Australian Journal of
DementiaCare

For all who work with people with dementia
Vol 10 No 4 October/November/December 2021

What's needed to stay at home together?

Also inside this issue:
- Golden Angels volunteer program
- Aducanumab explained
- Hearing & vision interventions
- Supporting the patient journey

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About time

By **Professor Belinda Goodenough**, *Australian Journal of Dementia Care* Co-Editor and Executive Director, Dementia Training Australia

A common theme trails through many articles in this issue of *AJDC*: time ...

- Two decades of research, to produce aducanumab, a controversial drug therapy for Alzheimer's disease (pp20-22) – itself described as a 'disease of time' that can develop over 30 years.
- Desperation for more time to stay home, with family – and the need for social supports to enable life together for as long as possible after a dementia diagnosis (pp30-33).
- Generosity in giving time, which is the hallmark of the volunteer – such as the Golden Angels donating time to a program to assist those in hospital at risk for dementia and delirium (pp16-19).
- The time it takes to build a team committed to comprehensive dementia care, and the time needed from a wide range of skilled allied health professionals ('How allied health can help', pp26-28).
- The time spent in anticipation – with '*AJDC* asks…' summarising different perspectives on the long-awaited Government response to the Royal Commission into Aged Care Quality and Safety (pp9-10).
- COVID-19, the contemporary thief of time, and the enhanced risks of SARS-CoV-2 infection (and management) for people with dementia (p12).

If there is one remotely silver lining of the pandemic for Australia, it is a potentially renewed appreciation of time. Stay-at-home public health orders have prompted many people to explore how to turn mere existence back into living. Being denied time in togetherness has perhaps ignited a more conscious appreciation of how time is a core currency in social connection.

Furthermore, simply having more time is insufficient; rather, it is how time is spent, and with whom, that gives life meaning and purpose. Whether it be extra demands on time (eg, juggling remote working with home schooling) or feeling insufficiently occupied. Recently I overheard a resident in an aged care complex (in lockdown) give this answer to a query on what they had been doing lately: "The most exciting thing we can do around here is get four people together and start an argument about what day it is".

The concept of 'social health' has been described as a potentially crucial concept in understanding why severe neuropathology is not 100% predictive for poor cognitive and psychosocial functioning (Vernooij-Dassen *et al* 2019). It relates to how people spend their time. The disparity between physical and cognitive markers of brain health were noted last century in the now famous 'Nun Study' (Snowdon *et al* 1997). Social resources might be a key influence in this fine balance between ability and limitation in dementia. For example, spending more time with others and better communication may be associated with better functioning across all levels of dementia severity (Vernooij-Dassen *et al* 2019).

Sadly, the true cost of the pandemic may not be known for some time yet. Have Australians who have spent long periods in lockdown also notched an increased lifestyle risk for dementia? A recent piece in *The Conversation* makes for sombre reading on the role of loneliness in social isolation (Harrington & Sliwinski 2020). Future longitudinal research may hold a potentially unwelcome answer.

Dedication over time to purposeful topics that matter to people living with dementia has been a priority theme in the activities of the Dementia Centres for Research Collaboration (DCRC). After 15 years of research, time has now been called on the DCRC model (pp15-16), with the centres closing on 23 December 2021.

The DCRC leaves an excellent legacy for building future research directions. One of the best ways to say thanks is to use the DCRC-produced resources to assist those who are negotiating the double time whammy: Australians who are living with dementia and living with COVID-19. ■

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Identifying and supporting hearing and vision impairments is an inexpensive and effective opportunity to improve quality of life for people living with dementia. Piers Dawes explains

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Cover image: Finding ways to support people with dementia to continue their meaningful activities is critical to enable them to continue living at home. But research reveals a gap between what people with dementia and their partners say they need and what service providers think they need. See article pp29-32.
Photo: www.freepik.com/pvproductions

News in brief

Aducanumab latest

Pharmaceutical companies Biogen and Eisai chose the Alzheimer's Association International Conference (AAIC) in July 2021 to announce details of the new observational Phase IV study in Alzheimer's disease (named ICARE AD-US) into the effectiveness and safety of aducanumab. The US Food and Drug Administration (FDA) recently approved aducanumab for the treatment of Alzheimer's disease, on the condition that Biogen conduct a post-approval clinical trial to confirm the benefit of the drug (see article pp20-22 for more on this). The ICARE AD-US trial is expected to enrol 6,000 participants with Alzheimer's disease over four years from about 200 sites in the US; all participants will be monitored for a period of up to five years. Two other research programs are also underway to generate post-approval data on aducanumab. *The Journal of Prevention of Alzheimer's Disease* has recently published clinical use recommendations for aducanumab, developed by a panel of experts and also presented at the 2021 Alzheimer's Association International Conference (AAIC) in July.

Aged Care Employee Day 2021

Minister for Senior Australians and Aged Care Services, Senator Richard Colbeck, paid tribute to the "extraordinary commitment" of aged care employees across Australia in a public statement to mark Aged Care Employee Day on Saturday 7 August. The national event was launched in 2018 but is now spearheaded by Leading Age Services Australia (LASA) as a way of acknowledging the contribution made by the entire aged care workforce, under the campaign banner #ThanksforCaring. Senator Colbeck said the aged care workforce was particularly important to Australia's ongoing response to COVID-19. "Many aged care workers have taken on additional training and worked harder than ever to protect senior Australians, as well as providing support for families who have suffered loss," he said. Further to this, the Australian Government has launched a new national campaign – called A Life Changing Life – to help grow the care and support workforce. More information can be found on the website for the campaign at careandsupportjobs.gov.au

Dementias Platform Australia launched

UNSW Sydney's Centre for Healthy Brain Ageing (CHeBA) has launched Dementias Platform Australia (DPAU) in partnership with the already established Dementias Platform UK (DPUK), with a collective vision of accelerating new discoveries in the understanding and diagnosis of dementia. The collaboration, which allows for access to research data from multiple dementia studies carried out in Australia, the Asia-Pacific region and beyond to all six continents, will enable new insights into ageing, age-related diseases and risk of Alzheimer's disease and other dementias.

Relocation to CHeBA

The Changed Behaviours Special Interest Group (SiG) and Anxiety and Depression in Dementia (ADD) Research Network (both reported in *AJDC* Jul/Aug/Sep 2021 issue) will be relocated from the Dementia Centre for Research Collaboration (DCRC) to the Centre for Healthy Brain Ageing (CHeBA) in 2022, following the closure of DCRC on 23 December 2021 (see article pp15-16). Future events will be organised, and resources will be available, on the CHeBA website at https://cheba.unsw.edu.au/

DAAC Mission sets out priorities

The Australian Department of Health has published two key documents – an Implementation Plan, and a Roadmap – both setting out the future direction for the Dementia, Ageing and Aged Care (DAAC) Mission, an initiative funded through the Medical Research Future Fund. The DAAC Mission Roadmap is a short, high-level strategic document that sets out the funding principles and priority areas for investment for the Mission. The longer, more detailed Implementation Plan outlines the priority areas for investment, evaluation approaches and measures, supporting activities and collaborative approaches. The Australian Government says it is also making a further $25.5 million available under the DAAC Mission. The Roadmap and Implementation Plan were developed by the DAAC Mission Expert Advisory Panel, led by the co-chairs, Professor Elizabeth Beattie and Professor Len Gray. Both documents are available on the Department of Health website.

Dementia Australia report on discrimination

Discrimination continues to be a major issue for people living with dementia and their family carers, according to Dementia Australia's latest report, *Discrimination and Dementia – Enough Is Enough*, launched to coincide with Dementia Action Week (20-26 September).

Even people who consider themselves to be at risk of developing dementia report anticipating that they will experience discrimination if they do receive a diagnosis.

More than 900 people responded to the 2021 Dementia Australia survey, and the sample included people living with dementia, family carers, family members and friends of people living with dementia, health and care professionals and people not impacted by dementia.

Key findings from the research include:

- 75% of respondents who identified themselves as at risk of dementia indicated that they expect they will be treated differently if they are diagnosed.
- 91% of people who have a loved one with dementia indicated other people don't keep in touch with that person as they used to.
- 87% of people living with dementia surveyed felt people patronise them and treat them as if they are not smart.
- 65% of people surveyed who live with dementia and 58% of those who feel at risk of dementia believe discrimination towards people with dementia is common or very common.
- 55% of professionals surveyed believe that often or always a doctor will speak to the carer/support person rather than the person living dementia.
- More than 90% of professionals, volunteers and people not impacted by dementia agree that people living with dementia are likely to be treated differently once they are diagnosed.

Maree McCabe AM, CEO Dementia Australia, said the research shows that people living with dementia and carers experience discrimination that can lead to social isolation, loneliness and poor mental health, and that COVID-19 has intensified these experiences.

"Research demonstrates that this discriminatory behaviour impacts all aspects of a person's life; from the way they engage socially to the types of services they access and receive and the way their human rights are interpreted," Ms McCabe said.

Dementia Australia has had a strategic focus on discrimination for the past three years, and last year also conducted a survey on discrimination in dementia. The 2021 report says recent figures suggest that discrimination towards people with dementia has changed very little over the past few years and that "a whole of community commitment is needed to truly have an impact in this space".

Dementia Action Week is an initiative of Dementia Australia, and this year the peak dementia body used the annual awareness week to spread its message that 'A little support makes a big difference'. The message of the campaign is that many people living with dementia can continue to live well for many years after their diagnosis. This year the focus has also been on supporting and celebrating carers of people living with dementia and on providing healthcare professionals with practical tips to help make their practice more dementia friendly.

The report is available at https://bit.ly/2XAORgJ

Dementia In Australia report

The Australian Institute of Health and Welfare (AIHW) launched *Dementia In Australia* – its first comprehensive report on dementia since 2012 – during Dementia Action Week.

The report sets out the latest known data from a range of sources on key aspects of dementia: population health impacts (prevalence, incidence, burden of disease and deaths), carers and care needs of people with dementia, health and aged care service use by people with dementia, and direct expenditure in relation to dementia.

A headline finding is that the number of Australians with dementia is predicted to more than double by 2058 – from 386,200 in 2021 to 849,300 in 2058 (533,800 women and 315,500 men).

Other key findings from the report include:

- Over 27,800 Australians aged under 65 are living with younger onset dementia.
- Dementia was the second leading cause of death in Australia, behind coronary heart disease, and the leading cause of death among women in 2019.
- Dementia was the fifth leading cause of death among Indigenous Australians aged 65 and over in 2019.
- Dementia was the third leading cause of burden of disease in Australia in 2018, behind coronary heart disease and back pain.
- In 2019-20, just under 132,000 (54%) of the 244,000 people living in permanent residential aged care had dementia.
- $3 billion of the total direct health and aged care system expenditure in 2018-19 was directly attributable to the diagnosis, treatment and care of people with dementia.
- It is estimated that between 134,900 and 337,200 people provide consistent unpaid care for someone with dementia.
- Over half of primary carers provide an average of 60 or more hours of unpaid care each week.

The report was launched at an online event by Senator Richard Colbeck, Minister for Senior Australians and Aged Care Services. Senator Colbeck said the report validated the prominence of dementia care in the Government's aged care reform plan. He commended the use of case studies within the report, which includes the personal stories of five people with a lived experience of dementia.

Dementia Australia Chief Executive Officer Maree McCabe AM welcomed the report and ongoing work by the AIHW to improve data about dementia.

"Better data about the experiences of Australians living with dementia and the people who care for them are essential and these can be used to improve policies and support services for those who need them most," Ms. McCabe said.

The report includes explanatory notes on key 'Dementia data gaps'. The full detailed report is available as an 'online compendium' and a summary report version is available to download at https://bit.ly/39oZBBu

New National Centre for Monitoring Dementia

A new National Centre for Monitoring Dementia is to be established within the Australian Institute of Health and Welfare (AIHW), to routinely monitor dementia care in Australia.

Minister for Senior Australians and Aged Care Services, Senator Richard Colbeck, used the launch of the latest AIHW report, *Dementia In Australia*, to announce that the Australian Government is providing $13 million in funding to the AIHW to establish the new centre. The funding is drawn from the May 2021 Federal Budget commitment of $229.4 million to improve quality of life and care for people living with dementia.

The Government says the centre's work will help address critical gaps to support national dementia policy and service provision.

Latest recipients of dementia research funding

In September Minister for Health and Aged Care, Greg Hunt, announced the National Health and Medical Research Council (NHMRC)'s successful applicants for nearly half of its total grant funding for 2021 – $472 million in total. Nearly $400 million of that funding goes towards 254 Investigator Grants, the NHMRC's largest scheme, which provides funding over five years.

$44 million of the funding will be used to fund new research centres, including three new Centres of Research Excellence (CRE) in dementia:

- CRE in Enhanced Dementia Diagnosis (CREEDD) (University of Melbourne, Dr Scott Ayton).
- On TRACK (Teaching, Research And Community Knowledges): CRE promoting brain health with older Aboriginal and Torres Strait Islander peoples (University of Melbourne, Associate Professor Dina LoGiudice).
- Vascular Contributions to Dementia (VCD-CRE): a transformative approach to reducing the burden of cognitive disorders (UNSW, Professor Perminder Sachdev).

Twelve Investigator Grants were awarded in the area of dementia research, including for example:

- Maximising quality of life in frontotemporal dementia (University of Sydney, $2 million).
- Improving dementia outcomes with new targets, trials and national standards (University of Sydney, $2.1 million).
- Investigating new targets and treatments for Alzheimer's disease: from biochemistry through to clinical trial (University of Melbourne, $3 million).

In July, Mr Hunt announced the successful applicants for the latest round of funding from the Dementia, Ageing and Aged Care Mission – part of the Government's Medical Research Future Fund – which in total amounts to $17 million. Some of the successful projects include:

- Drawing Out Care: Using animation and digital technologies to support Culturally and Linguistically Diverse (CALD) family carers and people living with dementia (National Ageing Research Institute, $798,000).
- Knowledge brokers for evidence translation to improve quality use of medicines in residential aged care (Monash University, $2 million).
- SENSEcog Aged Care: Hearing and vision support to improve quality of life for people living with dementia in residential aged care (Macquarie University, $1.2 million).
- Creating partnership in iSupport program to optimise carers' impact on dementia care (Flinders University, $1.4 million).
- Blood testing to predict and discriminate dementias (Florey Institute of Neuroscience and Mental Health, $4 million).
- Music Attuned Technology Care eHealth (MATCH): A music-based mobile eHealth (University of Melbourne, $2 million).

Details of all grants are available on NHMRC website (www.nhmrc.gov.au).

Global status report on the
public health response to dementia

World Health Organization

WHO status report: "The world is failing people with dementia," according to Dr Tedros Adhanom Ghebreyesus, Director-General of the World Health Organization (WHO). His comments coincide with the September launch of the WHO *Global Status Report On The Public Health Response To Dementia,* which reports on progress made to date towards the 2025 global targets for dementia in the WHO's Global Dementia Action Plan published in 2017. Only a quarter of countries worldwide have a national policy, strategy or plan for supporting people with dementia and their families. The report highlights the urgent need to strengthen support at national level, both in terms of care for people with dementia, and in support for the people who provide that care, in both formal and informal settings. The report is available to access here: https://bit.ly/3jLpaTg

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

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

Mandatory coronavirus vaccination praise

The Government has acknowledged the efforts of the residential aged care sector to implement mandatory vaccination within its workforce, with Minister for Senior Australians and Aged Care Services, Senator Richard Colbeck, expressing his thanks to the aged care workforce, providers, provider peak bodies and worker representatives for their efforts.

As of 26 September, 99% of residential aged care workers had received a first dose of a COVID-19 vaccine, and 81.8% were fully vaccinated. The Government says the figures represent one of the highest workforce vaccination rates in the world.

Compliance measures were due to take effect once weekly figures were updated on 22 September, in line with the state and territory public health orders on mandatory COVID-19 vaccination in residential aged care. Facilities where employees were yet to complete their vaccination would become the focus of further specific in-reach clinics.

From 5 October 2021, all Commonwealth Home Support Program (CHSP) and National Aboriginal and Torres Strait Islander Flexible Aged Care Program (NATSIFACP) home care providers will begin mandatory weekly reporting of workforce COVID-19 vaccinations via the My Aged Care portal for providers.

COVID-19 NEWS IN BRIEF

Isolation effects on people with dementia

The journal *EClinicalMedicine* (*The Lancet*) has published the findings from a systematic review led by Aida Suárez-González *et al* (University College London) on the effects of COVID-19 isolation measures on the cognitive, mental health and functional level of people with dementia. The study identified 15 papers, of which 13 related to people living in the community and two in care homes, all in either Europe or Latin America. Nine of the studies reported changes in cognition; 14 reported worsening or new onset of behavioural and psychological symptoms; and six reported a functional decline in daily activities in a variable proportion of the population analysed. The researchers conclude that COVID-19 isolation measures have damaged the cognitive and mental health of people with dementia across the world. They say guidance should be issued urgently that balances infection control measures against the principles of non-maleficence to guarantee fair and appropriate care during pandemic times for people living with dementia. The study can be accessed in full here: doi.org/10.1016/j.eclinm.2021.101047

Rapid antigen testing

In August, the Australian Government began providing COVID-19 rapid antigen testing (RAT) kits to residential aged care, home care and services delivered through the Commonwealth Home Support Program in high-risk local government areas of concern across Sydney and western NSW. Minister for Health and Aged Care, Greg Hunt, said the program will allow fast COVID-19 screening of aged care residents and visitors to be done on-site and more regularly. "Given the rate at which we know the Delta variant can be spread between people, the very fast turnaround of RAT – around 15 minutes – makes these tests useful in preventing asymptomatic transmission and outbreaks as they can be used on a daily basis," Mr Hunt said. This program expands on a trial undertaken at the Whiddon Residential Aged Care Facility in Glenfield.

Staff Vaccination Support Service

Aged and Community Services Australia (ACSA) and Leading Age Services Australia (LASA) have been working together to deliver the Staff Vaccination Support Service, on behalf of the Federal Department of Health. ACSA and LASA are offering a range of supports to residential aged care providers to respond to the mandate for COVID-19 vaccination for their staff, particularly in areas where uptake of vaccination is low or at risk of not being achieved by the 17 September deadline. To find out more, go to https://supporthub.agedservicesworkforce.com.au/

Visiting Code for aged care homes

Twelve aged care and consumer peak bodies have released an updated version of the Industry Code for Visiting Residential Aged Care Homes during COVID-19. The purpose of the code is to ensure that older people living in residential care have protection from COVID-19 while also ensuring their mental health and social connections are maintained during the pandemic. The Code signatories are calling for State and Territory Health Directives to list 'Partners in Care', people who go in every day to support their loved one, as 'essential care visitors' – meaning they could continue to visit and provide care at residential facilities during community outbreaks. The revised Code has been re-endorsed by the Australian Health Principal Protection Committee and was updated to reflect the requirement for aged care workers to receive the vaccine by 17 September 2021. The Industry Code should be consulted alongside the Department of Health's 'Visitation Guidelines for Residential Aged Care Facilities', most recently updated in February 2021.

Department of Health guidance

The Department of Health continues to update its website pages on 'Advice for the aged care sector during COVID-19'. Go to https://bit.ly/3yP7muO to stay up to date with the latest information on the National COVID-19 Aged Care Plan, visitor restrictions, immediate outbreak response supports, outbreak management and more.

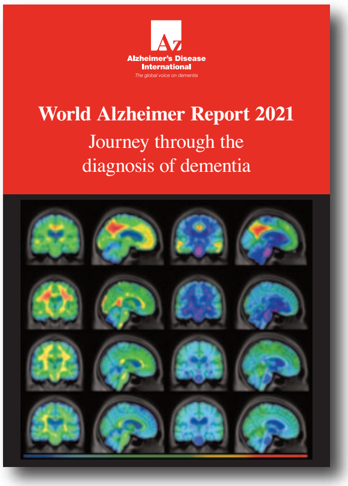
Dementia diagnosis: the global picture

Alzheimer's Disease International (ADI) estimates that 75% of people living with dementia globally are undiagnosed – equating to 41 million people. They say the figure could be as high as 90% in some low- and middle-income countries, where stigma and lack of awareness in dementia remain major barriers to diagnosis.

The findings come from the latest World Alzheimer Report, *Journey Through The Diagnosis of Dementia*, published by ADI and launched on World Alzheimer's Day (21 September), which includes results from a global survey which attracted over 3500 responses, from clinicians, people living with dementia, family carers, and dementia associations.

Key findings from the survey include:

- Just 45% of people with dementia and carers felt they were given adequate information at the point of diagnosis.
- Key barriers to diagnosis identified by people with dementia and carers included lack of access to trained clinicians (47%), fear of diagnosis (46%) and cost (34%).
- Key barriers to diagnosis identified by clinicians included lack of access to specialised diagnostic tests (38%), lack of knowledge in making a diagnosis (37%) and the belief that nothing could be done, thus making a diagnosis futile (33%).
- 75% of clinicians ranked the increasing number of people seeking a diagnosis as a major challenge in the future, followed by people seeking diagnosis due to self-testing (with the proliferation of online and at home tests), and an increase in disease-modifying treatments.
- 83% of clinicians maintain that the COVID-19 pandemic delayed access of people with cognitive decline for assessment.



Personal testimonies from people with dementia and carers included in the report consistently indicate the lengthy time taken before being given a diagnosis, as well as a lack of information at the point of diagnosis about specific types of dementia, progression and available support.

The report authors put forward 18 recommendations, including some key ones here:

- Healthcare systems globally should introduce annual brain health check-ups for the over 50s.
- Governments globally must urgently start to measure and record diagnosis more accurately.
- Improved dementia training and education, plus increased time allocation for diagnosis in primary healthcare.
- Healthcare systems must invest in, and improve, diagnostic capabilities, moving towards precision diagnosis, to eradicate high levels of misdiagnosis.
- Clinicians must become aware and better informed about information, support and planning available via national Alzheimer and dementia associations, and the vital role they play in pre- and post-diagnosis support.

Lead author Professor Serge Gauthier said, "The emergence of quicker, easier, cheaper, less invasive blood biomarker diagnostic tools will combine with emerging drug treatments and the global ageing population to create a tsunami of demand for diagnosis, putting extreme pressure on healthcare systems."

Paola Barbarino, ADI CEO, said that lack of awareness and stigma within healthcare systems was hampering efforts to support people living with dementia. "This misinformation in our healthcare systems, along with a lack of trained specialists and readily available diagnosis tools have contributed to alarmingly low diagnosis rates," Ms Barbarino said.

About the World Alzheimer Report

The report was prepared by Professors Serge Gauthier, Pedro Rosa-Neto and José A Morais, and Claire Webster, all from McGill University in Canada, and like previous years involved essay contributions from 51 experts from around the world, including Australia's Scientia Professor Perminder Sachdev AM from the Centre for Healthy Brain Ageing (CHeBA) at UNSW. The expert essays from clinicians and practitioners are presented in five sections: clinical assessment, laboratory tests, formulation of diagnosis, particular circumstances and the future of dementia diagnosis.

While no systematic literature search was performed for the report, its findings are based on a major global survey, as well as expert essays and case studies. The survey received over 3500 responses: 1111 multidisciplinary clinicians in 108 countries (62% from high-income countries, 38% from low- and middle-income countries), 205 people with dementia and 2122 carers in 83 countries, and 101 ADI member associations.

Duty of Care report

The Certificate III in Individual Support must be revised to include a focus on dementia care, palliative care and digital skills, says the think tank CEDA (Committee for Economic Development of Australia). In a new report, *Duty of Care: Meeting the Aged Care Workforce Challenge*, CEDA sets out practical steps for state and federal governments and the industry to take to grow the aged care workforce, which it says is facing a shortage of at least 110,000 direct aged care workers within the next decade. The recommendation about training is one of 18 made in the report, which overall argues for the need to expand training, wages and career opportunities for aged care workers. CEDA Chief Economist Jarrod Ball says Australia has failed to prepare for this challenge, despite multiple inquiries and the demographic future being well understood for decades now. The issue requires a "massive commitment" from the Federal Government, according to Mr Ball.

Workforce Census

The Federal Government has welcomed the findings of the 2020 *Aged Care Workforce Census Report*, published in September, which point to some positive changes in the aged care workforce since the last time the census was conducted, in 2016.

Key findings in the report include:

- A 32% increase in the number of direct care workers in residential aged care facilities since the last census in 2016.
- 89% of residential aged care facilities report having a registered nurse on duty or on call overnight.
- 66% of personal care workers in residential aged care facilities hold a Certificate III or higher in a relevant direct care field.
- A changing age profile, with half of all residential aged care direct care workers under the age of 40.

The census was conducted in late 2020 with providers of residential aged care, Home Care Packages Program and Commonwealth Home Support Program, through an online questionnaire.

Federal Government aged care reforms begin

1 July saw the commencement of some key elements of the Federal Government's aged care reform package – developed in response to recommendations from the Royal Commission into Aged Care Quality and Safety Final Report.

For people living with dementia, two key changes are new measures to reduce the use of restrictive practices and the introduction of the new basic daily fee supplement to support aged care providers to deliver better care and services to residents, with a focus on food and nutrition.

Legislative amendments made to the Aged Care Act 1997 and Quality of Care Principles 2014, implemented from 1 July, are intended to minimise the use of restrictive practices for consumers in residential aged care, and where a restrictive practice is used, to ensure that it is done so in accordance with legislative obligations (with the term 'restrictive practices' introduced to describe all forms of 'restraint'), and only as a last resort. As part of these changes, from 1 September, there is a new requirement for any resident who requires behaviour support or when a restrictive practice is imposed or likely to be imposed, to have a Behaviour Support Plan in place (for more on this, see p32).

Minister for Health and Aged Care Greg Hunt and Minister for Senior Australians and Aged Care Services Senator Richard Colbeck said the use of alternative behaviour management strategies will now ensure safer care for the most vulnerable people receiving care, particularly those living with dementia.

"Increased regulation, training and oversight on the use of restraints will help carers, the aged care workforce, and the sector comply with the strengthened legislation, facilitating safer and higher quality care for senior Australians," Senator Colbeck said.

The other key change, the new basic daily fee supplement – an additional $10 per day, per resident from 1 July 2021 – was developed in response to recommendation 112 from the Royal Commission into Aged Care Quality and Safety Final Report. The intention of the new supplement is to support aged care providers to deliver better care and services to residents, with a focus on food and nutrition.

The new supplement will be paid to eligible residential and respite aged care services and flexible care services that are multi-purpose services. The supplement is available to approved providers who formally agree and submit quarterly reports.

"This significant funding boost, worth $3.2 billion over five years, will provide a broad funding uplift to support the sector to deliver better care and services for residents," Mr Hunt said.

Some of the other key reforms implemented from 1 July include:

- The release over the coming two years of 80,000 new home care packages, equating to more than 750 packages each week.
- $178.9 million for Primary Health Networks (PHN) to support older people's health, including improved access to telehealth care and enhanced out-of-hours support for aged care residents, new health pathways to support assessment and referral, and early monitoring and identification of health needs to support people to live at home for longer.
- $45.4 million for medication management in residential aged care, including the use of electronic national residential medication charts.
- $42.8 million to boost the Aged Care Access Incentive to increase face-to-face servicing by general practitioners in residential aged care.
- Support for expanded independent advocacy to deliver greater choice for older people, improved quality safeguards, and diversity assistance for providers.

On 1 September, Mr Hunt introduced legislation into Parliament related to a second round of aged care reforms in the Aged Care and Other Legislation Amendment (Royal Commission Response No. 2) Bill of 2021. The wide-ranging bill covers matters such as the implementation of the Australian National Aged Care Classification by October 2022, the creation and enforcement of a code of conduct for providers, the establishment of an authority for aged care worker pre-employment screening, the requirement for aged care providers to notify changes to key personnel, and extends the Serious Incident Response Scheme (SIRS) to home care and flexible care from 1 July 2022. Mr Hunt told Parliament, "This is landmark reform. This is reform which will save lives, protect lives and improve lives."

LASA criticises lack of reform consultation

On 19 August, Leading Age Services Australia (LASA) issued a statement marking 100 days since the Federal Government released its aged care reform plans and challenging the Government over its lack of consultation and progress on key aged care reforms resulting from the Royal Commission into Aged Care Quality and Safety. "To say that we, as a sector, are disappointed by the lack of real consultation with the sector is an understatement," the statement says.

Commission updates Delirium Clinical Care Standard

The Australian Commission on Safety and Quality in Health Care (the Commission) has launched an updated version of the Delirium Clinical Care Standard. The clinical care standard aims to prevent delirium in at-risk patients and improve the early diagnosis and treatment of patients with delirium. The original version was released in 2016.

Commission Clinical Director, Dr Carolyn Hullick, said the original standard has helped to embed the right processes into hospital care. "The 2021 standard strengthens the need for patient information and involvement of carers and family, if the person wants this. The patient focus has never been more important than during this pandemic," she said.

The standard builds on other work undertaken by the Commission to improve care for people with cognitive impairment. Dr Hullick said there is still variation across Australia in recognition of delirium and its seriousness may be underestimated.

The standard is endorsed by the Australasian Delirium Association, Australasian College for Emergency Medicine, Australian and New Zealand Society for Geriatric Medicine, Dementia Australia and the Australian College of Rural and Remote Medicine, among other peak bodies and professional organisations. It is available to access on the Commission's website at safetyandquality.gov.au

AJDC asks...

What do you think of the Federal Government’s 2021 aged care reforms to support people living with dementia and their carers?

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

From left: Christine Bryden, Dr David Panter, Professor Lee-Fay Low, Sean Rooney and Mike Baird

Dementia care reforms

In response to the Royal Commission into Aged Care Quality and Safety, the Australian Government announced in the May 2021-2022 Budget that it will invest $229.4 million to improve quality of life and care for people living with dementia, while improving the sector’s focus on this core part of aged care. The Government says these initiatives will support people living with dementia and their carers at every stage from diagnosis through to residential aged care, ensuring connection with post-diagnosis support, enabling them to remain in their home for longer and access high-quality dementia-informed aged care services. Details of the key reform measures are available at: https://bit.ly/dementia-reforms

Christine Bryden (AM), PhD

Author and dementia advocate, awarded the Member of the Order of Australia (AM) for her advocacy work. Diagnosed with younger onset dementia in 1995

I’ve heard these types of promises for so long and yet remain disappointed. Dementia diagnosis is a huge shock, and we need support to be enabled to live well with this condition. The GP is our main support, as specialists are hard to see regularly, especially outside of the cities.

My main concern is adequate geographical reach – will these initiatives reach regional and rural areas, where there is a huge need? Also, nothing is said about people with younger onset dementia, who face unique challenges and fall between the cracks of community and nursing homes.

Dementia must be the core business for nursing homes. Improvements in the education and compassion of care workers is essential to see us as human beings with good days and bad days, and who can show pleasant as well as unpleasant and challenging behaviour. Often these changed behaviours are the result of stressful environments – what I call Basic Personal Signs of Distress (rather than Behavioural and Psychological Symptoms of Dementia).

We need more than just barely adequate care. We are not just physical objects to be washed, dressed and fed, but human beings fully worthy of respect and dignity.

Dr David Panter

Chief Executive, ECH. ECH is a not-for-profit provider of aged care services in South Australia

The Aged Care Royal Commission covered a lot of ground regarding people living with dementia but only came out with two specific recommendations. Whilst it is great that the Government has supported both recommendations, the real key to improving the experience and outcomes of people living with dementia is to ensure that the intent of all the other supported recommendations are delivered.

For example, will the new Aged Care Act be human rights based, as the Commission recommended and the Government accepted? If so, then this should ensure that people living with dementia are not discriminated against in the new system simply because of their dementia.

Are the new single assessment processes going to focus on identifying what people can do rather than what they can’t do, as our current assessment processes do?

This negative approach detracts from focusing on a person living with dementia’s potential and can all too often lead to premature entry to residential aged care when they could stay at home for longer with the right support.

We need to act now by advocating and lobbying the Government over the detail of the implementation to ensure that people living with dementia get the support and services they need in the future.

Professor Lee-Fay Low

Professor in Ageing and Health, NHMRC Boosting Dementia Research Leadership Development Fellow, University of Sydney, and a registered psychologist with a PhD in psychiatric epidemiology

The 2021 budget reforms had new initiatives relating to primary care (local dementia pathways and training). This suggests that dementia may be increasingly being diagnosed and managed by a primary care team rather than specialists. I welcomed the increase in funding for post-diagnostic support services and for behaviour management. However, these funds might not improve outcomes if people with dementia don't ever get these services – we know that Dementia Australia, which delivers post-diagnostic services, does not have wide market penetration (Dementia Australia (2019) *Annual Report 2018-19*).

Related to how people get services, I'm awaiting details on the item '*improved connection between services…*'. Service integration is crucial, so I hope that 'services' include primary care, post-diagnostic supports, behaviour management services, acute health care, aged care services, carer supports and allied health. I wonder how aged care plans and medical care plans might be integrated rather than continuing to be separate. I also hope that Aged Care Assessment Teams (ACAT)/ Aged Care Assessment Services (ACAS) and aged care services might routinely refer for dementia assessment, rather than recognising cognitive impairment but not seeing diagnosis referral as their role.

Sean Rooney

Chief Executive Officer, Leading Age Services Australia (LASA)

Access to high-quality and safe dementia care is critical, given that more than half of older Australians living in residential aged care have a dementia diagnosis.

In its final report, the Royal Commission into Aged Care Quality and Safety said that dementia care should be "core business" for care providers, particularly in residential aged care. It recommended a dementia support pathway be established, along with Specialist Dementia Care Services, and regular training for staff in dementia care and palliative care. It also recommended increased Government support for respite care for those caring for a loved one with dementia at home.

The Federal Government's Budget response to the final report included $49.4 million to enhance training for aged care workers, particularly in dementia care, and workforce development.

This welcome announcement will give aged care workers the opportunity to improve their skills and develop their careers while providing high-quality care. But workforce development also requires a greater recognition of the value of our aged care staff, with support from the Government for improved pay, as recommended by the Royal Commission.

A major missing piece in the Government's reforms is the level of resourcing for psychosocial care in residential aged care. It is not clear how the new AN-ACC funding model will accommodate an enhanced focus on quality of life, alongside the revised quality standards and new quality indicators. These must be drawn together in their design to ensure the reforms realise their intended outcomes for older Australians, particularly those with dementia.

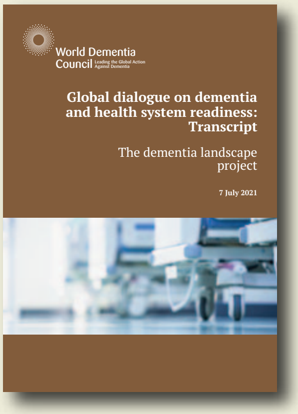
Mike Baird

Chief Executive Officer, HammondCare. HammondCare is an independent Christian charity providing health, aged and dementia care

HammondCare welcomes the Federal Government's very encouraging response to the Royal Commission in the announcement of its five-year plan committing over $17.7 billion to the aged care sector. The focus on dementia care and the increased investment into how care is delivered for residents and clients, with greater transparency based on quality of care, investments into food and nutrition, and higher standards and training support for frontline staff, is long overdue. The reforms are all about how we value and care for older people and how, as aged care providers, we can elevate and support those who care for them.

Each of the initiatives and investments in the *Five Pillars to Support Aged Care Reform* are well intentioned. As care providers, we must always focus on the specific, personal, and tailored needs of individuals. Across HammondCare's residential care home sites, over 50% of residents are people living with dementia, some with complex behaviours. Their needs are very different to those of the frail aged, and therefore reform must avoid viewing the sector as a homogenous group with the same needs.

Reform alone doesn't change care – it is our investment in people, and our approach to care, because every person matters. These reforms provide a foundation, and HammondCare welcomes the opportunity to engage with Government and the broader sector to bring about this reality. ■



World Dementia Council

Global dialogue on dementia and health system readiness: Transcript

The dementia landscape project

7 July 2021

The World Dementia Council (WDC) is currently conducting a review of international progress towards the goals pledged at the outset of the Council in 2013, where G8 governments promised to make substantial advances across research, care, awareness and prevention.

The review, called The Dementia Landscape Project, has consisted of a series of nine 'Dialogues' or discussion events, held virtually during 2021, involving over 350 leading researchers, practitioners and policy makers in dementia care from across the world.

The project's findings will culminate in an event and major report both due later in 2021. For now, transcripts from the nine 'Dialogue' events and related essay collections are available to read and download from the WDC's website, on these topics: health system readiness, an ageing society, data sharing for dementia research, low- and middle-income countries, clinical trials, technology, prevention, care, and biomarkers and treatments.

Access the transcripts, and related collections of essays, at https://bit.ly/3CFDpjE

Dementia Support Australia

Funded by the Australian Government
A service led by HammondCare

Can you imagine the impact **you can make** for people living with dementia?

As a leader in dementia care we're looking for like-minded people like you to join our team and help us improve the lives of over half a million Australians.

So if you are looking for a career with real purpose talk to us. We invest in people like you.

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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 part of a series by neuroscientist and *AJDC* Editorial Advisor **Dr Lezanne Ooi**, who presents short, easy-to-read answers to questions about neurological changes to the brain with dementia. In this article, Dr Ooi answers the question:

'COVID-19 and dementia: what do we know?'

As of the end of September 2021 there have been over 88,000 cases of COVID-19 in Australia and sadly, over 1100 deaths. In the first 10 months of 2020, among the 858 Australians who died due to COVID-19, 257 people (or 30%) of them also had dementia, with most deaths occurring among those aged 85 and over (AIHW April 2021).

We know that people with dementia are more likely to develop severe COVID-19 and die from the virus than people without dementia, and that they are less likely to report respiratory conditions as a result of COVID-19 (AIHW April 2021).

This article examines what is currently known about the impact of COVID-19 on the brain and on people living with dementia, and why they are more at risk of being infected.

Neuroinflammation

Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) is the virus that causes COVID-19. It affects not just the respiratory system but also many other tissues of the body. SARS-CoV-2 enters cells by hijacking a protein called angiotensin converting enzyme 2 (ACE2).

ACE2 is also present in brain cells and, as such, SARS-CoV-2 is also able to enter the cells of the brain. When this happens, our immune system in the brain becomes activated in a process called neuroinflammation. Even in the absence of dementia, SARS-CoV-2 infection is associated with impaired cognition, possibly due to neuroinflammation (Toniolo *et al* 2021).

Increased risk

Dementia, and particularly Alzheimer's disease, is associated with higher rates of infection and hospitalisation due to COVID-19 (Zhou *et al* 2021). So why are people with dementia more at risk from SARS-CoV-2 infection? Research is still in the early stages, however there are potentially a few reasons.

Firstly, the overwhelming majority of people living with dementia are elderly and at risk of more serious outcomes. Even when age is taken into account, people with dementia are at increased risk of having comorbidities, such as coronary artery disease, hypertension and diabetes.

A meta-analysis* of data from 10 articles representing 119,218 participants suggested that dementia comorbidities increase the risk of COVID-19 infection and mortality (Liu *et al* 2020). Another study showed that in locations around the world where there were more cases of dementia, these were linked with higher COVID-19 caseloads and death (Azarpazhooh *et al* 2020).

A person's risk of Alzheimer's disease is affected by a large number of their genes. One of the major genetic risk factors for Alzheimer's is *APOE*, which makes a protein called apolipoprotein E. There are three different variants of the *APOE* gene in the human population, and these variants are passed on from parents to their children.

Apolipoprotein E is important for transporting certain fats, such as cholesterol, into cells, a critical process for brain cell function. However, apolipoprotein E has various other important functions, in many different cell types, and the version of *APOE* that increases the risk of Alzheimer's (*APOE4*), also increases the risk of heart disease. Initial studies from the UK suggest that *APOE4* appears to lead to increased severity of SARS-CoV-2 infection, possibly due to increased neuroinflammation. (Kuo *et al* 2020).

COVID-19 and delirium

Among people diagnosed with dementia, one of the most frequent and earliest symptoms of COVID-19 is delirium (Beach *et al* 2020). Delirium is a serious medical condition whereby a person's mental ability is compromised. It affects up to 50% of elderly patients in hospital (Fong *et al* 2015), is often associated with poor outcomes for patients with dementia and can have significant consequences (Witlox *et al* 2010). The effects of respiratory failure due to SARS-CoV-2 infection can cause hypoxia (reduced oxygen availability) in the brain and this is thought to worsen cognition and increase the risk of delirium in people with dementia.

Conclusion

SARS-CoV-2 infection increases a number of health risks for people living with dementia, including delirium and psychiatric disturbances. Research into the reasons why this is the case is ongoing and will need to remain a priority to protect these most vulnerable members of our community. ■

For links to resources and further reading on this topic, visit https://journalofdementiacare.com/ask-a-neuroscientist-3/

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* Meta-analyses look at data from multiple studies and many participants.

Working together to support the patient journey

Dementia Training Australia Director **Ellie Newman** tells the story of working alongside St John Ambulance Western Australia to develop bespoke dementia training for the organisation's team of Ambulance Transport Officers

As part of a wider piece of work with one of the health services in Western Australia, Dementia Training Australia (DTA)* has worked with St John Ambulance Western Australia to develop a Tailored Training Program in dementia care, aimed at its Ambulance Transport Officers. This article reports on the program: its rationale, contents and results to date.

St John WA Transport Officer Nicole Cartwright and Clinical Educator Manager David Cutler. More than 250 St John WA Transport Officers in Perth and regional areas have completed the various online courses provided by DTA and attended the facilitated presentation to better understand dementia and optimise care transitions. Photos supplied by St John Ambulance Western Australia

Ambulances and dementia care

Historically, the ambulance service has been responsible for taking acutely unwell adults and children to local hospital accident and emergency departments (Craggs & Blaber 2012). But the increasing complexity of patients' needs, including the growing prevalence of dementia, has placed additional demands on ambulance services (King's Fund 2016).

It has been recognised that the scope of the ambulance service must be widened to include the development of psychosocial skills (Gaisford 2014), which can help prevent people living with dementia in their own home from being unnecessarily transferred to hospital (Tavares *et al* 2016) and, for those who are, optimise the comfort during their transition of care. To support this in practice, a number of resources from the UK are now available aimed at equipping ambulance services to offer person-centred care to people living with dementia (see for example, *Dementia: Best Practice Guidance for Ambulance Services*, produced by the Association of Ambulance Chief Executives (2017) and available to download at https://bit.ly/dementiabestpractice-guidance).

Introducing St John WA

St John Ambulance Western Australia (referred to as St John WA) is an organisation with over 130 years of service. It provides the state's ambulance service and delivers care to Western Australians in need. St John WA services the whole of Western Australia (with a few remote exceptions) from the Kimberley region in the north to the Great Southern region in the south, and operates from 160 regional locations.

The Patient Transfer Service (PTS) is a key component in the provision of an efficient and effective ambulance service. St John WA began its Patient Transfer Service in 1994, offering safe, comfortable and reliable transport to ensure patients have timely, easy and equitable access to health services.

The PTS works in the public and private sectors, with local hospitals, medical centres and care facilities, responding to pre-booked and on-demand non-emergency calls. The staff who work within the PTS are referred to as Ambulance Transport Officers (ATOs); a Certificate III or IV in pre-hospital care is desirable for this role but not essential.

Patient transport and dementia

A growing number of people living with dementia in the community require St John WA to bring patients to hospitals and health care settings, either via ambulance or transport vehicle services. Transitions of care can be frightening and unsettling. This is especially so for people living with dementia who may have limited communication, be disoriented, anxious or stressed, or be experiencing pain but unable to say so. Ambulance staff may have been given limited or no background information about the patient, making it harder to build rapport and understand the context of that person's presentation.

Transfers of people with dementia currently account for about 8% of the overall PTS work completed by St John WA, although St John WA believes this is a conservative figure as it only accounts for those patients where dementia has specifically been indicated in their medical notes.

The training program

Tailored Training Programs (TTPs) are core business for DTA and usually involve working with residential aged care organisations, community care providers and acute care teams in hospitals. However, a gap in

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* Dementia Training Australia (DTA) is funded by the Australian Government to provide dementia-specific accredited and non-accredited education, training and professional development for aged and health care professionals and organisations. It combines the expertise of the University of Wollongong, La Trobe University, QUT, The University of Western Australia and Dementia Australia to deliver a coordinated national approach to dementia training. For more information, visit www.dta.com.au

dementia training has been identified for health professionals who support people living with dementia during transitions of care between these establishments. St John WA is an organisation fundamentally involved in these transitions of care.

St John WA recognised that staff training to better understand dementia was required to optimise transitions of care. In 2020, DTA met with St John WA Clinical Educator Manager, David Cutler, to determine the organisation's training needs. David reported that staff had requested more information on how to support a person with responsive behaviours, strategies to optimise communication and develop a deeper understanding of dementia and the impact of the disease.

As David says: "Dementia poses a unique challenge to healthcare providers, as patients at different stages of dementia will experience different challenges. All symptoms of dementia pose a significant impact on how we communicate with patients, from minor memory loss to an inability to communicate."

Noting these requests, and in light of the publication *Dementia: Best Practice Guidance for Ambulance Services* from the Association of Ambulance Chief Executives (2017) in the UK (referred to above), we agreed on four learning outcomes:

- To understand communication considerations when caring for people living with dementia: incorporating feedback from people living with dementia and their carers to improve quality of services delivered.
- To understand strategies to prevent escalation of distress and support person-centred care: strategies can include personal and environmental processes that cause no avoidable harm to patients living with dementia.
- To be aware of responsive behaviour: to support the development of skills and ability to recognise early warning signs and modify approaches that champion compassionate care.
- To be aware of strategies to optimise transitions of care: how developing effective partnerships with the people living with dementia and local agencies in WA can improve care and outcomes.

DTA mapped the training needs to create a TTP. This included access to specific DTA online training modules, including the popular Dementia Discovery suite (see https://dta.com.au/dementia-discovery/). This is comprised of short, interactive, online modules to help develop an understanding of the brain, different types of dementia, why communication matters and information related to person-centred care.

Due to the particular nature of St John WA's work, DTA also prepared a bespoke presentation, with imagery provided by St John WA of their staff in action. This presentation covered four key topics:

- Understanding dementia and its impact on communication
- Person-centred care
- Responsive behaviour
- Supporting transitions of care.

Putting knowledge into practice

By Nicole Cartwright, Ambulance Transport Officer, St John WA

One day we took a patient from a care facility to hospital for an appointment. He was disoriented and so stressed – he gripped the side of the stretcher. Then later when he was inside the ambulance his grip on the yellow bars was vice-like. His breathing was rapid and he was sweating.

I was lucky – I had a fiddle mat* with me to distract him. We also played Elvis [Presley] on the radio which seemed to calm him. There wasn't any help from the care facility on how to help the patient to relax. We called our office and asked for permission to wait and do the return trip for this man, to ensure continuity of care.

** Fiddle mats or blankets have lots of things attached, such as wool, strings, buttons, zippers, buckles, bells, textured fabric, soft toys, rings, beads etc, that can be touched and played with by people with dementia to soothe, relieve boredom and provide stimulation and focus.*

This presentation made reference to other DTA resources, as well as other national and international pieces of related work, such as:

- *Dementia: Best Practice Guidance for Ambulance Services*, from the Association of Ambulance Chief Executives in the UK (2017).
- *Delivering Safe, Effective and Person-Centred Care*, from the Scottish Ambulance Service.
- A video clip demonstrating the first dementia-friendly ambulance in the UK (see https://bit.ly/3sFcUGy).

Due to the size of the St John WA organisation and its geographical reach, DTA recorded this presentation and delivered it to various members of the St John WA Education & Training Teams to enable the presentation to be delivered in-house on an ongoing, long-term basis. The training would form part of the mandatory SJA Continuous Education Program.

The Ambulance Transport Officer staff were selected as the initial cohort to complete the DTA training program, given that St John WA is such a large organisation. This was due to the older patient demographic they support (even though dementia is not a normal part of ageing) and that other staff members would benefit in time from the training too.

Progress so far

Since the TTP started in November 2020, more than 250 St John WA Ambulance

Transport Officers in Perth and regional areas have completed the various online courses provided (between three to five modules have been completed by each officer). More than 250 officers have also attended the facilitated presentation in person. David Cutler says the response from the Ambulance Transport Officer teams across the state has been "phenomenal".

"Providing our staff with customised resources and modules specific to our Transport Officer service has been extremely beneficial to enhancing our patient care. Our overarching goal with this program is to improve the overall patient experience when being transported by our officers and provide a sense of comfort to any family, friends or carers at the scene," Mr Cutler said.

From the post-training surveys completed, 100% of St John WA staff completing the survey reported they had acquired new knowledge that would help them support people living with dementia; their confidence in caring for a person with dementia had increased and that they would share their learning with someone else.

Some of the ATOs have shared positive practical examples of how they put the training into practice, for example, by making sure they include the person with dementia in conversations (rather than talking 'over' them or excluding them), making good eye contact (approaching them at eye level rather than talking 'down' to them), and offering reassurance to family, friends and carers that the person will be cared for with respect and dignity (see box p14).

Conclusion

The training continues to roll out successfully across St John WA with a view to extend to other areas within the organisation, specifically for their paramedics and volunteer workforce. ■

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DCRC's 15 years of research and capacity building

Australia's Dementia Centre for Research Collaboration (DCRC) will close on 23 December 2021 after 15 years of leadership, collaboration and great productivity. DCRC Directors **Henry Brodaty, Kaarin Anstey** and **Elizabeth Beattie** reflect on its contributions and legacy

DCRC Directors (from left) Professor Elizabeth Beattie, Professor Kaarin Anstey and Professor Henry Brodaty

We want to take this opportunity to thank all our members, colleagues and stakeholders across Australia and internationally for their important contributions to dementia research and the translation of that new knowledge into improved care for people living with dementia and their care partners.

Since its inception in 2006, the DCRC initiative has supported hundreds of researchers with small and large research grant funding, fellowships, PhD scholarships and travel grants. It has hosted forums, conferences, special interest groups and other capacity-building activities and research enrichment events.

Diverse collaborations

We are proud of our diverse collaborations with researchers, government bodies, advocacy groups and consumer advisory committees across Australia and internationally, including our flagship International Research Network on Dementia Prevention (IRNDP) and its collaborations with the World Health Organization on risk reduction, our Capacity Building for Care Research Program and our Behaviours & Psychological Symptoms associated with Dementia (BPSD) project.

The DCRC, funded by the Australian Government through the National Health and Medical Research Council, has been a trusted source of information, research, and knowledge translation about dementia across a range of contexts including prevention, GP education, nursing, allied health, epidemiology, psychosocial care and community, acute and residential dementia care. More recently the three DCRC hubs have each had flagship projects focused on changed behaviours, capacity building in dementia care and prevention and risk reduction.

Meaningful involvement

With a broad and inclusive remit across dementia research, we have endeavoured to support the meaningful involvement of people living with dementia in all our activities as a DCRC priority from the beginning. Those with lived experience have played a critical role in helping the research community identify gaps and set priorities in dementia research. We are grateful for these contributions and the wonderful connections that have been formed between researchers and those with lived experience via the DCRC networks. These have had a positive impact in advocating for positive change for people living with dementia, their families and carers and addressing the stigma associated with a dementia diagnosis.

Changing landscape

In our 15 years of operation, we have witnessed so many changes in the research landscape. In 2015 the NHMRC National Institute for Dementia Research (NNIDR) was established, tasked with coordinating the strategic expansion of dementia research in Australia. The DCRC was a key contributor to the implementation of the NNIDR strategic plan. The three DCRC Directors are now involved in the Australian Dementia Network (ADNeT), which includes a Clinical Quality Registry to track, benchmark and report on the clinical care of people with dementia.

Research and resources

The DCRC is proud to have supported and grown many dementia researchers across Australia, many of whom progressed to receiving NHMRC Fellowships.

Stand-out world class research projects funded by the DCRC in 2021 and exemplifying DCRC's relevance and diversity are: Professor Karen Charlton's world-first research trial of the 'purple diet' (anthocyanins) to prevent dementia in people with mild cognitive impairment; Professor Lynn Chenoweth's building capacity among healthcare staff to implement person-centred care in sub-acute care; Dr Joan Ostasziewicz's research into incontinence care and coping strategies; and Professor Lily Xiao's innovative delivery of the Australian iSupport for Dementia program to Chinese people in China, Hong Kong, Taiwan and Macau. DCRC has also funded a team led by Professor Simon Bell to provide *Guidelines for Psychotropic Prescribing for People With Dementia*, due for completion in 2022.

Over the years, the DCRC has produced a number of valuable resources for clinicians and the community. Our free resources continue to prove valuable and relevant across the world, with the Dementia Outcomes Measurement Suite (DOMS) and The General Practitioner assessment of Cognition (GPCOG) remaining our most active resources online.

While our website will no longer be active after DCRC's closure, we will be communicating the new e-homes which will house our materials and resources. Until then, you can visit the DCRC website at www.dementiaresearch.org.au to access and download resources before 23 December 2021. The International Research Network on Dementia Prevention will continue (https://coghealth.net.au/). ■

With thanks

Our sincere thanks to all who have been part of the DCRC network since 2006. We thank you for your commitment to dementia research and for all you do to improve the lives of people living with dementia and their families.

The 'Golden Angels' volunteer program for patients with dementia and delirium began in 2009 in one NSW rural hospital, has since spread across Australia, and is now being adapted for residential aged care settings. **Catherine Bateman, Katrina Anderson** and **Annaliese Blair** discuss the clinical outcomes for patients supported by the program, how it's implemented and the impacts and challenges of volunteer care for family carers and clinical staff

Older hospital patients with dementia and/or delirium are at far greater risk of adverse events and outcomes such as falls, pressure injury and death (Inouye *et al* 2013; Mukadam and Sampson 2011).

They can also experience significant fear, stress and anxiety when admitted to the busy, noisy hospital environment, which can pose particular challenges and stresses for staff and family carers. Volunteer support has been shown as one way of addressing the person-centred care needs of these patients and in turn provide support for families and staff (Bateman *et al* 2016).

The aim of the Volunteer Dementia and Delirium Care Program (VDDCP) is to provide person-centred emotional support and practical assistance to patients with dementia and delirium (or with identified risk factors for delirium) to reduce their risk of adverse outcomes.

The program originated as a pilot study in a rural NSW hospital in 2009 (Bateman *et al*, 2016). Findings from the pilot suggested improved patient outcomes such as enhanced safety, hydration and nutrition, reduced length of time in hospital and increase in analgesic medication. There was high acceptance of the volunteer support by staff. The volunteers became affectionately known as the 'Golden Angels' due to their gold-coloured uniform and compassionate care.

The NSW Agency for Clinical Innovation (ACI) subsequently funded the development of the Volunteer Dementia and Delirium Care Implementation and Training Resource © to support implementation of the program in other Australian hospitals. The resource, developed in 2014 in print format, is now available online and free to download at https://bit.ly/confused-hospitalised-aci

The hospital volunteers, affectionately known as the 'Golden Angels' due to their gold-coloured uniform and compassionate care, provide emotional support and practical assistance to patients with dementia and delirium. Photo courtesy the Volunteer Dementia and Delirium Care Program

‘Golden Angels’ going from strength to strength

Program evaluation

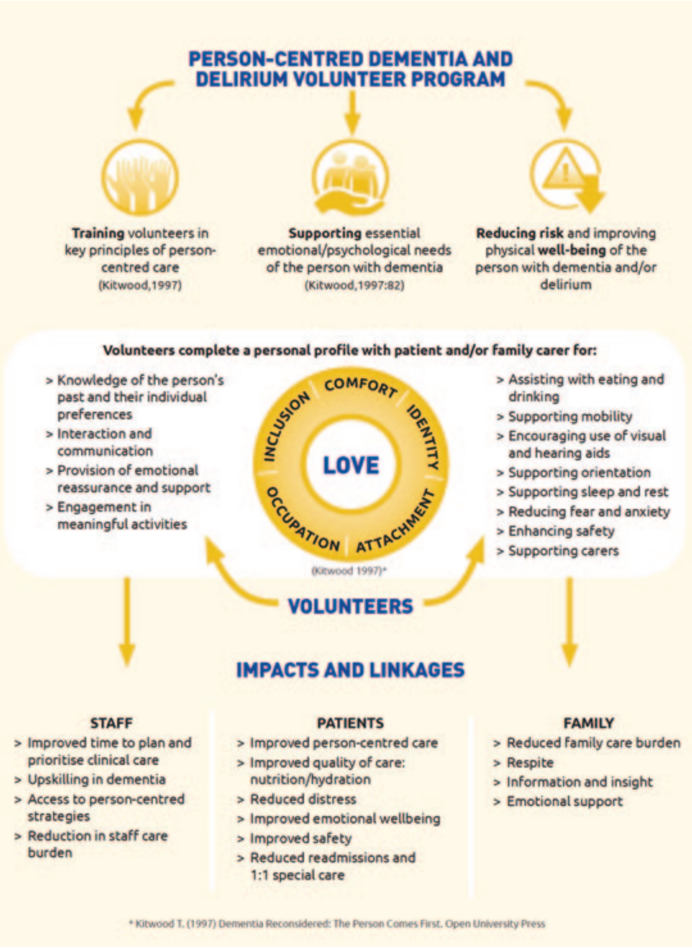
Following receipt of a Commonwealth grant, the Southern NSW Local Health District (SNSWLHD) Aged Care Evaluation Unit (ACEU) implemented and evaluated the VDDCP at another seven rural NSW hospitals between 2015-2017. Hospitals ranged from 13 to 79 beds, most with only one main ward.

The study aimed to evaluate the clinical outcomes for patients with dementia, delirium, or at risk for delirium, who were supported by the VDDCP, as well as the impacts and challenges of volunteer care for family carers and clinical staff. The study also explored the enablers and barriers to implementing the program.

It compared outcomes for 270 patients who were visited by a volunteer with outcomes of a control group of 188 patients who were admitted to the same hospital 12 months before the volunteer program started.

Using patient medical records, we looked at the number of volunteer visits, diagnosis, length of stay (LOS), behavioural incidents, readmission, specialling, mortality, admission to residential care, falls pressure injury and medication use.

We interviewed and surveyed 80 family carers of patients who received volunteer care about their perceptions of the program. Additionally, we surveyed 119 staff about their care confidence, care stress and their satisfaction with the program. We also held focus groups with 46 staff and 15 managers nine months after the volunteers started. Staff and managers were asked about what they saw as the enablers and barriers to implementation and the successes and challenges for the program.



Graphic courtesy of the Volunteer Dementia and Delirium Care Program

The volunteer intervention

We had four project officers working with us to oversee the implementation across the seven hospital sites. They were all clinical nurses experienced in aged and dementia care. The developer of the implementation and training resource (Catherine Bateman) provided the project officers with training and support over the course of the project.

Steering committees were set up to ensure everyone was kept in the loop, resolve any teething issues and monitor how the project implementation was progressing. Information sessions were provided for staff about the program and the role, scope and boundaries of the volunteers.

Volunteers were recruited via local media, shop flyers, word of mouth as well as promotion through existing volunteer groups. Selection requirements for volunteers included age greater than 18 years; preference that they had not experienced a significant loss in the preceding 12 months; an interest or experience with older people or people with dementia; good communication skills; respect for beliefs, values and culture of others; ability to be part of a team; current driver’s licence; desire and availability to become a volunteer.

A total of 101 volunteers were initially recruited across the seven sites. Selected volunteers participated in a two-day training program which used the VDDCP training resource (see Table 1). The role of the volunteer was clearly documented in their duty statement and covered in training, as were the specified boundaries (specific roles and boundaries are outlined in Table 2). Volunteers were required to sign their duty statement and a health service confidentiality agreement.

Our project officers provided the volunteers with orientation to the wards, introduced them to staff and managers and ensured they

Table 1: Volunteer training sessions

- About the program and the volunteer role
- Understanding Dementia and Delirium
- Communication and person-centred care
- Activities for patients
- Understanding and responding to behaviours that can occur in patients with dementia and delirium
- Assisting with eating and drinking
- Safe walking with patients
- Commencing as a volunteer
- Other hospital mandatory training such as infection control, PPE and fire safety

were well supported as members of the care team over the course of the project. The volunteers were easily recognised in their gold polo t-shirts by staff and families. Regular communication and networking meetings were held with the volunteers, who developed new friendships with each other and valued the opportunity to share their experiences of supporting patients.

A roster system was set up with volunteers indicating which day and shift they would prefer. Most volunteered to do either one shift a week or fortnight which allowed coverage for a morning and afternoon shift five days a week. The morning shift was from 8am-12.30pm and the evening shift 3pm-7pm.

To ensure the program was safe for the patients and volunteers, there was a one-page referral form completed by staff (see Table 3 for referral criteria) and written procedures for staff and volunteers. The volunteers gained valuable individualised information about the background of the patients, their likes, dislikes and activities they enjoyed by completing a personal profile with the patient and/or their carer. This was shared with staff and other volunteers. The volunteers also had a documented communication process between each other which conveyed information about their patient to the next volunteer, such as activities their patient may have enjoyed or things they liked to talk about.

Patient outcomes

Across all sites, there was a significant reduction of 6.4% in rates of one-to-one specialling by a nurse or security guard (χ2 (1, N=458) =6.51, p=.011) and a reduction of 8% in 28-day readmission for patients receiving the intervention (17.0%; χ2 (1, N=457) =7.501, p=.006). There was no significant difference in other outcomes such as length of stay, behavioural incidents, falls, pressure injury, admission to residential care, medication use and death rates for those who received volunteer assistance and those who did not.

Family carers and staff

Families rated the volunteer intervention as helping "a lot" (89%) or "a little" (8%). All families indicated they wanted to see the program continue. Of those who had had a previous admission without a volunteer, 87% of family carers reported a positive improvement in some way for the admission with volunteers. Overall, families talked about a sense of relief that someone else was able to be with their loved one when they were unable. They particularly valued the volunteers assisting with eating and drinking and individualised care.

In relation to staff, 97% of those surveyed agreed that the volunteers positively supported them in their care of patients. The majority were happy with how the program was running, felt that the program met or exceeded their expectations and that the volunteers were well prepared for their role. Staff conveyed a sense of reduced emotional and physical burden.

Managers, staff and families all considered the volunteer to be part of the care team and that volunteers were successful in implementing the principles of person-centred care:

"…being able to elicit information from their background, and then sharing that with staff is a great strategy when you've got those difficult moments to engage with them and do a bit of that reminiscing type of therapy."

"I think they're [volunteers] becoming more and more a recognised part of the team as they get more into their role. If the volunteers are seeing the patients, we want to document that in the notes and communicate with them and read their little progress notes […]. So, it's just a matter of ensuring they're part of the team and we communicate."

Cost savings

The evaluation of the VDDCP demonstrated an 8% reduction in 28-day readmissions. Even if readmissions were half the length of the initial stay (ie, five days on average), based on our 2018 analysis, this could save $32,000 per year per site. Therefore, just the savings from reduction in 28-day readmissions would cover the cost of the program.

There was a 6.4% reduction in 1:1 patient specialling. Due to lack of consistent data on specialling within the Local Health District, a sample of specialling data for older patients was taken from one hospital in 2015/16. These patients were specialled for an average of 15 hours by various staff from RNs, ENs, AINs and security staff. Based on these estimates, a reduction of 6.4% of specialling at 15 hours per patient at EN Year 5 wages, would save $20,519 for a rural health district over 12 months.

Estimated costs

The $29,860 estimated costs of running the program per annum in one hospital of 40-80 beds is calculated assuming a NSW Health Service Manager (HSM1; Paypoint 2) salary ($128,100 including 22% on-costs for 2021/22 FY) and assuming recruitment of no more than 15 new volunteers each year at each site.

Table 2:

Role of the volunteer	Specific boundaries for volunteers
• Completion of a person profile with the patient and or their carer • Communicate and interact with assigned patients • Sit with assigned patients one-to-one and in group activities • Assist and support assigned patients with therapeutic activities • Assist assigned patients with completion of their menus • Assist assigned patients with eating and drinking • Assist assigned patients with wearing visual and hearing aides • Report any concerns or changes in the assigned patients to the nurse • Report any other concerns or worries to the coordinator or Nurse Unit Manager (NUM) • Keep a record of time spent with assigned patients • Encourage assigned patients' walking as instructed by NUM, RN in charge or physiotherapist	Volunteers *were* not to: • Assist assigned patients with walking unless instructed or agreed to by volunteer coordinator or NUM, RN in charge or physiotherapist • Assist with care of any other patients that you are not assigned to - always talk with the NUM or RN in charge if you are concerned • Assist with duties a nurse might ask you to do that is not in your duty statement • Assist any other patients (not assigned) with eating or drinking • Buy food or other items for patients unless permission is obtained from the NUM • Enter a room where the door is closed without requesting or receiving approval from the NUM or RN in charge • Discuss or criticise a patient's treatment with them, their carers or relatives • Discuss any aspects of the patient's care outside of the health service

Table 3: Patient referral criteria for the volunteer program

- Patients with dementia or cognitive impairment identified with cognitive screen
- Delirium **OR** is confused or agitated or unusually lethargic

OR patients > 65 years or if Aboriginal > 45 years and has one or more of the following risk factors:

- Cognitive impairment
- Visual or hearing impairment
- Dehydration
- Severe illness
- High falls risk

Patients were excluded if they were exhibiting behaviours that posed risk to themselves or others OR consent was not obtained from patient and/or family for volunteer support

Efficiencies can be gained in smaller sites (<40 beds) by having one volunteer manager overseeing several sites or incorporating volunteer management into an existing role at the hospital, with extra time of up to one day per week allocated. Note that volunteer program resources such as large print playing cards, CD players, music, etc are also required and are not part of the costing. (For additional details on costings, refer to the links in 'Further reading' at the end of this article).

Success and challenges

In all new projects, there are always success factors and challenges. We found the key ingredients for success were careful selection of volunteers, comprehensive training, clearly defined roles and procedures for the volunteers, staff information sessions, and support by our project officers (for details, refer to the links to further information and published papers at the end of this article).

Common challenges were ensuring everyone knew about the roles and boundaries of the volunteers, building trust between staff and volunteers and having nursing staff complete the one-page referral form. Over the course of the six months these were mostly resolved.

The longer-term and continuing challenge is securing funding to support the program's continuation at all sites. A 2019 feedback survey conducted for other hospitals across Australia who have implemented the program highlighted similar success factors and challenges.

Conclusions

The VDDCP was seen by families and staff to be effective in addressing some of the main barriers to providing person-centred care to older patients with cognitive impairment in rural hospitals – namely lack of time, limited person-centred processes and knowledge and environmental limitations. Families and staff felt supported in their care, thereby reducing some of their care burden.

The volunteer intervention was found to be a safe, cost-effective and replicable way to support older patients with cognitive impairment in rural hospitals.

For residential care

In 2020, the SNSWLHD Aged Care Evaluation Unit was awarded a World Class Dementia Collaborative Research Grant to translate the existing VDDCP for hospitals into the residential aged care (RAC) setting. It involves adapting the existing implementation and training package for the RAC setting using a co-design workshop and consultation process with selected facilities.

Implementation and evaluation of the outcomes is occuring in two metropolitan and two rural RAC facilities over 2021 and 2022. Recruitment of rural and metropolitan intervention and control RAC facilities has occurred. The co-design workshop was held with the rural intervention facility in May 2021 and the co-design workshop with the metropolitan intervention facility was held in early August.

Program implementation committees with key stakeholders have been established at each implementation facility with fortnightly meetings being held to plan and monitor the program implementation.

Media releases and volunteer promotional material for volunteers, families, residents and staff have been developed and draft adaptations to the education modules and procedures have been made.

Consent is being gained from families and staff with a very positive response from families at the intervention facilities about the program's concept and the potential support it will provide their loved ones.

Although the COVID lockdowns this year have significantly impacted on the project timelines (including volunteer recruitment, definitive dates for training and commencement of the program), all facilities are very positive about the program being implemented and are continuing to work collaboratively towards this occurring. ■

Further reading

Further information about the project and team can be found at: https://bit.ly/golden-angels-dementiaresearch

The authors' two published papers are freely available:

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Blair A, Bateman C, Anderson K (2019) "They take a lot of pressure off us": Volunteers Reducing Staff And Family Care Burden and Contributing To Quality Of Care For Older Patients With Cognitive Impairment In Rural Hospitals. *Australasian Journal on Ageing* 38(S2) 34-45. Available at: https://bit.ly/AJAStudy

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For more about the VDDCP, including full costings, visit www.journalofdementiacare.com

■ (From left) Catherine Bateman is a Dementia Delirium Clinical Nurse Consultant with Southern NSW Local Health District who established and piloted the original Dementia Delirium Volunteer Program and is the author of the NSW Agency for Clinical Innovation (ACI) VDDCP Implementation and Training resource; Dr Katrina Anderson is a Clinical Psychologist and researcher with the Aged Care Evaluation Unit, Southern NSW Local Health District; Annaliese Blair is a clinical research officer in rural NSW based in Southern NSW Local Health District. Contact the authors via Catherine.bateman@health.nsw.gov.au

Aducanumab explained:
history, controversies and opportunities

New Alzheimer's drug aducanumab has been hailed as a first-of-its kind treatment, generating global interest, but also controversy. **Emily Rosenich, Paul Maruff, Rachel Buckley** and **Yen Ying Lim** explain

In June this year the US Food and Drug Administration (FDA) approved a novel drug for the treatment of Alzheimer's disease – on the condition that further research trials show a clinical benefit of the drug. The drug, called Aduhelm (also known as aducanumab), is the first treatment approved for Alzheimer's disease in almost two decades, and the headlines were certainly hard to miss:

"United States approves first Alzheimer's drug in 18 years, Biogen's aducanumab".

"If the FDA approves aducanumab, I won't prescribe it".

"Historic moment: US regulators approve landmark Alzheimer's drug".

"Bad medicine: aducanumab is a lacklustre drug with a high cost".

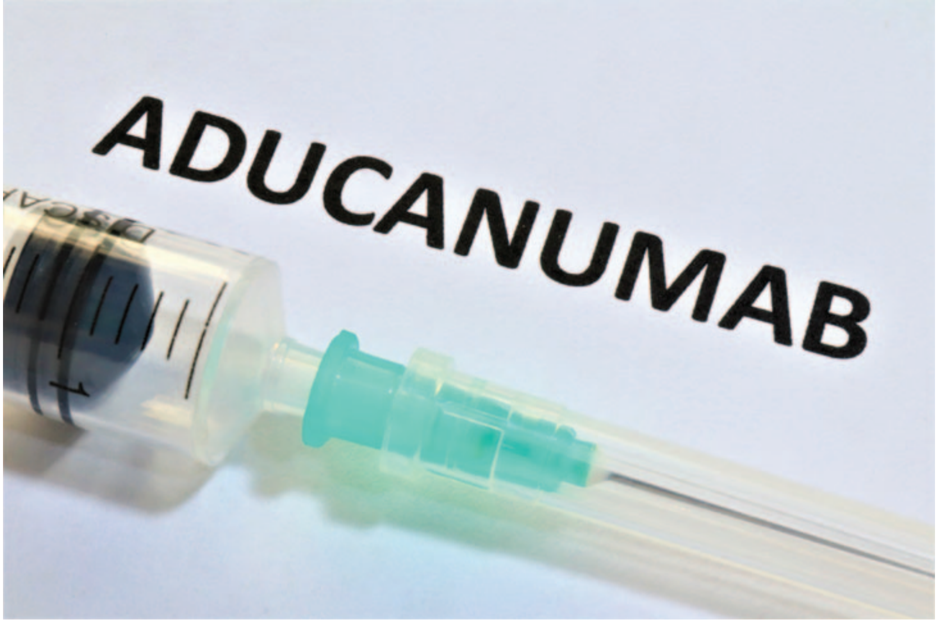
The FDA's approval of Aduhelm has been controversial amongst scientists, clinicians, not-for-profit organisations, and people living with dementia and their carers. The approval of Aduhelm is the first that the field has seen in recent decades, so why was this approval so controversial?

What is Aduhelm?

Aduhelm, developed by Biogen, is marketed as the first disease-modifying treatment for early-stage Alzheimer's disease. At the moment, Aduhelm has been approved only in the US. Companies that develop drugs must provide evidence of their effectiveness to the government health authorities in each country in which they intend to make it available. This process has not yet been completed in Australia.

Why is Aduhelm such a breakthrough?

All drugs that have previously been approved for use in the treatment of Alzheimer's disease (eg, donepezil) have been symptom modifiers. Symptom modifiers work by replacing brain chemicals or neurotransmitters that are lost as a consequence of brain cell death in Alzheimer's disease.


The major controversy with the FDA's approval of Aduhelm (aducanumab) was that the clinical trials did not show convincing evidence that the drug slowed decline in memory and thinking

Unfortunately, these drugs have a small beneficial effect on thinking and memory, and the beneficial effects do not last very long. This is because the root cause of cell death hasn't been treated, and any attempt to replace lost brain chemicals becomes ineffective as the disease becomes more severe.

Complex behaviours such as memory, thinking and conducting everyday activities are often underpinned by multiple brain pathways. Brain cell death in Alzheimer's disease often results in the loss of these pathways. Symptom modifier drugs typically only replace one type of brain chemical (ie, acetylcholine), which may be insufficient in overcoming the impairment in thinking, behaving, and feeling that arise from Alzheimer's disease-related cell death. This situation is summarised effectively with an analogy: "Imagine the damage caused by Alzheimer's disease in the brain is equivalent to a boat springing a leak. The drugs we currently have act to bail water out of the boat, but they don't do anything to plug the hole. Plugging the hole is the aim for disease modifying therapies" (Brain Health Scotland 2021).

Disease modifying drugs are designed to target the Alzheimer's disease processes that cause cell death. By stopping such processes, cells do not die and will continue to function normally, and brain chemicals will not be lost.

Aduhelm is a drug that is designed as a disease modifier, and Biogen has argued that data from its clinical trials suggests that it can plug the hole in the boat.

How was Aduhelm tested?

Biogen conducted two large clinical trials (ENGAGE and EMERGE) (Biogen 2020). Each trial included over 1500 people with Alzheimer's disease. Both trials showed that Aduhelm successfully cleared amyloid from the brain. However, in 2019, Biogen announced that it was stopping both trials early, as its data showed that it was very unlikely the drug would have a positive effect on slowing memory loss.

A short while later, Biogen released a

statement saying that, upon analysing the final data alongside new data that wasn't previously available, Aduhelm did have a very small, albeit positive effect on thinking and memory and a person's ability to carry out day to day tasks. Importantly, this finding was only apparent in a subset of individuals: those who received the highest dose of the drug. From these findings, Biogen sought approval for use from the FDA in the US.

Why was the approval of Aduhelm controversial?

The major controversy with the FDA's approval of Aduhelm was that the clinical trials did not show convincing evidence that the drug slowed decline in memory and thinking. Aduhelm does substantially reduce the amount of amyloid in the brains of people with Alzheimer's disease. Indeed, there are several drugs that can successfully remove amyloid from the brain.

However, in the world of drug development, the most important outcomes from clinical trials are how any new drug influences survival, or how it affects the way a person feels or functions. In trials of new drugs for Alzheimer's disease, this translates to how any drug can improve the ability of people to remember and think, as well as how it improves their ability to be able to live independently. With Aduhelm, these effects were quite small. Therefore, although the drug was effective in removing amyloid from the brain, this removal did not result in the improvements to the everyday life of participants.

The disconnect between drugs being able to remove amyloid but not improve symptoms is not unique to Aduhelm and has also been seen in other anti-amyloid drugs. This has raised two main questions. The first is whether the drugs are sufficiently effective. The second is whether removing amyloid is the right target if it has no impact on the clinical symptoms of Alzheimer's disease, such as memory loss. This speaks to a core debate within the field. Some scientists argue that disease progression in Alzheimer's disease refers to the biology of the disease (eg, the build-up of amyloid and tau) (Jack *et al* 2018). Others contend that disease progression should refer to the clinical symptoms of the disease (eg, memory loss), as this is what is meaningful to patients and their families.

Why has it taken so long to develop Aduhelm?

Alzheimer's disease is a disease of time and can develop over 30 years. For a long time, scientists had only a limited understanding of this disease in humans.

While we knew that amyloid and tau proteins build up to abnormal levels in people who have died with Alzheimer's disease, there was no technology to study these abnormal proteins in humans who were alive.

One crucial development to understanding Alzheimer's disease and developing a drug to treat it was having the right tools. Brain imaging and brain fluid analysis have allowed us to measure amyloid and tau in living individuals, and to understand how these levels were related to age, genetics, and memory and thinking abilities (Rowe & Villemagne 2011). This was only made possible by conducting long-term studies of people with a family history of the disease. By studying them over time, we were able to identify demographic, genetic, and behavioural factors that increased a person's risk of amyloid and tau build up and decline in memory and thinking. This provided important insights into who and what to target.

Research now suggests that Alzheimer's disease begins with the build-up of amyloid in the brain, which results in the development of amyloid plaques (Jack *et al* 2018). As amyloid builds up, there is a consequent build up in tau. Currently, we think that it is this build-up in tau that leads to cell death and declines in thinking and memory. Some scientists refer to amyloid as the 'trigger', as once the trigger has been pulled, then the 'bullet' (tau) is on its way.

Thus, stopping the build-up of amyloid, or removing it, became a key strategy in the development of disease modifying drugs for Alzheimer's disease. The idea is that if we get rid of amyloid, this will stop tau from accumulating, which will mean that cell death will be prevented, and the thinking and memory that depend on these cells will be preserved. This is the theoretical basis of Aduhelm. Aduhelm works by breaking down the toxic build-up of amyloid protein in the brain.

Why did the FDA approve Aduhelm?

When a company applies to the FDA to seek permission to market their drug, the doctors, scientists, and statisticians at the FDA pore over every detail of the clinical trial program. They examine everything from the original studies conducted in cells, in animals, and in humans. The company must provide the FDA with the raw data from their experiments and allow the FDA to analyse it independently to ensure that no errors have been made.

The BetterBrains trial

It is currently estimated that about 40% of all dementias can be attributed to risk factors that are highly modifiable, including low mood, poor sleep, poor heart health and low cognitive and social engagement.

The BetterBrains trial, led by Australia's Monash University and the University of Melbourne, will test whether personalised lifestyle and educational behaviour change strategies targeted at modifying these four risk factors can prevent thinking and memory problems in middle-aged adults aged between 40 and 70 years.

The BetterBrains trial is unique, in that it is delivered fully remotely (ie, online, via telephone and smartphone application). The trial aims to recruit 1510 people living in the community throughout Australia. After completing an initial assessment, participants will be allocated at random (like tossing a coin) to one of two study groups. Of these people, 755 participants will be randomised to the intervention group and will receive the personalised BetterBrains program, while the other 755 participants will receive health education materials about dementia risk reduction.

To learn more about the BetterBrains trial, or to sign-up, visit www.betterbrains.org.au

The Healthy Brain Project

Another Australian research initiative, The Healthy Brain Project, is also seeking volunteers – for a study to understand optimal brain health and ageing. To do this, neuroscientists at the Turner Institute for Brain and Mental Health, Monash University hope to gather a comprehensive amount of information from 10,000 volunteers and follow them each year for at least five years (or longer if possible) with the aim of identifying which parts of brain biology, genes, psychology and behaviour can help predict who will progress to develop dementia later in life. To volunteer or find out more, visit www.healthybrainproject.org.au

The process is incredibly detailed and thorough.

In addition to their own analyses, the FDA may seek advice from external experts in the field. These are often specialist doctors who treat the disease for which the drug is designed or other scientific experts who know the therapeutic area very well. This panel of independent experts will meet in a public forum, with the study sponsor (ie, Biogen) and the FDA to discuss the results of the studies that have been submitted for approval.

When assessing Biogen's proposal for FDA approval, 10 out of 11 experts on the expert advisory panel voted that the evidence for the therapeutic benefit of Aduhelm was inconclusive, and the remaining expert declined to vote. They recommended that Biogen's application for FDA approval of Aduhelm be rejected, based on the fact that they were asked to vote on the clinical efficacy of the drug (ie, benefit to memory and thinking ability, and ability to conduct everyday activities).

The FDA then integrated this opinion from the advisory board with its own consideration of the data provided by Biogen and approved Aduhelm.

It offered what was termed an 'accelerated approval', based not on the clinical efficacy, but on the evidence that the drug was effectively clearing amyloid plaques from the brain.

Consideration of the definition of an FDA accelerated approval helps to understand their decision. Under the Accelerated Approval pathway, the FDA may approve a drug for a serious or life-threatening illness that may provide meaningful therapeutic benefit over existing treatments when the drug is shown to have an effect on a surrogate endpoint that is reasonably likely to predict a clinical benefit to patients, despite there being some uncertainty about the drug's clinical benefit.

As Alzheimer's disease is considered in many developed countries to be a health emergency, the FDA required that Biogen continue to research the drug. It made Biogen commit to conduct another longer-term study and then come back to the FDA with those results. If this additional study fails to find a meaningful benefit, the approval will be withdrawn. Biogen is given almost a decade to provide data from this longer-term study (US Food & Drug Administration 2021a).

What's next?

After nearly two decades of research, we now have the first disease-modifying drug for Alzheimer's disease. Aduhelm is effective in clearing amyloid from the brain. However, the benefits on memory and thinking have been small. Additionally, consequential side-effects, including brain swelling and haemorrhages, were reported in one out of three people taking the highest dose of the drug (US Food & Drug Administration 2021b).

■ From left: Dr Emily Rosenich is a Postdoctoral Research Fellow at the Turner Institute for Brain and Mental Health at Monash University; Professor Paul Maruff is a neuropsychologist and has a company, Cogstate, that works with pharmaceutical companies to help determine the benefits and risks of new drugs being developed for the treatment of dementia; Dr Rachel Buckley is a neuropsychologist based in Boston, US, as Faculty at Massachusetts General Hospital/Harvard Medical School; and Yen Ying Lim is an Associate Professor at the Turner Institute for Brain and Mental Health at Monash University. She is the primary investigator of the BetterBrains Trial and the Healthy Brain Project (see box p21).

We, like all Alzheimer's disease researchers and clinicians, sincerely hope that this drug is found to be effective when it moves into more widespread clinical use.

From a broader scientific perspective, an enormous step has been taken. We have now achieved a small but important beachhead in the war on this terrible disease.

While drug development in Alzheimer's disease has focused on amyloid, the field is increasingly turning its attention towards other drugs, such as those that target tau and neuroinflammation, or even multi-combination drug treatments.

The approval of Aduhelm will now accelerate the development and improvement of other drugs that modify biology to diminish cell death that devastates people and their families.

This achievement also re-energises researchers like us. It shows us that we are getting closer to the core of this disease. For us, the approval of Aduhelm is not the end of a project, it is the beginning of the next step. ■

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Hearing and vision needs of people with dementia

Identifying and supporting hearing and vision impairments is an inexpensive and effective opportunity to improve quality of life for people living with dementia. **Piers Dawes** explains

Hearing and vision impairments are common among people with dementia. Unfortunately hearing and vision impairments tend to go unrecognised and under-supported, worsening the impacts of cognitive impairment on quality of life and other outcomes. Effective identification and management of hearing and vision impairments offers an acceptable, low-cost, and low-risk opportunity to improve quality of life for people with dementia.

This article highlights interventions and key recommendations for carers and hearing and vision professionals to support and address these impairments.

Prevalence and impact

People with dementia are more likely to have hearing and vision impairments than people of a similar age without dementia. UK studies reported that 90% of people in the general community with mild/moderate dementia have hearing loss (Allen *et al* 2003) and 32.5% have vision impairment (Bowen *et al* 2016). Hearing and vision impairments are even more common among people with dementia in residential aged care settings (Bowen *et al* 2016; Cohen-Mansfield & Taylor 2004; Mitchell *et al* 1997). Hearing and/or vision impairments exacerbate the impact of dementia on quality of life by:

- Increasing behavioural and psychological symptoms (agitation, hallucinations, aggression and depression), leading to increased use of pharmaceutical and physical restraint.
- Increasing communication barriers, social isolation, cognitive decline, and resulting in higher care need and care costs (Dawes *et al* 2018).

People with both hearing *and* vision impairment (dual sensory impairment) have even worse outcomes. Hearing and vision impairments among people with dementia also impact on informal and paid carers, increasing social isolation, depression, relationship stress and care burden (Leroi, Wolski & Hann 2019).

Dementia may affect a person's ability to learn how to use or understand the need for sensory aids such as hearing aids and glasses, and they may need extra support to do so.
Photo: Shutterstock

Interventions

Hearing and vision interventions (such as hearing aids, glasses and cataract surgery) are effective in improving quality of life, functional ability, mental wellbeing and social participation for people with normal cognition. Our systematic review found that hearing and vision interventions also improve outcomes for people with dementia (Dawes *et al* 2018). These interventions are relatively low cost, so are highly cost-effective.

Under-identification

Unfortunately, hearing and vision impairments tend to go under-recognised in people with dementia (Allen *et al* 2003; Bowen *et al* 2016). Age-related hearing/vision difficulties have a gradual onset, so many people may not realise they have a problem. Because dementia affects insight, people with dementia may be less aware of sensory difficulties and less likely to seek help than people with normal cognition.

Further, because some of the symptoms of dementia resemble the symptoms of hearing/vision loss (for example, disorientation, memory difficulties, not keeping up with the conversation, repeating questions, disengagement with friends and family), functional and communication difficulties may be misattributed by clinicians, friends and family as due to dementia, rather than due to a remediable sensory problem.

Clinicians and carers should be alert to the possibility of an unrecognised or under-supported hearing or vision problem. Ideally, reliable objective hearing/vision screening tests should be used to identify a hearing/vision problem. Two such tests are the Such as the HearCheck Screener (https://bit.ly/hearcheck-screener) and the PEEK vision testing app (https://peekvision.org/).

Hearing/vision assessment

If a person with dementia does see an audiologist or optometrist, they may have difficulty following instructions and/or completing the tests. Hearing and vision professionals report that they lack training and expertise in how to recognise and/or work with people with dementia (Bowen *et al* 2016; Shah *et al* 2015; Wright *et al* 2014). One study reported that only 5% of people with dementia in residential aged care could complete a full audiometric evaluation (Burkhalter *et al* 2009). But this study involved a large hearing test battery, and the hearing tests in this study were carried out 'by the book' without adjustment for the needs of people with dementia.

Assessments can be adapted to support the needs of people with dementia (Dawes *et al*, in press) (see Table 1, Assessment, item 3 for details, left). A recent systematic review reported that around 60% of people with dementia could complete a basic hearing test, and most people with mild dementia can be reliably complete a hearing assessment (Bott *et al* 2019). Hearing and vision services are available that cater for people with dementia (eg, www.nationaleyecare.com.au).

Sensory interventions

Dementia affects the ability to learn new things, including use of sensory aids such as hearing aids and/or glasses. Dementia may also affect insight for the need for sensory aids, so people with dementia may not continue to use them and may need extra support to do so. The stage of dementia may also impact a person's ability to adapt to the use of a sensory aid. Sensory needs should be identified and supported as early as possible, so that a person may adapt and continue to use and benefit from a sensory aid in the long term (see Table 1, Treatment and Support, for details, left).

If a person cannot reliably complete a full hearing/vision assessment and/or may not be a good candidate for hearing aid or glasses, consider:

- Trialling assistive devices that do not require full audio/opto-metric information to be prescribed, such as personal amplification devices (https://bit.ly/pocket-talker) and low vision aids (https://bit.ly/low-vision-aids).
- Focusing on training carers and friends in vision/hearing support strategies (https://bit.ly/hearing-assistance; https://bit.ly/visionaustralia-tips).
- Environmental modifications (eg, adjusting lighting, reducing background noise).

Memory clinics and mis-diagnosis

Hearing and vision impairments complicate dementia diagnosis and support. Unfortunately, memory clinicians do not routinely take sensory impairments into account (Leroi & Himmelsbach *et al* 2019).

Because the clinical presentation of hearing/vision impairment is like that of dementia, clinicians may confuse sensory difficulties for cognitive ones. As diagnosis of dementia is partly based on functional impairment in daily life, and un-treated hearing and vision impairments result in functional impairments, un-treated hearing and vision impairments may increase the

Table 1: Recommendations for ageing-related hearing and vision impairment in people with dementia. Adapted with permission from Leroi *et al* (2020) Hearing and Vision Impairment in People With Dementia: A Guide For Clinicians. *Archives of Physical Medicine and Rehabilitation* 101(9) 1667-1670.

Detection

1. Raise awareness among hearing, vision, and dementia experts about the overlap of these problems.
2. Detect hearing and vision problems early to ensure better outcomes, such as improved quality of life and functional ability.
3. Offer hearing and vision testing to people newly diagnosed with dementia.

Assessment

1. Consider the impact of hearing and vision problems on cognitive testing for dementia diagnoses to ensure accurate diagnosis.
2. Modify hearing and vision testing to consider a person with dementia's difficulty in self-reporting symptoms and providing accurate feedback during clinical examinations.
3. Hearing and vision specialists should adapt testing by: (1) doing home assessments, if possible; (2) scheduling sessions at times when a person is most alert; (3) simplifying instructions and allowing extra time for the testing; (4) allowing caregivers to be present during the testing; and (5) considering that a person with dementia may not fully understand instructions or may respond slowly.
4. Consider hearing and vision impairments as a contributing factor if a person with dementia develops responsive behaviours (ie, apathy, agitation, aggression) or hallucinations.

Treatment and support

1. Use person-centred approaches, tailored to individuals' needs, and with all relevant disciplines or specialties.
2. Provide dementia awareness training for hearing and vision professionals.
3. Give people with dementia and their care partners information about the impact of hearing and vision problems and offer support and advice about how to use and maintain sensory aids.
4. Offer opportunities to connect with community support services.
5. Ensure that local environments (ie, home, clinic, activity centres) have appropriate lighting, acoustics, and noise reduction.
6. Provide caregivers with additional means of support to reduce caregiving burden and stress.

Vision (and hearing) assessments can be adapted to support the needs of people with dementia. Photo: www.freekpik.com

likelihood of dementia diagnosis.

Additionally, the cognitive assessments that memory clinicians use to diagnose dementia rely on test-takers having good hearing and visual function. Hearing and vision impairments impact on performance of cognitive tests. For example, one study (Jorgensen *et al* 2016) simulated the effect of various levels of hearing loss on performance on a commonly used dementia screening test, the Mini Mental State Examination (MMSE). The researchers found that even relatively mild levels of hearing loss resulted in performance within the 'impaired' range on the MMSE by cognitively normal undergraduate students.

Attempts have been made to adapt cognitive tests for people with hearing or vision impairments, but they have mostly not been validated (Pye *et al* 2017), and modifications adversely affect the sensitivity and specificity of the test to identify dementia (Al-Yawer *et al* 2019).

My colleagues and I recently adapted and validated a version of the Montreal Cognitive Assessment (MoCA) (Nasreddine *et al* 2005) for people with hearing impairment (Dawes *et al* 2019), and this new MoCA is now freely available to registered persons via https://www.mocatest.org/. A similar effort to produce a version of the MoCA for people with vision impairment is under way (Dawes *et al* 2019).

The potential for confounding sensory impairments with cognitive impairment means that clinicians and carers may mis-diagnose a sensory impairment as dementia, or over-estimate the severity of cognitive impairment in someone who has dementia. It is therefore essential that memory clinicians screen for hearing/vision impairment using reliable objective measures and take hearing/vision impairments into account in dementia assessment and management.

Practice guidelines

With input from people with dementia and carers, an international multi-disciplinary working group (of which I am a part) recently published the first international practice guidelines for identification and management of hearing and vision impairment among people with dementia (Littlejohn *et al* 2021). These guidelines are available at www.karger.com/Article/FullText/515892.

The guidelines follow a set of key recommendations for clinicians (Leroi *et al* 2020) (https://bit.ly/hearing-vision-guide-pmr), published by a related group of authors (including myself), and summarised in Table 1 (see p24). These key recommendations were developed by an international multidisciplinary working group including memory clinicians, optometrists and audiologists.

Conclusion

Identifying and supporting hearing and vision impairments offers an inexpensive and effective opportunity to improve quality of life for people living with dementia. Hearing and vision professionals have a key role to play. ■

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How allied health can help

This is the second in a two-part series highlighting the vital contribution that allied health professionals make to the support of people living with dementia and carers. On the following pages, geriatrician **Dr Clair Langford** (below), clinical nurse specialist **Alexia Bradley** and three allied health professionals (dementia advisor **Robert Pinchin**, physiotherapist **Melissa Roach** and speech pathologist **Katie Tsacounis**) explain what this support looks like in practice. Part one*, in the previous issue of *AJDC*, looked at the role of dietitians and occupational therapists, along with neuropsychologists and geriatricians

Allied health is a term used to describe a range of health professionals who are not doctors, dentists or regular nurses. Allied health professionals aim to prevent, diagnose and treat a range of conditions and illnesses and work with doctors and nurses to optimise patient outcomes.

They include: physiotherapists and exercise physiologists, occupational therapists, social workers, neuropsychologists and clinical psychologists, dietitians, speech pathologists, Aboriginal and cultural and linguistically diverse health workers, counsellors, podiatrists, dental hygienists, dementia advisors, diversional therapists, music therapists, pharmacists, optometrists and audiologists.

The different types of dementia and different stages of dementia may require the input of different allied health professionals at different times.

It is not uncommon for dementia to be first flagged by an allied health professional while seeing a person for a routine issue. For example:

- A pharmacist may notice the person is missing tablets in a blister pack or that scripts are being renewed too often or not enough.
- A physiotherapist might notice the person is not remembering an exercise from one visit to the next or not remembering to use their walking aid.
- An optometrist or audiologist may not be able to fix a sight or hearing problem because the brain is not understanding what the person sees and hears – it is not processing the information correctly.
- The person may be losing weight and a dietitian realises that they are forgetting to eat.

These allied health professionals will then contact the person's GP and recommend further assessment.

A team approach to care

The health professionals featured in this series work with clients at the Geriatric Outpatients Therapy Unit at Bulli Hospital Aged Care Centre, in the Illawarra region of NSW.

The purpose-built facility for aged care services is operated by the Illawarra Shoalhaven Local Health District (ISLHD), providing inpatient, outpatient and allied health services.

There are currently six geriatricians (including Dr Clair Langford, author of the accompanying article) who work within the centre's outpatient services clinic. Each week the clinic sees an average of 10 new clients and reviews a further 25 clients.

The clinic provides a team of health professionals including allied health, geriatricians and clinical nurse specialist, working together to offer comprehensive care for older clients and their carers living in the community. A neuropsychology team works externally to the clinic on a referral basis. Similar clinics operate in other NSW area health services.

Typically, people are referred to the clinic by their GP if they are over the age of 65, with one or more of the following:

- Concerns with memory decline
- Concerns with increasing confusion
- Recurrent falls
- Assessment and opinion on driving
- Concerns about functioning at home alone
- Concerns with multiple medications
- Concerns with multiple health conditions.

On their first visit, new clients will undergo a comprehensive geriatric nursing assessment by a clinical nurse specialist before seeing a geriatrician.

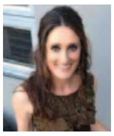
Illawarra Dementia Forum

The articles on these pages are edited versions of presentations given at the 2021 Illawarra Dementia Forum – *Dementia Support: How Allied Health Can Help You* – live-streamed on 10 March 2021. The annual forum is for people with dementia, their families and carers living in the community. The articles are published here with the permission of the speakers and the Illawarra Shoalhaven Local Health District (ISLHD). Information relating to clients and carers has been de-identified.

Geriatrician Dr Clair Langford was the forum's keynote speaker, with other presentations given by the allied health professionals and clinical nurse specialist featured in the articles in this series (parts one and two). Dementia Training Australia (DTA) Executive Director, Professor Belinda Goodenough, hosted the forum's panel discussion.

This year's event was supported by Dementia Australia, DTA, ISLHD, University of Wollongong and the Multicultural Communities Council of Illawarra.

A webinar recording of the forum is available to watch at https://dta.com.au/resources/illawarra-dementia-forum-2021/



Dr Clair Langford is a geriatrician, based at Bulli Hospital and Aged Care Centre, Illawarra Shoalhaven Local Health District, NSW

*** Part one in this series is available to read in full on the *AJDC* website at https://journalofdementiacare.com/how-allied-health-can-help/**

THE CLINICAL NURSE SPECIALIST

Alexia Bradley
Clinical Nurse Specialist,
Geriatric Outpatients Therapy Unit,
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Illawarra Shoalhaven Local Health District

People referred to the Bulli Health Aged Care Centre's Geriatric Outpatients Therapy Unit (GOTU) undergo a comprehensive geriatric nursing assessment by a clinical nurse specialist before seeing a geriatrician. The areas assessed include: eyesight and hearing, falls history, exercise, continence, nutrition, medication use and management, pain, functional ability and independence, home environment, cognitive ability, mood and social activity.

I'll use the example of John* to illustrate what this involves. John, 83, lives with his wife Jan. His GP has referred him to the clinic due to a history of memory impairment over the past several years.

First, I check if John has any eye or hearing impairments and a history of falls. If he hasn't had any falls I will discuss if he exercises daily, or has a home exercise program, and will refer him to the clinic's physiotherapist or provide him with a falls prevention booklet, *Staying Active On Your Feet*. If John has had falls in the past year, I will refer him to the occupational therapist and the physiotherapist.

I will then discuss with John if he is incontinent and whether this bothers him. If so, I can refer him to the clinical nurse specialist in the community.

A nutrition assessment determines if John has lost weight or has any difficulty with eating, including coughing. I will refer John to the dietician if he's lost weight, and to the speech therapist if he coughs when eating. People with dementia may experience difficulties chewing and swallowing, and repeated coughing or throat clearing after swallowing food or drinks can be one of the signs.

I check if John managing his own medications, does he forget, or take too many, and how many is he taking? We are concerned if he is on more than five medications.

How is John functioning at home? Can he go to the toilet by himself, does he need help to get in and out of bed, can he shower and dress himself? John does need a little help with showering and sometimes forgets, so I ask if Jan is happy to help, or could John access a community carer though his Home Care Package to help with this activity?

Next, I check if John and Jan need an occupational therapist to assess their home for safety (does the house have stairs, is the bathroom suitable?)

Each client has a cognitive assessment. John scored 25/30 on the Mini-Mental State Examination (MMSE), showing difficulties with remembering three items.

We then talk about John's mood – is he generally happy or sad, is he sleeping well? Because John is experiencing some agitation in the evening, I refer him to our dementia advisor Robert Pinchin, from the Dementia Advisory Service, who can help John and Jan with some strategies to manage this.

Because John is not able to manage at home alone, I will ensure that he has approval for respite care, in case Jan has to be away from home for any reason.

Each client and carer also receives advice on making an Advance Care Directive, which lets family and health care staff know your wishes about treatment and care should you become seriously ill or injured and not be able to make decisions.

Based on my assessment, I have referred John to the occupational therapist, physiotherapist, speech therapist, dietitian and dementia advisor. Jan has received a booklet for carers and the couple has received an Advance Care Directive booklet and the exercise guide, *Staying Active On Your Feet* to help with John's exercise program.

After completing my assessment, I then hand over to one of the unit's geriatricians who will see John (along with Jan) for further assessment and treatment.

** The information presented here is de-identified*

THE PHYSIOTHERAPIST

Melissa Roach
Outpatient Physiotherapy Clinical Lead, Bulli Hospital and Aged Care Centre, Illawarra Shoalhaven Local Health District

As a physiotherapist, my main role is in falls prevention, mobility retraining, strength and conditioning and improving activity levels in the elderly. The following story illustrates how physiotherapy helped Jim* and his wife, and main carer, Carol*.

Jim was referred to me in the early stages of Alzheimer's disease, with worsening mobility and recent falls – two in the last 12 months from tripping and losing balance on turning. He was having to hold onto furniture to keep his balance, had lost his confidence and was no longer going for his daily walk around the block. Jim's activity levels were decreasing and, as a result, his mood was low. He was starting to watch more TV and sleep through the day.

My assessment found that Jim's balance needed improving. He was slow and shuffling when walking and was struggling to get out of a chair without using his hands. Jim wanted to be able to walk around the neighbourhood on his own and visit local friends, go to the local café or club with his wife, catch up with family, and to overcome his fear of falling.

To achieve this, his physiotherapy goals were to improve his leg strength and ability to get out of a chair, along with his walking ability and balance. This would lower his risk of falls and improve function.

Jim's treatment sessions involved his wife Carol and included:

- Walking practice where Jim was taught to take 'big steps' and put his heel first. Carol was able to prompt and remind him with the same instructions at home.
- Jim purchased a four-wheeled walking frame to increase his confidence. We practised walking outdoors on slopes, ramps and grass. If Jim got tired, he was able to sit and rest.
- Jim practised how to get out of a chair easily and transfer safely from a car. Carol was given clear, simple instructions that she could use with Jim at home.
- A home exercise program was provided to improve Jim's leg strength and balance.

The exercise routine was incorporated into Jim's daily activities – for example doing standing-up practice and leg extensions whilst watching TV or doing balance exercises while at the kitchen bench. At a later time, Jim's Home Care Support person would also prompt and perform exercises with him after his shower or accompany him on a walk.

Physiotherapy helped improve Jim's strength, balance and walking after eight to 10 weeks. He was able to achieve his goal of walking around the neighbourhood using his four-wheel frame, and then later with his carer when he required more support. He could visit the local café or club safely and maintain social contacts with friends and family. His activity levels and his mood improved and he was able to stay connected with people – all things we know are important in slowing the progression of dementia.

** The information presented here is de-identified*

THE SPEECH PATHOLOGIST

Katie Tsaccounis
Speech Pathologist, Aged Care, Rehabilitation and Palliative Care Speech Pathology Clinical Leader, Illawarra Shoalhaven Local Health District

People with dementia may develop problems with both communication and swallowing.

For some people with dementia, difficulty talking is the first symptom they experience. Problems with communication can involve difficulty finding the right words to use when talking, making errors when talking, difficulty reading or writing, talking but not making sense, or difficulty understanding instructions.

Signs of problems with swallowing may include coughing when eating or drinking, needing to use extra swallows, eating and drinking less or taking longer to finish a meal.

Communication and swallowing problems can be distressing for both the person with dementia and the people around them. Education and support from a speech pathologist can help the person with dementia to live well despite these challenges.

We aim to promote independence, participation and maximise quality of life. For example:

- If a person with dementia has difficulty calling their family members by the right names, we might work with them to make some photo cards to use to remind them who is who.
- If a person gets stuck when talking because the word they want is ‘on the tip of their tongue’, we might work with them to find a strategy that is helpful, such as describing the word instead.
- If a person is coughing when drinking, we may be able to stop that by using a special cup or making the drink slightly thicker.
- If a person has a soft voice, we can try therapy to make it louder.
- If a person is unable to have a conversation but still enjoys interacting with others, we might work with their loved ones to make a life story book to help make those interactions meaningful and relevant.
- If a person has difficulty communicating, we might teach their loved ones how best to communicate with them using Communication Partner Training.

Speech pathologists often work together with dietitians and occupational therapists to help a person with dementia achieve their goals.

The following stories involve people with dementia who have recently seen a speech pathologist at my workplace.

The first story is about a 75-year-old man with a type of dementia called Lewy body disease. People with Lewy body disease can develop problems with communication and swallowing. This man was slowly talking less and less because of changes to his speech and voice. His voice was getting softer and his speech less clear, making it difficult for people to hear and understand him. This man saw a speech pathologist who did Lee Silverman Voice Treatment (LVST) with him – an intensive treatment program that has made his voice louder, his speech clearer and made it easier for him to have a conversation with his family and friends.

The second example is an 82-year-old woman with Alzheimer’s disease. She had always been a quiet person but was getting quieter with time. She was able to say hello, ask simple questions and follow simple instructions but was unable to have a conversation. The speech pathologist worked with her husband to create a life story book.

A life story book is a book about someone, with words and pictures or photos. It can include information about where the person was born, their life, family members, interests, previous hobbies, likes/dislikes etc. Having this book meant that when carers came to the house they could look through this book and have a meaningful interaction. “Oh I didn’t know you were born in Canberra, I was born there too!” “Is that your daughter, doesn’t she look lovely on her wedding day” or “Do you like roses? I’ll bring some from my garden next time”.

** The information presented here is de-identified*

THE DEMENTIA ADVISOR

Robert Pinchin
Dementia Advisor, Dementia Advisory Service, Illawarra Shoalhaven Local Health District

As a dementia advisor with the Dementia Advisory Service, I work with the Bulli Hospital and Aged Care Centre’s team to provide counselling and support for our clients and their carers. My role is to explain what dementia is, what is happening to the person who has been diagnosed, what is happening inside their brain, and how that will affect their overall life experience and that of the carer who is living with them.

I also work with the team to provide clients with a range of therapeutic approaches to help them achieve specific goals and improve their confidence to continue with activities they enjoy or skills they want to retain, such as singing, for example.

An example of the work I do with carers is the cooking group we established, at the Carunya Dementia Day Therapy Centre in Warilla, for the male partners of some of our female clients. After telling us they needed help with learning to cook, we set up the group so the men could join a cooking class while their partner was attending respite at the centre.

The male carers learnt how to prepare and cook a meal, their partners then joined them in the dining room and everyone had a lovely meal while sharing their stories.

You don’t need a good memory to enjoy beautiful meals, a beautiful cup of coffee or a beautiful walk along the beach. People with dementia live in the moment and it is up to us as clinicians and carers and families to make that a good moment.

Image: rawpixel.com/freepik.com

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.

What's needed to stay at home together?

Claire Morrisby, Marina Ciccarelli, Annette Joosten and **Janet Beilby** discuss research which reveals a gap between what people with dementia and their partners living in the community say they need and what service providers think they need

Love, humour, patience and tolerance were key values identified by spousal carers when it came to providing support to their partners through the disease process. Photo: www.freepik.com/pvproductions

Older adults often identify staying at home as a priority (McGrath *et al* 2021). A diagnosis of dementia rarely changes that, but it does create challenges as the person with dementia requires increasing support to stay at home.

Support is most commonly provided by families, in particular, spouses, with formal care services supplementing this. Reports over the past decade have indicated "a need for services that meet [carer and people with dementia] needs rather than the needs of the service providers" (Alzheimer's Australia 2011 p8) and that most recently, "when they do get access to care, they may receive less care than they need or they may not have access to specific services they need" (Royal Commission into Aged Care Quality and Safety 2021b p65).

Information and access to respite services for people with dementia continue to not meet carers' needs (Phillipson *et al* 2019). Ongoing restrictions in funding and availability of appropriate home-based care, where services are provided, mean that people with dementia and carers still experience unmet needs. In addition, carers experience difficulties in recognising their own needs, and those of the person with dementia they care for which may limit service use (Morrisby *et al* 2018).

This article reports on a study published in 2020, (Morrisby *et al* 2020) which aimed to identify what carers of people with dementia, and the person with dementia themselves, perceive they need. It also sought to identify whether this aligned or differed with what service providers perceive they need.

➤

Background

Spousal carers often transition from their roles as 'husband and wife' to 'carer and person with dementia', as the carer becomes the primary decision maker (Braun *et al* 2009; Fetherstonhaugh *et al* 2016). Changes occur in intimacy, identity, and perceived role within the relationship. Recognition and understanding of the unique needs of spouses as they interact with community aged care services is important in developing effective services (Braun *et al* 2009).

Consumer-directed aged care potentially provides greater flexibility and person-centeredness in the delivery of care services for people with dementia (Low *et al* 2011). However, a lack of information about available care, poor quality services and carers' sense of obligation to provide care may act as barriers to accessing support (Macleod *et al* 2017).

The views of people with dementia have not often been included in research; however, their inclusion in qualitative research is important in developing personalised and responsive services (Braun *et al* 2009; Carmody *et al* 2015).

Research on dementia-specific services in Australia has considered the experiences of carers who use services, including reasons for this service use (or non-use), evaluating strategies to understand and meet the needs of carers and understanding information-seeking behaviours of carers (Aoun *et al* 2018; Brodaty *et al* 2005; O'Connell *et al* 2012; Phillipson *et al* 2019; Robinson *et al* 2012).

A broader discussion of the needs of people with dementia and their spousal carers is important in developing services and systems that will support couples living in the community. Service providers have a unique perspective when addressing needs because they are positioned to provide support as a priority (Danaher & Gallan 2016) and may understand the barriers to meeting these needs at a broader level.

Method

The study described in this article involved interviews and focus groups. The interview and focus group data were analysed using a two-phased thematic analysis (Braun & Clarke 2012), which is a flexible and inductive approach to data analysis.

Ten qualitative interviews were conducted with people with dementia and their spousal carers living at home in Perth, Western Australia (WA), followed by two focus groups with spousal carers, and interviews with 10 community service providers within the same community of people in Perth.

Results

The interviews with people with dementia and their spousal carers explored the participants' experiences across a range of needs, and as dementia progressed, the changing nature of these needs. Three overarching themes emerged:

- Factors that support care. This theme included three sub-themes: institutional support that is timely, effective, and affordable; a safe home and community; and a social environment that is supportive and well-educated.
- Strong caring relationships.
- Engaging in meaningful activities for people with dementia and carers.

Conversely, service providers identified that:

- Services and supports required by people with dementia and their carers should be flexible, tailored and equitable.
- The skills, attitudes and power of people with dementia and their carers need to be identified and developed.
- Current systems designed to care are fragmented and difficult to navigate.

At a thematic level, the perspectives of both participant groups aligned (see Figure 1, below). However, service providers primarily considered the needs of people with dementia and spousal carers through the lens of the services available to them.

Factors that support care

Factors that support dementia care were described by spousal carers and people with dementia as encompassing three distinct levels: institutional (eg, government-funded support services and systems), social, and physical.

Institutional support that is timely, effective and affordable

This theme was articulated as important for spousal carers living with people in the later stages of dementia and aligned with the needs of people with dementia reported by service providers. In particular, it was highlighted how services should be tailored to meet progressive needs of people with dementia and should provide relationship-based care. Both participant groups identified a lack of consistent and skilled support workers available to provide relationship-based care:

"They [service providers] give them different placings, which I object to because when you get used to somebody, they know exactly what to do".

Access to skills training for community-based support workers and adequate education for health professionals involved in diagnosis and coordination of care was identified as inconsistent by service providers. There was agreement regarding the need for flexible hours of care and support to access services such as short-term respite.

Spousal carers reported that the cost of services restricted them from accessing the amount of services that would help them manage their loved one's needs successfully; in contrast, service providers reported that spousal carers required more education regarding fee waiver options.

Both groups agreed that Government Centrelink support was difficult to access and navigate. Service providers offered insights into the barriers that impacted the support and care available for people with dementia and

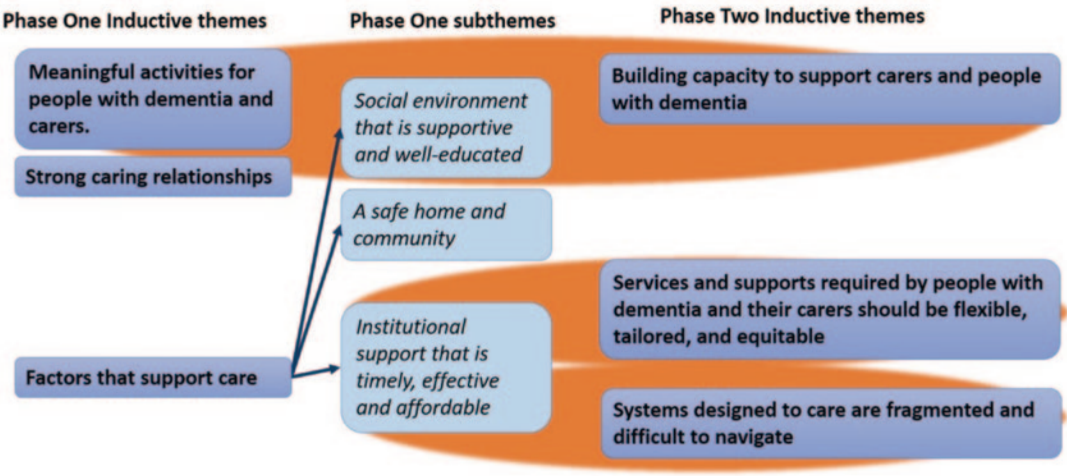

Figure 1: Phase one and phase two themes that emerged from the study described in this article

spousal carers:

"I think that's part of the challenge, you could have two people who are fairly similar in progression of their dementia and their needs, if you go to one service provider you might get this, if you go to another service provider you might get this. And it's trying to navigate the quality or equity."

Further, they identified how inequities existed in the current assessment and service access pathways, which is an issue corroborated by people with dementia and spousal carers in the navigation between public and private diagnostic services such as memory clinics and private geriatricians.

Fragmentation within the system, such as needing to contact multiple services to access information or support was described by service providers, though less commonly by spousal carers.

A social environment that is supportive and well-educated

Spousal carers and people in the early stages of dementia reported that knowledge and understanding of dementia in their social networks contributed to the amount of support they received. These social supports were outlined as family, friends and acquaintances.

Although supported in general by service provider participants, there was limited recognition of the extent of the impact of stigma, and thereby the buffering support offered by social networks.

Furthermore, the importance of social support from other people with dementia and family carers was almost exclusively described by spousal carers and people with dementia, eg: *"They've [the person with dementia] got people there, the same as what they are or similar to what they are. And we've got people that we can talk to and communicate with. So, to me that's a real asset"*, underlining a lack of recognition of the value of this support from service providers.

Key points

What is known about this topic?

- Spousal carers and people with dementia living at home need support to manage with the changes that occur with dementia.
- The available community services are often difficult to access and may not meet the needs.

What does this article add?

- It highlights that there is a gap between what spousal carers and people with dementia describe they need, and what service providers consider most important.
- It highlights that the needs of people with dementia and spousal carers are much broader than the available services.

Points for practice

- Providing education and reducing stigma about dementia for families and the general public is important.
- Finding ways to support people with dementia and their spouses to continue their meaningful activities is critical to enable people with dementia to continue living at home.

People with dementia and spousal carers identified that family who lived close by tended to provide more care and demonstrate greater awareness and understanding of the impacts of dementia.

Service providers recognised the importance of education and knowledge of dementia to improve family-based support in geographically separated families, however, identified that it was difficult to know who could provide this.

A safe home and community

The decisions made by spousal carers and people with dementia (in the early stages) regarding where they would live considered not just the family home (which was well understood by service providers) but also access to local shops, medical care and the overall feeling of safety in the community.

Service providers repeatedly identified the importance of adapting the home environment to maximise safety and function, however, they indicated that they were generally unable to provide comprehensive support in this area themselves, or refer on to another agency for this support, due to a lack of available funding.

Strong caring relationships

Spousal carers, people with dementia (in early to moderate stages) and service providers all recognised the importance of maintaining strong spousal relationships through adapting roles and responsibilities within the relationship and the importance of seeking ongoing support. Love, humour, patience and tolerance were key values identified by spousal carers when it came to providing support through the disease process.

Service providers identified a spectrum of adaptability in spousal relationships of carers with whom they had worked. Carers' knowledge and understanding of dementia was identified as a mediating factor that impacted upon adaptability, and that assessment needed to consider the needs of both:

"We allow them the opportunity to discuss things separately, because often, you know, we see the person with the spouse, but we need to make sure that we can separate at some stage, so they can really talk openly about what's going on."

Coping strategies, both effective and ineffective, were identified by service providers as developing organically with the progression of dementia; however, ineffective coping strategies were linked to early admission to residential care.

Education and collaborative development of coping strategies were identified as important for future community-based services.

Meaningful activities

Most spousal carers and people with dementia identified the importance and value of continuing to perform meaningful tasks and roles, such as being an active grandparent or contributing to home maintenance. People with dementia identified how they often needed help to continue to perform everyday tasks.

In comparison, only two service providers identified that an important part of their role included supporting carers and people with dementia to adapt to changes in functional performance related to the progression of dementia.

Conclusion

People with dementia and spousal carers interviewed for the study presented a dynamic care situation which inevitably poses a challenge for service providers.

Service providers identified a range of needs for their clients, but rarely considered needs that were beyond services and supports already funded, such as supporting spousal carers to develop caring skills.

Both groups of participants offered insights into the challenges and barriers of effective community care, including accessing the right types of information and support at the right time in the dementia journey, and access to well-trained community-based staff.

Although the study discussed in this article was completed during the introduction of Commonwealth Home Support Program and Home Care Packages, the Aged Care Royal Commission findings released this year echo the needs identified here for early and consistent support for informal and family carers, improved access to home modifications, assistive technology and respite support (Royal Commission into Aged Care Quality and Safety 2021a).

Key recommendations from the study include a greater focus on education about dementia for family carers, and the general community, as this may reduce the impact of stigma on availability of social support.

Finally, the importance of supporting people with dementia and spousal carers to adapt within their relationship and support ongoing meaningful roles as dementia progresses was highlighted.

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From left: Dr Claire Morrisby is an occupational therapist specialising in dementia care, and a lecturer in the School of Allied Health at Curtin University, WA; Marina Ciccarelli is an Associate Professor in the School of Allied Health at Curtin University; Annette Joosten is an Associate Professor in the School of Allied Health at Australian Catholic University, Victoria and Adjunct Associate Professor at Curtin University; and Janet Beilby is an Associate Professor in the School of Allied Health, Curtin University. To follow up on this article, contact Claire at Claire.morrisby@curtin.edu.au

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New resources to guide staff in delivering Behaviour Support Plans

Dementia Support Australia (DSA) has released a substantial toolkit of resources to support delivery of **Behaviour Support Plans** in residential aged care settings – which, as of 1 September 2021, are mandatory for residential aged care providers, whenever a resident is needing behavioural support or when a restrictive practice is imposed or likely to be imposed.

The suite includes a website hub with information and links to a long list of resources, including:

- Behaviour Support Plans: Your Essential Guide
- The When and What of Behaviour Support Plans
- The Behaviour Support Plan Template (when no restrictive practices are used)
- The Behaviour Support Plan Template (where restrictive practices are used)
- DSA Behaviour Frequency Chart
- DSA Behavioural Assessment Form
- Behaviour Support Flowchart
- Behaviour Care Planning Process
- ABCDE Posters
- DSA Lifestyle and social history form
- Brain and Behaviour Factsheet
- DSA Abbey Pain Scale
- The Guide to the Cornell Scale for Depression in Dementia

The key resource – the 36-page 'essential guide' – sets out in detail the three key steps that are required in offering behaviour support to a person living with dementia who is experiencing changes in their behaviour: (i) identify (ii) assess and (iii) plan, implement and evaluate.

The guide is aimed at all staff involved in delivering care to people living in residential care settings. It includes case studies and explains how to use each of the related DSA Behaviour Support Plan resources (eg the DSA Behaviour Frequency Chart). All the resources can be found here: https://dementia.com.au/bsp

RESEARCH NEWS

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

Mealtimes in residential care

UK researchers have conducted a systematic review to identify good practice in mealtime care for people living with dementia in residential aged care facilities, by focusing on carer-resident interactions at mealtimes.

Searches of seven databases resulted in 18 studies being included in the review. The studies varied in design, with the majority being qualitative (13); two were randomised controlled trials. The studies also varied in their focus: some assessed mealtime care interventions, while others explored factors that contribute to oral intake. Others looked at the overall mealtime experience.

The researchers used narrative synthesis to identify four broad categories of carer–resident interaction:

- 'Social connection': interactions which build relationship between carer and resident, and which facilitate social connection at mealtimes, identified in six studies.
- 'Tailored care': interactions which are tailored to the individual, identified in 12 studies.
- 'Empowering the resident': interactions which promote the resident's autonomy and independence, featured in six studies.
- 'Responding to food refusal': interactions which carefully and skilfully address the challenge of food refusal (five studies).

The researchers say the quality of the evidence was variable and that, while it was not possible to make definitive practice recommendations, the findings may be informative for practitioners seeking to improve the mealtime experience for people living with dementia in residential aged care. They say their identified categories are echoed in dementia care literature and broader mealtime care literature and provide important direction for future research.

Faraday J, Abley C, Beyer F *et al* (2021) How Do We Provide Good Mealtime Care For People With Dementia Living In Care Homes? A Systematic Review Of Carer–Resident Interactions. *Dementia*. First published online April 7, 2021. doi: 10.1177/14713012211002041.

End-of-life dementia care: qualitative study

Residential and care managers from HammondCare residential aged care homes in Australia have contributed to a new qualitative study on providing end-of-life care for people living with dementia.

The 20 residential or care managers came from 11 different residential aged care homes, in NSW and Victoria, and participated in either one of two focus groups (a total of 16 participants) or individual semi-structured interviews (with four participants). Transcripts from the focus groups and interviews were then analysed using thematic analysis, with six themes identified: laying the ground work to establish what families understand about dementia; playing the peacemaker in the face of unrealistic family demands and expectations; chipping away at denial and cultivating a path towards acceptance of death; recruiting general practitioners as allies; supporting and strengthening the front line; and dedication to optimal care is relentless but rewarding.

Participants said they found end-of-life dementia care to be rewarding, but also sometimes "fraught", requiring persistent efforts to personalise care and communication with family to support their acceptance of the resident's terminal condition.

The authors conclude that skill development, family discussions, and partnership building between aged care staff and general practitioners are all needed to support optimal end-of-life dementia care in residential aged care settings.

Borbasi JAL, Tong A, Ritchie A *et al* (2021) "A Good Death But There Was All This Tension Around": Perspectives Of Residential Managers On The Experience Of Delivering End Of Life Care For People Living With Dementia. *BMC Geriatrics* 21(1) 306. doi:10.1186/s12877-021-02241-7.

World-first research strategy for brain health, dementia: Alzheimer Scotland, Scottish Dementia Research Consortium and Brain Health Scotland have collaborated to produce what is being described as a world-first: a standalone research strategy for brain health and dementia (as opposed to a general dementia plan or strategy). The publication, *We Are All Researchers: Scottish Brain Health and Dementia Research Strategy* (pictured) launched in July, defines key areas for strategic actions, in order to achieve an increased national research portfolio over the strategy's lifetime (four years). It is hoped that the strategy will aid practitioners, researchers and the public to come together to pursue meaningful research to help improve the lives of people with dementia and their carers.

End-of-life home-based nutrition and hydration

Researchers from University College London have explored family caregivers' and professionals' awareness of eating and drinking difficulties experienced by people living with dementia towards the end of life at home, as well as caregivers' needs and ways of overcoming such difficulties.

They say that, until now, little has been known about the needs of caregivers and the strategies they use to manage eating and drinking difficulties at any stage of the dementia journey – despite the prevalence of eating and drinking difficulties among people living with dementia, particularly at the end of life.

The researchers conducted 41 semi-structured interviews with family caregivers (21) and professionals (20), which were recorded and then transcribed. Themes identified were: caregivers accessing and seeking help, perceived priorities of care, professionals' supportiveness and educational role, and strategies.

The researchers found that caregivers were not necessarily aware of the impact of dementia on eating and drinking when nearing the end of life, did not necessarily seek professional help when difficulties emerged and often struggled for some time before seeking help or finding a strategy that worked for them.

The researchers recommend that post-diagnostic support should sensitively cover this topic, and conclude that mutual collaboration and knowledge sharing between family caregivers and professionals may promote the successful identification of strategies to support comfort and enjoyment towards the end of life. They say cargivers' input is needed to tailor professionals' recommendations.

Barrado-Martin Y, Nair P, Anantapong K *et al* (2021) Family Caregivers' And Professionals' Experiences Of Supporting People Living With Dementia's Nutrition And Hydration Needs Towards The End Of Life. *Health and Social Care in the Community*. First published online 6 May, 2021. https://doi.org/10.1111/hsc.13404.

Skills and support needs of the home care workforce

A substantial UK ethnographic study has investigated the skills, training and support needs of home care workers who are supporting people living with dementia in the community.

The study involved interviews with 82 research participants: 11 people living with dementia, 22 family caregivers, 30 home care staff and 19 health and social care professionals, as well as 100 hours of participant observations with 16 home care workers.

The interview and observational findings were triangulated, and the data analysed thematically to identify four themes:

- ‘Navigating the home care identity and role’: describing challenges of moving between different role identities and managing associated expectations.
- ‘Developing and utilising relational and emotional skills’: boundaries between caring and getting emotionally involved felt blurred and difficult to manage.
- ‘Managing clients who resist care’: home care workers experienced clients’ reactions as challenging and felt “thrown to the wolves” without sufficient training.
- ‘Drawing on agency and team support’: home care work could be isolating, with no shared workplace, busy schedules and limited opportunity for peer support.

The researchers found that home care workers faced ethical dilemmas when supporting people living with dementia who resisted care, for example when offering personal care. They conclude that a key area for training is developing a clear understanding of how to provide care that is in the client’s best interests while also respecting their wishes, and that experiential learning may help to develop necessary skills to deliver safe and effective care, with empathy, dignity and respect.

The researchers say that it is important that training and support for home care workers addresses the relational, emotional and rights-based aspects of the role, and that where a flexible, responsive, person-centred service is required, corresponding training and support is needed, alongside organisational practices, taking account of the broader context of the home care sector.

Leverton M, Burton A, Beresford-Dent J (2021) ‘You Can’t Just Put Somebody In A Situation With No Armour’. An Ethnographic Exploration Of The Training And Support Needs Of Homecare Workers Caring For People Living With Dementia. *Dementia.* First published online June 10, 2021. https://doi.org/10.1177/14713012211023676.

Non-pharmacological care in hospital

Researchers from Austria and Switzerland have conducted a systematic review of non-pharmacological interventions for patients with dementia and cognitive impairment on regular wards in acute care hospitals (not intensive care units or emergency departments). The review was part of a larger project to develop a care model for people with dementia in the acute hospital setting in Switzerland.

A review of five databases resulted in 20 studies being included in the review, covering a broad range of interventions and outcomes. The researchers categorised the interventions into eight types: educational programs, special non-pharmacological interventions, delirium management programs, inpatient rehabilitation interventions, family-/person-centred programs, use of specially trained nurses, volunteer programs and special care units.

The most reported intervention type was educational programs (eight studies in total), and these did result in improved staff outcomes, including in knowledge and confidence. The researchers say this should be interpreted cautiously though, due to the high risk of bias (no control group and no blinding of outcome assessment).

Other interventions – such as the use of specially trained nurses, family-/person-centred programs and delirium management programs – did seem to have some influence on outcomes related to the organisation, staff, family caregiver and patients.

The researchers conclude that on current evidence it is not possible to say which interventions are effective in improving dementia care in acute hospitals.

Future research should focus on relevant patient and family caregiver outcomes and must consider the complexity of the interventions when evaluating them.

Karrer M, Schnelli A, Zeller A, Mayer H (2021) A Systematic Review Of Interventions To Improve Acute Hospital Care For People With Dementia. *Geriatric Nursing* 42(3) 657-673. doi: 10.1016/j.gerinurse.2021.03.006.

Support for carers: systematic review

Spanish researchers have conducted a Cochrane systematic review to assess the efficacy and acceptability of remotely delivered information, training and support aimed at reducing burden and improving mood and quality of life for informal caregivers of people living with dementia.

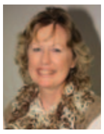
The review included 26 randomised controlled trials. The researchers examined: (1) interventions involving training, support or both, with or without information, and compared this with those receiving usual care or on a waiting list (12 studies, 944 participants); and (2) simple information provision compared with more complex interventions involving training or support (14 studies, 1423 participants). Interventions lasted an average of 16 weeks, and most of the studies were conducted in North America or Europe, with three in China. Interventions were generally delivered by telephone or internet (about half-half).

The researchers concluded that the caregiver interventions examined probably have little or no effect on caregiver burden, depressive symptoms or health-related quality of life. When comparing experimental interventions with a control condition of information alone, the researchers found that training and support interventions “may result” in a slight reduction in caregiver burden; “probably result” in a slight improvement in depressive symptoms; and “may result” in little or no difference in caregiver health-related quality of life. The researchers did not find any evidence on whether the interventions improved the quality of life of the people with dementia who were being cared for.

The researchers’ confidence in the findings was moderate or low, particularly given the risk of bias from self-reporting of subjective outcomes by participants who were not blind to the intervention. They say further research is needed.

González-Fraile E, Ballesteros J, Rueda J-R *et al* (2021) Remotely Delivered Information, Training And Support For Informal Caregivers Of People With Dementia. *Cochrane Database of Systematic Reviews* 2021, Issue 1. Art No: CD006440. DOI: 10.1002/14651858.CD006440.pub3.

DCRC seeks input for 'BPSD' resources updates



By Kim Burns, Knowledge Translation Fellow, Dementia Centre for Research Collaboration (DCRC)

In 2011 the Australian Government funded the Dementia Centre for Research Collaboration (DCRC) to develop the evidence- and practice-based document *Behaviour Management, A Guide to Good Practice, Managing Behavioural and Psychological Symptoms of Dementia (BPSD Guide)** and associated resources including:

- *A Clinician's Field Guide to Good Practice*
- *A Guide for Family Carers*
- The *BPSD Guide* app for clinicians
- The *Care4Dementia* app for family and frontline carers (both apps currently have limited functionality due to operating system updates).

The Australian Government Department of Health is now funding the DCRC to update these resources, to be completed by December 2022. This project extends beyond the closure of DCRC at the end of 2021 (see article pp15-16), under the Centre for Healthy Brain Ageing (CHeBA, which also sits within UNSW).

Consultation now open

The DCRC is seeking consultation with care partners, clinicians, hands-on care staff and service providers across Australia, particularly those who have used the current BPSD resources. Your input will help ensure the updated resources meet the needs of the targeted audiences.

If you are willing to participate in a short phone or Zoom interview, or you prefer to email your comments, please contact me at DCRC (k.burns@unsw.edu.au) by Monday 15 November. You can also email me to request hard copies (remaining stocks of some versions are limited).

References

Cunningham C, Macfarlane S, Brodaty H (2019) Language Paradigms When Behaviour Changes With Dementia: #BanBPSD. *International Journal of Geriatric Psychiatry* 34(8) 1109-1113. doi: 10.1002/gps.5122.

Dementia Australia (2021) *Dementia Language Guidelines*. Available at: https://bit.ly/DA-dementia-language-guidelines

To access the BPSD guides, go to https://dementiaresearch.org.au/resources/bpsdguide/

**The term 'behavioural and psychological symptoms of dementia (BPSD)' is used respectfully. Dementia terminology has changed since the BPSD Guide was published and this will be reflected in the updated versions. For more on this, see the article written by Cunningham et al (2019) in the* International Journal of Geriatric Psychiatry, *and for more information on terminology, consult the Dementia Australia* Dementia Language Guidelines (2021).

Quality improvement collaboratives

This paper reports on a process evaluation of the quality improvement collaboratives (QICs) set up as part of the Agents of Change trial, which sought to improve adherence to the Australian *Clinical Practice Guidelines and Principles of Care for People with Dementia* among 45 clinicians (the findings of which have been reported elsewhere). The evaluation involved asking participants from the QICs to complete a survey before and after the QIC intervention, as well as participate in an interview before and after the intervention, in order to develop, test and refine the program theory of a QIC. Of the 45 clinicians involved in the Agents of Change trial, 28 were involved in this process evaluation. The researchers established how and why clinicians built knowledge and skills in quality improvement in dementia care, identifying six mechanisms: motivation, accountability, identity, collective learning, credibility and reflective practice. When combined, these mechanisms operated to overcome constraints, role boundaries and pessimism about improved practice in dementia care. The researchers concluded that a quality improvement collaborative designed for clinicians in different contexts and roles was acceptable and feasible in building knowledge, skills and confidence of clinicians to improve dementia care. Supportive reflective practice and a credible, flexible and collaborative process optimised quality improvement knowledge and skills in clinicians working with people with dementia.

de la Perrelle L, Cations M, Barbery G *et al* (2021) How, Why And Under What Circumstances Does A Quality Improvement Collaborative Build Knowledge And Skills In Clinicians Working With People With Dementia? A Realist Informed Process Evaluation. *BMJ Open Quality* 10. doi: 10.1136/bmjoq-2020-001147.

Mortality rates in dementia

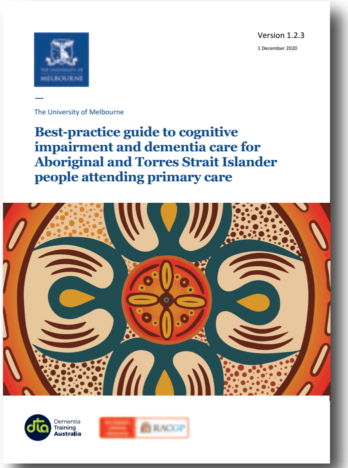
An international team of researchers has concluded that Alzheimer's disease has the most favourable survival-related outcomes compared with non-Alzheimer's dementias, and Lewy body dementias have the highest all-cause mortality rates, compared with individuals without dementia.

The findings come from an article published in July in *The Lancet Healthy Longevity* journal, which the authors say is the first systematic review and meta-analysis to compare mortality rates and survival outcomes between people with Alzheimer's disease, people with non-Alzheimer's dementias, and people without dementia, based on all available published evidence (78 studies, involving 63,125 individuals with dementia and 152,353 controls). They say the mean survival time was 7.6 years from Alzheimer's disease onset and 5.8 years from diagnosis. Compared with people with Alzheimer's disease, people with non-Alzheimer's dementias had higher mortality rates, shorter survival times from diagnosis, and younger ages at death. The researchers say the findings support the view that treatment and rehabilitation programs need to be tailored according to the person's specific dementia diagnosis.

Access the study here: https://bit.ly/3jzXlaL

Prevalence of younger onset dementia

JAMA Neurology has published a systematic review conducted by researchers from the Netherlands into the global prevalence of younger onset dementia. A total of 95 studies were included in the review, of which 74 were included in the meta-analysis. The global age-standardised prevalence of younger onset dementia was 119 per 100,000 population aged 30 to 64 years – which equates to 3.9 million people aged 30 to 64 years living with younger onset dementia across the world. This figure is double that reported by Harvey *et al* (2003) in one of few previous prevalence studies of younger onset dementia conducted in the world. That study reported a 54 per 100,000 prevalence rate of younger onset dementia in the UK. The 2021 study reported that prevalence was similar between men and women, while prevalence was lower in high-income countries compared with upper-middle-income and lower-middle-income countries, although the authors acknowledge that estimates of the prevalence in low-income countries and younger age ranges are scarce. Access this study here: https://bit.ly/3t91v27



Version 1.2.3
1 December 2020

The University of Melbourne

Best-practice guide to cognitive impairment and dementia care for Aboriginal and Torres Strait Islander people attending primary care

Best-Practice Guide To Cognitive Impairment and Dementia Care For Aboriginal and Torres Strait Islander People Attending Primary Care is a new RACGP-approved resource produced as part of the Let's CHAT (Community Health Approaches To) Dementia project, written by researchers from the University of Melbourne. The NHMRC-funded project is working with 12 Aboriginal Community Controlled Health Services across Australia to support increased detection of cognitive impairment and better dementia care in Aboriginal and Torres Strait Islander populations. The 24-page evidence-based guide aims to include cultural principles within its recommendations on health promotion and prevention, detection and management of cognitive impairment and dementia, including recommendations about care at the end of life and carer health and wellbeing. Consensus on the recommendations in the guide was reached through extensive consultation with clinical and cultural experts, including a modified Delphi process involving 39 clinicians, researchers and other health practitioners, Aboriginal, Torres Strait Islander and non-Indigenous. The guide is available at https://bit.ly/3lRX5et

In **Dementia in Practice**, a new series of podcasts released by Dementia Training Australia (DTA), general practitioners Dr Hilton Koppe, Dr Marita Long and Dr Steph Daly share their professional and personal experiences with dementia. The hosts are all GPs and members of DTA's GP Clinical Education Group. The GPs are hoping that listeners will be helped to better understand what dementia is and how to prevent it, diagnose it, manage it and live with it. The five episodes released now are: **Introducing Dementia in Practice; Life With Dementia: A First-Hand Account; Healthy Ageing and Dementia: How To Recognise The Difference; Diagnosing Dementia in General Practice Part 1 and Part 2.** A further four episodes are currently in production. The short introduction is six minutes; all other episodes are 20-30 minutes in length. Access the podcasts here: https://dta.com.au/general-practitioners/#podcast

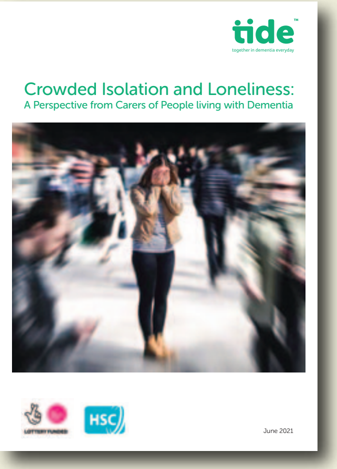
Dementia Australia has worked with community-based home care workers to develop a new educational resource which they can access anywhere, any time. **Ask Annie** is a mobile app that offers short, self-paced learning modules of 10-15 minutes on dementia care in the community, aimed at home and community care workers. According to Dementia Australia, 'Annie' guides users through a range of scenarios, based on real-life experiences, to strengthen their dementia care skills. It says that providers can purchase a multi-licence package for their staff by contacting Dementia Australia's Centre for Dementia Learning at https://dementialearning.org.au/askannie. The app was developed by Dementia Australia with Deakin University's Applied Artificial Intelligence Institute (A2I2), with financial support from Gandel Philanthropy.

Dementia UK has published a new series of online information, called **Going Out**. In each of the three articles, Admiral Nurses (dementia specialist nurses) share practical advice for navigating the experience of going out with a person living with dementia to a particular social or cultural venue: 'Going to the cinema with a person with dementia'; 'Going to galleries, museums and exhibitions with a person with dementia'; and 'A trip to the restaurant with a person with dementia'. The information makes practical suggestions such as things to consider ahead of time, making choices, and environmental issues and signposts readers to related resources too. Access the resources here: https://bit.ly/3s76EqN

During June/July 2021, OPAN (the Older Persons Advocacy Network) ran a series of three webinars which are now available to view (or to read the transcripts): **Communicating With People Living With Dementia; Alternative Approaches For People Living With Dementia; and Alternative Approaches To Chemical Restraint**. Each one-hour webinar involves a different panel of four to five people contributing to a discussion on the topic and responding to questions from participants. Panellists include academics, educators, practitioners and people living with dementia or caring for a person living with dementia. Access the webinars here: https://bit.ly/2Xiw0a0

The Lewy Body Society and Dementia UK have published a new eight-page booklet on **Managing Hallucinations and Changes In Visual**

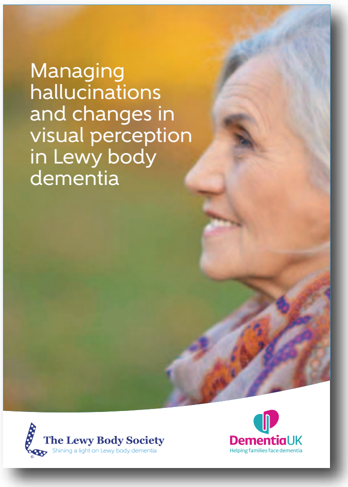
Crowded Isolation and Loneliness: A Perspective From Carers of People Living With Dementia is the title of a new report from tide (Together In Dementia Everyday), the UK-based network of family carers of people living with dementia. The report presents findings from a co-produced research project which investigated issues of social isolation and loneliness among carers of people living with dementia. It was led by a Steering Group consisting of eight carers with support from a tide development worker. The project's findings come from an online survey (103 responses, from family carers) and 29 interviews with family carers, all conducted during March and April 2021. Themes emerging from the research evidence included: family, friends, finances and the future; conversation, connection and self-care; grief and guilt; limbo, loss and lockdown; recognition and support systems. Additional areas of interest included the positive aspects of caring, gender, hidden lives, and the severe impact on mental health. The report says that while the pandemic didn't create the situation of 'crowded isolation and loneliness' it did make it more acute. The report and two associated films can be accessed here: https://bit.ly/2U6iWTN



tide
together in dementia everyday

Crowded Isolation and Loneliness:
A Perspective from Carers of People living with Dementia

June 2021



Managing hallucinations and changes in visual perception in Lewy body dementia

The Lewy Body Society

DementiaUK

Perception In Lewy Body Dementia. The resource is aimed at both people living with Lewy body dementia and family carers, and presents accessible answers to questions such as 'What are visual perceptual changes?' and 'What are hallucinations?'. It explains what treatments are available and makes suggestions for how to manage hallucinations, including 'Useful tips for managing hallucinations', with separate lists for people living with Lewy body dementia and family carers. The booklet is available here: https://bit.ly/3Au9ZTW

Silver Memories is a radio service developed by the Music Broadcasting Society of Queensland Ltd (a Brisbane community radio station known as 4MBS) in 2007 specifically aimed at people living in residential aged care facilities who may be socially isolated, depressed or living with dementia. The service plays "cheerful and gentle music from the 1940s to the 1970s", supporting opportunities for reminiscence and musical stimulation. The service has been the subject of several research studies which have validated its benefits, particularly for people living with dementia. Until recently, accessing Silver Memories has involved the installation of a satellite dish at the care facility, but now the service is available to individuals via the **Silver Memories app** downloaded onto tablets (not smartphones yet). The app costs $79.99 per year or $7.99 per month (via the App Store or Google Play). The app also includes Silver Scenes, a collection of over 5000 still images, also for engagement and activity purposes. Find out more here: https://silvermemoriesapp.com.au/

Dementia Support Australia (DSA) has launched a set of cards to support communication with an Aboriginal and Torres Strait Islander person living with dementia. Designed and illustrated by Samantha Campbell, a proud Dagoman woman from Katherine, in the Northern Territory, and co-designed with representatives from the Aboriginal and Torres Strait Islander community, the 58 culturally appropriate cards show images that have meaning to an Aboriginal and Torres Strait Islander person living with dementia. The **communication cards** are divided into eight categories: people, activities/objects, food/drinks, personal care, health, feelings, places and animals. Each card has the English word and includes space on the back to write the word in the language of the person. The colour box set can be ordered as a free hard copy, while digital colour and black and white versions (for people with visual challenges) are also available to download and print: for both, go to https://bit.ly/3AxKfGo

Communication Cards

For Aboriginal and Torres Strait Islander people living with dementia.

DS Dementia Support Australia

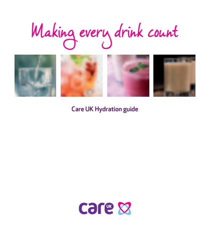
Funded by the Australian Government
A service led by HammondCare

The Deeble Institute for Health Policy Research (the research arm of the Australian Healthcare and Hospitals Association) has published a 56-page Issues Brief on the topic of **Reablement Interventions For Community Dwelling People Living With Dementia**, written by Dr Miia Rahja of Flinders University and Adjunct Associate Professor Rebecca Haddock, Director of the Deeble Institute. The paper summarises: research and policy work on reablement in dementia care; how reablement interventions work to address the needs of people living with dementia and their care partners; and how these interventions are, or can be, adopted in the Australian health and aged care context. The authors make recommendations to address the identified barriers to including evidence-based reablement interventions for people living with dementia in standard care provision. Access the report here: https://bit.ly/3yy8OSR

The Aged Care Quality and Safety Commission has worked with the Older Persons Advocacy Network (OPAN) to develop a series of resources entitled **Medication: It's Your Choice** to raise awareness of the issues relating to psychotropic medicines. The resources are aimed at helping older people and their supporters to make informed decisions about medication use, and include a booklet, brochure, short film and webinar series. The 20-page booklet covers medications to be aware of, questions to ask about medication, explains what constitutes a psychotropic medication, suggests alternatives to medication, and sets out explanations for key ideas such as informed choice, supported and substitute decision making, alongside some case examples including of people living with dementia. The brochure covers similar territory, but more briefly. The six-minute film gives an overview of potential side effects of some medications and explains the right to make informed decisions about medications. The webinar series consists of six one-hour webinars, each exploring the key ideas above in more detail. To access all these resources, go to https://opan.org.au/yourchoice/

In July the Australian Centre for Evidence Based Aged Care (ACEBAC) at La Trobe University launched a new suite of free online learning resources, called the **Victorian Aged Care Education and Training** (VACET) platform, aimed at personal care attendants, nurses and allied health staff working in residential aged care. VACET's development has been funded by the Victorian State Government and, in response to the findings of the Royal Commission into Aged Care Quality and Safety and other ACEBAC research, focuses on three key areas: dementia care, recognising and providing a palliative response to care, and oral hygiene. One module on Communication in Aged Care is also available. In total there are 20 modules available to complete, with each taking

HammondCare's Dementia Centre launched **The Dementia Podcast** in December 2020, and now over 15 episodes are available to listen to. Each episode is hosted by the Centre's Director, Professor Colm Cunningham (pictured), who talks with a changing line-up of experts across a range of topics in dementia care such as advocacy, culturally and spiritually aware care, design, music, palliative care, medication, lying in dementia care, and being present and creating connections. The sessions run for approximately 30 minutes each, and can be accessed at www.dementiapodcast.com/



Care UK has published a short practical guide to hydration, called **Making Every Drink Count** aimed at both formal and informal carers. The 20-page well-illustrated resource presents introductory contextual information (ie, the importance of hydration, causes and signs of dehydration) as well as sections on encouraging fluid intake, making drinks look as appealing as possible, making an occasion of drink, hydration from other sources and recipe suggestions. It can be found at https://bit.ly/3AvP1E3

about 30 minutes. The dementia-specific modules are: 'Understanding dementia', 'Recognising pain in people living with dementia', 'Understanding responsive behaviours', and 'Depression and dementia', 'Dementia and sleep'. The training can be accessed at www.vacet.latrobe.edu.au

The Australian Commission on Safety and Quality in Health Care has published **Delivering and Supporting Comprehensive End-of-Life Care: A User Guide**, with practical strategies for health service organisations and clinicians to use to offer safe and high-quality end-of-life care, and to meet the National Safety and Quality Health Service (NSQHS) Standards requirements. The Guide is set out in two key sections: the first covers processes of care and details practical suggestions for how clinicians can act on specific aspects of the 10 essential elements of care. The second looks at organisational and structural requirements for high-quality end-of-life care, with a focus on what health service executives and managers can do to support this. The guide is available at https://bit.ly/3iB2vZ4

Practitioners interested in the Newcastle Model of Dementia Care (pioneered by Dr Ian James in the UK) will be interested to watch a series of 10 short animations explaining the approach, with titles such as 'Understanding memory changes in dementia', 'Understanding sensory changes in dementia', 'Therapeutic lies in dementia', and 'Fundamental needs in dementia'. The (5-6-minute) training films are the product of a collaboration between Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust and the British Psychological Society (Faculty of the Psychology of Older People). The animations are part of a training program called **Communication and Interaction Training** (CAIT), which is part of the Newcastle Model. The films are available on YouTube at https://bit.ly/33x0O6D

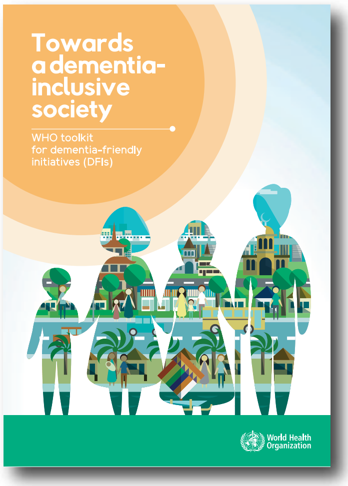
AD Biohub is the name of pharmaceutical company Biogen's new website for health care professionals, recently launched in Australia. The site requires users to sign up to access the content, which aims to present up-to-date information on the neurobiology of Alzheimer's disease and diagnosis technologies (for example biomarkers) and includes presentations from a range of leading figures in dementia research such as Professors Henry Brodaty and Chris Rowe. The site can be accessed here: www.adbiohub.com.au

The Centre for Cultural Diversity in Ageing (Victorian PICAC) has updated its sets of **Communication Cards** and **Aged Care Signage** to include four new languages: Urdu, Hebrew, Sinhalese and Gaelic. The communication cards show a wide range of daily activities, situations and items, with one image for each card, and the idea is that cards are used to help facilitate communication with clients. The aged care signage is intended to be used within residential aged care facilities, to help residents navigate their way around the site. The resources are now available in 61 languages in total, and are free to download from the centre's website here: https://bit.ly/3i66JWZ

The Aged Care Quality and Safety Commission (ACQSC) continues to develop a range of resources related to aged care reforms. New restrictive practices legislation strengthening and clarifying obligations for residential aged care providers began on 1 July 2021, and to support its implementation, the ACQSC has issued a regulatory bulletin, webinar and a fact sheet on the key changes for providers. ACQSC has also developed several resources (a brochure, poster and fact sheet) aimed at consumers on the Serious Incident Response Scheme, all titled **What Is The SIRS?** Access all the ACQSC resources at www.agedcarequality.gov.au/resource-library

In June, July and August 2021 the Department of Health ran a series of **webinars on the aged care reform program** set out by the Federal Government. Topics have included an overview of the aged care reforms, home care, residential aged care, ICT, the aged care workforce, dementia, and improving outcomes for people in aged care from culturally and linguistically diverse backgrounds and Aboriginal and Torres Strait Islander peoples. The sessions run for 90 minutes and include a panel of Department of Health staff and external stakeholders, with time given to responding to questions submitted from participants during the session. All sessions are available to watch later; go to https://bit.ly/3AWp6pd

The World Health Organization has published a new substantial resource on dementia, titled **Towards A Dementia-Inclusive Society: WHO Toolkit For Dementia-Friendly Initiatives**. The 100+ page resource aims to support individuals, communities and countries to raise awareness of dementia, and to empower people living with dementia to remain in, and be a significant part of, their community. The toolkit is divided into two parts: Part I contains background information and a conceptual framework for creating dementia-inclusive societies, and Part II includes four modules, each featuring a series of practical steps and exercises, on: (i) starting a new dementia-friendly initiative (DFI) (ii) integrating dementia into an existing initiative (iii) monitoring and evaluating a DFI and (iv) scaling up a DFI. The toolkit is intended to support individuals working in their communities, but who may have little to no experience in program planning, implementation, management or evaluation, but also more broadly consumer groups, non-government organisations, policy makers and planners, health and social care providers, researchers and academics, the media, business owners and/or their staff. The resource is available here: https://bit.ly/3jQ8OHC



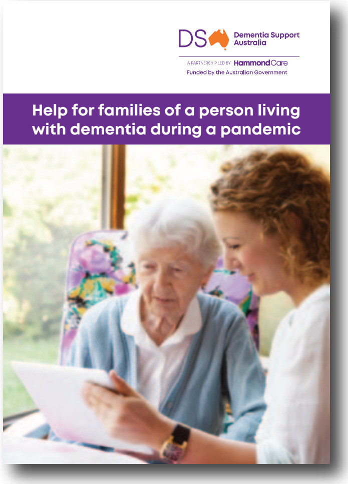
Dementia care event listings are available on the *AJDC* website at www.journalofdementiacare.com

COVID-19 RESOURCES

Dementia Support Australia (DSA) is now offering a **Dementia Engagement Modelling Program** as a free support service for residential aged care providers impacted by COVID-19 (by an outbreak or a precautionary lockdown), as part of the Federal Government's Aged Care COVID-19 Grief and Trauma Support package for older people receiving aged care, their families and aged care staff. DSA staff delivering the Dementia Engagement Modelling Program will work with lifestyle and care staff to develop tailored activities and provide resources for engagement to people living with dementia in residential aged care who have become withdrawn, frustrated or fearful and are at risk of developing responsive behaviours as a result of COVID-19 restrictions. The program will also provide support and coaching for staff. More information, including eligibility criteria, is available on DSA's website at https://dementia.com.au/ or by calling 1800 699 799.

How To Support Someone Living With Dementia Who Is Feeling Anxious is a two-page help sheet aimed at family carers of people living with dementia, published by Dementia Support Australia (DSA). The help sheet explains the various reasons why a person with dementia may be displaying anxiety at this time (beyond the obvious fact of the pandemic) and sets out eight practical suggestions for supporting a person with dementia who is feeling anxious due to the COVID-19 pandemic. Access the help sheet here: https://bit.ly/3fRMwUR

Help For Families Of A Person Living With Dementia During A Pandemic is a six-page resource from Dementia Support Australia (DSA) aimed at giving clear guidance to relatives and friends of people with dementia who are either in hospital or living in residential aged care during the COVID-19 pandemic on how best to stay connected with and support their friend or loved one. The resource sets out clear advice on two key questions: 'What your family member needs you to do', and 'What you can do to stay connected'. It is available from https://bit.ly/3s8a5O6. A shortened version, in a two-page help sheet is also available, just presenting information on 'What your family member needs you to do' (at https://bit.ly/3fRNJeR).



DS Dementia Support Australia

A PARTNERSHIP LED BY HammondCare

Funded by the Australian Government

Help for families of a person living with dementia during a pandemic

The Aged Care Quality and Safety Commission has published a three-page fact sheet aimed at aged care residents, their families and representatives, titled **COVID-19 Restrictions In Residential Aged Care – Your Rights**. It presents answers to a series of questions on this topic, such as 'Why are visitor restrictions used?', 'What are my rights when visitor restrictions are in place in my service?', 'Are there any exemptions to visitor restrictions?', 'What do I need to do to visit if I am exempt from the restrictions?' and 'Are there any restrictions on residents leaving an aged care service?', as well as information on where to go if you have concerns. Access it here: https://bit.ly/2UcxRvS

The **Older Persons COVID-19 Support Line** set up in 2020 continues to operate and has in fact been extended to 31 December, 2021. The service is a joint initiative between COTA Australia, National Seniors, Dementia Australia and the Older Person's Advocacy Network, supported by funding from the Australian Government. Older Australians, their families, friends and carers can call 1800 171 866 if they would like to talk with someone about the COVID-19 restrictions and its impact on them; are caring for someone and need information or a listening ear; need help with questions or concerns about aged care services; are concerned about themselves, a friend or family member living with dementia; or would like to arrange a one-off or regular wellbeing check for themselves, or someone else. The free **Multilingual Older Persons COVID-19 Support Line** was launched in February 2021 and provides information about COVID-19, aged care services, dementia care and other support services from 2pm-5pm (AEST) Monday to Friday to older people from culturally diverse backgrounds. It is available in Arabic, Cantonese, Greek, Italian, Mandarin and Vietnamese. Go to https://opan.org.au/opcsl/ to find out more about both services.

The Older Persons Advocacy Network (OPAN) has developed a series of **11 videos** featuring **Dr Norman Swan** answering frequently asked questions in relation to the COVID-19 vaccines. The one-minute films cover topics such as: 'Known issues with other vaccines or medications', 'The known side effects', and 'How does the right to choose affect people with reduced capacity or dementia?'. The questions were also addressed in two longer one-hour webinars on this topic, which are available, alongside the short films, here: https://opan.org.au/covid19_vaccine/

The Australian Centre for Grief and Bereavement (ACGB) has launched a new aged care-specific website, **Aged Care Grief and Bereavement Support**, as part of its efforts to provide national grief and loss support for those living and working in aged care, and for the families and friends of aged care recipients, who have been impacted by COVID-19. The website acts as a gateway to a range of resources offered by the ACGB, such as written resources, bereavement counselling, support groups, webinars and online courses. The ACGB resources and services are aimed at aged care residents, home care recipients, their families, friends, community workers and residential aged care staff and external organisations associated with aged care. The website can be found at https://aged.grief.org.au/AgedCare/

Phoenix Australia has developed a free online course called **Trauma Awareness Training** aimed at all aged care staff. The course is intended to help learners understand the nature of trauma and its impacts in aged care settings, manage common responses to trauma, and to understand self-care strategies. The 45-minute module is one of a growing collection of resources (including fact sheets, animations and webinars) now offered by Phoenix Australia to the aged care workforce; go to https://bit.ly/3yP2iXY to find out more.

The Australian Government has published the **National COVID-19 Residential Aged Care Emergency Communication Guide**, providing guidance on communication in advance of, and during, a COVID-19 outbreak. It covers roles and responsibilities, communication protocols and communication processes for Australian Government, State and Territory Governments, the Aged Care Quality and Safety Commission (ACQSC) and residential aged care facility providers. This guide will also be of interest for peak bodies, and advocacy and cultural organisations involved in residential aged care communication activities. Templates have been included as an attachment, to guide and support aged care facilities, though the Government says that the information should be used in a flexible way that best suits the event, situation, location and facility. Access the guide here: https://bit.ly/3jNE6jy