry, music, storytelling and aspects of theatre and dance (Hafford-Letchfield 2012, Killick 2013; Low *et al* 2013). These types of projects needed to be significantly adapted for people living with advanced dementia. While a number of projects focused on sensory experiences using sensory materials and creating sensory rooms, few explored the impact of self-contained hand-held objects that could be used with minimal supervision.

Personalised design

Researchers on the LAUGH project engaged with over 170 experts in ageing and dementia in 70 organisations, including psychologists, dementia care management and staff working directly with people with advanced dementia, occupational therapists, and activities specialists, alongside designers and technologists.

The project was partnered by Pobl Gwalia Care, one of the largest providers of residential social care in South Wales. An advisory team included experts such as John Killick (Killick 2013) and Dr Jane Mullins, author of *Finding the Light in Dementia* (Mullins & Fawcett 2017). The project also brought together experts from ageing and dementia organisations such as Age Cymru and Alzheimer's Society.

Participants attended a series of co-design workshops to contribute to the research and development of a series of objects made for six residents of two care homes. Workshop participants were given 'personas' of each resident and asked to think about how they would design highly personalised objects and activities to promote positive wellbeing. The personas were developed from information provided by the care facility, family members and care staff, including the person's age, cultural background, previous occupations and likes and dislikes around music, activities or hobbies.

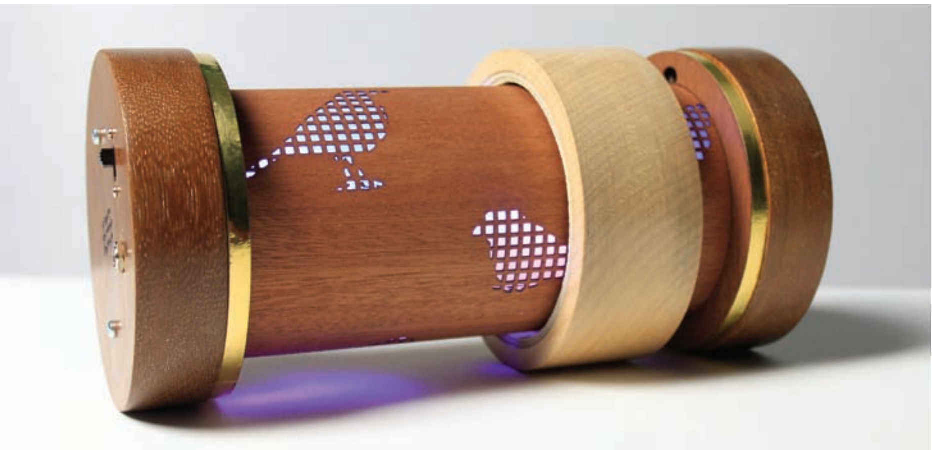
This hand-held steering wheel was designed for a man who had worked for a vehicle breakdown service and loved driving

Six workshops were held over one year. In each, participants were given tasks that required them to think about fun and laughter and to reflect on their own responses to various stimuli. They were also asked to draw on their knowledge and experience of engaging with people with dementia in their professional or caregiver capacity, and to explore what materials, situations and activities might be considered fun. One workshop focused on hand use, exploring bread making and playfulness such as clapping games. Another focused on procedural memory and craft activities, looking at how we use tools. A design prototype brainstorming session asked participants to create a playful object for a person living with dementia from a range of craft materials. They 'played' with materials, made playful objects, played games and then were asked to report back on their own feelings and responses.

Data was collected during each of the workshops; they included the objects, comments and notes made by participants and researchers, and audio and video recordings.

People with an early diagnosis of dementia and people living with advanced dementia were consulted as experts and advisors and provided feedback on the prototypes produced. People with advanced dementia contributed through verbal and non-verbal responses to materials, prototypes and objects in various stages of production. People living with an earlier diagnosis took part in interviews and provided insights into their journey of living with dementia.

The involvement of people with dementia, as with all participants, needed to be handled with great sensitivity. People living with advanced dementia had specific access requirements for mobility, communication and engagement and needed to participate in smaller groups and in quieter venues. It was also recognised that people living with the earlier stages of the disease might find it stressful to think about what happens in the more advanced stages. Therefore, because of the content of the workshops, the number of people involved, and the



LUMA is an interactive hand-held crafted wooden object designed to stimulate interest through changing light, colour and sound

venue, it was decided that to enable all participants to contribute from a position of strength it was not possible for all experts to attend the same workshops.

Compassionate design

From the outset the LAUGH project focused on positivity and potential rather than viewing ageing and dementia through a lens of deficit. We developed a compassionate design approach (www.compassionatedesign.com) which focuses on the importance of designing with compassion to stimulate the senses, facilitating personalised experiences and encouraging connections between people. Within this overall framework six key themes were identified from the data collected during the first three workshops:

- Nurturing: the need for people to reflect on caring tendencies through objects.
- Security: the importance of feeling safe.
- Attention: how objects and activities can be used to redirect focus and change mood.
- Purposeful: the need to feel that an activity is meaningful.
- Replay: the importance of familiarity and how objects can draw on existing knowledge and skills and re-present them in a new form.
- Movement: to both stimulate and calm.

In the final stages of the LAUGH project a core team of design researchers worked with all findings from the workshops to explore what types of objects could be made in response to these themes and produced a series of highly personalised objects for the six residents. The prototypes were examined and critiqued by the advisory group and care staff and management of the two care homes with regard to safety, security, robustness and infection control. After the 'all clear' the objects were tested and evaluated with the six people for whom they had been designed. Researchers evaluated the response to the objects, how they were introduced, the types of engagement, interaction and social connection they encouraged, and for frequent or intense responses.

The objects

The objects produced included:

- A telephone that plays music and the sound of people speaking Spanish, for a woman who had lived in Wales most of her life, but had grown up in Spain and liked hearing the Spanish language.
- A set of giggle balls – soft palm-sized felt balls, with a smiling face and embedded electronics that, when tilted, make the sounds of children laughing.
- A hand-held steering wheel for a man who had worked for a vehicle breakdown service, who loved driving. The steering wheel has inbuilt electronics so the 'radio' plays his favourite music and the indicators can be switched on or off.
- LUMA, an interactive crafted wooden object, based on a garden bird feeder. When activated, images of garden birds are illuminated. An outer wooden ring slides along the tube to change the colour of the lights and activate the sounds of bird song. It was made to stimulate a man who had become withdrawn, apathetic and bored.
- Fidget jewellery – simple, personalised jewellery designed to rest in the palm of the hand and provide something to fiddle with and touch.
- A soft cat with embedded electronics that makes purring noises, for a woman who had had a white cat.
- A 'hug'– a soft cushion-like object with long arms and legs that can be wrapped around the body, with embedded electronics that plays personalised music and has an electronic heartbeat. This was made for a woman called Thelma.

Thelma and her 'hug'

Thelma's 'hug' built on the theme of nurturing identified during the workshops, and was made in response to care staff who explained that Thelma was moving into end-of-life care and what she needed most was a hug. Thelma's response to 'hug' was immediate. She was brought into a bright, airy day room in a wheelchair, where members of the research team and care staff were sitting. Thelma's eyes were closed, although she was not asleep. The care staff commented that it was not a good time of day for her

This telephone plays music and the sound of Spanish-speaking voices. It was designed for a woman who had grown up in Spain and loved hearing the Spanish language

When tilted these soft palm-sized felt 'giggle balls' make the sounds of children laughing

and that they thought she might be in pain.

They said "look, Thelma, these people are here to see you". She responded with an inaudible comment, keeping her eyes closed, not showing any sign of interest or concern. 'Hug' was placed on Thelma's lap and the arms and legs wrapped gently around her. Researchers observed as one of the care staff placed Thelma's hand on the back of 'hug' so that she could feel the heartbeat. There was the beginning of a smile, as she seemed to 'settle in' with her head cwtching* the hug. Thelma sighed audibly and began to gently stroke the back of 'hug'. Her hands were closed tightly and she had little dexterity. Care staff asked questions of Thelma as she sat with 'hug'. "Thelma, do you like that?" She replied each time with one or two words, softly whispered, "hmmmmm" or "yes". Thelma's eyes remained closed and her hands retained the tight closed position as they had when she entered the room, but she voluntarily moved her hands as she held on to 'hug'. Thelma remained in a state of quiet contentment, relaxed, but not smiling or engaging with others (see photo p22).

'Hug' was left with Thelma to interact with and after three weeks care staff were interviewed and asked to comment on Thelma's engagement with 'hug'. One carer reflected that when she first met Thelma "she was just a bundle of laughs", but her health had deteriorated and "she [now] spent a lot of time doing nothing". She then suggested that 'hug' had brought back glimpses of the Thelma they had known. The care facility manager commented: "'hug' has been life changing…I don't think anyone would believe the transformation". When researchers then saw Thelma she was holding 'hug' on her lap with the arms wrapped around her. It was noticeable that Thelma's eyes were open, she appeared clearly more engaged with the world and the people around her, and her hands were no longer held in a tight closed position; they were much more open and she was able to use them with greater ease.

After having 'hug' for three months there was noticeable change in Thelma's condition (see photo p23). While she remained frail, she spent more time out of bed and out of her room, her eyes were open most of the time and she was awake for longer, she would speak a few words occasionally, her hands were no longer as stiff, and importantly she had not had any falls since being introduced to 'hug'. The care staff and manager were highly enthusiastic about 'hug' and suggested that the changes were due to the relaxing impact that 'hug' had on Thelma, and how it encouraged other people to engage and interact with her, as they asked questions about 'hug'. For the time being, Thelma had been taken off end-of-life care.

Thelma's story also had an important impact on the wellbeing of the care staff working in the homes. Staff commented on how 'hug' gave them peace of mind because Thelma was 'settled'. Thelma's response to 'hug' also encouraged staff to start thinking about what could be made for other residents in the care home.

Project impact

Researchers observed moments of connection and engagement between residents, staff, with researchers, and with the objects. The qualitative evaluation of the objects took into account the reporting from care staff and management, reporting by doctors and clinical care staff visiting the homes' residents, observation by the researchers, and the interviews with care staff and family members. Further details of these findings will be published in due course.

An unexpected outcome of the project was the extent to which the workshop participants revisited some of the ideas and concepts during their day-to-day lives working in the care homes. For example, Karen, a manager at one of the homes, showed researchers a range of objects and activities that she and her staff

Fidget jewellery is simple, personalised jewellery designed to rest in the palm of the hand and provide something to fiddle with and touch

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* Cwtching is a Welsh word describing an action somewhere between hugging and cuddling

had made for residents in their care based on ideas from the workshops. The objects included sensory textiles, kinetic mobiles, and decorative objects placed in and around the care home.

The LAUGH project also highlighted the importance of care staff being involved in this type of research. Researchers found that it is important for designers to gain the trust of all participants, to focus on both individual and relational experiences, and to work with a thorough understanding of the individuals and the broader social and cultural context in which they live and work. Without the active engagement of busy care staff, it is all too easy for the importance and potential impact of objects and activities to get lost.

Furthermore, how people living with advanced dementia are introduced to and given access to objects and activities is key to how they respond. Without the active support of care staff, objects and activities may be left to sit in cupboards, or out of reach of the people who need them most. We're now carrying out research to determine how care staff can receive training to engage through creative activities and objects. (Anyone interested in taking part in this project can contact the author for more details).

LAUGH exhibitions

The LAUGH project concluded in Wales in April 2018 with an event at the Senydd in Cardiff and an exhibition of copies of the objects at the Royal Society of Arts in London. In Australia a LAUGH Symposium was held at the Art Gallery of NSW in April where Professor Cathy Treadaway, myself and Dr Jac Fennell presented the findings from the three-year project. The objects were also exhibited at a Sydney gallery.

Distribution

The LAUGH team is now seeking further research and investment funding to explore how the objects can be reproduced and distributed, how the process in which the objects were made can be scaled to reach more people, and whether it is possible to distribute details and information to enable Do-It-Yourself versions of these highly personalised objects to be made.

For details about our ongoing projects in relation to improving the quality of life of people living with dementia contact me (Dr Gail Kenning) gail@gailkenning.com in Sydney or Professor Cathy Treadaway ctreadaway@cardiffmet.ac.uk in the UK. ■

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The LAUGH objects on display in Sydney in April

In March this year we released a report of our research project detailing the effects of regulation on aged care services for people with cognitive decline. *The organisation of risk: how do dementia care providers adapt to regulation* (Carr & Biggs 2018) presents findings at the system, organisation and practice levels, and suggests a series of recommendations.

The project was funded by the NHMRC Cognitive Decline Partnership Centre and carried out between 2014 and 2017. Throughout we worked with three aged care providers – Brightwater Care Group, HammondCare and Helping Hand Aged Care –as well as Dementia Australia's National Consumer Network. Research also took place through the Brotherhood of St Laurence's Research and Policy Centre.

The research involved literature and policy reviews, interviews with stakeholder groups, mapping the aged care system and care pathways, and interviews with three levels of organisation – senior managers (17), facility managers (13), and care workers (30), which were PCA or equivalent. Interviews were also conducted with care users (10 in total), including people living with dementia in the community and care partners (see box p28).

The report suggests a need to move beyond debates about good versus bad, more versus less regulation to develop a deeper understanding about how aged care organisations and their employees respond to the pressures of various, overlapping and often competing regulatory demands. While there has been limited recent research in this area, such a focus demonstrates the different ways organisations and care workers seek to balance innovative care practice with regulatory compliance.

In this article we outline key findings at the system and organisation levels, followed by a more in-depth discussion of the effects of regulation on daily practice and the ways in which care workers respond to regulation in residential care.

Aged care regulation in Australia

Many of the care and support services that people living with dementia use are located within the aged care system. The regulatory system designed to govern aged care is complex with duplication and overlap occurring at the Commonwealth, state and local government levels and between different regulatory agencies.

Whilst moves have been made to reduce red tape and promote light touch

Balancing compliance and care in dementia practice

Simon Biggs and **Ashley Carr** discuss the strategies used by aged care organisations and care workers to manage the demands of dementia care within a regulated environment. How they do this, while still allowing room for innovation, is of interest to aged care providers, care practitioners, care-users, policy makers and regulators

approaches to regulation, measures have also been proposed to increase regulation and focus regulatory attention towards care activities and facilities considered higher risk. Much of the latter emerged as a consequence of the Oakden Report and the subsequent independent *Review of National Aged Care Quality Regulatory Processes*, conducted by Kate Carnell and Professor Ron Paterson, and released by the Australian Government in October 2017. A key outcome of the review was that for residential care facilities in particular the market alone proved "an inadequate mechanism to ensure the safety and wellbeing of highly vulnerable residents". The report argues that government regulation, including a rigorous accreditation process, should remain, as a means to ensure quality care standards and the protection of residents.

The Aged Care Act 1997 sits at the centre of Australia's regulatory system, and includes 17 principles covering areas such as care standards, requirements for approval, allocation of care places, fees and payments, sanctions, record-keeping, prudential requirements and care recipient rights. State legislation deals with other areas related to care, such as building certification, medication management and aspects of food provision. There are currently more than six independent or semi-independent regulatory agencies, including the Aged Care Complaints Commissioner, the Australian Aged Care Quality Agency (see box p29), the Aged Care Funding Authority, as well as national and state authorities covering food, building and training/skills. State and federal courts of law provide another source of regulatory influence.

Our policy and literature reviews found very few regulations specific to dementia within the Act and other relevant regulations. As a result, the implementation of formal regulatory requirements within organisational settings, and their integration within daily dementia care emerged as an area of critical concern. We began by examining 'soft' regulation, which is one means by which 'hard' forms of regulation, such as laws and legislation, are implemented within organisational and care settings. These soft forms of regulation, which include guidelines, organisational policies, practices and procedures, and care protocols, are what providers and professionals use to help translate legislation into everyday compliance (Heimer 2013).

Australia's aged care regulatory system is complex, with duplication and overlap occurring at the Commonwealth, state and local government levels and between different regulatory agencies

The process of translating hard regulation into everyday practice via soft regulation suggested a middle ground, which leaves significant room for flexibility and manoeuvre (Huising & Silbey 2011). It also means that standardised regulatory controls can be adapted to the specific care needs of people living with dementia, though this was an ongoing challenge for care providers.

Regulation 'clusters'

We found that the distribution of regulation throughout the system and in care settings was uneven. From this we developed the idea of 'regulatory clusters' to show how regulation tended to collect around particular points along a care pathway, for example, at care transition points, such as the move into residential care. This type of clustering suggests where additional support services might be needed to assist care users negotiating multiple regulatory demands, including eligibility requirements, care assessments and income/financial assessments.

Another form of clustering was used to show how regulation collects around particular daily care activities of residential care and not others. A continuum of regulation was proposed, indicating how activities like medication management are subject to high levels of regulatory control and prescriptive rules, whereas morning routines appear the least affected by regulation.

As our report states: "Care workers are able to exercise flexibility around certain care activities, but may be more constrained around others. Once these clusters of risk and control are understood, it is much easier to identify areas where innovation can be quickly achieved and where regulation may create a risk-averse response." We identified an ongoing need for organisations to provide support and guidance to help care workers balance discretion, best practice and caring relationships amidst regulatory control.

Organisational responses to regulation

We found that care providers adopted particular strategies as a way to cope with regulation. These proved important for balancing care principles, such as the creation of a homelike environment or the promotion of resident choice, with different regulatory demands, some of which were experienced as intrusive.

We categorised the strategies, all of

Care user views on regulation

Five people living with dementia currently accessing community care services and five carers or advocates were interviewed as part of this project. Findings emphasise the increasing importance of user-voice, plus the need to ensure that residents' rights and choices are maintained in care settings. They highlighted the following themes:

Rights and entitlements: regulation was important for supporting rights and entitlements in a fair and accessible way, and for determining the level and type of care that care users were entitled to. Failure to ensure rights and entitlements, including the right to choose and self-determine within facilities, was viewed as a cause of inadequate regulatory control or non-compliance by care organisations and their workers.

Regulation and care quality: regulation was often associated with high-quality care. While many observed the various other inputs that contribute to care, such as staffing levels and staff training/education, these were often assumed to be controlled by formal regulatory requirements and the responsible regulatory agencies, such as the Aged Care Quality Agency, rather than the care provider.

Advocacy: the ability to advocate for oneself or others was seen as a necessary part of formal care, and one that could be enhanced through regulation, such as formal processes related to complaints, co-creation and substitute decision-making.

Managing transitions and navigating a complex system: care users may be confused and frustrated by complex regulatory requirements when navigating the system and managing transition between service systems. Assistance with navigating the system appears to improve their experience of care.

Autonomy: In a best-case scenario regulation should form a secure background that allows people with dementia to simply get on with their lives.

Care users made a number of suggestions for improvement around regulation, including:

- More care staff, particularly in residential settings, and more time spent caring to enhance person-to-person interactions in formal care.
- More stringent accreditation and care quality processes.
- Improved integration of care services at the system and organisational levels.
- Limits to the intrusiveness of regulatory processes.
- More attention to a care user perspective on rights and entitlements.

Reference

Carr A, Biggs S (2018) *The organisation of risk: how do dementia care providers adapt to regulation?* Victoria: Brotherhood of St Laurence.

which were adopted by the organisations in our study to varying degrees, as follows:

- **Above and beyond:** using regulation as minimum standards which the organisation seeks to exceed. Examples include providing training; including dementia-specific training beyond the minimum mandated topics; and a strict dysphagia management regime for all staff to follow.
- **Pushing back:** challenging regulations, regulatory decisions and regulators in the perceived interests of the organisation, its workers and clients. Examples include rejecting specific regulatory decisions, such as a requirement to have both hot and cold taps coloured yellow, excessive food labelling requirements and advice on food cooking times that restricts resident choice; and challenging assessor expectations where these were not thought to be in the interests of quality care.
- **System-based:** developing systems that translate regulation into action, especially around the admission process, care planning and food provision. This approach aimed to 'engineer out' problems before they became critical. Examples include risk management systems for monitoring, detecting patterns and reporting emerging risks.
- **Organising space:** we observed the following approaches towards organising space to minimise the effect of regulation that might confuse residents or lead to misunderstanding:
  - Building planning/facility design (co-creating building design with architects, providers and consumers).
  - The use of open and restricted spaces (frontstage/backstage) – for example placing items such as fire safety equipment and notices in service corridors rather than living environments; dividing space into high- and low-risk areas (eg high-risk areas such as medicines management or large cooking areas were separated from living areas to reduce intrusiveness and the feeling of an institution and maintain the normality of everyday living spaces).
  - Environmental cues: sensory prompts such as visual cues, smells and sounds were used to attract residents to certain areas at certain times or reduce interest in thoroughfares and specialist equipment.

Overall, a key challenge identified in the report is for aged care service providers to ensure that the specific needs of people with dementia are accommodated within a generic system of compliance and that it is not just a box-ticking exercise.

How care workers respond to regulation

Care workers expressed different views about the role and effects of regulation. On the one hand, regulation was recognised as important for the protections it provided to workers and residents, and for the sense of order it could potentially provide. On the other hand, through reporting and documentation requirements, regulation was seen to increase workload, and the presence of multiple requirements could be experienced as confusing.

Care workers sought a balance between prescriptive rules and the ability to exercise some judgment and discretion, both of which were considered important for effectively relating to residents. As such, regulation was perceived as most effective where it provided a broad framework of limits that also left room for meaningful interaction and interpersonal communication. Indeed, the majority of care workers valued this aspect of their role and desired to spend more time interacting with residents. However, most felt that strict routines, workload, staffing and rostering, and reporting requirements could prevent this from occurring.

An important part of providing care within a regulated environment was for

New commission to oversee aged care regulation

The Federal Government will establish a new and independent quality and safety commission from 1 January 2019 to bring together aged care regulation, compliance and complaints handling – measures recommended by the Carnell-Paterson review.

The move, announced by Aged Care Minister Ken Wyatt in April, is in response to the Carnell-Paterson review into failures at South Australia's Oakden Older Persons' Mental Health Service, which found Australia's current aged care regulatory framework is fragmented and does not adequately provide the assurance the community expects.

The new Aged Care Quality and Safety Commission will bring together the functions of the current Australian Aged Care Quality Agency, the Aged Care Complaints Commissioner and the aged care regulatory functions of the Department of Health.

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care workers to determine which of the internal regulations had to be followed to the letter and which permitted flexibility. While more experienced care workers knew where points of flexibility existed and could pass on this knowledge to new workers, organisational policies and procedures could support care workers in daily decision-making and enable more time and opportunity for flexibility and resident engagement.

Emotional labour

The emotional labour involved in dementia care is not always recognised in the person-centred literature. It is, however, a critical aspect of care work. Not only is the display of particular emotions prescribed through 'soft' regulation, but care workers are also required, in the interests of personalised and relational care, to engage with residents at a deeper level. Knowing the person, relating to them and providing comfort in times of distress all require significant emotional input. In cases of advanced dementia, such input is not always reciprocated in conventional ways (Bailey *et al* 2015).

Our research identified two distinctive strategies commonly used by personal care workers to manage the competing demands of emotional engagement in the context of regulation. We have called these 'misattention' and the 'puzzle approach'. We hope that highlighting these may help personal care workers fine-tune their care strategy and see how others cope.

Misattention

A combination of regular reporting schedules, emotional stress and frequent regulatory visits can lead to a form of distancing termed 'misattention'. Here the individual loses contact with the intent behind regulation, replacing caring interaction and emotional engagement with residents with mechanical, routine compliance, as bureaucratic tasks are given priority in the individual's care approach. Misattention occurs when such rule-following behaviours are mistakenly identified as the core purpose of a caring role. It attends to the letter rather than the spirit of risk avoidance.

Workers who feel that they are being negatively evaluated may then defend themselves against complexity and emotional connection to residents by relying on routine work and reporting practices. Such an approach was referred to by our interviewees as "box-ticking", "rule following" and "looking busy".

While regular, accurate reporting is a necessary part of aged care work, the problem here is that workers 'misattend' to performance by associating best practice with successful reporting on individual tasks rather than with positive and appropriate interaction with residents. This gives a feeling of task compliance but misses the key element of interpersonal connection, resulting in:

- individual staff behaviour that is routinised
- timetabling that fails to allow opportunities for interaction
- detailed attention to monitoring regimes that intrude upon residents' everyday behaviour
- an overly prescriptive approach towards 'soft' guidance
- introducing specifications that do not actually exist in the regulations.

A 'puzzle approach'

A more effective and rewarding approach towards the multiple demands of providing care is to see dementia and dementia care as a puzzle. In this approach good care becomes a process of finding and implementing solutions to such puzzles, in a way that is meaningful for both the worker and the person living with dementia. This approach usually occurred when the organisational environment was more relaxed and supportive mechanisms were in place.

The puzzle motif suggests the complexity of individuals and the many factors that can contribute to their wellbeing or distress. This is consistent with feedback from facility managers and care workers who likened understanding people living with dementia to learning a different language, an approach that resonated with care workers from non-English speaking backgrounds.

In crafting solutions to people and behaviour as puzzles, knowledge is gleaned from other care workers, health professionals, experts and relatives. The approach empowers care workers to make certain care decisions and gain satisfaction from the care they provide. It allows the care worker to achieve a healthy balance between intimacy, curiosity and distance.

According to the care workers we interviewed, the dimensions of people as puzzles might include:

- Knowing the person's story, their likes/dislikes, and what activities they find meaningful.
- Attending to verbal and non-verbal communication to determine what causes or makes people feel good or bad.
- Watching for signs, such as when a resident looks tired or unsteady on their feet, to be ready to act in a pre-emptive or preventative fashion.
- Identifying basic physical causes, such as infections and pain, to explain distress or other responses.
- Modifying aspects of the physical environment that can foster wellbeing or reduce distress and confusion.

On further analysis we identified that the puzzle strategy used by care staff had three components: empathic understanding, professional distancing or detachment, and the adoption of a problem-solving approach.

Empathic understanding

The ability of care workers to empathise with residents is an important element of dementia care. The idea of seeing the world from a resident's perspective was expressed by care workers as the need to know the resident, leading many to cultivate a professional type of closeness. This involved knowing individual biographies and social identities, awareness of individual likes and dislikes, and attention to moods and feelings. From these elements care workers were able to put themselves in the shoes of someone experiencing dementia and respond in more sensitive and effective ways.

Professional distancing

At times, for effective care to take place, care workers were required to distance themselves from the feelings evoked by residents and avoid emotionally-charged situations. Using their professional and practical experience care workers could stand back and assess the events, triggers and/or patterns that prompted particular responses. Through such distancing, otherwise confusing situations could be recognised as an understandable response to factors such as the physical environment or individual fears and anxieties. From this standpoint care workers were able to logically and reasonably assess the cause of particular behaviours, and potentially engage with individual residents more effectively.

Problem-solving

By combining empathic understanding and professional distancing, care workers were able to develop a problem-solving approach to the puzzle that dementia presents. Solutions to puzzles came from a range of sources, including:

- clinical practice
- modifying the physical environment
- flexible work schedules
- personal biographies and social identities, plus information gleaned from families and friends.

Care workers played a key role in contributing, trialling and refining solutions, and could experience the puzzle approach as rewarding. While most participants acknowledged the impossibility of arresting the progress of dementia, much could be done to engage with its effects, even though the solutions to particular puzzles could change from day to day and from individual to individual.

The 'puzzle' approach leading to problem solving that takes into account the feeling as well as the thinking elements of the care task holds considerable promise for future training for dementia care staff.

Conclusion

The policy and practice of regulation emerged from this research as both complex and nuanced, and not a uniform phenomenon.

We recommend that a national review of the aged care regulations is needed to identify the intent of current regulations and simplify areas of operational overlap. Such a review would build on the work of Kate Carnell and Professor Ron Paterson (see box p29), which sought to determine the effectiveness of regulatory arrangements on quality care. It would specifically aim to (1) re-state the intent of regulation, including relevant regulations beyond the Aged Care Act 1997, and (2) identify ways to reduce the duplication and overlap that exists between aged care regulations and other regulated areas.

Examples might include identifying areas where the work of Quality Agency assessors overlaps with or duplicates the work of other regulatory bodies, such as in building design, fire safety, food safety and workplace health and safety. In such instances, we suggest that specific technical assessments are collated by an overview agency in what could be called a 'specialism and overview' model. This would have the advantage of reducing the number of inspections in some areas, and enable bodies like the Quality Agency to focus more on overall care quality.

The three key findings of our research are summarised below.

- First, regulation clusters around particular activities or transitions. Sometimes this reflects risk, but clustering also occurs for administrative reasons or through an overlap of multiple authorities on the same issue. An analysis of clustering may help to target services and identify areas requiring review of their efficiency and effectiveness. It may also be used to identify areas where innovation may be more easily or more difficult to achieve.
- Second, provider organisations respond to the demands of regulation through a process of interpretation, cultural preference and specialisation by organisational level. Organisations spend a lot of time and resources translating formal regulation into everyday practice through guidance, training, monitoring and environmental design. As part of this, they would seek a workable balance between care principles, resident and worker wellbeing and compliance.
- Third, an analysis of everyday practice identified two distinctive staff approaches toward dementia care: misattention and a puzzle approach, with the latter considered an effective and novel approach to dementia care, particularly in balancing emotional connection and professional distance in staff-resident interactions.

Care workers are not simply constrained by regulation, but use it as a means to cope with the uncertainty of dementia care and the emotional demands of care work. As such, positive regulatory cultures allow for problem-solving innovation while containing the emotional demands of dementia care.

Finally, viewing regulation as an interpretative process reveals significant areas of flexibility, particularly at the organisational and practice levels, and how such flexibility might be used to enhance dementia care.

We will be doing further work this year based on these research findings and their impact on aged and dementia care policy and practice. ■

The organisation of risk: how do dementia care providers adapt to regulation? by Ashley Carr and Simon Biggs (2018) is freely available to download at: https://bit.ly/2ruu0J2 and www.bsl.org.au/research/

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Australian Journal of DementiaCare Research Focus

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

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

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

Understanding the barriers facing BAME communities

What are the barriers confronting ethnic minority communities attending memory services? **Jasmine Martinez** and **Naomi Wynne-Morgan** devised a research project to find out

When we audited the demographic profile of clients attending our memory service in the UK, it was immediately apparent that it did not reflect the ethnic make-up of the local population. Funding for a six-month project enabled us to investigate the barriers for black, Asian and minority ethnic (BAME) communities with the aim of identifying interventions to increase referrals and attendance from these communities.

One of the authors (Jasmine Martinez) was recruited specifically to the project, supervised by the second author (Naomi Wynne-Morgan). The project began by exploring the National Health Service (NHS) Trust's historical relationships with BAME communities and the work it has done with them. Liaison with other organisations supporting BAME communities was invaluable in setting the scene and developing learning along the way.

To understand the barriers facing people from minority groups it was important to hear from different perspectives (Carter *et al* 2014); for example, GPs whose opinions on low rates of referral and attendance were sought since they are the gatekeepers to the memory service. Interpreters can be involved in GP appointments and have experience with BAME communities so they were considered to be an avenue of exploration. Finally, we wanted to hear from community leaders and the people themselves.

We decided that an online questionnaire would be the best method of getting broad feedback from time-pressured GPs and interpreters across Greenwich, one of the London boroughs covered by our trust and the focus of our project. The questionnaires were developed in consultation with clinical staff, BAME services and community organisations such as HealthWatch Greenwich, Culture Dementia UK and the Greenwich Inclusion Project (GrIP).

For GPs, the questions predominantly used a Likert scale (eg strongly agree/ agree/ don't know/ disagree/ strongly disagree) and covered the following topics: confidence in assessing for dementia with BAME individuals, language barriers, perception of dementia in BAME communities, and cultural barriers such as stigma. Respondents were also given space for their own feedback.

A similar online questionnaire was developed for interpreters, addressing their opinions on the barriers to referral and perceptions of cultural differences preventing diagnosis and access to support services for dementia. Both questionnaires were analysed using the online polling system built into the questionnaire website.

At the same time local BAME organisations were mapped out and contact was made with over 100 groups, including charities, cultural and religious groups. A semi-structured interview method was chosen as it allowed flexibility to explore issues that may have been unknown to the researchers. The interview questions were developed from similar research (eg Smith 2011; Berwald *et al* 2016) and responses were written down as close to verbatim as possible.

We opted for convenience sampling – that is, interviewees were selected on the basis of their accessibility – because it is a good method for initial research projects to use in generating hypotheses (Etikan *et al* 2015). Interviews were conducted with individuals across a range of BAME communities and subjected to thematic analysis (Boyatzis 1998).

Results

Participants and demographics

There was a 14% response rate from the GP questionnaire (24 respondents) while 11 respondents completed the interpreter questionnaire. Interpreter questionnaires were disseminated indirectly via the NHS interpreter service manager so it was difficult to determine exactly how many received it.

Semi-structured interviews were conducted in the community with 55 individuals from various ethnicities, including; black Asian, Caribbean and British, Asian Pakistani, Chinese, Vietnamese, Bangladeshi, Nepalese, Somali, and Irish Travellers. The age range was 36-86 years old, which gave perspectives from working age to retirement age.

GP questionnaire

Just over half of the GPs thought language barriers (58%) and written and spoken English (53%) prevented assessment of dementia in BAME communities. In spite of

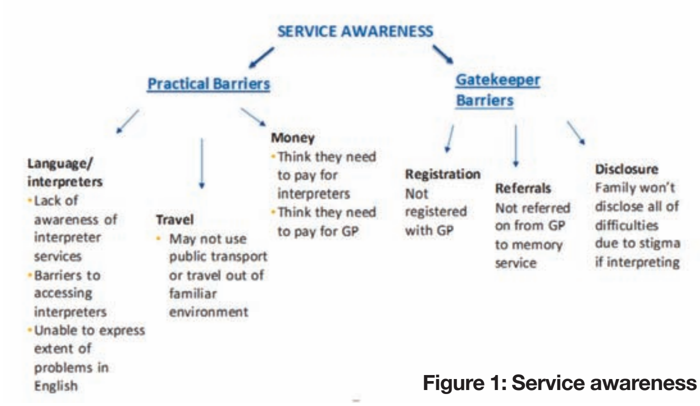

Figure 1: Service awareness

this fact, GPs still felt confident assessing for dementia in BAME communities (76%), a conflict between findings that warrants further investigation. They felt that stigma prevented individuals from revealing their memory problems (86%) and stopped people seeing their GP (52%). GPs also thought that BAME communities viewed dementia as normal ageing (58%) and felt that they had limited awareness of dementia and available services (82%).

Interpreter questionnaire

The GP findings mirrored the interpreters' views. Interpreters thought that screening tools for assessing cognitive impairment changes were appropriate (73%), but just over half thought that reading and writing skills in English played a role in preventing assessment of dementia (54%). Interpreters thought it was a mix of stigma (45%) and dementia being perceived as a normal part of ageing (52%) which contributed to limited awareness of services and contact with them.

Semi-structured interviews

Two overarching themes emerged from the interviews: service awareness and cultural differences in perception.

Service awareness relates to the barriers faced by BAME communities that arise either from GPs as gatekeepers or from practical issues. Cultural differences categorise the issues specific to BAME communities.

Service awareness

Our overarching themes of service awareness and cultural differences were further analysed into themes and sub-themes. To take service awareness first, this comprised two main themes – practical barriers and gatekeeper barriers – each with its own sub-themes (see Figure 1, left).

Theme 1: Practical barriers

The main practical barriers to referral were identified as

Implications for practice

Engagement

From a service perspective, there were changes that could be made by clinicians to have a positive impact on engagement by creating a welcoming environment and encouraging a more curious attitude about BAME communities.

'Top tips' were written and published on the intranet for staff, highlighting barriers and issues they should be mindful of. By prompting staff to be proactive in offering interpreter services, the tips encourage them to ask how the word dementia is translated in their clients' languages.

To address language barriers a document was put together containing electronic links to information on dementia and other ICD-10 diagnoses in all languages spoken by local communities. The 10 main languages spoken in the borough, after English are: Nepalese, Polish, French, Lithuanian, Chinese, Punjabi, Somali, Turkish, Yoruba and Spanish (Office for National Statistics 2011).

This document is being shared with Alzheimer's Society and NHS England. Clinicians across the trust can now use the information with clients to help explain different conditions and mental health challenges in the person's own language.

All local BAME community group contact details have been amalgamated so that they can be given out to clients in the memory service and community mental health team. This links people to groups of which they may have been unaware and cultivates social inclusion. Additionally, it has had a knock-on effect of helping forge stronger ties between our services and these groups. Both the language document and the contact details have been added into the 'Oxleas Dementia' app for people with a dementia diagnosis.

A stall promoting the memory service and research project during Mental Health Awareness Week displayed the national flags of BAME communities. The flags attracted people to the stall to talk to researchers about their countries of origin, often leading to detailed discussions about dementia within their cultures. As a result, national flags have been displayed in the memory service waiting room in the hope that minority groups will feel more welcome there.

Pathway to memory services

The semi-structured interviews prompted interest from BAME community leaders which resulted in requests for more information on dementia and the memory service. One of the authors (Jasmine) returned to these community groups and gave culture-specific presentations, for example for the Chinese community group (in collaboration with the Chinese National Healthy Living Centre) and a Sikh community group in their Gurdwara Sahib.

We are establishing a 'Trusted Leaders' network, which will comprise community leaders who will come together to work with the trust. They will be offered training on dementia – and eventually, we hope, other mental health diagnoses. The trust will also benefit from learning about their cultural differences and expertise.

The Trusted Leaders will become formal Oxleas NHS Trust volunteers, receiving training and other volunteering opportunities. The aim is that this relationship will work as a mode of liaison between community groups and trust services. Together we will be able to identify and support those living with dementia in BAME communities.

In the future, the development of drop-in clinics within BAME community groups will help to remove the barriers of travel and cost, and may begin to remove stigma as dementia support becomes more visible in the community.

Dissemination

The project findings have been shared with GP syndicates in the locality as well as the Alzheimer's Society Equality, Diversity and Inclusivity committee. They were also presented at the Memory Services National Accreditation Programme (MSNAP) Forum.

In addition, we hope that this article will encourage contact with other health services, health care organisations and charities that are seeking to break down barriers for BAME communities and develop a network of learning.

language, travel and money.

Sub-theme: Language and interpreters:

One person explained how she had written down her mother's problem on a piece of paper which was then taken to the GP as she did not speak English. Many people were not aware that they could ask for an interpreter.

Sub-theme: Travel Some individuals had never travelled away from their local area. There was a concern about travelling to other parts of the borough outside the perceived safety of the cultural group.

Sub-theme: Money Many people thought that accessing the GP or interpreters would incur a cost which they may have been unable to afford.

Theme 2: Gatekeeper barriers

The sub-themes under this category were related to the pathway into the memory service.

Sub theme: Registration Some people were not registered with a GP and would have been unable to access the memory service as referrals are only accepted from GPs.

Sub theme: Referrals There were examples of people who knew about the memory service but were not referred by their GP. It was not possible to establish the clinical decisions behind these situations. This may also connect to language barriers, where it may have been difficult for GPs to communicate rationales for clinical decisions.

Sub theme: Disclosure Some people relied on family members to interpret when seeing a GP. Stigma and privacy can influence how much individuals feel happy about sharing in these circumstances.

Cultural differences in perception

Our second overarching theme of cultural differences in perception was analysed into two further themes about the cause of dementia and about fear and respect. A series of sub-themes around normal ageing, personal characteristics, mental health, and blame and shame emerged from the cause of dementia theme (see figure 2, above).

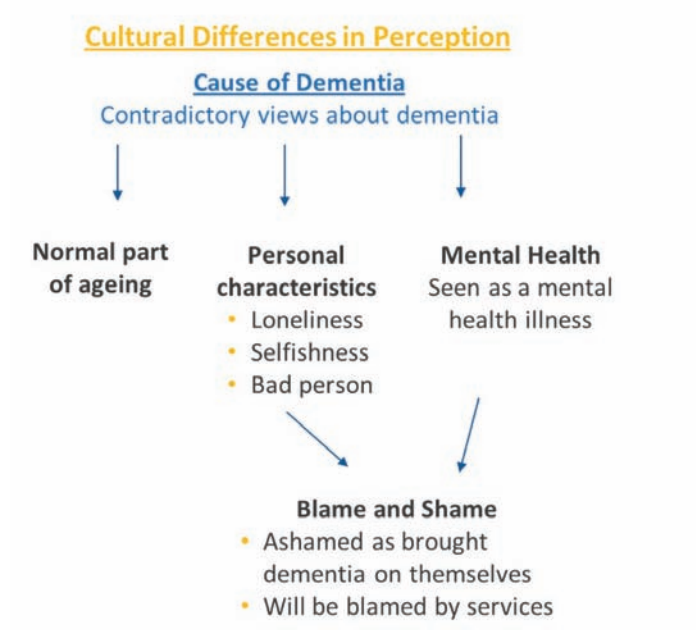

Figure 2: Cause of dementia

Theme 1: Cause of dementia

There was a variety of views on the cause of dementia, many of which posed challenges to referral arising from cultural beliefs.

Sub-theme: Normal ageing Some communities considered dementia to be a normal part of ageing and therefore there was no need to access support from services.

Sub-theme: Personal characteristics

Some communities saw dementia symptoms as being a result of character flaws. Dementia may occur if the person was selfish or 'bad'.

Sub-theme: Mental health

Dementia was seen as a mental health difficulty rather than a neurological condition.

Sub theme: Blame and shame An unspoken sense of blame and shame came out of the interviews. People were either concerned about being blamed for developing dementia or spoke about blaming others who had the condition. There was a feeling of shame about receiving a diagnosis. Several individuals spoke of shying away from dementia and avoiding a diagnosis at all costs.

Theme 2: Fear and respect

Sub-themes emerging from the fear and respect theme included feeling disrespected, lack of engagement, generational differences and stigma (see figure 3, below).

Sub-theme: Disrespected and undervalued As this research was conducted at the time of the Brexit vote, several community groups felt unwanted and fearful of how they would be perceived and treated. At a time of austerity many organisations had their funding cut and so were feeling undervalued. Many groups spoke of feeling "used" for research purposes and as though people would come in to pry and not give anything in return.

Sub-theme: Engagement Concern around how they would be seen and treated appeared to extend to people working for the public sector, for example the government or NHS. They spoke about avoiding services and remaining within their own cultural groups as they felt like outsiders in society. People would engage when necessary, possibly at a point of crisis.

Sub-theme: Generational differences

Individuals from the first generation who moved to live in England spoke about the concern of being a burden to their children. They were also afraid of suffering alone, yet did not want to seek outside help or support. Second generation individuals talked

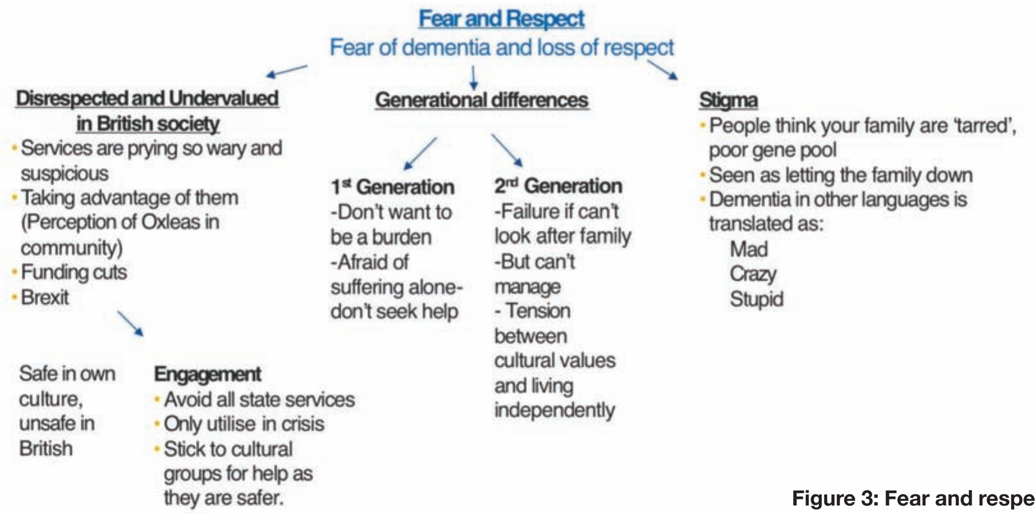

Figure 3: Fear and respect

about the conflict between the duty to look after their parents and yet not being able to do so. There was also a tension between the cultural values of their family and the independence they had developed growing up in an individualistic society.

Sub-theme: Stigma Many groups also spoke of the need to hide any problems that may appear to be a "mental illness," due to stigma and consequent perceptions of the family's "gene pool" as making future generations less attractive for marriage. The word dementia was translated as mad, crazy and stupid in some cultures, reinforcing the stigma of this diagnosis.

Discussion

The project identified a range of issues which prevented BAME people from accessing the memory service in proportion to their numbers in the wider population. Barriers were mapped on to the service pathway to help identify where problems could potentially be resolved (see Figure 4 below).

During our discussions with BAME leads in the NHS Trust and with minority communities, it was apparent that there was a level of 'research fatigue'. Communities had been approached many times by various organisations about their views and consequently felt frustrated at the lack of change – they felt it was all give and no gain. Some people's first interaction with NHS services had been at a point of crisis and had been stressful and difficult.

In combination, these factors caused a level of mistrust and reticence with 'outside' organisations and services. It was imperative that this preliminary research did not repeat these patterns, which meant it was vital that the trust developed a lasting relationship with the communities. Engagement, pathway to the memory service and dissemination of learning were highlighted as the main areas in which to focus interventions (see box p32).

Conclusion

Our research was based on small samples and a follow-up with focus groups or interviews with GPs and interpreters would be useful. There may also be advantages in involving members of BAME communities themselves in drawing up the questionnaires and training them to carry out the interviews. This would have given ownership back to the communities and may have elicited other perspectives.

Even so, our research has significant implications for practice (see box p32). We saw that changes could be made by clinicians that would have a positive impact on engagement and by having a more proactive approach to offering the services of interpreters. Displaying the national flags of local BAME groups is one among several other initiatives to stir up interest in the memory service.

By going out to community groups and giving culture-specific presentations, the pathway to memory services has been smoothed.

A 'Trusted Leaders' network of community leaders has come together to work with the trust, which will offer training on dementia and will learn from the network's own cultural differences and expertise.

We believe that, by sharing and disseminating the findings of our project, we can help to break down barriers between memory services and BAME communities. In this way, we hope that our service and others like it will be used by many more people from minority groups. ■

■ Jasmine Martinez is assistant psychologist and Naomi Wynne-Morgan is principal clinical psychologist, both at Oxleas NHS Foundation Trust in the UK

Acknowledgments

We would like to thank the following for their help with our project: everyone from the BAME communities and community groups who took part, including the 'trusted leaders' who welcomed us and are with us on this journey to break down more and more barriers; Alzheimer's' Society Equality, Diversity, and Inclusion Steering Group; Greenwich Inclusion Project (GrIP); Healthwatch Greenwich; Oxleas older people clinicians and staff; our clinical commissioning group who supported this project; and Culture Dementia UK.

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This article was first published in the UK *Journal of Dementia Care* 26(2) 28-31.

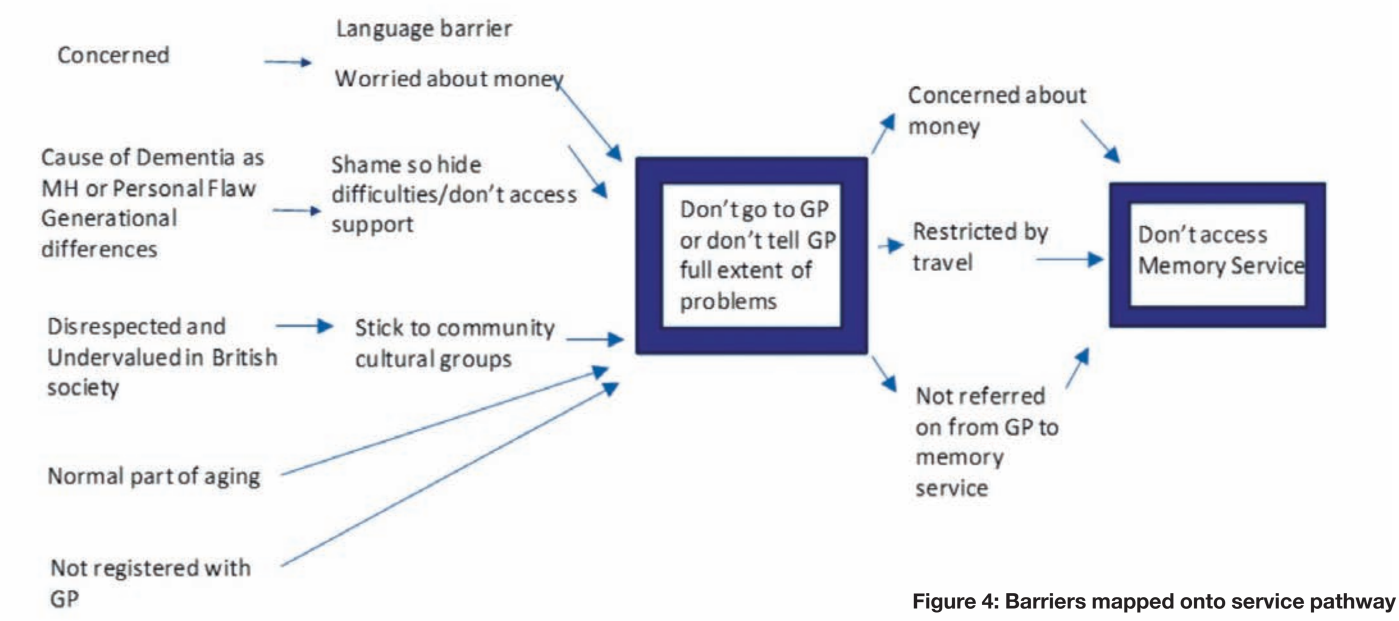

Figure 4: Barriers mapped onto service pathway

RESEARCH NEWS

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

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Successful transition into care

To provide practice recommendations for improving transitions in care for elderly people living with dementia, two US researchers conducted a literature review of evidence-based interventions that aimed to delay and improve transitions in care between the hospital, home and residential care settings.

Seven evidence-based interventions that targeted transitions in care were identified. All focused on delaying or avoiding unnecessary transitions. Effective psychosocial and care coordination interventions that included a care team, prompt communication of assessment findings, caregiver education, professional consultations, plans for emergency department visits and established goals of care successfully delayed care transitions.

The following five themes were identified and used to develop recommendations to guide successful transitional care interventions for people living with dementia and their caregivers:

- Prepare and educate the person living with dementia and their caregivers about common transitions in care.
- Communicate all information relevant to the person across facilities and do so in a timely manner.
- Establish and revisit goals of care for the person living with dementia, including their treatment preferences, advance directives, as well as social and living situation preferences.
- Create a strong interpersonal collaborative team environment to assist people living with dementia and their caregivers as they transition between their home, hospital and residential care facilities.
- Use evidence-based models to avoid unnecessary transitions and delay placement into a residential care facility.

The researchers note that while there is a growing need for services that reduce unnecessary transitions, putting these five recommendations into practice will require a shift in current health care policies and practices.

The health care team should also be compensated for the time required to adequately educate and assess the needs of the person with dementia and their caregivers.

Hirschman KB, Hodgson NA (2018) Evidence-based interventions for transitions in care for individuals living with dementia. *The Gerontologist* 18(58) 129-140.

Social interactions and mood

Australian and US researchers examined whether unstructured daily social interactions between people with dementia and care staff in long-term stay residential care facilities were associated with expressions of positive and negative mood.

A total of 126 people with dementia living in residential care were recruited from 12 care homes in the US. Residents were video recorded for 20 minutes twice daily over five consecutive days. The times of the recordings were pre-selected individually to capture interactions between residents and others in the care home.

Measures of social interaction and mood were taken from the video recordings by trained raters. Levels of social interaction were measured using the Interacting With People subscale of the Passivity in Dementia Scale. Mood was measured using the Philadelphia Geriatric Centre Apparent Affect Rating Scale.

Greater social interaction predicted higher interest in daily life, feelings of pleasure, as well as higher levels of anxiety and sadness by people with dementia. Social interaction did not predict an individual's level of anger. Both interest and anxiety were more common in the afternoon than morning hours and residents with higher cognitive functioning were more likely to display pleasure than those with lower cognitive functioning.

This study had several limitations. Firstly, the measure of social interaction captured a variety of interactions with people but did not distinguish the characteristics of those interactions. It was not clear who the resident was interacting with (eg caregivers, other residents or others) or what type of interactions were involved (eg friendship-focused or task-focused interaction) and this may have impacted the findings. Furthermore, while the findings revealed a significant relationship between social interaction and positive and negative moods, the cause and effect relationship cannot be established.

The authors conclude that these findings are useful for those who develop and evaluate interventions aimed at enhancing positive mood and reducing negative mood for older people living with dementia in residential care. Further research is required to validate the findings and understand the cause-effect relationship between social interaction and mood.

Jao Y-L, Loken E, MacAndrew M, Haitsma KV, Kolanowski A (2018) Association between social interaction and affect in nursing home residents with dementia. *Aging & Mental Health* 22(6) 778-783.

Art program improves wellbeing

UK researchers developed a 12-week visual arts program for people living with mild to severe dementia. They recruited 125 people living with dementia from a residential care home, a country hospital and community venues.

Participants were given water-based paints, pastels, coloured pencils, collage materials, iPads, modelling clay and print-making supplies. The aim of the art sessions was to encourage creativity without overwhelming participants with complex instructions.

The Greater Cincinnati Chapter Well-Being Observational Tool, Dementia Quality of Life measure and the Holden Communication Scale were used to assess wellbeing, quality of life and communication, respectively. Interviews were conducted with participants at baseline before

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starting the 12-week program, and three and six months later.

In terms of their wellbeing, participants had improved scores after the program for interest, attention, pleasure, self-esteem, negative mood and sadness. Quality of life improved following the program, however the improvements were not sustained at the six-month follow up. Communication improved for participants recruited from the residential care home, however there was no change for participants recruited from the community, and communication deteriorated for participants recruited from the hospital.

Qualitative data was also collected. Participants reported that the art program was a stimulating experience which brought them social connectedness, feelings of improved wellbeing and inner strength.

The findings highlight the potential for incorporating creative activities into aged care for people with dementia. Future research is recommended to investigate the effectiveness of the art program using a randomised controlled trial and analysing the longitudinal impact on the family and professional carers of people living with dementia.

Windle G, Joling KJ *et al* (2018) The impact of a visual arts program on quality of life, communication, and wellbeing of people living with dementia: a mixed-methods longitudinal investigation. *International Psychogeriatrics* 30(3) 409-423.

Facial, head massage relieves agitation

Researchers in Iran conducted a randomised controlled trial to determine whether head and facial massage was beneficial at reducing agitation in elderly people with Alzheimer's disease living in residential care.

A total of 35 people with Alzheimer's disease received the intervention which involved massage therapy performed by a trained nurse using effleurage and compression techniques for 10 minutes daily for 10 days. A further 35 people with Alzheimer's disease were randomly allocated to a control group and received no intervention during the 10-day period.

The Cohen-Mansfield Agitation Inventory was used to measure the participants' agitation levels. Before the massage therapy, both groups scored similarly on the agitation questionnaire. Following 10 massage therapy sessions, participants in the intervention group had improved scores for aggression, physically non-aggressive behaviours, hiding and hoarding, verbally aggressive behaviours and overall agitation levels.

The authors concluded that head and facial massage is a safe, simple, low-cost and non-pharmacologic intervention for agitation management and they recommend including massage therapy as a complementary intervention for people with Alzheimer's disease.

Future research is recommended to examine the longer-term effects of massage therapy on agitation levels, as well as other common symptoms in people with Alzheimer's disease, including stress, pain and anxiety.

Keshavarz S, Mirzaei T, Ravari A (2018) Effect of head and face massage on agitation in elderly Alzheimer's disease patients. *Journal Of Evidence-Based Care* 7(4) 45-54.

Nursing staff and moral distress

Canadian researchers have investigated the prevalence of moral distress among nursing staff who care for people living with dementia in long-term care and assisted-living residential homes.

The Moral Distress in Dementia Care Survey was distributed to 23 residential care homes in Canada. A total of 389 nursing staff from public and private care homes in urban and rural settings rated the frequency and severity of situations that caused them moral distress.

The researchers found that 76% of nursing staff who provided care to people with dementia experienced at least a moderate degree of moral distress. Nursing staff reported experiencing moral distress at least weekly and many reported it daily, over the past year.

The most frequently reported situations that caused moral distress were: telling a person with dementia things that are not true so they won't get upset, having to make one person wait for care because another needs care at the same time, and seeing a low quality of life for people with dementia because there are not enough activities available.

The situations that caused the most severe moral distress included: seeing people with dementia suffer because there are not enough staff, having to rush care due to lack of time, and seeing care that does not show respect to people with dementia.

The frequency and severity of moral distress increased with the amount of time spent at the bedside of people with dementia. Moral distress was also found to have negative psychological and physiological effects on nursing staff.

This study was limited to one geographic area and one point in time. Additionally, there was no comparison group, such as acute care nursing staff, so it is unknown whether experiences of moral distress are unique among long-term care and assisted-care staff.

Further research is needed to inform potential solutions at the individual staff level and at a system level to support nursing care staff working with people with dementia.

Pijl-Zieber EM, Awosoga O, Spenceley S, Hagen B, Hall B, Lapins J (2018) Caring in the wake of the rising tide: moral distress in residential nursing care of people living with dementia. *Dementia* 17(3) 315-336.

Staff and family attitudes to fences in aged care homes

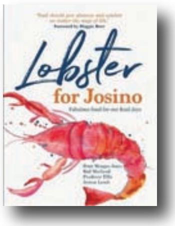
Australian researchers have investigated staff and family attitudes towards the use of fences that surround many aged care homes. The researchers conducted focus groups with direct care workers, family members of people living in the aged care homes, nurse unit managers and care home managers.

Concerns were raised about the confinement of fencing around care homes, with participants commenting on the loss of autonomy and emotional safety for residents. Family members in particular noticed the decline of their family member with dementia when contained within locked residential care homes. Despite these concerns, all participants considered fencing a necessary feature of aged care homes to ensure the physical safety of residents.

Care home managers showed the most support for fencing while direct care workers, nurse unit managers and some family members preferred more freedom. Participants also identified a number of positive features of fences. These included feelings of security and homeliness for people with dementia, helping anxious residents feel safe and providing residents with a sense of ownership over their space.

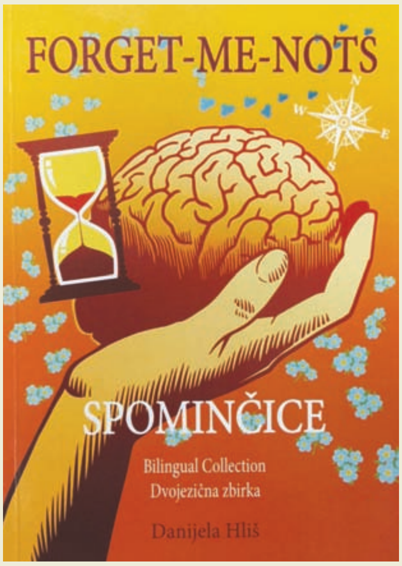
The findings illustrate the tension between physically protecting people with dementia and their emotional safety. The researchers conclude that the presence of fences around Australian aged care homes needs to be reduced in order to support freedom of movement for people with dementia living in those homes.

Dreyfus S, Phillipson L, Fleming R (2018) Staff and family attitudes to fences as a means of detaining people with dementia in residential aged care settings: the tension between physical and emotional safety. *Australian Journal Of Social Issues* (early view): http://dx.doi.org/10.1002/ajs4.34.



Lobster for Josino: fabulous food for our final days is a new book by HammondCare chef Peter Morgan-Jones, who has teamed up with palliative care specialist Professor Rod MacLeod, speech pathologist Prudence Ellis and dietitian Jessica Lynch to write what is being promoted as a world first – a cookbook that provides advice and tips about food at the end of life, including more than 100 recipes. The recipes are safe and appropriate for people at various stages, including those who enjoy a normal diet, those on modified diets and those who are at a stage of eating very little or are 'nil by mouth'. Recipes include innovative twists on favourite foods and flavours such as vodka and tonic ice blocks, Scotch mouth swabs, Christmas pudding mist as well as tasty meals, drinks and modified foods. The book begins with clinical advice on many of the issues that someone facing a life-limiting illness or the end of life may experience. The book's title was inspired by a chef's dying request to Morgan-Jones for lobster as his 'last meal'.The 232-page book costs $39.95 and is available from www.hammond.com.au.

Book giveaway winners



The winners of the *Forget-Me-Nots / Spomincice* book giveaway from the April/May 2018 issue of *AJDC* are: Kerrie Friend from Kiwan, Queensland; Karen Gall, Alexander Heights, WA; and Kylie Chuter, Margate, Tasmania. Each receives a copy of Danijela Hlis' book *Forget-Me-Nots* (*Spomincice* in Slovene) – a bilingual compilation of poems and prose, based on the author's contact and relationships with people with dementia and their families over many years. Thanks to all who entered.

An Exeter University project called A Life More Ordinary has led to the creation of a book of images and poems compiled by people affected by dementia working with well-known professional artists. The book is called **The Allotment of Time** because it involved people with dementia and their partners spending time on Age UK Exeter's allotment or at a local art studio. They took part in creative workshops with photographer Ian Beesley, cartoonist Tony Husband and poet Ian McMillan, resulting in the book, which is designed to capture poignant or humorous moments showing what it is like to live with dementia. Professor Linda Clare, who heads the A Life More Ordinary Project, said: "We hope people will read the booklet and ask themselves whether they can understand the needs of people with dementia better, and support them in their needs." Available at: https://issuu.com/universityofexeter/docs/allotment_of_time

Knowing me! Dementia, depression and delirium – a person centered education and training resource is a new 110-page production from the Life Story Network in the UK, which was commissioned by the Yorkshire and Humber Clinical Network to review and refresh the 2006 'Let's Respect' toolkit. This new resource is aimed primarily at health and care staff and is intended to be used as the basis for staff induction, training or discussion. The wide-ranging resource has detailed sections on each of dementia, depression and delirium, including a section on identifying the difference between the three conditions, as well as coverage on more general areas such as 'Health and wellbeing', 'Quality of life', 'Person-centred care and support', 'Know my rights' and 'Staff health'. Each section includes links to related resources or documents. The resource is available to download from the Life Story Network website at www.lifestorynetwork.org.uk/knowing-me/

Dementia Australia has released two new resources, both specifically on younger onset dementia. The first is an online training module for health and care staff, called **Understanding younger onset dementia**, and available through the Centre For Dementia Learning website. The three-part course takes approximately 90 minutes to complete, and is available for free. The course aims to increase awareness of the issues involved when a younger person is diagnosed with dementia, the impact it has on their life and how to support care partners. The second resource, **Support pathways for people with younger onset dementia** (pictured below left), is available on Dementia Australia's website and is aimed at people living with younger onset dementia and their families as well as health professionals. The 40-page resource acts as an introduction to younger onset dementia, while also signposting readers to a wide range of referral and service options, including health, social, community and legal services and organisations. The resources were developed with assistance from the NSW Government's Family and Community Services and as a result include listings of many NSW-specific organisations, as well as national organisations. Available to download at: https://bit.ly/2rvHX9G

The Dementia Centre for Research Collaboration at QUT in Queensland has launched a new 16-page guide, in partnership with the Red Cross, aimed at family carers of people living with dementia in the community. **Preparing for a natural disaster – guide to using RediPlan for carers of people with dementia** is available as an e-book or as a PDF, and covers preparing for a natural disaster, what to do during one, and tips for the aftermath, including returning home and how to access psychological support. The guide was prepared with input from family carers of people with dementia and emergency services workers. It is intended to be updated as carers take the necessary action suggested in the guide, and also used in conjunction with the Red Cross RediPlan tool and a new Get Prepared App. It also details the person with dementia's essential needs and can be shared with a support network including their doctor and pharmacist. The guide can be accessed from the

DementiaKT website: http://dementiakt.com.au

KalendarKards is described as a comprehensive ‘memory support system’ aimed at people with mild cognitive impairment and people with early stage dementia, developed in the US and available to purchase for $US59 (about $A75) through Amazon. KalendarKards come in a display box, and caregivers arrange the cards in the box in the appropriate sequence for each day of the week – including (for example) appointments, medication reminders, activities, visits or chores. As well as pre-printed cards for certain activities, the box also includes a supply of blank cards and a permanent marker for personalising the cards as necessary. The idea is that the person with dementia looks at the display box, takes the next card in the display, acts on it and then moves the card to the ‘discard’ slot within the box. The system comes with a silicone wristband for the person to wear to prompt them to look at the card display regularly. The system is promoted as capitalising on the comfortable and familiar act of playing with cards, without needing to make use of any technology or power source, and as a way of supporting a person to help them stay safe and independent longer in their own home. For more information, go to www.kalendarkards.com.

HammondCare Media in association with Bible Society Australia has launched **Faith for life**, a series of new resources aimed at supporting people with dementia to continue in their Christian faith and to engage with the Bible. The resources include A4 and A5 cards (*Textures of God’s love*, *Words of hope*, and *God is so good*), devotional books (*Time with Jesus* and *Jesus loves me*) and spiral-bound desktop devotions (*Yesterday, today, forever*). The resources feature powerful images and themed materials including Bible verses, prayers and lines from familiar hymns. They were developed in consultation with people with dementia and their families and carers, and with input from Professor John Swinton, a leader in practical theology and spiritual care for older people and those living with dementia. The resources have been designed to be dementia-inclusive (with good contrast, low glare, clear layout and familiar content). The resources vary in price from $20-$45 and are available to purchase from the shop on the HammondCare website (www.hammond.com.au).

The NSW Government’s Department of Family and Community Services has funded the production of a new 20-page A5 booklet published by Dementia Australia, called **Family, friends and community**, and aimed at people from Aboriginal and Torres Strait Islander communities. The content of the booklet has been developed from the 2015 Dementia Australia resource, *Family and friends matter*, and *Look after your brain – a guide to dementia for Aboriginal people* (2012) compiled by Ageing Disability and Home Care, NSW Department of Family and Community Services and with input from a number of Aboriginal community groups. This new resource covers the following areas: ‘When someone you care for finds out they have dementia’, ‘Dementia facts’, ‘When someone has dementia they might…’, ‘Helpful things to remember’, ‘Communication’, ‘Tips for making the most of your visit’ and ‘Where to go for help’. The text is easy to read and well supported by good images and a clear structure. Available to download at: www.dementia.org.au/files/resources/Family-Friends-Community-booklet.pdf

A guide to reducing and managing job stress for home care and support workers in the aged and disability care sectors is a new 19-page publication by Dr Sarah Oxenbridge and Justine Evesson (formerly Employment Research Australia). The guide brings together innovative strategies identified in 2016 research which involved the authors talking to people from over 30 Australian organisations about what works in reducing work-related stress for home care workers, and asking 49 home care workers from six organisations about what worked – or what they thought would work – to prevent job stress. The guide – aimed at both employers and workers – covers a wide range of areas, such as recruitment, hours of work, financial security, preventing exhaustion, burnout and injury, self-managing teams, and technology, but does not address the particular needs of working with people with dementia. It is available to download from the Centre for Applied Disability Research Clearing House website.

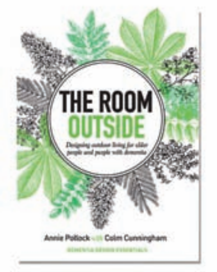
End of Life Directions for Aged Care (ELDAC), a government-funded initiative that aims to connect people working in aged care to palliative care and advance care planning information, resources and services, has developed five online toolkits. The toolkits provide up-to-date clinical evidence, learning opportunities and tools to support palliative care and advance care planning. The suite comprises: **The residential aged care toolkit** and **Home care toolkit** which cover: ‘What I can do’, evidence-based clinical guidance; ‘What I can learn’, where staff identify their learning needs and set a learning plan; and ‘What my organisation can do’, which provides direction in setting up a palliative care and advance care planning working group and includes organisational and clinical audits linked to a quality improvement framework. **The primary care toolkit** has clinical information, links to education and mapping of health pathways across Australia. **The legal toolkit** features factsheets and practical help for seven commonly encountered legal issues in palliative care and advance care planning. **The working together toolkit** provides evidence-based strategies for connecting the aged care, specialist palliative care and primary care sectors. Access the toolkits at www.eldac.com.au

Apps for dementia: the benefits and use of apps for people living with dementia is a one-hour webinar presentation from Dementia Training Australia (DTA) for professional carers working in residential, in-home, community or acute care. The presentation covers the benefits of touchscreen tablets and apps for people with dementia and their carers; how to select apps that are tailored to the person’s interests, background and abilities; and practical strategies for using apps to enable the engagement of people with dementia and facilitate social connections. The webinar may contribute to one hour of continuing professional development (CPD). It’s presented by Alissa Westphal, a lecturer in dementia care at the Academic Unit for Psychiatry of Old Age, University of Melbourne. Access the webinar via the DTA website at https://bit.ly/2IQdBZq

A new report from the UK claims that while people with a learning disability are three times more likely to develop dementia than the rest of the population, a review of government dementia policies and strategies shows that their needs are barely mentioned. **Hidden in plain sight – dementia and learning disability** is released by the Foundation for People with Learning Disabilities, part of the Mental Health Foundation. It reports that according to the latest research, more than one million people with learning disabilities are not being appropriately supported in the UK's national dementia policy. Although this is a UK report, the recommendations will make interesting reading for health and aged care practitioners and policy makers elsewhere, including Australia. The recommendations seek to reduce the inequalities experienced by people with learning disabilities and dementia, support their wellbeing and reduce costs to individuals and societies. It is freely available to download from the Mental Health Foundation website at www.mentalhealth.org.uk

The room outside: designing outdoor living for older people and people with dementia

Hammond Press (2018) ISBN 9780994546166, $32.95



Architect and landscape architect Annie Pollock and Dementia Centre Director Colm Cunningham present the case for well-designed gardens and outdoor spaces with ease of access to enhance the wellbeing of older people in care settings. The book sets out to encourage the creation of outdoor spaces and provide a better understanding about what makes outdoor spaces meaningful for people living with dementia. Practical advice is interwoven with sound design principles to inspire a range of readers to adapt or build outside areas that work to improve the quality of life for everyone, especially those living with dementia. This beautifully illustrated book includes sections on garden design, site planning, plant selection, and maintenance. It is available through the HammondCare website.

The **Dementia: post-diagnosis support report,** recently released in the UK, showcases positive initiatives to support people living with dementia and their care partners. Produced in partnership with the Dementia Action Alliance, the Local Government Association report outlines key learnings and innovative practices implemented by local councils in the UK to support the wellbeing of people living with dementia following their diagnosis. Initiatives include peer support, a 'living well with dementia' website, and a six-monthly multi-agency forum aiming to co-design new and improved dementia services with consumers. One council used an integrated service design to set up a grant to enable independent living. The grants pay for person-centred and environmental assessments that inform adaptations and adjustments to the person's home, as well as items such as dementia clocks, touch lighting and contrasting coloured toilet seats. Although this is a UK report, the initiatives and learnings provide positive examples relevant to service providers in Australia. Download the report from: www.local.gov.uk/dementia-support-guide-councils

Animal Welfare League Australia (AWLA) has just published **The pets in aged care national snapshot**, which aims to highlight the aged care sector's current levels of pet-friendliness. The 26-page report's key findings are from a desktop audit of websites for residential aged-care facilities and home-care places, which reveals low rates of pet-friendliness towards pet owners, and considerable variation across states. Factors stopping aged care service providers implementing initiatives that keep owners together with their own pets include (but are not limited to) an inability to fund programs, a shortage of employees and volunteers who are able or willing to deliver support, and workplace health and safety concerns. The AWLA argues that these findings suggest an urgent need for more services and practices that keep the older person together with their pet for as long as possible. The report is available to download on the AWLA website.

Events

- 4-5 June 2018 – NSW
  NNIDR Australian Dementia Forum 2018: Cooperation, Collaboration, International Connections
  Hosted by the NHMRC National Institute for Dementia Research (NNIDR), in Sydney. Details: www.nnidr.gov.au

- 7-8 June 2018 – NSW
  HammondCare International Dementia Conference: Mission Impossible? Truth & Lies In The Age Of Choice
  In Sydney. Details: www.dementiaconference.com/

- 7-15 June 2018 – national
  Dementia In Diverse Groups
  Two-day symposium, comprising six two-hour workshops each focusing on the unique needs of individual groups of people living with dementia (includes people who identify as LGBTI, Younger Onset Dementia, Homeless, Veterans, Aboriginal and Torres Strait Islander, and CALD). Presented by Dementia Training Australia in Canberra, ACT (7-8 June); Twin Waters, Sunshine Coast, Queensland (12-13 June); Melbourne, Victoria (14-15 June). Details and registration: www.dta.com.au/listings/?listing_types=dta-events

- 22-26 July 2018 – US
  Alzheimer's Association International Conference
  In Chicago. Details: www.alz.org/aaic/overview.asp

- 26-29 July 2018 – US
  Alzheimer's Disease International (ADI) Conference
  In Chicago. Details: https://www.adi2018.org/

- 23-24 August 2018 – NSW
  Better Practice For The Future National Conference: Living The Life I Choose
  Hosted by the Australian Aged Care Quality Agency, in Sydney. Better Practice Award winners to be announced at the conference dinner on 23 August. Early bird registration now open until Friday 13 July. Details: www.aacqa.gov.au

- 19-21 September 2018 – VIC
  Diversional & Recreation Therapy Australia National Conference
  In Melbourne. Details: http://diversionaltherapy.org.au/

- 9-10 October 2018 – VIC
  Embolden
  A conference for service providers and older people: respecting elders; challenging ageism, preventing elder abuse; building an age-friendly world. Presented by Celebrate Ageing, in Melbourne. Abstract submissions close 9 August. Details: https://www.celebrateageing.com/embolden.html

Details of more events at www.journalofdementiacare.com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For all who work with people with dementia
Something for everyone
Also inside this issue:
■ Mooving and Grooving ■ 'Kinecting' through digital games
■ Eat Walk Engage ■ Co-design for advanced dementia