

Australian Journal of **DementiaCare**

For all who work with people with dementia

Vol 8 No 3 June/July 2019

Why intimacy matters



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- Bridging the gap in YOD care
- StepUp for Dementia Research
- A rights-based approach to risk
- Bringing generations together

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The *Australian Journal of Dementia Care* is published six times a year by Hawker Publications Australia Pty Ltd, 7 Conrad Place, Wishart, QLD 4122.

Printed by iPS, Sydney.

© Hawker Publications Australia Pty Ltd 2019
ISSN 2049-6893

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Subscriptions \$99 per annum (see
page 40 for details) from DCA,
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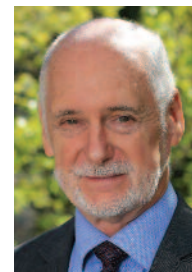
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Outside the comfort zone

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

A sense of a common cause, a unity of vision, is one of the most satisfying outcomes from recent workshops I attended on designing environments for people with dementia. Even when these workshops have people from very different backgrounds, such as marketing, capital works, building and grounds maintenance, lifestyle, personal care, nursing and management, it is possible to arrive at a consensus on what needs to be done to improve a building. This can be achieved by systematically focusing on the problems identified by each of the participants, working out what can be done using what is currently available, what will need some additional authority or resources and what needs to be put on the capital works program. Progress is almost guaranteed when these discussions are informed by knowledge of a set of easily understood principles of design.



This rational, systematic approach works quite well, but can be much more enjoyable and unifying with the addition of another activity. This activity takes the participants outside of their comfort zone, engages their creativity and breaks down the barriers between them. It's called the 'Perfect Day' exercise.

The instructions for this exercise are to work in groups of about eight people and to use a variety of materials (feathers, paints, magazine photos, pipe cleaners, cotton balls, etc) to illustrate hour by hour a perfect day for a person with dementia. By the end of two hours, each group is able to show the other groups a clear picture of what they want to provide for people with dementia. The results are always full of life, choices and experiences.

The combination of the systematic, problem-oriented approach with this creative, life-oriented approach can lead to some surprising results, not least being the sense of common cause and willingness to explore new ideas.

Taiwan's Ministry of Health and Welfare is hosting a Global Health Forum in October. The forum topic is 'Urban Life of the 21st Century: Sustainable, Safe and Healthy'. It will involve 500 participants from 30 countries. One of the sessions will focus on 'A perfect day for people with dementia'. I am sure that not all 500 participants will take part in this session, but there is something very encouraging about the thought of groups of very senior practitioners and policy makers from around the world unleashing their creativity and beginning to understand and share what they want to achieve for people with dementia. It is even more encouraging to understand that this session is part of a conference on urban life, not on dementia care per se.

Taiwan's Ministry of Health and Welfare is well aware of the problems it faces in improving the care it provides to people living with dementia. I have no doubt that a great deal of effort is going into the systematic exploration of these problems but, at the same time, the ministry is willing to step outside of the problem-oriented paradigm and address the issues and challenges from a different point of view.

I am wondering if it would be useful for the Commissioners and Counsel leading the Royal Commission into Aged Care Quality and Safety in Australia to engage in a similar exercise with a range of practitioners, policy makers and people living with dementia. Perhaps this would help all sides agree on what it is that we are aiming for in our efforts to improve the care of our elderly, particularly those living with dementia. A whimsical idea perhaps, but the Commissioners might welcome a respite from the constant barrage of problems and negativity they are exposed to.

And, on a serious note, there has been quite a lot of talk about paradigm shifts but, if there is one thing we know about paradigm shifts, it is that they don't come from within the existing paradigm. If the paradigm is to be shifted we have to find a way to look at the issues from outside of our current comfort zone. ■

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

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

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Cover image: Edie Mayhew (right) hugs her friend Catherine Barrett. Catherine's article on pp7-8 highlights a new project exploring the importance of intimacy for older people and people with dementia. Photo: Anne Tudor

CCTV trial Latest on Specialist Dementia Care Units

The Commonwealth Dementia and Aged Care Services fund is being used to provide \$500,000 for a 12-month trial of CCTV in at least five SA Health aged care facilities in South Australia. The pilot is due to start in the second half of 2019.

The SA Government will deliver the project with a UK company called Care Protect which specialises in audio-visual monitoring systems and services in health and social care settings. The technology detects excessive noise, and movement and light changes, triggering an alert to a reviewer who can view the footage within seconds of an event happening. All footage is stored off site in a secure and protected web-based setting and is monitored continuously by an independent team of clinical experts.

South Australian Premier Steven Marshall said, "This CCTV pilot will strengthen the safeguards in place for our frail, older population, provide greater transparency than ever before and hopefully give [people] greater peace of mind that their loved ones are receiving quality care."

Consumers, stakeholders and government representatives will be included on the steering committee which oversees the pilot. The outcomes of the pilot will guide the future use of the technology in SA Health aged care facilities.

The first competitive grant round of applications for Specialist Dementia Care Units (SDCU) was due to close on 28 May 2019, with providers in 12 Primary Health Networks (PHNs) able to apply for about \$1 million of funding per year for an eight-bed unit through a competitive grant round. The phase one units are expected to be operational from about April 2020.

Providers in the following PHN areas were invited to apply: Central and Eastern Sydney, South Eastern NSW, Country WA, Northern Territory, Tasmania, ACT,

Brisbane South, Brisbane North, Northern QLD, Central QLD Wide Bay and Sunshine Coast, North Western Melbourne and Adelaide.

The Specialist Dementia Care Program is intended to be a transitional service for people with dementia with complex responsive behaviours, allowing residents to move into a less intensive care setting when their situation improves.

The plan is that 35 units will be established across the country, with one in each PHN. The first prototype SDCU is at Brightwater's 'The Village' in Perth, and is set to open by

mid-2019. The second grant round is expected to be advertised in early 2021.

It was announced in March that HammondCare has already been awarded funding for two SDCUs through a non-competitive grant opportunity: one at its Kooyong Rd facility in Caulfield, Melbourne, and one on Macquarie Road in Port Macquarie, NSW. Both SDCU facilities are eight-bed units, and both will receive \$1.1 million per year until 30 June 2024. Residents moved into the Kooyong Rd facility after Easter, and Macquarie Road was completed in May.

Inquiry: standard of care key issue

The standard of care for people living with dementia in residential aged care facilities was a major issue of concern raised by many witnesses and submitters to the long-running inquiry into aged care regulation conducted by the Senate Community Affairs References Committee, which submitted its final report in April.

Specific concerns in relation to people with dementia included the lack of non-pharmacological interventions being used, physical and chemical restraint being applied indiscriminately, and the communication barriers presented by dementia not being appropriately addressed, resulting in a lack of overall clinical care such as pain management.

The inquiry began in 2017

and initially focused on the care failures at the Oakden facility in South Australia. In its second phase it focused on the standard of clinical care provided to aged care residents across Australia. The Committee made 14 recommendations in its final report, including that government expand the role of the Aged Care Quality and Safety Commission, develop benchmarks for staffing levels and skills mix, make changes to ensure that the use of antipsychotic medications in aged care facilities are approved by the Chief Clinical Advisor of the Aged Care Quality and Safety Commission, and that the Commission develop a regulatory model to oversee medications management in residential aged care facilities.

Funding for PainChek® trial

In late April, the Morrison Government announced a \$5 million grant to fund a national trial of PainChek® – the pain identification app for smartphones originally conceived at Western Australia's Curtin University and then developed by Australian digital health company PainChek Ltd. The PainChek® app uses artificial intelligence to determine a person's pain using facial recognition analytics.

The funding will allow for a one-year universal PainChek® access license for the more than 1000 residential aged care providers in Australia and their 100,000 residents living with dementia. In early May, the contract was in the process of being finalised.

PainChek® CEO Philip Daffas said the funding would allow broader application of the app to strengthen analysis of its effectiveness. "This is welcome, given the significant benefits being reported at the dozens of residential aged care centres that already use PainChek®," Mr Daffas said.

"This will help refine how the app can be integrated into everyday clinical care, where PainChek® effectively gives a voice to people who cannot verbalise their pain."

Palliative care and dementia

People with dementia are under-served in terms of accessing palliative care, and it should be a priority to support people with dementia to prepare, use and maintain an advance care plan, according to the recently released updated National Palliative Care Strategy, published by the Department of Health. The previous strategy was produced in 2010. Palliative Care Australia (PCA) CEO Rohan Greenland said the updated strategy provides a road map for the future of palliative care services across Australia. PCA released an associated document, *Palliative Care 2030*, to coincide with the publication of the updated strategy, in which it also noted that a "change in focus towards people living with dementia" will be needed. *Palliative Care 2030* outlines guiding principles to assist the health, disability and aged care sectors, governments and the general community to plan and prepare for the future where Australians will live longer, demand an improved quality of life, and access to high-quality palliative care when living with a life-limiting illness.

Strengthening restraint regulations

Stronger regulations relating to the use of physical and chemical restraints in residential aged care homes were signed into law in April – requiring providers to satisfy a number of conditions before restraint can be used.

From 1 July 2019, following amendments to the *Quality of Care Principles 2014*, providers will have to arrange for an assessment by an approved health practitioner before physical restraint can be used, or assessment by a medical practitioner or nurse practitioner who has prescribed the medication before chemical restraint can be used.

The aged care home must also have the informed consent of the consumer or their representative before using

physical restraint, unless restraint is necessary in an emergency. In all cases of restraint, the home will also be required to document the alternative options to restraint that have been used. Any use of restraint must also be regularly monitored.

The Government was also requiring the collection of three quality indicators for all Commonwealth-subsidised residential aged care providers from 1 July 2019: the use of physical restraint, pressure injuries and unplanned weight loss. This will be part of the National Aged Care Quality Indicator Program, which began in 2016. Until now participation has been voluntary, but it will be compulsory from July.

Royal Commission into disability abuse

The establishment of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability was announced in April, with Ronald Sackville AO QC as Chair, supported by five other Royal Commissioners.

The Royal Commissioners will be inquiring into all forms of violence against, and abuse, neglect and exploitation of people with a disability, whatever the setting or context. Funding will support people with disability to participate in the Commission.

The Commissioners are required to provide an interim report no later than 30 October 2020, and a final report by no later than 29 April 2022. As of early May, the Royal Commission was not yet accepting submissions. More information is available at: <https://disability.royalcommission.gov.au>

Meantime, on 22 March 2019 the Federal Government published a *Younger People in Residential Aged Care National Action Plan* to take concrete actions to reduce the number of younger people with a disability living in aged care and to help them access more age-appropriate housing and supported living options. The Department of Health has reported that in September 2018 there were 5905 people aged under 65 living in residential aged care facilities across Australia. The plan is available to view on the Department of Social Services website (www.dss.gov.au).



Port Macquarie sees RED: Clients living with dementia knitted decorations for trees and fixtures in Port Macquarie's Town Green in March ahead of a two-day annual dementia conference hosted by support provider Omnicare Alliance. These included a beanie for the head of a bronze statue of Edmund Barton, Australia's first Prime Minister (pictured). RED Conference 2019 (A Regional Experience in Practical Dementia Care) attracted 300 delegates from across Australia. US Montessori for Dementia pioneer Dr Cameron Camp and UK dementia design specialist Lesley Palmer, from the University of Stirling, were the keynote speakers. John Quinn, who lives with younger onset dementia, provided an inspiring and insightful first-hand perspective.

News in brief

New dementia discovery

An international group of 35 researchers has reviewed thousands of post-mortem results and concluded that a new type of dementia exists – called Limbic-predominant Age-related TDP-43 Encephalopathy, or LATE. The group has now put forward recommended diagnostic criteria and guidelines for advancing future research into LATE, and published the work in the journal *Brain*. In LATE, there is an accumulation of the protein TDP-43 in the brain (rather than amyloid and tau in Alzheimer's disease), with three brain areas primarily affected: the amygdala, hippocampus and middle frontal gyrus. Some of the symptoms are similar to Alzheimer's disease (for example substantial cognitive impairment), but LATE tends to present more among people over 80 years old and with a more gradual decline in memory. LATE can also coexist with Alzheimer's disease. The researchers say one in five in the over-80s age group has LATE (with potentially up to one in two), and that the public health impact of the disease is likely to be quite significant. The researchers believe that LATE may explain the failure to discover effective pharmacological treatments for Alzheimer's disease to date and that there is an urgent need to develop a biomarker for LATE.

Dementia Centre of Excellence

Curtin University Vice-Chancellor Professor Deborah Terry has announced that planning is underway for a new Dementia Centre of Excellence to be established at the university's Bentley Campus in Perth. Curtin University will contribute \$10 million to fund the centre's fit-out, implementation of activities and an initial research program. \$10 million of Federal Government funding was promised in March 2019 as part of the Federal Budget to go towards building the centre. Professor Terry said the new centre would focus on the prevention, diagnosis, treatment and management of dementia. She said it would provide targeted workforce training programs for community, hospital and residential care staff and implement important prevention initiatives through collaborative research. A key element of the centre's design will be making it a dementia-friendly environment to support a range of activities for people living with dementia, as well as their carers and health professionals.

Charter of Rights launched

The Australian Department of Health has reminded aged care providers that they have responsibilities to support consumers to understand the new Charter of Rights that comes into effect from 1 July 2019. From that date, providers must give consumers a copy of the new Charter signed by the provider, and ensure that the consumer or their authorised person has been given a reasonable opportunity to sign a copy of the Charter. Residential aged care services will have until 30 September 2019 to provide the signed Charter to their residents. Home care providers will have until 31 December 2019. Consumers are not required to sign the Charter and can commence, and/or continue to receive care and services, even if they choose not to sign. The new Charter builds on the new Aged Care Quality Standards which also come into effect from 1 July 2019. It will be available on the Department of Health's Ageing and Aged Care website (<https://agedcare.govcms.gov.au>, search 'News and resources').

Shining a light on research outcomes

The NHMRC National Institute for Dementia Research (NNIDR) annual Australian Dementia Forum will take place in Hobart on 13-14 June 2019. This year's theme, Shining a Light On The Impact Of Dementia Research, will bring together over 370 delegates and feature 209 presentations from 198 researchers, seven people living with dementia and three carers, addressing the impact and outcomes across diagnosis, treatment and care. A free public information session on Friday 14 June aims to translate the latest research for a non-scientific audience, with an in-depth Q&A session for members of the public featuring Dr Alex Bahar-Fuchs, Dr Jeff Williamson, Dr Sharon Naismith and Dr Michele Callisaya discussing the impact of their research. To register for the session, visit <https://adf19.eventbrite.com.au>.

Coalition to continue aged care reforms

The Morrison Government has been given a mandate to continue with its reforms in aged care, with the Liberal-National Coalition claiming victory in the federal election held on 18 May.

In its efforts to be returned to Government, the Liberal Party campaigned on its record, saying that the Government has increased aged care investment by \$1 billion a year since 2013, with a further \$7 billion boost announced in the latest budget.

It said the Government understands the need to grow the professional aged care workforce.

A key Coalition election promise was a \$34 million commitment for a

Response to campaigns: In the days leading up to the election, key sector organisations had challenged both parties on their lack of interest in aged care reform and said that urgent action was needed now – before the Royal Commission has concluded its work.

The National Aged Care Alliance, a coalition of 52 national organisations in aged care, said it was “disappointed by the lack of real and decisive action by both major parties to get aged care right for everyone”.

COTA Australia Chief Executive, Ian Yates, said the next Government must eliminate the 125,000-strong wait list in home care and that COTA was “extremely disappointed” at the lack of clear funding for extra home care packages.

Dementia Australia Chair, Professor Graeme Samuel AC, said: “At the first opportunity after the election we will be approaching the Prime Minister and Health Minister with an urgent call to action that those living with dementia can’t wait another 12 months for the Royal Commission to hand down its findings.”

new Aged Care Workforce Research Centre.

The Morrison Government’s April budget saw a new major commitment to dementia research (\$185 million to the Dementia, Ageing and Aged Care Mission through the

Medical Research Future Fund), but other dementia-specific funding commitments (eg, an increase to the home care supplement for dementia and cognition) had already been announced.

Before the election, the

Morrison Government committed more than \$1 million for Alzheimer’s WA to expand the Building a Better Dementia Response in Indigenous Communities project over the next two years.

Dementia care focus for Royal Commission

Residential care – with a focus on dementia care – was the topic for the third public hearing of the Royal Commission into Aged Care Quality and Safety in May.

Peter Gray QC, Counsel Assisting, said that the “constant theme” of this hearing was “the need to respect the enduring humanity of the people in care, no matter how far their cognitive function might have declined and no matter how challenging it might seem to be to care for them”. “The expert evidence suggests that a lack of understanding of dementia is common in the health and aged care sector and is likely to lead to substandard care,” he said.

The Royal Commission heard from over 40 witnesses, including people living with dementia and relatives, service providers, academics and subject experts, health professionals, care and nursing staff and Department of Health staff.

A number of witnesses gave personal and at times distressing testimonies about their, or a relative’s, experiences in aged care facilities. Issues of restraint, pain management, activities, communication between hospitals and care facilities, and within facilities and with families, came up repeatedly.

Lucy O’Flaherty (Glenview), Jennifer Lawrence (Brightwater) and Tamar Krebs and Jonathan Gavshon (Group Homes Australia, GHA) – all chief executives of

aged care organisations – were questioned on what constitutes good practice for people living with dementia, particularly in residential aged care. Ms Krebs described GHA’s home-like approach, saying she believed it can be adapted to other residential aged care facilities. Ms Lawrence said good care started with getting to know the resident, “what their care needs are, but also who they are as a person”. Ms O’Flaherty said that staff skills and training make the difference in offering good dementia care.

Professors Dimity Pond, Elizabeth Beattie and Henry Brodaty were asked questions on a wide range of issues, including the complexities of diagnosis, the significance of person-centred care, the need for education and training among health and care staff, pain assessments, and polypharmacy. Dr Juanita Westbury spoke about the use of psychotropic medication in residential aged care facilities, and her work on the RedUSE project. Professor Joe Ibrahim spoke about risk factors for residents in care facilities, and the “dignity of risk”. He said there was no evidence that physical restraints “improve your life or protect you from anything”.

Glenn Rees, chair of Alzheimer’s Disease International and previously CEO of Alzheimer’s Australia (until 2015), shared his vision for the key elements of a system of care for those with dementia, and how it

might be achieved in Australia. Associate Professor Stephen Macfarlane, Head of Clinical Services with HammondCare’s Dementia Care, and for Dementia Support Australia, said the dementia training that many aged care staff received was “really inadequate”, and was a more important issue than staffing levels within facilities.

Dementia advocates Trevor Crosby and Kate Swaffer also gave evidence, with Ms Swaffer speaking about the critical importance of human rights in dementia care. She said that stigma about dementia was still very prevalent, and that “being denied access to rehabilitation is stigma within the health care system”.

The Commission’s second hearing, in Adelaide from 18-22 March, focused on home care, with Senior Counsel Assisting, Dr Timothy McEvoy, detailing seven topics that were “cause for great concern”: My Aged Care; the home care waiting list; approval of home care providers; regulation; fees and charges; Consumer Directed Care policy; and the workforce.

The Commission released three new background papers in May, including one on the prevalence of dementia and another on restraint. Its next hearing is expected to begin on 17 June. For details and to access the background papers, visit <https://agedcare.royalcommission.gov.au>. The Commissioners’ interim report is due by 31 October 2019.

Intimacy Bank: promoting connection and wellbeing

The Australian Association of Gerontology's (AAG) Glenda Powell Travelling Fellow for 2019, **Catherine Barrett**, explains how her Fellowship project will create a 'vault' of wisdom and evidence related to intimacy and ageing, to be shared with service providers, older people and people living with dementia

This year's AAG Fellowship 'Hot Topic' is intimacy and ageing. This hot topic considers how longer lives and changing norms affect older people's intimate relationships. It also looks at the role that sexuality plays in health and quality of life of older people. Some of the issues raised include: what is the role and meaning of sexuality and intimacy for older people? What happens to older couples when one of them has dementia? How can we support lesbian, gay, bisexual, transgender and intersex (LGBTI) people with their sexuality and identity in later life? What can we do to prevent abuse of older people in intimate relationships? (AAG 2019).

My focus for the Fellowship is an innovative approach to education called Intimacy Bank. The aim of Intimacy Bank is to promote health, wellbeing and interpersonal connection through recognition of the ways intimacy matters and changes as we age. At the heart of Intimacy Bank is a 'vault' of wisdom and evidence related to intimacy, which will be shared in workshops for service providers, older people and people living with dementia.

Filling the vault

The process for filling the Intimacy Bank vault involves learning from service providers, researchers, older people and people living with dementia. AAG hosted a workshop in May, with another to be held later this year (date TBA), to engage service providers in articulating their concerns and suggestions for



Anne Tudor (left) and her partner Edie Mayhew, who is living with younger onset dementia, have afternoon tea in the garden of their Ballarat home in 2018, shortly before Edie moved into residential aged care. The voices of people such as Anne and Edie are informing the development of the Intimacy Bank resource. Photo: Catherine Barrett

aspects of intimacy they want addressed by the Bank. In addition to this, I will be working with older people, people with dementia and their families to identify their issues and priorities.

While multiple perspectives are often gathered in research and consultation, the voices of older people and people living with dementia are often not privileged in the resulting resources and other outputs. It has been argued that the lack of first-person accounts in research and other reports has contributed to the failure to adequately address intimacy as a critical aspect of health and wellbeing. To bridge this gap, the resource development for Intimacy Bank is being led by older people, including people living with dementia. Their voices are being privileged and early indications, from my

discussions, demonstrate a shift to a broader focus on intimacy.

Learning from people with dementia

The power of learning from people with dementia and their families has been highlighted in the work I have done with the Museum of Love. The Museum concept emerged from discussions with people living with dementia, who reported that initiatives to address intimacy or sexuality too often had a limited focus on sex, or sexual consent in particular. While these topics are seen as important, the critique by people with dementia and their families is that they are just one of the many aspects of intimacy that need to be considered. What is seen as particularly pressing is the need to broaden the focus to addressing the

challenges that can arise in intimate relationships with partners, children, grandchildren and friends.

The challenges that can present in intimate relationships when someone has dementia are the focus of the Museum of Love's Small Acts of Love project. This online resource has been produced from presentations by people with dementia and their families at the Festivals of Love and Dementia hosted by the Museum of Love in 2017 and 2018. Presenters were invited to identify challenges and their strategies to address these. The resulting resource is considered by people with dementia and their families as an invaluable tool for learning practical ways to improve their relationships, health and wellbeing. The Small Acts of Love resource is also a useful tool for service providers to learn from people with dementia and their families and can be accessed at: www.museumoflove.com.au/small-acts-of-love.html.

Intimacy Bank topics

This approach to learning from people with dementia and their families also underpins the Intimacy Bank project. Conversations with older people and people living with dementia have already shaped the project design and the topics that will be addressed. Topics that have been suggested include: skin hunger; connection; desire; communication; pleasure; masculinity and power across the intersections of disease, disability, sexual orientation, gender identity and ethnicity.

The topics and content are

2019 Glenda Powell Travelling Fellow: Dr Catherine Barrett

Each year the Australian Association of Gerontology (AAG) hosts the Glenda Powell Travelling Fellowship, honouring AAG's first female president, Dr Glenda Powell.

The Glenda Powell Travelling Fellow (GPTF) is awarded to a leading Australian expert who presents on the annual 'AAG Hot Topic' in various locations across Australia over the course of the year. The GPTF is selected by the AAG Board and announced for the following year at the AAG Conference in November.

This year the AAG's Hot Topic is 'Intimacy and ageing' and the 2019 Fellow is Dr Catherine Barrett (pictured), the Founder and Director of the Celebrate Ageing Program, a social enterprise challenging ageism and building respect for older people. Celebrate Ageing uses art and narrative-based approaches to create social and policy change. The program includes: The Museum of



Love, exploring the importance of love in the lives of people living with dementia; The OPAL Institute, addressing the sexual rights of older people; and Alice's Garage, empowering LGBTI elders and promoting healthy LGBTI ageing.

In 2018, Dr Barrett was shortlisted as a finalist for the Human Rights Medal awarded by the Australian Human Rights Commission. She has worked with older people for over 30 years in a range of roles, including as a clinician, educator, researcher, academic and capacity builder, and has conducted extensive research on sexuality and ageing. To find out more about the work of Celebrate Ageing, go to www.celebrateageing.com.

A short essay introducing this year's AAG Hot Topic, 'Intimacy and ageing', is available to read on the AAG website, at www.aag.asn.au/education/aag-hot-topic-2019.

A co-leadership approach

The Intimacy Bank offers an opportunity to learn from people with dementia and their families about what matters to them. It steps beyond principles of co-design and co-production to co-leadership. In doing so the process and outcomes are shaped in ways that resound strongly with those they are being shaped for.

How to get involved

For more information about the Intimacy Bank project, workshops and training sessions this year, visit the AAG website (www.aag.asn.au), the Celebrate Ageing website (www.celebrateageing.com) or email Dr Catherine Barrett at director@celebrateageing.com ■

■ Dr Catherine Barrett is the Founder and Director of Celebrate Ageing, a social enterprise challenging ageism and building respect for older people

Reference

Australian Association of Gerontology (AAG) (2019) *AAG Hot Topic 2019: intimacy and ageing*. Available at: www.aag.asn.au/education/aag-hot-topic-2019

currently being refined in workshops with older people and will be further explored in the workshops for service providers held as part of the Glenda Powell Fellowship. A specific call-out will also be made in September via social media for people with

dementia and their families to help shape the process. The Intimacy Bank workshops will then be piloted with older people and people living with dementia to check that the information is useful and that the delivery is accessible. Workshop participants will be

given Bank books and invited to document their own intimacy wellbeing plan for each of the topics discussed. Train-the-trainer sessions will then be offered for peer educators and service providers who are interested in rolling out the training nationally.

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Nurse mentoring to build capacity and capability

Michelle Harris-Allsop highlights the value of an on-site mentor in helping nurses to build their capacity and capability to lead best practice care

A crucial component in implementing person-centred care for people living with dementia is dedicated dementia care specialists out *on the floor* supporting staff, volunteers and family carers to communicate with people who live with a cognitive disability. Despite training, there are still gaps in how to translate what we learn into everyday practice. Many nurses are highly skilled in dementia care, but adjusting the structure of a care team to include a designated dementia care specialist can help to provide practical leadership and build staff capability and confidence in communication skills that support people living with dementia.

Whilst a number of organisations do employ dementia consultants as part of their senior management structure, the people in these positions often oversee multiple sites or community care regions or are based at head office, external to the day-to-day care team. Care teams need mentors on the floor to role model effective communication approaches and the incorporation of person-centred philosophies into day-to-day routines.

Making A Difference

In September 2018 I had the pleasure of mentoring the nursing team at My Vista Aged Care in Perth, Western Australia in my role as a specialist dementia consultant with Care Partnerships Australia – a private consultancy for people with dementia and their carers (family and professional). My role as a coach is to build the



Michelle Harris-Allsop (far right) with members of the My Vista Aged Care nursing team and Clinical Director Dr Mya Daw Sein (far left)

capability of teams working with people who have a diagnosis of dementia in residential care services and private hospitals.

My Vista Aged Care provides care to 102 residents from culturally diverse backgrounds including Macedonian, Yugoslavian, Italian and Vietnamese. With support from My Vista's Clinical Director Dr Mya Daw Sein, I worked with a team of 12 nurses over two weeks in the care environment, sharing experience, knowledge and providing solutions for best practice in dementia care. We spent time reviewing the nurses' knowledge and how they can de-escalate responsive behaviours, communicate and create a calm environment for residents with dementia. The mentoring project was funded by My Vista and supported by its CEO Irene Mooney.

Care Partnerships Australia introduced the dementia mentoring program Making A Difference in 2018 for teams of Registered Nurses (RNs) and Enrolled Nurses (ENs) working in the community or in residential aged care. The

program aims to promote the online training from Dementia Training Australia (dta.com.au), with additional ongoing practical support from myself in translating the information into effective practice when the nurses are working and supporting a person living with dementia. I am currently providing similar support through the Making A Difference mentoring program at four other organisations this year: Braemar Aged Care, Curtin Heritage Aged Care, My Flex Care and St John Of God Hospital Subiaco.

The Making A Difference program's objectives are to:

- Provide an understanding of person-centered care.
- Provide practical strategies for effective communication.
- Improve the enablement and emotional wellbeing of the person living with dementia.
- Support calm environments.
- Improve knowledge on advance care planning and build capability and capacity.
- Support the staff to support family carers.
- Build partnerships of care.
- Support staff to recognise when the person with dementia is at

the end of their life.

Training includes: assessment and care planning for dementia, delirium and depression; communication techniques and responsive behaviours, including use of The Newcastle Model – a framework and process for understanding responsive behaviours in terms of unmet needs (Jackman & Beatty 2015); maximising quality of life for clients; dementia-friendly environments; promoting a restraint-free environment; pain management and palliative care approaches for people with dementia; managing sexuality in dementia care; and supporting families and carers of people with dementia.

Project evaluation

Nine out of the 12 nursing staff who took part in the two-week mentoring program responded to a survey seeking feedback on the program. The majority indicated they were 'very satisfied' with the introduction of the program, the advice, support and solutions offered using The Newcastle Model, the mentoring and advice provided by the consultant on the floor in the context of staff delivering care, development of staff skills, and the training modules provided.

When asked what areas they felt would be most important to address in family support and education, the nurses identified the following, in order of importance: communicating with a person with dementia; understanding the symptoms of dementia; advance care planning; ways to make interactions more meaningful (eg, reminiscence, memory

books); what to expect from a residential dementia care wing; self-care strategies and options for carer respite; and different care options and services available.

Project outcomes

- There has been a change in staff practice, knowledge and attitude in seeing the person with dementia first, not their disability.
- An improvement in the nurses' communication skills, using appropriate techniques (eg validation, reminiscence and reality orientation in their language).
- The nurses were enabled to support relatives and carers about a relationship model of care.
- Collaborative learning and engagement of the team.
- Renewed enthusiasm for best-practice dementia care.
- Staff were interested in challenging their feelings and became more enthusiastic in leading the care.
- The link between dementia

and disability is much clearer in the nurses' minds following the program. They became invested in the human rights of people living with dementia and how their attitude and approach to caring impacts on the wellbeing of the person in their care.

Feedback

Comments from participants included:

- "[the consultant was] able to share knowledge with team members to improve the quality of care to clients with dementia and their family."
- "Staff applied knowledge and took on the training and resource tools and shared with clients/families and peers."
- "One staff member nominated her colleague for suggesting and implementing a care plan strategy that promoted wellbeing and security for the client."
- "Strength-based assessments identified opportunities to improve care plans and

results were witnessed by [sic] increased client happiness and reduced behaviours, leading to reduced carer stress."

- "[It] was a great course. [It] would have been beneficial to have everyone who was doing the modules together for at least one full day."
- "Increased knowledge and building capability within the nurses at site."

Challenges

The challenge was always finding RNs/ENs to backfill the roster when the team worked with me in small groups during the two-week program.

Dementia mentoring

The Making A Difference dementia mentoring program is structured around a model of professional practice in a practical setting. For further details contact me at carepartnershipsaustralia@gmail.com or visit the Care Partnership's Australia website at www.careptyltd.com

Acknowledgments

Thanks to residents and staff at My Vista Aged Care, Dr Andrew Stafford and Katrina Fyfe from Dementia Training Australia, Irene Mooney CEO My Vista, and Dr Mya Daw Sien, Clinical Director My Vista. Care Partnerships Australia is not affiliated with any particular organisation.

■ Michelle Harris-Allsop is a specialist dementia consultant at Care Partnerships Australia where she oversees the clinical practice of student nurses and the delivery of care for people living with a diagnosis of dementia across residential and community care in Western Australia, Kuala Lumpur and Singapore. She is a Registered Nurse with a Master's Degree in Gerontological Nursing. Contact her at carepartnershipsaustralia@gmail.com

References

Jackman L, Beatty A (2015) Using the Newcastle Model to understand people whose behaviour challenges in dementia care. *Nursing Older People* 27(2) 32-39.
Rahman S (2017) *Enhancing health and wellbeing in dementia: a person-centred integrated care approach*. London: Jessica Kingsley Publishers.

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Bridging the gap in YOD diagnosis, care

Younger onset dementia (YOD) is a debilitating terminal illness, with dementia onset prior to 65 years of age. It affects approximately 25,000 Australians and makes up 10% of all dementia cases (Brown *et al* 2017). While dementia is a National Health Priority Area, people with YOD fall through clinical service gaps and struggle to access the highly specialised expertise required to diagnose and manage their unique sets of needs.

Diagnostic delay is common in those experiencing YOD, taking on average two to four years to reach a diagnosis (Van Vliet *et al* 2013). A diagnosis of YOD can result in up to 20 years of life lost (Brodady *et al* 2012) with multiple and complex presenting features requiring specific expertise for diagnosis and care. The spectrum of disorders causing YOD is broad, from conditions such as Alzheimer's disease and frontotemporal dementia, through to very rare disorders such as Niemann-Pick Type C. People with YOD and their carers face hurdles at all stages, including navigating employment, caring for school age children, financial and psychological stress, grief, and the prospect of facing a life-limiting, possibly hereditary illness.

Specific challenges

Delay in diagnosis

Despite the differing conditions which cause YOD, those experiencing it share common issues, particularly delay in diagnosis. A recent audit of 304 inpatients (2014-2017) from our service, the Melbourne Young Onset Dementia Service (MYOD) in the Neuropsychiatry Unit at



Dr Wendy Kelso (front left) and Dr Sarah Farrand (front right) with (on screen) social worker Jacinta Flood (left) and neuropsychologist Dr Deborah Goff, from the Albury Cognitive Dementia and Memory Service, during a BRIGHT-YOD telehealth meeting.

Photos: Melbourne Health

Royal Melbourne Hospital, revealed that each person had seen an average of five specialists prior to referral, (without including general practitioners or allied health assessments), with a mean duration of symptoms of 5.6 years and mean diagnostic delay of 2.9 years, in keeping with worldwide estimates (Van Vliet *et al* 2013).

Timely diagnosis is crucial to ensure early intervention, adequate treatment and the ability to plan for the future. A delay in diagnosis can have wide-ranging consequences for the person with YOD and their family, including loss of employment and entitlements, increased carer burden, marital breakdown and significant psychological difficulties for affected children. The average life expectancy from onset of symptoms for YOD ranges from 1.3 years (ie for rapidly progressive illness such as frontotemporal dementia with motor neuron disease) to 7.9 years (Brodady *et al* 2012).

Given a diagnostic delay of up to and sometimes more than four years (Van Vliet *et al* 2013), the diagnosis is often made when there are few quality years left for the person with dementia and their carer/family unit.

Barriers to early diagnosis include difficulties accessing appropriate YOD services, a lack of medical awareness/confidence in diagnosing YOD, the broad range of aetiologies and the clinical overlap with psychiatric conditions. The initial symptoms of YOD are often changes in emotion, personality or behaviour, which are misattributed to a psychiatric condition, resulting in the person then being directed to psychiatric services (Van Vliet *et al* 2013).

Quality of life and carer burden

Individuals with YOD have markedly increased rates of anxiety and depression and significant reductions in quality of life. This is equally true for partners and carers.

BRIGHT-YOD is a new and innovative telehealth project designed to improve access to specialist diagnosis and care and reduce costs for people with younger onset dementia (YOD) across Victoria, particularly in regional and rural areas.

Sarah Farrand, Wendy Kelso, Stefanie Colella, Melinda Sorraghan and Dennis Velakoulis explain how the project is tackling the specific challenges faced by people with YOD

Recent assessment of quality of life of 69 YOD outpatients in our service using the EQ-5D-5L (a standardised instrument for measuring general health status), found a mean index of 0.551, indicating 2.75 Quality Adjusted Life Years (QALYs). Thus, if one presumed a further five-year life expectancy (where one QALY equates to one year of perfect health), these outpatients had only 2.75 years out of these five with good health. Prominent difficulties experienced by people with YOD, such as anxiety, depression and inability to work/drive, do not fit as well into support services or systems such as the National Disability Insurance Scheme. To the frustration of individuals and carers, their needs fall between service gaps – “too young for some, too old for others, too complex for most”.

Other issues faced by people living with YOD and carers include limited access to community care or meaningful activity, high

levels of child, family and carer burden, the prospect of the illness being genetic and the significant lost productivity costs for the person with YOD and their carer. High levels of carer burden due to a lack of appropriate YOD specialist services, community day programs and specific respite options lead to crisis hospital admissions and earlier entry into residential care (Kane *et al* 2005).

Service access

Despite reporting high levels of carer burden, people living with YOD and carers under-use formal specialist services (Cations *et al* 2017). There are approximately 6213 people living with YOD in Victoria (Brown *et al* 2017), however actuarial estimates suggest that less than half of these will access YOD specialist services. Reasons for service under-use include (Cations *et al* 2017):

- Limited accessibility (distance/financial cost/loss of productivity/absence of childcare).
- Lack of appropriate services for younger people (education/support groups/planned activity groups/residential aged care facilities).
- Community awareness and stigma.

A recent review of YOD service access found that people with YOD and carers were calling for YOD specialist services that allow for tailored and timely intervention, flexible access, financial accessibility, case management and meaningful engagement (Cations *et al* 2017; Sansoni *et al* 2016). Centralised multidisciplinary care has been proven to confer a survival advantage for people with neurodegenerative illness and is superior to devolved community-based care (Rooney *et al* 2015).

YOD-specific factors impacting on access to care

Due to the degenerative nature of their illness, the



The BRIGHT-YOD team (from left) Melinda Sorrhagan, Dr Wendy Kelso, Stefanie Colella, Dr Sarah Farrand and Professor Dennis Velakoulis

majority of people living with YOD have cognitive and/or physical limitations that impact on their ability to travel to hospital appointments independently. Families with YOD face economic disadvantage due to loss of income both for the person with YOD and the carer/family unit if they are absent from work. Due to the younger age of the carers, work and childcare commitments can negatively impact on ability to attend medical appointments.

Enabling YOD-specific care

Telehealth has the potential to efficiently and effectively deliver specialist healthcare to those living in regional, rural and remote areas, as well as for those with impaired cognition, mobility and social isolation. Uptake of telehealth across Australia has soared in the past decade, with government data showing 1808 specialist services delivered via telehealth in the first quarter of the 2011-12 financial year, compared with 36,729 in the first quarter of the 2015-16 financial year. Psychiatry has thus far led the charge, with 39.5% of all specialist telehealth items billed in the 2017-2018 financial year, though this still makes up only 3% of all psychiatry consults (Department of Health n.d.).

Based on current service and

prevalence data it's estimated that of the approximately 6000 Victorians with YOD, about 500 people are living in residential aged care facilities and may not be able to attend specialist clinics; approximately 500 individuals with YOD are managed by private practitioners (GPs, geriatricians, neurologists and psychiatrists) and up to 3000 people with YOD are not attending specialist YOD clinics, suggesting substantial unmet need and service under-use.

Analysis of service data from the Neuropsychiatry Unit's MYOD Service over a 12-month period (2017-2018) revealed that 130 (37%) individual outpatients and 47 (49%) inpatients were from outside a major city. For the rural and regional Victorian outpatients, the average distance travelled was 269km (for those travelling more than 50km). Interstate outpatients travelled on average 540km. To translate this to travel and lost productivity costs for a person with YOD/carer attending from a distance less than 50km this equated to \$257 per visit; between 50-100km, \$455 per visit; and greater than 100km, \$633 per visit.

The BRIGHT-YOD Project

Given the projected unmet need in a relatively small state such as Victoria, and the significant costs to people

living with YOD and carers, the BRIGHT-YOD project was launched in Victoria on 1 April 2019 to improve access to diagnosis and care for those with possible younger onset dementia, whilst reducing costs associated with accessing specialist clinics. BRIGHT-YOD (Bridging Gaps in Health using Telepsychiatry for Young Onset Dementia) is a collaboration between the MYOD Service based in the Neuropsychiatry Unit at Royal Melbourne Hospital, four Cognitive, Dementia and Memory Services (CDAMS) (Ballarat, Shepparton, Albury-Wodonga and Royal Melbourne Hospital), Huntington's Victoria and Dementia Australia. The MYOD Service is one of the few services nationally that can provide tailored, flexible and expert services to those affected by YOD. The project is funded and supported by Better Care Victoria, a branch of the Department of Health's Safer Care Victoria.

Services offered through the project include: neuropsychiatric and neuropsychological assessment, primary or secondary consultations, second opinions, education and carer/client support. Video interpreting services are also available.

The aims of this project are to:

- Further assess and understand the needs of people living with YOD and families, and the unmet need across Victoria.
- Increase access to YOD-specific care (including diagnosis and ongoing management).
- Reduce costs for people with YOD and carers in accessing YOD-specific care.
- Partner with rural care providers, including CDAMS, Dementia Australia and Huntington's Victoria, and deliver capability-building sessions for these multidisciplinary teams.
- Assess and improve quality of life, and burden of

illness/caring for people with YOD and carers.

- Formally assess the cost-effectiveness of this telehealth service.

Early outcomes and learnings

Since the BRIGHT-YOD project went live on 1 April 2019 there have been 13 people seen as part of the pilot implementation. Whilst more data is required to assess the overall aims and outcomes of the project, there have been over 7600km saved for clients and their families with over 1.9 tonnes of carbon emissions saved.

Of particular value to the project team has been the involvement of people with YOD and families through participation in a focus group and as members of the project steering committee. Themes that have emerged from this have included:

- The need to offer telehealth and face-to-face contact as a choice to those being referred to the service – not assuming that people may want one or the other.
- Being mindful of delivering diagnoses via telehealth. Those who lived closer to major metropolitan centres felt more likely to want to do this face-to-face, whereas those who were a three- or four-hour drive away felt telehealth would be more acceptable for delivering diagnoses, but may wish to have these appointments at their GP clinic rather than home, to enable more professional support face-to-face if required.
- Considering terminology: as health professionals, we may refer to those using the service as our ‘patients’ and their spouse, children, neighbours etc their ‘carers’, but these are terms that our clients may not identify with and, in fact, may reject. People felt that they entered a diagnostic assessment as partners, competent workers, parents and the like, and came out as a ‘patient and carer’ even

though they didn’t feel any different than before the appointment.

Our other learnings from interactions with colleagues and clients, attending telehealth conferences, and learning from enthusiastic telehealth teams, have been that whilst clinicians may feel that telehealth is ‘less than’ or that they can’t offer the same care, clients are often very satisfied with this option. Whilst clinicians may feel they have to work harder to develop rapport, and do things slightly differently to normal (ie arranging tests in the person’s local area), clients can feel empowered and like the fact that there is a ‘levelling of the playing field’, or that they can undertake cognitive assessment in the comfort of their own home, which reduces their anxiety.

Client feedback

Regarding the use of telehealth: “It was a great benefit as we have had extreme difficulty getting [person with YOD] to attend any of his appointments. This was a great option for us.”

Perceived benefits include: “Travel, accommodation costs, time on roads, embarrassment, food, fuel, frustration, anger. The list could be endless depending on the road and weather conditions.”

Challenges

The challenges are both the expected, such as internet connection difficulties, overcoming health service firewalls, and rescheduling appointments when things do not go to plan; and the unexpected – the ‘metrocentricity’ of clinicians, assumptions that Victoria is a small state without a need for telehealth services, overestimation of clinical risk involved with undertaking telehealth consultations, or the view that telehealth consults can only be ‘better than nothing’ as opposed to equal or even preferable.

Future directions

Recent figures showed that psychiatry is leading the charge with telehealth, but there is still huge scope for incorporating telehealth into business as usual. The utility of telehealth is not just in enabling client-doctor interactions, but in facilitating case managers, care coordinators and distant relatives to join in important discussions, broaden multidisciplinary care planning, deliver education and many other areas. Critical to the development of telehealth services is the inputs of service users as well as considering the preference not only of rural clients but those in cities, where clients may still travel up to an hour one way to reach specialist appointments. For areas of practice such as YOD, where centralised specialist care is the gold standard, development of evidence-based telehealth models of care needs to be a priority in order to provide equity of access to all Australians. ■

Inquiries and referrals

For more information about the BRIGHT-YOD project and the MYOD Service, visit <http://www.neuropsychiatry.org.au>. For inquiries and referrals, email NPUReferrals@mh.org.au. A referral form can also be found on the website.

Acknowledgments

The BRIGHT-YOD project is funded by Better Care Victoria and supported by the executive teams of Melbourne Health and NorthWestern Mental Health. We acknowledge the time and perspectives of the people living with dementia and their supports who have shared their journey with us to shape this project and our ongoing clinical work. We would also like to acknowledge the telehealth team at The Royal Melbourne Hospital for their time, willingness and expertise, as well as the telehealth and virtual care community more broadly for their enthusiasm, expertise and knowledge sharing. Acknowledgment is also made to Hugh Sarjeant, who undertook actuarial estimates based on MYOD service data in order to

make the BRIGHT-YOD project a reality.

■ Dr Sarah Farrand (BRIGHT-YOD Clinical Lead and Consultant Neuropsychiatrist), Dr Wendy Kelso (BRIGHT-YOD Clinical Lead and Senior Clinical Neuropsychologist), Stefanie Colella (BRIGHT-YOD project manager) and Melinda Sorraghan (administration) are all with the Melbourne Young Onset Dementia Service (MYOD), Neuropsychiatry Unit, Royal Melbourne Hospital, Victoria; Professor Dennis Velakoulis is BRIGHT-YOD Project Lead and Clinical Director and Consultant Neuropsychiatrist at the Melbourne Neuropsychiatry Centre, University of Melbourne, Victoria. To follow up on this article, contact Sarah at Sarah.Farrand2@mh.org.au or Wendy at wendy.kelso@mh.org.au

References

- Brodaty H, Seeher K and Gibson L (2012) Dementia time to death: A systematic literature review on survival time and years of life lost in people with dementia. *International Psychogeriatrics* 24(7) 1034-1045.
- Brown L, Hansnata E and La HA (2017) *Economic cost of dementia in Australia 2016-2056*. Canberra.
- Cations M, Withall A, Horsfall R *et al* (2017) Why aren’t people with young onset dementia and their supporters using formal services? Results from the INSPIRED study. *PLOS ONE* 12(7) doi.org/10.1371/journal.pone.0180935.
- Department of Health (n.d.) *Medicare benefits schedule statistics*. Department of Health. Available at: <http://bit.ly/2H4MBDz>.
- Kane RL, Gaugler JE, Newcomer R *et al* (2005) Early community-based service utilization and its effects on institutionalization in dementia caregiving. *The Gerontologist* 45(2) 177-185.
- Rooney J, Byrne S, Heverin M *et al* (2015) A multidisciplinary clinic approach improves survival in ALS: a comparative study of ALS in Ireland and Northern Ireland. *Journal of Neurology, Neurosurgery & Psychiatry* 86(5) 496.
- Sanson J, Duncan C, Grootemaat P *et al* (2016) Younger onset dementia: a review of the literature to inform service development. *American Journal of Alzheimer’s Disease & Other Dementias* 31(8) 693-705.
- Van Vliet D, De Vugt ME, Bakker C *et al* (2013) Time to diagnosis in young-onset dementia as compared with late-onset dementia. *Psychological Medicine* 43(2) 423-432.

In Australia general practitioners (GPs) are often the first health professional consulted about memory problems. GPs tell us that one of the most challenging aspects of clinical dementia care is the assessment of driving safety (Scott *et al* 2019a).

We conducted a series of focus group discussions with a total of 29 GPs at their primary care practices in metropolitan and regional Queensland in 2016-2017. Our research identified that a lack of resources, support programs and referral pathways make it more difficult for GPs and other health professionals to facilitate driving cessation in their patients with dementia (Scott *et al* 2019a). While some drivers living with dementia may voluntarily stop driving, many others will resist their doctor's advice and continue to drive, for emotional, logistical and mobility reasons, or lack of insight and awareness into their own driving abilities (Liddle *et al* 2013; Scott *et al* 2019a).

Huge expectations

GPs tasked with managing the complex issues around driving and required to assess competence of drivers living with dementia have huge expectations placed on them. While medical professionals have a duty of care to the wider Australian community to monitor unsafe driving in their patients with dementia, GPs recognise that they are also advocates for their patients' health and this creates tensions around their relationship of trust with patients.

GPs acknowledge that they are best placed to diagnose health conditions that impact driving competence. However, they question whether it should also be their role to 'police' fitness to drive with their patients. In particular, a concerning outcome for GPs of monitoring driving with patients with dementia is worrying that patients who fear losing their licence will

Becoming car-free

Advising patients about when to stop driving is one of the most challenging aspects of clinical dementia care for GPs. A team of Queensland researchers has developed the CarFreeMe education program to support GPs and their patients in decision-making and the transition to driving cessation. **Theresa Scott, Jacki Liddle, Nancy Pachana, Elizabeth Beattie and Geoff Mitchell** report

withhold important clinical information from their GP, or fail to report memory issues or to seek medical attention for other health conditions (Scott *et al* 2019a). The Australian Medical Association's 2008 position paper pronounced that a treating doctor should not be the decision-maker in licensing due to the unacceptable ethical conflict that arises and the negative impacts on the therapeutic relationship (AMA 2008). With increasing numbers of older adults driving in later life and increasing numbers of people living with dementia, perhaps it is time that we re-examined Australia's system of managing driver retirement with people with dementia.

A complex issue

Driving is a complex task requiring the functions that dementia affects; not memory alone, but also visuo-spatial skills, reaction time, judgment, attention, and psychomotor functioning. Managing driving decisions with patients with dementia in primary care presents complex issues and difficult decisions for GPs, further complicated by lack of access to consistent medical information and advice. While a specialist driver-trained occupational therapist on-road assessment remains the gold standard, these can be associated with lengthy waiting periods or high out-of-pocket expenses for patients. There are no suitable off-road tests for identifying potentially at-risk drivers without also falsely identifying a large proportion of drivers as unsafe



The CarFreeMe program supports people with dementia to stay active after they stop driving and continue to engage in their normal activities out and about in the community.

Photo: rawpixel.com/Freepik

when in fact they are safe.

While there have been several attempts to develop suitable tests to be used in primary care, these have not yielded valid and reliable tests or batteries of tests (Rapoport *et al* 2018; Rapoport *et al* 2015). GPs must therefore resort to using what tests are available to them, often memory tests (Scott *et al* 2019). The problem with these tests is that they may impart the wrong message to patients – that safe driving requires memory only. If patients do not perceive the relevance of the tests to their own driving and perceive their own performance accurately, they may feel that the decision was unfair, or reject their doctor's advice and doctor-shop with the intention of getting a licence approval, or continue to drive unlicensed (Scott *et al* 2019).

The need to reduce stigma

around a dementia diagnosis is internationally recognised (Batsch & Mittelman 2012). The stigma surrounding the potential loss of a driving licence must also be addressed because stigma is a noticeable barrier to disclosing driving difficulties and acceptance of decisions, according to our research (Scott *et al* 2019).

Community education and awareness about the impact of dementia on driving is particularly important for the person with dementia and their family members, to ensure acceptance of the decision to eventually cease driving. Similarly, the general public would benefit from awareness-raising campaigns about the existing testing protocols to reduce stigma around people with dementia who continue to drive while safe to do so.

Significant personal cost

For people living with dementia, the transition to non-driving comes at significant personal cost to their social and occupational wellbeing. Being told that you can no longer drive can seem unfair and unbearable. Without necessary planning and supports in place, it can be overwhelming to think that you might not be able to do the things that driving enabled you to do, or get to the places that driving allowed.

While some people with dementia may voluntarily stop driving before they are advised to, for many, especially those who are unprepared, or informed that they must no longer drive at

the same time as receiving a diagnosis of dementia, the decision is often not accepted. Driving is a privilege, it is not a right. Nonetheless, immediate revocation of a driving licence should not be an outcome of a diagnosis because individual differences and disease progression is so variable, and because people have a right to drive for as long as they are safe.

Be prepared

Preparation is key. According to GPs, unprepared patients react with the most anger or grief when told that they can no longer drive. However, they report that such preparation is not always possible because of the difficulties already mentioned of objectively identifying when driving was likely to be impaired enough to impose restrictions (Scott *et al* 2019). Acceptance of the decision to stop driving is fundamental to successfully managing the transition to no longer driving, and finding, trying out and becoming comfortable with alternative modes of transport.

CarFreeMe

There are several driving 'decision aids' available which aim to support people with dementia to arrive at the decision to stop driving on their own. Our intervention, 'CarFreeMe', aims to fill a gap in clinical practice. We have developed the education and support-based driving cessation program for people living with dementia and their family members to support GPs and their patients in decision-making and transition to driving cessation. The focus is on early intervention, an approach which GPs tell us is pivotal to optimal management of patients with dementia. However, our intervention also supports people who have stopped driving, eg to deal with grief and loss associated with giving up their licence, to develop other habits and look for practical solutions to access the

Table 1: The CarFreeMe for people living with dementia intervention modules

Modules	Title and example content
1	Living with dementia: focuses on the changes that may occur with dementia, and strategies to live positively.
2	Balancing independence and safety: provides information about driving safety in later life and things for consideration regarding retirement from driving.
3	Adjusting to losses and changes: covers changes that may occur to lifestyle and feelings of loss and grief that may result from retiring from driving. It also includes strategies to use to help with adjusting.
4	Experience of retiring from driving: covers what it can be like to give up driving. Stories from other retired drivers and family members are included to highlight different ways that people have adjusted to giving up driving.
5	Alternative transport: covers the range of alternatives to driving that may be useful and ideas of where to find out more.
6	Lifestyle planning: covers things to consider in planning for achieving a balanced lifestyle.
7	Advocacy and support: focuses on services that are available to participants and the steps to take to improve the service/s, and to make service providers aware of these needs.

community and stay engaged (Scott *et al* 2019b).

CarFreeMe is a seven-week, workshop-style individual and small-group program facilitated by a professional CarFreeMe coach. The program includes seven modules (see Table 1 above) that are delivered by a health professional (eg occupational therapist, psychologist) who is trained in CarFreeMe delivery. The modules are delivered in person or by telehealth, on a portable computer or tablet.

Content and delivery

The content and delivery is designed to be person-centred and flexible, eg one-to-one, in-home, or small groups in community settings. Each individual session is one hour and each group workshop is between two to three hours. The intervention is individualised according to geographic location and participants' needs. For example, participants are encouraged to consider future transport arrangements, plan for lifestyle changes, and form realistic expectations of life changes after driving cessation. The experienced health professional will plan practical outings and practice using alternative transport

with participants. Importantly, participants are supported in their emotional adjustment to the role loss.

In the telehealth format the program is delivered by a mix of local health professional support (eg practical outings and local transportation use) as well as the health professional delivering content from the Telerehabilitation Clinic at The University of Queensland (UQ) in Brisbane via a secure telehealth videoconferencing app at the client's end.

Development

The CarFreeMe for people with dementia intervention is an adaptation of an effective driving cessation intervention for older people *without* cognitive decline: formerly known as UQDRIVE (Liddle *et al* 2014). It has been modified for people living with early-onset as well as late-onset dementia. The effectiveness of the original UQDRIVE program has been systematically examined with a general older adult population in a randomised controlled trial (Liddle *et al* 2014). Participants reported improvement in community mobility outcomes, self-efficacy, individualised transport and lifestyle goals,

and high levels of satisfaction following their participation.

How to participate

The dementia-specific program is available via participation in our current randomised controlled trials. At the moment we are offering our CarFreeMe program to people living with dementia in Queensland, ACT and southern NSW.

If you are outside these recruitment areas and are interested in referring a client or becoming involved, please contact us because we will have further trials and locations opening up across Australia to meet demand.

New participants can be enrolled in the study immediately. All participants and care partners are interviewed about their community life and wellbeing and then allocated to a CarFreeMe program.

Following our research trials, it is expected that the program will be made available to people living with dementia via service providers and health professionals who are trained in CarFreeMe delivery. To this end, an online training program is being developed and will be available via Uniquist at www.carfreeme.com.au ►

CarFreeMe Coaches

CarFreeMe Accredited Coaches are qualified and registered allied health professionals who have successfully completed the CarFreeMe Coach Accreditation Course, enabling them to conduct CarFreeMe Program workshops in their local area. For further information, contact Theresa Scott at theresa.scott@uq.edu.au.

Conclusion

For people living with dementia, stopping driving can signal the loss of independence, mobility, and a pleasurable activity. For GPs, who play a key role in identifying changes in functioning that impact driving competence, driving cessation is one of the hardest conversations to have. There is an urgent need for clear protocols for optimal patient management of driving and dementia and a national

standardised approach to medical assessment of driver fitness, including appropriate referral pathways to other health professionals who may contribute positively to transitioning someone from driving to non-driving. ■

For more information

For information about CarFreeMe, visit the website www.carfreeme.com.au. To find out more about our current face-to-face and telehealth-delivered CarFreeMe trials for people living with dementia in Queensland email Theresa Scott at theresa.scott@uq.edu.au or Donna Rooney donna.rooney@uq.edu.au; and in the ACT and southern NSW areas, Amy Nussio at a.nussio@uq.edu.au.

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The University of Queensland; Professor Elizabeth Beattie is Professor of Nursing and Director, Dementia Centre for Collaborative Research and Director Dementia Training Australia, at Queensland University of Technology; and Professor Geoff Mitchell is Professor of General Practice and Palliative Care at The University of Queensland.

References

- Australian Medical Association (2008) *The role of the medical practitioner in determining fitness to drive motor vehicles – 2008*. Available at: <http://bit.ly/2V7F76s>.
- Batsch NL, Mittelman M (2012) *World Alzheimer Report: overcoming the stigma of dementia*. London: Alzheimer's Disease International.
- Liddle J, Bennett S, Allen S, Lie DC, Standen B, Pachana NA (2013) The stages of driving cessation for people with dementia: needs and challenges. *International Psychogeriatrics* 25(12) 2033-2046.
- Liddle J, Haynes M, Pachana NA, Mitchell G, McKenna K, Gustafsson L (2014) Effect of a group intervention to promote older adults' adjustment to driving cessation on community mobility: a randomized controlled trial. *The Gerontologist* 54(3) 409-422.
- Rapoport MJ *et al* (2018) An international approach to enhancing a national guideline on driving and dementia. *Current Psychiatry Reports* 20 1-9.
- Rapoport MJ, Weegar K, Kadulina Y, Bedard M, Carr D, Charlton JL *et al* (2015) An international study of the quality of national-level guidelines on driving with medical illness. *QJM* 108(11) 859-869.
- Scott TL, Liddle J, Pachana NA, Beattie E, Mitchell, G (2019a) Managing the transition to non-driving in patients with dementia in primary care settings: facilitators and barriers reported by primary care physicians. *International Psychogeriatrics* doi:10.1017/S1041610218002326.
- Scott T, Liddle J, Mitchell G, Beattie E, Pachana N (2019b) Implementation and evaluation of a driving cessation intervention to improve community mobility and wellbeing outcomes for people living with dementia: study protocol of the 'CarFreeMe' for people with dementia program. *BMC Geriatrics* 19(1) 66.



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StepUp for Dementia Research

At present there is no systematic way for people with dementia and others to get involved in research in Australia. For researchers, recruiting study participants can be costly and time consuming. **Yun-Hee Jeon** and her team at the University of Sydney have launched a 'one-stop shop' for dementia research participation to tackle these challenges

Despite significant medical and technological advances, and the decades of research to find a cure for dementia, dementia remains largely incurable. The need to boost research investment in dementia prevention, diagnosis, treatment, care and cure is paramount.

However, recruiting participants in research can often be costly and time consuming. Delays in finding the right people for studies can result in funding extensions for study delivery, study samples insufficient for robust analysis and generalisation of findings, ultimately limiting the timeliness and effectiveness of research and evaluation. The problem can be especially challenging in research concerning stigmatised health conditions such as dementia. One in four people with dementia conceals their diagnosis and two in five withdraw from social and daily activities (Alzheimer's Disease International 2012).

Research has repeatedly shown that timely diagnosis and early intervention is critical to help people with dementia and their families to access appropriate services and treatments. However, symptoms of dementia are noticed by families on average three years before a firm diagnosis is made, and many people with dementia and carers are experiencing significant challenges to access care and the support services they need (Phillips *et al* 2011). Stigma and low dementia health literacy may lead to social exclusion and isolation, delayed diagnosis and avoidance of seeking help.

Limited support is available



The StepUp for Dementia Research service aims to increase the speed and reduce the cost of research, and to make recruitment more efficient and community engagement easier

to facilitate a broader public engagement in dementia research. Currently, there is no systematic way for people with dementia and others to get involved in research in Australia. A 2014 study conducted by Clinical Trials Connect found that just 1 in 5 clinical trials in Australia met their recruitment deadlines. A 2009 study by the Pharmaceutical Industry Council (PIC) found that 9 in 10 industry-sponsored trials failed to meet their recruitment targets.

Leveraging UK success

In the UK, the public engagement platform Join Dementia Research (JDR) started in 2015 to address such challenges associated with public engagement in dementia research. JDR has attracted over 40,000 volunteers, facilitating 12,881 instances of volunteer study recruitment into 253 studies across more than 100 locations (Join Dementia Research 2019). Leveraging the experience and knowledge of JDR, in partnership with University College London and

University of Exeter, we have created and are implementing a new national service called StepUp for Dementia Research, to tackle the challenges in Australia.

Introducing the service

Our new online, telephone and postal service will use innovative matching technology to provide people with a way of registering interest in studies, and allowing researchers to access matched volunteers, to speed up study delivery, and provide a better, more inclusive service for people affected by dementia. The UK JDR model has shown benefits in several areas of research and evaluation that in turn contribute to earlier and positive engagement with advice and support services (Smith *et al* 2017).

StepUp for Dementia Research aims to increase the speed and reduce the cost of research, and to improve opportunities for access by facilitating recruitment efficiency and broader community engagement. This innovative program has the

potential to inform and guide dementia services and research policy development, and lead to an inclusive and integrated system. By improving the quality of research and evaluation, the StepUp for Dementia Research service can also play a role in addressing a major gap in building the evidence base to inform policy and practice and knowledge translation.

StepUp for Dementia Research went live on 1 March 2019. The program is in its early implementation phase and functionality is being gradually released. What this means is that:

- In order to be able to effectively match volunteers with researchers, we need to ensure that a large enough pool of volunteers is registered on the service. Our goal at this point is to get as many volunteers as possible, so we would like professional carers and aged care staff, researchers and clinicians to tell their residents, clients, patients, carers, neighbours, and other networks about StepUp for Dementia Research to promote the service (and even sign up themselves). Without enough volunteer numbers in our database, researchers won't be able to use the system.
- Researcher registration will be made available at a later stage – we expect by August 2019 – than volunteer registration. This means it may take a little while for volunteers to be matched with studies.
- The initial launch is focused in NSW and Western Australia ahead of nationwide coverage. While anybody in Australia can

StepUp for Dementia Research: information for volunteers

Who can register as volunteers?

Anyone living with or without dementia, 18 years or older and residing in Australia can register. We encourage people living with dementia, carers, families and friends of people with dementia to register on StepUp for Dementia Research because researchers need all kinds of people to participate in studies. Volunteers are needed for studies looking at things like early diagnosis, dementia prevention, and treatment and care – this includes people with dementia, carers, family and the wider public. Anybody can help advance vital dementia research through participation in studies.

By registering, are volunteers committing themselves to research?

No. Once the volunteer has registered their interest, the website will check if their details match to any of the current studies, and then continue to check automatically every time new studies are added. It may take some time to match to a study, as explained in 'Will I match to a study?' When a match is found, they will be contacted through their preferred manner (by phone, email or letter). Detailed information will then be provided about the study, both through the website and by the researcher, and they will have the opportunity, only if they wish to do so, to answer any further screening questions. The volunteer may ask as many questions as they like. They can then decide if they want to take part, and can stop taking part at any time.

How will registering benefit volunteers?

StepUp for Dementia Research helps the volunteer to become involved as a participant in dementia research studies. It will also help them learn more about the research in their local area, region or other parts of Australia, and help signal to researchers, the government, media and the public that Australians are interested in participating in research.

How does StepUp for Dementia Research protect volunteers' information?

Information security is very important to us. StepUp for Dementia Research will keep the volunteer's personal information private, secure and confidential. Their information is managed by StepUp for Dementia Research administration based at the University of Sydney. Only the StepUp for Dementia Research administration and helpline staff (1800-Step-123 or 1800-7837-123) will be able to access the volunteer's information after they register and until they match to an ethically-approved study. At that point, their information will be available to the approved researchers of that study. All researchers agree to operate in accordance with The Australian Code for the Responsible Conduct of Research and comply with the National Statement on Ethical Conduct in Human Research.

What sorts of research can volunteers take part in?

StepUp for Dementia Research helps many different types of studies. These studies include but are not limited to:

- surveys about what works in improving quality of life for people with dementia and their carers;
- drug trials;
- longitudinal follow-up studies for people who do not have dementia, but may be at risk based on family history, genetic testing or brain imaging;
- intervention studies, where a behavioural change such as diet, socialising or exercise is introduced and research is conducted on whether this improves outcomes; or
- genetic and brain imaging studies to identify risk factors, biomarkers and possible drug targets for dementia.

The service is designed to match people with appropriate research studies based on their health information and research interests. There are studies focused on each type and stage of dementia, as well as lots of research participation opportunities for people without dementia.

sign up now, this means that people living outside of these two states will be less likely to be matched to studies until late 2019.

Frequently asked questions

Below and in the box above are some of the frequently asked questions, and more information is available from our website at www.stepupfordementia.org.au/

Who runs this service?

I lead the StepUp for Dementia Research program, which is funded by the Australian Government Department of Health and run by the University of Sydney. The website and technology behind the service have been created by me and my team, in collaboration with the

University of Exeter and using expertise from University College London, UK.

Is there a cost?

The service is completely free for all volunteers and researchers and used only to recruit people to ethically approved research studies. It is used by (1) approved researchers working in universities and in healthcare across Australia to list their study and (2) by volunteers to express interest in potential involvement.

What steps do researchers need to take to register their study?

- Submit their study registration form via our website.
- Complete the short Research User training via online and

telephone support.

- Submit their Institutional Data Access Agreement with the University of Sydney, if they haven't already done so.
- Submit ethics documents and the Research User Acknowledgment of Account User and Confidentiality Terms.

All studies on the service have ethical approval. This means that they have been reviewed by independent panels to make sure there are protections for the rights, safety and wellbeing of participants.

We would like you to sign up today and help us promote StepUp for Dementia Research by sharing this information as widely as possible.

Visit: www.stepupfordementiaresearch.org.au/ ■

■ Professor Yun-Hee Jeon is the Susan and Isaac Wakil Professor of Healthy Ageing and the Program Director of StepUp for Dementia Research, at The University of Sydney. Contact her at: yun-hee.jeon@sydney.edu.au



References

Alzheimer's Disease International (2012) *World Alzheimer Report 2012: Overcoming the stigma of dementia*. Available at: <http://bit.ly/2DRz5B6>.
Phillips J, Pond D, Goode SM (2011) *Timely diagnosis of dementia: can we do better? A report for Alzheimer's Australia*. Available at: <http://bit.ly/2JqQeFk>.
Smith A, Kotting P, Rossor M (2017) Encouraging public participation in dementia research: analysis of take-up and costs following mail out to 10,000 patients within General Practice. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association* 13(7) 861.

Research participation: what's it like to be involved?

One of the strategic directions at BlueCross is 'to be a great place to learn and work'. **Bridget Howes** and **Steven Baker** consider the impact for staff and residents when they are invited to participate in research projects

As a leading provider of aged care services, BlueCross is often approached by academic teams looking for older residents, including people living with dementia, to participate in research studies. There are opposing views on the value of this for the participants. Some believe that residents should not be expected to participate, as residential aged care is supposed to be a home-like environment, that residents may feel obliged to participate and that those living with dementia do not have the capacity to give informed consent.

The other view is that residents actually enjoy being invited to contribute to purposeful and meaningful projects, that they should be trusted to make their own choices about whether they wish to participate, and that university and research teams take their ethical responsibilities seriously when recruiting research subjects. Staff involvement also attracts varying responses. Some aged care managers and staff suggest that they are too busy and that the workplace should not be disrupted by research teams, while others are keen to participate and interested in the subject matter and benefits to residents.

The Boulevard VR trial

A small team of researchers from The University of Melbourne spent two weeks at The Boulevard, a 90-bed BlueCross aged care residence in Melbourne, trialling



Dr Steven Baker with one of The Boulevard residents participating in the virtual reality technology trial

interactive virtual reality (VR) technology that aims to engage residents in immersive experiences. Interactive VR combines a head-mounted display (HMD) with 3D cameras and hand controllers that allow the user to interact with objects in fully immersive virtual worlds. The researchers were interested in gathering data about the residents' experience of using interactive VR and staff feedback about the benefits and responses of the residents.

This article reports on the responses from staff and residents when asked about participating in research and explores the views of the research team on engaging residents.

Participating staff feedback

Bridget Howes, BlueCross Dementia Care Specialist (and co-author here) asked Robyn Borelli, The Boulevard Lifestyle Coordinator and Kathryn Stone, Lifestyle Assistant, to describe the experience for staff supporting this research project. They began by saying that it makes the residents feel important and excited, that it's "something different for them to do. They feel connected to the community and they like to be helpful".

When asked about their own experiences they said "It's an honour for us, it's something new and we are interested in being involved with anything that has the potential to improve our residents' lives".

When asked about agreeing to participate, Robyn explained the importance of planning and communication. When approached to support this project they were given plenty of notice and were able to plan the participation around their own programs and resident preferences.

In particular, they valued being included in the briefing provided by the research team and were able to select residents that met the criteria and who would value the experience.

Both Robyn and Kathryn had been involved in a previous external evaluation project and explained that that project was more of a challenge than the VR trial.

They said that in the previous project, the external evaluator had been rushed and didn't seem to listen to their views. The activity being evaluated required residents to have good hearing and eye sight and, despite the aged care staff explaining this, the researcher seemed to be more concerned about gathering data than being respectful to staff and residents.

These two staff experiences of research participation reflect the differences between a respectful, well-managed, organised approach that is well communicated and a less professional approach.

Alyson George, Residential Manager at The Boulevard, explained that she is always keen to support research and support staff and residents to participate. She sees her responsibility to residents and staff as her primary aim and ensures that choice is promoted when participating in any research projects.

Participating residents' feedback

A female resident who participated in the University of Melbourne VR trial said: "I loved the VR, I really enjoyed it". When asked what she thought about being asked to take part in research and if she minded being approached, she said that the researchers explained it all to her and that she was happy to help, knowing she could cease participation at any time. She said, "I tried the game four times and I liked it, I hope that my opinion counts and that this type of thing gets into places like The Boulevard. It's fun." She explained that she was always willing to be approached and enjoyed doing something a bit different. She acknowledged that it gave her a sense of purpose and that contributing to improving knowledge about aged care was a worthwhile goal.

A male participant, who experiences some memory difficulties said, "Oh yes, I remember that, I am too old



A resident at The Boulevard uses the interactive virtual reality technology during the trial

for it now and not really interested. I told them when I had had enough and they let me go". When asked, he said he preferred football and reading. He was then asked, if a student wanted to do some research about football, would he like to participate? He said, "How old do you think I am? No it's too much trouble now".

These two residents reflect differences and highlight the importance of choice. If the resident is not interested, it is essential that they are not persuaded to participate and that their views are respected.

Participating research team feedback

Steven Baker, the lead researcher on the VR project (and co-author here), agreed that taking the time to consult with staff and being clear with residents about their right to withdraw from research was vital. "We were very aware of the fact that we were entering into a complex environment that was both a busy workplace for staff and a home for residents. As such, we wanted to take the time to make sure that the staff were consulted about the project and that our work would fit in as best as possible with the routines at The Boulevard. We also wanted to ensure that the residents who participated in the research remained in

control of their involvement. This included checking in with residents at each session to make sure they were happy to continue and reminding them of their right to withdraw at any time."

While Steven admitted these processes meant that additional time was needed and that the goals of the project had to be adapted in response to the needs of both staff and residents, he was also confident that this resulted in better outcomes. He believes that consulting with staff and being mindful of their work needs helped to create an atmosphere where the staff felt comfortable contributing to the project. This improved the data that was able to be collected. "If staff know that we are respectful of their workspace and that we genuinely wish to engage with them, this leads to an environment where meaningful conversations can occur, ultimately benefitting our research in terms of the types of insights we were able to gain about the impact of new technology in residential aged care environments."

Steven was also positive about the benefits of their approach with residents. He felt this was especially important when working with residents who were living with dementia.

"We were very concerned to

be respectful of the fact that we were entering into the residents' homes and that some had memory problems. Continuously checking in with each resident that they were happy to continue was one of the steps we could take to make sure that we were mindful of this."

Steven felt that this approach also contributed to better research outcomes. "By continuously checking in, we were better able to pick up on subtle cues that we might otherwise have missed, and this helped us to better understand what residents were thinking about after their VR experiences."

Conclusion

In summary, it is evident that some residents and staff are more willing and interested in participating in research than others and that choice and respect for everyone involved is central to successful experiences and outcomes.

VR research outputs

Two papers have been produced from the University of Melbourne Interactive VR trial described in this article. The first looked at the data that staff provided about using technology in aged care, and was published at the 2018 Australian Conference on Computer-Human Interaction: Cavenett W *et al* (2018) *Deploying new technology in residential aged care: staff members' perspectives*.

The second article examined the residents' use of the interactive VR system and has been submitted to the journal *Information Processing and Management*. ■



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Research Fellow, Microsoft Research Centre for SocialNUI. Contact him at: steven.baker@unimelb.edu.au

Jo Croft explores the benefits of a 'can do' rights-based approach to care planning and risk management to facilitate an active lifestyle for people living with dementia, and shares an example of a positive risk assessment tool

At the heart of any quality service providing care to people living with dementia is a passion for delivering holistic care which responds to the needs of the individual. Person-centred care planning is by no means a new concept, but taking this a step further to ensure we are taking a 'rights-based' approach to care planning for those living with dementia is what provides genuine choice and agency and that requires us to make a commitment to actively listen to our clients (Pieters-Hawke 2018). The objective is to provide empowerment and a 'can do' emphasis in care planning by enabling and supporting a culture which maximises the quality of daily life for our clients and continues to provide them with a sense of purpose.

Most care providers and practitioners working with people who are living with dementia would argue they are already providing clients with maximum choice and agency, but in reality this is a very challenging task and one we frequently fail to deliver as fully as we intend. In the main this is because, as well as promoting independence and choice, we have a legal and moral duty to protect those in our care from foreseeable harm and this causes an inevitable tension between the risks and benefits of the 'can do' approach.

Risk averse

Research suggests that care providers and practitioners are often risk averse (Royal College of Nursing 2013) and are inclined to lean towards protectionism in their delivery of care. So whilst most of us would like to think we give our clients choice, in reality many care providers and practitioners limit choice due to fear of causing unintended harm.

There is a tipping point where

A rights-based approach to risk



With Positive Risk Assessments in place, residents in Colten Care's dedicated dementia communities continue to enjoy a wide range of activities including dancing, cooking, gardening, horse riding, swimming, playing golf and even hot air balloon rides.

Photos courtesy Colten Care Ltd

protection becomes restraint and this doesn't have to be overt or physical. Depriving someone of their liberty can be as subtle as a gently but firmly applied coercion on the part of the care giver. Exactly where the tipping point is can be subjective and confusing and care givers need guidance and support to ensure a balanced and positive approach to risk management is maintained. Therefore, providing them with a positive risk assessment tool which can be used within the care plan can give the necessary guidance.

The nursing and allied health professions have long recognised the importance of risk assessment tools with regards to physical health and wellbeing. For example, the use of risk assessment tools in planning and management of pressure ulcer and malnutrition prevention are not only commonplace but have become an essential and expected part of care planning. Living an active life inevitably involves risk-taking, as it is not possible to eliminate risk altogether. If we are to maximise the lived experience of our clients, which will be unique to each individual and situation arising (Croft 2018), we must also realise that risk management is a fundamental part of our role in planning activities for our clients and should be exercised with similar skill.

Positive risk-taking tool

The Colten Care Positive Risk Assessment Tool (see next page) provides a framework which aims to remove subjectivity and help the practitioner to plan care based upon the principles of defensible decision making. The purpose

of the positive risk-taking tool is to support the practitioner's professional integrity and confidence when making care-related decisions which involve an element of risk. It aims to uphold the rights of the individual to make choices, whilst simultaneously protecting the interests of the individual client and enhancing client confidence in the practitioner.

The tool was developed by UK aged care provider Colten Care Ltd and is used in its care homes with residents living with dementia or who otherwise have reduced mental or physical capacity. It has been informally externally validated by the Mental Capacity Lead for Dorset County Council UK and received positively by several Care Quality Commission Inspectors, but has not been formally validated.

When using the tool it is essential the rights of the individual are upheld by ensuring the client's wishes and opinions are clearly documented and taken into account, irrespective of their level of capacity and insight. This is to ensure that the care provider fully listens to and aims to understand the client's point of view. Often the view of the risks associated with an activity will differ greatly between the care provider and the client, but when deciding how to minimise the risks, the care provider will be better able to recognise potential problems if they have fully explored the client's aspirations and associated understanding, or lack thereof.

It is equally important to involve the client's relatives and representatives in discussions to ensure a balanced approach and outcome are reached and

COLTEN CARE POSITIVE RISK ASSESSMENT TOOL				
Name of Person: Mr George Example				
Assessed by: A Practitioner		Date of Assessment: xx/xx/xx		
Name and relationship of others involved in the risk assessment and decision-making process:				
Miss Annie Example (Daughter)				
Dr Foster (GP)				
Mr Harry Biker (Friend)				
Description of the Risk: George would like to ride on the back of his friend's Harley Davidson motorcycle. George is living with dementia and lacks insight into his abilities and is unable to assess risk. George has poor balance and is prone to falls. He has recently had an epileptic seizure.				
Person(s) at risk: George, his friend and members of the public.				
Nature of the Risk: George is at risk of falling off the motorbike whilst it is travelling at speed, which would result in serious injury/death to George. His friend may have an accident if George causes a distraction whilst riding and this could affect members of the public.				
Calculate the risk using the Risk Calculator (at right)				
Hazard	Consequences	Likelihood	Risk Score	Risk Rating
George falling off the bike and causing an accident involving others as a result	5	4	20	Very High
What are the advantages and disadvantages of taking the risk? (Ensure the Person's beliefs and values are explored and record discussions below)				
Advantages:		Disadvantages:		
Medical & physical well-being:		Medical & physical well-being:		
None identified		If George loses his balance whilst on the back of the bike or has a seizure he could suffer a severe injury or fatality. This could also affect the stability of the bike and cause an accident involving his friend and members of the public.		
Psychological & Emotional well-being:		Psychological & Emotional well-being:		
George has been quite withdrawn and mildly depressed lately. Being able to pursue his hobby will have a positive effect on his self-image and self-esteem		None identified		
Social: George is looking forward to spending time with his friend Mr Harry Biker away from the care home "just like old times"		Social: Mr Harry Biker doesn't wish to take George to the Bikers Club because he is worried about getting George in and out of the sidecar on his own or George being tempted to try to do so unaided if they stop at the club		
Ethical/Spiritual/Cultural:		Ethical/Spiritual/Cultural:		
George has been a member of a bike club most of his adult life. He had his own Harley Davidson motorbike until he was diagnosed with dementia				
Having discussed the balance of risk with the resident, do they have the mental capacity to agree the control measures required to manage the risk?				
Yes		No		(Circle as appropriate)
Refer here to method of assessment in accordance with your local policy guidelines and state legislation. For example, Mental Capacity Assessment completed and attached.				
If no, who has been consulted in the making of a Best Interests Decision/Giving Consent?				
Refer here to your local policy guidelines and state legislation and follow due process. For example, guardian consent obtained or Best Interests Decision documented and attached				
Control Measures identified:				
Physical: George will not sit on the pillion of the bike. His friend will arrange to have a sidecar fitted to the bike by a manufacturer-approved/authorised installer and George will ride in the sidecar with a seat belt in place.				
Equipment: George and his friend will wear appropriately sized crash helmets.				
Procedural: Care home staff will assist George in and out of the sidecar using appropriate hoisting apparatus (see separate Moving and Handling Assessment and Care Plan). George will remain in the sidecar whilst he is out with Mr Harry Biker and they will go for a ride without making any stops. If and when George visits the Bikers Club it will be by car, accompanied by his daughter, Miss Annie Example.				

Other: Mr Harry Biker has fully comprehensive motor insurance. George has had a recent medication review and his dose of anticonvulsant medication has been increased to significantly reduce the likelihood of epileptic seizure. George's lack of insight and ability to assess risk remains unchanged.

With Controls in place, re-calculate the risk rating using the Risk Calculator:

Hazard	Consequences	Likelihood	Risk Score	Risk Rating
George falling off the bike and causing an accident involving others as a result	5	1	5	Low

Integrate the control measures into the care plan and determine frequency of evaluation

For example, if this was going to become a weekly event, the risk assessment would need to be reviewed periodically as George's general health is likely to deteriorate over time.

I understand the risks involved in the planned activity and consent to the control measures identified above:

Signature of Person:	Unable to give informed consent due to lack of mental capacity	Date:	Xx/xx/xx
Other: (State relationship)	Miss Annie Example (Daughter)	Date:	Xx/xx/xx
Other: (state relationship)	Dr Foster (GP) – Verbal telephone consultation (verified by Nurse A. P)	Date:	Xx/xx/xx
Other: (state relationship)	Mr Harry Biker (Friend)	Date:	Xx/xx/xx
Signature of Assessor:	Registered Nurse A Practitioner	Date:	Xx/xx/xx

Left and above: Table 1, the Colten Care Positive Risk Assessment Tool. Below: Table 2, the Colten Care Risk Calculator

COLTEN CARE RISK CALCULATOR			
Identify the consequence score and the likelihood score separately.			
Consequences x Likelihood = RISK SCORE			
Use the risk score to identify the risk rating and guidance on actions required			
Consequences	Score	Likelihood	Score
Minor injury	1	Remote – would not happen in 5 years	1
Lost time injury/illness	2	Unlikely – would not happen in 2-3 years	2
Serious injury/disablement	3	Likely – would expect to happen once a year	3
Death	4	Very likely – could occur 2 or 3 times a year	4
Multiple fatality	5	A certainty – likely to happen at the moment	5
Risk Score	Risk Rating	Action Required	
1 - 2	Trivial	No further action required and no changes to the care plan are needed. Continue to monitor in case of change of circumstance and reassess as required.	
3 - 6	Low Risk	No additional controls are required, although consideration may be given to improvements that will not impose restrictions on the resident. Monitoring is required to ensure that the controls are maintained. Continue to monitor in case of change of circumstance and reassess as required.	
7 – 11	Medium Risk	Efforts should be made to reduce the risk and risk reduction measures should be implemented. However, the balance of risks and benefits to the resident should be carefully measured and restrictions limited accordingly. Where a moderate risk is associated with extremely harmful consequences, further assessment may be necessary to establish more precisely the likelihood of harm as a basis for determining the need for improved control measures.	
12-16	High Risk	Urgent action is required to reduce the risk. Considerable resources may need to be allocated to reduce the risk and the Operations Manager may need to be consulted about procuring the necessary resources.	
17-25	Very High Risk	If it is not possible to reduce the risk even with unlimited resources, safeguarding procedures must be implemented.	

that all interested parties are in agreement with the care plan. Relatives can exert a lot of influence over their loved ones, which may have either a positive or a negative influence on the ambitions of the client depending on their own attitude to risk.

However, they are often the people who know the client best and can give context to the aspirations of the client and their support is invaluable.

The Colten Care Positive Risk Assessment Tool incorporates, and is based upon, the following key elements (Dix & Smith 2009):

- Description of the identified risk (usually an activity which the resident wishes to partake in).
- The nature of the risk (what it is about the particular activity which has the potential to cause harm).
- An exploration of the potential benefits to taking the risk (weighing up the potential benefits and harms of exercising one choice of action over another, whilst reflecting the aspirations of the resident in accordance with *their* aspirations, values and beliefs. We must remain focused on the desires of the client, which is to support them to live life *their way*, not ours, *so far as is practicable*).
- A record of any advice given by the person supporting the resident to make a decision (eg nurse or other health or social care practitioner and the involvement of family or other representatives as appropriate, as they may wish to be present during the discussion and *their* views need to be considered and appropriately responded to as well. It is important to recognise that this is a collaborative process).
- Measurement of the risk (using a simple but robust risk-rating table).
- Identification and agreement *with the resident* or their representative of any control measures required to help reduce the level of risk. (Use all available resources to minimise potential harm and ensure the least restrictive options are identified and implemented. This will require some lateral thinking and teamwork and needs to be specific to the individual and their particular circumstances).
- Evidence of consent (with reference to your local statutory legislation).

The outcomes from the positive risk assessment and, in particular, the control measures will need to be cross-referenced with any other relevant aspect of the care plan. The plan will need to be

communicated to everyone involved, reviewed regularly and evaluated (which is in line with the nursing process). It may of course, need to be rewritten as the needs and abilities of the client, and therefore the measure of risk, change over time.

On the page opposite is an example of how the Colten Care Positive Risk Assessment Tool could be used, loosely based upon a recent case study but fictionalised for client confidentiality:

It is important to note that the Risk Score is calculated and recorded as a 'before and after' measure. That is, *before* control measures have been identified and *after* they have been put into place. This demonstrates that due diligence has been observed in the management of the risk, by selecting appropriate and effective control measures. The Colten Care Risk Calculator is shown on the page opposite.

It is important to note that at every stage of the risk assessment process the emphasis is on encouraging the resident to express their views and exercise their choices, enabling them to grow in confidence and gain as much independence as possible. Where the resident lacks insight into their capabilities and physical and mental limitations, it is the role of the care practitioner to explore the gap between the resident's perception of the risk and the actual level of risk. Furthermore, where the risk score is medium to high, it is recommended that the control measures to reduce the risk be agreed and documented in conjunction with other members of the multidisciplinary team including, where appropriate, the resident's named nurse, GP, physiotherapist or mental health practitioner, thus spreading the responsibility for decisions made.

Explore possibilities

If, instead of putting limits on people, we explore possibilities in all of our discussions relating to individual care planning and we champion the pursuit of fulfilling goals and aspirations for our clients, positive benefits for them will inevitably result and they will be able to continue to enjoy hobbies and activities which they have participated in prior to coming into care. By using the Positive Risk Assessment Tool and putting Positive Risk Assessments in place, Colten Care clients living in our dedicated dementia communities continue to enjoy a wide range of activities. These include cooking, gardening, horse riding, swimming, playing golf and even hot air balloon

rides and many other fulfilling activities that most of us would take for granted.

The Colten Care Positive Risk Assessment Tool can help care providers and practitioners to promote a 'can do' rights-based approach and to challenge the negative connotations surrounding the concept of risk, so often thought of in terms of danger and damage limitation. Professionally, these need replacing with a culture of enablement and support with as few restrictions as possible. It supports us to fulfil our duty of care to protect our residents from foreseeable harm whilst bringing the metaphorical scales of choice and independence vs safety into balance. It helps the staff who support our clients to overcome the fear factor of being held to account if things should go wrong, as it provides evidence of a carefully thought out strategy which is legally defensible and well documented. This, in turn, provides reassurance to relatives and builds trust.

The importance of training staff to use a positive risk assessment tool as part of the individual care plan cannot be stressed enough, as it helps to remove fear of doing the wrong thing and supports the creation of a culture of positive risk management and values. For this reason, Colten Care has developed a tool which is neither complicated nor legalistic for the user (although it is robust if applied correctly). It is very simple to use on an individual basis whenever a client wishes to undertake an activity which has an element of risk and which has not already been covered by another form of commonly used risk assessment within the care plan.

Our mission

Providing high-quality dementia care requires dedication on the part of care providers and practitioners. The 21st International Dementia Conference held in Sydney in June 2018 was entitled 'Mission Impossible: Truth and Lies in the Age of Choice'. Fortunately, as discussed and explored at this very inspiring conference, the mission is not an impossibility, though it is a challenging one. John Swinton, Professor in Practical Theology and Pastoral Care in the School of Divinity, Religious Studies and Philosophy at the University of Aberdeen summed up the challenge perfectly in his description of dementia care, not as a 'mission impossible', but certainly as a story of truth and lies: "The lie: the 'person' disappears once they have dementia and that a life without memory is no life at all. The truth: people living with dementia *can* have a good life" (Swinton 2018). ➤



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And it is our mission to support them individually in every way we can to make that possible, for as long as possible and as well as possible. ■

Accessing the risk tool and calculator

The author is happy to forward copies of the Colten Care Positive Risk Assessment Tool and The Colten Care Risk Calculator to individuals upon request. Email Jo Croft at JoCroft@ColtenCare.co.uk

References

- Colten Care Ltd (2016) Person Centred Risk Assessment Tool (Version 2).
- Croft J (2017) Enabling positive risk-taking for older people in the care home. *Nursing & Residential Care* 19(9) 515-519.
- Croft J (2018) International Dementia Conference – Mission Impossible? Truth and Lies in the Age of Choice. Sydney 7-8 June 2018. Leaders in the Field Agenda Item 4: *Enabling positive risk taking – a framework for supporting choice and an active lifestyle within the care home setting*. 2018. Sydney: HammondCare.
- Dix M, Smith S (2009) *Managing risk positively: a guide for staff in health and social care*. Available at: <http://bit.ly/2vyl8Cw>.
- Pieters-Hawke S (2018) International Dementia Conference – Mission Impossible? Truth and Lies in the Age of Choice. Sydney 7-8 June 2018. Leaders in the Field Agenda Item 1: *Dementia and human rights – rising to the challenge*. Sydney: HammondCare.
- Royal College of Nursing (2013) RCN Congress and Exhibition Liverpool 21-25 April 2013. Agenda Item 25: *A risk worth taking? Older People's Forum*. London: Royal College of Nursing.
- Swinton J (2018) International Dementia Conference – Mission Impossible? Truth and Lies in the Age of Choice. Sydney 7-8 June 2018. Plenary Agenda Item: *Taking time for those things that the world considers trivial: choosing to be with and for people living with dementia*. Sydney: HammondCare.

Going to Stay at Home: support when it matters

Meredith Gresham, Deborah Moore and Colm Cunningham describe a novel program that combines caregiver training with a residential respite stay to reduce carer distress, prevent an increase in behavioural symptoms and enable the person with dementia to remain living at home for longer

Family carers play a critical role in the lives of people who are living with dementia. The impacts of this role on family carers can be profound. Despite this, an overwhelming number of family members choose to support their loved one to remain at home in the community. Although around 70% of people with dementia in Australia are estimated to be living in the community supported by the care of family or friends, more than half of spending on dementia by the Australian Government has been directed to residential aged care (AIHW 2012a; b).

Impacts of the caring role may have negative physical, psychological, social and financial outcomes. Carers undertake countless daily activities as well as often assuming the roles and responsibilities that were previously performed by the person with dementia. The progressive nature of dementia eventually results in carers needing to provide support for a family member with a high level of disability. In addition, the changes that dementia can bring to former relationship dynamics may leave the carer experiencing greater levels of stress than those who are caring for someone with other chronic conditions or disability.

Behavioural and psychological symptoms associated with dementia, such as aggression, agitation or psychosis can be associated with increasing carer stress. Higher levels of carer stress have been shown to correlate with earlier and increased rate of placement in residential care (Rabinowitz *et al* 2007; Schubert *et al*

2008). Stress does not always decrease following admission to residential care. A two-year study of 517 family carers in the US found that the 152 carers who admitted their family member to residential care still continued to care for their loved one, although in an "altered but still stressful way" (Zarit & Wiltch 1993). Stress became more complex, not only relating to the guilt of placement but also potentially exacerbated by poor quality interaction with care home staff (Almberg *et al* 2000). Carer stress may also persist up to two years after the person with dementia has been admitted to residential care. Furthermore, carers often report having poorer health (including more symptoms of depression) and greater use of health services themselves.

Support for carers

Support services in Australia generally are focused on providing practical assistance (eg Community Care Packages, centre-based care) when the person with dementia requires significant support for activities of daily living. Carer support groups operate nationally and offer an opportunity to share experiences but are usually limited to only a few hours each month. Other services available include literature for self-education and telephone support services such as the Dementia Australia Helpline or Dementia Support Australia.

Residential respite care offers carers a short-term break. However, although respite is the most requested service, rates

of uptake of this service in Australia have remained low. The decision to access respite care can often be a stepping stone towards permanent placement in formal care with over 50% of respite admissions converting to permanent care (AIHW 2010).

Combining respite with training

The course of dementia is long and years may lapse between diagnosis and the provision of support. Structured, post-diagnostic intervention and support is lacking. However, combined information, education and respite care have been shown to assist carers to maintain the person with dementia living at home (Elvish *et al* 2013). A previous randomised controlled trial conducted at Sydney's Prince Henry Hospital in the 1980s, where people with dementia and their carers attended a 10-day training course, resulted in carers experiencing lowered psychological stress, better general health, and increased time until placement in residential care for the person with dementia. This program still showed positive effects eight years post-training and was shown to be cheaper for health and aged care systems over the long term (Brodaty & Gresham 1989; Brodaty & Peters 1991).

Through this program, carers gained skills and knowledge of what to expect, how to cope and how to harness formal and informal assistance. Carers demonstrated increased confidence, as well as positive impacts on their wellbeing, anxiety, depression and quality of life. Carer training provided early in the course of dementia also had significant positive effects on the outcomes of people living with dementia, enabling carers to proactively manage situations that may have produced negative outcomes.



Co-author Dr Meredith Gresham with a participant in the residential cottage during the Going to Stay at Home training program. Photos: The Dementia Centre, HammondCare

Going to Stay at Home study: key findings

- Carer depression and burden remained stable, despite increasing dependence of the person with dementia.
- Carers' needs were being met.
- Reduction in behavioural symptoms in people with dementia.
- Reduction in transfer to permanent care.

Going to Stay at Home

The Going to Stay at Home program (Gresham *et al* 2018; Gresham *et al* 2014) was designed as a novel intervention method that combined the principles of the Prince Henry Hospital training program and respite care. It aimed to reduce carer distress, prevent an increase in behavioural symptoms and enable the person with dementia to remain living at home for longer. Funded through the (former) Department of Health and Ageing, the program was conducted in an eight-bedroom self-contained cottage, comprising one of HammondCare's residential aged care cottages in Miranda, a suburb south of Sydney. Participants were recruited through referral by their health or care service, or through self-referral.

Overall 90 pairs consisting of a person living with dementia and their carer participated in a comprehensive training program while staying in the cottage over a period of seven days from Sunday afternoon to the following Saturday morning. During this time, groups of three-to-six carers participated in an intensive program which involved attending 14 sessions that focused on various aspects of supporting someone with dementia. These included sessions on: psychological support to reduce distress and depression; education and information about dementia and its progression; understanding the change of roles and effects on relationships that may be brought about by dementia (re-rolling); combating isolation; improving coping and home care skills; problem solving and techniques to manage behavioural symptoms; developing personal, family, community, and professional support systems; and planning for the future, such as legal and financial planning, and coping with emergencies. A typical schedule for the Going to Stay at Home program is shown in Table 1 (see next page).

The schedule was arranged so that

carers could initially 'tell their story' and promote the understanding that other carers shared aspects of their experience to decrease feelings of isolation. Education about dementia and other practical information were programmed early in the week, allowing sessions that dealt with more challenging aspects of care, such as incontinence or end-of-life care, to be delivered later in the week after carers had time to build support within their group. Sessions lasted between one and two hours and were led by experienced health professionals using experiential learning, refocusing lifelong skills and coping mechanisms on new challenges presented by dementia.

While the carers were attending training sessions, the people with dementia participated in a program which focused on daily domestic, creative, exercise and social activities in the cottage, as well as outings. Information about dementia and practice of simple mnemonic (memory) techniques was also made available, if desired. Social and leisure activities, such as movies, table tennis, lawn bowls, music and dancing, were arranged for everyone to participate in together during the evenings.

Nineteen programs were conducted over a 12-month period, allowing both the person with dementia and their carer to meet others in a similar situation. Where possible, groups were arranged to include couples from similar geographic areas, allowing the possibility of forming ongoing support networks. One program was also conducted in commercial serviced apartments in a regional town in NSW to explore the 'portability' of the program.

The program was evaluated using pre-program measures and repeating these at six and 12 months to determine whether there was any ongoing impact. Transfer to permanent residential care was compared against a similar group of people with dementia who received residential respite care, but without the carer training component (Gresham *et al* 2018).

Positive outcomes

Key outcomes of the Going to Stay at Home program were that:

- there was an increase in the number of carers' needs being met
- there was a reduction in transfer to permanent care
- there was a reduction in behavioural symptoms in people with dementia that were responses to both situational stressors and psychiatric symptomatology, such as depression, paranoia and mania
- carer depression and burden remained

stable, despite increasing dependence of the person with dementia.

After the program, the needs of carers being met increased significantly. These specific needs included knowledge and information regarding how to support a person with dementia, practical tasks, communication/management of daily activities, financial/legal entitlements and managing behavioural symptoms.

There was a marked increase in the number of people with dementia remaining at home 12 months after completing the program. In fact, only 15 (17.6%) of people with dementia (n=85) who had attended the program were transferred to permanent care, compared with 63 (52.9%) of a similar group (n=119) who received respite care in the same organisation but without the carer training component.

Behavioural symptoms in people with dementia also decreased significantly, despite the severity of dementia increasing over time. This was possibly attributed to the positive impacts of the program in meeting the needs of carers through developing a better understanding of dementia and how to manage distress-provoking situations for the person with dementia.

There was no significant change in carer burden, psychological distress or depression, however this was over a 12-month period during which most people with dementia experienced an increase in dementia severity and decrease in

functional ability.

Overall, the Going to Stay at Home program was successful in delivering effective education and information to carers about dementia and its progression, as well as improving carers' coping, home care skills, problem-solving and management of behavioural symptoms. Carers reported that the program being carried out in a residential setting was beneficial and did indeed provide respite, as there was no meal preparation, housework or shopping to attend to and the stress of getting to the training was 'once only'.

In addition, carers were able to observe staff model skills and to try new skills themselves in a supportive environment. Participating in the program alongside others in a similar position also helped with issues of social isolation, with each group offering each other mutual support and comfort in sharing of problems, solutions and experiences. Importantly, the program focused not only on education and skill development, it included adding fun back into life. The evening program included dancing, table tennis and a dinner outing.

Future implementation

The Going to Stay at Home program is a feasible and practicable model with benefits for both the carer and the person with dementia. The program provides knowledge and information to carers about supporting people with dementia, especially regarding avoiding behavioural



A Going to Stay at Home physiotherapist-led exercise circuit class in the cottage garden

symptoms as a response to stress. It is likely that the education contributed to the reduction in behavioural symptoms that was observed over the 12-month period following the program, which in turn may have led to increased numbers of people with dementia remaining at home. In addition to knowledge acquisition and skill development related to caring for their loved ones, carers learnt about community services that are available to support them, and how to proactively seek their assistance as symptoms progress and needs change.

The success of the program in the regional town in NSW supports the idea that this program can be carried out in a range of geographical locations. This would be most beneficial to those living in rural communities where there may be limited access to healthcare and social support networks, and so more knowledge and confidence in various aspects of how to care for a person with dementia would be highly valued in these areas. An important lesson learnt from this study is that not only could a similar program be implemented in other locations, but it could also be applied to other chronic illnesses where carers play a pivotal role.

It is critical that there are strategies in place to provide assistance to carers who support people with dementia, and other chronic diseases, in order to increase the confidence level of carers in implementing learned skills and managing challenges, as well as looking after their own health and wellbeing. The current health policy and funding models available in Australia place emphasis on acute disease treatment, rather than prevention and proactive management strategies, however the cost of this approach will increasingly overwhelm health systems and budgets with an ageing population.

Dementia costs are currently set at over \$A14 billion each year and forecast to exceed \$A1 trillion within the next 40 years (Brown *et al* 2017). Annual costs of formal residential care alone are estimated at about \$A88,000 per person

Table 1: Going to Stay at Home sample timetable for carers

Day	Morning	Afternoon	Evening (examples)
Sun		Welcome / Orientation	Socialising
Mon	Combating isolation	Medial aspects of dementia Relaxation	Sausage sizzle
Tues	Fitness and physiotherapy Reminiscence and reality orientation	Communication Assertion	Classic movies or dancing
Wed	Re-rolling Nutrition and diet	Using activities therapeutically Simplifying work and safety in the home	Carpet bowls
Thurs	Nursing skills	Planning for the future Using community services	Carers' dinner out
Fri	Caring for self Relaxation	Carers' choice of topic	Table tennis competition
Sat	Farewell		

(Gnanamanickam *et al* 2018). In contrast, the Going to Stay at Home program was, at the time of writing, offered by HammondCare as an ongoing service at a cost of approximately \$A3000 per dyad, so the cost of the program would be covered by staying out of residential care for just 13 days (Gresham *et al* 2018). It is therefore vital that there is a 'cultural shift' towards providing more early intervention programs, such as the Going to Stay at Home program, that help carers to support their loved ones effectively, and in turn reduce the use of health and community services. ■

Further information

Further details, articles describing the program and the results are available in open access format. The protocol paper is at <https://www.springerplus.com/content/3/1/330> and the results article can be found at <http://bit.ly/GTSAH-results>. The project was evaluated by Dr Megan Heffernan and Professor Henry Brodaty at the University of NSW.

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References

AIHW (2010) Dementia and the take-up of residential respite care. *AIHW Bulletin* No 78. Cat No AUS 124. Canberra: Australian Institute of



The program included daily domestic, creative, exercise and social activities in the cottage

Health and Welfare.

AIHW (2012a) *Dementia in Australia*. Cat No AGE 70 Canberra: Australian Institute of Health and Welfare.

AIHW (2012b) Residential aged care in Australia 2010-2011: a statistical overview. *Age Care Statistics Series* No 36 Cat No AGE 68. Canberra: Australian Institute of Health and Welfare.

Almberg B, Grafstrom M, Krichnbaum K, Winblad B (2000) The interplay of institution and family caregiving: relations between patient hassles, nursing home hassles and carers' burden. *International Journal of Geriatric Psychiatry* 15(10) 931-939.

Brodaty H, Gresham M (1989) Effect of a training programme to reduce stress in carers of patients with dementia. *British Medical Journal* 299 (6712) 1375-1379.

Brodaty H, Peters K (1991) Cost-effectiveness of

a training program for dementia carers. *International Psychogeriatrics* 3(1) 11-22. Brown L, Hansnata E, La HA (2017) *Economic cost of dementia in Australia 2016-2016*. Canberra: The University of Canberra.

Elvish R, Lever S-J, Johnstone J, Cawley R, Keady J (2013) Psychological interventions for carers of people with dementia: a systematic review of quantitative and qualitative evidence. *Counselling and Psychotherapy Research* 13(2) 106-125.

Gnanamanickam E, *et al* (2018) Direct health and residential care costs of people living with dementia in Australian residential aged care. *International Journal of Geriatric Psychiatry* 33(7) 859-866.

Gresham M, Heffernan M, Brodaty H (2018) The Going to Stay at Home program: combining dementia caregiver training and residential respite care. *International Psychogeriatrics* 30(11) 1697-1706.

Gresham M, Tsang RSM, Heffernan M, Brodaty H (2014) Study protocol of the Going to Stay at Home program: evaluation of a residential carer training program to reduce dementia carer distress and burden. *SpringerPlus* 3(1) 1-7.

Rabinowitz YG, Mautsach BT, Thompson LW, Gallagher-Thompson D (2007) The relationship between self-efficacy and cumulative health risk associated with health behavior patterns in female caregivers of elderly relatives with Alzheimer's dementia. *Journal of Aging and Health* 19(6) 946-964.

Schubert CC, Boustani M, Callahan CM, Perkins AJ, Hui S, Hendrie HC (2008) Acute care utilization by dementia caregivers within urban primary care practices. *Journal of General Internal Medicine* 23(11) 1736-1740.

Zarit S, Wiltach C (1993) The effects of placement in nursing homes on family carers: short and long-term consequences. *The Irish Journal of Psychology* 14(1) 25-37.

Introducing the Intergenerational Care Project

A major research project – the first to formally trial and evaluate different models of intergenerational learning programs in Australia – is coming into its final phase, and preliminary results suggest the program has been positive. The researchers say intergenerational learning programs have “the potential to solve many of today's economic challenges associated with child and aged care, while enhancing the educational and social benefits in encouraging relationship building between generations” (Fitzgerald *et al* 2018).

The Intergenerational Care Project is a two-year research project being conducted by Griffith University on the Gold Coast in Queensland. The project is being supported by the Australian Government's Dementia and Aged Care Services (DACs) Fund and officially commenced in June 2017.

Intergenerational learning programs are defined as planned ongoing activities that purposefully bring together different generations to share experiences that are mutually beneficial.

This project aims to evaluate two models of intergenerational learning programs within community care settings:

- Shared campus model: aged day care and child day care centres offer their programs on the same site with shared infrastructure and facilities. The intergenerational care program is then provided in a multi-function room common to both aged care and child care facilities.
- Visiting campus model: centres are located separately and either children or older people are transported to the other site and intergenerational activities are held on that site for one to two hours, twice per week.

The research involves working with older people living with dementia and children aged three to five years, across four locations within Queensland and NSW.

The researchers say that while the psychological and social benefits of intergenerational learning for children and older people are well recognised, this research is investigating more specifically the socioeconomic implications, workforce implications and educational implications of intergenerational learning.

A full article on the project will appear in *AJDC* later in 2019. ■

References

Fitzgerald A, Radford K, Kirsnan L (2018) A new project shows combining childcare and aged care has social and economic benefit. *The Conversation* (3/9/2018). Available at: <https://bit.ly/2MQXgXc>. Intergenerational Care Project website <http://www.intergenerationalcare.org/>.

Melissa Hull, Alyssa Hill, Edoardo Rosso, Hannah Keage, Tobias Loetscher and Ashleigh Smith reflect on the collaborative efforts required by a school, local council, aged care organisation and university to develop and implement an intergenerational dementia education project

In Australia alone, approximately 1800 people are diagnosed with dementia each week, corresponding to one new diagnosis every six minutes (Dementia Australia 2018a). Without a significant medical advancement, the number of people diagnosed with dementia is projected to increase to approximately 4550 people each week by 2056 (Dementia Australia 2017).

Providing opportunities

Recently, a study from the UK has identified that adolescents commonly express poor attitudes towards, and limited knowledge of dementia (Isaac *et al* 2017). People with dementia and their carers have also previously identified that it is important to them that children should be educated about dementia (Baker *et al* 2018b). Specific recommendations include an emphasis on ensuring 'personhood' is retained and developing appropriate communication skills to interact with people with dementia without stigma and fear. Providing opportunities in childhood that improve knowledge and attitudes towards dementia and people living with dementia is essential to the ongoing development of dementia-friendly communities.

Public education programs are starting to address the lack of community dementia awareness, dispel common dementia misconceptions and increase understanding, inclusion and respect for people with dementia (Crampton *et al* 2012; Dementia Australia 2018b). However, these education programs have typically targeted adults and business owners (Hebert & Scales 2017). To ensure a more sustainable long-term strategy, it is imperative we begin to tackle stigma at a much younger age. Ideally this would occur when children are at an age when their beliefs and attitudes towards ageing are malleable (O'Driscoll *et al* 2012).

Intergenerational programs

Intergenerational programs, which link people from different generations for a

Forget Me Not brings generations together



An ECH Day Program client plays pool with children participating in the Forget Me Not program. Photos courtesy University of SA

common activity, have previously been used in several community and aged care settings. Programs may involve contact from the younger generation visiting the older generation at an aged care facility, the older generation visiting a school, or meeting in a neutral, community-based centre. Intergenerational programs have become more popular in recent years, with several programs implemented both in Australia and internationally (Galbraith *et al* 2015; Radford *et al* 2018). Programs typically provide a meeting place for the two generations to interact with each other as either a singular event or as a regular series of scheduled visits (such as across the school term). Benefits can include the promotion of understanding, respect and sharing between generations, relationship building that may reduce social isolation, increased quality of life for older adults and increasing self-esteem and satisfaction for both groups (BC Care Providers 2009; Radford *et al* 2018).

The Forget Me Not program

Forget Me Not is a collaborative community-driven dementia education program which was piloted in 2018 in a local council area in Adelaide, South Australia. Ninety school children in Years 4 and 5 from Unley Primary School participated in an eight-week school-

based dementia education program and six excursions to a day program centre operated by aged care provider ECH where they met community-dwelling older adults living with dementia and took part in activities with the ECH clients.

The activities (including art and craft) centred on the theme of exploring the differences between the past and present in how people shop and how food is grown. One activity station involved printing and dyeing fabric to make sustainable shopping bags (sewn by local volunteers), while others included botanical drawing and creating recycled planters using plastic drink bottles.

An evaluation of the program was conducted by researchers from the University of South Australia (UniSA), with publication of the main outcomes in preparation. The evaluation will be used to develop a program that can be rolled out to other schools in South Australia.

On reflection, the successful partnerships developed during this process were critical to ensure the project's ultimate success. One important pragmatic consideration identified early in planning was the shared overall goal and vision of the project and the importance for each partner to understand their individual role and responsibility. The individual roles

fulfilled by each of the four project partners in collaborating to co-design, co-implement and evaluate the success of the program, were: community development expertise (City of Unley); expertise in intervention and evaluation methods (UniSA); knowledge of working with people with dementia (ECH); and pedagogies of childhood learning (Unley Primary School).

The City of Unley

The City of Unley was the link between all the Forget Me Not partners. It was the first local government in South Australia to become a member of the World Health Organisation Global Network of Age-Friendly Cities in 2016. As part of this membership, the City of Unley developed its Active Ageing Strategy with the purpose of adapting the city's structures and services to be accessible to, and inclusive of, older people with varying needs and capacities.

Pivotal to the implementation of the Active Ageing Strategy is the role of Community Development Officer for Ageing. This role was imperative in identifying, developing and maintaining relationships between the partners. With the council's strengths in community and partnership development, it provided a clear community lens to the process, and drew on previous successful relationships with all partners.

The council was also a key driver on the initial co-design of the project concept with UniSA. Both partners identified the opportunity for an intergenerational program to build respect and inclusion, a focus area of the Active Ageing Strategy. The council then secured the principal funding from the Office for Ageing Well Grant (South Australian Government), which took the project from a concept to a community program. This funding paid for project consumables, the community artists, transport for the children and seed funding for the evaluation by UniSA.

Unley also has a strong volunteering culture, and the council was able to leverage this to support more ambitious projects planned by the artists. This included community donations of fabric to be used in one of the main projects – the design and construction of sustainable shopping bags. Community volunteers were also recruited to help with the final sewing of these bags, before they were placed around the Unley community for use.

University of South Australia (UniSA)

UniSA provided widespread support for the program across staffing, and project design and evaluation. The UniSA

research team consisted of research fellows, a project manager, honours students and a visiting international scholar. The team's expertise ranged across the fields of cognitive neuroscience, psychology, health promotion, health policy, health economics and education. With this breadth of knowledge, the team provided critical dementia-specific information, which they then taught to the students in the weekly lessons. As well as presenting the educational component, the UniSA team was also responsible for securing funding (UniSA Research Themes Investment Scheme) and conducting the program evaluation.

The specialist knowledge used in this evaluation helped to identify the initial overall success of Forget Me Not, but also the related economic costs, and estimate the cost-benefits participants received. As mentioned previously, UniSA also employed a specific project manager for Forget Me Not who worked closely with the Community Development Officer from Unley Council to ensure all components of the program ran smoothly. The project manager was also a key link for any of the partners or participants who had questions about the evaluation process.

Enabling Confidence at Home (ECH)

ECH is a leading aged-care organisation based in Adelaide. It provides services such as home care support, day respite and independent living villages to a wide range of clients. ECH has a strong ageing lens and provided essential knowledge and understanding of the needs of people living with dementia (from a social respite setting) in this case. In addition, one of ECH's priorities is to reduce social isolation through an 'Engagement with Life' approach. Engagement with Life is at the core of the

notion of successful ageing, along with remaining relatively free of disease and disease-related disability and maintaining relatively high levels of mental and physical function (Rowe & Kahn 2015). This considers the importance of maintaining close relationships and remaining engaged in meaningful and productive activities. On balance, Forget Me Not was well supported across all levels within ECH.

In addition to the organisation's strengths in aged care, ECH also supplied key personnel who planned and ran the main excursion sessions. Two of the key ECH staff were a therapy coordinator and horticultural therapist. They were responsible for planning and conducting activities based on their understanding of their clients' abilities and needs, and previous experience working with community groups. In addition, ECH was also able to engage two community artists to assist with the program and guide the more specialised tasks participants completed (including a historical sun-based photography technique, and mural-making activities).

Unley Primary School

Unley Primary School (UPS) is a government-funded public primary school in metropolitan Adelaide. Not only was the school extremely receptive to the initial idea, it also helped to guide the development of the specific dementia-education lessons. Specifically, classroom teachers worked alongside a UniSA education student to modify Kids4Dementia content (Baker *et al* 2018a), develop new lesson plans and a unit overview, draw links between the content and the Australian curriculum and ensure lessons would be delivered in an engaging way to maximise learning.

Teachers also offered indirect support through liaising with parents, helped



Unley Primary School students Zara and Aachan with ECH clients Iris (centre left) and Pat, at one of the activity stations



A Forget Me Not workbook being used by one of the Unley Primary School students during class

manage classroom behaviour during lessons and reposted weekly newsletters regarding the study on the school communication app.

At the end of the program, UPS teachers, students and parents provided critical feedback that will be used to inform our future plans. During the evaluation, the teachers also discussed their plans to continue to expand and consolidate the dementia education the children had received through their ongoing Civics and Citizenship subject in subsequent teaching modules. For example, each of the classes involved in the program had identified a specific method they could use to educate other students/ classes and schools about what they learnt during Forget Me Not.

Challenges to overcome

Despite the success of Forget Me Not, this collaboration did face challenges that at times required quick thinking, flexibility and amended planning to overcome. While the final four-way partnership was ultimately successful, this partnership mix was not originally planned. The initial art and community education partners that were identified and consulted with extensively eventually declined to participate in the program. The reasons given included the large scale of the project, and associated costs. This then led to ECH coming on board as a project partner (through a previously established network), and the role of UniSA changing from evaluation only to also providing dementia education to the children. Implementation of the intergenerational sessions was relatively straightforward.

Weekly reflections from staff were used to refine activities from week to week. During the first two excursions it became apparent that increased leadership was needed early in the sessions to ensure participant engagement. During this discussion, concerns were also raised by the project partners about noise and use

of space, which resulted in modified activities and smaller groups of children and older adults being dispersed around the facility more effectively. Other suggestions that were implemented across the program included settling older adults at activities before the children entered. This provided additional incentive for the children who were directed to activity stations to focus on the task provided and helped to maintain the older adults' engagement.

A further consideration, which was initially overlooked, was that some ECH activity staff did not have experience working with children, and this negatively affected their confidence in supervising the activities. This is a consideration that was shared by an intergenerational care program run in NSW (Cartmel *et al* 2018), however it was not initially identified as a potential problem by partners.

During the evaluation it became clear that the assumption that most people would be comfortable interacting with children was not necessarily the case for all staff members. While the children involved in this study were generally very well behaved, there were instances where ECH staff expressed concern over the noise and general excitement they were confronted with.

Additional training regarding children's group dynamics and techniques to quickly get the students' attention may have helped staff manage more effectively and with increased confidence when supervising activities. Conversely, as class teachers were present during the school-based dementia lessons, they had engaged in preparatory learning about dementia before the excursions. This prior knowledge may have helped them during any interactions they had with people with dementia while on excursion.

Considerations for future programs

- Future programs with multiple partners, such as Forget Me Not, should consider and plan for one or two dedicated personnel who coordinate the program across all partners to ensure adequate budgeting of time and resources. The provision of clear leadership and a close working relationship between both the Community Development Officer at Unley Council and the UniSA Project Manager provided a direct link between organisations and individuals.
- Mutually agreed goals between all partners must be explicit and agreed upon. This is particularly important for projects that span a longer time frame,

where organisational-level change from partners may impact on their roles and responsibilities. These changes are likely to require quick responses to ensure the wider project remains viable for other partners.

- The choice and availability of appropriate activities is another factor that requires careful planning. In this pilot program, a healthy budget provided through grants enabled unique arts interventions that were designed by the community artists. Throughout the intervention it became clear that some of the simplest, most flexible activities worked best to facilitate organic and meaningful interactions between participants (for example pool/snooker and a group mural).
- Based on our experiences, we would also suggest that closer interaction and discussion occur with the participant groups before implementation. This would allow initial preferences and abilities of participants to be considered and allow for plans to be amended if necessary to better suit the participant groups (eg preference for paired activities vs larger groups). This process may also enable early identification of potential pairs or small groups of adults and children who share similar interests.
- Throughout Forget Me Not, the children's parents were kept informed of the weekly progress through regular newsletters, however feedback from some parents suggested they would have also liked the option to undertake a similar education program themselves.

Conclusion

Community partnerships between industry, end users and organisations are vital to continue to provide sustainable, innovative and rewarding projects such as Forget Me Not into the future. In this case, the ability of the City of Unley to act as the conduit to manage expectations between ECH, Unley Primary School and UniSA was key to the project's overall success, as was the shared goal of all partners to increase community-level dementia awareness. This successful collaboration between four community, end-user and research partners has provided a framework, based on a shared understanding of each partner's unique strengths, that can direct the development of future dementia education programs. ■

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Useful resources and additional reading

Dementia Resources For Kids And Teens

Blog produced by Dementia Australia library staff. Good overview of a long list of helpful resources on dementia aimed at children and young people. Available at: <http://bit.ly/dem-kidsandteens>.

Kids4Dementia

This project has involved developing classroom-based learning resources on dementia for Australian primary schools (Years 5 and 6). The Centre for Healthy Brain Ageing (CHeBA) is now supporting the roll-out of the program to interested schools across Australia. Details: <https://cheba.unsw.edu.au/kids4dementia>.

The Milk's In The Oven

This Mental Health Foundation (MHF) booklet is aimed at children and young people. It gives information about dementia, the different parts of the brain, how a person with dementia might be feeling, and some activities to help kids try to step into the shoes of a person living with dementia. Available at: <http://bit.ly/dem-milksintheoven>.

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References

Baker J, Goodenough B, Jeon YH, Bryden C, Hutchinson K, Low L-F (2018a) The Kids4Dementia education program is effective in improving children's attitudes towards dementia. *Dementia*. doi:10.1177/1471301217731385.
Baker JR, Jeon Y-H *et al* (2018b) What do children need to know about dementia? The perspectives of children and people with personal experience of dementia. *International Psychogeriatrics* 30(5) 673-684.
BC Care Providers (2009) *Creating caring communities: a guide to establishing intergenerational programs for schools, care facilities and community groups*. Available at: <http://bit.ly/2J44q8c>

Cartmel J, Radford K *et al* (2018) Developing an evidenced based intergenerational pedagogy in Australia. *Journal of Intergenerational Relationships* 16(1-2) 64-85.
Crompton J, Dean J, Elery R (2012) *Creating a dementia-friendly York*. Joseph Rowntree Foundation. Available at: <http://bit.ly/2ZX11Di>.
Dementia Australia (2017) *Economic cost of dementia in Australia 2016-2056*. Available at: <http://bit.ly/2J4XuYa>.
Dementia Australia (2018a) *Dementia statistics*. Available at: www.dementia.org.au/statistics.
Dementia Australia (2018b) *What is a dementia-friendly community?* Available at: <http://bit.ly/2DTSpOj>.
Galbraith B, Larkin H, Moorhouse A, Oomen T (2015) Intergenerational programs for persons with dementia: a scoping review. *Journal of Gerontological Social Work* 58(4) 357-378.
Hebert CA, Scales K (2017) Dementia friendly initiatives: a state of the science review. *Dementia*. doi:10.1177/1471301217731433.
Isaac MG, Isaac MM *et al* (2017) Knowledge and attitudes towards dementia in adolescent students. *Journal of Mental Health* 26(5) 419-425.
O'Driscoll C, Heary C, Hennessy E, McKeague L (2012) Explicit and implicit stigma towards peers with mental health problems in childhood and adolescence. *Journal of Child Psychology and Psychiatry* 53(10) 1054-1062.
Radford K, Gould R, Vecchio N, Fitzgerald A (2018) Unpacking intergenerational (IG) programs for policy implications: a systematic review of the literature. *Journal of Intergenerational Relationships* 16(3) 302-329.
Rowe JW, Kahn RL (2015) Successful aging 2.0: conceptual expansions for the 21st century. *The Journals of Gerontology: Series B* 70(4) 593-596.

Human rights and the built environment

A new project is investigating the impact of restrictive design in residential aged care facilities (RACFs) on the quality of life of people with dementia. The project team is aiming to present its findings later in 2019 in a written submission to the Royal Commission into Aged Care in a bid to ensure the Commission considers the effects of the built environment.

Safe and Just Futures

The Safe and Just Futures for People Living with Dementia in Residential Aged Care research project will explore a range of questions including:

- Why do we house people living with dementia in large numbers separate to the rest of the community and most often separate to residents without dementia?
- Why do we have buildings that lock up people living with dementia and prevent them from accessing the community?
- What impact does this have on people living with dementia and the overall

diversity and vibrancy of our communities as a whole?

Dr Linda Steele from the University of Technology Sydney is coordinating the project, working alongside Professor Richard Fleming and Dr Lyn Phillipson from the University of Wollongong and Kate Swaffer from Dementia Alliance International and the University of South Australia.

Dr Steele says in most RACFs, people living with dementia are separated in locked facilities with limited access to outdoor spaces and the wider community.

The project will use the United Nations Convention on the Rights of Persons with Disabilities as a framework through which to view the restrictive environment of aged care facilities' segregation as an injustice to residents with dementia. Ms Swaffer, an international dementia rights advocate and person living with dementia, says most care providers restrict people with dementia's personal movement and access to all areas of society, and further segregate

them from the rest of the community, including other residents.

How to participate

The project team held forums in Wollongong and Sydney in May to bring together people living with dementia, care partners, aged care facility residents and employees, dementia advocates, lawyers and aged care regulators for focus group discussions.

More focus groups and interviews are being planned and anyone interested in participating or finding out more about the research should contact Dr Steele on (02) 9514 4103 or email Linda.Steele@uts.edu.au

The forums will seek people's views on buildings and other aspects of indoor and outdoor environments in RACFs. Questions will explore the extent to which residents with dementia have freedom to move through environments, including having community access that supports their quality of life. The forums will also explore human rights perspectives on community access. ■

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.

The effects of engaging with PARO

Social disconnect and loneliness are a common experience of people living with dementia in residential aged care. **Sharon Stoddart** and **Rebecca Galvin** explored residents' engagement with the therapeutic robot PARO and found it contributed to enhanced quality of life

In a residential aged care setting, people living with dementia can find life difficult, experiencing feelings of worthlessness and invisibility. They may also feel homesick and isolated and do not experience a sense of belonging (Mjørud *et al* 2017). This sense of isolation has been related to anxiety and a decrease in self-confidence (Ruthirakuhan *et al* 2012).

Engaging in social interaction can help reduce the sense of loneliness, isolation and lack of self-worth (Ruthirakuhan *et al* 2012). The experience of loneliness has been shown to be alleviated through having meaningful things to do. People with dementia can quickly lose interest in activities that lack meaning and they may fall asleep or sit alone for large parts of the day (Mjørud *et al* 2017).

People living with dementia can find it difficult to engage in meaningful activity due to progressive cognitive deficits. They can experience difficulties with communication which affects socialisation and consequentially impacts on their quality of life (de Vries 2013; Nazarko 2015). It has been suggested that spontaneous interactions are rare between people living with dementia in residential care, and residents miss companionship and friendship (Mjørud *et al* 2017).



A care home resident with the PARO robot seal. The authors' study examined the interactions of residents with dementia with the PARO and the effect on wellbeing. Photos: Sharon Stoddart

Difficulties with communication can also result in mood changes and irritability (de Vries 2013).

A variety of drugs including antidepressants, anxiolytics, antipsychotics or cholinesterase inhibitors are commonly prescribed to treat agitation or aggressive behaviours. There is, however little evidence of their efficacy (Olsen *et al* 2016). Moreover, there are multiple undesirable side effects of using these pharmacological interventions which are known

to increase mortality (Nordgren & Engström 2014). Non-pharmacological interventions are widely and increasingly considered the preferred strategy (Olsen *et al* 2016).

Introducing the PARO

The PARO robotic seal was invented by Takanori Shibata. It was designed to be socially responsive (Birks *et al* 2016) and to promote social interaction (Šabanović & Chang 2016). The robot, which resembles a furry baby seal, squeals, blinks and

turns its head in response to touch, light, sound, temperature and positioning, using sensors to perceive people and its environment. It can recognise light and dark, the direction of voice and words, including its name, greetings and praise, and feel being stroked or held.

PARO in the literature

Birks and colleagues (2016) observed that interactions with the PARO were "powerful" but that it was not a therapeutic tool that was universally applicable. The use of the PARO as a therapeutic intervention has previously been found to contribute to an improvement in the quality of life in participants with "severe" dementia (Jøranson *et al* 2016). Robinson, MacDonald & Broadbent (2015) reported that older residents in care homes showed an improvement in blood pressure measurements as a result of engaging with the PARO. Communication was shown to have improved in participants in a study by Sung and colleagues (2015), while positive responses were observed by McGlynn and colleagues (2017).

PARO and wellbeing study

Our qualitative exploratory ethnographic study sought to observe and understand the effects of the use of the

therapeutic robot PARO on people living with dementia in an aged care home. Wellbeing is commonly used as an indicator of quality of life. In his work on the personhood of the person with dementia, Professor Tom Kitwood suggested five descriptors of subjective wellbeing: comfort, inclusion, identity, occupation and attachment (Kaufmann & Engel 2016). Our study sought to examine the interactions of care home residents with the PARO and explore the manner in which the use of PARO contributed to the wellbeing of the person living with dementia.

Eight care home residents were selected to participate in the study. Seven had a diagnosis of dementia (four with Alzheimer's disease) and one participant had a diagnosis of mild cognitive impairment. The participants were residents in a Special Care Unit in an Australian aged care home and had been living in the home for a minimum of four months. Participants were selected based on their natural affinity towards interacting with the PARO. This was determined by observations made on presenting the PARO to the participant before the study began. All participants freely chose to interact with the PARO.

Participants' next of kin were provided with information about the project and consent was obtained. We also obtained consent before each session from participants where capacity to consent existed. The names of the participants have been changed to protect their identity.

Method

Participants engaged in half hourly sessions five days a week for four weeks. The PARO was presented to the group who were seated in a circle around a table. Each participant was offered the opportunity to interact with the PARO twice during each session. The sessions were facilitated by recreational staff. The staff were directed to maintain a low profile, allowing the PARO to be

the stimulus for the sessions. Observations were made by three researchers. Two of the three researchers were care home employees familiar with baseline behaviours. The third was a volunteer. The contribution of multiple researchers brought a broader perspective to the observations. Hand-written field notes were coded and themed by the primary researcher. A focus group was held with the three researchers at the end of the study.

Results

Four themes emerged from a review of the field notes: communication, focus, affect and personification. A reduction in aggressive and anxious behaviours was also observed.

Communication

It was observed that engagement with the PARO resulted in the generation of conversation. This included speaking to the PARO as well as communication between participants during the session. Participants typically engaged in conversation with the PARO while they stroked or patted the robot. The appearance, movement and noises made by the PARO appeared to provide stimulus for conversation. For example:

Edith: *"Where are your beautiful eyes? I can't see...oh I see a flash of them...all right, goodnight"*.

Some of the conversation between participants during the sessions was general discourse, but participants also often discussed the attributes of PARO:

Harry: *"The thin little things that come out of there [whiskers], if I touch them it seems to irritate him"* [waves fingers in front of PARO's face].

Communication appeared to have a cumulative effect, with conversation increasing in frequency towards the end of the study.

Focus

Participants were focused during the session, which typically lasted half an hour.

Focus related to examination of the body and features of the PARO. The eyes and eyelashes of the PARO received particular attention. Participants displayed curiosity, gazing intently at the PARO and asking questions of the robot. A tactile focus was observed which included stroking, cuddling, touching, scratching, tickling and holding the PARO. Participants' attention was sustained while they interacted with the PARO, stroking, crooning and conversing with it. This focused attention largely continued while others had a turn. Participants followed the PARO with their gaze and commented on interactions, appearing to vicariously engage with the PARO while others took a turn. It was observed that most participants stayed for the duration of the activity.

Affect

Interactions were characterised by a demonstration of emotion, with participants exhibiting positive emotions during the sessions. They smiled, laughed and were animated during interactions with the PARO. The expression of positive emotions continued after the participants had taken their turn with the PARO, for the duration of the session:

"Hilda chuckles, shoulders moving, while others interact with the PARO."

Personification

Participants personified the PARO, appearing to ascribe a personality and character to it. They related to the PARO based upon this assumed personality. For example, Norma assumed a bossy voice when speaking to the PARO, as one would to a child or a pet. This persona emerged at every session and characterised her interaction with the PARO: *"Oh come on, it's all right. Hush, be a good boy. Night-night"*.

Neville's interactions were characterised by tenderness, speaking gently in a low voice: *"That's right, you and me"*.

Participants alternatively appeared to regard the PARO as child, animal or person,

interpreting the sounds made by the PARO:

Edith: *"I think he said 'yes'"*.

Reduction in aggressive and anxious behaviours

Participants appeared settled and calm during the intervention. The sessions were characterised by a lack of aggressive and anxious behaviours. This was deemed unusual for the participants who were known to demonstrate these behaviours.

Discussion

The findings of this study provide insight into the nature of interaction between the person living with dementia and the PARO. These findings add to existing knowledge of the nature of the impact that engaging with the robotic animal PARO has on people living with cognitive impairments.

The primary value that can be attributed to the PARO is enablement. This enablement was found to be fourfold. While communication for people living with dementia becomes progressively more difficult, the participants appeared to enjoy communicating with the PARO. This may have been because the communication difficulties that can be experienced by people with dementia, such as lack of coherence, problems with finding the right words and lack of logic (de Vries 2013), do not apply in this context. Circumventing the need for specific vocabulary, coherence, logic or subject matter, participants conversed with the PARO without inhibition. In this sense the PARO served as a conversation enabler.

The intervention also facilitated the sustained attention of the participants. This may relate to design features of the robot. It is an item that is both attractive and socially reactive, making interactions a rewarding experience. Positive emotions were overtly expressed while participants engaged with the PARO. This was generally sustained beyond the individual's interaction,

extending for the duration of the session. A personification of the robot provided the participants with meaningful and pleasurable interactions.

When considering therapeutic interventions for people living with dementia, Kitwood proposed five psychological needs that the intervention must have as its foci: comfort, attachment, inclusion, identity, occupation (Kaufmann & Engel 2016). Agency is also an important consideration.

Comfort

The derivation of pleasure from an intervention satisfies the criterion of comfort. The participants in the intervention derived discernible pleasure from the interaction:

“Edith laughs with the others as they discuss what PARO might have said.”

Pleasure was also observable through conversation.

Attachment

The PARO served as a focus for attachment for the participants. Attachment was fulfilled on two levels as a result of the intervention. The participants were observed to develop an attachment to the PARO, demonstrated through a display of positive emotional behaviour:

“Norma smiles when others interact with the PARO...eyes light up...looks tenderly at the PARO”.

Participants also developed an attachment to the intervention itself – the task of taking a turn to engage with the PARO:

“Norma spoke in a loud voice during the session; it seemed as though she was playing to the crowd.”

Inclusion

Belonging to a community fulfils the criterion of inclusion in terms of therapeutic interventions (Kaufmann & Engel 2016). Over the four-week intervention a camaraderie developed among the participants. This may have been a result of a shared experience:



The PARO robot resembles a furry baby seal. Using sensors to perceive people and its environment, it can squeal, blink and turn its head in response to touch, light, sound, temperature and positioning. Photo: Sharon Stoddart

“Everyone laughed when PARO squealed; Edith says: ‘what did you do? Pinch him?’”

Occupation

The criterion for occupation was met through participation in the intervention and through engaging in conversation. The participants were also observed to engage in a number of tasks relating to the PARO. This included stroking the PARO with the intent to soothe:

Norma (translating for the PARO): *“More love and attention please!”*

Participants were engaged in problem solving:

Yolanda: *“What’s the matter? Do you want to go somewhere?”*

Identity

Engaging in the intervention satisfied the need to feel approved in a role that one would engage in as part of everyday life (Kaufmann & Engel 2016). These include occupational or family roles. The participants assumed one of a variety of roles including mother (to the PARO) or pet owner:

Edith: *“You’re getting tired, but you’re not allowed to sleep yet”.*

Within the safety of the group, participants’ feelings were accepted and validated. Engaging with the PARO appeared to provide them with the opportunity to reconnect with their memories of

nurturing and with the people around them.

Agency

The criterion of agency was fulfilled as the participants asserted their independence by freely choosing to engage in the intervention. They were free to engage with the PARO and each other in any manner that seemed appropriate to them. The intervention thus supported self-determination.

When considering the ethical principles associated with engaging with a robotic device such as PARO it is suggested that the importance of autonomy and beneficence should apply (Mitchell & Templeton 2014). The right of the person with dementia to engage with the PARO should be upheld. In this study the participants all freely chose to engage with the PARO. As the engagement resulted in improved communication, focus and affect, the principle of beneficence is deemed fulfilled.

Study limitations

The participants’ awareness of being observed by the researchers may have affected their interaction with the PARO. The group of participants were monocultural; all participants were Anglo-Saxon Australians. There was no control group of participants engaged in activity.

Further research

Further research that measures incidence of responsive behaviours prior to, during and post intervention may broaden the scope of use of the PARO. In this study the PARO was used to facilitate a group activity. An observational study on the engagement of people living with dementia in a Special Care Unit without supervision would add to current knowledge of engagement with the PARO.

Conclusion

The provision of a therapeutic environment that encourages communication and social interaction is an important goal in a Special Care Unit. This is not easy to achieve when considering the social limitations experienced by people living with dementia. Progressive cognitive deficits interfere with the person’s ability to focus attention, reducing the pool of meaningful activities that they may engage in.

Engaging with the PARO was observed to produce social interaction with the robot itself as well as with other members of the group. Additionally, participants were able to focus on the activity for the majority of the sessions. They were also observed to display positive emotions during the sessions. A significant finding relating to quality of life was the absence of responsive behaviours during the sessions. Engagement with the PARO satisfies criteria for therapeutic interventions. The benefits of the PARO to the quality of life of the residents living in the Special Care Unit justify the investment. ■

Acknowledgments

The authors would like to thank all the participants and their relatives and carers for their assistance with this study. The authors would also like to thank Thompson Health Care for the provision of the PARO and enablement of research at one of its care homes.

■ Sharon Stoddart has worked with people with dementia in aged care for 12 years, in the field of leisure and recreation, and as a trainer for aged care workers. Her qualifications include a Bachelor in Medical Science

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References

- Benbow B (2014) Design features for resident engagement and meaningful activity. *Canadian Nursing Home* 25(4) 4-8.
- Birks M, Bodak M, Barlas J, Harwood J, Pether M (2016) Robotic seals as therapeutic tools in an aged care facility: a qualitative study. *Journal Of Aging Research*. Article ID 8569607.
- De Vries K (2013) Communicating with older people with dementia. *Nursing Older People* 25(4) 30-37.
- Jøranson N, Pedersen I, Rokstad AMM, Ihlebæk C (2016) Change in quality of life in older people with dementia participating in PARO-activity: a cluster-randomized controlled trial. *Journal of Advanced Nursing* 72(12) 3020-3033.
- Kaufmann EG, Engel SA (2016) Dementia and well-being: a conceptual framework based on Tom Kitwood's model of needs. *Dementia* 15(4) 774-788.
- McGlynn SA, Kemple S, Mitzner TL, King CHA, Rogers WA (2017) Understanding the potential of PARO for healthy older adults. *International Journal of Human-Computer Studies* 100 33-47.
- Miesen BM (1993) Alzheimer's disease, the phenomenon of parent fixation and Bowlby's attachment theory. *International Journal of Geriatric Psychiatry* 8(2) 147-153.
- Mitchell G, Templeton M (2014) Ethical considerations of doll therapy for people with dementia. *Nursing Ethics* 21(6) 720-730.
- Mjørud M, Kirkevold M, Røsvik J, Selbæk G, Engedal K (2014) Variables associated to quality of life among nursing home patients with dementia. *Ageing & Mental Health* 18(8) 1013-1021.
- Mjørud M, Engedal K, Røsvik J, Kirkevold M (2017) Living with dementia in a nursing home, as described by persons with dementia: a phenomenological hermeneutic study. *BMC Health Services Research* 17(1) 93.
- Nazarko L (2015) Top-quality communication skills remove obstacles to communicating with people with dementia. *British Journal of Healthcare Assistants* 9(2) doi:10.12968/bjha.2009.3.9.43988.
- Nordgren L, Engström G (2014) Effects of dog-assisted intervention on behavioural and psychological symptoms of dementia: Lena Nordgren and Gabriella Engström present the results from a study that used dogs as an alternative or a complement to pharmacological treatments. *Nursing Older People* 26(3) 31-38.
- Olsen C, Pedersen I, Bergland A, Enders-Slegers MJ, Patil G, Ihlebæk C (2016) Effect of animal-assisted interventions on depression, agitation and quality of life in nursing home residents suffering from cognitive impairment or dementia: a cluster randomized controlled trial. *International Journal Of Geriatric Psychiatry* 31(12) 1312-1321.
- Robinson H, MacDonald B, Broadbent E (2015) Physiological effects of a companion robot on blood pressure of older people in residential care facility: a pilot study. *Australasian Journal On Ageing* 34(1) 27-32.
- Ruthirakuhan M, Luedke AC, Tam A, Goel A, Kurji A, Garcia A (2012) Use of physical and intellectual activities and socialization in the management of cognitive decline of aging and in dementia: a review. *Journal Of Aging Research* 1-14 doi:10.1155/2012/384875.
- Šabanović S, Chang WL (2016) Socializing robots: constructing robotic sociality in the design and use of the assistive robot PARO. *AI & Society* 31(4) 537-551.
- Sung HC, Chang SM, Chin MY, Lee WL (2015) Robot-assisted therapy for improving social interactions and activity participation among institutionalized older adults: a pilot study. *Asia-Pacific Psychiatry* 7(1) 1-6.

Research updates

Withdrawal of psychotropic medication

An Australian study published in the journal *Drugs and Ageing* has investigated the current evidence about withdrawal of psychotropic medication for people with dementia in long-term residential aged care and found that it can be achieved without adverse effects for the person with dementia. The review examined five areas of research: psychotropic use for people with dementia living in long-term aged care; non-pharmacological approaches for people with dementia living in long-term aged care; approaches to deprescribing psychotropic medications in long-term aged care; facilitators and barriers to deprescribing psychotropic medication in long-term aged care; and areas of future research. The researchers concluded that in order to achieve a change in culture of over-prescribing psychotropic medication in long-term aged care several key things were required: education and training of staff, effective communication between GPs, staff, residents, their families and carers, and management commitment to change.

Dementia prevalence in Australia

The prevalence of dementia among older Australians accessing home or long-term care services is declining according to a large-scale evaluation undertaken by the South Australian Health and Medical Research Institute (SAHMRI). The study, which appeared in *The Journals of Gerontology (Series A)* retrospectively analysed the prevalence of dementia among older people who accessed long-term care (between 2008 and 2014) and home care (2005 to 2014). The study of 188,846 older people receiving home care services found the prevalence of dementia (age- and sex-standardised) fell from 26% in 2005 to 21% in 2014. For 348,311 older people starting long-term care the dementia rate fell from 50% in 2008 to 47% in 2014.

Gender differences

Researchers from the University of Queensland and the Florey Institute for Neuroscience and Mental Health have examined 1.1 million Australian death certificates of those aged 60 or older who died between 2006-2014 to identify those where Alzheimer's

disease, vascular dementia or unspecified dementia had been indicated as a cause of death or underlying cause (184,562). The data revealed that women had 14% higher rates of death from Alzheimer's disease compared with men, and men had a 20% higher rate of death from vascular dementia. The findings were published in the *American Journal of Epidemiology*.

Dementia inclusion

The views of people in the early stages of dementia will be included in a new Australian Research Council Linkage project to develop an instrument to measure quality of life for older people. The tool will be the first of its kind in Australia. Flinders University Professor of Health Economics, Julie Ratcliffe, said the involvement of people with dementia represents something new for this type of research, which until now has excluded people with cognitive impairment or dementia from health economics studies. The project brings together academics as well as five partner aged care organisations (ECH, Helping Hand, Uniting AgeWell, Uniting ACT NSW and Presbyterian Aged Care). Professor Ratcliffe says the Values in Quality Of Life instrument for older people (VQoL) will have wide applicability in quality assessment and aged care system decision making.

MIND brain health diet

A new study into dietary patterns in older adults in Australia has shown that those who followed a diet designed to promote brain health had a reduced risk of developing cognitive impairment. The research, led by NeuRA (Neuroscience Research Australia), reviewed the potential protective effects of the MIND diet, which is partly based on the Mediterranean diet but also includes foods specifically relevant to brain health. The study involved following 220 adults aged 60 and older over a period of 12 years. During this time, a dietary pattern that followed the MIND diet was linked to 19% reduced odds of developing clinically diagnosed mild cognitive impairment or dementia. In contrast, no benefit was found for adhering to the Mediterranean dietary pattern. The study's findings were published in the journal *Alzheimer's and Dementia*.

RESEARCH NEWS



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

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Dementia Care Mapping trial

UK researchers have investigated the clinical and cost effectiveness of the Dementia Care Mapping™ intervention for reducing agitation and improving care outcomes for people living with dementia in residential care homes versus usual care.

The researchers conducted a pragmatic cluster randomised controlled trial. Fifty care homes were randomised (31 intervention, 19 control), with 726 residents with dementia recruited at baseline and a further 261 at 16 months. All homes were audited on delivery of dementia and person-centred care awareness training and those not reaching a minimum standard were

given training ahead of randomisation.

The primary outcome was agitation levels at 16 months (measured by the Cohen-Mansfield Agitation Inventory). Secondary outcomes included resident behaviours that staff may find challenging to support (measured by the Neuropsychiatric Inventory) and quality of life (measured by the Quality of Life in Late Stage Dementia scale, Quality of Life in Alzheimer's Disease measure and Dementia Quality of Life measure).

There were 675 residents in the final analysis, with 388 exposed to the intervention.

There was no evidence of

difference in agitation levels, behaviours or quality of life between the intervention and control group. The health economic analysis indicated that Dementia Care Mapping™ was not cost-effective.

Perceived limitations included very low intervention adherence and staff-completed surveys on behalf of residents due to self-report difficulties among residents with advanced dementia.

Surr CA, Holloway I, Walwyn REA *et al* (2019) Dementia Care Mapping™ to reduce agitation in care home residents with dementia: the DCM™ EPIC cluster randomised controlled trial. *Health Technology Assessment*. In press.

Exercise, physical performance and falls

Australian researchers conducted a randomised controlled trial to determine the effect of an exercise intervention on physical performance and reported fall incidents among people with dementia living in residential care homes.

Sixty people from two residential care homes in Australia were randomly allocated to either exercise intervention 1 (physical exercise for 45 minutes, once a week), exercise intervention 2 (physical exercise for 15 minutes, three times a week) or usual care control group.

Physical performance was assessed before and after the 12-week intervention using the Six Metre Walk test, Five-Times-Sit-to-Stand test, Times Up and Go test, a modified version of the Functional Reach test and the timed static pedalling test. The number of reported falls was determined by incident reports completed by residential care staff.

Physical performance improved over time in both intervention groups compared to the control group. During the intervention period people with dementia who were assigned to the exercise intervention groups experienced less falls.

This study was limited by a small sample size which was not large enough to generate meaningful effect sizes and the limited information researchers had about the level of cognitive function and dementia diagnosis of participants.

Future studies should monitor physical activity intensity during exercise interventions and consider the effect of other health aspects on physical decline of people with dementia, such as comorbidities and body composition.

Brett L, Stapley P, Meedya S, Traynor V (2019) Effect of physical exercise on physical performance and fall incidents of individuals living with dementia in nursing homes: a randomised controlled trial. *Physiotherapy Theory and Practice*. Published online 26 March doi: 10.1080/09593985.2019.1594470.

Profile of a world-first memory clinic

Researchers in Singapore have assessed a world-first interdisciplinary memory clinic which gives its patients access to general practitioners, specialists in geriatric psychiatry, case managers, social workers and community partners who do home visits.

A retrospective audit was conducted on the medical records of all patients seen at the memory clinic from August 2013 to March 2016. The information collected included gender, referral source, presence of behavioural and psychological symptoms of dementia, patient trajectories (ie whether they could be managed within the memory clinic or were referred to a specialist clinic) and percentage of caregivers found to be in need of support.

A total of 489 patients were seen over the 2.5-year period. The majority were female (66.2%). Most were referred from other general practitioners in the same region (89.5%) and a small proportion were referred from hospital specialist clinics (10.5%). Behavioural and psychological symptoms of dementia were present in 22.7% of patients. The majority of

patients (93.5%) had their memory problems managed at the memory clinic without escalation to other specialist services. The majority of patient caregivers (82.2%) required support services, with 99.5% of these caregivers' needs addressed within the memory clinic services.

A limitation of this study is that the researchers did not look at the types of dementia that were managed within the memory clinic or the stages of dementia that patients had.

The researchers conclude that redesigning and evolving healthcare services to promote close collaboration between general practitioners, specialist services for dementia care, social workers and community partners can facilitate enhanced delivery of care for the benefit of patients.

Lai SH, Tsoi T, Tang CT, Hui RJY, Tan KK, Yeo YWS, Kua EH (2019) An integrated, collaborative healthcare model for the early diagnosis and management of dementia: preliminary audit results from the first transdisciplinary service integrating family medicine and geriatric psychiatry services to the heart of patients' homes. *BMC Psychiatry* 19(1) 61.

Care and support needs in the community

Australian researchers have explored the care and support needs of people with dementia who live in the community and their spousal carers. The researchers conducted semi-structured interviews with 10 dyads of spousal carers and people with dementia across metropolitan Perth.

Using comparative analysis, three major themes related to care were identified from the interviews and were refined by two focus groups of spousal carers.

Need 1: Environmental and societal factors. Social support for people with dementia is needed at three levels: family, friends and broader social networks. Dyads reported that formal community services,

such as respite care or domestic assistance, need to be timely, affordable and able to provide high-quality services.

Need 2: Developing and maintaining strong caring relationships. People with early-stage dementia and their carers recognised that love, humour, patience and tolerance were key attitudes when it came to supporting each other through the disease process. Developing coping strategies and getting support from other carers were important for maintaining strong relationships.

Need 3: Changing daily activities and roles. People with dementia recognised the need to participate in daily activities and maintain their

roles in order to feel a sense of self-worth. Maintenance of these activities required support from carers. Needing to adapt and change daily activities with disease progression was a concern for people with dementia.

The authors conclude that formal support services in the community need further refinement to better support the identified needs of people with dementia and their spousal carers.

Morrisby C, Joosten A, Ciccarelli M (2019) Needs of people with dementia and their spousal carers: a study of those living in the community. *Australasian Journal of Ageing* 1-7. Published online 20 January doi.org/10.1111/ajag.12609 (Epub ahead of print).

Using music in an emergency

This case study reports on a UK researcher who was called with an urgent request to help a care home manager who was unable to get close enough to an agitated man with advanced dementia. This man was fond of music and the researcher aimed to connect and engage with him through playing the cello.

The researcher played fast-paced, upbeat Scottish and popular music, hoping to capture the man's attention by matching the music to his current agitated state. He engaged with the researcher and the music, tapping his feet and singing along.

When the researcher felt that the man was fully connected though the fast-paced music, she began gradually slowing down the tempo of the music, aiming to calm him. This took several attempts over a three-hour period before the man became gradually calmer. After this music intervention, the care home manager was able to sit beside the previously agitated man and provide the care that he needed.

This unplanned 'emergency' intervention provides rare insight into the capacity for music to reach and improve the circumstances of an agitated person with advanced dementia.

Garabedian CE (2019) Dementia: when music is the only way in – an emergency intervention: innovative practice. *Dementia* 0(0) 1-5.

Is telling a 'white lie' acceptable?

Researchers in the UK and Ireland explored the concept of lying from the perspective of people living with dementia in the community and their carers.

Six focus groups were conducted with people with memory problems (n=14) and carers (n=18). The interviews were transcribed verbatim and a qualitative content analysis was conducted.

All participants considered that blatant lying with the intention to deceive and do harm to the person with

dementia was not acceptable. However, telling a 'good lie' or a 'white lie' to alleviate distress was, in certain circumstances, considered acceptable. For carers telling the lie, the intention had to be positive and be mindful of family preferences.

Some carers thought it may be acceptable for health care professionals to tell a 'small lie' in certain circumstances. In these situations, health care professionals need to have worked with the person with memory problems over an

extended period of time and need to have considered the family's wishes.

Further research involving professional regulatory bodies is needed to agree on guidelines for the correct and incorrect use of lying to minimise distress in dementia care.

Casey D, Lynch U, Murphy K, Cooney A, Cannon M, Houghton C, Hunter A, Jordan F, Smyth S, Felzman H, Meskell P (2019) Telling a 'good or white lie': the views of people living with dementia and their carers. *Dementia* 0(0) 1-19.

Doll therapy to reduce anxiety, agitation and aggression

Australian researchers compared a lifelike baby doll intervention for reducing anxiety, agitation and aggression in people with dementia in long-term care with usual facility care.

Thirty-five residents from five long-term care facilities in Queensland participated in a pilot randomised controlled trial. The three-week baby doll intervention consisted of three, 30-minute, individual, non-facilitated sessions per week.

The study found that doll therapy can provide some residents with enjoyment and purposeful engagement. Staff-perceived benefits for

residents included emotional comfort, a calming effect and providing a purposeful activity.

Perceived limitations were that doll therapy may only be suitable for some individuals, some of the time, and the potential for residents to care for the doll at the expense of their own health.

Moyle W, Murfield J *et al* (2018) Can lifelike baby dolls reduce symptoms of anxiety, agitation, or aggression for people with dementia in long-term care? Findings from a pilot randomised controlled trial. *Ageing Mental Health*. Published online 24 November doi: 10.1080/13607863.2018.1498447 (Epub).

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The Aged Care Quality and Safety Commission is offering several new resources to support the implementation of the new Aged Care Quality Standards, due to come into effect on 1 July 2019. The **Aged Care Quality Standards Chatterbox** (pictured) is a downloadable chatterbox template to support aged care service providers and consumers engage with the new standards. The intention is that the chatterbox is used as a prompt to help service providers become familiar with the consumer outcome for each of the standards, by discussing what each of the outcomes means (for providers and consumers), and how the service will engage with consumers to ensure the outcome is being achieved. A **fact sheet** is also available, setting out the key changes impacting providers as they transition to the new standards. And two new **videos** are available: one aimed at service providers (30 minutes in length), produced in collaboration with Altura Learning, introducing the new standards, and another shorter video (3 minutes) aimed at consumers explaining what the new standards mean in practice. To access all these resources, go to www.agedcarequality.gov.au and search under 'Resources'.

HammondCare's Dementia Centre has launched **Dementia Choices**, a new program which aims to formally accredit well-designed products that make the aspects of everyday life more comfortable for people living with dementia. The Dementia Choices program will review and accredit products based on key dementia design principles, including the impact the product has on air quality and the acoustic environment. Accredited products will feature a

A new online course from Dementia Training Australia (DTA) – called **The Dementia Friendly Pharmacy** – aims to increase dementia knowledge among community pharmacists. The online course is available for free via the DTA website (www.dta.com.au), and explores steps to becoming a dementia-friendly pharmacy, including training for staff and assessment of the physical environment. It looks at the important role of community pharmacies as a source of information and social support, particularly for family carers. It also explores medications commonly prescribed for dementia, including risks, side effects and how they may interact with other prescribed medications.

DTA Director and course developer Dr Andrew Stafford said pharmacies are the most frequented health care destination, with Australians estimated to visit their community pharmacy on average 14 times every year. He said, "The implication of this is that community pharmacists are likely to be the healthcare professional they encounter most commonly. Pharmacists are considered to be a good source of advice for carers of people living with dementia, and can ease some of the stress associated with the carer role."

DTA is working in partnership with the Pharmaceutical Society of Australia (PSA) and the Pharmacy Guild of Australia (PGA) to upskill Australian pharmacists in dementia care. The online course builds on a series of face-to-face workshops for pharmacists across the country, which was also a collaboration between DTA and PSA.

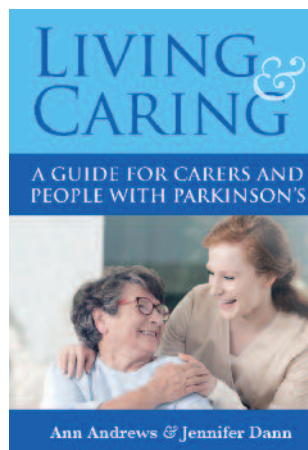
PGA has developed two online training modules to improve understanding of dementia care among pharmacists and pharmacy assistants, complementing DTA's more advanced course. The training modules and the DTA course can be accessed via PGA's online learning platform GuildEd (to find out more, go to www.guild.org.au).

Dementia Choices logo, which is a symbol of the manufacturer's commitment to improving quality of life for people living with dementia.

The Dementia Centre says that a Dementia Choices logo can be applied to a wide range of building products, components and furnishings that are commonly used in environments where people living with dementia spend most of their time. Examples of these include door sets and hardware, flooring and carpets, bathroom fittings, seating, soft furnishings, light fittings and more.

A Dementia Choices Review will involve the product being reviewed by an expert Dementia Centre consultant using the Dementia Choices rating tool. A peer reviewed report will then be issued, outlining the review findings and may highlight areas that need improvement. Dementia Choices sponsorship will be provided for products that meet the standard, confirmed by a receipt which is valid for three years. It says a Dementia Choices Review can be undertaken based on product design 'blueprints' or schematics prior to manufacture, prototypes or pre-production samples, existing products or product ranges, or products in an actual building setting.

To find out more about the Dementia Choices Program, go to www.dementiacentre.com



Cognitive changes and coping with dementia are two of the chapters that appear in a new book called **Living and Caring: A Guide for Carers and People With Parkinson's** by Ann Andrews and Jennifer Dann. The 272-page book draws on the personal experiences of over 40 people living with Parkinson's, and includes contributions from both the person living with the illness and their care partner. The book is published by New Holland Publishers for \$32.99. For more information go to www.newhollandpublishers.com

The **Fidgit Widgit Toolkit** is a collection of five wooden, handheld tactile tools, each with a particular motion – to spin, slide, twist, turn or roll. The idea behind the tools is to help to relax or calm a person with dementia, or simply support their repetitive actions. The toolkit was

developed over a two-year period, with an Alzheimer's Society dementia advisor working closely with a graphic designer from the University of Central Lancashire to develop and trial the new resource, now produced by Active Minds. The five tools are available to purchase separately or together (in the toolkit), from the UK Alzheimer's Society online shop. The full toolkit costs approximately \$A110 (£59.95), with international delivery costs quoted upon request. To find out more, go to <https://shop.alzheimers.org.uk>

The UK Alzheimer's Society has worked with 10 care homes in the UK to develop a new resource on sex, intimacy and relationships aimed at care home staff, called **Lift The Lid**. The aim of the resource is to equip care homes to run their own sessions, which will challenge perceptions around sex, intimate relationships and people affected by dementia, provide a framework for respectful management of in-the-moment situations, and help align with a shared set of values and actions for the care home. The resource comes in a box and contains all the tools needed for care homes to run their own creative workshops (either one 2-3 hour workshop, or three individual workshops lasting 30-45 minutes each). The box contains a facilitator's guide as

well as all the resources to deliver three substantial activities, for 100 participants in total. Lift The Lid costs approximately \$A70 (£38) with international postage costs quoted upon request. To find out more, go to <https://shop.alzheimers.org.uk>

The Gerontological Nursing Competencies (GNCs)

framework for RNs and managers working with older people was released in March 2019 as a guide for aged care providers on how to structure the delivery of best practice care and inform staff education programs. The GNCs comprise 11 core competencies, including 'providing evidence-based dementia care', and 33 domains of practice which explain the everyday activities and responsibilities of RNs working with older people in aged care. The GNCs are organised around two levels of gerontological nursing practice: 'essential' and 'enhanced', which provides a career framework for RNs who can use the GNCs to describe their specialist gerontological nursing competence. The evidence-based workbook guides nurses through the five-step process of becoming accredited gerontological nurses. The framework was developed by researchers at the University of Wollongong (UOW) and the Illawarra Health and Medical Research Institute, in partnership with aged care providers, to address the lack of specialist knowledge in caring for older people and limited professional development opportunities for nurses. The

Researchers at Leeds Beckett University in the UK have completed a major study into 'What works' when it comes to dementia training for the health and care workforce, and two key resources from the study are now available on open access.

The research involved conducting a national audit of people responsible for dementia training and education to find out what is provided, and a survey of staff who have completed dementia training to assess impact on their knowledge and attitudes as well as barriers and facilitators to implementation. The study also included case studies from a number of organisations, looking in detail at the ingredients for effective dementia training and education.

Key resources arising from the study are the **Dementia Training Design and Delivery Audit Tool (DeTDAT)** and accompanying **Manual**. These can be used by care and training providers, commissioners of training and others involved in training design, delivery or purchasing to assess how well a training package meets the good practice criteria identified in the 'What works?' study or to inform the development of new training programs. Both resources are now available to download on the study website, at <https://bit.ly/2vAW3YY>

competencies were developed through a two-year research project involving consultation with more than 400 nurses working in clinical care, education, management and research. For details and to access the resource, visit www.adhere.org.au/g-nursing-competencies.html or email Professor Victoria Traynor victoria_traynor@uow.edu.au.

The UOW team was also involved in developing **The Dementia Care Competencies Framework** in 2015. This resource is targeted at all healthcare professionals, including ENs, and also has a workbook for guidance on developing a portfolio of evidence. It's available to download at: www.adhere.org.au/competencies-framework.html

Meaningful Ageing, the peak national body for spiritual care and ageing, has launched a new campaign called **See Me Know Me** to highlight the importance for older people to find an aged care provider who understands the whole person and recognises their spiritual needs as much as their clinical needs. The campaign's website includes various resources, such as case studies, a top 10 list of conversation starters for older people to share with their friends and family (such as 'I like to...', 'I know a lot about...' and 'I am afraid of...'), and a set of questions for older people who are looking for aged care to ask of aged care providers ('How will you support me to maintain connections and relationships?', 'What do you do to support a good transition?' and 'Who is

available to be with me if I'm struggling?'). The website can be found at seemeknowme.org.au



HammondCare Publishing has published a new book called **Talking Sense: Living With Sensory Changes And Dementia**, written by long-time dementia advocate Agnes Houston with Julie Christie. The book examines each of the senses in detail, looking at the impact of ageing, the impact of dementia, and tips for self-management and care partners. Agnes Houston was diagnosed with younger onset dementia in 2006. She has campaigned for years for increased awareness of the common experience of sensory changes, and has already published on this topic. Julie Christie is the Region Manager for the UK and Europe, Dementia Centre, HammondCare. The 64-page book is available to download for free from the HammondCare Dementia Centre's website (go to www.dementiacentre.com/resources).

Events

■ 5 June & 17 July 2019 – NSW & VIC

Dementia Cottage Experience Workshop

For architects, designers, service commissioners, managers, and direct care staff. Learn about the HammondCare design story and model of care, dementia design principles and tour a HammondCare site and dementia-specific cottage. In Cardiff, NSW (5 June) & Caulfield, VIC (17 July). Details and bookings: <https://bit.ly/2XIRzSB> or www.dementiacentre.com/events

■ 13-14 June 2019 – Tasmania

Australian Dementia Forum 2019

Presented by the NHMRC National Institute for Dementia Research, in Hobart. Details: <https://nnidr.eventsair.com/australian-dementia-forum-2019/>

■ 21-28 June 2019 – NSW, TAS, VIC

Dementia Fundamentals Symposium

Intensive one-day seminar, designed to empower carers and practitioners

with vital expertise and capability across the core areas for day-to-day care in aged care settings, the community and homes. Each topic is evidence-based and proven in clinical practice. Register up to four weeks prior to each event for an early bird discount at <https://bit.ly/2DTnp08> or visit www.dementiacentre.com/events

■ 26 June 2019 – National

Assessing particular aspects of memory in adults

Free webinar: 12.30pm-1.30pm (AEST). This webinar, hosted by Pearson, will look at: the Cambridge Prospective Memory Test (CamProMT), the Autobiographical Memory Interview (AMI), and Doors and People. Can't attend the live event? Register for a link to view the webinar recording in your own time. Visit: <http://bit.ly/30jsTeL>

Details of more events at www.journalofdementiacare.com

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