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DementiaCare

For all who work with people with dementia

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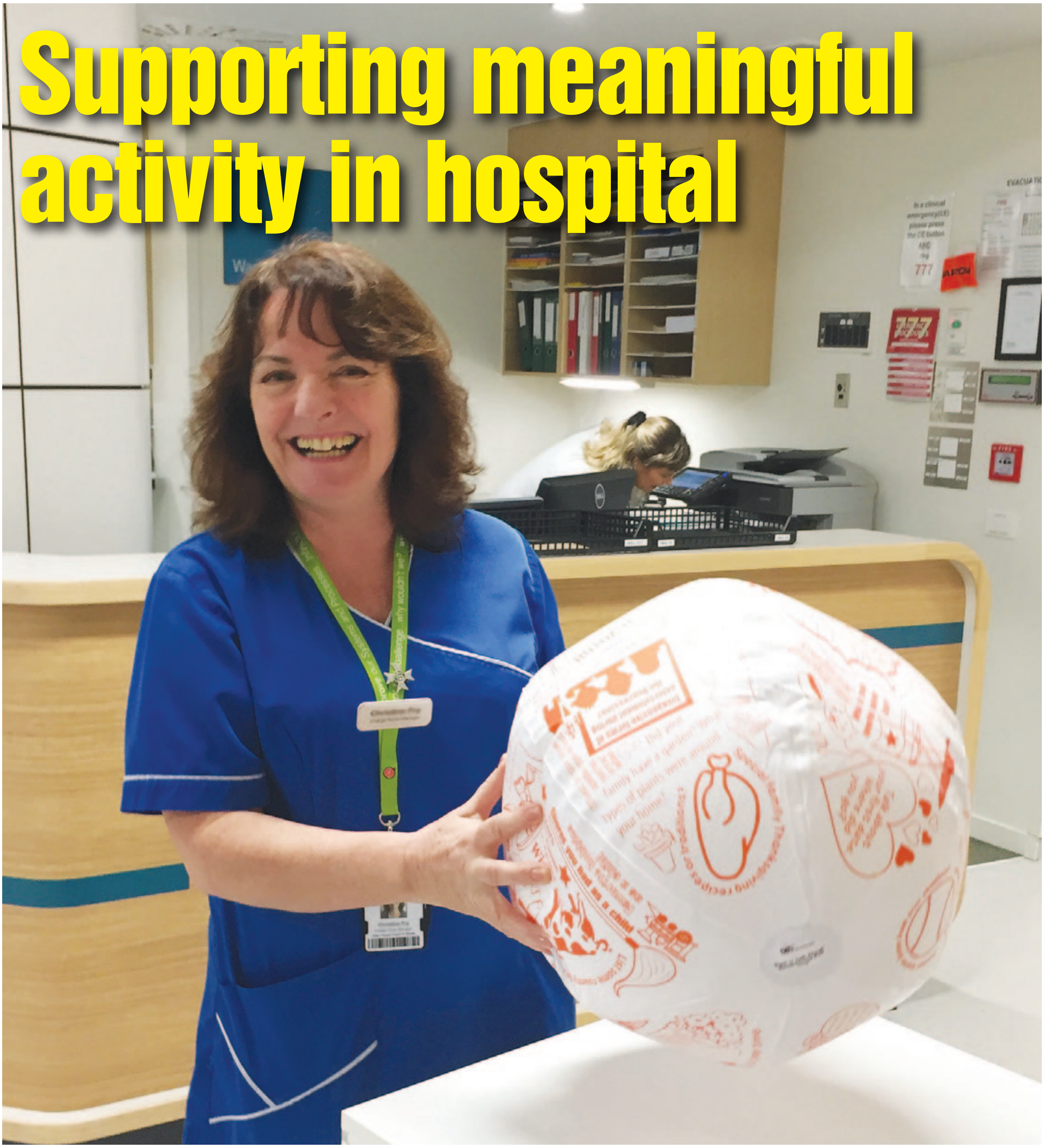
Supporting meaningful activity in hospital



Also inside this issue:

- The Royal Commission and dementia
- A GP's reflections
- New series: Ask a neuroscientist
- Fostering empathy

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Older Australians deserve better

By **Associate Professor Lyn Phillipson**, *Australian Journal of Dementia Care* Co-Editor and Principal Research Fellow, University of Wollongong

In response to shocking allegations of abuse and neglect within Australia's aged care system, the Royal Commission into Aged Care Quality and Safety (ACRC) was established on 8 October, 2018. The scope for the ACRC included both quality and safety of care in residential aged care facilities and community and flexible aged care settings.

Over 22 months (from 18 January 2019 to 23 October 2020) the ACRC received a total of 10,574 public submissions. Public hearings and workshops were held in every capital city and in regional and remote locations across Australia. A total of 641 witnesses gave evidence across 99 hearing days. Twelve community forums were also held between March and November 2019. In total, 228 people told their stories and about 2416 people attended the 12 forums. Commissioners attended 13 roundtable discussions with invited experts on a range of themes in Sydney, Melbourne, Adelaide and Canberra. ACRC staff members also conducted meetings with members of the public, advocates and service providers in many locations in preparation for the hearings.

Across all of these engagements, the Commissioners heard a clear message: older Australians, including those living with dementia, were being neglected by an aged care system that is broken and for many has become a source of national shame. To remedy this, the system needs fundamental structural reform, including changes to the way it is funded, accessed and staffed.

There was much anticipation surrounding the release of the ACRC's Final Report and the Recommendations from the Commissioners, tabled on 1 March, 2021. In this issue of the *AJDC*, we bring you a range of perspectives from a panel of contributors regarding the implications of the recommendations for people living with dementia and their care partners (see *AJDC asks* on pp9-10). Our panel come from backgrounds which include health law, aged and dementia care, dementia research, dementia education, dementia advocacy and carer experience.

Consistently, the panel welcome the ACRC key recommendations for dementia, including: the establishment of a dementia support pathway; a review of specialist dementia care services; mandatory and minimum-level training for workers in dementia care; and improvements to the design of residential aged care facilities to incorporate dementia-friendly principles.

However, they also highlight what they see as significant limitations. These include shortfalls in what they regard as institutionalised discrimination against people with dementia, including the use of physical and chemical restraints (eg psychotropic medications).

To improve the current system, there is universal agreement that both more funding and different funding mechanisms are needed. This issue of *AJDC* provides a link to an article published on our website, which gives readers an overview of the Australian National Aged Care Classification (AN-ACC) – the proposed funding system that's being trialled as a replacement to the Aged Care Funding Instrument in residential aged care (see p12). Anita Westera (Research Fellow from the Australian Health Services Research Institute at the University of Wollongong) also provides a more detailed overview of the Royal Commission recommendations affecting people with dementia and their carers, and gives her take on the 'missing pieces' and the different views of the two Commissioners regarding how the problems should be fixed (see pp11-12).

As we await an official Government response to the ACRC recommendations, there is one thing for certain: older Australians, including those living with dementia and their carer partners, deserve a better aged care system which delivers them 'care, dignity and respect'. ■

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*. Email the Editorial Team at admin@journalofdementiacare.com

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: Burwood Hospital in Christchurch, New Zealand, successfully trialled the use of activity resources trolleys, combined with brief education sessions, to help ward staff feel more able to support personalised meaningful activities for older people, including those living with dementia. See article pp20-22. Photo courtesy Burwood Hospital, Christchurch, New Zealand

Royal Commission final report

From left: Royal Commissioners Richard Tracey AM QC, Lynelle Briggs AO and Tony Pagone QC

Key facts

- The Royal Commission into Aged Care Quality and Safety was established on 8 October 2018, with the Honourable Richard Tracey AM QC and Lynelle Briggs AO appointed as Royal Commissioners.
- In September 2019, a third Commissioner, the Honourable Gaetano (Tony) Pagone QC, was appointed. Commissioner Tracey died on 11 October 2019.
- Commissioner Briggs presented the Interim Report to the Governor-General on 31 October 2019, authored by herself and Commissioner Tracey.
- In total, the Royal Commission heard evidence from 641 witnesses across 99 hearing days.
- The Royal Commission received a total of 10,574 public submissions.
- The Final Report is authored by Commissioners Pagone and Briggs and was presented to Parliament on 1 March 2021.
- The Royal Commission Final Report makes 148 recommendations – including that the Government make a formal response to the Report by 31 May 2021.
- The Final Report is available at https://agedcare.royalcommission.gov.au/publications/final-report

The Royal Commission into Aged Care Quality and Safety has published its final report, *Care, Dignity and Respect*, set out over five volumes, and including 148 recommendations.

The report follows two years of intense scrutiny of the aged care sector, with 23 hearings and workshops conducted in eight cities and four regional locations across Australia, and over 10,000 submissions received from the public.

The report's overarching direction to Government is to establish universal entitlement to aged care based on need, to introduce a new rights-based Aged Care Act to underpin a new aged care system, to revolutionise the way the sector is funded, and to strengthen governance and regulation.

The Final Report says the inquiry had revealed that the quality of aged care that people living with dementia receive is, at times, "abysmal". "Substandard" dementia care was a persistent theme in the inquiry, it said.

"We are deeply concerned that so many aged care providers do not seem to have the skills and capacity required to care adequately for people living with dementia," say the Commissioners.

Dementia care needs "significant and immediate improvement". On multiple occasions, the Final Report says that dementia care should be "core business" for aged care services. This will only be possible if there are "the right number and mix of staff who are trained in dementia care, having the right physical environment (in residential care), and having the right model of care," it says.

The 148 recommendations are detailed and extensive – but the two Commissioners disagreed on some key points and chose to present a number of separate recommendations (Ms Briggs made 29 separate recommendations, while Mr Pagone made 14). For example, Ms Briggs favours a Government-led approach to reform (enlarging the Department of Health to become the Department of Health and Aged Care, with reform from the inside) while Mr Pagone considers this should be the responsibility of a new statutory agency which should be set up, called the Australian Aged Care Commission.

Some key recommendations specifically relating to people living with dementia include:

- establishment of a dementia support pathway
- review of Specialist Dementia Care Units
- urgent review of the Aged Care Quality Standards, specifically in terms of the needs of people living with dementia
- improving the design of aged care accommodation (including publishing national guidelines on accessible and dementia-friendly design for residential aged care)
- increased access to Older Persons Mental Health Services (not excluding people living with dementia from eligibility for such services)
- no younger people in residential aged care
- dementia and palliative care training for all direct care workers (to be a condition of approval of aged care providers)
- immediate funding for education and training of the direct care workforce.

Some key broader recommendations include:

- a new Act, as a foundation of a new aged care system, focusing on the safety, health and wellbeing of older people and putting their needs and preferences first
- a new role of an independent Inspector-General of Aged Care to investigate, monitor and report on the administration and governance of the aged care system
- clearing the Home Care Package waiting list (by 31 December 2021)
- amendments to the regulation of restraints (independent expert assessment and subject to ongoing reporting and monitoring)
- a new aged care program that combines the existing Commonwealth Home Support Program, Home Care Packages Program, and Residential Aged Care Program, including Respite Care and Short-Term Restorative Care
- restricted prescription of antipsychotics in residential aged care (initial prescription by geriatrician or psychiatrist only)
- the establishment of a national registration scheme for the personal care workforce
- mandatory minimum qualification for personal care workers (Certificate III)
- minimum staff time standard for residential care
- increases in award wages and improved remuneration for aged care workers.

Recommendations also addressed systemic issues such as pricing and funding for the sector (via a new levy), research and innovation, and various aspects of governance and regulation. Both Commissioners regard the Aged Care Quality and Safety Commission as not being a strong or effective regulator,

Royal Commission: the Government's response

The Australian Government says it welcomes the Final Report from the Royal Commission into Aged Care Quality and Safety, noting its "significant and sweeping proposals for reform" of the aged care sector.

Speaking at a press conference on 1 March, Prime Minister Scott Morrison immediately committed $452.2 million in funding to address the most pressing priorities raised by the report.

"This report provides an honest assessment and an important roadmap to deliver still greater respect and care for our older Australians. As a nation we commit to further honouring our elders and giving them respect and care," he said.

Minister for Health and Aged Care, Greg Hunt, and Minister for Senior Australians and Aged Care Services, Senator Richard Colbeck joined the Prime Minister to explain the actions the Australian Government would be taking immediately:

"Our comprehensive response to the Royal Commission final report will be driven by the principle of respect and care and through the lens of five broad pillars: Home Care; Residential aged care quality and safety; Residential aged care services and sustainability; Workforce; and Governance," Mr Hunt said.

Key commitments

1. Home Care

- $18 million to enhance the oversight of the Government's Home Care Packages Program.

2. Quality and safety in residential aged care

- $32 million to enhance the capacity of the Aged Care Quality and Safety Commission and greater regulation around the use of restraints in care.

Senator Colbeck committed the Government to reviewing and improving the current quality standards with a focus on areas of concern identified in the report, including dementia, governance, diversity, food and nutrition.

"In response to the Royal Commission, the Government will further establish clear new obligations and guidelines around the use of restraint to protect older Australians receiving care. A Senior Restraint Practitioner will be appointed to the Commission to lead an education campaign for the sector and general practitioners, to minimise the use of restraint, and bring practice into line with those in the disability sector," he said.

3. Residential aged care services and sustainability

- $189.9 million for residential care providers "to provide stability and maintain services while the Government considers the recommendations of the Royal Commission's Final Report".
- $90 million to support a Viability Fund to assist those facilities which are facing financial challenges.

4. Workforce

- $92 million to create over 18,000 places for workers between now and mid-2023.

"There will be a significant increase in activity to attract job seekers into the sector, and a new Home Care Workforce Support Program will provide additional targeted support, including assistance to employers to access support and training for new recruits," Mr Hunt said.

5. Governance

- $30.1 million to strengthen the governance of aged care providers and legislative governance obligations on the sector.

"Along with the measures to further develop residential aged care governance, our Government is also strengthening the arm of the Aged Care Quality and Safety Commission, by appointing an Assistant Commissioner for Sector Capability with responsibility for leading a transformative change program," the Prime Minister said.

Mr Hunt also confirmed that work will immediately begin to replace the Aged Care Act 1997.

The Government described the immediate measures announced in March as a "starting point" for further reform, with more measures to be announced in the May Budget.

Final report, continued

➤ and that its 'light-touch' approach has been inadequate for aged care.

However, on a number of these matters the Commissioners presented widely divergent recommendations. Concern has been expressed within the sector that this stance by the Commissioners may weaken the resolve of the Government to implement the recommendations.

The Royal Commissioners have recommended that the Government has until 31 May 2021 to give a full and formal response to the Final Report, setting out what action it will take (if any) on each of the Report's recommendations.

ROYAL COMMISSION: SECTOR REACTIONS

Dementia Australia

Dementia Australia CEO Maree McCabe welcomed the publication of the Final Report, saying it demonstrates that the Commissioners have listened to Australians impacted by dementia.

"Within the 148 recommendations are 14 key areas with a specific focus on dementia. We welcome these recommendations and now call on the Federal Government to demonstrate they are serious about making quality dementia care core business for aged care in Australia," Ms McCabe said.

"Dementia Australia will be focusing on the detail of the Final Report and will continue to advocate to the Federal Government to ensure they act on this once-in-a-generation opportunity to transform dementia care and the aged care system overall," Ms McCabe said.

Dementia Australia says it has provided the Federal Government with a clear plan on what is needed to deliver quality dementia care and to respond to the Final Report. The Dementia Australia plan, called *A Roadmap for Quality Dementia Care*, was launched formally at a Parliamentary Friends of Dementia event at Parliament House, Canberra on 16 March. It focuses on three key areas:

- dementia support pathways
- transformed dementia workforce capability
- dementia-friendly design.

"We will continue our dialogue with the Federal Government to ensure the dementia-related recommendations will be supported in the 2021-22 Federal Budget to be handed down in May," Ms McCabe said.

The Roadmap was developed following extensive engagement and consultation, including with people living with dementia, and was developed through the Quality Care Initiative (to access the Roadmap, go to https://bit.ly/38IBEVL). ➤

News in brief

Free trial of PainChek®

Australian residential aged care providers have until 31 May 2021 to sign up to a 12-month free trial of the pain assessment tool, PainChek®. The national trial is being funded by the Australian Government as part of an initiative to promote innovation in aged care and to support improved care and pain assessment for those living with dementia or other cognitive impairments. PainChek® is an app for smartphones that uses artificial intelligence to assess pain levels in people who are unable to communicate clearly, including those with dementia. To sign up for the free trial, go to https://painchek.com/

iSupport in China

The National Foundation for Australia-China Relations has given a $400,000 grant to adapt the World Health Organization's iSupport for Dementia program – an online knowledge and skills training program for informal carers of people living with dementia – into Chinese. The project is being led by Professor Lily Xiao from Flinders University, who is working with researchers from Australia and China. iSupport is a self-help tool designed to prevent and/or decrease mental and physical health problems experienced by carers of people living with dementia, and to improve their quality of life. It has already been adapted for the Australian context. The Chinese adaption of the program will be evaluated for its effectiveness and cost-effectiveness in a multicentre trial with 204 Chinese carers in Adelaide and in regions of Beijing, Xi'an, Taipei, Hong Kong and Macau.

Australia Day Honours

Two key individuals have been honoured in the 2021 Australia Day honours for their service to people living with dementia. Neil Samuel OAM received the Medal of the Order of Australia in the General Division, for his service to people living with dementia and to the community. Mr Samuel has served on the Board of Alzheimer's Australia Limited (from 2007) then with Dementia Australia Limited until 2019. He continues to serve on the Board of Dementia Australia Research Foundation and as a member of Dementia Australia's Finance, Audit, Risk Management committee. Dr Stephen Judd AM – Chief Executive of HammondCare for 25 years, from 1995 to 2020 – was appointed a member of the Order of Australia "for significant services to older persons living with dementia".

State funding for training

New online training in dementia care, oral hygiene and palliative care will be offered to staff working across all of Victoria's 780 aged care services, with the backing of $1 million in funding from the Victorian Government. The State's Minister for Disability, Ageing and Carers, Luke Donnellan, made the announcement in February, saying the funding was going to La Trobe University's Australian Centre for Evidence Based Aged Care to develop the new resources. The training will be targeted at personal care attendants, allied health staff and nurses in both public and non-government services.

Food in aged care

In March, the Maggie Beer Foundation delivered a report to the Department of Health on food, nutrition and the dining experience in aged care. The report's 56 findings and 139 possible action points have been put forward by a working group which came together for Australia's first National Congress on Food, Nutrition and the Dining Experience in Aged Care in February in Sydney. Dietitians Australia is also part of the working group and is calling for the Australian Government to fund the development of evidence-based National Meal Guidelines, including governance and accountability frameworks, for residential aged care providers. It has recently published eight position statements addressing key topics in aged care including one on 'Aged Care staff skills and training' which says Accredited Practising Dietitians should be essential members of dementia care teams.

SECTOR REACTIONS continued

➤ Australian Aged Care Collaboration

The Australian Aged Care Collaboration (AACC) – a new coalition of six aged care peak bodies launched in February (reported on p7) – described the release of the report as a "critical watershed moment in Australia's quest for a fair and just system that gives older people the care and choice they need and deserve".

AACC representatives Patricia Sparrow and Sean Rooney said more than 20 government aged care reviews in 20 years had left fundamental questions about sustainability, accountability, transparency and service for older Australians largely untouched.

"The standard of reform required has been set by the Royal Commission. As providers, we stand ready to play our part. It's now over to the Prime Minister and his Government to drive the significant reforms that will set up Australia for our ageing population and guarantee older Australians the respect they deserve," Ms Sparrow said.

"We will of course need time to go through the recommendations in detail, but it is concerning the Royal Commissioners did not provide a unanimous and clear position of how aged care should be funded in future."

Mr Rooney said: "What Australia needs is a regulatory and funding model that recognises older Australians' fundamental human rights, whether they live in a communal residential aged care facility or are supported by a government-subsidised care package within their own home."

COTA Australia

"When it comes to the crisis consuming our aged care system, the Royal Commissioners are unanimous in identifying the issues of neglect, abuse, indifference and poor leadership," Council on the Ageing (COTA) Australia Chief Executive Ian Yates AM said.

"The fact that there are a few alternative recommendations from the Commissioners on the best way to manage and fund the aged care system in no way lets government off the hook. There are no barriers to commencing urgent and long-awaited reforms."

COTA said it will engage with the Government to argue for the following reforms to be prioritised:

- home care without waiting
- a stronger regulator
- star rating system for staffing
- consumer control and rights
- transparency.

National Seniors Australia

National Seniors Australia welcomed the release of the Royal Commission's findings – and the Government's initial response.

National Seniors CEO Professor John McCallum said, "Tearing up the Aged Care Act and replacing it with one based on individual rights is a good start". He also said the strong emphasis on fixing home care was long overdue.

"It's the pivot point for transformational change," he said.

National Seniors Chief Advocate, Ian Henschke, pointed to the unacceptable number of deaths on the waiting list for home care. "The Government needs to especially target the waiting lists of higher levels of home care for patients with dementia and high levels of disability," he said.

Professor McCallum said he was encouraged by the Government's announcement of an initial $452 million: "The $452 million is a start but we're on a five-year journey for change. We have said all along it's not just about the money. We need a bigger workforce and better culture to make this transition in the aged care sector work."

Funding for DTA and DSA

In January, Minister for Senior Australians and Aged Care Services, Senator Richard Colbeck, announced that the Australian Government would be extending grant agreements to Dementia Training Australia (DTA) and Dementia Support Australia (DSA).

He said $44 million would be provided to extend a number of national programs from July 2021 to June 2022: the Dementia Training Program (DTP), delivered by DTA, and the three programs delivered by DSA – Dementia Behaviour Management Advisory Service (DBMAS), Severe Behaviour Response Teams (SBRT) and Needs Based Assessment (NBA), which is a component of the Specialist Dementia Care Program. The Minister said the programs have delivered "great outcomes and significant clinical improvements" in recent years.

The Government's response to the Final Report of the Royal Commission into Aged Care Quality and Safety will inform decisions about the delivery of these programs beyond 30 June 2022.

Coalition care campaign

'It's Time to Care About Aged Care' is the name of a campaign – and report – launched in February by a new coalition of major aged care organisations. The Australian Aged Care Collaboration is a group of six aged care peak bodies: Aged & Community Services Australia (ACSA), Anglicare Australia, Baptist Care Australia, Catholic Health Australia, Leading Age Services Australia (LASA) and UnitingCare Australia.

With an election looming, the organisations have come together to identify the 30 Members of Parliament who represent electorates with the oldest populations, and therefore are most vulnerable to continuation of the current aged care system. The organisations are calling for Australians to sign a petition saying that they encourage their MP to support "comprehensive reform of the aged care system".

The accompanying report sets out the major challenges in the Australian aged care system (including the need for dementia education for the workforce) and explores the question of who can fix the system – concluding that a key lever will be targeted campaigning in the 30 electorates with the oldest populations. To access information and resources about the campaign, and the report, go to www.careaboutagedcare.org.au/

Voluntary Industry Code of Practice

In February Minister for Senior Australians and Aged Care Services, Senator Richard Colbeck, launched the Aged Care Voluntary Industry Code of Practice, hailing the event as marking "a new chapter in the delivery of quality aged care services in Australia".

The Aged Care Workforce Industry Council has led on the development of the Voluntary Industry Code of Practice, which was originally drafted as part of a key recommended strategic action within *A Matter of Care*, Australia's Aged Care Workforce Strategy, launched in 2018. The Code identifies seven key principles that underpin proactive industry-led improvement to aged care. The Council is now encouraging providers to pledge their commitment to the Code. It says it recognises that not all aged care providers support the Code in its current form, and it will work with the sector over coming months to refine it and address these concerns. More information on the Voluntary Industry Code of Practice is available at www.acwic.com.au

News in brief

DA Research Foundation grants

Twelve new dementia research projects are set to benefit from nearly $1 million in grants from the Dementia Australia Research Foundation, announced in early March. The Foundation's Project Grants are valued at $75,000 over one to two years, with funding commencing in 2021. Research topics include: developing tools to measure depression and anxiety in people living with dementia in the Torres Strait (Dr Leander Mitchell from the University of Queensland); dementia-friendly eye care (Marianne Coleman from the University of Melbourne); redressing neglect and abuse of people living with dementia in residential aged care (Dr Linda Steele from the University of Technology Sydney); and self-harm in people with dementia (Dr Simone Reppermund from UNSW Sydney). Five of the projects were co-funded by the Dementia Centre for Research Collaboration (DCRC) as part of its DCRC pilot grants scheme, which also sponsored two separate dementia research projects with $75,000 funding for each. Professor Graeme Samuel AC, Chair, Dementia Australia Research Foundation, said that it was promising to see so much diversity in the research topics. The full list of recipients is available on the Dementia Australia website at https://bit.ly/3sKDIEe

International research funding

Researchers Dr Adekunle Bademosi from The University of Queensland and Dr Andrew McKinnon from The University of Sydney have each been awarded funding of $A405,000 in total, over three years, which will cover salary and project expenses. The funding comes from the UK Race Against Dementia charity and the Dementia Australia Research Foundation, which together have funded a new 'Race Against Dementia – Dementia Australia Research Foundation Post-doctoral Fellowship' program. Dr Bademosi's research is investigating how and why frontotemporal dementia begins by using advanced imaging tools, while Dr McKinnon's research will investigate sleep problems in older adults with early dementia or those at risk for dementia.

Restraints Principles Review

In March, Australian Healthcare Associates (AHA) submitted its independent review of the Restraints Principles contained in Part 4A of the Quality of Care Principles 2014 (as required under legislation relating to the first year of operation of the principles). AHA had been tasked in May 2020 with investigating whether the principles were effective, whether they were promoting a restraint-free environment, any unintended consequences, and opportunities to improve the principles. AHA makes 10 recommendations, some of which relate to changing the principles (including the need to clarify the definition of physical restraint), and some which relate to broader practice changes. A number of the sub-recommendations make specific reference to the particular needs of people living with dementia in relation to this issue such as the need for workforce training in dementia care, and providing dementia-friendly environments. The Australian Government has said in its initial response that it will be working towards strengthened legislative obligations for aged care providers and an independent review mechanism through a Senior Restraint Practitioner to be appointed to the Aged Care Quality and Safety Commission. The review is available to read at https://bit.ly/2P6XXgF

Dementia SIGs Perspectives

Two NHMRC National Institute for Dementia Research Special Interest Groups (SIGs) have published Perspectives pieces in the *Medical Journal of Australia*. In February, the SIG in Rehabilitation and Dementia wrote that services for people with dementia in Australia are "often fragmented, challenging to navigate and hard to access". The authors, led by Professor Lee-Fay Low, review possible models of service delivery, present lessons from these, and argue that investment is needed in developing a new model. The authors of the March paper, led by Dr Terence Chong and the Prevention SIG, say there is a need for "substantial, timely, and sustained investment in dementia prevention", and are calling for a National Dementia Prevention Plan.

COVID-19 NEWS

International review of visiting policies

A new report has concluded that there is considerable evidence from across the world to show that the policy of restricting visitors to care homes during the COVID-19 pandemic has been detrimental for residents living with dementia.

Professor Lee-Fay Low (pictured) from the University of Sydney is the lead author of *Safe Visiting at Care Homes During COVID-19: A Review of International Guidelines and Emerging Practices During the COVID-19 Pandemic*, a new publication distributed through the ltccovid.org website.

The paper presents a review of international policy and practices relating to visitors to care homes during the COVID-19 pandemic, examines the impact of the restrictions on residents, caregivers and staff, and then presents five recommendations to inform future policies on visiting in care homes.

The authors conclude that blanket visitor and family caregiver bans should not be used to prevent COVID-19 infections in care homes, and instead safe visiting practices should be used on-site (informed by local levels of community transmission and in discussion with residents, families, staff and health authorities). They say family caregivers should be regarded as essential care partners during the pandemic, and governments should fund the extra measures needed to facilitate their safe ongoing hands-on involvement.

The ltccovid.org website was set up in March 2020 as a hub of resources related to long-term care responses to COVID-19. It draws on the resources of the International Long Term Care Policy Network and is hosted by CPEC at the London School of Economics and Political Science. Access the paper here: https://bit.ly/3qg4OBB

National review

In late December 2020 the Department of Health commissioned Professor Lyn Gilbert and Adjunct Professor Alan Lilly to undertake a national review of COVID-19 outbreaks in Australian residential aged care facilities. In March the reviewers conducted an online survey and a series of online workshops, in order to gather a range of views about experiences related to the pandemic. The reviewers were tasked with examining lessons learnt from the management of COVID-19 outbreaks and identifying critical factors which could reduce the risk of future outbreaks of COVID-19 and increase the likelihood of rapid detection and timely response to COVID-19 or any other infectious disease outbreaks. The final report was required to be provided to the Secretary of the Department of Health by 31 March 2021.

COVID-19 and dementia

Dr Katya Numbers and Professor Henry Brodaty from UNSW Sydney's Centre for Healthy Brain Ageing (CHeBA) say increased caregiver support and skilled staff to provide extra support for people living with dementia is essential – both during and after the pandemic.

Their call is based on their review of the international research evidence, recently published in the journal *Nature Reviews Neurology*, which they say shows that older adults with dementia have a high risk of contracting COVID-19 in the first place (due to difficulties maintaining physical distancing and wearing masks, and if living within an aged care facility). International data also shows that, once infected, people living with dementia have a high risk of disease-related morbidity and mortality. They say people living with dementia are at "extremely high risk" of worsening neuropsychiatric symptoms and severe responsive behaviours when living in isolation from others, required because of strict lockdowns. The full article can be accessed at https://go.nature.com/388sMIH

A recently published US study (Wang *et al* 2021) reports similar conclusions. The full study can be accessed at https://bit.ly/3sKAzUU

Vaccination program

The Department of Health's COVID-19 vaccination program – which it describes as "one of the country's most complex logistical operations" – began on 22 February 2021, with residential aged care staff and residents being in the first of three priority groups eligible to receive the COVID-19 vaccine in phase 1a, along with quarantine and border workers, and frontline health care workers.

The Department says workers in community and in-home aged care will be eligible for COVID-19 vaccination in Phase 1b along with other health care workers, and that people receiving Commonwealth-funded home and community aged care will be able to access vaccination through vaccination clinics or GP practices as they meet priority eligibility.

In order to support the roll-out of the COVID-19 vaccine across the aged care sector in Australia, the Department has published a wide range of resources specifically aimed at the aged care sector (see p38 in this issue for more information).

AN-ACC shadow assessments begin

From 1 April 2021, all residents in Australian Government funded residential aged care facilities (excluding palliative residents) will undergo an Australian National Aged Care Classification (AN-ACC) assessment. It will be conducted by clinical assessors from one of six independent Assessment Management Organisations contracted by the Department of Health to conduct the shadow assessments. The AN-ACC assessments will run alongside the current Aged Care Funding Instrument (ACFI) arrangements for a period of 12 months. The Government says the shadow assessments will help to facilitate an easy transition to the AN-ACC funding model – if the Government elects to proceed with this as a replacement for the ACFI. The Department of Health has published two short factsheets explaining the new arrangements. These are titled 'AN-ACC Funding Model: An Introduction' and 'AN-ACC Assessments: Shadow Assessment Period'. Both are available on the Department's web pages, 'Residential Aged Care Funding Reform' at https://bit.ly/307wDRY. **[Read more about the AN-ACC and what it means for residential aged care on the AJDC website at www.journalofdementiacare.com].**

SIRS guidelines

In March, the Aged Care Quality and Safety Commission (ACQSC) published detailed guidelines for residential aged care providers in relation to the Serious Incident Response Scheme (SIRS) – due to commence within a matter of weeks from the publication of the guidance – as well as best practice guidance on effective incident management systems. The SIRS Aged care legislation amendment (Serious Incident Response Scheme and other measures) Bill 2020, first introduced to the House of Representatives in December, was passed by Parliament on Monday 15 February 2021, paving the way for the scheme to commence on 1 April 2021. SIRS will be administered by the ACQSC and will require providers of residential aged care to manage and take reasonable steps to prevent incidents, with a focus on the safety, health, wellbeing and quality of life of aged care consumers. Both pieces of guidance are available on the ACQSC website at https://bit.ly/388pDIY

AJDC asks...

What are the key implications for people living with dementia and their care partners of the Royal Commission into Aged Care Quality and Safety Final Report?

‘AJDC asks’ is a new column in which we invite a range of contributors to consider topical issues relevant to dementia care

From left: Joseph E Ibrahim, Lucy O’Flaherty, Juanita Breen, Lynda Henderson and Danijela Hlis

Professor Joseph E Ibrahim

Head of the Health Law and Ageing Research Unit, Department of Forensic Medicine, Monash University, Victoria

The sense of anticipation surrounding the release of the Final Report of the Royal Commission was a mixture of hope and trepidation for the aged care sector and persons living with dementia. The Commissioners’ 148 recommendations were a smorgasbord with something for everyone. In all, the term ‘dementia’ appears 17 times across the recommendations, with three headline ones in relation to dementia (establishment of a dementia support pathway, review of specialist dementia care services, and dementia and palliative care training for workers).

The remaining recommendations are designed to shift the aged care sector towards delivering better care for all older people, through improved workforce numbers, qualifications and access to mental and allied health, as well as a new Act with a rights focus. The underlying assumption – that these general improvements in the system will eradicate the underlying discrimination issues facing people with dementia – is too optimistic.

While changes addressing the use of restrictive practice are most welcome, it would have been preferable to eliminate the practice. Similarly, while improving reporting and management of serious incidents is worthy, it’s always better to prevent harm.

Gaps remain in addressing the institutionalised discrimination towards people with dementia. While the Royal Commission offers hope for the future, the proposed changes, should government choose to implement the recommendations, are a step in the right direction. It’s just not quite the leap forward needed.

Lucy O’Flaherty

CEO of Glenview, a not-for-profit aged care organisation based in Tasmania

Dementia is recognised across several key proposals of the Royal Commission’s Final Report, which is a demonstrable sign of the importance placed on dementia and the changes required within the aged care system.

Among a host of recommendations outlined in the report, an important one to note proposes changes in workforce capability by mandating minimum levels of training on dementia. This will ensure our aged care workforce has the required skills to deliver quality person-centred care to people living with dementia.

The recommendation that the Australian Government should establish a post-diagnosis support pathway for people living with dementia and their carers will be a tremendous help for people when they are navigating the complex system, in order to obtain information on care, education and social support services.

Another key recommendation centres on environment. People living with dementia can become sensitive to their environment because it can change the way in which individuals perceive the surroundings. The report recognises that good design in aged care involves smaller, lower-density living arrangements rather than larger, more institutional settings. Dementia design elements are evident at Glenview’s Korongee Village in Tasmania, which opened up in 2020. It is affirming to see the recommendation that dementia-friendly design should also be the norm for new residential aged care buildings.

Establishing high-quality care for people living with dementia across Australia will have a profound impact on their quality of life, and it is our responsibility as a society to provide this level of care to our elders.

Juanita Breen

Affiliate A/Prof with the Wicking Dementia Research and Education Centre, University of Tasmania ➤

I testified at the Sydney hearing in May 2019. As both a pharmacist and aged care researcher I spoke about the high and often inappropriate use of psychotropics in this setting, but also about what we can do to address this issue.

The Royal Commission's focus on restraint has certainly raised awareness. Since the Sydney hearing there have been some important developments such as Australia's first aged care restraint legislation. The Final Report goes further with tighter legislation on restraint which aligns with the NDIS and restricting initial prescribing of antipsychotics to psychiatrists and geriatricians.

Aligning the legislation makes sense, but I do have concerns about the Royal Commission's focus on antipsychotic use. Experience in the US and Canada has shown that targeting one psychotropic class exclusively usually results in prescribing shifts to easier to obtain medications such as benzodiazepines (eg, oxazepam) and opioids.

However, I feel that other recommendations made in the Final Report will reduce psychotropic use, especially mandated staffing ratios and better training in dementia care. The recommendation to rewrite the Aged Care Act to embed a stronger focus on human rights for older people, especially those with reduced capacity, is an essential first step to ensure restraint is viewed as an infringement of human rights, instead of a convenient way to manage the behaviour of people living with dementia.

Dementia Australia

Information, education, resource and advocacy organisation for Australians living with dementia and the people involved in their care

Dementia Australia welcomes the release of the Royal Commission's Final Report and is now calling on the Federal Government to demonstrate it is serious about making quality dementia care core business for aged care in Australia.

Getting quality care right for people living with dementia will have a profound and lasting impact for all – systemically, economically and as a human right. It is our responsibility as a society to provide appropriate care for those who are most vulnerable. Funding is important; however, dementia care should not just be a line item in the next health budget – it is about people, their care and wellbeing.

The Royal Commission has brought focus to key themes for the aged care sector to better meet the needs of people living with dementia, their families and carers, including dementia support pathways, specialist dementia care services, building workforce capacity, and dementia-friendly design of aged care accommodation.

Dementia Australia will be focusing on the detail of the Final Report and will continue to advocate to the Federal Government to ensure it acts on this once-in-a-generation opportunity to transform dementia care and the aged care system overall.

Further information on Dementia Australia's Quality Dementia Care initiative can be found at https://bit.ly/3cyKCWB

Lynda Henderson

Care partner, founding member of the Kiama Dementia Advisory Group, Dementia Australia dementia advocate, and member of the OPAN (Older Persons Advocacy Network) National Reference Group

Two years ago I testified at the Royal Commission's hearings into home care, along with V, the person I support, who has a rare form of younger onset dementia and is losing language. We criticised her previous Home Care Package (HCP) provider for inadequate staff education and care planning, price gouging, high fees and charges and inflexibility.

I've been assisting V to self-manage her HCP for the past six months. We feel like we're back in control of our lives after seven long years of being told what we're 'not allowed' to do. She has a nominal provider that holds her care plan and takes care of paperwork for a small fee. We chose her support team, who have the skills and experience that she needs.

We are Boomers, just a tad too old to be eligible for the NDIS, which means that V's funding is capped, regardless of her increasing needs.

We want a non-ageist system. We demand a new Aged Care Act that enshrines human rights, including the UNCRPD and the rights of older persons, and is based on the principle of 'no profit on care'.

Adequate support at home is what most people want. Informal, unpaid care from notional 'family' tries to fill the gaps left by government: it's unsustainable and unrealistic. We 'carers' (care partners/advocates) need space and time to take breaks, but our only options at present are to 'place' the person we love in an institution.

That's not living one's best life. People living with dementia want, need and are entitled to community inclusion, not segregation. It's time for innovation at the local level.

Danijela Hlis

Dementia Australia advocate, member of OPAN/NOPRG (Older Persons Advocacy Network-National Older Persons Reference Group), and passionate about better care for older people, especially from diverse backgrounds

The Final Report is the culmination of 28 months of work, with the Royal Commission taking receipt of over 10,500 public submissions, and hearing from 641 witnesses. I was one of them.

Recommendation 147 calls on the Department of Health to establish a taskforce to implement the Royal Commission's recommendations. To this I say, we – older people with lived experience – must be involved.

For me, it is very important that the rights specified for the new Act include rights for people providing informal care, and that the 'Key principles' of the new Act address the needs of informal carers, Aboriginal and Torres Strait islander people, and people of diverse backgrounds. Unfortunately, in my opinion, this is not enough to help achieve equality in quality care, but it is a start.

Commissioner Briggs' recommendation to establish a Council of Elders is an excellent initiative, and so is the recommendation to establish a dementia support pathway. The recommendations setting out instructions for designing for diversity, difference, complexity and individuality (Rec 30) and for respite support (32) are very important. But I am very concerned about the recommendation to implement a new aged care program that would combine all current programs – I fear too much confusion.

Today, as I read through all the 148 Recommendations, I have hope, I feel some disappointment, but overall, I believe that things will improve, provided that we, all diverse older people of Australia, are involved in and drive the changes that we want and need. ■

The Royal Commission and dementia

Anita Westera, from the Australian Health Services Research Institute, presents this overview and analysis of the Final Report of the Royal Commission into Aged Care Quality and Safety and highlights the major flaws in the logic, and inconsistencies, within the recommendations

Care, Dignity and Respect – the title says it all. After more than two years of submissions, evidence and deliberations, the Royal Commission into Aged Care Quality and Safety has delivered its final report that signals the key attributes that should underpin Australia's aged care system.

The report (all five volumes) provides detailed commentary and analysis of the problems that have beset the aged care sector over the past two decades. It outlines what the Commissioners claim is a "transformational change" of the sector which will require "genuine commitment" of aged care providers, stakeholders and government to implement.

Sub-standard care

It is clear that the stories and voices of the many older people, families and friends, care workers and volunteers, providers, health professionals and academics who have contributed to the Commission have been heard. The Commissioners have identified dementia, as well as mental health and palliative care, as the most common areas of sub-standard care:

"…our inquiry has revealed that the quality of aged care that people living with dementia receive is, at times, abysmal" (Vol 1 p92).

At the heart of the problem in aged care, the Commissioners argue, is the way in which the aged care system has been designed and operates:

"The systemic problems we have identified include inadequate funding, variable provider governance and behaviour, absence of system leadership and governance, and poor access to health care" (Vol 1 p73).

The Commissioners found that, for too long, the primary driver for aged care delivery was to contain costs on the part of government. It has resulted in aged care providers feeling stretched financially, a workforce lacking in dementia skills and knowledge, and interactions with older people being reduced to a transaction rather than a caring relationship.

Fundamental differences

While there is agreement between the Commissioners on the detail of the problems within the sector, there are fundamental differences regarding their views on how they should be resolved. One third of the 148 recommendations in the final report are contested, including important issues such as funding, financing, capital and, importantly, what an aged care program should look like. Both agree that the key to reforming aged care must start with the way it is governed, but differ in terms of how this should occur. Commissioner Pagone recommends the establishment of a new system that is overseen by an independent body separate from government, while Commissioner Briggs sees a reformed bureaucracy within government as the answer.

They are united, however, in their view that the existing legislation should be replaced with an Aged Care Act that is underpinned by "a universal right to high quality, safe and timely support and care" that assists older people to live "active, self-determined and meaningful" lives (Vol 1 p121).

Of those recommendations where there is agreement between the Commissioners, these will, if implemented, bring substantial improvements to the care and support of older people, and in particular people living with dementia and their carers. Many are related to improving the pay, conditions and training requirements of care staff, and improved organisational capacity, accountability and governance arrangements for aged care providers. For those living in residential aged care, the recommendations regarding the number and skills mix in residential aged care, including minimum staffing levels for Registered Nurses, are particularly important.

Suite of improvements

In recognition of the systemic failings within the aged care system for people living with dementia and carers, the Commissioners have recommended a suite of improvements from the point of diagnosis through to palliative care, within aged care services as well as the general community, primary care and hospital care, including:

- Establishment of a dementia support pathway that provides "comprehensive and accessible post-diagnosis support" to assist people navigate the "complex systems through which care is provided – the information, coordination, care, education and social support services" (Recommendation 15, Vol 1 p220).
- Review of specialist dementia care services in terms of their overall numbers, capacity and suitability for supporting people with a mental health condition (Rec 16, Vol 1 p220).
- A significant area of concern has been the use of restraints within aged care, and the report includes several recommendations to ensure people using aged care are "equally protected from restrictive practices as other members of the community" (Vol 1 p221).
- Regulation of restraints, including the requirement for an "independent expert assessment" before use, and "ongoing reporting and monitoring" (Rec 17, Vol 1 p221).
- Review of Aged Care Quality Standards to ensure "best practice" care for older people, including people living with dementia (Rec 19, Vol 1 p223).
- Importantly, the report also recognises the impact of environmental design, access to specialist services to better support people experiencing or at risk of 'changed behaviour', and staff training.
- Development of National

Guidelines and amendments to the National Construction Code to ensure “accessible and dementia-friendly design standards for [new builds and substantial refurbishments]” (Rec 45, Vol 1 p239).

- Improved access to State and Territory government operated older persons mental health services (Rec 59, Vol 1 p249).
- Staff working with people living with dementia will be required to undertake “regular training about dementia care and palliative care” as part of the conditions of the ‘approved provider’ status (Rec 80, Vol 1 p262).
- Additional funding be immediately available for staff education and training (including dementia) to improve the quality of care (Rec 114, Vol 1 p287).

Reforms anticipated

The Commissioners have provided a three-month timeframe (by 31 May 2021) for the Federal Government to respond to the recommendations contained in the final report. The Government has already signalled that a number of reforms were anticipated, and have been factored into program and funding forecasts. For example, the proposed new case-mix funding instrument for residential aged care (Rec 120, p290), called the Australian National Aged Care Classification (AN-ACC) and associated AN-ACC funding model, was developed by the Australian Health Services Research Institute (AHSRI), University of Wollongong, in 2019, and this will support the implementation of the star-rating system (Rec 24, Vol 1 p225) **[you can read an overview of the AN-ACC and what it means for residential aged care on the *AJDC* website at www.journalofdementiacare.com]**.

At the release of the report the Government indicated a commitment of $452.2 million to address specific priorities identified in the report, with an indication that more would be forthcoming within the context of the May 2021 Federal Budget. These investments are clearly welcomed by the sector.

Missing pieces

There are a number of major flaws within the logic and inconsistencies within the recommendations that threaten the likelihood of transformational and sustainable change occurring within the aged care sector.

Both Commissioners fail to challenge the conceptualisation of aged care as a competitive market, when the majority of funding continues to be delivered through public funding and despite the evidence – including that of research it commissioned – of the risks this presents to quality and safety.

Similarly, both recognise that the centralised program structure currently in place presents a major barriers to responsive service planning, development and management, however neither have proposed models that support integration of health, community and aged care at the local level.

And while underpinning the new Aged Care Act with a universal entitlement to quality aged care is appealing, it fails to address public policy concerns such as population equity and system efficiency and community objectives including affordability, accountability and equity.

Conclusion

The Royal Commission has highlighted the significant inequities and risks to quality and safety experienced by older people, people living with dementia and carers, and for the staff and management tasked with supporting them.

It has been presented as a once-in-a-lifetime opportunity to get things right. While the Final Report does provide a roadmap to address some of the issues it has uncovered, the failure to address fundamental issues such as program design, governance and funding means there’s still a long way to go. We will need to continue keeping government on task if we want the goal of ‘care, dignity and respect’ for older people to become a reality. ■

References

Commonwealth of Australia (2021) *Royal Commission into Aged Care Quality and Safety Final Report: Care, Dignity and Respect, Volume 1 Summary and Recommendations.*

Commonwealth of Australia (2021) *Royal Commission into Aged Care Quality and Safety Final Report: Care, Dignity and Respect, Volumes 1-5.*

■ Anita Westera is a Research Fellow with the Centre for Health Service Development (CHSD), Australian Health Services Research Institute (AHSRI), University of Wollongong and has worked in aged care and dementia policy, research, advocacy and governance roles for over three decades. Along with Professor Kathy Eagar and colleagues within AHSRI she has been involved in evaluations of specialist dementia programs, the development of the new funding model for residential aged care, as well as research for the Royal Commission on staffing levels in aged care. Contact her at westera@uow.edu.au

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Psychosocial therapies ‘best for severe behaviours’

HammondCare is releasing the results of a major study, provisionally accepted for publication in the journal *Frontiers in Psychiatry* in late March, which it says clearly shows that psychosocial treatments – not drugs – are best for people living with dementia who are experiencing severe behaviours.

The study involved analysis of 5914 referrals from 1996 care homes across Australia to Dementia Support Australia (DSA), specifically in terms of behaviour outcomes as measured by pre- and post-treatment scores on the Neuropsychiatric Inventory (NPI). The analysis showed significant reductions in total NPI scores of between 61.4% (for the Dementia Behaviour Management Advisory Service) and 74.3% (for Severe Behaviour Response Teams) – which the authors say contrasts with an average reduction (using the same instrument) of around 8% when antipsychotic medications have been studied for the same purpose.

The authors say their study is the first and largest population-based study in the world to report on behaviour outcomes in people living with dementia after broad program-based psychosocial interventions.

DSA Head of Clinical Services Associate Professor Stephen Macfarlane, lead study author, said the findings confirm that psychosocial/non-pharmacological therapies are the “gold standard” for interventions.

The article, *Evaluating the Clinical Impact of National Dementia Behaviour Support Programs on Neuropsychiatric Outcomes in Australia*, was due for publication in late March 2021.

DSDC cements Australian connection

Kirsty Bennett, **Terri Preece** and **Deb de Fiddes** (Evoke Collective Australasia) have been appointed as Australian-based Design Associates for the Dementia Services Development Centre (DSDC) at the University of Stirling in Scotland. Here, they talk with **Lesley Palmer**, chief architect for the DSDC, about what the new relationship could offer to Australian aged care providers

LifeCare's Gaynes Park Manor, in South Australia, was the first Australian residential care facility to achieve a DSDC Gold Standard. Photos: *World Alzheimer Report 2020*, Volume 2, p90

Lesley, for those who are unfamiliar with DSDC, can you tell us about the centre?

Simply put, the DSDC is a centre dedicated to improving the lives of people with dementia.

Since our formation in 1989 we have worked with individuals and organisations to influence and improve services through design, dementia-friendly communities and policy. The centre is globally renowned for evidence-based knowledge exchange and expertise, and is overseen by an international advisory board, whose members include Scientia Professor Henry Brodaty (AO) from the University of Sydney, NSW.

The DSDC is based in the Faculty of Social Sciences at the University of Stirling in Scotland, UK. Being attached to a university means our approach is underpinned by research and is impartial, and we follow the university's strict guidelines for ethics, research and policy. Our landmark Iris Murdoch building is open to the public and includes a comprehensive design resource centre with a bookstore and a library including our own publications. These range from helpful hints guides to more complex and in-depth material for professionals to use in their place of work. Our design and technology suite showcases innovative technology and equipment and is available to the public.

Why is DSDC coming to Australia now?

There has always been a connection between DSDC and Australia. Our founder, Professor Mary Marshall, is well connected in Australia having spent time here early in her career and then visiting regularly.

Over the past few years we have experienced an increased interest from Australian aged care providers and architects. Dr Martin Quirke, one of DSDC's architects and researchers, has recently completed his PhD at the University of Newcastle in NSW. Martin and I have been building an Australian network through conferences, private invitations etc. As part of this effort, a strong connection has already been established with the individuals of the Evoke Collective.

Does DSDC have a particular style to designing for people with dementia?

We do not have a particular style, but we do have a particular approach; evidence-based. We adopt the internationally recognised dementia design principles of our founder, Professor Mary Marshall, which include that design should:

- compensate for disability
- maximise independence
- enhance self-esteem and confidence
- demonstrate care for staff
- be orientating and understandable
- reinforce personal identity
- welcome relatives and the local community
- allow control of stimuli (Marshall 1998).

Our team adopts this evidence-based approach to each and every project, irrespective of project scope or size.

There is a lot of overlap between the DSDC philosophy and the work done in Australia in the early years by people including architect Brian Kidd, environmental design expert Professor Richard Fleming from the University of Wollongong, NSW, and Elizabeth Marshall and Dorothy Eaton with the Lodge Program in Victoria, along with Professor Mary Marshall in the UK and Uriel Cohen and Gerald Weisman in the US. Professor Fleming and architect Kirsty Bennett wrote the Dementia Training Australia *Environmental Design Resources* (https://bit.ly/DTA-ED-Resources) which are also principles-based and are commonly used in Australia. This exploration of design and design principles continues today.

What sort of services does DSDC provide?

Our team includes architects, engineers, designers and health care professionals. We provide consultancy and training services to industry clients, charitable organisations and individuals. We advise on the development of products, services and the design of environments where dementia matters.

We undertake research –

The Evoke Collective Australasia

By **Kirsty Bennett**, **Terri Preece** and **Deb de Fiddes**

Terri and Deb visited the DSDC in 2016 and really enjoyed the cross-exchange of information and ideas with staff. It was interesting to explore the similarities but also the subtle differences in the key design principles that are generally applied in Australia.

As individuals, each of us at Evoke has been connecting with DSDC in our own way over the past decades. We work together as DSDC Associates under the banner of the Evoke Collective Australasia, which was founded by Deb and Kirsty in 2018. As a DSDC team within Evoke, we are able to combine an experienced and high-quality service which is local to Australia.

We can meet the specific requirements of aged care locally and in an Australian context, with Evoke being accessible throughout Australia, having DSDC Design Associates on both the east and west coasts. Our combined networks mean we can link organisations to DSDC and provide the best pathway forward.

As DSDC Design Associates we bring a diverse set of skills and expertise to the table. Each of us has long experience in the field, whether it be in the field of architecture, interior design, management or policy development.

For more information on DSDC accreditation or any of its other services and products, contact Terri Preece at info@evokecollectiveaustralasia.com.

policy and practice-relevant social scientific research – working collaboratively with other universities, nationally and internationally. We work with clients and their design teams to deliver dementia-friendly built environments which reflect the most recent research in this field. We work with product designers and manufacturers across the globe to develop new products for market.

DSDC has developed its own evidence-based Dementia Design Audit Tool, colloquially known internationally as the 'Stirling Gold'. This is currently being reviewed and updated to reflect the most recent research (with Kirsty and Terri from Evoke on the reference group for reviewing this tool). The tool is weighted according to best practice and research in the field and is used as part of the audit process.

As DSDC Design Associates, the team at Evoke will be using the DSDC's Dementia Design Audit Tool to accredit facilities in Australia.

We provide accreditation for commercial and residential buildings, including residential aged care dementia design accreditation. This includes provision for older people, for palliative and end-of-life care, as well as design for ageing vitality and younger people (under 65) diagnosed with dementia.

We also provide a two-day dementia design school titled 'Intersections of Dementia Design'. This is delivered by a multidisciplinary team of construction industry specialists including architects, engineers, landscape architects and nurses with a focus on dementia design.

Can you expand on the DSDC dementia design accreditation scheme?

Our dementia design building accreditation is recognised world-wide and represents a benchmark for quality design for ageing and dementia. DSDC offers a full expert audit service which leads to an independent Dementia Design Audit Certificate with a rating of Bronze, Silver or Gold. This has proven of great practical and reputational value to organisations over the past 10 years. One of its strengths is the impartiality that DSDC brings to this process. We are a team of multidisciplinary unaligned experts, guided only by the best research and practice.

If someone wanted to learn more about accreditation, how could they find examples of DSDC's work?

Our multidisciplinary team has worked on projects in over 23 countries, including Australia, New Zealand, Japan and America. To celebrate 30 years of operation we have just launched our new book *Architecture For Dementia: Stirling Gold 2008-2020* (DSDC 2020) – providing a showcase of our work. Our website also has examples and celebrates the Gold awards (https://bit.ly/Stirling-design-audit).

The *World Alzheimer Report 2020: Design, Dignity, Dementia*, co-written by Professor Richard Fleming, Dr John Zeisel and Kirsty Bennett (2020), includes case studies of some DSDC clients, with at least two from Australia. One case study is of LifeCare's Gaynes Park Manor in South Australia, which was the first Australian facility to achieve a DSDC Gold Standard.

When LifeCare decided on accreditation as a pathway, they went looking for an organisation that was a leader in the field and chose DSDC as a result of informed research and opinion. Gaynes Park Manor is now reaping the benefits first-hand of becoming accredited.

Accreditation can be a costly process. Why would organisations bother?

Accreditation does cost money. The first thing providers may say is that they cannot afford it; their current building could never meet such rigorous standards. This may be true as a Gold standard is the ultimate, however, achieving a 'Highly Commended' shows that an organisation has focused on improving their environment for people living with dementia. The result is world recognition of achieving a high standard within the industry.

I think the important point here is to remember that not getting the environment right is also costly. There are so many examples of how inappropriate environments have detrimental effects on residents living with dementia. These costs are

Worthington Lake Care Home, Wigan, UK, is a purpose-built 32-bed specialist dementia care home, owned by Millennium Care. DSDC worked closely with the Worthington team to design and build a customised living environment to achieve 'Stirling Gold' accreditation

recurrent and so always present, whereas any capital costs are not. Good design can result in a reduction in recurrent costs. For example, if a staff member needs to show a resident to a room, that takes staff time and also is likely to lead to resident frustration, which also takes staff time and skill to respond to. When a resident can locate their room independently, staff time is freed up for other things.

Does accreditation matter?
DSDC's impartiality is key. The Australian Aged Care Quality Standards – Standard 1 focuses on dignity and choice for the consumer. Accrediting a facility or building through the DSDC helps the organisation to stand apart from others and be recognised as a place of choice.

DSDC accreditation means recognition that the facility is a place that puts emphasis on resident wellbeing and has invested in thoughtful design, knowing that this will make a big difference to residents and staff. The importance of a well-designed environment has been highlighted especially now with COVID and the isolation that many residents have experienced. Applying key design principles can help address this.

From a commercial point of view, a Gold standard property is an indicator in the market of value adding and standing out from the crowd.

Is it your plan to develop a new model for Australia?
We are a unique centre which bridges academia and industry. Whilst dementia design is not new to Australia, our approach to bringing academia and industry together is.

We are largely funded by our commercial activity with industry. We act as a conduit between industry and research, with opportunities for our commercial clients to participate in new research projects and benefit from the cutting-edge learning which these projects bring.

Are design associates a new trend by DSDC?
At DSDC we've always recognised the value of working in collaboration with partnering organisations and individuals who bring something unique to our organisation. We have Associates located throughout the UK and partnering organisations in Japan and China. However, this is the first time we have established Associates in Australia.

Why have you appointed Evoke?
There are financial and logistical challenges of providing a specialist service and building an accreditation scheme from a UK base. I am also mindful of the need for a localised / regional approach to the application of the international dementia design principles to ensure design responses are tailored and relevant to the local context. It was important that we could continue to offer a quality service and to do so with an experienced and skilled team based in Australia.


From left: Lesley Palmer, Kirsty Bennett, Terri Preece and Deb de Fiddes

Our new Australian associates bring a breadth and depth of expertise in dementia research, design and training. Kirsty is an architect and author specialising in designing for people living with dementia, Terri is experienced in aged care sector management, operational design and policy and Deb is an interior designer with a focus on environments for older people and people living with dementia. We have known of, and / or worked with all three over a period of time. Individually they have a wealth of talent along with many years of experience in this sector.

What's next?
Since Evoke's appointment we have been busy working behind the scenes planning our 2021 projects, especially while on-site work has been limited – both in Australia and especially in the UK.

DSDC projects in the pipeline for Australia this year include:

- Online Master Class for Dementia Design and Ageing, with an Australian focus.
- 'Stirling Gold' Dementia Design Audit Tool V3 due for publication mid-2021.
- Release of the next wave of technology for the international award-winning IRIDIS Dementia Design Audit Tool app, developed by the University of Stirling and Space Architecture (Europe) Ltd.
- Local workshops around Australia.

For more information, contact Terri Preece at info@evokecollectiveaustralasia.com.

References
Dementia Services Development Centre (2020) *Architecture For Dementia: Stirling Gold 2008-2020.*
Fleming R, Zeisel J, Bennett K (2020) *World Alzheimer Report 2020: Design, Dignity, Dementia*. Volumes 1 and 2, London, England: Alzheimer's Disease International.
Marshall M (1998) Therapeutic Buildings For People With Dementia. In: Judd S, Marshall M, Phippen P (1998) *Design for Dementia* 308. London: Hawker Publications Ltd.

New resource for dementia design and environments

Supporting Comfort and Belonging for People Living with Dementia: A Guide for Team Members to Enhance the Environment in Senior Living is a new publication from the Research Institute for Aging at the University of Waterloo in Canada.

The 22-page practical guide is aimed at supporting care staff to assess living environments for older people (all living environments, including residential settings, secured or unsecured living areas), and guiding them in how to create a sense of comfort and belonging for people living with dementia, particularly those who repeatedly try to leave the premises. According to the guide, people usually attempt to leave their environment because:

- Walking, exploring and being curious are natural to humans.
- Something in the environment is distressing them and they are trying to get away from it.
- Something in the environment is missing and they are trying to find it.

The guide's framework does not consider the above to be symptoms of dementia, but "expressions related to environmental, interpersonal and operational factors that do not meet someone's needs".

The resource covers sensory challenges due to ageing and dementia, physical environment, addressing unmet needs, and interpersonal and operational factors. It includes a range of prompts that can be used in conjunction with the resource, such as 'Pause and reflect' questions (with space to provide answers), practical exercises to undertake, and a draft action plan to complete.

Access the resource here: https://bit.ly/2ZLm07d

Rose and Carl: a GP's reflections

Hilton Koppe shares the story of Rose and Carl*, and the learning that arose from supporting this couple and their extended family, in his role as their GP, for over a decade as Rose's dementia progressed

Image courtesy Dementia Training Australia, from the video *GP Home Visit*

It was one of those conversations that I wished I had been able to record. It would have made a great example of how to maintain a person's dignity in the face of advanced dementia.

Rose was being admitted to a residential aged care facility. I was her GP. We were having a conversation with Rose's two daughters and the care staff about the goals of care for Rose's admission.

We got round to the question of what to do if Rose had a serious illness from which there was little chance of recovery or if the only treatment available would require hospital admission.

"I can see no point in any of that," Rose said. "When your time is up, your time is up. I've had a good life. What's the point in prolonging it?" Rose was very clear about this. She didn't know what day it was. She didn't know where she was. She would not be able to recall a random name and address. She might not have been able to take a sheet of paper, fold it in half and place it on the floor. Or correctly respond to other prompts from cognitive screening tests. But she was still able to express with absolute clarity her long-held views about end-of-life care.

A colourful life

I had known Rose and her husband Carl since they moved to our region to be closer to their daughters a decade earlier. Rose and Carl spent their early married life in inner Sydney, living in a community of artists, actors, American servicemen on R'n'R, nightclubs, drinkers, prostitutes. They lived a colourful life in that milieu.

They moved to suburbia when their children came along but retained their sense of mischief. It was a delight to get to know them. I already cared for their daughter's family, so when they arrived it was a precious opportunity to be a real family doctor.

Planning for the future

Early on in our time together, it became clear that Rose was developing dementia, most likely a mixed pattern of Alzheimer's and vascular. Her cognitive and functional decline was exacerbated by significant visual impairment. A comprehensive dementia management plan was put in place. Her vision was optimised, cardiovascular risk factors minimised, medications reviewed and optimised, including the addition of an anticholinesterase inhibitor. With the family's involvement, we began discussions about planning for the future, including preparing a Delirium Action Plan to assist Carl and the family to know what to do if Rose developed delirium (using a locally developed form, listing key information and contacts).

We also put in place a plan for Rose to visit me on a regular basis. This gave us an opportunity to regularly review our management plan and its objectives. It was an opportunity for "just in time" education on dementia for Rose and Carl as well as guiding them towards what was likely to occur in the coming weeks or months.

An uneasy truce

Carl was extremely protective of Rose. As her dementia progressed and her reliance on Carl for support increased, his protectiveness increased. "We don't need any interfering do-gooders coming into our home," he'd say.

Try as I might, I could not convince Carl to accept extra help. His views were in line with many working class folk of his generation: "I made a vow to care for Rose. Till death do us part! I'm not letting anyone lock her up."

We came to an uneasy truce in this battle. Carl agreed that their daughter Jo could join them in their visits with me. Rose was delighted with this arrangement because each visit to me was followed by coffee and cake at her favourite café. And we agreed that they would continue to come for visits at least monthly, more often at times of need.

An advocate and conduit

Throughout this time, my objective was to keep Rose central to all discussions and decisions. Even during times when Jo or Carl needed to be involved in helping with decisions about treatments, I would continue to speak directly to Rose as much as possible, while at the same time acknowledging the input from Carl or Jo.

Together we managed this dance through heart failure, bowel cancer and repeated urinary tract infections. I saw

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***The names of the people in this article have been changed to maintain their anonymity. Permission has also been granted by the surviving relatives for their story to be shared in this format.**

Resources for GPs

DTA resources for GPs

Dementia Training Australia (DTA) offers a range of free resources aimed at GPs, including a compendium of links to helpful organisations and resources titled *Dementia Resources for General Practice* (go to http://bit.ly/GP-dementia-resources), two online courses ('Recognising, diagnosing and managing dementia in general practice', and 'Demystifying dementia'), and three webinars ('Diagnosing dementia in general practice', 'Demystifying Dementia', and 'A structured approach to managing dementia in general practice'). In 2021, DTA is hosting a new four-part series of webinars aimed at GPs. The first was held on 25 March (on 'Changed behaviours associated with dementia utilising a stepwise patient-centred approach to management'); the second will be held on 27 May and will focus on legal issues relating to dementia, including capacity: https://dta.com.au/

People With Dementia: A Care Guide For General Practice

This substantial, practical 2019 resource from the Cognitive Decline Partnership Centre is aimed at GPs and covers communication, behavioural and psychological symptoms of dementia (BPSD), elder abuse, dementia in people with an intellectual disability, dementia prevention, and supporting carers: http://bit.ly/GP-care-guide

Dementia Outcomes Measurement Suite

The website for the Dementia Centre for Research Collaboration hosts this hub of validated tools for the assessment of various aspects of dementia by health care professionals, including a range of tools available for cognitive screening: http://bit.ly/outcomes-suite

The Silver Book

The 2019 edition of the *RACGP Aged Clinical Book* (referred to as *The Silver Book*) includes sections on 'Dementia', 'Behavioural and Psychological Symptoms of Dementia', and also on 'Short-term pharmacotherapy management of severe BPSD'. Each section includes information on general principles, practice points, clinical context, and 'In practice': http://bit.ly/silver-book

Dementia Australia: Clinical Resources for General Practice

A range of practical information on dementia, with links to a range of resources for GPs: http://bit.ly/clinical-tools-resources

myself as an advocate for Rose and a conduit between her and the other practitioners involved in her care – geriatrician, physiotherapist, occupational therapist, cardiologist, surgeon, ophthalmologist, pharmacists and more.

Despite her increasing ailments and progressive dementia, Rose always appeared happy, engaged in family activities and well cared for.

Until Carl died suddenly. The phone call came in the middle of a busy morning at my clinic. "Hello Dr Koppe, it's Constable Robinson. Your patient Carl Jones has been found dead at home. We need you to come down and certify him as deceased before his body can be moved."

It transpired that Carl had died two days earlier, beside his bed, out of sight. Rose thought he might have been having a long session at the pub. It was only when their daughter Jo called in to check on her parents that Carl's body was discovered.

Going to certify Carl's death was my first visit to their home. It was a shocking experience. The sight of Carl, face down on the floor, his mottled complexion matching the stains on his favourite track suit, is a vision that continues to haunt me.

I was expecting the eerily familiar odour of grief as I entered their home, but was also struck by how disorganised and dishevelled it looked. The medications that I had been assiduously prescribing for Rose were jumbled in an old shoe box on the kitchen counter. No wonder some of the drugs didn't seem to be working as I had expected! Who knows if they were even being taken?

They must have barely been coping. I could now understand why Carl forbade visits from non-family. He must have been terrified that they would take Rose away if they saw how they were living. I wished that I'd done a home visit earlier. Might some of their problems have been avoided if I really knew their domestic situation?

After Carl died, the impact of Rose's cognitive decline on her ability to function became more obvious.

It quickly became clear that Rose was going to require 24-hour care. She needed assistance with all activities of daily living. She couldn't dress herself. She couldn't prepare a meal. She was unable to manage her medications. She needed help with bathing. Jo stayed with Rose for the next few days, but she had a full-time job and a young family, so it was not possible for this arrangement to continue. I was able to relieve some of Jo's guilt by helping her understand that Rose's requirements for safety and comfort were so extensive that it would require a team approach to meet her

needs. After two days, she did not need much convincing of what was best for Rose and the rest of her family.

Urgent respite was arranged which progressed to a full-time admission to a local residential aged care facility. And that remarkable end-of-life care conversation.

A moment of recognition

Rose's condition declined rapidly. I recall visiting her just before she died. She looked shrunken. Her bed appeared to now be too big for her body. She was staring at the ceiling when I arrived.

"Hi Rose, it's Hilton," I offered as I sat by her side and gently rested my palm on the back of her hand. She looked up at me and for a moment there was a sparkle of recognition in her eyes before her gaze returned to whatever was occupying her attention before I walked in.

It reminded me of one of my last visits to see my father before he too died from dementia.

"Hi dad, it's Hilton," I offered as I sat by his side and gently rested my palm on the back of his hand. My dad looked up at me and for a moment there was a sparkle of recognition in his eyes. "I used to know someone who looked just like you," he said before his gaze returned to whatever was occupying his attention before I walked in. ■

■ Dr Hilton Koppe is a general practitioner from Lennox Head. Since 2016, Hilton has been working with the GP Education Team at Dementia Training Australia (DTA) to develop and deliver innovative education programs to assist with the recognition, diagnosis and management of dementia in the general practice setting. Hilton also runs creative writing workshops for doctors and health professionals with the goal of deepening their compassion, overcoming professional isolation and reducing the risk of burn out. Hilton's writing can be found in a range of publications including *Grieve*, *The Examined Life*, *Pulse*, *Chrysalis*, *The Universal Doctor* and *More Voices*.

Ask a neuroscientist…

AJDC is aimed at all who work with people with dementia, including those who are new to the dementia workforce and may want to learn more about the basics of dementia. This article is the first in a new four-part series by neuroscientist and *AJDC* Editorial Advisor **Dr Lezanne Ooi**, who will present short, easy-to-read answers to questions about neurological changes to the brain with dementia. In her first article, Dr Ooi answers this question:

'What is going on in the brain of a person with Alzheimer's disease as the disease progresses?'

There are approximately 100 different types of dementia. Alzheimer's disease is the most common type, accounting for about two-thirds of all cases. Nearly 50 million people worldwide are affected by dementia. In fact, nearly 10 million new people are diagnosed each year, suggesting one person is diagnosed with dementia every three seconds (ADI online information; ADI 2015).

Tips for practice

- Remember that memory problems are due to the disease – the person with dementia is not deliberately ignoring you or not paying attention.
- Be aware that memory problems are just one feature of Alzheimer's disease, but there are a range of other signs and symptoms, for example language difficulties and reasoning.
- It is important for care providers and care partners to identify and work to the strengths of a person with dementia – those areas where the brain impairment is less or not evident.

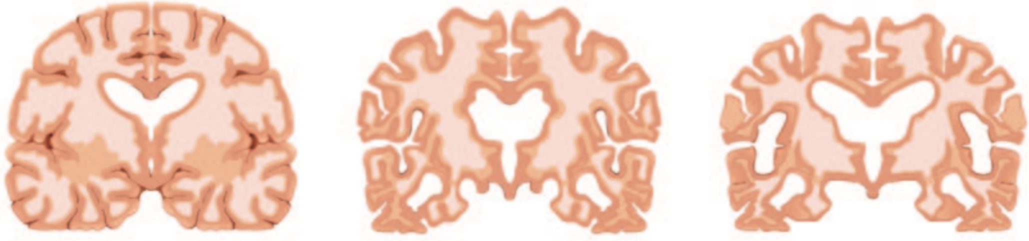
A healthy brain

A healthy brain has developed many protection mechanisms to make sure it functions appropriately, allowing us to communicate, make and retrieve memories and perform all of the other tasks that our brains must coordinate. I'm sure it hasn't escaped your notice that during the normal process of ageing there are many changes to our bodies and to our brains. With ageing, many of us feel that we are not as quick as we used to be. Losing our keys or forgetting someone's name seems to happen more often as we get older.

Toxic protein clumps

It is important to note that Alzheimer's disease is not a part of *normal* ageing and is caused by a build-up of certain proteins that become sticky and collect together in clumps in the brain. Different types of dementia are characterised by these toxic clumps that contain specific proteins. The toxic proteins that characterise Alzheimer's disease are called amyloid beta and tau.

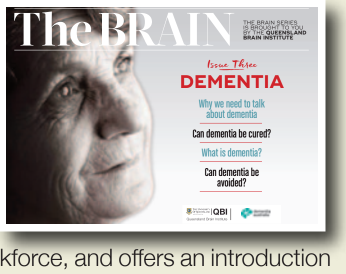
In the same way that we take out the rubbish for removal from our homes, a healthy brain is able to remove these toxic clumps and get rid of them before they can do any damage. However, in Alzheimer's disease the brain's ability to remove these toxic protein clumps is reduced. Very recent evidence suggests that these clumps increase in the brain over



Progression of Alzheimer's disease

Over the course of Alzheimer's disease, more of the brain is affected, resulting in death of the brain cells and reduction in brain volume (from left to right). Photo: www.freepik.com

Resources on Alzheimer's disease



The Brain: Dementia
The Queensland Brain Institute's (QBI) website has accessible online information about dementia, including Alzheimer's disease, and also offers a link to a free copy of Issue 3 of the QBI magazine *The Brain*, which focuses on dementia: https://qbi.uq.edu.au/dementia

Dementia Discovery
This 2020 series of free seven brief modules from Dementia Training Australia (DTA) is aimed at those new to the dementia workforce, and offers an introduction to the basics about the brain and dementia, including a module on Alzheimer's disease (which takes 15 minutes to complete): http://bit.ly/Dementia-Discovery

Alzheimer's disease
Dementia Australia and the National Institute on Aging in the US both publish helpful fact sheets giving an introduction to Alzheimer's disease: https://bit.ly/3qThsGN and https://bit.ly/3ttaGtd

decades, well before symptoms of Alzheimer's disease appear. Over a lifetime these clumps increase to the point that they change the structure of individual brain cells, affect their ability to function and ultimately cause the death of these brain cells.

For reasons that scientists still don't fully understand, certain areas of the brain are more susceptible to the toxic protein clumps than others. Some of the most affected areas control the parts of the brain that are important for forming and retrieving memories – one of these areas is called the hippocampus. This is why people living with Alzheimer's disease and their families often identify an inability to remember new things as one of the first symptoms that they noticed.

As the disease progresses there is spreading of the clumps to other parts of the brain and eventually these areas can also succumb to the disease. For this reason, as the degeneration continues, people living with Alzheimer's disease may develop difficulties with language, reasoning or social behaviour.

Promising research

Some parts of the brain are spared and seem to be more resilient against this disease. A major area of research now is trying to understand how certain brain cells protect themselves against cell death while others are more sensitive to it.

Other promising areas of research include looking into reducing the toxic clumps during the very early stages of the disease, and boosting the brain's ability to remove the clumps. It is believed that if these protection mechanisms can be harnessed early enough in the disease course, they can be used to protect the brain against Alzheimer's disease. ■

References

Alzheimer's Disease International (ADI) *Dementia statistics* online information. Available at: www.alzint.org/about/dementia-facts-figures/dementia-statistics/

Alzheimer's Disease International (2015) *The Global Impact Of Dementia: An Analysis of Prevalence, Incidence, Cost and Trends.* World Alzheimer Report. London: ADI.

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Research updates

Hearing loss and dementia risk

Researchers from the Centre for Healthy Brain Ageing (CHeBA), UNSW Sydney and Macquarie University's Centre for Ageing, Cognition and Wellbeing have identified significant associations between self-reported hearing loss and cognition, as well as increased risk for mild cognitive impairment (MCI) or dementia.

The finding comes from probing data from the Sydney Memory and Ageing Study (led by CHeBA) and has recently been published in the journal *Aging, Neuropsychology and Cognition*. The study used data from 1037 Australian men and women aged 70-90 years enrolled in the Sydney Memory and Ageing Study from 2005 to 2017. Participants who reported moderate to severe hearing difficulties had poorer cognitive performances overall, and they also had a 1.5 times greater risk for MCI or dementia at follow up at six years.

CHeBA Co-Director and co-author, Professor Henry Brodaty (pictured), said the study was the first of its kind to identify the relationship between hearing loss and risk for mild cognitive impairment or dementia in a large Australian-based study of older adult men and women.

Prevalence in the Torres Strait

Researchers from James Cook University and Queensland Health have concluded that the prevalence of dementia in Torres Strait Islander communities is similar to dementia prevalence in Aboriginal Australian communities – among the highest in the world.

The findings come from a study, now published in the journal *Alzheimers & Dementia*, which was conducted in all 18 island and five mainland communities in the Torres Strait and Northern Peninsula Area of Far North Queensland.

The researchers found that the prevalence of dementia in the sample (322 people, median age 64.58) was 2.94 times higher than the wider Australian population, with over 14% in the sample diagnosed with dementia. Particular risks for this community identified in a preliminary analysis were age, education, hypertension, heart disease, chronic kidney disease, previous stroke, falls risk and pain.

The researchers conclude that tailored interventions are needed to address the particular dementia risks for different Indigenous communities.

Supporting meaningful activity in hospital

Meaningful activity is known to be beneficial for older people in hospital, but health care staff may not feel confident about encouraging engagement, particularly with people living with dementia. **Susan Gee** (pictured) and **Tracey Hawkes** introduce a hospital project which trialled the use of an activity resources trolley and education sessions to increase staff confidence in providing activities for patients

It is well known that people living with dementia do badly in hospital, with a greater risk of falls, delirium and loss of function during their stay (George *et al* 2013). Older people are admitted to hospital more often and for longer periods than younger people, and the hospital environment can lead to a downward spiral in functioning, particularly for people living with dementia (Lakey 2009). In addition to their illness, the older patient is dislocated from their familiar settings, activities and routines (Lourida *et al* 2020).

Across studies, older people in hospital report feeling fearful, worthless, and without control (Bridges *et al* 2010). Boredom and a lack of meaningful activity is common (Steele & Linsley 2015; Clark *et al* 2018).

Benefits of activities

Clinically, engagement in meaningful activities can reduce the negative impact of stress on the immune system (Wheeler & Houston 2005), and may help prevent delirium (National Institute for Health and Clinical Excellence 2010; Kolanowski *et al* 2018). Indeed, enabling meaningful activity has been identified as an essential area of quality of hospital care for older people with cognitive impairment (Naef *et al* 2018) and for older people in general (Nolan *et al* 1995).

The activity resources are housed in a sturdy metal trolley

Alison Phinney and her colleagues provide a useful summary of three main ways activities can be meaningful for people living with dementia (Phinney *et al* 2007), which can be applied to hospital settings as well. Firstly, meaningful activities provide pleasure (Phinney *et al* 2007). This potential for relaxation and enjoyment can be very important in a hospital environment, as activities can help reduce anxiety and stress (Stuckey & Noble 2010). This enjoyable engagement can also act as distraction from worry and discomfort.

Secondly, meaningful activities foster a sense of connection (Phinney *et al* 2007). Meaningful activities can provide a mechanism for friendly interactions and social stimulation in an unfamiliar hospital setting (Charalambous 2014). This feeling of connection to staff is very important to the hospital experience. Older people often take it for granted that technical care will be adequate during their hospital stay, and it is the relationships that determine their perception of the quality of care (Bridges *et al* 2010).

Thirdly, meaningful activities help maintain a sense of autonomy and personal identity (Phinney *et al* 2007). In a hospital setting, the opportunity to choose and engage in meaningful activities may help patients to experience a sense of control (Steele & Linsley 2015; Charalambous 2014) and help people feel more like themselves (Cohen-Mansfield *et al* 2010). This involves knowing the person in order to know what to offer. Activities are more likely to be accepted and to be successful if they are a good fit for the individual (Cohen-Mansfield *et al* 2010).

Our project

While the importance of activities is clear, there can be subtle barriers that discourage staff from offering fulfilling activities for older patients. There may be a lack of resources (Charalambous 2014), mixed messages about the importance of non-task interactions (Nolan *et al* 1995) and a lack of confidence in how to best engage people in activities, especially people living with dementia (Galvin *et al* 2010).

Our project, at Burwood Hospital in Christchurch, New Zealand, trialled the use of an activity resources trolley, combined with brief education sessions, as a way to help ward staff feel more able to support personalised meaningful activities for older people, including those living with dementia.

Method

Setting

Burwood Hospital is a specialist rehabilitation facility with 310 inpatient beds, 230 of which are new beds following a refit and extension in 2016. The inpatient wards include older persons' assessment and treatment wards, as well as a specialist stroke ward, adult rehabilitation wards catering for people with brain injury and spinal cord injury, and two psychogeriatric wards. While an informal estimate from clinicians is that perhaps 20% of our older inpatients have a cognitive impairment, the proportion of patients with a formal diagnosis in hospital records is much lower.

In a previous quality improvement project, which involved engaging with staff and their vision for the hospital, it was highlighted that staff wanted more resources to help engage with older patients – particularly when supporting people living with dementia, to help maintain cognitive conditioning during their stay.

With the support of the hospital's dementia and delirium committee we then embarked on a pilot, introducing an initial version of the activity trolley and education to two wards (involving 28 staff in total). This pilot highlighted the positive impact the activity trolley project had for staff and their interactions with patients.

We followed this up with a formal trial involving three other wards, led by the authors, from February to June 2018. Two were general older persons' wards and one was a post-surgical orthopaedic rehabilitation ward. Each ward has a 24-bed capacity, but is kept at 20 admissions. Around half the rooms are single bed and the other half are two-bed rooms. A ward is divided into three 'pods' of eight beds, each with its own lounge-like communal space. The average length of stay for older people on these wards is two to three weeks.

Staff participants

- Ward A: five nurses, one health care assistant, and one allied health staff member took part.
- Ward B: one nurse and five health care assistants.
- Ward C: three nurses and four health care assistants.

The activity trolleys

The first component of the project was providing activity resources in an activity trolley. An experienced occupational therapist led the selection of items, taking into account feedback from the pilot. Each activity trolley, one per ward, included a range of different resources for people with and without cognitive impairment. These included:

- Cognitively stimulating resources – for example, large-print puzzles, letter tiles, and large-piece jigsaws.
- Relaxation/creativity resources – for example, simple and complex pictures for colouring with pencils, picture books and magazines (including local history, animals, gardening), and manicure supplies.
- Reminiscence resources – for example, photo discussion cards, a 'toss and talk' ball with reminiscence questions, and paua shells (a shellfish unique to New Zealand).
- 'Usefulness' resources, such as wool and knitting needles to contribute to a blanket for children in an overseas orphanage, mixed nuts and bolts or buttons to sort, and a screwdriver and small coat rack with hooks to tighten.
- Sensory resources to be manipulated by hand, such as a rubbery-tassled band, tangle therapy, and therapeutic putty.
- Māori (indigenous) themed items including te reo (Māori language) puzzles and reading, and Māori and Pacifica-themed colouring books.

A Nurse Manager and hospital aides from Burwood Hospital with some of the activity resources used to engage patients

An information folder was also provided in each trolley with tips for staff on things to check before getting started, maximising engagement and thinking flexibly about different ways to use the specific resources on the trolley, and correct infection control procedures. A pump bottle of hand sanitiser was also attached.

Education sessions

The second component of the trial was two brief education sessions for staff, developed and presented by the authors. The first 30-minute interactive education session focused on raising awareness of the benefits of activities, familiarisation with the trolley, and encouraging staff to think flexibly and use what they know about each patient to match activities to the individual.

After at least two weeks' experience using the resources with their patients, the staff took part in a second 30-60 minute education session. This session enabled participants to discuss, reflect, and learn from their experiences and reinforced the key messages.

The trial

We conducted the trial on three wards. We introduced the trolley package to each of the three wards one at a time during a five-month period. The 'waiting' ward that was next in line acted as the control group.

Staff completed a baseline questionnaire to rate their comfort, confidence and experience in engaging in activities with patients.

In the control group, participants then had no further contact with the research team until the follow-up survey. No activity trolley was available on the ward.

In the intervention group, an activity trolley was available on the ward throughout the intervention period. Participating staff received two education sessions at least a fortnight apart. Staff participants were then given a follow-up survey within two to four weeks post-intervention. The trolley stayed on the ward after this study period.

The follow-up questionnaire for the participants who had the activity trolley and education also asked them to rate whether the project had an impact for themselves (eight questions) and for the patients (six questions), along with opened-ended questions about their experience and suggestions. This study received ethics approval from the University of Otago Human Ethics Committee (Health).

Results

When staff received the activity trolley and education, there was a significant improvement in self-efficacy from baseline to follow-up. In contrast when staff were waiting, there was no change in self-efficacy between baseline and follow-up.

All of the staff (100%) agreed or strongly agreed that they were more aware of how important activities were, that the activity trolley was useful, and they felt more confident about offering activities; 93% felt that the educations sessions were worthwhile; and 78% agreed or strongly agreed that they felt that their work environment was less boring, that it was easier to relate to patients, and that they got more work satisfaction.

All of the staff (100%) felt that the activity trolley helped them worry less about how to help keep patients occupied and to have friendly interactions with patients; 93% felt that the activity trolley helped reduce boredom and that the patients benefited from the trolley; 71% felt that there was something to interest most patients on the trolley; and 64% felt that the patients had been calmer and

A Burwood Hospital staff member on the ward with one of the activity trolleys

less anxious using the activity resources.

Discussion

The activity trolley project was a way to help staff to value their own potential to make a positive difference to older people's experience of being in hospital. Initiatives like the activity trolley can be a way to let patients know that they are seen as individuals and not just someone with a physical condition. Part of this is knowing the person in order to know what might be useful to offer.

Our experience with the trolleys reinforced that it is important to offer patients, particularly those living with dementia, just one or two appealing possibilities. Simply offering the trolley with all the resources at once can be overwhelming.

Having physical objects to stimulate engagement was seen as being particularly helpful for people living with dementia. Stories from staff included a staff member being amazed at one lady's extended engagement with colouring, using relaxing activities for a patient who could not sleep during a night shift, and using a DIY task to distract a gentleman who was dismantling his wheelchair.

The education sessions were an integral part of this project. Recognising the importance of engagement and having the skills and confidence to initiate that engagement cannot be assumed to be instinctive (Rybacka *et al* 2017). In particular the pre-trial pilot study highlighted the importance of a follow-up session after the initial training and provision of resources.

Embedding a change in practice requires real-world experience and the opportunity to reflect on this experience and receive feedback, and to discuss good news stories and more challenging situations (Loveday 2010). Providing the initial education and resources is akin to planting a seed, and that seed will need to be nurtured.

As with any culture change, the probability of success is strengthened by an integrated approach that includes clear processes, staff skills, knowledge, and attitudes, interdisciplinary teamwork, and leadership support (George *et al* 2012). Ongoing support is vital to sustain confidence and momentum (Loveday 2010). In particular, the support of ward managers was essential during our trial to enable staff to be released for the education, and to reinforce and lead the change. The wards involved in this trial specialised in older persons' health and rehabilitation, making the project particularly salient.

There can be times when the combination of a patient's cognitive abilities and the ward environment limit their access to appropriate levels of stimulation. An important part of the activity trolley project was giving staff permission to take the initiative in offering engagement.

Project sustainability

The activity trolley project has led on to a further two-day education initiative for the hospital's health care assistants involved in close observation of at-risk patients (previously known as 'sitting' or 'watching'). We adopted the slogan 'be an engager not a sitter', to encourage hospital aides to see this as an opportunity to engage actively.

The activity trolleys are still in use and are now found on nine wards across the hospital. During the COVID-19 lockdown they were incredibly appreciated and were supplemented by individual activity packs.

Conclusion

Staff were overwhelmingly positive about the usefulness of the activity trolley project and its positive impact on patients. The project reinforced that, with appropriate support, activities can be a useful tool in helping to humanise the hospital experience for older people, including those living with dementia.

At the end of the day it is the staff that make change happen. Maybe as the label on the activity trolley urges, in both Māori and English, it is now time for staff in public hospitals to recognise the importance of meaningful activities for people living with a dementia and to 'karawhiua' ('go for it').

We welcome any feedback or questions that would help you with your own journey of fostering meaningful activities for all people living with dementia, wherever they may be. ■

Acknowledgments

We would like to thank Megan Thurlow for her invaluable help with the pilot study, and the Burwood Hospital and Christchurch Hospital volunteer groups for financially supporting the activity trolleys.

References

Bridges J, Flatley M, Meyer J (2010) Older People's And Relatives' Experiences In Acute Care Settings: Systematic Review And Synthesis Of Qualitative Studies. *International Journal of Nursing Studies* 47(1) 89-107.

Charalambous L (2014) The Value Of Volunteers On Older People's Acute Wards. *Nursing Times* 110(43) 12-14.

Cohen-Mansfield J, Thein K, Dakheel-Ali M, Marx MS (2010) The Underlying Meaning Of Stimuli: Impact On Engagement Of Persons With Dementia. *Psychiatry Research* 177 216-222.

Galvin JE, Kuntemeier B, Al-Hammadi N, Germino J, Murphy-White M, McGillick J (2010) 'Dementia-Friendly Hospitals: Care Not Crisis' An Educational Program Designed To Improve The Care Of The Hospitalized Patient With Dementia. *Alzheimer Disease and Associated Disorders* 24(4) 372–379

George J, Long S, Vincent C (2013) How Can We Keep Patients With Dementia Safe In Our Acute Hospitals? A Review of Challenges and Solutions. *Journal of The Royal Society of Medicine* 106(9) 355-361.

Kolanowski AM, Fick DM, Clare L, Therrien B, Gill DJ (2010) An Intervention For Delirium Superimposed On Dementia Based On Cognitive Reserve Theory. *Aging and Mental Health* 14(2) 232-242.

Lakey L (2009) *Counting The Cost: Caring For People With Dementia On Hospital Wards*. London: Alzheimer's Society.

Loveday B (2010) Leadership In Dementia Care: What Does It Take? *Journal of Dementia Care* 18(6) 24-26.

Lourida I, Gwernan-Jones R, Abbott R, Rogers M, Green C, Ball S, Hemsley A, Cheeseman D, Clare L, Moore D, Hussey C (2020) Activity Interventions To Improve The Experience Of Care In Hospital For People Living With Dementia: A Systematic Review. *BMC Geriatrics* D20 1-4.

Naef R, Ernst J, Bürgi C, Petry H (2018) Quality of Acute Care For Persons With Cognitive Impairment and Their Families: A Scoping Review. *International Journal of Nursing Studies* 85 80-89.

National Institute for Health and Clinical Excellence (NICE) (2010) *Delirium: Diagnosis, Prevention and Management (Clinical Guidelines 103)*. London: NICE.

Nolan M, Grant G, Nolan J (1995) Busy Doing Nothing: Activity and Interaction Levels Amongst Differing Populations of Elderly Patients. *Journal of Advanced Nursing* 22 528-538.

Phinney A, Chaundhury H, O'Connor DL (2007) Doing As Much As I Can: The Meaning of Activity For People With Dementia. *Aging and Mental Health* 11(4) 383-393.

Rybacka M, Brooke J, Wright L (2017) *The Impact of Meaningful Activities For People With Cognitive Impairment or Dementia in Acute Hospitals: A Literature Review.* In: Angela Boskin Faculty of Health Care (Eds) 10th International Scientific Conference: Continuous Development of Nursing In Society and Its Contribution To Health Promotion. Bled Slovenia: Angela Boskin Faculty of Health Care 36-46.

Steele R, Linsley K (2015) Relieving In-Patient Boredom in General Hospitals: The Evidence for Intervention and Practical Ideas. *BJPsych Advances* 21 63-70.

Stuckey HL, Nobel J (2010). The Connection Between Art, Healing, and Public Health: A Review of Current Literature. *American Journal of Public Health* 100(2) 254-263.

Wheeler SL, Houston K (2005) The Role of Diversional Activities in the General Medical Hospital Setting. *Holistic Nursing Practice* 19(2) 87-89.

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Visit with Viv fosters empathy

Gail Kenning introduces an award-winning immersive artwork, called *The Visit*, developed by researchers at fEEL (felt Experience and Empathy Lab) at the University of New South Wales to cultivate empathy and overcome the stigma related to dementia. Viewers are invited to engage with 'Viv' a character who shares her experiences of living with dementia – and who was created directly from real-world accounts of women living with dementia

Awareness of dementia is growing as the prevalence of dementia continues to increase nationally and internationally. However, dementia continues to be stigmatised and misunderstood. Many people in the community have lived experience of dementia through having a diagnosis, being a family member or carer, or being engaged with dementia in a professional capacity.

But, as dementia may be caused by over 100 different diseases, even people with lived experience may not be fully aware of the impacts dementia can have. For those without lived experience, their knowledge of dementia is often from information in the media, from dementia advocacy organisations, clinical and medical sources or from anecdotes. Information dissemination is important, but it is just one step in promoting understanding. Often people with limited experience of dementia primarily relate to the later stages of the condition, when people need most help and support. They may fail to recognise the agency and abilities of those in earlier and middle stages. Many people fear the unknown and are unable to engage emotionally or affectively with how they feel about dementia.

The Visit is an immersive experience that aims to cultivate empathy in the viewer to overcome the social stigma and stereotyping of people with dementia. For many, dementia is only associated with deficit, loss and grief. They are not aware that people can have a good quality of life living with dementia. The media artwork challenges viewers to engage with 'Viv', a digital character with dementia, and to sit alongside her and simply listen as she talks about her lived experience of dementia.

In doing this they come to acknowledge her agency and wit, her ability to understand aspects of her dementia and to make choices about how she responds to it. They see this alongside her moments of confusion and her hallucinations. They are invited to explore their own feelings and how they feel towards her.


Viv is a digital character (avatar) living with dementia

What is empathy?

Empathy is an experience that connects the responses of one person to another (Davis 2006). It is how we come to understand what another person is feeling without pity, judgment or sympathy. It is not about knowing the right things to say or having the answers to the problems. It is the ability to *be with* someone – not trying to feel what they feel, but to be with them as they share their feelings. Empathy is a skilful practice that can be developed through deep listening and attuning with others (Rogers 1957; 1959). In relation to dementia, this means developing more understanding and awareness of the personal perspective and lived experience of dementia and not only relying on other kinds of information about dementia, such as clinical or medical information (Papadopoulos *et al* 2021).

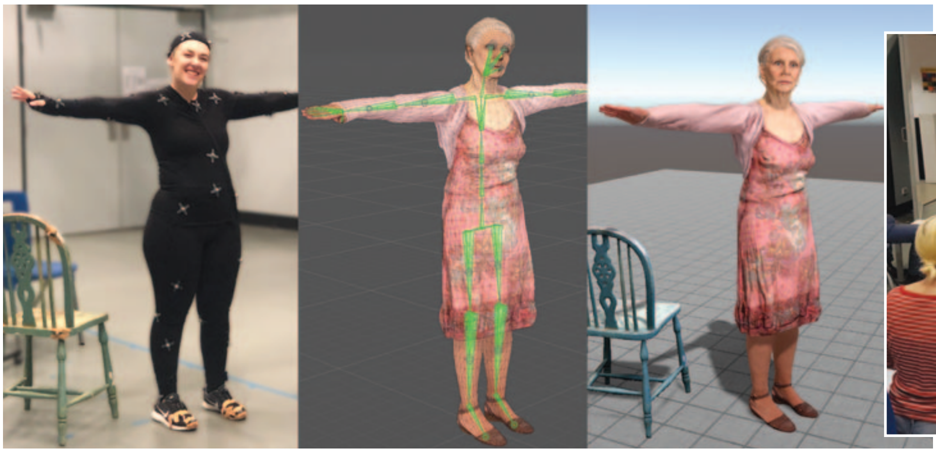
Making *The Visit*

The Visit immersive media artwork was made for virtual reality (VR), as a life-size screen and as an app that can be downloaded to a smart phone or tablet.

The immersive format was chosen as the technologies have been shown to increase empathy when the viewer is in close proximity to the content of the artwork. The artwork is interactive as the character of Viv recognises the presence of the audience member and turns to address them directly. The viewer is invited by the digital character (avatar), Viv, into the kitchen of her home. She welcomes them in and invites them to stay for some tea.

Viv also appears to talk to other people in the room, but no one else can be seen. Viv tells us about her garden shed that "disappeared" and "reappeared", and about seeing her father in the hallway. We, the viewer, come to realise that she is experiencing hallucinations. At times Viv is forgetful and confused, but we also see her agency, how she is witty and charming, and at times lucid and clear about her likes and dislikes. The stories Viv tells and the words she speaks are taken verbatim from interviews with four women with vascular dementia.

Researchers at fEEL (felt Experience and Empathy Lab) at the University of New South Wales (UNSW Sydney) scripted Viv's dialogue from the interviews and she was voiced by Australian actress Heather Mitchell using LipSync technology. Viv's



Movements are authentically created using a motion captor (MoCap) actor. Viv's dialogue, taken from interviews with women living with dementia, is voiced by Australian actress Heather Mitchell using LipSync technology

The production team create the composite character Viv

movements are authentically captured from a motion capture (MoCap) actor, as she takes on the gait and movements of an older woman.

The Visit consists of two storylines played at random and triggered by the presence of the viewer. Each are 14 minutes long. Viv (voicing the words of the four interviewees) tells the viewer about her hallucinations and how she hears her father typing in the room upstairs, or how she hears the sound of bees around her head. She talks about her carers and how they are "just delightful" or "disrespectful" to her. Viv shares her love of music, reading and swimming. On occasions she appears to remember things in great detail, such as birthdays and the names of authors she likes. Viv walks around her kitchen, looking out of the window, chatting on the telephone and chatting to the viewer and to one of her hallucinations of a child.

The research team

fEEL (felt Experience and Empathy Lab) is a research lab at UNSW Sydney led by Scientia Professor Jill Bennett. The team consists of artists and designers, dementia experts and psychologists (the author is one of the team). The research uses participatory arts-based approaches to understand how people experience anxiety, stress, trauma and the impact of neurological conditions such as dementia. The interdisciplinary make-up of the research team offers a unique perspective with which to carry out robust research into how people feel and respond to dementia and how we can engage with their reservations to cultivate empathy and overcome stigma. They work closely with people to hear their stories and to understand how they feel.

Professor Bennett explains, "...the real value of art is that it's very much grounded in lived experience. So, throughout the history of art it's found ways to express complex mental and emotional states, in ways that are often very helpful for people whose experiences are marginalised and disenfranchised. Historically there's been this sort of distinction between arts and science, but now we are able to bring them together in useful ways."

She continues, "...the real value lies not in just communicating or messaging about knowledge translation and disseminating mental health knowledge and knowledge about dementia, it's in doing work that can't easily be undertaken within the health medical sector and through diagnostics. A 'bottom up' approach starts with experience and is about inquiry through feeling. It is the story of people's lives which is so very powerful." In essence this is what *The Visit* does. It engages with the lives of four women and explores their stories and shares the experience through the composite character, Viv.

Access to *The Visit*

The Visit has been shown in a wide range of venues and through online festivals and conferences. It was initially created as part of The Big Anxiety 2019 arts and mental health festival in Sydney, Australia.

It can be viewed online as part of an online introduction to empathy at courseofempathy.org. It has also been shown at the Australian Association of Gerontology Conference; Dementia Lab, Vancouver; Engaging Dementia, Dublin; Frameless, US; Siggraph 2020, Virtual; IEEE VR (Virtual Reality) 2020, and won the Award for Originality and Impact at the 25th ACM Symposium on Virtual Reality Software and Technology (VRST), 2019. *The Visit* has also been demonstrated in a range of Visual Matrix (this is introduced below) and arts engagements with psychology students, people with dementia from a local community centre, and national and international experts in dementia. There has been a wide range of emotional and verbal responses.

Overwhelmingly, viewers engaged with the character of Viv and were both surprised and delighted with the agency she exhibited.

Evaluation

The impact of *The Visit* on a wide range of viewers was examined using a variety of assessment methodologies to understand audience responses, including five Visual Matrix engagements, of between seven to 15 people.

The Visual Matrix is a psychosocial approach that explores the shared experiences of a group of people to an artwork. People are invited to view the artwork, and rather than say if they like, dislike or critique it, they are invited to respond through associations and imagery. For example, one person began to think about their grandmother's house and flower garden, another spoke about enclosed rooms and the feeling of wanting to go outside.

It became apparent through this approach that the younger adults engaged were surprised by the agency and independence of the character. People from a local community centre, which included people living with dementia, identified closely with the character, but suggested "she needed to make more effort to get out of the house more, and not dwell on it". It was also apparent that people with lived experience were sometimes confronted by Viv's experiences as they differed greatly to what they already knew of dementia.

In addition to the Visual Matrix evaluation, researchers assessed the extent to which there would be a change in empathy and emotional distancing after viewing *The Visit*. The immersive artwork

Other VR resources for building understanding of dementia

Dementia Australia's Centre for Dementia Learning offers two three-hour workshops that both incorporate the use of virtual reality technology to promote empathy among aged care professionals about the lived experience of dementia: one is **EDIE** (which stands for Educational Dementia Immersive Experience), launched in 2016; the other is **A Say In The Life: Mealtime Experience**, launched in 2019. These can be delivered to groups at their workplaces. To find out more, go to https://dementialearning.org.au/

A Walk Through Dementia is the name of Alzheimer's Research UK's virtual reality resource, also launched in 2016. It is available as an app on Android and iOS devices, to be used with a VR headset, as well as simply watching as an immersive 360 degrees video on YouTube. The resource looks at three situations – at the supermarket, on the road, and at home – and shows the challenges that may arise for a person with dementia as they navigate these environments. To find out more, go to www.awalkthroughdementia.org/

Dementia Training Australia (DTA) has developed the **Meaningful Spaces** half-day workshop, which uses virtual reality technology to build empathy, knowledge and skills about dementia among participants, with a particular focus on environmental design and medication management. To find out more, go to https://dta.com.au/events/meaningful-spaces-2021/

was experienced using the VR Oculus Quest headset at a university library and on a screen with immersive audio track in an art gallery.

People attending the gallery and the library were invited to view *The Visit* and respond to a self-reporting survey. In total 70 people responded, 34 of whom were female. Comprehensive State Empathy Scales (CSES) and Change in Emotional Distance Scale (CEDS) (Levett-Jones *et al* 2017, Papadopoulos *et al* 2021)) were used to assess participants before and after the viewing. The findings showed that there was a significant shift in state empathy and decreased emotional distancing recorded after viewing the artwork ($F(1,68)=30.78$, $p<.001$ and $F(1,68)=7.68$. $p<.01$ respectively).

Findings

The feedback from the art gallery viewings, conference presentations, the Visual Matrix engagements and the survey suggests that, in line with other research, immersive technologies can support experiences and foster empathy. However, importantly, this work goes beyond technology use to provide rich affective content that helps people begin to understand the nuanced and ambiguous nature of dementia.

The viewer is placed in a position of engaging with and listening to Viv. They are not able to challenge her agency by doing things for her, which so often happens when people have a diagnosis of dementia. By being with Viv, and by proxy the experiences of people living with experiences of hallucination and confabulation, the viewer is encouraged, by the pacing of the engagement, to engage with their own responses and pay attention to their own feelings. The work allows for ambiguity and individual response and therefore does not actively prompt behaviours or responses from the viewer.

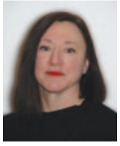
What next?

The Visit shows the impact that artworks using 'bottom up' and participatory approaches can have. It shows the potential for digital technology to engage with viewers through composite, sophisticated and complex characters and challenge the everyday perceptions of dementia. The character of Viv has had an impact on younger people, older people, people with a diagnosis of dementia and those who are experts in the field.

fEEL researchers are now exploring how digital characters with rich content like Viv can become companions to people living with dementia to promote regular social engagement and interaction. We are currently looking for participants who would be interested in engaging with the research. ■

The feedback from the art gallery viewings, conference presentations, the Visual Matrix engagements and the survey suggests that, in line with other research, immersive technologies can support experiences and foster empathy

If you would like to find out more about *The Visit*, arrange an online or real-life viewing, or to find out more about our current projects, contact the author Dr Gail Kenning via email: gail.kenning@unsw.edu.au



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References

Davis M (2006) Empathy. In: Stets J, Turner J (Eds) *Handbook of the Sociology of Emotions*. Boston: Springer.

Levett-Jones T, Lapkin S. Govind N, Pich J, Hoffman K, Jeong S *et al* (2017) Measuring the Impact of a 'Point of View' Disability Simulation on Nursing Students' Empathy Using the Comprehensive State Empathy Scale. *Nurse Education Today* 59 75-81.

Papadopoulos C, Kenning G, Bennett J, Ginnivan N, Neidorf M (2021) A Visit with Viv: Empathising With a Digital Human Character Embodying the Lived Experiences of Dementia. *Dementia: International Journal of Social Research and Practice.*

Rogers CR (1959) A Theory of Therapy, Personality and Interpersonal Relationships as Developed in the Client-Centered Framework. In: Koch S (Ed) *Psychology: A Study of a Science. Study 1, Volume 3: Formulations of the Person and the Social Context* 184-256. New York: McGraw-Hill.

Rogers CR (1992) (originally published 1957) The Necessary and Sufficient Conditions of Therapeutic Personality Change *Journal of Consulting and Clinical Psychology* 60(6) 827-832.

Reframing dementia to improve quality of care

Changing the way we view and treat people with dementia, coupled with a human rights approach, underpinned by a social model of disability, has the potential to transform the narrative about what authentic dementia care practices should look like, explains advocate **John Quinn**

I would like to ask you to visualise the following fictional scenario. Hopefully it rarely happened, even in the past, but we know from evidence presented to Australia's recent Royal Commission into Aged Care Quality and Safety, that events like this did happen. It's a scenario which evokes outrage, but fortunately through education, training and better modelling, I have to hope that it rarely happens now.

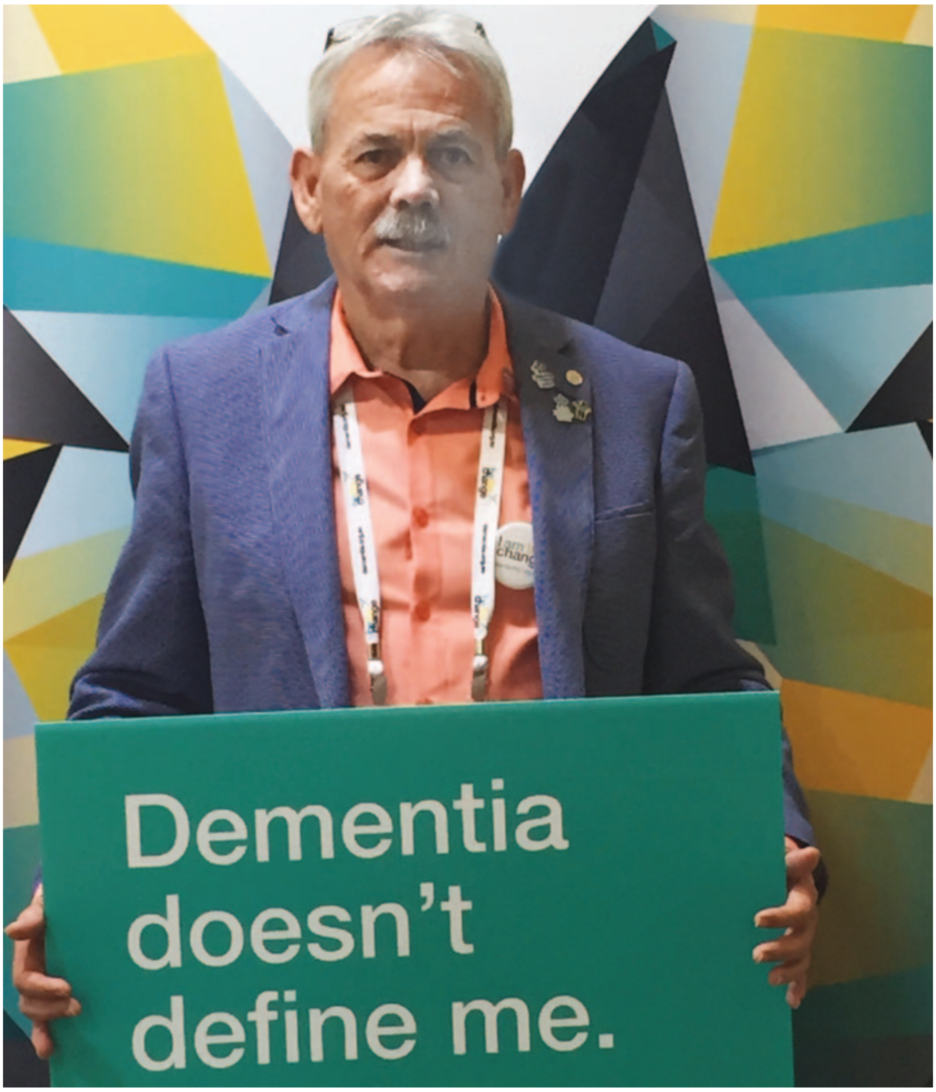
Your home is in aged care. You haven't slept well for a few nights due to undiagnosed pain in your shoulder and neck but you are now having a deep, restful afternoon sleep. A staff member holding a tray with a cup of tea and a snack walks into your room unannounced.

The staff member places the tray onto your nearby bedside table, leans over your bed, shakes you, and says, "Wake up, I have a cup of tea." You are half asleep, startled and disorientated, and despite being frail, you instinctively fling your arms in the air, accidentally making contact with the worker. That also creates more shoulder pain for you.

You are in the later stages of dementia and non-verbal, but make some incoherent noises in response to being disturbed and shaken unexpectedly. You have unintentionally struck the staff member, who immediately grabs your arms and forcefully places them to the sides of your body. You grunt and squirm as a reaction to the tight grip exerted by the staff member and the resulting pain that you are experiencing.

In response, the staff member makes a derogatory reference and then proceeds to manhandle you to prop you in an upright position against your pillow. Despite knowing that you can't feed yourself, the person leaves the room and the tray is left out of reach on a bedside table.

Upon entering the main hallway, the staff member calls out in a loud and angry voice, "The one in room 12 has just hit me. I'm sick of these people doing that." At the same time there is a loud bang and more utterances from room 12. It's discovered about 10 minutes later by another staff member, who comes to follow up a complaint, that you [the resident] are on the floor beside the bed.



In his dementia advocacy work in Australia and overseas, John Quinn addresses issues such as reablement, policy, reframing how people living with dementia are viewed and the role of the lived experience in research. Photos courtesy John Quinn and Glenys Petrie

We are all human and when under stress we may make poor decisions. However, in this scenario, I pose these questions:

- Are the behaviours and derogatory language used by the staff member dehumanising?

Above: John Quinn and his partner Glenys Petrie with geriatrician, author and dementia advocate Dr Allen Power (right).
Left: As members of their local Dementia Alliance, John and Glenys, pictured with Father Michael Twigg, Rector of Iona College, Brisbane, delivered an education program to students and staff on how to make their school community dementia-friendly

- Why have such behaviours and demeaning language use continued for so long towards the most dependent, loneliest and vulnerable members of our communities?
- Why has cruelty, neglect, inhumane behaviour and treatment existed within what is supposedly a caring society?
- Why have these incidents occurred despite policies and procedures and the ensuing expectations of the people living with dementia, and others in need of specific care and support, and their families?

With the life-expectancy of Australians increasing, age being a risk factor for developing dementia, and with one in three elderly citizens over the age of 80 in full-time care living with a diagnosis of dementia, the reality is that this could be you or I in the future.

In need of reform

Fortunately, this scenario is not what plays out in all care homes. However, the fact that these interactions and practices still exist is indicative of:

- a culture whose origins are a hangover from the past because only a few decades ago people with dementia were considered senile or mad and, before that era, relegated to asylums
- in a number of instances, a reflection of a workforce that is inadequately trained, poorly paid, time-poor, and task-focused, rather than adopting a person-centred positive, wellbeing approach.

These workplace issues highlight a system that has demanded comprehensive reforms.

Too often we still hear comments such as:

- dementia is 'a thief that robs them of their loved ones'
- that the person is the 'patient', the 'sufferer', or a 'shell of her/his former self'
- that the family caregiver is the 'hidden victim'
- the 'long goodbye'
- that the person is 'no longer there'
- referring to people with dementia as 'ferals' who are 'out of control'
- 'the burden of dementia'; and
- 'a dementia tsunami' (should a major global health issue be likened to a sudden catastrophic environmental event?).

As asserted by Cahill (2019) in an article in *The Irish Times*, "These words do nothing to promote the agency, dignity and humanity of the individual who, no matter how severe their cognitive difficulties, is never gone and is still a recognisable human being that must be treated with dignity and respect." Moreover, Cahill (2019) believes that, "words are powerful and influence how we perceive and interact with people".

Therefore, disabling language simply reinforces the public's perceptions of those living with dementia and the stigma about dementia. Words and images can be emotive, and, consequently, can and do medicalise many behaviours which, in turn, often precipitates pharmacological prescription.

Fortunately, these commonplace depictions of dementia are being challenged through greater public awareness, often led by dementia advocates. Their personal stories have demonstrated that not all people with dementia are the same and that, with appropriate and timely support and adaptations to their daily lives, it is possible for people with dementia to continue engaging with their previous lifestyles beyond the diagnosis.

However, the focus within the aged care sector is still largely on the biomedical model due to:

- a lack of comprehensive inclusion of information about dementia in courses at tertiary institutions
- the lack of awareness about quality of care and social care principles to support the activities of daily living for the person living with dementia; and,
- the influence and profits of pharmaceutical companies. Some service providers present a major impediment to change as they are expressions of powerful, vested interests whose motives for resistance to change are motivated by the money to be had by portraying the negative aspects of the disease.

This can be seen in a number of funding areas, including the basics, where the focus is on a person's emerging needs as opposed to support in an effort to delay those needs through the adoption of restorative and enabling principles of care. This highlights that the aged care funding model needs to also be addressed.

For example, additional funding is provided for those requiring incontinence pads. However, wouldn't it be better to receive additional funding to delay the need for incontinence pads through a proactive approach involving allied health professionals? A similar argument may be made for mobility. Funding to maintain a person's core strength will benefit both issues.

And, whilst talking about funding for care, dignity and respect, what about a basic support package provided at the time of diagnosis of dementia regardless of age?

➤

Impediments to change

Sadly, past perspectives of dementia have been the roadblock to any initiatives to look at the disease through different lenses.

One of the most significant impediments to change is the existence of a culture underpinned by ageist beliefs whereby, as people age, it is thought:

- their value to their communities is diminished
- their contributions to society aren't valued; and
- as their health deteriorates, they become more dependent on society.

These beliefs are exacerbated when dementia is involved.

As suggested by Macdonald *et al* (2019 p1ff), we need to "create a society in which vulnerability is a legitimate, well-supported life experience, and care is valued as central to all life... Instead of starting with dementia as a cruel, feared and vilified disease, let us start with a revaluing of vulnerability and care as intrinsic to all life."

Their beliefs align with many of us who advocate that challenging the stigma of dementia engenders conditions for viable rich lives for all who are living with dementia.

Reframing dementia

We need to move beyond the deficit-based, biomedical model of dementia, where knowledge about the pathology of the disease presents a narrow, clinical view of pathways of care for people with dementia. Therefore, there needs to be a paradigm shift in the way we view people with dementia. We need to reframe dementia.

The concept of reframing dementia is not new. It has been around for decades and has been informed and guided globally by the work of people living with dementia, researchers, medical professionals, activists and policy makers, through the written and spoken narrative.

By reframing dementia, it should not be assumed that all the energy and commitment that has gone into finding a cure; developing a better understanding of the disease, including preventative measures; and improving treatment and care practices, are not valued. All of these efforts provide people with dementia *hope*. However, these are not enough. People with dementia need to live as well as possible, *now*.

Concerted efforts to change the dominant dementia narrative by introducing new viewpoints have emanated from a number of fronts.

John Quinn at the Alzheimer's Disease International Conference in Budapest in 2016, where he presented on the topic Exercise Helps Me Remember My NAMES (Nutrition; Attitude, Acceptance and Art therapy; Mental activities/games, Music and Meditation; Exercise and Enjoyment; and Sleep, Support, Socialisation and Setting goals)

The new perspectives about dementia proffered by Kitwood (1997) about personhood; Bartlett and O'Connor's (2007, 2010) citizenship model; a social constructivist view (Sabat 2011, 2014, 2018); and a wellbeing stance (Power 2010, 2014, 2018) were instrumental in transcending the narrative about dementia beyond the myopic, reductionist model and embracing a bio-psychosocial viewpoint of the disease highlighting concepts of personhood, agency, social inclusion, independence, connectedness, participation, dignity, empowerment, autonomy, and maintaining capacity and wellness.

In addition, numerous researchers and organisations have added to the conversation about quality of life through, for example:

- the Alzheimer's Australia NSW (now Dementia Australia) *Living Well with Dementia* Discussion Paper (Stupar & Moore 2016)
- University of Exeter's Professor Linda Clare's IDEAL (Improving the Experience of Dementia and Enhancing Active Life) and IDEAL-2 projects (Clare *et al* 2014-2018 and 2018-2022) (www.idealproject.org.uk); and
- Professor Henry Brodaty and colleagues' ongoing COGNISANCE (Co-Designing Dementia Diagnosis and Post Diagnostic Care) project at UNSW Sydney (www.cheba.unsw.edu.au/consortia/cognisance).

They, along with other researchers have looked, or continue to look, at the key aspects of positive pathways of care which will lead to living well during the pre- and post-diagnostic period for people with dementia. Such projects will also contribute to changing the dementia narrative.

The global social movement using the dementia-friendly communities initiative as a vehicle for greater public awareness and understanding has also been instrumental in demystifying and de-stigmatising dementia. With regard to public awareness, Macdonald *et al* (2019 p9) assert, "Raising social awareness and changing dominant narratives about ageing and dementia with more empowering frameworks will be crucial in moving towards reducing ageist abuse and building capacity for equitable resource distribution."

Importantly, it could also be argued that the most pivotal moment that has contributed to a seismic shift in the way we view dementia was the acceptance of dementia as a disability under the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) in Geneva in 2016, to which Australia is a signatory, and the human rights ascribed to this acknowledgment. This recognition has elevated the hopes of those living with dementia and those who support them.

Transforming the narrative

Notwithstanding the lived experience stories, the intersection between the contemporary perspectives about dementia previously highlighted, coupled with a human rights approach, underpinned by a social model of disability, have the potential to transform the narrative around dementia about what authentic dementia care practices should look like.

Moreover, they provide a framework or analytical tools by which we can interrogate the alignment of their inherent principles with regards to current policy, regulations and social and clinical care practices for people living with dementia. As asserted by Cahill (2019) in *The Irish Times*, this model "gives agency, power and control back to the individual whose voice is elevated. The voice of the lived experience should be front and centre in any conversations about their health and wellbeing."

Furthermore, Cahill (2019) writes that "…people with dementia have the same legal rights as others throughout all stages of their life; these legal rights are inviolable and can never be removed no matter how advanced the dementia." After all, aren't we the ones that endure the indignities, the shame, the stigma, social isolation and discrimination that almost invariably follow from a dementia diagnosis?

On a global level, a number of dementia activists have attempted to draw greater attention to the recognition of dementia as a disability as acknowledged under the UNCRPD. Unfortunately, they feel the need to highlight this issue because of the slow response by their own governments, health care professionals, some service providers and others who work in the dementia space to put in place the legislation, policies, practices and programs for people with dementia which reflect their rights under this Convention.

I believe that one of the most powerful ways we can change the narrative about dementia, thus reducing the stigma, the fear and negative mindsets, is to speak openly about dementia, like we do with other medical diagnoses. We need to respond to a dementia diagnosis just like we do when someone gets a chronic health condition such as cancer, heart disease or has a stroke. The use of the word 'dementia' should be normalised and comfortably incorporated into our everyday language as necessary.

We need to challenge people who hear a diagnosis of dementia and say, 'how tragic', and encourage them to say, 'How can I support the person and his/ her carers?'. At this point it's also important to highlight that not everyone who receives a diagnosis of dementia has the support of family, and may in fact live alone.

As mentioned at the outset, to change the way we view and treat people with dementia, and ultimately enhance their quality of life, there needs to be systemic reforms.

Assessing outcomes

From this viewpoint, how has the reframing narrative translated into better support and quality of life for people living with dementia?

Over several decades in Australia there have been a number of inquiries into the quality of care provided to the aged, particularly those in full-time residential care, of which a number live with dementia. Sadly, many of the recommendations were not adopted.

Following widespread outrage due to a number of public revelations about the continued sub-standard care provided within the aged care sector, a Royal Commission into Aged Care Quality and Safety commenced in 2019. The Commission's recommendations, released on 1 March 2021, *must* not only be mandated, but also implemented. The regulatory body *must* have some 'teeth', and punitive disincentives for non-compliance *must* be enforceable.

During the Royal Commission's hearings, new Aged Care Quality Standards (Quality Standards) were established to "focus on outcomes for consumers and reflect the level of care and services the community can expect from organisations that provide Commonwealth subsidised aged care services" (Aged Care Quality and Safety Commission 2019). These Quality Standards incorporate the benchmarks against which service providers are audited for accreditation and funding.

The Royal Commission's Interim Report, titled *Neglect*, (Commonwealth of Australia 2019), documents incidents of neglect and, in a number of cases, financial and physical abuse within the aged care sector. It also highlights that the aged care sector is grappling with how to attract, train, retain and sustain its workforce. With regard to dementia, expert witnesses cite an over-reliance on the use of physical and chemical restraints as a way of managing dementia clients' responsive behaviours.

Witnesses appearing before the Royal Commission provided statements including the following:

"My father was like a caged animal and we asked how long he was restrained at any one time. The policy is two hours and then they are unrestrained but with one-to-one care for a bit for him to be toileted before being restrained again. It's appalling to see this" (Commonwealth of Australia 2019 p116).

"Dad was off his face, drugged up to the eyeballs, incoherent and lying in a pool of urine. I have video of this, it was very, very distressing" (Commonwealth of Australia 2019 p117).

Since these testimonies, the Australian Government has introduced new, mandated guidelines to minimise the use of physical and chemical restraint in residential aged care (which are to be followed by all aged care providers).

In relation to the new Aged Care Quality Standards (Aged Care Quality and Safety Commission 2019), following the release of the draft Quality Standards in 2017 for public consultation, people with the lived experience of dementia expressed concern that the eight Quality Standards would not necessarily ensure quality dementia care is delivered. This led to a series of discussions in 2019, initiated by Dementia Australia's Consumer Engagement Team, with over 31 focus groups across Australia, with 137 people participating, including people living with dementia, their families and carers. A thematic analysis identified recommendations in the context of each draft Standard. These were published by Dementia Australia in 2019 as a communique titled *Our Solution: Quality Care for People Living with Dementia.*

I will share with you the recommendations and comments from dementia advocates relating to draft Standard 1, Consumer Dignity and Choice from the communique. You will see from reading these that people with dementia and their carers are quite clear as to what they believe dignity and respect should look like – and feel like. Respect and dignity reflect *how* things get done rather than *what* gets done. The following excerpts from the communique are re-published here with the permission of Dementia Australia:

Standard 1: key themes

- Trained, caring and empathetic staff.
- Relationship building and taking time to get to know the person.
- Patience.
- Respect.
- Maintaining identity.
- Human rights.

The communique goes on to outline the following expectations by dementia advocates with regard to organisations:

1. The workforce understands and recognises the diversity of dementia through building personal relationships with the person living with dementia, their families and carers.
2. Additional time is allocated for the workforce to care for a person living with dementia, to understand their needs, behaviours and potential triggers.
3. The workforce is trained to communicate effectively with the person living with dementia, their families and carers with respect and empathy.
4. There is a focus on active involvement with the person living with dementia, their families and carers in decision making.
5. The workforce demonstrates knowledge and practice of what is important to the person living with dementia and respects their preferences through a human rights and person-centred approach to care.
6. There is acknowledgment and inclusion of the person living with dementia as a valued member of the community through engagement, recognition and participation in activities and social gatherings.

The following statements from the communique are from people living with dementia and carers about what dignity and respect looks like and feels like to them:

"The most important thing is that the care worker has empathy and recognises that individual person not just as another person they need to shower and feed – this is Grace

[not her real name], she likes wearing lipstick and these clothes, she still has her identity and this is very important." (carer).

"Every person with dementia is different and every day is different." (carer).

"Maintain my identity – let me do the things I can do." (person living with dementia).

"It is having the time to spend with people. Getting to know who they are, their likes and dislikes. That's what matters." (carer).

Where are we at now?

In March 2019, the Australian Department of Health facilitated workshops in Hobart, Brisbane and Sydney on co-designing policy to support people to live well with dementia, as part of a project called Dementia in the Community, conducted in 2019-2020. The Dementia in the Community Policy Co-Design workshops were attended by people living with dementia, carers, allied health professionals, GPs, medical specialists, dementia educators, specialist dementia services, researchers (including for Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse people) and Primary Health Network staff.

My partner Glenys and I were involved with the Brisbane workshops. This exercise itself was empowering because we were able to place *all* issues on the table for discussion and inclusion.

As a result of these workshops, a number of policy concepts were developed, namely:

- becoming a dementia-inclusive society
- timely diagnosis and early supports to live well with dementia
- ongoing supports for people with dementia and their carers
- a health and aged care workforce that delivers exemplary dementia care.

The policy concepts resulting from the Dementia in the Community project were submitted as evidence to the Royal Commission into Aged Care Quality and Safety. The policy concept document, which is publicly available, states that the "Department of Health will continue to work collaboratively with people living with dementia and those supporting them, to shape these ideas into future policy and program recommendations over the short, medium and long term…" (Commonwealth of Australia 2020). The concepts are part of the inputs that will assist to inform the Government's response to the Royal Commission recommendations.

As a requirement for ratifying the CRPD all signatory countries agreed to develop policies, legislation and guidelines to comply with the CRPD. In Australia to date there has been little, if any advancement in this area. Hopefully the above policy work will go some way to achieving this.

Conclusion

The opportunity is there for organisations and practitioners to use the CRPD, the Department of Health's Dementia in the Community Policy Co-Design Workshop Outputs document described above, and Dementia Australia's recommendations contained in the *Our Solution: Quality Care for People Living with Dementia* communique (2019) to interrogate practice, identify inequalities, enhance care and lobby for protection and fulfilment of the rights of people with dementia.

But there *must* be transparency and accountability because at the moment we are stripped of our dignity, our sense of worth and agency because of the stigma that accompanies a diagnosis of dementia.

Recently, the level of interest by those working in the dementia space, including people living with dementia and those who are either paid or undertaking voluntary work, to challenge current practices, language-use and highlighting our rights is encouraging.

I'm optimistic that now is a crossroads of intersecting viewpoints, regulations and a demonstration of respect towards those of us who have the lived experiences.

As a person living with dementia, I would have some *hope* for the future if this was to happen. Why? Because I want to live well *now*. ■

This is an updated version of John Quinn's presentation to The Dementia Centre, HammondCare International Dementia Conference in Sydney (11-12 June 2020), titled *Reframing Dementia: A Catalyst for Change in Quality of Care*. Published with the permission of The Dementia Centre, Hammondcare.

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References

Aged Care Quality and Safety Commission (2019) *Aged Care Quality Standards*. Canberra: Commonwealth Government. Available at: agedcarequality.gov.au.

Bartlett R, O'Connor D (2007) From Personhood To Citizenship: Broadening The Lens For Dementia Practice and Research. *Journal of Ageing Studies* 21(2) 107-118.

Bartlett R, O'Connor D (2010) Broadening the Dementia Debate: Towards Social Citizenship. Bristol, UK: The Policy Press.

Cahill S (2019) Reframing Dementia as a Disability and a Human Rights Concern. *The Irish Times*. Available at: http://bit.ly/3ctklDO.

Clare L *et al* (2014-2018, 2018-2022) IDEAL and IDEAL-2 projects. University of Exeter. Available at: www.idealproject.org.uk.

Commonwealth of Australia (2019) Royal Commission into Aged Care Quality and Safety *Interim Report: Neglect* Vol 1. Available at: www.agedcare.royalcommission.gov.au/publications.

Commonwealth of Australia (2020) *Dementia in the Community Policy Co-Design Workshop Outputs.* Document presented to the Royal Commission into Aged Care Quality and Safety. Available at: CTH.0001.1000.5602.pdf (royalcommission.gov.au).

Dementia Australia (2019) *Our Solution: Quality Care for People Living with Dementia*. Consumer Summit Communique. Available at: https://bit.ly/3qGkIFC.

Kitwood T (1997) *Dementia Reconsidered: The Person Comes First.* Buckingham: Open University Press.

Macdonald G, Mears G, Naderbagi A (2019) Reframing Dementia: The Social Imperative. In: Macdonald G, Mears J (Eds) *Dementia As Social Experience: Valuing Life and Care.* Abington, UK: Routledge.

Power GA (2010) *Dementia Beyond Drugs: Changing the Culture of Care.* Baltimore: Health Professionals Press.

Power GA (2014) *Dementia Beyond Disease: Enhancing Well-being*. Baltimore: Health Professionals Press.

Power GA (2018) Looking Beyond Disease. *Australian Journal of Dementia Care* 7(2) 17-19.

Sabat SR (2011) A Bio-Psycho-Social Model Enhances Young Adults' Understanding Of And Beliefs About People With Alzheimer's Disease: A Case Study. *Dementia* 11(1) 95-112.

Sabat SR (2014) *Understanding People With Alzheimer's Disease – A Bio-Psycho-Social Approach.* Paper presented at the Genio Annual Dementia Conference, Davenport Hotel, Dublin, December 2014.

Sabat SR (2018) *Alzheimer's Disease & Dementia: What Everyone Needs To Know.* New York: Oxford University Press.

Stupar M, Moore B (2016) *Living Well with Dementia, Alzheimer's Australia NSW Discussion Paper 17*, August 2016.

WHO (2016) *Draft Global Action Plan On Public Health Response to Dementia*. Report by the Director-General. EB 140/28, 29 December. Available at http://bit.ly/2x3cRf9.

Australian Journal of DementiaCare Research Focus

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

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

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

UTAS MOOC makes its mark in China

Mark Carter, **James Vickers** and **Zara Quail** share their learnings about working internationally to adapt and launch a version of the Wicking Dementia Research and Education Centre's popular massive open online course (MOOC), *Preventing Dementia*, in China

The global prevalence of dementia is escalating, along with the increasing ageing population, especially in low- and middle-income countries (Prince *et al* 2015). Over the next 30 years there will be significantly increased pressure on health care facilities and providers, aged care residential organisations, communities and care givers to provide appropriate care to people living with dementia (Xu *et al* 2017; Keogh-Brown *et al* 2016).

However, it is estimated that about 40% of risk factors for dementia are potentially modifiable and, if addressed at a population level, could reduce the prevalence of dementia (Livingston *et al* 2020). If societies are in any way able to stem the tide of the increasing prevalence of dementia, there is an urgent need to improve education on dementia care and prevention for health care providers and the general population (Wang *et al* 2019).

In recognition of this urgent need, the Wicking Dementia Research and Education Centre (the Wicking Centre) at the University of Tasmania has realised its goal of developing effective, high-quality e-health interventions to build knowledge in dementia as well as capacity for risk reduction through production of two massive open online courses (MOOCs) *Understanding Dementia* and *Preventing Dementia* (Wicking Dementia Research and Education Centre at the University of Tasmania 2019a, b). By the beginning of 2020, over 350,000 people world-wide had enrolled in these free courses, with an overall completion rate of 39%, amongst the highest of all MOOCs internationally.

In 2017, a substantial proportion of the *Preventing Dementia* MOOC was translated into Mandarin and promoted to families in Beijing, China in partnership with Care Visions China, a subsidiary of the UK-based Care Visions Group and a wholly foreign-owned home care service providing services to people living with dementia.

The two organisations initially began collaborating when Care Visions approached the Wicking Centre to endorse its training and education program on the delivery of therapeutic interventions for people living with dementia as an international standard. This engagement led to an ongoing working relationship between the two organisations which included academic expert advice and the subsequent delivery of the MOOC in China.

Dementia in China

China has the largest number of ageing people globally (United Nations 2017). The current number of people over the age 60 in China will more than double by 2050 when the over-60 population will account for 35.1% (478.9 million) of the overall Chinese population (United Nations 2017). Of those over 60, it is predicted that 66 million will require daily care and assistance (World Health Organization 2015), of whom 35.98 million will be living with dementia (Wang *et al* 2019).

However, there is still significant lack of dementia awareness and education for both health care providers and communities in China (World Health Organization and Alzheimer's Disease International 2012; Zhang *et al* 2017). This in turn contributes to the ongoing issue of stigma around dementia (Chen *et al* 2014; Chen *et al* 2017).

The aim of offering the *Preventing Dementia* MOOC in China was to increase health literacy around dementia and enable families caring for those living with dementia to implement lifestyle modification to reduce their personal dementia risk. ➤

Adapting and promoting

The *Preventing Dementia* MOOC is offered in four modules over about eight hours, covering dementia as a disease, prevalence, non-modifiable and modifiable risk factors and the evidence to support health and brain maintenance through lifestyle interventions at an individual and population level (Wicking Dementia Research and Education Centre at the University of Tasmania 2019a).

The content includes videos of specialists, academics, care providers and people living with dementia, online articles, discussion forums and quizzes. About 154,000 participants world-wide have registered for the *Preventing Dementia* MOOC since 2016, with an average completion rate of 43% across course offerings.

The English-language version was adapted and translated for a Chinese audience through liaison between the Care Visions team and the MOOC production team at the Wicking Centre. The main elements that were translated were the transcripts. The collaborative effort involved teams across the learning management platform, marketing, legal, public relations and research domains. Translated modules were produced by a Chinese academic at the Wicking Centre. This helped to ensure consistency of the message across the two languages and cultures. Chinese video channels were created for the MOOC videos as well as participant feedback processes integrated into the MOOC.

A joint marketing plan covering China and Australia was implemented which included media interviews, radio and traditional media channels. Care Visions used its far-reaching social media channels, such as WeChat, Weibo, Youku and Vimeo, in China to further promote the launch of the MOOC to over 160,000 people there for five weeks pre-launch.

The Chinese *Preventing Dementia* MOOC was also highlighted as part of promotional activities at the Alzheimer's Disease International conference in Kyoto, Japan two weeks before the MOOC launch in China. The official *Preventing Dementia* MOOC launch was also presented as part of a symposium in June 2017 in Beijing. Of the 80 attendees at the symposium, 90% registered for the MOOC at the event. High-level attendees included representatives from four embassies, trade groups from Australia, UK, Holland and China, as well as Beijing government health officials and industry leaders.

James Vickers, Director of the Wicking Dementia Research and Education Centre (back row, centre) and Care Visions founder Mike Reid (back row, centre right) with the Care Visions China team at the Preventing Dementia MOOC launch in Beijing, China

Launch and uptake

Users registered through Care Visions' China website, which then took them through to the University of Tasmania's website for consent and data protection and in turn, linked them to the Wicking Centre's Learning Management System to access the *Preventing Dementia* MOOC.

In China, 373 people registered for the Chinese version which was made available in two periods in 2017 and 2018. The overall completion rate was 24.7%, compared to the 53% completion rate of the 2018 English version. These are still all relatively high completion rates for a MOOC, with the typical completion rate globally being of the order of 5-15% (Goldberg *et al* 2015). We think this may be indicative of the eagerness of the participants to learn more about this disease and how to mitigate its effects, likely as participants may have experience of family members with dementia for whom they are providing daily care. The 2017 and 2018 MOOCs have also generated further interest in a country-wide rollout in China during 2021/2022 by organisations and care providers.

Interestingly, despite the accessibility of the online version, over 50 organisations and 100 families inquired about having the course content delivered in a face-to-face learning environment.

The *Preventing Dementia* MOOC receives thousands of reviews on public ratings sites such as Class Central, and is currently listed as the 14th most highly-rated MOOC internationally, as well as number two in 'Diseases and Disorders Courses' (Class Central 2020).

Barriers and challenges

When delivering online education between different systems in different countries, a number of technological issues can arise. In China, there were some problems with access to the MOOC content, particularly videos, due to the firewall in China and a numbers-based email system which filters out non-number-based emails. During the testing phase solutions to email verification and IP address issues were implemented to enable access to the Learning Management System from China. However, due to other technological barriers and issues, some interactive aspects could not be implemented within the Chinese version of the MOOC, which meant it was not a complete translation of the 2018 English-language version of the course.

Moderation of the discussion forums for the Chinese MOOC required a Chinese respondent specifically dedicated to the course. This role was fulfilled by a Mandarin-speaking academic member of the Wicking Centre who had helped develop the current English MOOC version and was fluent in the Mandarin translation of the course and its context.

As the course progressed, we found that many participants from China communicated in English rather than in Mandarin, indicating that take-up of, and progression through, the MOOC was likely to be largely by people with additional English language capacity.

After completing the *Preventing Dementia* MOOC, participants are offered a certificate. However, in the case of the Chinese MOOC, the completion certificate had to be recognised within China's health and care industry and delivered by a local organisation, instead of by the global e-health intervention platform. The participation certificates were offered by Care Visions as the Chinese intermediary.

Funding and support

As part of the collaborative partnership between Care Visions and the Wicking Centre, Care Visions funded marketing, promotion, content hosting and certification for all MOOC-related activities in China. The cost to Care Visions was about $A18,000 for the seven-week process from pre-marketing to certification.

There was significant industry involvement from the Australian Chamber of Commerce in venue and event marketing. The e-learning platform, technical infrastructure and support, translation and discussion forum moderation were all provided by the Wicking Centre.

Part of the initial MOOC project in China was to identify the possible future funding streams or potential avenues for market access. The need for sustainable funding was highlighted in the initial Chinese MOOC delivery in order to achieve the levels of participation and completion needed for countries such as the US and UK, which have the largest Chinese populations outside of China. There are plans to launch the *Understanding Dementia* and *Preventing Dementia* MOOCs more widely in 2022.

Future MOOC plans

The Wicking Centre is now developing a complete Mandarin translation of the *Preventing Dementia* MOOC.

The *Preventing Dementia* MOOC is now also a key behaviour change tool used for the Island Study Linking Ageing and Neurodegenerative Disease (ISLAND) Project, an online program that is targeted as a broad community- and public-health initiative to help develop self-efficacy in dementia risk management (Wicking Dementia Research and Education Centre at the University of Tasmania 2020). The ISLAND Project is being developed and implemented initially in Tasmania with a target of one tenth of the population over the age of 50.

Plans are also developing to establish a version of this unique MOOC program in languages other than English and make the *Understanding Dementia* and *Preventing Dementia* MOOCs available more widely.

The COVID-19 pandemic has led to greater community uptake of internet-based educational initiatives, and recognition of the value of online learning. However historically, there has been a degree of reluctance on behalf of Chinese students and authorities to acknowledge the value of online education. The MOOC approach, addressing critical health issues that confront an ageing China, may help to broaden knowledge of dementia risk and individual capacity to modify such risk.

Conclusion

The *Preventing Dementia* MOOC is an e-health intervention that provides practical education on dementia as a disease, non-modifiable and modifiable risk factors and the evidence around lifestyle modification for prevention of cognitive decline (Wicking Dementia Research and Education Centre at the University of Tasmania 2019a).

The course has the potential to both impact lifestyle and health choices of individuals as well as effect societal thinking of dementia as a disease, rather than an expected normal part of ageing.

The development of scalable and accessible online e-health interventions for dementia is an essential educational advancement if there is any hope of impacting escalating dementia prevalence in countries such as China.

Factors to consider in implementing efficient MOOC delivery should include country-specific system support for technological access and forum moderation personnel with the relevant knowledge, cultural considerations and language. Content developed for online delivery can also potentially be delivered in a communal group setting or adapted for face-to-face lectures to promote social interaction and community awareness.

Accessible educational resources such as MOOCs have the potential to reach large populations in both urban and rural areas with adequate access to the internet on any device. By harnessing the power of such technological reach, educational resources such as the *Preventing Dementia* MOOC have the potential to educate people at an individual, community and population level.

Further research is needed to understand the precise influence this level of education can have to reduce dementia risk-related health factors and behaviours, but every effort is required at an educational, policy, and strategic population level to reduce the prevalence of dementia and improve the resources available to care for those people living with dementia. ■

■ From left: Mark Carter is Managing Director of Care Visions Home Services in China, Director of Product Development and Service Delivery for Care Visions Healthy Ageing in the UK, Clinical Associate of the University of Tasmania School of Medicine and Associate Fellow of the Australasian College of Health Service Executives; Professor James Vickers is Director of the Wicking Dementia Research and Education Centre, University of Tasmania, and Head of the Tasmanian School of Medicine, University of Tasmania; Dr Zara Quail is Clinical Scientific Research Lead Care Visions Limited, Stirling, Scotland, a qualified medical doctor, clinical editor and medical writer. To follow up on this article, contact Zara Quail at zara.quail@carevisions.co.uk

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References

Chen S, Boyle LL, Conwell Y, Xiao S, Chiu HF (2014) The Challenges of Dementia Care in Rural China. *International Psychogeriatrics* 26(7) 1059-1064.

Chen Z, Yang X, Song Y, Song B, Zhang Y, Liu J, Wang Q, Yu J (2017) Challenges of Dementia Care in China. *Geriatrics (Basel)* 2(1).

Class Central (2020) *The Best Online Classes of All Time.* Available at: http://bit.ly/3eQyGT5 (Accessed 26/11/2020).

Goldberg LR, Bell E, King C, O'Mara C, McInerney F, Robinson A, Vickers J (2015) Relationship Between Participants' Level Of Education And Engagement In Their Completion of the Understanding Dementia Massive Open Online Course. *BMC Medical Education* 15 60.

Keogh-Brown MR, Jensen HT, Arrighi HM, Smith RD (2016) The Impact of Alzheimer's Disease on the Chinese Economy. *EBioMedicine* 4 184-190.

Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S *et al* (2020) Dementia Prevention, Intervention, and Care: 2020 Report of the Lancet Commission. *Lancet* 396(10248) 413-446.

Prince MJ, Wimo A, Guerchet MM, Ali GC, Wu Y-T, Prina M; Alzheimer's Disease International (2015) *World Alzheimer Report 2015 – The Global Impact of Dementia: An Analysis Of Prevalence, Incidence, Cost and Trends*. Available at: http://bit.ly/3eRCkMg (Accessed 26/11/2020).

United Nations, Department of Economic and Social Affairs Population Division (2017) *World Population Ageing 2017* (ST/ESA/SER.A/408). Available at: https://bit.ly/3s4tCOM (Accessed 26/11/2020).

Wang Y-Q, Jia R-X, Liang J-H, Li J, Qian S, Li J-Y, Xu Y. Dementia in China (2015-2050) Estimated Using the 1% Population Sampling Survey in 2015 (2019) *Geriatrics and Gerontology International* 1-5.

Wicking Dementia Research and Education Centre at the University of Tasmania (2019a) *Preventing Dementia* MOOC. Available at: http://bit.ly/2P8tizW (Accessed 26/11/2020).

Wicking Dementia Research and Education Centre at the University of Tasmania (2019b). *Understanding Dementia* MOOC. Available at: http://bit.ly/3r6lFr3 (Accessed 26/11/2020)

Wicking Dementia Research and Education Centre at the University of Tasmania. (2020) *The ISLAND Project.* Available at: https://island.mooc.utas.edu.au/ (Accessed 26/11/2020).

World Health Organization (2015) *China Country Assessment Report on Ageing and Health.* Available at: https://bit.ly/2Q80HLk (Accessed 26/11/2020).

World Health Organization and Alzheimer's Disease International (2012) *Dementia: A Public Health Priority*. Available at: http://bit.ly/30Us9OY (Accessed 26/11/2020).

Xu J, Wang J, Wimo A, Fratiglioni L, Qiu C (2017) The Economic Burden of Dementia in China, 1990-2030: Implications for Health Policy. *Bulletin of the World Health Organisation* 95(1) 18-26.

Zhang H, Loi SM, Zhou S, Zhao M, Lv X, Wang J, Wang X, Lautenschlager N, Yu X, Wang H (2017) Dementia Literacy Among Community-Dwelling Older Adults in Urban China: A Cross-sectional Study. *Frontiers in Public Health* 5 124.

RESEARCH NEWS

The latest published dementia research from Australia and around the world. Compiled by *AJDC* Contributing Editor **Catherine Ross**

Variation in medication reviews

There is considerable national variation in how Australian residential aged care facilities (RACFs) approach government-funded Residential Medication Management Reviews (RMMRs), despite the fact that they are recommended for all new residents of RACFs, and overall they are generally underused.

These are some key findings from a new retrospective cohort study conducted by Australian researchers, who used the National Historical Cohort of the Registry of Senior Australians (ROSA) to review de-identified data for 143,676 residents from 2799 RACFs – all individuals aged 65 or above who first entered permanent residential aged care in Australia between 1 January 2012 and 31 December 2015, who received at least one medication in the previous year, and were alive at 90 days after admission to the RACF.

Findings of interest were that:

- 21.5% of individuals received a timely RMMR within 90 days of entry into permanent residential care.
- In 93.8% of RACFs, fewer than half of all new residents received a timely RMMR.
- In 10.8% of all Australian RACFs, timely RMMRs were not provided to any new residents.
- Residents with dementia were 5% more likely to receive a timely RMMR and those speaking a primary language other than English were 4% more likely to receive an RMMR.
- Individuals in non-metropolitan areas were 25% to 33% less likely to receive a timely RMMR.

While conceding limitations to the study, the researchers conclude that there is considerable geographical and facility-level variation in timely RMMR provision, and that the RMMR service is generally underused. They say their findings point to a need for increased efforts to deliver timely RMMRs, especially in non-metropolitan areas, with strategies tailored to individual facilities and organisations.

Sluggett JK, Bell S, Lang C *et al* (2021) Variation in Provision of Collaborative Medication Reviews on Entry to Long-Term Care Facilities. *Journal of the American Medical Directors Association* 22(1) 148-155. doi: 10.1016/j.jamda.2020.10.027

Culturally appropriate care valued

A new study has produced strong evidence that Aboriginal and Torres Strait Islander Australians prefer Aboriginal Community Controlled services, particularly when it comes to aged care and disability services.

A team of researchers led by NeuRA (Neuroscience Research Australia) has conducted a mixed-methods cross-sectional study including 336 Aboriginal and Torres Strait Islander people aged 60 years and older from regional areas in NSW and Sydney.

The study found that 64% of the study participants only access health and aged care from Aboriginal Community Controlled Organisations (ACCOs). This tendency to have an exclusive preference for Aboriginal Community Controlled services was higher in regional areas compared to urban areas.

NeuRA said that the results showed the two most important factors for Aboriginal people when seeking health and aged care services were the ability to relate to their doctor or carer on a cultural level, and to have access to an environment that is spiritually, emotionally and socially safe. In particular, researchers found that Aboriginal Australians avoided mainstream services because of cultural barriers and previous experiences with discrimination.

The researchers conclude that, given the anticipated increase in service demand in this population (there will be over half a million older Aboriginal and Torres Strait Islander people in Australia by 2050), there is a growing need for culturally safe services, particularly in regional settings.

"Aboriginal people are getting good care at these facilities and their cultural needs are being met. ACCOs are working and we want to see more recognition of that and investment in these services," said researcher, Dr Kylie Radford.

Larke BM, Broe GA, Daylight G *et al* (2020) Patterns and Preferences for Accessing Health and Aged Care Services in Older Aboriginal and Torres Strait Islander Australians. *Australasian Journal on Ageing*. First published 6 November 2020. Doi: 10.1111/ajag.12864

Oral health and dental care

A team of multidisciplinary researchers from King's College London (including a former carer of a person with dementia) has conducted an exploratory study to look at the experience of community-dwelling people living with dementia, and their carers, around oral health and use of dental care.

The qualitative study involved 17 people, with a total of 12 semi-structured interviews conducted: five with just a carer, two with just a person living with dementia and five jointly with a person living with dementia and their carer.

Overall, oral health was not considered a primary concern, especially in the context of dementia's progression and other long-term conditions – and often only became a priority when problems arose. Assisting with oral health did not seem to be routinely included in home care workers' tasks and dental services were not said to be routinely included in 'packages of social care'. There appeared to be little information available on how to access dental services when needed.

Participants suggested that in England, current oral health care can be insufficient for some people with dementia, both in relation to daily self or assisted care within the home and access to professional dental services, particularly as their condition progresses, or in emergencies.

The researchers say that dementia-specific health and social care providers should have information on local, accessible dental services and how to access them and actively support clients to do so.

Curtis SA, Scambler S, Manthorpe J *et al* (2020) Everyday Experiences of People Living with Dementia and their Carers Relating to Oral Health and Dental Care. *Dementia*. First published online December 19, 2020. doi: 10.1177/1471301220975942

Cancer care for people with dementia

Research led by Leeds Beckett University in the UK has resulted in a practical list of recommendations for oncology departments on how to better support people living with dementia who are also living with a diagnosis of cancer.

The researchers conducted an ethnographic study across two sites in the north of England, including 37 interviews involving 50 participants (13 people with dementia and cancer), 18 caregivers and 19 staff, as well as individual observations of 12 people with dementia and cancer, which included one or more of their caregivers (and which related to consultations, treatment, scans and tests). The interviews were analysed thematically and an overarching theme of 'accumulated complexity' was proposed to capture the wide range of ways in which cancer care was complicated by also living with dementia.

More specific issues emerging from the interviews included:

- The difficulties hospital staff had in identifying dementia, with limited documentation about the dementia in oncology medical records.
- Unmet dementia training needs amongst oncology staff.
- Challenges for people with dementia and cancer and caregivers around understanding and using cancer and treatment information.
- The complicating impact of dementia on treatment decision-making.
- The crucial role played by family caregivers in enabling treatment.
- How dementia complicates the practicalities of attending hospital appointments, due to the poor built environment.
- The greater total burden of 'illness work' – that is, the cumulative burden of managing a range of medical conditions at the same time.

The researchers went on to use the findings to propose 14 recommendations for oncology hospital services and staff to improve cancer care and treatment for people with dementia and their families (for example, 'Offer flexibility in timing and location of appointments where possible', and 'Mitigate hospital travel challenges'), with accompanying potential strategies and interventions for implementation. The researchers say this is the current most comprehensive single list on this topic.

Ashley L, Kelley R, Griffiths A *et al* (2021) Understanding and Identifying Ways to Improve Hospital-Based Cancer Care and Treatment for People with Dementia: An Ethnographic Study. *Age and Ageing* 50(1) 233-241. doi: 10.1093/ageing/afaa210

Dementia support and education

Australian researchers have surveyed 179 staff from 36 public sector Victorian residential aged care facilities in order to establish the extent to which they are aware of, and engage with, dementia-specific support services and education – and concluded that more needs to be done to promote awareness of these resources for staff.

The survey was conducted between March and June 2019 and included open and closed questions relating to respondents' awareness, engagement and experiences of dementia-specific support and education services.

Some key findings include:

- 60% of respondents were aware of dementia-specific support services.
- 27% of respondents had accessed dementia-specific support services in the past two years (with the two most commonly used services being Dementia Australia and Dementia Support Australia).
- 77% were aware of dementia-specific education (such as the Wicking Dementia Research and Education Centre at the University of Tasmania's Massive Open Online Courses, and education offered by Dementia Australia and Dementia Training Australia).
- 66% had completed some dementia education in the previous two years.
- Approximately 60% of dementia-specific education completed by respondents in the past two years was online education, and a small proportion included an element of in-person delivery.

While acknowledging the small sample size, the researchers say the findings prompt concern about the currency of staff knowledge and skills needed to promote wellbeing of older people living with dementia in residential aged care facilities. They highlight the finding that nearly a quarter of respondents didn't know about dementia education available to them.

Williams R, Ockerby C, Rawson H, Redley B, Hutchinson A (2021) Residential Aged Care Staff Awareness of and Engagement with Dementia-Specific Support Services and Education. *Australasian Journal on Ageing*. First published online 31 January, 2021.doi: 10.1111/ajag.12904

Research into social robot PARO and sleep duration

New research investigating the potential impact of the social robot PARO to support people living with dementia and chronic pain in residential aged care has shown that it can have some effect on sleep duration.

The pilot randomised controlled trial was conducted across three residential aged care homes in Australia and involved 41 residents. The study involved randomly allocating people living with dementia and chronic pain into one of two groups for six weeks: one group had 30 minutes of contact daily with the social robot (PARO), the other group received usual care. The researchers recorded sleep and motor activity, captured via actigraph (wearable) devices, on four occasions: at baseline, weeks one and six, and after the intervention.

From week one, residents engaging with PARO had a greater increase in the night sleep period compared with those receiving usual care, and by week six this margin had increased, along with a reduction in daytime sleep.

The reseachers found no significant results for motor activity, and did note that using wearable actigraphy for research with people with dementia is challenging.

Pu L, Moyle W, Jones C, Todorovic M (2020) The Effect of a Social Robot Intervention on Sleep and Motor Activity of People Living with Dementia and Chronic Pain: A Pilot Randomized Controlled Trial. *Maturitas*. Published online September 24, 2020. doi: 10.1016/j.maturitas.2020.09.003

Unlawful Sexual Contact in Residential Aged Care: A Practical Guide for Aged Care Providers Supporting Victims is a new 28-page booklet developed by Dr Catherine Barrett from the OPAL Institute and Tonye Segbedzi from the Australian Association of Gerontology (AAG). It is based on an AAG workshop held in Sydney on 5 November 2019 titled 'Unlawful Sexual Contact: Compliance, Resourcing and Prevention' run with the OPAL Institute. The resource aims to provide information for managers and staff of aged care service providers on how to respond to unlawful sexual contact in ways that respect and support victims and their families. It addresses some key questions (for example, what is reportable unlawful sexual contact? What is not reportable?); then presents 'Sandra's story', as told by her daughter for the OPAL Institute's #InHerShoes Project, and later returns to the story to pose a series of questions for care teams to reflect on, were they to find themselves responding to a situation like Sandra's. The resource covers victim and perpetrator characteristics; signs of unlawful sexual contact; strategies for responding to unlawful sexual contact; and resources. The resource is available at https://www.aag.asn.au/documents/item/3899

The Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Sydney is investigating the health status, service use and service pathways of people with less common types of dementia, such as frontotemporal dementia and dementia due to other disorders or diseases (most research to date has focused on the health status of people living with Alzheimer's disease). Four resources are now available arising from the study: a postcard for people living with dementia (titled **Health Care for People Living with Less Common Types of Dementia** with tips for the person and information for the person's GP); two fact sheets, one aimed at people living with dementia, the other at care partners, both titled **The Health Service Use of People Living with Less Common Types of Dementia** and which provide information on the main reasons that people living with less common types of dementia are admitted to hospital in NSW and how to avoid hospital admissions; and a poster (untitled) for health professionals giving a brief summary of the study's findings and recommendations. All the resources can be found at https://bit.ly/3kTvLbu

Dementia Australia's Centre for Dementia Learning has launched an online education program aimed at people working in banks and the financial sector, called **Better Banking for People with Dementia**. The one-hour program focuses on the impact of dementia and how to provide improved services for people living with dementia, their families and carers, and includes interactive videos and quizzes designed to engage the learner. The resource was developed with input from people living with dementia and their carers, as well as staff from Bendigo Bank, Victorian Police and the Age Discrimination Commissioner, Dr Kay Patterson AO. For inquiries about purchasing access to **Better Banking for People with Dementia** contact the Centre for Dementia Learning on 1300 336 368 or via email: cdl@dementia.org.au.

In November, Advance Care Planning Australia launched an updated version of its **Advance Care Planning Aged Care Implementation Guide**. The guide presents an overview of advance care planning (introducing key ideas), then goes on to consider a range of issues in more detail, including staff education, consumer engagement, taking a multidisciplinary approach, as well as presenting a step-by-step guide to advance care planning. The guide includes some guidance specifically on advance care planning with people living with dementia, and also provides advice on making sure aged care providers' advance care planning practices comply with the Aged Care Quality Standards, as well as links to other resources. To access the resource, go to https://bit.ly/3khUcRi

The Aged Care Quality and Safety Commission has published a three-page fact sheet titled **Partnerships in Care: Supporting Older People's Wellbeing in Residential Care** which looks at how residential aged care teams can facilitate the ongoing involvement of a key relative/s or friend in the life of a care home resident. The fact sheet provides information on supporting partnerships in care safely while COVID-19 remains an ongoing risk. The fact sheet sets out the benefits of a partnership in care, looks at who might be considered a partner in care and how they might be able to assist, explains how to implement a partnership in care approach in your service (for example, covering the need for induction and ongoing training and education), and how to negotiate and implement individual partner-in-care arrangements. The fact sheet is available at https://bit.ly/3aSkZAI

The UK's Alzheimer's Society has published a report addressing the particular challenges faced by people living with dementia during the pandemic. The report, **Worst Hit: Dementia During Coronavirus**, explores the disproportionate death toll on people with dementia, the increase in loneliness and isolation, and the pressure on health and social care services. It makes a series of recommendations, including that the national UK governments need to set out a clear strategy to enable people affected by dementia to recover from the effects of the pandemic, and that more support is needed for informal carers. Access the report here: https://bit.ly/3nFsuhs

SIRS resources

The Serious Incident Response Scheme (SIRS) is a new initiative to help prevent and reduce incidents of abuse and neglect in residential aged care services. It is subsidised by the Australian Government, administered by the Aged Care Quality and Safety Commission and commenced on 1 April 2021.

The Aged Care Quality and Safety Commission (ACQSC) has published a range of resources – including detailed guidance (see news p8) – on SIRS to support aged care providers. A series of four free webinars conducted during February and March 2021 are available to view, and three fact sheets can be downloaded too: **What is the SIRS?** (one version aimed at aged care providers, the other at consumers), and **What is an Effective Incident Management System?** (aimed at aged care providers). The ACQSC website also addresses some basic questions about SIRS, such as 'What is the Serious Incident Response Scheme (SIRS)?', 'Why is the SIRS important?', 'How will the SIRS work?', 'When will the SIRS commence?', and 'The role of the Commission under the SIRS'.

All the ACQSC SIRS-related materials can be accessed at www.agedcarequality.gov.au/sirs

New resources from HammondCare

Webinars: HammondCare's Dementia Centre has launched a collection of **webinars** which can be accessed at any time, with more scheduled for release over the first six months of 2021. Two are available now (March 2021): **#BPSD: A Long and Winding Road**; and **Dying Well With Dementia: A Conversation with Sue Pieters-Hawke**.

A further seven are in the pipeline for launch in 2021 and expressions of interest can now be registered to access the webinars when available: The BPSD Series: Addressing Behaviours and Psychological Symptoms of Dementia; Aged Care Makeover: How to Maximise Your Home's Potential on a Budget; Music Speaks: An Introduction to Music Engagement in Dementia Care; Acoustic Intrusions: Acoustic Design in Dementia Care Settings; Design and Behaviours: How and Why Design Makes a Difference; Understanding Dementia: An Introduction; and Psychotropic Medication and Behaviours: Which Behaviours are Likely to be Medication-Responsive?. To access or to register your interest, go to www.dementiacentre.com/events

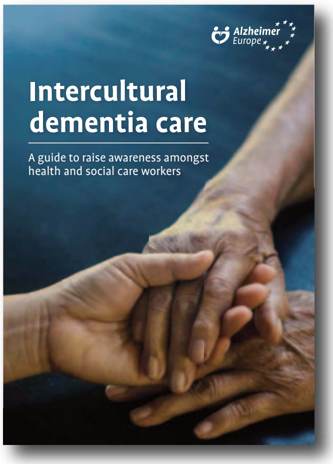
Podcasts: In December 2020, HammondCare's Dementia Centre launched a new resource, **The Dementia Podcasts**, which offers an expanding list of podcasts on a range of topics in dementia care, hosted by the Centre's Director, Professor Colm Cunningham. Three early podcasts (all released in December) focus on Christmas (and relevant issues for people with dementia and carers), two are on 'Understanding behaviour' (one a clinician's perspective, and the other a client story), and one addresses sensory challenges and dementia. The podcasts can be accessed at www.dementiapodcast.com/

Setting goals: HammondCare has launched two new practical resources to support the delivery of reablement programs for people living with dementia. **Setting Goals and Evaluating Meaningful Outcomes for People Living with Dementia Who Are Participating in Reablement Programs: Practitioner Guide** is aimed at allied health practitioners and provides a structured approach to evaluating meaningful reablement program outcomes for the person living with dementia. The 22-page guide sets out three stages: (1) identifying meaningful therapy goals with clients using newly developed Reablement Goal Lists; (2) defining these goals using a new dementia-specific adaptation of the SMART (Specific, Measurable, Achievable, Relevant and Time-bound) Framework; and (3) scoring using the Gas-Light adaptation of Goal Attainment Scaling (GAS) to record and evaluate program outcomes. The accessible guide includes lots of examples, three case studies and important information about the particular issues to consider when goal setting with people living with dementia.

The practitioner guide links directly with the second resource, **Setting Goals and Evaluating Meaningful Outcomes for People Living with Dementia Who Are Participating in Reablement Programs: Client Workbook**. The client workbook is intended for clients to use alongside the allied health practitioner they are working with in a reablement program. The workbook summarises the practical content from the practitioner's guide, and includes a blank template for completion with the client, 'My Reablement Plan'.

To access both resources, go to https://bit.ly/2Z38JX1

Intercultural Dementia Care: A Guide to Raise Awareness Amongst Health and Social Care Workers is a new guide from Alzheimer Europe. The 30-page resource covers five key areas: 'About minority ethnic groups and dementia', 'Different cultural approaches to dementia care', 'Intercultural care and support', 'Language and communication', and 'Collaboration with families'. The aim of the guide is to help health and social care staff to provide good dementia care to people from a wide range of ethnic groups. The guide includes lots of tips for practice, including examples of the sorts of questions staff could use in order to learn more about a client's needs and preferences. Although European-focused, a lot of the content is relevant to care staff working in Australia. A policy briefing on this topic has also been produced by Alzheimer Europe, and both can be accessed on the Alzheimer Europe website at https://bit.ly/2ZqUagh



Therapeutic Horticulture Australia has launched a new online guide called **Community Gardening and Dementia** to help people involved in community gardens to learn how to become more dementia-inclusive. The guide is the work of the DIGnity Supported Community Gardening project just outside Hobart, Tasmania, which has been offering a therapeutic outdoor environment for community members with a range of needs, including people living with dementia, since 2016. The resource was co-produced with DIGnity participants, with support from Dementia Australia and the Centre for Rural Health at the University of Tasmania, and shares the learning from the project over recent years. The guide presents four key practical tips (eg, 'Have a variety of things to do') as well as 'Tips for collaboration' aimed at both community gardeners and aged care providers, and a short film about the project. Quotes from DIGnity participants feature alongside practical tips and suggestions.

The resource is available at http://bit.ly/gardening-and-dementia

UK community interest company, Innovations in Dementia, is behind a new project launched in December 2020 which is encouraging people living with dementia to share their tips for living with dementia with others who are also living with dementia – known as **Dementia Tip-Share**. The project's website says it aims to be clear, easy to use, searchable and informative. Tips contributed so far already cover a wide range of topics, for example the coronavirus situation, emotional and family life, friends and peers, money and legal matters, health issues and symptoms, and work and meetings. The project is asking contributors to share ideas for how they 'work around' some of the challenges they face living with dementia, and how they have adapted to, and 'outmanoeuvred' dementia. To find out more, go to https://dementiatip-share.org.uk/

Being Active at Home: A Resource for People Living with Dementia and Their Care Partners is a new free five-page booklet developed by the Dementia-Inclusive Choices for Exercise (DICE) project at the University of Waterloo in Canada. The accessible resource sets out physical activity guidelines for people living with, or at risk of, dementia, advice for planning an at-home physical activity plan and strategies that may help support physical activity among people living with dementia. It is aimed at people living with dementia and their care partners. Although the resource is based on Canadian public health advice, much of the information is applicable in an Australian context, for example in relation to setting routines, having an exercise plan, and ways in which people with dementia can be supported to continue with physical exercise. The resource is available on the website for the Research Institute for Aging (RIA) at the University of Waterloo, at https://bit.ly/2ZDg3ZQ

COVID resources

The Centre for Cultural Diversity in Ageing has launched the **Multilingual Older Persons COVID-19 Support Line**, which aims to provide in-language support and information about COVID-19, and referrals to aged care, dementia care and other support services for older Australians from culturally diverse backgrounds. The Australia-wide support line is funded by the Department of Health and will operate until 31 July 2021. All calls are free from 2pm-5pm AEDT/AEST Monday to Friday (except public holidays). The phone numbers are: Arabic: 1800 549 849; Cantonese: 1800 549 848; Greek: 1800 549 845; Italian: 1800 549 844; Mandarin: 1800 549 847 and Vietnamese: 1800 549 846.

The Aged Care Quality and Safety Commission continues to add to its online hub of resources on COVID-19 aimed at aged care providers, and includes links to resources from other key stakeholders too. **COVID-19 Provider Resources** includes links to ‘Outbreak management guidance’, ‘Lessons learned by aged care providers experiencing outbreaks of COVID-19 in Victoria’, ‘Visitor access for residential aged care services’, ‘Infection control spot checks’ and ‘COVID-19 information’. The resources can be found here: https://bit.ly/3uuXdCt

The Department of Health has a section dedicated to **Information For Aged Care Providers, Workers and Residents About COVID-19 Vaccines** within its online information hub on COVID-19 vaccines. Regular updates are also available by signing up to receive the ‘COVID-19 vaccines update’ emails, which can be accessed on this part of the site. The Department’s new **COVID-19 Vaccine Aged Care Readiness Toolkit** (go to https://bit.ly/3pR6XDz) is a collection of resources designed to assist aged care providers to prepare for the roll-out of COVID-19 vaccines, while its **COVID-19 Vaccination – Aged Care Stakeholder Kit** (go to https://bit.ly/3knNjh7) contains information about the COVID-19 vaccine national roll-out program for aged care residents, workers and their families. It has also published a **Decision Guide** to help people who are frail or very old, including those living in residential aged care facilities and their representatives, make an informed decision about getting a COVID-19 vaccine.

Alzheimer’s Society UK is now offering its substantial activities resource as a free download. **The Activities Handbook: Supporting Someone with Dementia to Stay Active and Involved** is an 80-page book which presents a long list of possible activities that may be enjoyed by a person living with dementia, presented in three broad areas: ‘Social, physical and outdoor activities’, ‘Activities at home’, and ‘Online and digital activities’. It begins with an opening chapter, setting out some important considerations for supporting a person with dementia to engage in activities, and goes on to include helpful ideas for activities, resources and links to organisations. The resource is primarily aimed at family carers who are supporting a person living with dementia in the community, and quotes from family carers feature throughout. Although many resource links are UK-specific, the broader vast range of suggestions is still applicable to readers and practitioners in Australia. The handbook is available here: https://bit.ly/3boskXq

Dementia Australia’s Centre for Dementia Learning (https://dementialearning.org.au) has launched its new 2021 **Dementia Learning Guide**, setting out the organisation’s most up-to-date offerings for building the capacity of the dementia care workforce. The Centre says this year it is offering more digital education, using virtual classrooms and interactive elements to maximise engagement and learning outcomes. To find out more, contact the Centre for Dementia Learning on 1300 336 368, email cdl@dementia.org.au or go to https://bit.ly/3uoQtWQ

ACE – the Aged Care Enrichment Podcast launched in August 2020 is now into its second season. Season one included 10 episodes, each on a topical issue in aged care, and each lasting about 45 minutes. The sessions are hosted by Ash De Neef, and produced by SilVR Adventures, and so far guests have included dementia specialists such as Daniella Greenwood (talking on the Royal Commission and a human rights approach), Jason Burton (talking on ‘The human condition of dementia’) and Christine Bryden (‘Life in the slow lane of dementia’). Access the podcasts here: https://ace-aged-care-enrichm.captivate.fm/

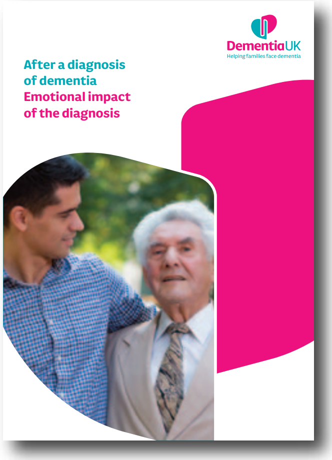
A UK All Party Parliamentary Group (APPG) Inquiry into housing and dementia has presented its final report, titled **Housing for People with Dementia – Are We Ready?** The APPG on Housing and Care for Older People conducted the inquiry over four online sessions during 2020, inviting a range of expert witnesses including people with a lived experience of dementia, with the aim of exploring the policy changes needed to help people live as well as possible with dementia in their own homes – from mainstream housing to supported environments (but not residential care or nursing homes). The inquiry report covers five key areas (‘What older people told us about their housing experiences and living with dementia’, ‘Understanding dementia and planning for the best possible housing options to be available’, ‘The importance of housing choice within communities’, ‘Using technology and making adaptations to improve the wellbeing of people affected by dementia’ and ‘Every decision about care is also a decision about housing’) and makes a series of recommendations as a result. To access the inquiry report, go to https://bit.ly/3bznWVP

In 2019-2020 the Good Things Foundation in the UK supported a local library service (the Leeds Library Service) to deliver a project to promote digital participation among people living with dementia and family carers. The final report from that project, **Dementia and Digital Participation for Health and Wellbeing** has now been published. The scale of the project was extensive (involving 798 people over 12 months: for example, 81 carers trained as ‘Digital Champions’, 91 library staff and volunteers trained as ‘Digital Champions’, and 69 carers trialled iPads or Alexa), and the findings make for interesting reading. Some key ‘Impacts and insights’ reported include that the social aspect of digital engagement was particularly valued; providing equipment and face-to-face support in local places where carers already met was important, and that carers reported both practical and wellbeing benefits from being involved in the project. The accessible report presents 'Ingredients for change', and again, though written from a UK context, is still very relevant to an Australian audience. The report can be found at https://bit.ly/3kj7mgZ

Dementia Support Australia now offers a growing range of **help sheets** on a range of topics related to dementia care: 'Looking after a person with dementia in the acute care setting'; 'Post-traumatic stress disorder and dementia care'; 'The use of activity sheds in dementia care'; 'The Use of Global Positioning System (GPS) location devices in dementia care'; 'The use of music engagement and personalised playlists in dementia care'; 'The use of simulated pets in dementia care'; and 'Providing one-to-one care for the person living with dementia'. The help sheets are all two to four pages in length, and present accessible, practical introductions to these topics, with links to related resources. Access all these help sheets here: https://dementia.com.au/resources/library

Despite progress, there is still much to do to improve data sharing in dementia research according to Alzheimer Europe, in its new report, **Data Sharing in Dementia Research**. The report reviews recent changes in EU research policy and sets out recommendations to improve data sharing. It says researchers still face a range of technical, financial and motivational obstacles to data sharing, with the loss of privacy being the most frequently-cited concern for research participants. Key recommendations to improve data sharing include developing pathways for faster, secure sharing of research data between sectors and across borders; supporting researchers to maintain datasets and platforms after projects end, and embedding academic reward systems that place a greater value on data sharing and transparency; increasing digital literacy in the general population; and involving people with dementia in the design and conduct of research, as well as in data governance. The report is available to download at http://bit.ly/DataSharing_AE

Dementia UK continues to expand its range of **advice leaflets**, with new topics added such as 'Caring from a distance', 'Coping with feelings of guilt', 'Emotional impact of the diagnosis' (pictured), 'Getting the most out of a remote consultation', 'Practical guide to getting the best out of GP and other health appointments', and 'Looking after yourself when you care for someone with dementia'. Dementia UK offers a specialist dementia nursing service for families through its Admiral Nurse service in the UK, and the ideas and tips within the leaflets are drawn from practical experience of supporting family carers of people living with dementia. Leaflets vary in size from eight to 12 pages, with easy-to-read text. The full range of leaflets can be found at www.dementiauk.org/get-support/our-leaflets/


After a diagnosis of dementia
Emotional impact of the diagnosis

Dementia Australia has announced that it now offers a **Post-Diagnostic Support Program** for people recently diagnosed with dementia, to help them manage their diagnosis and live well, with support also available for family and carers. As part of the program, a skilled Dementia Australia staff member will be the single point of contact over six sessions, helping people impacted by dementia to increase understanding of dementia, plan support services and networks, develop personal and lifestyle strategies, and prepare and plan for any changes. The service is offered across Australia, via phone or video conference. Dementia Australia continues to offer its popular Living With Dementia Program for those who prefer a group approach. To find out more, contact Dementia Australia's National Dementia Helpline on free call 1800 100 500 or complete the online service inquiry/referral request form: www.dementia.org.au/support/service-enquiry

The Alzheimer's Society in the UK has published updated versions of its two popular easy-read guides: **What Is Dementia?** and **Helping A Person With Dementia**. Both are aimed at people with learning disabilities but will also be useful for anyone who would benefit from a very basic, clear introduction to dementia. The guides use short sentences with simple words presented alongside images, spread out generously across 16 pages. They were developed in conjunction with the Belfast Dementia Champions with learning disabilities group and are available at https://bit.ly/2OY6yz6.

In September 2020, the Wicking Dementia Research and Education Centre hosted a seminar titled **A Life-Course Approach to Dementia Prevention** which is now available to view online. Dr Maree Farrow gave a presentation on 'Life-course model for dementia prevention' which was followed by a presentation by Dr Edward Hill on 'Later life education for dementia risk reduction' and a Q&A segment. The one-hour session can be viewed online at www.utas.edu.au/wicking/about/seminar-series#1

New cognitive assessment tool

Health professionals, people living with dementia and researchers have all contributed to the development of a new cognitive assessment tool, which is now available for free from the Greater Manchester Mental Health NHS Foundation Trust.

Free-Cog is intended for use in clinical practice. Researchers from the University of Manchester, the University of Cardiff and the Greater Manchester Mental Health NHS Foundation Trust were involved in the development of the scale, and have gone on to conduct a major study to check its validity, now published in the *International Journal of Geriatric Psychiatry*. Free-Cog was assessed in 25 clinical settings in England, Wales and Scotland, involving 960 patients with clinical diagnoses of dementia, Mild Cognitive Impairment (MCI) and normal controls. It was compared to three other cognitive tests routinely administered in clinical practice (the Mini-Mental State Examination (MMSE), the Montreal Cognitive Assessment (MoCA), and the Addenbrooke's Cognitive Examination (ACE)) and correlated well with these.

The authors say the new test was developed because some of the most commonly used cognitive tests are now subject to copyright restrictions (eg the Montreal Cognitive Assessment or MoCA), and no existing scale assesses both executive and cognitive abilities (which this does).

The full validity study can be accessed here, and includes a link to the test which can be downloaded: https://bit.ly/3kjVdlu

Dementia care event listings are available on the *AJDC* website at www.journalofdementiacare.com

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