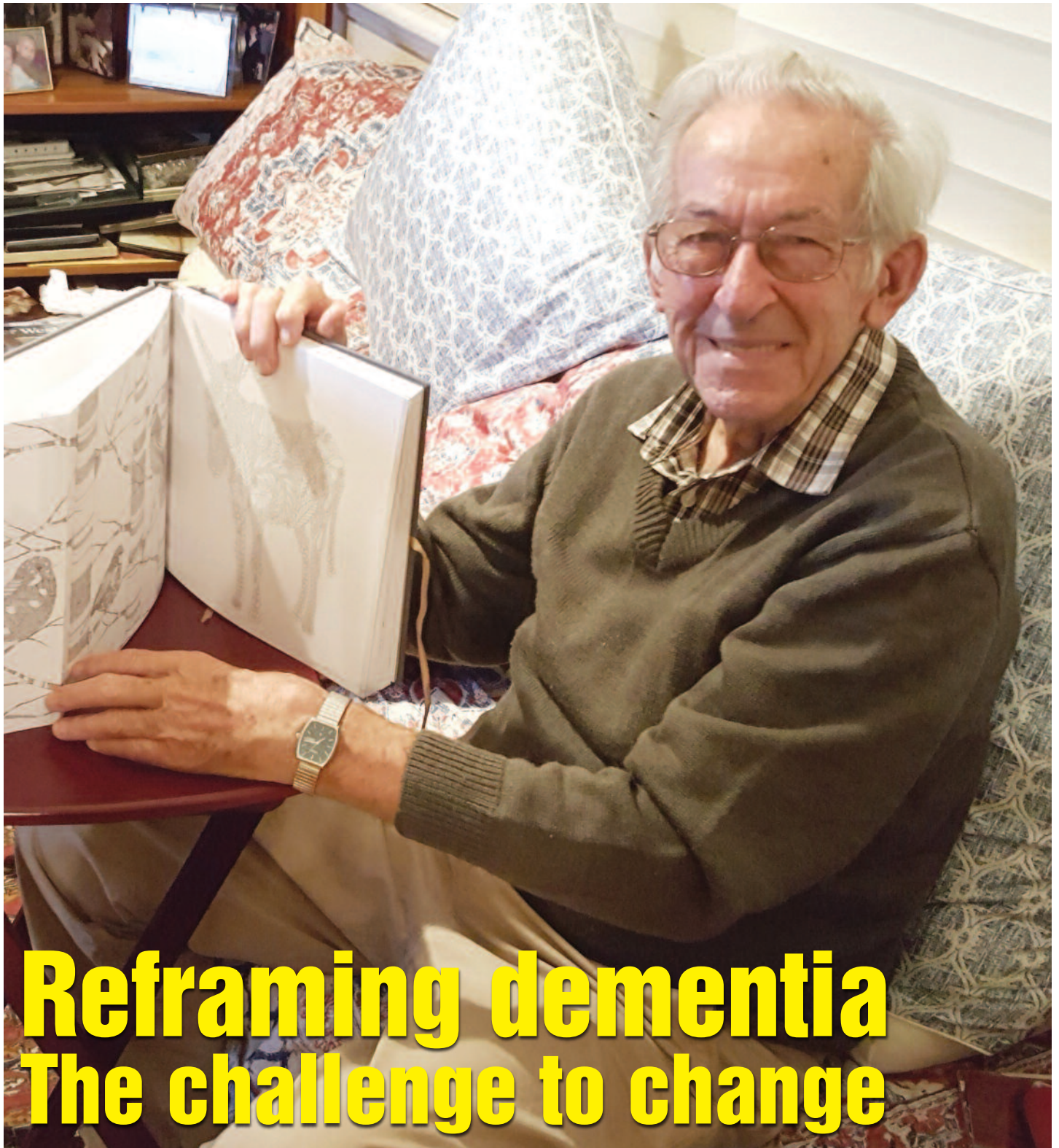


Australian Journal of DementiaCare

For all who work with people with dementia

Vol 7 No 4 August/September 2018



Reframing dementia The challenge to change

**Also inside
this issue:**

- Unlocking the DSU
- RedUsing medication use
- Helping people feel safe
- Exercise prescription

Executive Editor Professor Richard Fleming
(02) 4221 3422, rfleming@uow.edu.au

Managing Editor Kerry Schelks
kerry@australianjdc.com

Contributing Editor Catherine Ross

UK Editor Mark Ivory

Production Editor Andrew Chapman,
andrew@hawkerpublications.com

Website Manager Emma Paul

Publisher Dr Richard Hawkins

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Advertising Kerry Schelks
kerry@australianjdc.com

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Innovation Campus, University of Wollongong,
NSW 2522

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Risk: unlocking the barriers



By **Professor Joseph E Ibrahim**, Head, Health Law and Ageing Research Unit, Department of Forensic Medicine, Monash University, Victorian Institute of Forensic Medicine

“...we will put the enemy in the position where they will have to choose between giving us freedom or giving us death” (Emmaline Pankhurst 1913).

As a health professional it is confronting, if not offensive, to be considered an enemy of the residents with dementia whose health and lives we seek to enrich. Sadly, from a social justice point of view this pejorative label is accurate. We can refute this view if we challenge the current paternalistic approach in which a person’s physical safety takes precedence over freedom of movement and which prioritises defensive professional practices.

‘Give us freedom or give us death’ is a recurring theme in the history of civilisation. The vulnerable or subjugated population eventually rise to resist, and at times successfully overthrow, dictatorships. We need to challenge the antiquated idea that protecting people with dementia requires locking them in for their own safety. Exploding these antiquated ideas about the care of people with dementia in a high income, democratic country with a paternalistic approach to older people is no easy task. Why? It’s because we are comfortable, self-satisfied, have the necessary laws and so see no need to rebel.

Change, especially social change, requires persistence, visible, vocal and passionate advocacy from the affected population and eventually legislative change to protect their rights. The *Aged Care Act 1997* (Commonwealth) and its accompanying principles would seem to be sufficient. It stipulates “each resident has the right to full and effective use of his or her personal, civil, legal and consumer rights and, to be treated with dignity and respect, and to live without exploitation, abuse or neglect”. So there is no need to foment a rebellion. Residents can come and go, they have freedom of movement, they can walk where and when they please. It’s unnecessary to ‘lock up’ people with dementia for their own safety; our society should be better, we should be humane and we have the ability to do better.

Many people with dementia leave their care homes and very few ever come to any serious harm. Most are found within 1km of the home (Woolford *et al* 2018). Imagine what could be achieved if we collectively put effort into the planning, design and building of more suitable environments and better training of staff and education of families and the community?

At the very least we should open the doors of the care home literally (as described in Mark Aros’ article in this issue) and also figuratively. Our close-minded approach of locking care home doors to prevent residents leaving while unaccompanied is driven by deep-seated psychological fears. These usually fall into one of the following categories: ‘the person with dementia will die’, ‘the family will litigate’, ‘I will be struck off the register of health professionals’, ‘I could not live with myself if something happened’, or ‘I do not want to be in the Coroner’s Court (Ibrahim & Davis 2013).

It is rare to see a rationale stated from the person with dementia’s point of view. Our fears are ephemeral; there will not be a mass exodus of residents if the doors are open. People like to be somewhere warm and comforting; people who are frail and have painful arthritis do not have the energy to go far. Opening the doors to the care home challenges health and aged care professionals to think and to innovate to make the world better. We continue using antiquated solutions for the problems from yesterday. What we should recognise is that yesterday’s problems are easier to solve with our modern, enlightened, knowledgeable resources.

Adhering to and respecting a person with dementia’s dignity of risk, which includes freedom of movement if that is what the person desires, requires health professionals becoming allies. As allies we are able to collaborate and reach a middle ground that enables choices to be respected and minimises but does not, and cannot, remove all the dangers.

What we need now more than ever are leaders with the passion, fortitude and the support of their colleagues to innovate and to change the existing social paradigm. ■

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Australian Journal of DementiaCare

For all who work with people with dementia

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



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Cover image: Charlie Eldridge, diagnosed with Alzheimer's disease in 2013 when he was 83, inspired his wife and researcher Dr Gaynor Macdonald, along with her friend Dr Jane Mears, to create and launch the 'Reframing Dementia' project to help change attitudes and explore better ways to support carers. Read their story on p22.

News in brief

Palliative care and dementia

Dementia Australia and Palliative Care Australia (PCA) have joined forces to issue a joint policy statement on 'Palliative Care and Dementia'. The two-page statement was released in May and sets out the united stance taken by the organisations: a person living with dementia has the right to appropriate, compassionate and timely palliative care, which includes pain relief and symptom management and the prevention and relief of suffering. The statement says people with dementia should be able to access palliative care when and where it is needed, and that it is essential that palliative care is discussed from the point of diagnosis of dementia. PCA and Dementia Australia are advocating for improved awareness and understanding of the unique palliative care needs of people living with dementia, their families, carers and community, and in the statement they set out nine specific recommendations for action to support this position. The statement is available to view on both the PCA and Dementia Australia websites.

Outcomes for Indigenous Australians

Minister for Aged Care and Indigenous Health Ken Wyatt has launched a major report from the Australian Association of Gerontology (AAG) which recommends some key actions to be taken to improve the aged care system for older Aboriginal and Torres Strait Islander peoples. The report, *Assuring equity of access and quality outcomes for older Aboriginal and Torres Strait Islander peoples: what needs to be done*, highlights the high level of need for dementia services in particular among these communities.

New software improves diagnosis

Scientists at Imperial College London and the University of Edinburgh have created new software that can identify and measure the severity of small vessel disease (SVD) – one of the most common causes of vascular dementia and stroke. The study, recently reported in the *Radiology* journal, used data of 1082 CT scans of stroke patients from 70 UK hospitals between 2000-2014. The software identified and measured a marker of SVD, and then gave a score indicating how severe the disease was. This was then compared with the results given by a panel of expert doctors, and the level of agreement of the software with the experts was as good as agreements between one expert with another. Lead author Dr Paul Bentley said it also has applications for widespread diagnosis and monitoring of dementia.

States boost funding

Dementia Australia has applauded the initiative of several State governments that have committed additional funding to support delivery of the NDIS and mental health services – saying such support is critical for younger people with dementia. The NSW Government has committed \$3.2 billion to the NDIS transition, and \$700 million towards a state-wide mental health infrastructure program. The ACT Government has also committed \$1.8 million to establish an integrated services response program to support people with high and complex needs, not currently met by the NDIS, and funding of \$3 million over four years to provide additional mental health support in residential aged care facilities. The Tasmanian Government will put more money into acute public services and mental health: \$202.3 million for recurrent and capital initiatives for acute hospital services, and \$40.2 million to support state-wide and mental health services.

HETI Awards now open

The 2019-20 HETI Awards in Psychiatry and Mental Health are now open to mental health practitioners from across NSW, providing an opportunity for recipients to undertake specialist training or research in an area where little or no training is available. The two categories are: the Psychiatry Special Training Award for psychiatry registrars; and the Mental Health Research Award, open to all mental health practitioners who wish to develop their research skills and undertake a research project. Applications for the full-funded awards (formerly the NSW Institute of Psychiatry Fellowships) close on 20 August 2018. Past recipients have undertaken studies related to Alzheimer's disease and cognitive decline. Details: <https://bit.ly/2zvTEBJ>

DTA on the road for rural, remote training



Narrabri Hospital Community Health nurses Michel Trindall and Lavinia Hill and clinical nurse consultant Usha Kuthirayodan were among about 30 aged care professionals at the DTA workshop in Narrabri in June. Photo courtesy The Courier, Narrabri

Dementia Training Australia (DTA) is embarking on a series of road trips to rural and remote parts of the country to get an understanding of the training needs of people involved in dementia care in these areas.

DTA Executive Director Richard Fleming made the first trip in the last week of June, visiting Narrabri and Moree in NSW, and Goondiwindi in Queensland.

Before each trip, aged and health care facilities in each town are invited to send representatives to a half-day meeting which includes a workshop on an area of topical interest (eg reducing psychotropic medication, responsive behaviours), and a discussion of DTA courses and resources. The aim is to identify gaps and areas of need that are

specific to services operating at a distance from the support available in metropolitan areas.

As part of this project, DTA has also contacted the most remote services in Australia, identified from Department of Health records, and invited them to complete a training needs analysis questionnaire on their special circumstances and needs. Each of the remote services has also been given a 12-month subscription to the *AJDC* and a 'Journal Club' guide designed to stimulate discussion on the needs of people with dementia and care practice.

DTA expects that this outreach into rural and remote Australia will result in new courses or resources being developed that go beyond the needs of metropolitan services.

Transition to new Quality Standards begins

Transition to the new Aged Care Quality Standards has begun. Subject to Parliamentary processes, providers will be assessed against the new Aged Care Quality Standards from 1 July 2019.

Service providers are being encouraged to use this transition period to: align their system, policies and practices with the new standards; support staff to understand the new requirements; and support care recipients, their families, carers and representatives to understand what the changes mean for them.

During the transition period the Australian Aged Care Quality Agency will assist consumers to understand the new arrangements; provide information and support for service providers and quality surveyors to implement the new standards; and continue to get feedback on the guidance and assessment process.

The final draft standards can be downloaded from the Department of Health website.

Australian Dementia Network announced

A new Australian Dementia Network (ADNeT) is to be established, which will see the development of a national network of memory clinics and a national register for clinical trial volunteers. It will be at least a year until the network is up and running.

It is being backed by \$18 million from the Federal Government, and a further \$20 million committed from universities, industry, research centres and State governments. The Federal Government funding will be drawn from its \$200 million, five-year Boosting Dementia Research Initiative launched in 2014 by the National Health and Medical Research Council (NHMRC). This will be the largest single project launched so far under that initiative.

ADNeT will:

- Establish a national network

of memory clinics to speed assessment of cognitive disorders and improve specialist access for all Australians, through advanced imaging, genetics and lifestyle data.

- Register and prepare volunteers for participation in clinical trials and other research programs, by providing them with state-of-the-art diagnosis and tracking their disease trajectory.
- Collate and compare data to chart dementia causes, progression and risks and potential new treatments, while supporting research participants and benchmarking clinical care.
- Ensure Australian and international data can be shared, providing unprecedented research access to global data and collaboration, to inform

prevention, treatment and care.

“Through ADNeT, Australia joins the international push to use large-scale national registries to expedite research and beat dementia,” Aged Care Minister Ken Wyatt said.

“ADNeT will lift the standard of Australian dementia diagnosis and care, with a coordinated and consistent approach. By significantly increasing public access to, and participation in, clinical trials it will also speed the development and approval of new prevention and treatment therapies.”

Professor Christopher Rowe of Austin Health will lead ADNeT as Chief Investigator.

Dementia Australia CEO Maree McCabe said Australian researchers, Dementia Australia and people impacted by

dementia have long held a vision for an integrated registry of researchers, studies, information, data and clinicians to ensure there is more targeted, effective research.

“For researchers, ADNeT is about harnessing the power of ‘big data’ to ensure that we have a far more comprehensive and integrated picture of clinical research that will provide a more comprehensive picture of the characteristics of dementia.

“The establishment of the ADNeT registry and research program will improve access to more timely diagnosis and specialist services for people impacted by dementia, ensuring that they can put in place strategies that will enable them to live better with the disease,” Ms McCabe said.

For all ADNeT inquiries, email Denise. el-sheikh@austin.org.au

Boosting Dementia progress report

“Australia is now a world leader in many aspects of dementia research,” according to Aged Care Minister Ken Wyatt, who used the HammondCare conference in June to launch the first public progress report on research projects funded under the Boosting Dementia Research Initiative.

The five-year initiative began in 2014 to support research into ways to prevent, treat or cure dementia. By the end of 2017 it had supported 127 projects, involving 285 researchers, working across 24 universities and research institutions.

The five priority areas for the initiative include prevention, assessment and diagnosis, intervention and treatment, living with dementia, and care. For each area of research, the report presents why that area of research is important, the

desired outcomes, and the total number of funded research projects within this area, including key examples.

The initiative includes:

- \$95 million for large-scale research projects in priority areas of dementia.
- \$46 million to expand research capacity in dementia and build the future research workforce.
- \$9 million for research focused on prevention and treatment at the Clem Jones Centre for Ageing Dementia Research.
- \$50 million to target, coordinate and translate the national research effort into better care for people with dementia.

The 56-page progress report highlights key research, such as ultrasound technology to improve memory and slow the onset of dementia, the impact

of childhood stress as a dementia risk factor especially among Aboriginal Australians, the potential for eye scans to reveal three biomarkers associated with early signs of cognitive decline, and improved diagnosis of frontotemporal dementia. It includes more detailed profiles of a small number of research projects, including the work of Dr Moyra Mortby from the University of NSW on improving the management of responsive behaviours associated with dementia in aged care settings. Dr Mortby is developing and trialling a staff training program, in partnership with Goodwin Aged Care, Canberra.

Australia's Boosting Dementia Research Initiative: report on early outcomes is available to download from the NHMRC's National Institute for Dementia Research website.

Grim assessment on Global Action Plan

One year on from the World Health Organisation's adoption of the *Global action plan on the public health response to dementia 2017-25*, and the assessment of Alzheimer's Disease International's (ADI) CEO Paola Barbarino is that, “Too little has changed since May 2017. Governments need to do more.”

The new ADI publication, *From plan to impact*, reports on progress towards targets of the Global Action Plan on dementia. It concludes that at the current rate the plan's targets will not be achieved by 2025.

Since the adoption of the global plan, Chile is only country that has developed a dementia plan, although Canada's Bill C-233 has given approval for the development of a plan. The report warns that unless action is taken in sub-Saharan Africa it will be impossible to meet the plan's targets.

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

New workforce strategy ‘robust, pragmatic’

Chair of the Aged Care Workforce Strategy Taskforce, Professor John Pollaers, presented his final report, *A matter of care – Australia’s aged care workforce strategy*, to Aged Care Minister Ken Wyatt at a Parliamentary breakfast on 29 June.

Professor Pollaers described the strategy as “robust, comprehensive and pragmatic”, and said it has the potential to transform aged care services in Australia.

“My message to industry is to act now. Put in place workforce strategies that will deliver real improvements to the quality of care – and unite to create an industry that all Australians are

proud of,” he said.

The strategy has been developed over nine months, and involved consultation with providers, consumers and the workforce, in addition to newly commissioned research.

Professor Pollaers said some key actions in the strategy are already underway: improved education and training is to be the focus of a new Industry Reference Committee dedicated to aged care services; peak bodies have committed to establishing a voluntary code of practice; and providers in remote Australia will have a stronger voice through a new Remote Accord. He said some of the recommended changes

are “wholly in the grasp of industry to make immediately”, such as better workforce planning, holistic individual care plans, and improved strategies to attract and retain high-quality staff.

The Federal Government has also published its response to the June 2017 Senate Community Affairs Committee Report, the *Future of Australia’s aged care sector workforce*.

The Government noted that 12 of the Committee’s 19 recommendations related to work currently being pursued by the Aged Care Workforce Strategy Taskforce, and that it supports eight of the recommendations.

Update to landmark dementia guideline

The UK’s National Institute for Health and Care Excellence (NICE) has issued a new guideline, *Dementia: assessment, management and support for people living with dementia and their carers*, to replace its landmark 2006 guideline on dementia. Australia’s 2016 *Clinical practice guidelines and principles of care for people with dementia* are an adaptation of the 2006 UK NICE guideline.

The new 420-page guideline includes over 130 recommendations and is a reference point for best practice in dementia care. It was developed by a multidisciplinary committee after an extensive review of research evidence. NICE Deputy Chief Executive Professor Gillian Leng said it “highlights the need to properly train staff and says that carers should be helped to improve support for people living with dementia. The recommendations focus on person-centred support, placing a particular emphasis on involving people with dementia in every decision about the care they receive.”

Some of the new recommendations include:

- An initial assessment should involve taking a history from the person with suspected dementia and a family member.
- Each person diagnosed with dementia should have an individual care plan that is reviewed at least once a year.
- People with dementia should be made aware of research which they may wish to participate in.

The guideline also includes detailed recommendations relating to different types of dementia. Access it at: www.nice.org.uk/guidance/ng97

A win for dementia-friendly work

Gerald Burns Pharmacy, the Perth pharmacy featured in the April/May 2018 issue of *AJDC* for its efforts to become dementia-friendly, has won the category of Excellence in Professional Innovation at the recent Australian Pharmacy Professional (APP) conference on the Gold Coast. The award was one of three Pharmacy of the Year awards presented by Federal Health Minister Greg Hunt. In 2017 Gerald Burns Pharmacy owner Amanda Bryce (pictured fifth from left, with her team) supported 10 staff members to complete the Dementia Training Australia workshop ‘The Dementia Friendly Pharmacy: Pharmacist Masterclass’ and took a number of practical steps to support people with dementia



and family carers who were regular customers.

Pharmacist award

Meantime, Dr Andrew Stafford, a Director with Dementia Training Australia and Consultant Pharmacy Services, has won the 2018 Australian Association of Consultant Pharmacy (AACP)

MIMS Consultant Pharmacist of the Year Award at the AACP’s annual seminar, ConPharm 2018, in Brisbane in June. The AACP praised Dr Stafford’s work as a researcher, author and educator, and described him as “outstanding role model and mentor for established and developing practitioners”.

Consumers take centre stage with researchers at ADF2018

Simon Denegri OBE spoke eloquently on the need and benefit of involving consumers in the early stages of dementia research during his keynote speech at the NHMRC National Institute for Dementia Research annual Australian Dementia Forum (ADF2018) in June.

Mr Denegri, National Director for Patients, Carers and the Public at the UK’s National Institute for Health Research, also provided insight into the advances made in

the UK to involve consumers in dementia research.

This year’s forum in Sydney, with the theme *Cooperation, Collaboration and International Connections*, also included a Public Involvement in Research Workshop facilitated by Anne McKenzie AM, Head of the Consumer and Community Health Research Network, University of WA, and Mr Denegri. The workshop was an opportunity for consumers and researchers

to consider methods to encourage further consumer involvement in dementia research. ADF2018 brought together over 270 delegates who heard from 138 researchers across the field, five people living with dementia and three carers, who addressed the need for collaborative efforts across diagnosis, treatment and care.

ADF2019 will take place in Hobart. Registrations and a call for abstracts open later this year. Visit nndr.gov.au for details.



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HammondCare conference highlights

More than 1000 delegates attended HammondCare's 2018 International Dementia Conference in June in Sydney, titled 'Mission Impossible? Truth and Lies in the Age of Choice'.

The two-day program featured presentations from 75 speakers from more than 15 countries, including eight people living with dementia, covering topics such as innovation in care practices, implications of new clinical research, new treatment practices, creative arts, design and more.

The opening plenary session saw Professor Craig Ritchie, an expert on dementia clinical trials from the University of Edinburgh, emphasise the importance of dementia risk reduction strategies being put into place in mid-life.

On day two, Professor John Swinton from the University of Aberdeen spoke on the significance of time, saying that

to give time to, and to spend time with, people with dementia demands that we think of time differently. In his presentation he argued that "busyness kills compassion", and counselled delegates to remember that "love takes time".

John Quinn, a leading dementia advocate, spoke about his experience of living with dementia and how it has altered

his sense of identity. John spoke about his research into the effect of a dementia diagnosis on men and their sense of masculinity, which has involved speaking to a wide range of people with younger onset dementia.

Theresa Flavin, recently appointed as a consumer representative for HammondCare, spoke about her involvement in research on supported decision-making.



Dementia advocate John Quinn and Dementia Support Australia consultant Catherine Buckley at the HammondCare Conference in Sydney

DSA to target GPs: Associate Professor Stephen Macfarlane, Head of Clinical Services at Dementia Support Australia, spoke at the HammondCare conference about the progress made by DSA in its delivery of the Dementia Behaviour Management Advisory Service (DBMAS) and the Severe Behaviour Response Teams (SBRT) – and highlighted the challenges still facing DSA in reducing inappropriate use of medications.

Through its multidisciplinary, intensive casework – which prioritises behavioural interventions and deprescription of medication – DSA has been able to document a significant decrease in the frequency and severity of all distress behaviours, but not in use of medications. Associate Professor Macfarlane said that in only about 10% of cases were the DSA recommendations around de-prescription implemented in full by GPs. He said DSA's next challenge is to increase its engagement with GPs and other health professionals.

In a separate session, HammondCare's Research and Data Analyst Dr Thomas Morris presented detailed statistics on DSA's work from May 2017 to May 2018. The most common reasons for referral to both services are agitation and aggression: 82% for DBMAS, and 97% for SBRT.

DSA consultants have identified over 60 factors that may contribute to why a person with dementia is responding as they are. The most prevalent of these among DBMAS clients is pain (41%), carer approach (33%), memory impairment (31%), over or under stimulation (26%), and loneliness or boredom (25%). SBRT findings were similar – though with higher prevalence rates across all these factors.

SHARE YOUR VIEWS

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

Academics, health care professionals, dementia consultants, families and people with dementia are collaborating and advocating for change.

We, the undersigned, met recently to create an urgent campaign for new and innovative approaches to dementia and aged care philosophies and practices.

Basic human rights are being ignored and worse, severely breached by the care sector today. As a result, people with dementia have become vocal activists locally, nationally and globally at organisations such as the United Nations to demand their rights.

Chemical and physical restraints remain the most overused forms of 'care' for people with dementia. This is predominately due to prejudicial labelling with the artificial construct 'Behavioural and Psychological Symptoms of Dementia' (BPSD) originally intended to improve care.

Currently no disease-modifying drugs are available for dementia, and a cure remains elusive despite massive investments in ongoing research.

As a result of the BPSD paradigm, physicians can and do prescribe

Rethinking dementia care

medications for 'behaviours of concern' that generally are a result of a person's responses to unmet needs, or the challenges of living with changing cognition within environments that reflect an inadequate understanding of, and accommodation for, those changes.

We believe medicating human beings is an unacceptable approach to 'care', and whilst it generally remains unquestioned by others, we fiercely advocate against its use and work towards promoting more optimal, restraint-free care.

Along with a growing number of experts, we believe a small minority of people experience distress as a direct result of brain disease. Thus if we remove the negative, stigmatising label of BPSD, and move towards compassionate care embedded with human rights, much of this distress will be alleviated.

We advocate an approach that comprises removing all forms of segregation and restraint by acknowledging everyone has

the right to 'freedom of expression', with provision of care based on remaining assets and rehabilitative support for acquired cognitive disabilities. People with dementia will then have a higher quality of life.

We therefore are campaigning to #BanBPSD altogether, moving instead to a more progressive and expansive view of the person who lives with a diagnosis of dementia.

Sonya Barsness, gerontologist, Sonya Barsness Consulting LLC (US); Leah Bisiani, MHlthSc, DipBus, RN1, dementia consultant (Australia); Daniella Greenwood, consultant, author, activist (Australia); Susan Macaulay, care partner, author, dementia care advocate (Canada); Dr Al Power, geriatrician, author, educator, Schlegel Chair in Ageing and Dementia Innovation (US/Canada); Kate Swaffer, human rights activist, author, MSc Dementia Care, PhD candidate, University of Wollongong (Australia).

Stories to tell

The six students who won prizes in Australia's National Dementia Storytelling Competition found inspiration for their entries in their experiences supporting people living with dementia – either as professionals or family carers and volunteers.

Tara Kannan, Matthew Boom, Denise Edwards, Kate Galtos, Gina Macleod and Danielle Dyce were among second- and third-year undergraduate students from more than 25 universities across Australia who accepted Dementia Training Australia's (DTA) challenge to explore 'A salutogenic approach to caring for people living with dementia: how my discipline can support a life that is manageable, understandable and meaningful', in a medium of their choice (eg, written word, animation, short film, video, infographic).

DTA Executive Director Professor Richard Fleming said salutogenesis means 'sources of health' from the Latin word 'salus' (health) and the Greek word 'genesis' (source).

"A salutogenic approach to dementia care is about focusing on factors that support health and wellbeing, and opportunities for a person with dementia to live as full a life as possible. The judges were very impressed by how students, and the winning students in particular, embraced the concept of 'salutogenesis' in their entries.

"This approach is widely used around the world – in health, education, workplaces, architectural design – and we believe it has enormous relevance in dementia care."



University of Canberra Bachelor of Physiotherapy student **Matthew Boom**, who took first

prize in the 3rd year category for his poster *Maintaining adventure with dementia*, said his interest in dementia began when he started working with older

people in residential aged care in 2014, a role he's continuing while he studies physiotherapy.

"Working closely with older people opened my eyes to the missed opportunities to improve people's lives through the known benefits of physiotherapy, particularly those with dementia, whose needs are often overlooked," Matthew said.



Tara Kannan, (Bachelor of Medical Science and Doctor of Medicine, University of Newcastle),

took first prize in the 2nd year category for her essay *Mind over matter*, exploring the definition of the salutogenic model, its origins and its implications for dementia in our global community.

Tara said her interest in dementia was sparked through her volunteer work in an aged care home.

The other winners are:

2nd year

2nd Prize



Denise Edwards is studying a Bachelor of Dementia Care at the University of

Tasmania and working full-time for an aged care provider.

Denise said she wrote her essay, *Residential care but not as we know it: a salutogenic approach to caring for people living with dementia, and how residential care can support a life that is understandable, manageable and meaningful*, in the hope that it will inspire politicians, aged care providers and others to think more creatively about environments for people living with dementia.

3rd Prize



Kate Galtos is studying a Bachelor of Dementia Care at the University of Tasmania. Her

multimedia presentation is titled *Salutogenesis and living well with dementia: a family care giver's story*. Kate is a key care partner for her father, who is living with dementia, and an active advocate for others. Her entry strives to remind us of the importance of listening to people living with dementia, their families and care partners.

3rd year

2nd Prize



Gina Macleod is studying a Bachelor of Medical Science and Doctor of Medicine at Monash

University. Her entry, *Margie's tale: a reflection upon the importance of salutogenesis in dementia care*, reflects her interest in holistic approaches to dementia care. "My time within the clinical environment this year has been challenging, albeit very enjoyable, and I am grateful for the numerous opportunities I have received to become involved in patient-centred care," she says.

3rd Prize



Danielle Dyce is studying a Bachelor of Dementia Care at the University of Tasmania. Her

video, *A salutogenic approach to dementia care*, is about providing residents with opportunities to "be themselves and continue enjoying life". Danielle has

worked in aged care for more than 20 years, and has experienced dementia from a family perspective. She is currently working as a dementia care program coordinator in a dementia-specific unit that follows a household model of care: "We aim to give every resident the best day possible every day they are living with us."

Tara and Matthew each win \$2000 for their entries. The second prize winners receive \$1000 each and third prize winners \$500. All entrants will receive a free subscription to the *Australian Journal of Dementia Care*, worth \$99.

Awareness initiative

The National Dementia Storytelling Competition is a dementia awareness initiative run by DTA, a consortium of leading dementia educators and trainers from five universities and Dementia Australia.



"This is the first year that the competition has taken a multimedia approach," Professor

Fleming (pictured) said. "By opening it up to any medium, DTA has succeeded in its aim of attracting entries from disciplines previously unrepresented in the competition."

More than 20 fields of study were represented this year including nursing, medical science, communication, speech pathology, psychology, primary education, physiotherapy, midwifery and design.

To view the winning entries, and for more on the competition, visit www.dta.com.au/storytellingcomp/

With a little help from friends

Dementia Australia's new initiative, Dementia Friends, is a social movement that aims to transform the way Australians think, act and talk about dementia.

During this year's Dementia Awareness Month in September, Dementia Australia will be encouraging all Australians, including politicians, business and community leaders, to become a Dementia Friend by completing a free online education module at www.dementiafriendly.org.au. It's designed to help people understand dementia and learn how they can better support the people in their community – a family member, friend, neighbour or co-worker – living with dementia to feel accepted, safe, included and involved.

"We now know from research that 70% of people living with dementia are living in our communities, yet the majority feel a profound sense of isolation and lack of purpose due to the lack of awareness of dementia," Dementia Australia CEO Maree McCabe said.

Federal Minister for Aged Care Ken Wyatt, Senator Helen Polley, Shadow Assistant Minister for Ageing and NSW Premier Gladys Berejiklian, along with other state and federal politicians, recently signed up to become a Dementia Friend, with Mr Wyatt calling on MPs across Australia to join the program.

Dementia Friends is funded by the Federal Government as a significant part of the \$3.9 million national Dementia Friendly Communities project and has been developed in consultation with the Dementia Australia Dementia-Friendly Communities Advisory Group, comprising people living with dementia and carers as members. It builds on the Dementia Friends programs already in place in the UK, other parts of Europe, the US and Canada.



Australian singers Jessica (second left) and Lisa Origliasso (second right), from The Veronicas, were named Dementia Australia's newest Ambassadors at the Federal Parliamentary Friends of Dementia event at Parliament House, Canberra on 27 June, where they encouraged Members of Parliament to become a Dementia Friend. The twins said their mother, Colleen, was recently diagnosed with dementia and "...by talking openly about it, and sharing our story, we hope we can let others know they are not alone and that there is help and support available". They were joined at the event by Aged Care Minister Ken Wyatt, Dementia Australia CEO Maree McCabe (centre), Ita Buttrose AO OBE, one of Dementia Australia's longest-serving Ambassadors (far right), and people living with dementia and carers.

Take the time to understand

Dementia Australia recently hosted a series of Parliamentary Friends of Dementia events in the Federal, NSW and Victorian Parliaments, where invited presenters, including people living with dementia, carers and politicians, spoke about the importance of raising awareness of dementia in the community. One of the speakers at the NSW event was dementia advocate **Dennis Frost** who was diagnosed with frontotemporal dementia shortly after his 59th birthday. This is an excerpt of Dennis' speech, which he has kindly shared for publication

There are currently more than 425,000 people who are living with dementia in Australia. That's nearly 2% of Australia's population – and if we think about their families, their partners, children and siblings we see that more than 10% of the population have a direct relationship with someone living with dementia. Of those

diagnosed with dementia, more than 30,000 are under the age of 65 and living with younger onset dementia. Younger onset dementia has an increased impact not only for the individual diagnosed and their family, but for the entire community.

Dementia is terminal and there is little hope of a significant cure or treatment in

the near future. That is why I am actively involved in many research projects that aim to better understand the diseases or investigate ways of improving our quality of life.

A typical diagnosis of dementia in our younger cohort may take several years. For our elderly it may take several minutes. When diagnosed we are given no

hope or encouragement to 'fight'; we, at the best, are told to go home, get our affairs in order and wait to die.

It was six years ago when I told my GP that I was having difficulty recognising my colleagues, particularly if they dressed differently or I encountered them outside of my workplace. I was still in my 50s. In the following nine

months she referred me to a number of specialists and they dismissed my concerns outright.

I had a variety of cognitive tests, a CAT scan, a MRI, and several ECGs and none showed any definitive abnormalities.

Finally a geriatrician referred me to the [Frontier Frontotemporal Dementia Research Group], and after their cognitive tests and MRI I was diagnosed with frontotemporal dementia.

'Go home and retire'

I was given three, maybe eight and up to 20 years to live and told I should go home and gracefully retire. Apart from the diagnosis, all I received was a list of phone numbers for dementia nurses in each local health district.

After about a year I rang the local number and they arranged for a younger onset dementia worker to visit. The only support that she could offer was a younger onset coffee group – if I was willing to travel 200km round trip. I declined as I couldn't imagine that the coffee would be that good to justify the trip. About six months later my key worker informed me of an opportunity to be involved in the Kiama Dementia-Friendly [Communities] pilot project. This was much closer and appeared to be a bit more relevant.

Now contrast receiving a diagnosis of dementia with that of another chronic condition. In 2016, after some routine blood tests, my GP

called me in to discuss the results. It appeared I had type 2 diabetes. Before I left his office I had been booked into a local diabetes education program and within 15 minutes they called back to confirm the details. The program ran the following month.

This contrast highlights several things for me. Firstly, there is little awareness in General Practice of any support for those diagnosed with younger onset dementia and no obvious or automatic pathway to connect us with those services, and secondly how grossly underfunded those resources are. I believe that if community-based dementia re-enablement programs received a level of funding and support commensurate with dementia's place as Australia's second leading cause of death, we could all live better lives.

My involvement in the [Kiama] Dementia Australia Dementia-Friendly Communities program has done more for my wellbeing than the route of prescribed disengagement that had been laid out for me. In the three and a half years I have been involved, I have seen a marked reduction in stigma in the local community.

Much of the local population have experienced dementia awareness training that has been delivered largely by Dementia Australia, but has always involved people living with dementia as co-designers and co-deliverers of the program.

The University of Wollongong has been able to measure a significant change in community attitudes and expectations with respect to dementia. This project was unique in that people living with dementia and their immediate care partners not only informed and guided the project but were active in delivering all aspects of the project.

This project has contributed significantly to the design and rollout of the national

What is a Dementia Friend?

A Dementia Friend is someone who wants to make a positive difference to the lives of people living with dementia through increased awareness and support.

- It means you have increased your understanding of dementia and how small things you can do can help support people with dementia to remain included, accepted and connected with their community.
- A Dementia Friend is someone who understands small acts can make a big difference.
- By having a better understanding of dementia, it is hoped you will be empowered to do small, everyday things that can make a difference to someone with dementia.

How to become a Dementia Friend

Visit www.dementiafriendly.org.au for more information and to register (it's free to join). Here you can listen to people with dementia share their stories and be guided through a short education module designed to increase your awareness and knowledge of dementia and its impacts. Once you have completed the module you will receive a Dementia Friend certificate and badge (pictured).



Dementia-Friendly Communities program. Dementia-friendly programs are beginning to help people diagnosed with dementia to overcome the social stigma and isolation that has traditionally gone with the diagnosis, and to remain active within their communities longer. Placing people with dementia at the centre of creating a dementia-friendly community has many benefits, not least of which is credibility. It can help keep us active in the community much longer, slow the progression of our symptoms and help reduce overall health costs for all. It can enable us not only to continue to contribute socially but economically as well, keeping economic resources in the community rather than being siphoned off to large 'care' providers.

The economic cost to become dementia-friendly is minor – all it takes is a small amount of time and a

willingness to listen to us. The return to the individual is a better understanding of us all, and a real investment in all our futures.

All it takes [to become a Dementia Friend] is less than an hour of study and a willingness to demonstrate your increased understanding of dementia. In that time, you can possibly do more for people with dementia than the pharmaceutical giants have done in the last century.

I encourage all who are reading this to visit www.dementiafriendly.org.au, sign themselves up and encourage their friends and family too.

Just remember, we all can do a lot with a little help from our friends. ■

■ Dennis Frost is a member of Dementia Australia's Advisory Committee, Dementia Alliance International and Inaugural Chair of the Southern Dementia Advisory Group in Kiama, NSW, which guides the Kiama Dementia-Friendly Communities Project



Dementia advocate Dennis Frost speaking at the Parliamentary Friends of Dementia event in the NSW Parliament in June

Comfort care, peace and dignity at the end of life

Good end of life care is essential in dementia, but not always delivered. **Angela Liddament** explains her role as an advanced nurse practitioner in a Norfolk care village

The rising prevalence of dementia has drawn particular attention to the need for good end of life care. Both the UK Department of Health's End of Life Care Strategy (DH 2008) and the National Dementia Strategy (DH 2009) emphasised the importance of improving end of life care for people with one or more chronic long-term conditions, including dementia. The aim has been to bring it up to a level received by people with a cancer diagnosis.

Evidence shows that care provision has failed to meet the complex needs of the growing numbers of people living with dementia (Dempsey *et al* 2015). Furthermore, few people with dementia have access to palliative and hospice care (Ballard 2016). So, it is essential that good quality end of life care, whether in the community, hospital or care home, is made available (Bracegirdle 2012).

One of the problems is that, despite the availability of different prognostic indicators to aid clinicians in recognising when a patient is nearing the end of life, it can be particularly challenging in the case of dementia. It is another reason why this group often receives inadequate end of life care (Dempsey *et al* 2015).

The most used prognostic indicator in primary care is the Gold Standards Framework (GSF) Proactive Identification Guidance (PIG) (2016). This guidance has three triggers to suggest a person is nearing the end of life:

- the surprise question:

"Would you be surprised if this person were to die over the next few months, years or days?"

- general indicators of decline
- specific clinical indicators related to certain conditions.

It remains unusual for a person with advanced dementia to be on a GSF register in primary care. Care homes, however, have improved considerably since the GSF in Care Homes (Badger *et al* 2007) and Six Steps (DH 2008) programs emerged with the aim of educating both care staff and managers in awareness and development of better end of life care for their residents.

Notwithstanding this improvement, the social care funding crisis has led to a worrying trend in which residential placements are increasingly at a premium,

resulting in more people with advanced dementia dying in hospital (Middleton-Green 2016).

The decision to move a loved one to a care home is often painful, a last resort and frequently seen by family, carers and friends as 'failing' them. But this feeling can be misplaced because a good care home should provide a nurturing, caring and supportive atmosphere for people with advanced dementia as they approach the end of life. Although care staff come and go, there will be some staff who are a consistent presence and offer continuity of care, ideally enabling a close bond to develop with resident, family and friends.

Bowthorpe Care Village opened in Norwich in early 2016 and, although not a new concept in the UK, it was new to Norfolk. On a single site,

which is part of a housing estate, there are 90 flats providing 'housing with care' and 'extra care', as well as a dementia unit with 80 residents. The dementia unit is a protected and locked environment with most residents covered by the deprivation of liberty safeguards (DoLS). It is seen as the best way, at this late stage of their dementia, to protect them from harm.

Although in a locked unit, residents are still encouraged, wherever possible, to participate in the day-to-day life of the village. Volunteers, carers and families are available to escort the residents to whichever activity they want to partake in. This includes a shop, hairdressers, restaurant, café, gardens and entertainment areas offering a wide range of planned activities.

Specialist palliative care

I am the advanced nurse practitioner (ANP) (DH 2010), on site Monday to Friday during office hours overseeing the medical care of all residents, with part-time support from a health care assistant and a GP visit twice weekly. Together with my ANP skills, I have extensive knowledge and experience in both palliative and end of life care.

Multidisciplinary team (MDT) meetings are held weekly, which include representation from local community nurses. We have a GSF register which is reviewed weekly and updated monthly using the PIG, ensuring that the best and

Five priorities of care

When it is thought that a person may die within the next few days or hours:

1. This possibility is recognised and communicated clearly and appropriately to the resident and family: decisions are made and actions taken in accordance with the dying person's needs and wishes. Needs and wishes are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with passion.

Source: LACDP 2014

most appropriate care is given. Information from the MDT meetings is then cascaded down to all care staff by team leaders, one of our priorities being to avoid unnecessary hospital admissions, especially for those residents at the end of life.

Both specialist and generalist palliative care are accessible for all from our community care service, in line with guidance from the National Institute for Health and Care Excellence (NICE 2011). There is a telephone helpline for advice from the specialist service, and community nurses are available for nursing support and symptom assessment as well as to provide equipment. Specialist and generalist services are 24-hour, so there is continuity even when I am not on duty. I ensure that medication and administration charts are in place for those residents the GP has agreed are at the end of life.

A resident with advanced dementia can have symptoms associated with the end of life for many months before death, such as being unable to mobilise without assistance, being chair or bed-bound, having double incontinence, variable verbal and non-verbal communication, loss of ability to swallow, reduced food and fluid intake and significant loss of weight, as well as high risk of infection and pressure sores. So, it can be hard to know when care and treatment should change to 'comfort care' – care oriented to the end of life – in accordance with the GSF.

Over the years I have developed my own approach to comfort care because it seems more sensitive to the needs of residents with advanced dementia. Dementia is a life-limiting terminal condition resulting in most of our residents being at least GSF 'green'. In fact, approximately half of this group are actually at 'amber+', indicating an increasing level of support and care as a resident passes from green to



A resident's memory box

amber and eventually red as they near end of life.

However, because of the nature of advanced dementia and the difficulty of diagnosing when someone is truly at the end of life, I have introduced an extra 'amber+' level for those residents for whom it is more appropriate to have comfort care only (led by the patient's family).

Amber+ indicates that the resident has most end of life symptoms but is not actively dying. If the individual is having a sleepy day, they do not have to get up but are left to sleep either in bed or in a suitable recliner chair. If they show their inclinations by keeping their eyes or their mouth closed when food or fluid is offered, they are not forced to accept but care staff will perform mouth care, for example, and return later to try again. Staff will be aware that the resident is on comfort care only because they have a mayflower card in their memory box and a mayflower on their allocation sheet.

It is at this point that continuity of care from myself and care staff can be critical, as we are better able to recognise and respond to any distress, often knowing what simple actions will relieve agitation and whether medication is required to alleviate symptoms. Amber+ residents are reviewed at least every two weeks by the GP as symptom management is the key to good end of life care.

Useful assessment tools

A person with advanced dementia is often unable to communicate their pain, nausea or any other discomfort they are feeling, yet there are several assessment tools that can be used to assess for pain and distress. The Abbey Pain Scale (National Council for Palliative Care 2012) is designed to assist in the assessment of pain in patients who are unable to clearly articulate their needs. It measures vocalisation, facial expression, change in body language, and behavioural, psychological and physical changes, and should be completed hourly initially. Once the patient appears comfortable, it can be completed every four hours for 24 hours to ensure the patient remains that way.

Alternatively, there is the Disability Distress Assessment Tool (Mackey & Dodd 2011). It is designed to describe the patient's cues indicating that they are content, making it easier to identify distress cues by contrast. It is not a scoring tool but makes care staff more confident about their observation skills and their accuracy.

Medication

Not all people with advanced dementia will require medication at the end of life. Dying peacefully, in comfort and with dignity, may come after a period in which the resident has become more

withdrawn and sleepy. This is especially so if they die 'from' dementia. However, if, as often happens, a person dies 'with' dementia from an acute illness such as pneumonia, end of life medication may be needed to ease symptoms of pain, agitation and excessive secretions.

Once I have identified a resident as being GSF amber+ and they are receiving comfort care, I will put in place anticipatory arrangements for medication together with an administration chart to ensure symptoms can be relieved if and when they occur. If it becomes clear that the dying person needs ongoing regular medication, I will set up a syringe driver for continuous delivery. At all times I liaise with the GP, who will be aware of the resident's condition and prognosis, and if a resident reaches the point of requiring continuous pain relief they are reclassified as GSF 'red'.

Communication is vital

Carers and family members of people with dementia often suffer significant levels of distress, burden and anticipatory or pre-death bereavement (Rahman 2017). Spouses, in particular, express feelings of loss in advance of their loved one's death. Memory loss and personality changes in advanced dementia, and the necessity of making decisions alone which used to be shared, all contribute to these feelings.

To help families (and care staff) understand comfort care, I have introduced a leaflet explaining what is happening and what to expect over the next few weeks. It has assisted families to understand the process their loved one is experiencing and what they can do to help. It also explains what symptoms may be experienced as life draws to a close.

Whether the resident is in the dementia or the 'housing with care' unit, it is vital to remember to liaise with the GP and communicate with the resident and their family. It

was because of communication issues that the Liverpool Care Pathway for the Dying (Watts 2013) was phased out and the *More Care, Less Pathway* review (Neuberger 2013) was published with recommendations leading to five priorities of care (see box p12). The point is to focus all care in the last hours of life on to the dying person (Leadership Alliance for the Care of Dying People 2014).

Having an advanced nurse practitioner permanently on site in the village to care for all of the residents has been a successful model for both those with dementia and those without. Because I am based in the village, all residents and their families know of me and feel able to discuss any concerns they have. If there is a complex issue I am unable to deal with, I can pass it on to the GP. Consequently, there are very low admission rates to acute care, falls are monitored closely, medical care is given and reviewed regularly, and palliative and end of life care are of high quality.

A 'good death' is desirable both for residents and for their families and carers. If their loved one has a good death, that is the best care we can offer to the family. It gives them the chance of a peaceful bereavement and a sense that everything has been done for their loved one. We only have one chance to get it right. ■



■ Angela Liddament is a soul midwife (level one and two) and an advanced nurse practitioner at Bowthorpe Care Village, Norwich. For further information contact her at angela.liddament@nhs.net

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This article first appeared in the UK Journal of Dementia Care 26(3) 21-23.

Lynne Phair and Denise Edwards describe the power and value of a single journal article in improving dementia care practice in Australia and the UK

With so much information available on the internet, you might wonder whether professional journals like this one still have a place in modern health and social care learning. Journal articles serve many purposes; whether to improve practice, give opinion, or provide updates on research, policy and news. When writing for a journal, it is hard to envision whether the article will succeed in its intention to inform, change practice, perceptions, or knowledge.

Journals are used by people in different ways, with some glancing, some flicking, and some reading and saving useful articles; but are they influenced and changed by what they read?

Sit&See® in Australia

Three years ago the *AJDC's* sister publication, the *UK Journal of Dementia Care*, published a short article co-written by one of the authors here (Lynne Phair), describing the development of the Sit&See® tool (Phair & Heath 2015). (The article was re-published in the April/May 2016 issue of *AJDC*). Sit&See® is an observation tool designed to be used in any care setting to capture the

smallest things that make the biggest difference in care, celebrate care and compassion, and improve practice and the culture of the care setting. An independent evaluation demonstrated the tool's value in improving understanding of care and compassion in staff, thus enabling both confirmation of compassionate care and evidence for development of the practice.

The article was read in Australia by Denise Edwards (co-author here), project manager in the Service Engagement and Innovation team at Blue Care, one of the country's largest aged care providers, based in Queensland. She noted the common themes of care and compassion between the UK and Australia. At the time, Denise was involved in memory support evaluation and was looking for a tool that would measure person-centred care, that was simple to use, and would not be too time-intensive. Denise contacted Lynne and, after several telephone and Skype conversations, felt that the tool, with some small adjustments to reflect Australian cultural differences, would benefit her project at Blue Care.

Going through many stages



The Sit&See® tool captures care and compassion in the everyday small interactions that make the biggest difference in care

International networks nurture innovation

of development and organisational approval for the project, Denise applied for a philanthropic grant for funding. The first application was unsuccessful, but the following year funds were granted for the project to begin in 2017.

After a lot of planning, Lynne visited Blue Care Services in Queensland three times in 2017. The first visit was to learn and understand Australian care culture and adapt the Sit&See® tool for Australia and Blue Care. The second visit in May was to deliver 12 Sit&See® training sessions to Blue Care staff in a variety of services and offer webinar support across Blue Care facilities from the Sunshine Coast to Cairns, training 89 staff. Lynne's third visit in August involved further training with managers.

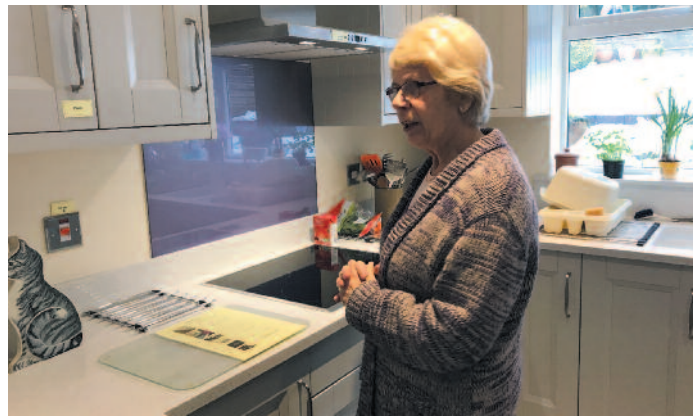
A pre- and post-course evaluation questionnaire identified a 62.5% improvement in Blue Care staff's knowledge of care and compassion and how to capture it. Staff have continued to use Sit&See® and more are being trained following the initial implementation. A formal evaluation of the impact and benefits of the tool is due shortly.

Montessori in the UK

While in Australia, Lynne saw a number of services in Blue Care starting their journey to introduce Montessori Elder



Blue Care service manager Michelle Thomas undertakes Sit&See® in one of Blue Care's residential care homes



Heather in her new kitchen, which has a prepared environment in keeping with Montessori principles. Heather uses signs and task breakdown sheets to help her cook independently

Care into their memory support (dementia care) units. Montessori schools for children are well known in the UK but using Maria Montessori's principles in interventions in elder care has not been introduced to the UK. It is currently only used in America, Canada, Australia and a few places in Europe.

The method is evidence-based and uses Montessori principles to create a caring community that is aligned with the individual's needs, interests, abilities, skills and strengths. The environment is carefully prepared to meet and nurture the needs of each person and lives are enriched through the environment, the engagement in roles, routines and activities, fostering a sense of belonging and wellbeing.



This bathroom is an example of a Montessori prepared environment

For Lynne, seeing the Montessori method in action was inspiring and a paradigm shift from current good dementia care in the UK. Residents, even if experiencing advanced dementia, can have a role and activities to enhance their remaining skills. Montessori environments support people to be independent by using a number of methods including colour contrast signage, labelling, cueing, activity stations available to use at any time, interactive wall hangings, drink stations, individualised schedules and name badges for residents, staff and visitors. The Montessori philosophy is also supported in comfort care programs for those at the end of life.

Excited by Lynne's interest, Denise introduced her to Anne Kelly, Director of Montessori Ageing Support Services in Australia who, in turn, introduced Lynne to the Montessori Institute and Association Montessori Internationale. Lynne, a nurse, and her Occupational Therapy colleague, Sally Dando, attended the first World Montessori and Aging Symposium in Prague in July 2017 on a self-funded visit to learn more of the benefits, evidence base, and research behind this method.

Continuing the collaborative

exchange, Lynne worked with the Montessori Institute to take Anne Kelly to the UK to run three workshops in January 2018. The first care homes in the UK are now introducing Montessori methods and have begun their journey, while Lynne and Sally are training to become qualified Montessori educators.

Power and value

This story of the journey of two practitioners illustrates the power and value of a journal article. It also demonstrates that innovation and good practice can be introduced and spread across the world by practitioners with determination, enthusiasm and skills in project management.

The implementation of these two practices – Sit&See® and Montessori – has not been straightforward or easy, but this story demonstrates how innovation does not need to wait for a government directive or an international strategic plan from lobbying organisations. International practice development is occurring because of the power of journals like this one to spark thoughts in a practitioner's mind, grow enthusiasm, and overcome obstacles to improve practice. ■



■ Lynne Phair (left) is an independent consultant nurse in the UK. Denise Edwards is Project Manager at Blue Care Australia. For more information contact lynne@lynnephair.co.uk or D.Edwards3@bluecare.org.au

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Time travelling with technology

Karen Watson, Deborah Parker, Andrew Leahy, Daniel Piepers and Kate Stevens

discuss the use of technology-enriched reminiscence therapy for people with dementia

"Memories are the key not to the past, but to the future"
(Corrie ten Boom, p17).

For people with dementia, reflecting on the past can raise their awareness of their personhood. This becomes more and more vital as short-term memory deteriorates.

Responsive behaviours and psychological symptoms of dementia (including anxiety, depression, hallucinations and delusions) affect up to 90% of people with dementia, with distressed behaviours challenging to manage due to communication and comprehension impairments often present in the trajectory (Feast *et al* 2016). This may result in decreased quality of life for people with dementia and their carer, increased self-isolation and higher rates of admittance to residential aged care homes (Cerejeira *et al* 2012; Spector *et al* 2016).

The Time Travelling with Technology (TTT) project is a unique approach to responsive behaviours that attempts to enable people with dementia by working with their existing

strengths and abilities to promote wellbeing. This project combines Google Liquid Galaxy (LG) technology and reminiscence therapy (RT) to provide an enhanced carer-driven intervention for responsive behaviours that promotes communication and enhanced quality of life.

The TTT project is a joint collaboration between The MARCS Institute for Brain, Behaviour and Development at Western Sydney University, University of Technology Sydney, BaptistCare, and supported by the Dementia Centre for Research Collaboration (DCRC). Our team is investigating if there are additional benefits of reminiscence therapy when coupled with a high-tech immersive experience.

We conducted two research studies at the BaptistCare Yallambi and Waldock Centres in Carlingford and BaptistCare The Gracewood Centre, Kellyville, Sydney, where the Google Liquid Galaxy was temporarily installed. Wraparound screens displayed still and moving



It was not unusual for residents, where mobile, to step up to the immersive display, recall an event elicited by the visual landmark and then gesture to other nearby locations and recall other adventures or activities associated with those locations



Week 1 of the Time Travelling with Technology (TTT) intervention familiarised residents with the immersive screens and technology. The technology enabled small groups to travel to 'landmarks' associated with experiences and activities from their early and/or adult life. Here we're viewing Palm Beach and Pittwater from Barrenjoey Head, north of Sydney, Australia

images in high definition to elicit a sense of travelling through space and time for the participants. The experience is non-invasive, enjoyable and engaging.

Imagine Elaine and Martin, two people living with dementia, given the opportunity to take care staff and family members to visit the neighbourhoods where they grew up. The group is seated in front of a large Liquid Galaxy screen displaying images sourced from Google Maps and Street View. While watching the moving images, Martin directs the group through the intricate maze of London's backstreets by pointing out the direction on the screen as he retraces his childhood journey from the family home to his local primary school, animatedly providing commentary and recalling locations and sites along the way. Martin's eyes widen. He leans forward, approaching the screen as the location of the sweet shop – a regular detour on his route to and from school – comes into view. The group members ask questions, make comments, chat and remember.

Next stop is La Perouse, Australia. Elaine shares her recollections of spending time there with her grandmother

who would tell Dreamtime stories while making necklaces from the shells Elaine had collected on the beach. Elaine and Martin's feelings of uncertainty, evident moments before, have disappeared. Everyone is absorbed. Time travelling. Reminiscing.

How does it work?

Reminiscence therapy (RT) uses personal triggers such as music, objects and sound to engage a person's long-term memory, assisting them to recall life experiences (O'Rourke *et al* 2011), to facilitate the ability to talk, reflect and remember events from earlier times (Li *et al* 2017; Dempsey *et al* 2014; Woods *et al* 2018). RT has been used to support people with varying levels of cognitive ability to support communication, reduce social isolation and improve mood (Gonzalez *et al* 2015; Woods 2009). TTT uses the new engaging technology of Liquid Galaxy and the web resources of Google Earth and Street View to enhance the effect of RT. Locations meaningful to the resident are displayed as life-size, hyper-real, software-rendered images that are navigable through space and time and elicit a sense of envelopment and continuity

(see images on the previous page).

Our research team conducted two TTT experiments, in October 2016 in Carlingford and May 2017 in Kellyville, that compared RT enriched with full immersion envelopment and continuity with a static image control to examine feasibility and evaluate effects on responsive behaviours for people with dementia.

Immersion and dynamism vs static images

Large immersive, wraparound displays were used to present images to resident groups with a facilitator to guide the session (these displays are shown in a short film on the project, available to view at www.youtube.com/watch?v=YK8NF4-vgaI). Each group consisted of three to four residents 'travelling through' pre-loaded Google Earth and Street View landmarks over the six-week intervention. The residents in the intervention condition experienced three immersive and dynamic, personally meaningful locations (such as their first school, family home, favourite holiday destination) displayed on five screens at each weekly session (see image below). The control condition displayed personally meaningful locations as static, large 'postcard-like' images across three instead of five screens (see image above right). This latter comparison condition controlled for immersion and dynamism of the display.



In the 'intervention', personally meaningful locations from Google Earth or Street View were pre-loaded and displayed across five interconnected, immersive screens

Feedback

Feedback from family and staff suggest some reduction in responsive behaviours. For example:

"Thank you so much for doing this; he loves it; he thinks it's amazing how you have all the big screens and take him to places he knows."

"It's lovely, [it's] wonderful for the residents. You know, the other day I was [taking] a resident back from a session [who] is usually quite withdrawn and she said, 'Oh no take me down to the dining room, I feel like chatting after that'."

"Abby loves it. Just to get a smile out of her you're doing well... because she has very... [points to her face demonstrating flat affect]. Coming back in the bus yesterday, as we were pulling back up to the unit she said, 'That was really good'."

Next steps

Our team is currently working on a technical solution to improve the practicality of TTT by using existing aged care resources (large-screen TV/tablet), to provide an accessible, low-cost intervention to reduce responsive behaviours that has the potential to promote wellbeing. An implementation guide will also be made available later this year to help guide staff in conducting future sessions. The guide will be available to users of TTT free-of-charge from the researchers.

By enabling carer-driven TTT, new technology such as Liquid Galaxy can be enjoyed by the person with dementia and their carers to improve communication, potentially decrease responsive behaviours and provide alternate platforms for conversation to strengthen relationships and reduce carer burden.

Results from the TTT studies are expected to be published in early 2019. For more information on the project and forthcoming implementation guide, contact Professor Kate Stevens at



A 'control' condition was used to bring into relief differences between the more immersive and dynamic intervention condition with a condition where the visual display and experience was less immersive (three instead of five screens) and static rather than dynamic. All other features of the small group sessions were common to the intervention and control conditions

kj.stevens@westernsydney.edu.au ■

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■ Dr Karen Watson is an aged care clinician, adjunct researcher at The MARCS Institute for Brain, Behaviour and Development, Western Sydney University and an academic in the Faculty of Health, University of Technology Sydney (UTS); Deborah Parker is Professor of Aged Care (Dementia) in the Faculty of Health, UTS; Andrew Leahy is Technical Advisor in the Information Technology and Digital Services, Western Sydney University; Dr Daniel Piepers is researcher at The MARCS Institute and an academic in the School of Social Sciences and Psychology, Western Sydney University; and Professor Kate Stevens is Director of The MARCS Institute and Professor in Psychology at Western Sydney University. To follow up on this article contact Professor Stevens at kj.stevens@westernsydney.edu.au

Challenging tradition: unlocking the DSU



Mark Aros describes what happened when the doors to the dementia-specific unit at Goodhew Gardens were unlocked and argues that providers must move towards a more respectful and humane approach to providing residential care for people living with dementia

With the increasing need and demand for high-quality, safe and appropriate residential care for people living with dementia, the team at Anglicare Goodhew Gardens, in Sydney's Taren Point, set out to challenge the well-established models of care that place secure dementia-specific units (DSUs) at the centre of care for people living with dementia in residential aged care homes.

It is time to challenge the assumption that it is necessary and respectful to keep people with dementia in a locked environment. Recommendations about locked dementia-specific environments were developed at a time when the profile of aged care residents was different to that of today. Today's residents are older, frailer and less mobile than even five years ago. This should be a trigger for the sector to reconsider the need to keep people living with dementia 'locked in'.

The very act of denying personal liberty by keeping someone in a confined space should be challenged. While the sector adopts the approach that the need for freedom of movement should be balanced with the need for safety, most homes interpret this by providing a secure unit within the confines of a larger facility. This approach denies people with dementia freedom of movement to access their whole home environment. Goodhew Gardens' initiative of unlocking the DSU challenges this assumption.

This article outlines the processes that led to the 'unlocking' of the DSU at Goodhew Gardens, the effect of this change on the lives of the residents, and the challenge faced by the industry to move towards a more respectful and humane approach to providing residential care for people living with dementia.

The role of the DSU

Dementia-specific units are standard practice within aged care. One of the



primary purposes of the DSU is to 'manage' and restrict mobile residents at risk of leaving the home and getting lost. They are generally considered to be the 'safest' environment for people living with dementia. The DSU also offers a contained space to develop a 'dementia enabling environment' with all the requirements that aim to provide a reassuring and comfortable homelike environment to reduce confusion and frustration.

When Goodhew Gardens was purpose-built in 2007 the DSU was designed within the framework of best-practice principles of environmental design for people living with dementia. The DSU contained four communities (or wings), each accommodating 17 residents in individual rooms, within the larger home. Each wing was self-contained and furnished in a homelike style that enabled small groups of residents to meet for meals and social activities. The wings were secure, while still allowing areas for

walking internally and in external courtyards.

For a period of time this design went unquestioned. In subsequent years however, there have been two significant shifts that have led the management team of Goodhew Gardens to question the ethics of the locked environment. These are:

- the changed profile of the 'average' person in residential aged care, and
- a focus on person-centred care.

Legislative amendments have changed the aged care industry significantly in recent years. The profile of the 'average' person now entering what was once called a 'low care facility' is considerably different to the average person entering residential care just five years ago. A person entering Goodhew Gardens for residential care now is older, frailer, has greater care needs, and has a shorter length of stay than in previous years. The Goodhew Gardens experience is not

unique; it reflects a government strategy that encourages people to remain in their own homes for as long as possible, and delay or avert entry into residential care altogether.

The risk of people with dementia leaving the home and losing their way is significantly decreased as a result of their frailty and reduced mobility. Despite this change there had been no reflection by our management team, the Government or the aged and health care sector on whether a restricted environment remained necessary or relevant to prevent people leaving the home, nor any reflection on whether this restriction was unnecessarily dishonouring personhood.

Our observations and data analysis showed us that our two secure dementia environments only existed because we had not questioned the efficacy of the unit, and we had not challenged the orthodoxy that secure dementia-specific units still had a place in the current operating environment.

The shift towards person-centred approaches at Goodhew Gardens has led to the inclusion of meaningful activities which are individually tailored to engage each resident. By increasing the focus on meaningful engagement we sought to improve the quality of life for people living with dementia and to decrease incidents of unsafe walking and responsive behaviours.

We hypothesised that the combined effect of providing meaningful activities and a less restrictive environment would reduce responsive behaviours and enhance the quality of life for residents with dementia.

A two-staged approach

The initiative evolved in two stages. The first involved implementing an 'Engagement Shift' based on the principles of meaningful activity and Montessori*. The second stage related to the environmental design of the DSU. In stage two, staff members were challenged to question the fundamentals of providing a secure environment, and to reflect on whether these fundamentals truly respect the liberty and personhood of residents living with dementia.

Stage 1: The Engagement Shift

The development of the Engagement Shift followed a four-stage process: design, pilot, review and implementation. The program was designed based on principles of meaningful activity (Gitlin *et al* 2009), person-centred care (Mitchell & Agnelli 2015; Kitwood 1997) and Montessori. Initially the shift was named

the 'behaviour shift' and care staff-to-resident ratios were increased over the afternoon period. Through the pilot and review stages it became clear that this approach was not fully meeting our objective of engaging residents in meaningful ways. Many staff members were still focusing on care tasks rather than engagement.

As a result, the shift was renamed the 'Engagement Shift' and ownership of the program was given to the Lifestyle Team. This team consists of staff with a minimum Certificate IV in Leisure and Health. Renaming the shift represented a significant development in the staff's understanding that targeted engagement, rather than increased care ratios, is important to prevent the escalation of anxiety in people living with dementia.

In response to literature advocating an individualised approach it was agreed there needed to be flexibility to include a range of approaches and techniques to meet individual needs. The Lifestyle Team, together with the Clinical Leader, Nurse Educator and Dementia Clinical Nurse Consultant then designed the individualised approach we would implement.

There was a commitment to understanding the triggers for each person's frustration and what they were communicating through their 'behaviour'. In addition to ensuring physiological needs such as pain, hunger and medication management were met, it was also vital to use each resident's personal

history and activity preference to identify specifically targeted activities. This follows Kitwood's principle of person-centred care that "a person's life story should be built into all interactions in the care setting" (Kitwood 1997).

Along with the Lifestyle Team, family members and residents were key to completing the Lifestyle Overview, which included:

- Life Story: records each individual's unique story including past, present and future interests and relationships.
- Lifestyle Assessment: identifies key meaningful activities based on Montessori Principles for Dementia.
- Key to Me: highlights key points about the individual.

The Lifestyle Team was included in clinical handover meetings to ensure information about each person's engagement needs was discussed with care staff.

Stage 2: Unlocking the DSU

"It is widely recognised that a building and an environment can have a significant effect on a person with dementia. It can support them or it can hasten their deterioration" (NSW Government, Family and Community Services, Ageing Disability and Home Care 2011).

When the built environment at Goodhew Gardens was assessed against principles of design for people with dementia (Dementia Enabling Environments 2017) it met many of the requirements including:



Anglicare Goodhew Gardens has opened the doors between the dementia-specific unit and the rest of the home (above), giving the residents access to the entire home, including larger outdoor areas and gardens (see photo previous page). Photos courtesy Anglicare

* The Montessori method for people with dementia is adapted from principles developed by Italian educator Dr Maria Montessori in the early 1900s and focuses on supporting the person to engage in meaningful activities in a prepared environment, based on their individual needs, interests, abilities and skills. Read more about the Montessori approach in dementia care in the following *AJDC* articles: *Using the Montessori approach in community dementia respite centres* (Feb/Mar 2017); *Creating a world with meaning and purpose* (April/May 2017); *Developing purposeful activities* (Oct/Nov 2015); and *The Montessori approach to dementia care* (Oct/Nov 2013). To access these articles, email admin@australianjdc.com for details.

- Small in size so as not to be overwhelming.
- Reduced number of people – there were a maximum of 17 people in each community within the DSU.
- Domestic furnishings – each community within the DSU was homelike and included small lounge and dining areas.
- Blend of privacy/individual spaces and small group spaces.
- Guided pathways and unobtrusive security to balance safety and security with freedom of movement within the DSU.

Despite the DSU meeting these design principles, the management team was not fully convinced that the physical environment was not contributing to the frustration experienced by many residents. The team made an executive decision to ‘open up’ the DSU in a staged process. First, corridors between each wing within the DSU were unlocked, giving residents access to the group spaces in each community.

Then the doors between the DSU and the rest of the home were opened, giving the residents entry to the lift areas and access to the entire home if they wish. This enables independent access to the café, hairdressing salon and nail artist, reception area, resident mailbox, water features, large fish tank, children’s play area and larger outdoor sitting areas.

Fundamental to the success of this initiative has been the appointment of Goodhew Gardens’ receptionist who was recruited both for her reception skills and her experience in dementia care. Her role as receptionist is to not only greet visitors to the home but to assist with meeting the needs of residents who come to the reception area. Residents are attracted to the hustle and bustle and pleasant environment of the reception foyer and it has become a place for much incidental socialisation. As it is also the exit of the home, the receptionist monitors movement within the area to ensure no one’s safety is compromised.

Staff working in the other services in the foyer, such as the hairdresser, nail artist and café staff, also monitor the wellbeing of all residents in the area.

Residents return to the DSU for breakfast and the evening meal, where they receive focused attention from staff to ensure adequate nutrition and hydration.

Outcomes

Una and John are among the residents whose lives have been changed by unlocking the DSU at Goodhew Gardens:

John

John is a gentleman who was constantly pacing within the DSU. He would rattle and shake any doors he came to and did not engage with other residents or staff. His situation was discussed at one of the care conferences. Individualised activities were designed for John, in conjunction with his family, as a means of engaging him and diverting his attention before his frustrations escalated. Exits were obstructed as much as possible and the pathway through the DSU was made clearer using lighting and colour contrast in an attempt to guide his walking.

These measures settled John to some extent, however he continued to look for and rattle doors. The effect of restricting John’s freedom of movement was undignified and dishonoured his personhood.

When the DSU was unlocked, John immediately walked into the adjacent area and went directly up to a group of male residents who were sitting at a small table, shook their hands and introduced himself. The staff who witnessed this were moved to tears.

Una

Una mobilises slowly with a frame. She has an easy nature and is happy to walk between activities when offered, however has difficulty initiating an activity and rarely chooses to join a group activity. When the DSU was unlocked Una spontaneously raised her hands from her walking frame and said “yippee”. All Una had wanted to do was go downstairs and sit in the sun. Now, each day Una takes herself, independently, down in the lift to

the ground floor where she can sit in the sun in the entrance foyer, surrounded by activity from the nearby café and children’s play area.

Social impact

The greatest gain from unlocking the DSU has been the opportunity for incidental socialising among residents. All residents now have greater access to all areas of their home. This has allowed more personal connection with other residents and with reception, maintenance and grounds staff. The Goodhew Gardens’ foyer is now alive with activity.

Atmosphere

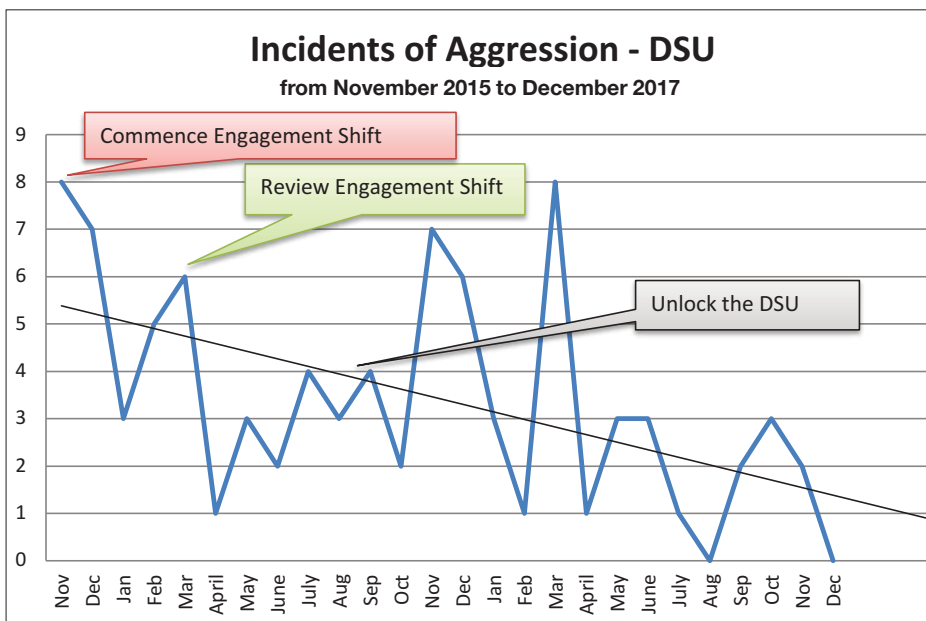
Staff members commented that the environment is more peaceful. Before opening the doors between the DSU and the rest of the home there was significant noise every time someone unlocked and opened or closed the door when entering and leaving the area. No one had commented on this previously, however now that it no longer occurs the staff are aware of how much more peaceful the environment is.

Impact on responsive behaviours

The incidence of residents’ responsive behaviours is measured monthly. When the data was reviewed there was a definite trend towards decreased incidents of aggression by residents each month between November 2015, when we launched the initiative, and December 2017 (see graph next page). This significant reduction has a direct and positive impact on individual residents, family members and staff.



The greatest gain from unlocking the DSU has been the opportunity for more socialising among residents and with staff



Discussion

The success of ‘unlocking the DSU’ at Goodhew Gardens should compel others in the industry to question the ethics of unnecessarily restricting access for people living with dementia.

Although Goodhew Gardens did not unlock the DSU in response to specific research, there are several research areas that support this as a way forward for providing care for people with dementia including:

- least restrictive approaches
- dignity of risk, and
- agency theory.

A person-centred approach has been described as a “restraint-free approach which preserves the human rights of any person” (Commonwealth of Australia 2012). Restraint is defined by the Department of Health and Ageing as “any aversive practice, device or action that interferes with any person’s ability to make a decision or which restricts their free movement. The application of restraint, for any reason, is an imposition of an individual’s rights and dignity”. Restraint is defined as incorporating environmental restraints such as locked doors that restrict access to certain areas. It also includes preventing a resident from leaving the building. The Department of Health and Ageing definition also encompasses psychological restraint, which “creates a belief that limits choice” (Commonwealth of Australia 2012), such as placing an item over a doorway to indicate lack of access.

The Australian Commission on Safety and Quality in Health Care (ACSQHC 2009) also defines locked doors as a form of restraint. It expands this by stating that “restraints should not be used at all for

residents who can walk safely and who wander or disturb other residents. Wandering behaviour warrants... alternatives to restraint use”.

Embracing the philosophy of a person-centred approach also warrants considering the provision of ‘dignity of risk’. “Dignity of risk describes the right of all individuals to choose to take risks when engaging in life experiences” (Williams 2015). This concept recognises that restricting an individual’s choices in an attempt to limit risk is detrimental to the sense of personhood and wellbeing (Kurrle 2014). Williams makes the link between environmental restraints and ‘behaviours of excess’ being the way in which people communicate the frustration and lack of personhood experienced when a physical barrier restricts their choice of movement.

The concept that the function of ‘behaviours of excess’ may be a response to environmental restraint is expanded by Boyle (2014) in her article *Recognising the agency of people with dementia*. Boyle demonstrates that despite cognitive decline in people living with dementia, there remains a capacity for ‘agency’, or the “ability to influence their own personal circumstances”. Boyle comments that behaviours and emotions associated with dementia should not solely be considered symptomatic of the illness but potentially indicative of agency in response to environmental and other constraints.

Once a locked environment is considered as a ‘restraint’ it becomes evident that a secure dementia unit denies people a fundamental freedom to make choices about their movements within their own home. The aged care industry therefore has an obligation to question the

use of locked environments for people living with dementia.

Challenge to the industry

All levels of the industry need to reflect on the pressures that they bring to bear on residential aged care homes to provide a ‘locked’ environment for people living with dementia. This includes the funding structure, Government regulations, and the medical sector advising families it is ‘safest’ to find a placement that includes a locked environment.

Residential aged care homes need to compete for bed placement and these factors all combine to constrict the innovation that they can use to truly implement a person-centred approach.

Pressures within the industry are reinforcing an inhumane principle that it is permissible, under the guise of safety, to limit personal freedom of movement and human dignity for people living with dementia. ■

■ Mark Aros is Residential Care Manager at Goodhew Gardens in Taren Point, Sydney, NSW. Contact him at mark.aros@anglicare.org

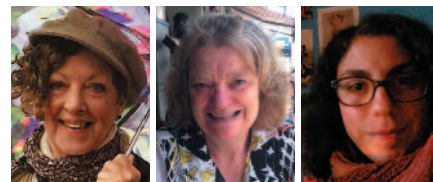
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Reframing dementia: the challenge to change

Dementia is a challenging but inspirational starting point from which to reconceptualise our understanding of 'being in relationship', so that care is always central. This is the aim of the Reframing Dementia project.

Gaynor Macdonald, Jane Mears and Ailin Naderbagi explain



Dementia is more than a diagnosis received by an individual; it is a social experience.

Although dementias are diseases of the brain, both the diagnosis and the disease progression change the ways in which people engage with each other – for those with dementia, as well as those who share their lives.

Reframing Dementia as Social and Cultural Experience is a project we launched in mid-2016 to examine different ways of understanding dementia beyond the medical understanding of cause and treatment. Biomedical diagnosis and treatment is necessary, but medical interventions are not designed to provide insights into how the experience of living with

dementia can be improved for all those touched by it.

Because the day-to-day challenges of dementia are social rather than medical, the complex social and relational challenges of dementia are inadequately addressed. Cures, and medication to alleviate symptoms, are important but the priority must be improving the quality of life for all those living with dementia.

A broader understanding

The Reframing Dementia project is an initiative of the University of Sydney's Department of Anthropology and the School of Social Sciences and Psychology at Western Sydney University. It is part of a growing global movement that seeks to

broaden the understanding of 'living with dementia' to include all those who are impacted by a diagnosis. This includes the person themselves but also, and most importantly, the social constellation within which the person *with dementia* lives, and on whom he or she will increasingly come to depend: family members, caregivers, friends, health professionals, neighbours, shopkeepers and the wider community.

Reframing dementia as social experience means:

- Working to identify, address and change the prevailing constructions of dementia as loss, tragedy or deficit. These create fear and stigma, and exclude and marginalise rather than enable families to live with dementia more effectively.
- Developing and strengthening cultural values, understandings and practices that value, include, support, and care

Charlie 'our inspiration'

My husband Charlie Eldridge (pictured) was diagnosed with Alzheimer's disease in 2013 when he was 83. If you meet Charlie, he will give you his beaming smile and convince you how easy he is to care for – but the reality is different. Committed to caring for Charlie at home, I found I could access medical information but little practical advice, although I read many warnings about the carer burden and became determined to avoid it.

With my friend (and co-author here) Dr Jane Mears, who has long experience of working with carers, especially in the context of old age, we committed to create the Reframing Dementia project to help change attitudes and explore better ways to support carers.

Charlie was the reason we embarked on this journey to inspire more positive attitudes and he continues to challenge and teach us!

– Dr Gaynor Macdonald



for and about those living with dementia.

- Encouraging and supporting research and practice that focus on social support and more effective communication with people with dementia and their carers.
- Reconceptualising 'care' as a total social responsibility.
- Exploring ways to create a more caring society.

The caring society

What does it mean to envision a society where an ethics of care is everyone's concern, across all contexts of our lives? How do different knowledges and practices interact such that they diminish or enhance the lives of those experiencing dementia and those who live alongside them?

The caring society is one in which care is a taken-for-granted part of the social fabric, from cradle to grave; a society in which people who have short- or long-term disabilities are valued, as opposed to being seen as abnormal. All human beings are inherently vulnerable: we all need care and support at some time during our lives.

The ways in which 'care' is being represented as a burden or a cost to the rest of society needs to be challenged because these representations distance and stigmatise those who require care.

Dementia is one manifestation of the various situations in which people come to depend on others, and it leads to extreme forms of dependency. This confronts us with the question of what is required to develop a more caring society where all are equally valued, able to access the supports each requires. To imagine a liveable life with dementia is, by implication, to imagine a more liveable society, one in which there is awareness and sensitivity around what it means to relate to people who are, for whatever reason, different. Dementia is the challenge to change: if we get it right in the case of dementia, we will be headed in the direction of building a caring society.

An alternative framework

Many of us will experience dementia – a third of us who live beyond 80 years of age. Care that is for and about us throws up major social, moral, political and economic challenges. The first dimension to reframing dementia includes recognition of discrimination linked to ageing, social inequalities, cultural attitudes about cognition and rationality, and social histories of stigma and misinformation. Understanding social,

Reframing Dementia: project outcomes and plans

Workshop

The first initiative of the project was an innovative interdisciplinary workshop, Reframing Dementia as Social and Cultural Experience, held in February 2017 at the University of Sydney. This brought together people committed to a focus on the social experiences of dementia: academics working in different disciplines, representatives from leading aged care organisations, nurses, and people with dementia as well as their carers.

The theme of reframing dementia as social experience is multifaceted and this was evident in contributions. The workshop included topics such as: ageism and personal integrity in a competitive resources environment; the importance of the voices of those with dementia and their carers in research; perspectives of families living with younger onset dementia; the use of new technologies in care; and the experiences of older women with dementia. Discussion unequivocally highlighted the importance of a social approach.

Symposium

A symposium panel entitled, Why Dementia Care Is Different: The Relational Impacts Of Dementia On Family Carers, formed part of the 7th International Carers Conference in Adelaide in October 2017. Panellists were invited to explore the relational changes required of family members, especially those who are primary carers.

Family members are not an adjunct to professional care, and their experiences are not the same. Living day by day with dementia is demanding but not well understood or valued. Programs designed to support and inform family carers are ill-conceived if conceptualised by people who have not had to live through the roller-coaster of relational change that is 'living with dementia'. Care is not about 'doing things' for others, but being for and with them. Relationship change must become the focus, not care tasks. A relational approach reflects the value that must be placed on all those, with and without dementia, who share this life experience. A lively discussion focused on envisaging a new approach to family carer support.

For more on the workshop or panel symposium, see: www.sydney.edu.au/arts/research/reframing-dementia/

Publications



Dementia as social experience: valuing life and care (Routledge, July 2018), Gaynor Macdonald and Jane Mears (Editors). Details: <https://bit.ly/2KTVilq>

This collection, based on the February 2017 workshop in Sydney, examines what it means to reframe dementia, both in terms of broader social attitudes and in care practice.

Contributions from people with many years of experience, but different concerns and disciplinary perspectives, make for a rich discussion into the challenges of reframing dementia. Along with a comprehensive introduction on the need for and implications of reframing dementia as social experience, the book has three sections: challenging social constructions of ageing and dementia; autonomy and dignity; and persons in relationship: the dynamics of care.

The collection critiques the stigmas, the language and fears often associated with a diagnosis of dementia, with the intent of improving quality of care; and focuses on the social changes required to live a good life with dementia, discussing issues such as advanced care planning, decision-making and person-centred care. It is aimed at those practising, studying or researching dementia, wellbeing and health.

***Dementia as social experience* will be officially launched during the authors' next Reframing Dementia symposium – Experiences of Dementia: Stories From Those Who Care, on Wednesday 26 September 2018 at the University of Sydney. For further information (to contribute or attend), email Jane Mears j.mears@westernsydney.edu.au**

Death in life or life in death? Dementia's ontological challenge (2018), by Gaynor Macdonald. In: Goodman-Hawkins B, Dawson A (Eds), *Life's End: Ethnographic Perspectives*. *Death Studies* 42(5) 290-297. Details: <https://bit.ly/2KFCPes>

historical and ideational contexts assists in challenging them, in turn enabling us to improve quality of life and care. This is an essential social investment. We know this; the challenge is to get our leaders listening and acting.

A second dimension of an alternative social framework focuses on how to conceptualise, so as to change where necessary, the relationships which are required to live a good life with dementia. Those with dementia will progressively require more care and support. Framing dementia as 'decline' negatively impacts on approaches that aim to enhance the lives of those living with dementia. Adjustments have to be made by all who care for people who are dependent, but in the context of dementia, these are particularly demanding. The fact that carers are forced to change much about their own lives, values and futures is overlooked. They are often profoundly affected by the stigmas that stem from lack of education and training, and negative social attitudes, adding considerably to their stress.

Learning from people with dementia

It is essential to learn from people who live with dementia about the kinds of information, support and insights they require. These discussions involve moral and legal concerns when certain capacities are diminishing, as well as what constitutes acceptable standards of care. Central to this is a critical conversation around personhood and social value. Our value as persons and the quality of our social relationships are influenced by philosophical, social, economic and medical ideas.

Symptoms associated with dementia challenge dominant ideas about the significance of cognition in determining that value. Media coverage of dementia focuses on new research towards prevention or cure, informing the public about its prevalence and symptoms, but even well-intentioned articles exacerbate fear and dismay.

Those diagnosed with dementia are commonly depicted as suffering a loss or deficit of personhood, being lost to a world of relationships, and as a burden for carers. Stories about community efforts to live well with dementia are harder to access. This leads us to ask: what are the taken-for-granted understandings of the good life, and of the abilities required of citizenship, which inform these limited understandings?

The Reframing Dementia project centres on the need for a caring society. Efforts are underway to create

community awareness about how to live well with dementia. Such initiatives include Dementia Australia's dementia-friendly communities program, providing online resources to enable individuals and organisations to begin their journey in becoming a Dementia Friend (see pp10-11 for details). Another is the Welsh Government's support for building a 'dementia friendly nation' (<https://bit.ly/2J5snrf>). Initiatives such as these are based on a recognition that living with dementia can be enhanced when the right support systems are in place, within enabling social relationships.

A call for social change

Reframing Dementia is thus a call for social change. We look for inspiration to the growing movement focusing on *relational care*. In the publications that have stemmed from this project (see box p23), we critically examine the importance of person-centred approaches to care, but move the reader beyond some of the triteness of this phrase to the growing awareness that person-centred care must be relational care. The differences are significant even while they appear similar.

Relational care turns the lens around to engage the carer in the ways in which change is being experienced, meaning that dementia is reconceptualised as a social experience, requiring a social response. Relational care explicitly takes up issues of social attitude and morality, and the need to move towards a society in which care is valued as central to all life.

The prospect of a cure for dementia is not close enough to offer support to those living with dementia now and in the immediate future. By challenging the ways in which we think about dementia as a disease experienced by an individual, we can identify the understandings and values that get in the way of the caring society. The changes required to ensure informed and compassionate attitudes and better care for those with dementia are changes that will ensure a better life for us all.

Dr Gaynor Macdonald is a Senior Lecturer and Consultant Anthropologist in the Department of Anthropology, University of Sydney. Contact her at: gaynor.macdonald@sydney.edu.au; Dr Jane Mears is an Associate Professor in the School of Social Sciences and Psychology at Western Sydney University. Contact her at: j.mears@westernsydney.edu.au; Ailin Naderbagi is a Research Assistant and PhD candidate in the Department of Anthropology, University of Sydney. Contact her at anad1213@uni.sydney.edu.au

Helping Hand Aged Care has taken a different approach to delivering exercise for people with dementia, in the process challenging the assumptions of care staff and family members.

Gaynor Parfitt, Megan Corlis, Wendy Hudson, Alison Penington and Danielle Post report

Two thirds of adults with dementia experience significant functional limitations, particularly individuals living in residential aged care facilities (RACFs). Providing ways for these residents to maintain functional capacity as dementia progresses is important and a key recommendation of the Clinical Practice Guidelines and Principles of Care for People with Dementia (Guideline Adaptation Committee 2016).

Exercise is identified as a key component, with studies showing exercise programs for aged care residents with dementia are beneficial (Brett *et al* 2016) and associated with maintenance of independence (Csoznek *et al* 2017). Exercise is reported to improve performance of activities of daily living (ADLs), as well as balance and mobility (Poulos *et al* 2017). Exercise is also recommended as a comprehensive reablement approach for people living with dementia to help maintain physical functioning and mobility with potential benefits on cognition, mood and quality of life (Poulos *et al* 2017).

The typical approach to exercise is to support individuals one-to-one in gyms; however, this approach or environment may be a barrier for many. Exercise programs in gyms or group sessions may not suit people with cognitive decline and it is frequently challenging for older people living in RACFs to participate in community activities.

Another approach is through exercise prescribed by Accredited Exercise Physiologists (AEPs) and delivered in RACFs. AEPs are allied health professionals specialising in the delivery of exercise for the prevention and management of chronic diseases and injuries. They are equipped to design personalised exercise programs to suit individual needs and abilities.

Helping Hand Aged Care (HHAC) in South Australia has just completed a two-year trial exploring the service that AEPs provide to enhance the cognitive and functional capacity of residents with

Changing hearts and minds

dementia in RACFs through an exercise prescription approach. The Exercise Physiology (EP) in Aged Care Project involved personalising physical activity using participants' lived experience to motivate and engage them. The project is being independently evaluated by Associate Professor Gaynor Parfitt (co-author here) from the University of South Australia, with funding from the Cognitive Decline Partnership Centre (CDPC).

This article discusses the successful implementation of EP services for people with dementia in four HHAC residential units, perceptions of the program's impact from family members and care staff, and how aged care organisations can apply such evidence-based practice to sustain and embed exercise into care.

Lived experiences

The EP in Aged Care Project was developed by HHAC in 2015 and led by Megan Corlis and Alison Penington (both co-authors here). The project built on initial work by University of South Australia EP students working under supervision during placements within HHAC care units. They began using the previous life experiences of residents to help motivate them to exercise and observed that this approach seemed to have some relationship with residents' level of engagement in the exercise.

Collaboration between CDPC funding partners HHAC and Brightwater Care Group with UniSA, as part of the CDPC-funded evaluation, led to the project team incorporating aspects of the wellbeing mapping approach used by Brightwater. Wellbeing mapping is an individualised approach to support and care planning that places the person at the centre of care, recognises and includes family, carers and residents as 'partners in care', and involves discovering and documenting the personal history, needs, strengths and abilities of each individual (Jarrad & Hudson 2017). The EP in Aged Care Project used this personalised approach in assessing participants' exercise needs and tailoring exercise to meet those needs.

Personalising exercise

Identifying and responding to the individual needs, goals and preferences of a person living with dementia, their carers and family is a fundamental principle of personalised care (Guideline Adaptation Committee 2016). The act of gaining

Betty's wellness profile: the other side of the one-page profile provides 'Betty's favourite 3 in action', with images and descriptions of the three exercise activities

knowledge and understanding about the person helps us see the person, not just the clinical diagnosis.

We can identify and respond to individual needs and preferences by knowing and understanding the difference between what is important *to* an individual and what is important *for* them.

By important *to* a person, we mean what increases their wellbeing, makes them feel happy, content and fulfilled. People show what really matters to them through their words and actions. By important *for* a person, we mean the supports that help a person stay healthy, safe and well. Encouraging and supporting an individual to participate in an exercise program is identified as important *for* that person. Important *for* a person also includes support to be a valued member of the community, in terms of how they are regarded by others and how their dignity and autonomy is supported.

Due to the nature of the condition, people living with dementia in RACFs are often unable to reliably report on their past medical history and current abilities. The EP relies on excellent communication skills and, in particular, his/her ability to engage with the person living with dementia in his/her world, rather than the expectation that the person living with dementia comes into the EP's world. The EP also engages partners in care (allied health

professionals, care and nursing staff, and family), to help plan exercise sessions. Gathering information from partners in care ensures EPs understand what is important *to* and *for* the individual in relation to health and exercise.

The following example, involving Maggie, a participant in the EP in Aged Care Project, demonstrates how this personalised approach occurs in practice.

Maggie

Maggie (not her real name) is living with younger onset dementia within a HHAC memory support unit. Through discussions with her partners in care, the EP learns that horses and horse riding are important *to* Maggie.

Engaging Maggie in exercise is important *for* Maggie, to reduce her risk of cardiovascular disease and other chronic conditions. Maggie grew up in the country and loved to ride horses as a child; she is a mother, worked in health care, and enjoys walks.

Maggie is not keen on exercise, so the EP adjusted programs to try to get the best outcomes by using horse riding, important *to* Maggie, as a motivator for her to exercise. Maggie was seated in front of a computer tablet which played a YouTube video of people on a horse ride. The video was filmed from the point of view of the horse rider and, from Maggie's perspective, it seemed like she was riding the horse. Maggie was given a set of bike pedals to use while watching the video. This theme was applied throughout the exercise sessions with Maggie; images of horse riding were used as a cue for her to exercise. In addition to pedaling, Maggie seemed motivated to participate in upper limb strengthening exercises, including bicep curls and rowing movements, using cables or dumbbells for resistance, as this related to horse handling and improving and maintaining her balance for riding. Maggie participated in these EP-led sessions once or twice a week in her care unit, in addition to walking sessions.



Images of horse riding were used as a cue to motivate Maggie to exercise. She pedalled while watching a YouTube video of people on a horse ride

We do not yet have outcome analyses for the EP in Aged Care program's impact on participants' physical functional capacity; however, Maggie's story demonstrates how the personalised approach (ie understanding Maggie's likes and needs) validates her past role as a horse rider and was key to engaging her in the exercise.

Maggie's family reported they were encouraged by her memories of horse riding and considered arranging visits to stables so that she could reconnect with horses.

The EP in Aged Care Project

The 12-week EP in Aged Care exercise program was implemented within four residential units across two HHAC sites between 2016 and June 2018. Participants, with varying levels of dementia, had one-to-one sessions with an EP each week, plus two group sessions during the 12-weeks. The intention was to empower residents by providing a sense of purpose; increasing their engagement and opportunities to socialise; and contributing to improved physiological function.

Key features of the EP in Aged Care Project:

- The use of portable exercise equipment, which could be moved around the RACF on a trolley. The equipment included: bike pedals and arm ergometers; weights such as dumbbells and ankle weights; balls; exercise resistance bands; and balance training equipment.
- Engaging participants in the environment where they felt most comfortable and safe, rather than in a gym or other place outside the RACF. For the one-on-one sessions this was their room or outdoors in the garden. The group exercise sessions were held in



The portable exercise equipment and trolley used in the EP in Aged Care Project. The equipment included bike pedals and arm ergometers; weights such as dumbbells and ankle weights; balls; exercise resistance bands; and balance training equipment

lounge areas of the residential units – not only to maximise participation from residents who felt comfortable in this space, but also to encourage participation by those who might be influenced by seeing others exercising. Residents were also exercising where care staff could see them, which helped change their perceptions of the residents and challenged assumptions that people with dementia are unable to participate in reablement activities.

In the one-on-one sessions, which lasted 30 to 45 minutes, exercises were individualised to suit participants' physical and cognitive needs and abilities. They focused on challenging proprioception, balance, strength, and incorporating dual task activities, such as throwing and catching a ball while pedaling. Moderate-intensity interval training was used for some individuals to improve cardiovascular health.

To support sustainability, for 12 weeks after the exercise intervention participants were encouraged to attend the regular HHAC lifestyles activity program and take part in two exercise initiatives – 5-Minute Moves and Movement With Benefits (circuits) – supported by their partners in care.

5-Minute Moves was designed as a short, chair-based exercise program delivered by trained lifestyle staff, EP students or volunteers. The exercises were done when residents were sitting together, such as before regular activities and /or before meal times.

The Movement With Benefits circuit program was co-designed by the EPs and HHAC lifestyle staff for more active residents who wanted to participate in structured exercise activities and didn't require one-on-one assistance to exercise. Once a week a circuit comprising individual exercise stations (with colour-coded instructions on how to perform the activities) was set up in the RACF's living area. Exercises were done while seated and included leg raises, arm raises using weights, and arm stretches using bands. Each participant was partnered with a fellow resident and they moved between the stations, helping each other to complete the exercises. Partners in care assisted throughout the circuit when needed. After five sessions participants received a voucher to use at the RACF's café.

Outcomes

Outcomes of the project to date challenge assumptions that people living with dementia, including those with advanced dementia, are unable to participate in and

benefit from prescribed exercise activities. Evidence also suggests that the perception of families and care staff around the likely benefits of participation for residents with dementia can shift as a result of observing the residents participating in the program.

While the majority of family members and care staff perceived that there were benefits for participants with respect to physical function (physical strength, mobility and flexibility, and ADLs), they also reported improvement in communication, contentment, and social involvement, with little to no deterioration perceived by family members or care staff. Socialisation opportunities and outcomes for participants were perceived to be particularly beneficial. It was reported that there was a great deal of enjoyment expressed by individuals involved in the program, and for the care staff who saw the participants exercising. For example, care staff reported that they saw people doing things they did not expect them to, as indicated by comments such as, *"I got really excited about it, we'd all stand around going 'oh look, oh look' "*.

Following the 12-week sustainability period, the majority of care staff perceived that, on the whole, participants had maintained benefits from the exercise program; however, only a quarter of family members perceived the improvements associated with participation in the initial 12-week program had been sustained. The likely explanation for this difference in perception is that family members' responses were specific to one resident; their own family member. In contrast, the perspectives of care staff accounted for all participants in their care, and as such, they may be more likely to perceive sustained benefit when considering individuals overall.

An emerging theme from our evaluation of this project is that sustainable benefits are only likely if a concentrated, long-term program is in place. Further, people who were cognitively aware that the sustainability activities were available in their RACF, and physically able to access these exercise activities, were perceived to be more likely to sustain any positive benefit than those who were cognitively unaware of the activities, or physically unable to attend them.

Accommodating the specific exercise needs and requirements of participants based on their circumstances reinforces the importance of understanding what is important to a person in terms of outcomes for a community of people living with dementia and related functional decline in aged care homes.

Observations from the EPs indicated

that residents were able to remain focused on a task and activity for longer periods of time during the exercise sessions compared to other times, suggesting the task-oriented exercise created a sense of purpose and that achievement was important to the person. Group sessions were reported to create a sense of togetherness and unity among residents.

Challenges and sustainability

There are challenges in prescribing exercise to people living with dementia and related functional decline in RACFs. Some of these include: negative connotations around the use of the word 'exercise'; participants' cognitive and physical limitations; and the environment. Circumventing these can be achieved through applying principles of the wellbeing mapping approach. For example, the EPs used several techniques to accommodate individual capabilities in attempts to improve exercise outcomes for residents. These included:

- Using language that focused on getting people "moving" or "warming up in the cold", rather than exercise, which can be perceived as an unpleasant activity.
- Considering cognitive limitations by demonstrating the activities for residents; using simple cues such as "heels up, toes up".
- Adapting activities to suit individuals with physical limitations.
- Increasing staff engagement in exercise delivery to enhance their awareness of individual residents' capabilities; using portable exercise equipment.

Despite the positive reports associated with this EP intervention, it can be hard to sustain positive outcomes. Recommendations to sustain the EP in Aged Care Project, based on the observations of the EPs involved, include



Left to right: Gaynor Parfitt, Megan Corlis, Wendy Hudson, Alison Penington and Dannielle Post

participation by EP students and family members in facilitating exercise delivery.

Student involvement would increase the number of people available to deliver exercise and therefore the opportunities for residents to exercise. Teaching simple exercises to family members would enable them to deliver exercise when they visit their relative, leading to greater involvement in their relative's care.

Recommendations

Based on the evaluation findings to date, we would recommend educating care staff and family members about the benefits that exercise can have for residents, regardless of their level of cognitive or functional decline.

For long-term sustainability of exercise programs it is recommended that care organisations put in place processes to gather information about an individual's previous experiences, likes and dislikes that can be used by partners in care, so that there is a shared understanding of what is important *to* and *for* the person in their ongoing care.

Indeed, in the last HHAC care unit to receive the EP intervention, we compiled a 'one-page profile' for each participant (see example p25). This records what is important *to* the person and what is important *for* the person (based upon the activities and their abilities over the previous 12 weeks of the exercise program). The profile was then shared with the resident's partners in care to support sustainability of exercise activity.

Evaluation of data from the EP in Aged Care intervention is continuing, with outcomes to be reported in 2019 including the program's impact on participants' physical and cognitive functional capacity.

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■ The CDPC Exercise Physiology in Aged Care (EPAC) Evaluation project Chief Investigators are Gaynor Parfitt, Associate Professor of Exercise and Sport Psychology at the University of South Australia (UniSA), and Megan Corlis, Director of Research and Development, Helping Hand Aged Care; Wendy Hudson is Wellbeing and Dementia Support Coordinator, Brightwater Care Group; Alison Penington is Project Exercise Physiologist, Helping Hand Aged Care and has implemented the EPAC project; Dr Dannielle Post is a research officer at UniSA and a member of the CDPC EPAC Evaluation project team, along with Dr Kade Davison, a clinical exercise physiology expert from UniSA. For more information contact Gaynor Parfitt at gaynor.parfitt@unisa.edu.au.

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EPs in aged care

Despite the success of Exercise Physiologists' (EP) input for many people within the community, there appears to be little information about the EP role with older people, particularly for those living with dementia and related functional decline in residential aged care facilities (RACFs).

EP interventions are a largely underused resource in the Australian health setting (Deloitte Access Economics 2015). This is in part due to EPs not being recognised as allied health professionals under the current Aged Care Funding Instrument

(ACFI) model. Recent recommendations have been made to include EPs in an updated funding model (Stoyles 2017). The current ACFI arrangements mean that RACFs are responsible for funding EP roles; an obvious barrier to the employment of EPs in RACFs.

Information on EP services and how to find a practitioner is available from the Allied Health Professions Australia website at www.ahpa.com.au/allied-health-professions/exercise-physiology/ or Exercise and Sports Science Australia www.essa.org.au/for-consumers/

Helping people with dementia to feel safe

From years spent exploring and observing the points of view and experiences of people diagnosed with dementia, **Steven R Sabat** demonstrates that there are ways to facilitate communication and social interaction even when the person has great difficulty finding the words he or she wants to use

The title of this article implies at least two things: that people with dementia often do not feel safe in social situations and that they need the help of others to do so. Why would this be the case and what kind of actions on the part of others might be helpful?

When I engaged people diagnosed with dementia as my teachers and earned their trust by spending extended periods of time with them (up to two years, once a week), I came to understand that they often find social situations to be anxiety-provoking for a number of reasons. First, there is the person's psychological reaction to their losses due to brain damage. Reactions such as frustration, sadness and anger can result when the losses a person experiences affect abilities that they valued dearly during decades of adult life. Those feelings are compounded when, in their eyes at least, such losses have a negative effect on their ability to engage with others in social situations. As well, there is the need that most people feel, regardless of medical status, to present themselves in the most positive way socially by not displaying faults or dysfunctions to others. We all wish to 'save face' whenever necessary and many people with dementia even in the moderate to severe stages are no different.

Dr M, for example, was a retired professor when I met her. Her entire adult life was marked by her love of language and her ability to use it gracefully and wittily so as to engage her students compellingly as a teacher, as well as engaging other adults in enlivening ways in informal conversation. She experienced memory problems and was diagnosed with probable Alzheimer's disease (AD) years before I met her. One of the losses she experienced due to AD was her ability to recall and pronounce correctly the words she wanted to use. By her own admission, words had been akin to a musical instrument for her and now she could not



For people living with dementia to enjoy social relationships with others they need reassurance, understanding, and the feeling that they are safe to be themselves with others. This photo was taken during the 'Opening Minds Through Art' (OMA) program, founded by Dr Elizabeth Lokon at the Scripps Gerontology Centre, Miami University in Ohio, US. Details: www.scrippsoma.org. Photo courtesy Steven Sabat

'play her music', as it were, and speak with élan and in the erudite manner she knew before AD. As a result, she was very reluctant to speak and was, for the most part, silent at her support group meetings because she did not want to embarrass herself by struggling in front of others to find the words she wished to use. That is, she did not feel safe to be herself in those situations.

At the same time, she sorely missed having enlivening social relationships with people, a fact that emerged when we were discussing her experience of having gone to a speech therapist who gave her standard language assessment tests. In order for this fact of her experience to emerge in conversation with me, however, Dr M had to feel safe in the first place. She had to trust that I would be patient with

her and support her in whatever ways I could so that she could express herself without fear of embarrassment.

The Intentional Stance

We can do a number of things to help people living with dementia to feel safe. We can do something called 'taking the Intentional Stance' (Dennett 1990) toward the person living with dementia. This means that we assume that the person is trying to communicate something even if we don't understand it at first, even if what the person is saying sounds incoherent initially. From this point of view, each utterance is assumed to be an attempt to communicate.

In the following conversational extract, not only did I take the Intentional Stance, but I also used what linguists call 'Indirect

Repair': checking with the speaker to determine if the listener understands correctly what the speaker is trying to say.

For example, when I was not sure that I understood what Dr M was saying, I did not assume that she was 'confused'. Rather, I assumed that she knew what she wanted to say and I assumed further that I was the one who was confused! In this situation, I listened actively to what she was saying, took responsibility for not understanding her clearly, and so said things like, "I'm not sure that I understand what you're saying... Let's see if I do... You're saying that...", and then I said what I thought she was trying to say, thereby giving her the opportunity to answer yes or no, or to add something else.

By listening actively this way, I was conveying to Dr M that (a) I was paying close attention to her and not dismissing her as being confused, (b) I was very interested in what she was saying and trying to say, (c) I was invested in working with her in the process of understanding her thoughts, (d) that I viewed our conversation as something important and (e) that *by working together*, we would communicate meaningfully. In this way, she could feel safe because I was not judging her for her foibles, but moving past them and attending closely to her as a person worthy of my attention and time.

In the following conversational extract about Dr M's reaction to having seen a speech therapist, the numbers in brackets indicate the use of Indirect Repair (Sabat 1991 p291).

Dr M: *I had three days, no, times, and on the third day I told her [the speech therapist] that I would have to give up the program. It was, and she wanted very much to know why, and I said uh, that uh, 'I have too many things on my head and they aren't, don't fit together' or something like that. At any rate, that's not something that's helping me uh, if, and then she – before we're going away, you will tell me what you feel about this. (Shows me the results of the tests.)*

SRS (Steven R Sabat): Well, I'm familiar with some of the tests that they gave you.

Dr M: *And uh, this was at the time, it was about three weeks ago and um, I was doing other things and it didn't, it didn't give me a feeling that there's something that I should have another thing.*

SRS: It didn't give you the feeling that going back and doing some kind of speech therapy would be helpful to you? (1)

Dr M: *No, I didn't think about that and uh, I, it wasn't, it wasn't important and I, you know, at this time too, I found that I really don't like to be uh, talking about what, what's my trouble. It's gotten, I know what my trouble is. And I think that what I would like it uh, only if there's something that is, uh, a time, a uh, a*

time and with a person who there is a real (gestures with hands, holding them vertically in front of her, parallel to one another about 12cm apart and moving the right hand toward the left hand and then the left hand toward the right hand back and forth repeatedly).

SRS: Back and forth – a relationship? (2)

Dr M: *Um hum. You know you could go out, out of this area, and you could get so many people who would want to, to for one reason or another, to do uh, something uh, with me, and I don't want that. I don't want my life to be uh, not uh, I don't want to be part of what does this person can do, what that person do.*

SRS: Let me back up for a second because I think I'm missing your point. You don't want your life to be...? (3)

Dr M: *Going always to see people to see what's wrong with me.*

SRS: Ah!

Dr M: *And how to, and how and how it could sometimes uh, what can we do about it? But otherwise, I've, I've, I've had it.*

SRS: Ya... let me see if I understand. At least one of the things that you're saying is that it's, it's not something you, you don't want to put yourself in situations where you're constantly being shown what you can't do? (4)

Dr M: *That's one. That a real thing.*

So feeling safe means, at least in part, being in a social situation in which one is not being shown or reminded often about what one cannot do and then judged accordingly. This is entirely reasonable for anyone, whether or not the person is diagnosed with dementia. In this sense, Dr M was reacting as would any person deemed healthy. Who among those deemed healthy wants 'desperately' to be in an embarrassing situation that shines

light on his or her foibles and to experience embarrassing situations most of the time?

In her support group Dr M was often 'put on the spot' by the group leader who would call on her to say something ("And what do you think about this, Dr M?"). In conversation with me, however, she was willing to talk because I worked hard to help her to feel safe in a number of ways, as demonstrated in the preceding paragraphs, including (1) not putting her on the spot, as it were, (2) actively listening to her, (3) using Indirect Repair in working with her so that I could come to an understanding of what she wanted to convey, and (4) allowing for long pauses in the conversation when she was attempting to recall the words she wanted to use. This last point is very important because, oftentimes, people are uncomfortable with long periods of silence in a conversation and feel that they have to "fill the unforgiving minute", as Kipling would say, with chatter.

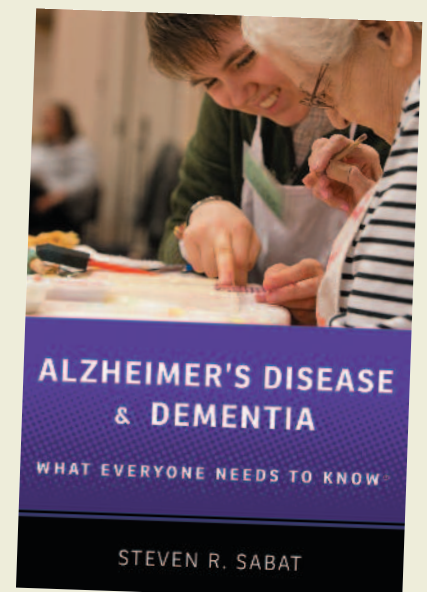
A non-anxious presence

Allowing the person with dementia to have the time to think about what they want to say is tremendously important because that person really does need the time to think and truly does not need to be burdened by the need to respond quickly.

So another way to help the person with dementia to feel safe is to be relaxed about long pauses in conversation and to bring a *non-anxious presence* to the conversation. This is especially important because most people, including those diagnosed with dementia, can sense whether or not those around them are relaxed or on edge. Anxiety can be 'contagious' and when a person with dementia feels anxiety in

What everyone needs to know

Alzheimer's disease and dementia: what everyone needs to know, by Steven R Sabat, was published by Oxford University Press in February 2018. It explores key topics related to Alzheimer's disease and dementia; identifies strengths of people with dementia in the areas of thinking, emotion, memory, selfhood, creativity, spirituality and social cognition/awareness; helps caregivers identify how these strengths manifest; and how people with dementia experience their diagnosis, sense of self and social world – in their own words. Details: <https://bit.ly/2u50s69>



others, this, in turn, can have a tremendously negative effect on that person's ability to recall the words they want to use to communicate their thoughts. So maintaining a non-anxious presence can be extremely helpful to those diagnosed so that they remain calm and feel the safety that that brings and thereby communicate clearly with the help of interested and facilitative partners.

In addition, I made it clear to Dr M several times that she could still communicate even without the use of words, as in years past. The famous mime, Marcel Marceau entertained people the world over and communicated a great deal without uttering even a single word and I brought that to her attention a number of times. Indeed, in the previous conversational extract, Dr M used a gesture with her hands to communicate the idea of the mutuality of a social relationship. She did likewise on a number of other occasions and so I called that to her attention by saying that she actually did communicate what she wanted to convey with gestures and I said, "You made your point." She replied immediately with a brilliant insight saying, "I made your point" and then, a few moments later, she said with great exuberance, feeling utterly free, "Who needs words!". Here, she felt safe enough to express herself in whatever ways worked to achieve clear communication.

Giving undivided attention

Active listening can take forms other than that exemplified in the preceding conversational extract. When we are truly

interested in what another person is saying to us, we give that person our *undivided attention* and when we do not quite understand their point we say as much, thereby taking the responsibility for not understanding clearly. There is a difference between saying, "You're not being clear" and "I am sorry, but I don't think I am understanding what you're trying to tell me". Or, for instance, if the person is talking about a painful situation we might commiserate and say something like, "That really must have been difficult for you, especially after having gone through that other difficulty so recently". In other words, we do not utter, "Uh-huh" in that flat-toned, vacant way that is spoken usually at the wrong time because we are not paying careful attention to what our partner in conversation is saying, but doing something else instead, like thinking about what we need to do later in the day or looking at our computer screen and reading something.

Listening actively to the person with dementia is truly nothing less than showing that person the common courtesy that says, "I am with you completely in this conversation and I will do all I can to work with you and thereby try to understand what you want to say to me".

Reassurance, understanding, safety

In summary, people diagnosed with dementia often experience great sadness, frustration, and embarrassment in connection with the losses they experience in various abilities due to brain damage. These altogether appropriate reactions can

have negative effects on their ability to enjoy social interactions with others and they often withdraw from a variety of social situations as a result. Therefore, in order for people living with dementia to enjoy social relationships with others, they need reassurance, understanding, and the feeling that they are safe to be themselves with others. That feeling of safety can be enhanced by how others act toward and with the person diagnosed, as I have discussed in this article.

A diagnosis of dementia does not strip a person of their humanity or their ability to enjoy and benefit from social interactions with others, especially if that person has a history of enjoying such interactions. The degree to which a person diagnosed can feel safe among other people is, in the end, dependent on the humanity and understanding of healthy others and their willingness to extend their minds and hearts in the process. People in general and people living with dementia in particular deserve nothing less. ■

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■ Steven R Sabat, PhD, is Professor Emeritus of Psychology at Georgetown University, Washington DC, US. Contact him at: sabats@georgetown.edu

Supporting spouses of residents with dementia

Placing a partner with dementia into residential care has been described by spouses as being amongst the most difficult and stressful times of their lives. A research project led by Deborah Brooks from the Dementia Centre for Research Collaboration (DCRC) at Queensland University of Technology (QUT) is seeking to improve support to partners of people with dementia who have moved into residential care.

The Dementia Australia/DCRC Consumer Priority PhD research project aims to test the effectiveness of a multi-component psychosocial intervention designed to improve the psychological and emotional health of spouses and partners of people with dementia following placement into permanent residential care.

Ms Brooks is now seeking residential aged care facilities in Queensland and NSW to take part in the research. Care home personnel will be asked to complete a short seven-item survey about their facility and help with recruitment by passing on a letter, information sheet and consent form to English-speaking spouses of residents with dementia who have moved into the care home in the past 12 months.

Spouses of residents who agree to participate will be randomly allocated to either an intervention group (telephone support program) or a control group (printed information) depending on the residential care facility where their relative lives. If you are interested in helping with this research, contact: Deborah.brooks@qut.edu.au

Study to measure physiological responses to art

University of Canberra researcher Nathan D'Cunha is currently working with the National Gallery of Australia's long-running Art and Dementia program to assess the physiological and quality of life impact it has on its participants.

The research will use questionnaires (aimed at family carers) and saliva samples (from participants) over a six-week period to investigate the benefits of participation in the program, which began in July.

The saliva samples will be tested for the stress hormone cortisol, as well as various markers of inflammation in the body. The questionnaires will explore quality of life and any changes in relation to responsive behaviours and nutritional status.

While the benefits of such interventions have been probed before, Mr D'Cunha said that, "To our knowledge, this is the first study of its kind to look at the physiological effects of an art gallery intervention for people with dementia."

Mr D'Cunha is a recipient of a Dementia Australia PhD scholarship.

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.

RedUSing psychotropic medication use

For at least two decades concerns have been raised about inappropriate psychotropic prescribing in Australian residential care homes, due to their modest therapeutic benefits and high risks. **Juanita Westbury** explains how the RedUSE initiative, rolled out nationally from 2014-2016 to more than 12,000 aged care residents in 150 care homes, was able to achieve significant reductions in psychotropic medication use

While working as a locum in a small pharmacy in Adelaide in the late '90s I received a phone call from a local aged care home (ACH). The Director of Nursing (DON) wanted to know if she could order one of the pump packs she had seen us measure out methadone syrup with. She thought it would be a good idea to use one to quickly prepare all the risperidone solution doses they were giving to residents.

This request didn't sit well with me. Apart from the fact that methadone pumps are intended to accurately measure doses up to 0.1ml – not to pump out multiple quantities, I couldn't help but wonder why they needed one. Why were so many of their residents taking this antipsychotic anyway? Wasn't this medication for severe mental health conditions like schizophrenia and linked to tremors, rigidity and falls? When I mentioned these concerns to the DON she reassured me that residents were only prescribed tiny doses and that the risperidone was needed to "comfort and calm" those with dementia.



A RedUSE training session for champion nurses

I couldn't help recalling this phone call when working as a GP practice pharmacist some years later in England when all health practitioners were sent an urgent safety warning by the Medicines and Healthcare products Regulatory Agency (MHRA) (MHRA 2004) advising that risperidone caused an increased risk of stroke when given to people with dementia. When I audited this antipsychotic at my GP practices I noted two things; firstly, the GPs and the homes themselves were genuinely surprised by the actual number of older residents taking these medications, and secondly, the marked resistance

from the GPs and staff to alter them. This complex issue has intrigued me ever since.

Psychotropics: benefits and risks

Antipsychotics, including risperidone, belong to a group of medications called 'psychotropics' "*capable of affecting the mind, emotions and behaviour*" (Farlex Partner Medical Dictionary 2012). Other psychotropic classes include antianxiety, antidepressant and sleep-inducing or hypnotic agents. Although all psychotropic medications should be used cautiously in older people because they are

more likely to experience adverse effects, additional concerns have been raised about the use of antipsychotic, antianxiety hypnotic agents (mostly benzodiazepines).

Antipsychotics were developed to treat schizophrenia. As some symptoms are similar to responsive or distressed behaviours, particularly delusions and agitation, antipsychotics are often prescribed for people with dementia as well, despite modest effectiveness. Trials show these medications reduce agitation and psychosis in about 20% of people with these symptoms; however, they have not been shown to be effective for behaviours such as calling out and wandering (Loi 2015). Antipsychotics are associated with such adverse effects of sedation as worsening confusion, falls, urinary tract infections, fluid retention and movement disorders (RANZCP 2016).

Shortly after the first MHRA warning of increased risk of stroke associated with risperidone use, the US Food

and Drug Administration (FDA) released its own safety alert linking antipsychotic use in people with dementia to an increased risk of death from all causes (FDA 2005). The Royal Australian and New Zealand College of Psychiatry (RANZCP) now advises that people with dementia should only be prescribed antipsychotics (after psychosocial approaches have proved ineffective) for:

- severe agitation and aggression associated with risk of harm
- delusions and hallucinations
- pre-existing mental health conditions (RANZCP 2016).

Benzodiazepines, including oxazepam, diazepam and temazepam, are prescribed in older people to manage agitation, anxiety and insomnia. These medications are effective short-term but their use is associated with over-sedation, confusion and falls. When taken for more than a few weeks people often become tolerant to their effects and may become dependent on them (Madhusoodanan 2004). The Royal Australian College of General Practitioners (RACGP) now recommends that older people with chronic anxiety be treated with antidepressants and psychological therapies rather than with benzodiazepines. In insomnia, the RACGP stresses that “the magnitude of effect on sleep is small and the benefits of these drugs may not justify the increased risk” and recommends that treatment be short-term (not more than four weeks) and at the lowest possible dose (RACGP 2015). Benzodiazepines are not recommended to manage responsive behaviours in people with dementia due to insufficient evidence for effect and risk of adverse effects (Tampi & Tampi 2014).

Overuse?

For several decades, high rates of psychotropic use have been reported in ACHs around the world. The first major Australian study looking at use

was conducted in 46 Sydney ACHs during 1993 (Snowdon 1995). The rates of regular antipsychotic (27%), hypnotic (27%) and antianxiety (9%) benzodiazepine use were said to be, “among the highest reported in the world” (Snowdon 1995). As a consequence, this study attracted considerable media and public attention, resulting in the establishment of a NSW Ministerial Taskforce (NSW Health 1997) and Federal Senate inquiry.

Snowdon repeated his study four times in the same area of Sydney from 1993-2009. During this period benzodiazepine use declined markedly. In contrast, antipsychotic use declined initially but by 2009 levels had returned to 1993 rates (Snowdon 2011).

There is limited data on ACH psychotropic use in other regions of Australia. However, research has shown that antipsychotic prescribing to older Australians increased during the 2000s, with olanzapine and risperidone dominating (Hollingworth 2010). Hollingworth *et al* (2010b) also reported that benzodiazepines are used by over 15% of people over 65 years in Australia, with the highest usage found in those aged 85-89 years.

Best practice

In recent years, the overall concept of person-centred care

has been embraced by the nursing profession and aged care as a whole. Person-centred care puts the person, their experiences, wellbeing, needs and feelings at the centre of the caring process, so care is based on principles of human rights such as respect, dignity and having genuine choices (Love 2015).

Many responsive behaviours are the result of untreated delirium, pain, infections, unmet emotional needs, boredom, poor communication and a lack of knowledge about the person. Insomnia can be caused or exacerbated by these factors as well, for example, untreated pain or excessive napping. Likewise, anxiety can be prompted by exposure to certain triggers or worsened by untreated medical conditions. Unless staff attempt to understand why responsive behaviours and psychological symptoms are occurring and are skilled in detecting ‘unmet needs’ there is the risk that staff ‘manage’ these symptoms through psychotropic medication (DCRC & DBMAS 2012).

Non-pharmacological strategies are recommended as initial treatment for the management of responsive behaviours, anxiety and insomnia as they offer two main advantages over psychotropic treatment. Firstly, these approaches address the

psychosocial/ environmental reasons for the symptom/s, and secondly, the limitations of pharmacological treatment are avoided, namely adverse effects and limited efficacy (DCRC & DBMAS 2012).

In summary, person-centred care can be provided by establishing why responsive behaviours and psychological symptoms occur and also by implementing non-pharmacological strategies to manage them.

Background research

When I returned to Australia in 2006 I decided to start a doctorate looking into ACH chlordiazepoxide use. Initially, I examined prescribing patterns by auditing over 3000 resident medication charts from 40 Tasmanian ACHs. I found a high use of benzodiazepines (37% of residents were taking a benzodiazepine every day!), alongside moderate antipsychotic use when compared to Snowdon *et al*'s (2011) Sydney measures (Westbury 2009). When psychotropic use was audited in the same residents a year later, over 65% of agents and doses taken were exactly the same, providing a strong indication that review of these agents occurred infrequently (Westbury 2010a).

Next, I wanted to understand why these agents were being prescribed, who influenced their use and their review. To do this I went out and interviewed GPs, nurses, pharmacists and relatives.

Reasons for prescribing

So, why are they prescribed so frequently? The findings of this study aligned closely with overseas research in that there was a strong belief among prescribers and ACH staff that these medications were very effective and were needed to “comfort” residents (Cornegé-Blokland 2012). In the words of one enrolled nurse interviewed: “...surely it’s far nicer to have them medicated and calm than distressed. On the whole, they seem to have a positive impact on their life”.

Fred hates pumpkin soup

The following report comes from one of the Tasmanian care homes involved in the RedUSE trial:

Fred was a very quiet resident. In fact, staff could not recall him speaking at all for over nine months. Fred did become agitated during some evening meals so he was given risperidone. [As part of the RedUSE trial] his GP and the nursing staff agreed to slowly reduce this sedative medication.

About a week after Fred’s antipsychotic was ceased, one of the carers heard him say “I hate soup”. When she asked him to repeat this to another carer, Fred said “pumpkin soup”. Sure enough, when staff checked with relatives whether Fred had an issue with pumpkin soup they were told he had always disliked it.

Pumpkin soup was a particular specialty of the cook at the care home, who always served it up several times a week.

Fred was never served pumpkin soup again.

Although staff displayed a good knowledge of assessment and non-pharmacological strategies they often felt unable to use them due to time and resource constraints. Another important reason why psychotropic agents were used so extensively was due to the limited knowledge of GPs, nurses and pharmacists about evidence for effectiveness, their adverse effects, doses and recommended duration of use. Not a single health practitioner could recall a guideline on psychotropic use in older people.

Who influences use?

Like similar research overseas, I found nursing staff were very influential when antipsychotics and benzodiazepines were initiated (Cornegé-Blokland 2012). GPs said ACH staff requested sedative medication but that they assumed that assessment of residents and non-pharmacological management had been implemented before they were asked to intervene. Relatives said they were rarely involved in decisions to start or alter psychotropic medication.

Barriers to reviewing

With regards to review, many health practitioners interviewed felt that behaviours would return if psychotropic medications were reduced. One of the main barriers to review was uncertainty over exactly whose role it was to do this. GPs spent limited time at ACHs, nurses felt this was the GPs' responsibility as they were the legal prescribers, and pharmacists, although funded to perform medication reviews, were reluctant to suggest reductions to psychotropic medication due to prior resistance from GPs and staff.

The RedUSE project

So what can be done about this long-standing issue? That was my next challenge; to devise an intervention aimed to reduce the use of antipsychotic and benzodiazepine in residential aged care. Ultimately, such a

project needed to challenge positive beliefs about the benefits of psychotropics. I also needed to enhance knowledge about these medications across all professional groups, raise awareness, promote good practice guidelines and encourage regular review by providing a structured process in which professional roles were clearly defined. Thus the **Reducing Use of Sedatives (RedUSE)** project was born.

RedUSE is a multi-component and interdisciplinary structured initiative, which employs several strategies targeted to reduce antipsychotic and benzodiazepine use (collectively referred to as 'sedatives') in ACHs. During the six-month project, each ACH's sedative medication use is audited at baseline, three months and six months.

The audit results are then presented to nursing staff and carers in educational sessions. Following this education, all residents taking these medications are reviewed. This is an interdisciplinary process involving a pharmacist, a champion nurse at each home and the resident's GP or nurse prescriber. The diagram above (see Figure 1) illustrates the main RedUSE strategies.

To test RedUSE, a controlled trial was conducted in 25 ACHs in the two major cities of Tasmania during 2008-9. Thirteen Hobart ACHs were recruited as the intervention group, with 12 Launceston homes acting as control (Westbury 2010b). By the trial's conclusion, benzodiazepine use was significantly reduced in intervention homes (32% to 26%, $p < 0.005$), whereas use increased in control homes. Likewise, antipsychotic use significantly reduced in intervention homes (20.5% to 18%, $p < 0.05$). Pleasingly, the proportion of psychotropic dose reductions occurring in intervention homes was more than double that observed in control homes (Westbury 2010b).

Expanding RedUSE

In August and October 2012, two ministerial roundtables of

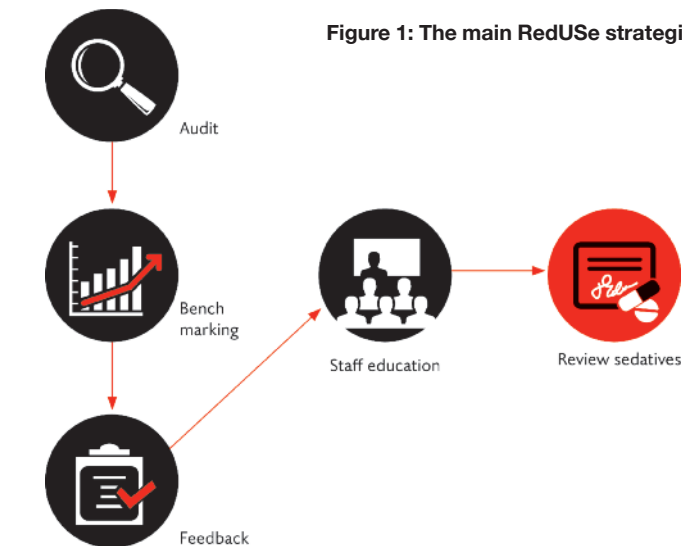


Figure 1: The main RedUSE strategies

experts on the use of antipsychotics were convened by the then Minister of Health and Ageing, Mark Butler. These roundtables led to the prioritisation of funding for research on antipsychotic deprescribing (Peisah 2014). The University of Tasmania submitted a grant proposal for a national expansion of RedUSE, with funding granted in June 2013 through the Australian Government's Aged Care Service Improvement and Healthy Ageing Grants (ACSIHAG) Program (now the Dementia and Aged Care Services (DACs) Fund). ▶

We wanted to enhance RedUSE before national expansion so invited industry, aged care advocacy bodies (ACSA and LASA), consumer groups (COTA and Alzheimer's Australia (now Dementia Australia), NPS MedicineWise and the Pharmaceutical Society of Australia) to be part of our steering group. The group was instrumental in suggesting strategies, reviewing educational materials and guidelines, and providing vital feedback.

We realised that a more interactive training program for ACH staff was needed, along with customised guidelines. Acknowledging that nursing and care staff were stretched and did not have time to attend lengthy training sessions, the RedUSE project provides educational content in just two one-hour

sessions delivered by a trained pharmacist, ideally known to staff at each home. Health professional roles were also clearly defined and included within a structured sedative review process.

On the advice of the funding body, a 'champion nurse' role was created for an expert peer to promote 'good practice' behaviour. Finally, academic detailing was delivered by NPS MedicinesWise and the Drug and Therapeutics Information Service to inform and engage our GPs and nurse practitioners.

The audit and feedback process was almost fully automated due to clever IT programming. The audits were not conducted by time-strapped ACH staff or health practitioners. Instead, prescribing data from the community pharmacies providing medication to the care homes was collected by the e-health program. One of the tasks of the champion nurse was to check that this resident psychotropic data was correct. The champion's other roles included helping to organise staff training sessions and participating actively in the sedative review process.

Aged care homes' response

ACSA and LASA put out a recruiting call for RedUSE in September 2013. As a result we were inundated with requests for ACHs to be involved. Initially, we had recruited 50 homes from two large national

aged care organisations (one for-profit group and the other a religious non-profit group) but wanted to include homes of various sizes and from different organisations. Although we only needed an additional 100 homes, we received over 320 expressions of interest from ACHs, providing an indication of the willingness to ensure psychotropic medication was used appropriately.

RedUse expansion statistics

The project was run in four separate 'waves' from 2014 to 2016. A total of 150 homes in all six Australian states and in the ACT completed the six-month intervention. Two thirds of homes were located in urban areas, 23% in regional areas and 7% were rural. About half the homes were categorised as 'for profit' and half were 'not-for profit', most with religious affiliations.

An average of 12,165 residents from the total 150 ACHs were audited for each psychotropic audit. A total of 300 training sessions were delivered to over 2500 ACH staff by 76 pharmacists. Nearly 400 GPs and nurse practitioners attended educational sessions. Finally, over 8400 sedative reviews were completed throughout the project.

Final results

Our main outcome measures were the average proportion of residents taking antipsychotic and benzodiazepine medication at baseline, 3 months and 6 months. At baseline we found that over a third of residents (37%) were taking a sedative medication every day. Specifically, 22% were taking an antipsychotic and 22% were taking a benzodiazepine. With 'prn' or 'as required' prescriptions included, over half of all residents (54%) were charted for a sedative medication.

Overall, a significant reduction was found in both antipsychotic and benzodiazepine use. A 13% relative reduction was observed in the overall use of antipsychotics from baseline to

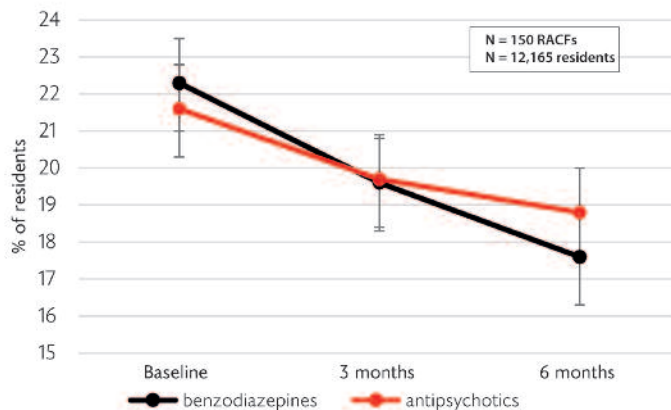


Figure 2: Average proportion of residents per ACH taking sedative medication over the project

6 months (from 22% to 18%). The reduction in benzodiazepine use from baseline to 6 months was higher; at 21% (from 22% to 17%) (Westbury 2018). The graph above (Figure 2) shows the average proportion of residents per ACH taking sedative medication over the project.

When we tracked residents taking sedative medication at baseline over the RedUse intervention we found that 40% had their medication ceased or reduced. Interestingly, residents were more likely to have agents ceased outright as opposed to having their medication dosage reduced. The reduction was also predominantly sustained during the project: over 80% of antipsychotics, and 90% of benzodiazepines ceased or reduced at 3 months were still ceased or reduced when these residents were re-checked at 6 months.

The response rate to the RedUse project from the ACHs involved was very promising. Two thirds of ACHs (99 homes) reduced both antipsychotic and benzodiazepine use, 29% reduced the use of either agent (44 homes) and only 5% (8 homes) did not record a reduction in sedative use; as the graph below illustrates (Figure 3).

We could not determine which of the RedUse strategies was the most influential because they were not tested separately. However, interim qualitative evaluation indicates that the strategies were perceived as building upon each other, starting with

awareness raising by dissemination of local prescribing data, reinforced by staff education, and followed by interdisciplinary review.

Interim clinical outcome data and economic impact

We are currently examining clinical data collected from a sample of residents involved in the project. The aim of this research is to compare the residents who reduced their sedative use against residents who did not have their sedative medication altered. Put simply, the main question we would like to answer here is if reducing sedative use affects a resident's quality of life. Would a sedative reduction result in an increase in responsive behaviours or affect a resident's risk of having a fall? Interestingly, and contrary to what you may expect, results to date indicate that agitation levels declined in those residents who had antipsychotic doses reduced or ceased, whereas levels of agitation in residents continuing antipsychotics stayed static or increased slightly.

We are also conducting a health economics analysis. Early results indicate that the cost savings generated from

reducing medication costs alone would cover the expenses associated with running the RedUse project.

One of our first observations was that many ACHs were not even aware of the proportion of residents actually prescribed sedative medication. Although some ACHs collect this data, they don't know how their use compares to other homes, or what they can do if usage is high or increasing.

The RedUse project increased awareness around sedative use by regularly measuring and monitoring use. The project also provided interactive education designed to challenge beliefs around psychotropic effectiveness and risks, and established a structured review process. RedUse resulted in significant reductions in the use of psychotropic medication in a large sample of Australian ACHs. Not only was the project well accepted by staff and health practitioners; more importantly, interim data suggests that reducing sedative medication use offers positive benefits to residents and is cost effective.

What's next?

Ideally, the strategies of RedUse should be made available for all Australian ACHs, particularly for homes with high rates of sedative use.

In the new draft Aged Care Quality Standards, awareness of psychotropic rates of use, and strategies to ensure that these agents are used appropriately are endorsed through Standard 3, along with specific advice about ensuring that least restrictive practices are used (ie minimising chemical restraint). RedUse would help ACHs to achieve these objectives of care but funding is needed to update the RedUse eHealth website, train champion nurses and

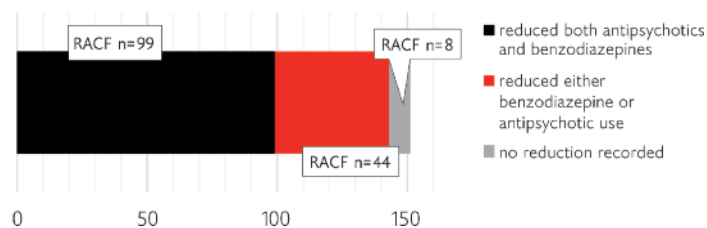


Figure 3: Response rate from ACHs

Quality Use of Medicines (QUM) pharmacists and employ part-time facilitators who work with the homes to ensure key staff are engaged, coordinate training sessions, and ensure the review process goes smoothly. The feedback we received was that this role was vital. I'm not sure if the RedUse initiative would be as successful if no one was actually coordinating it or updating education and training materials.

We would love the opportunity to roll out RedUse to more care homes. As a researcher, I would welcome the chance to improve and further enhance our offering: strive to improve GP uptake and involve care staff, relatives and people with dementia to a greater extent than they were initially. However, we have been told, as with all grants, that there is no surety of future funding. Ideally, the program could be offered as part of the existing Federally-funded Quality Use of Medicines (QUM) program for community pharmacists.

In the absence of a dedicated implementation project such as RedUse, the majority of residential aged care organisations wanting to ensure appropriate psychotropic use should, in the first instance, ask their QUM pharmacist to organise audits and request training sessions on psychotropic medication for all staff (see box above for details). ■

Acknowledgments

This initiative was very much a team effort. Dr Westbury wishes to acknowledge the contributions of the RedUse steering group, research team, our eight fantastic project facilitators, GP educators, staff and residents at all 150 participating aged care homes, their pharmacists, supply community pharmacies and the GPs who provide medical care to their residents.

The study, RedUse: reducing antipsychotic and benzodiazepine prescribing in residential aged care facilities, by Juanita Westbury, Peter Gee, Tristan Ling, Donnamay Brown, Katherine Franks, Ivan Bindoff, Aidan Bindoff and Gregory Peterson, was published in the *Medical Journal of Australia* in

Pharmacy programs for residential care

Under the Sixth Community Pharmacy Agreement (6CPA) there are two pharmacy programs which relate specifically to services provided in residential aged care facilities, and include education, point of contact for inquiries on medicines information and appropriate management of medicines:

Residential Medication Management Review (RMMR) is a service provided to a permanent resident of an Australian Government funded aged care facility. It is conducted by an accredited pharmacist when requested by a resident's GP (related MBS item 903) and undertaken in collaboration with the resident's GP and appropriate members of the resident's healthcare team. A comprehensive assessment is undertaken to identify, resolve and prevent medication-related problems and is provided to the resident's GP.

Quality Use of Medicines (QUM) program is a service provided by a registered or accredited pharmacist and focuses on improving practices and procedures as they relate to the quality use of medicines in a residential aged care facility (the agreement between the pharmacist and residential aged care facility relates to medication advisory services, education activities and continuous improvement activities).

The rules of the RMMR and QUM programs make specific reference to such items as Frequency of Service, Residential Care Eligibility and List of Eligible QUM activities. The current program rules can be found on the 6CPA website at: <https://bit.ly/2KK3GGr>

Information supplied by the Australian Department of Health

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■ Dr Juanita Westbury is Senior Lecturer in Dementia Studies, Wicking Dementia Research and Education Centre, College of Health and Medicine, University of Tasmania. She has a background as a community, government and research pharmacist and has been accredited to perform medication reviews in aged care homes and the community since 1997. Contact her at: juanita.westbury@utas.edu.au

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RESEARCH NEWS



Briana Lees is a PhD candidate and research assistant at the University of NSW. Contact her at: admin@australianjdc.com

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

Rigorous exercise doesn't stop cognitive decline

Researchers in the UK examined the effect of a moderate to high intensity aerobic and strength exercise training program on cognitive impairment and other outcomes in people with mild to moderate dementia.

A total of 494 people with dementia from 15 regions in the UK were recruited into the investigator-blind, randomised controlled trial. Random allocation was 2:1 in favour of the exercise arm compared to the usual care arm. A total of 329 people with dementia were assigned to an aerobic and

strength exercise program and 165 were assigned to usual care.

The exercise arm of the intervention involved usual care plus four months of exercise delivered by physiotherapists and exercise assistants. The intervention was delivered in community gym facilities and National Health Service (NHS) premises.

Twelve months after the intervention, physical fitness improved in the exercise group but cognitive impairment had declined for all participants. No differences were found for

dementia type, severity of cognitive impairment, gender or mobility.

The strengths of this study included the large sample size, the high retention rate at follow up and the use of gold standard measures.

The number of people who declined participation in the trial was high. The authors interpreted this trend as moderate to high intensity exercise not being an attractive proposition for older people with dementia.

The authors conclude that

moderate to high intensity aerobic and strength exercise cannot be recommended as a treatment option for cognitive impairment in dementia. Future research should explore other forms of exercise to reduce or stabilise cognitive decline in people with dementia.

Lamb SE, Sheehan B, Atherton N, Nichols V, Collins H, Mistry D, Dosanjh S, Slowther AM, Khan I, Petrou S, Lall R (2018) Dementia and physical activity (DAPA) trial of moderate to high intensity exercise training for people with dementia: randomised controlled trial. *BMJ* 361:k1675.

Identifying Alzheimer's risk

Australian researchers have examined a biomarker in the brain and scores on the Mini-Mental State Examination test to identify people with mild cognitive impairment who are at a greater risk of converting to Alzheimer's disease in the near future.

The researchers used neuroimaging and questionnaire data from the Alzheimer's Disease Neuroimaging Initiative database. A total of 660 participants were included in the study; 187 people had mild cognitive impairment which converted to Alzheimer's disease in less than five years, 112 people had stable mild cognitive impairment for more than five years, 39 people had mild cognitive impairment and reverted to no cognitive impairment in less than five years, and 322 people remained cognitively healthy for the whole follow-up period.

The combination of the Mini-Mental State

Examination and the hippocampus-to-cerebellum volume ratio measures successfully identified individuals who progressed from mild cognitive impairment to Alzheimer's disease within five years, from other mild cognitive impairment types (stable, reverts) and those who remained cognitively healthy.

The researchers highlight the importance of these findings for clinical practice. This study stands out in its use of a combination of simple structural and functional measures with potential diagnostic value for identifying mild cognitive impairment individuals at risk of converting to Alzheimer's disease within five years.

Tabatabaei-Jafari H, Walsh E, Shaw ME, Cherbuin N (2018) A simple and clinically relevant combination of neuroimaging and functional indexes for the identification of those at highest risk of Alzheimer's disease. *Neurobiology Of Aging* 69 102-110.

Improving dementia communication

Researchers in the UK have developed and pilot-tested a dementia communication skills training course for healthcare professionals in hospital settings to improve communication with people with dementia.

The researchers developed a two-day course with one month between the days. The training was based on experiential learning theory to focus on learning in action. The course involved three 15-20 minute interactive computer-based learning modules on person-centred care and basic communication skills, role plays with actors playing the role of patients, video workshops on person-centred dementia care in hospital wards and reflective diary sessions. Healthcare professionals who attended the course completed a questionnaire on their confidence in dementia communication (The Confidence Dementia Scale), a dementia communication knowledge test and a participation satisfaction survey.

A total of 45 healthcare professionals were recruited,

including doctors, nurses, allied health professionals and hospital activity coordinators. Following the two-day course, the healthcare professionals increased their knowledge and confidence in dementia communication. One-month after the course, blind-raters found that they demonstrated the dementia communication skills. When closing an interaction with a person with dementia the healthcare professionals were less likely to make vague arrangements, more likely to announce the completion of each task and more likely to be specific about closing the conversation.

The healthcare professionals nominated the role plays, specific communication techniques and the reflective diary exercises as the most valued parts of the course.

Future research should test communication skills training courses in other settings.

O'Brien R, Goldberg SE *et al* (2018) The VOICE study – a before and after study of a dementia communication skills training course. *PLOS ONE* 13(6): e0198567.

Support helps self-esteem and mood

Researchers in Italy, Poland and the UK implemented the Meeting Centres Support Program for people living with dementia. This program aims to provide local community support for people living with dementia and their family carers.

A total of nine pilot meeting centres participated, including five in Italy, two in Poland and two in the UK. In the intervention there were 85 people with dementia and 93 carers. The control group received usual care and included a total of 74 people with dementia and their carers.

People in the intervention group could attend the support program up to three days per week. On average, 10 to 15 people with dementia and their carers were supported per day.

Effectiveness of the Meeting

Centres Support Program was compared with usual care on outcomes measuring behavioural and psychological symptoms, depression, and quality of life. The outcomes were measured in a six-month pre/post-test, controlled trial design.

The attrition rate was 27%. The intervention group showed significant improvement in self-esteem, positive affect and feelings of belonging. There was no change in depression symptoms. Higher attendance levels at the meetings was associated with greater neuropsychiatric symptom reduction and a greater increase in feelings of support.

The study had a number of limitations in evaluating the impact of the intervention. Allocation to the intervention

group was not random, assessors were not blind to the intervention that participants received, the baseline measurements took place up to one-month after commencing the intervention and only participants who completed six-months of the program were included in the analysis.

The positive findings replicate the successful implementation of the Meeting Centres Support Program in previous studies. The researchers support further international dissemination of the intervention.

Brooker D, Evans S *et al* (2018) Evaluation of the implementation of the meeting centres support program in Italy, Poland, and the UK; exploration of the effects on people with dementia. *International Journal of Geriatric Psychiatry* 33(7) 883-892.

Pain assessment has no effect

Researchers in Norway evaluated the effectiveness of regular pain assessments on pain prevalence and analgesic use in people with severe dementia living in residential care homes.

The randomised controlled trial was conducted in 16 residential care homes across four counties in Norway. To be included in the trial, residents had to be over 65 years, have been diagnosed with severe dementia, and have an inability to self-report pain or were non-verbal. A total of 112 people were recruited for the study.

Trained residential care staff assessed for pain using the Doloplus-2 standardised scale, twice a week for 12 weeks. The control group received usual care. Pain and analgesic outcomes were collected at baseline and at the end of week 12.

No overall effect of regular pain assessment was found on pain scores or analgesic use. These results indicate that pain continued to be inadequately treated in people living with dementia in residential care homes. The researchers note that the null result may have been from the lack of translating assessment findings to practical action. Future research is needed to examine how standardised pain assessment can be used to support effective pain management in people with dementia.

Rostad HM, Utne I, Grov EK, Smastuen MC, Puts M, Halvorsrud L (2018) The impact of a pain assessment intervention on pain score and analgesic use in older nursing home residents with severe dementia: a cluster randomised controlled trial. *International Journal of Nursing Studies* 84 52-60.

Musical dual-task training improves attention

Taiwanese researchers conducted a randomised controlled trial examining the effectiveness of Musical Dual-Task Training for people with dementia. This training involved practicing walking and making music simultaneously to enhance attentional control.

Participants were recruited via referrals by neurologists from a specialised dementia outpatient unit in Taiwan. Fifteen people diagnosed with mild-to-moderate dementia were randomly assigned to the intervention and 13 people were assigned to the control group who completed non-musical cognitive and walking activities.

Participants attended training in eight weekly, individual, one-hour sessions. Each participant received the intervention across

a two-month period. All participants were assessed approximately one-week before and one-week after the intervention.

The effects of dual-task training were evaluated through attentional control, dual-task performance, balance, fears of falling and agitation. To measure these outcomes, participants completed the Trail Making Test, the Timed Up and Go Test and the Falls Efficacy Scale-International. The researchers completed the community-version of the Cohen-Mansfield Agitation Inventory Scale to assess the frequency of agitated behaviours.

Prior to the intervention, the control group demonstrated significantly greater stride length and recall in the dual-

task. Following the intervention, the training group showed significant improvement in attentional control, fear of falling and agitation compared to the control group.

The main limitations of this study were the small sample size and participant characteristic differences at baseline. The researchers recommend future studies with larger sample sizes investigating how dual-task training benefits different types of dementia and other conditions with increased risk of falling that are related to executive function decline.

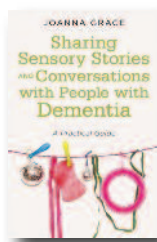
Chen YL, Pei YC (2018) Musical dual-task training in patients with mild-to-moderate dementia: a randomised controlled trial. *Neuropsychiatric Disease and Treatment* 14 1381-1393.

Relationships and well-being: Researchers in the UK investigated the association between relationship closeness and the negative and positive emotional impact of caregiving for a spouse of a person with dementia. A convenience sample of 71 spouses of people with dementia was recruited from services providing support for people with dementia and their families. The spouses completed three questionnaires: the Zarit Burden Interview, the Positive Aspects of Caregiving measure and the Birmingham Relationship Continuity measure. Higher relationship

closeness was significantly associated with fewer negative emotional reactions to caregiving and more positive emotional reactions towards their spouse with dementia. Further research is required on the best way to promote relationship closeness when caring for a partner with dementia and how to more effectively assist spouses' emotional adjustment to dementia.

Riley GA, Evans L, Oyeboode JR (2018) Relationship continuity and emotional well-being in spouses of people with dementia. *Aging & Mental Health* 22(3) 299-305.

Books



Jessica Kingsley Publishers (JKP) has released two news books on sensory engagement with people

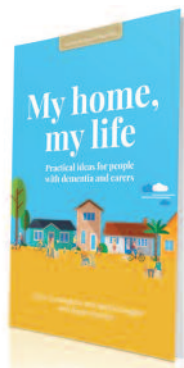
with dementia. The first, **Sharing sensory stories and conversations with people with dementia: a practical guide**, by Joanna Grace, looks at how sensory engagement can help someone with dementia feel safe and secure, to minimise anxiety and support cognitive abilities. The book's nine sections cover the relevance of sensory engagement for people with dementia, sensory conversations, sensory support, sensory environments, and sensory support for mental wellbeing. It includes practical guidance aimed at both dementia care practitioners and family members.

The second JKP book is called **Sensory modulation in dementia care: assessment and activities for sensory-enriched care**, by Tina Champagne. Sensory modulation refers to the neurological function of organising sensory information. Here the author introduces her Sensory Modulation Program and covers sensory processing and ageing, assessment of sensory processing with people with dementia, a guide to implementing the program, and links to helpful resources, such as a range of downloadable assessment tools to help review individual sensory-processing patterns. The book includes a range of sensory-based activities to carry out with people with dementia, both with individuals and in groups. Both JKP books are available to purchase from Footprint Books in Australia at www.footprint.com.au, the first for \$39.99, and the second for \$32.99.

The palliative care handbook was first published in 1994 and its latest edition – the 9th – now

includes comprehensive guidelines for people with dementia receiving end-of-life care. The 172-page book contains two main sections: the first explains palliative care and guidelines for alleviating symptoms and challenges commonly encountered. This section now gives particular consideration to the needs of people with dementia. The second section is a comprehensive listing of drug information, including unlicensed uses and interactions. The HammondCare Media publication has been written by Professor Rod MacLeod and Dr Stephen Macfarlane and is available to purchase from the HammondCare website for \$19.99.

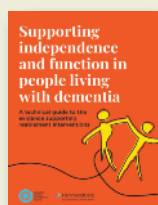
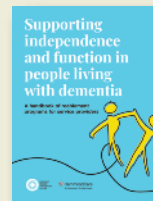
My home, my life: practical ideas for people with dementia is a new book published by HammondCare Media and written by Dementia Centre Director Associate Professor Colm Cunningham and aged care specialist Natalie Duggan, with dementia activist Agnes Houston. The book is aimed at people living with



dementia and their family carers and, true to its title, contains more than 280 tips and ideas to make life at home easier for people with dementia and their supporters. Topics covered include understanding dementia, changed or distressed behaviours, care and communication, food and nutrition, getting a good night's sleep, lighting and noise, sensory challenges and more. The book includes real-life stories of others sharing how they have tackled challenges related to dementia, and readers are being encouraged to contribute their own ideas too via www.myhomemylifebook.com. It is available to buy from the HammondCare website for \$14.99.

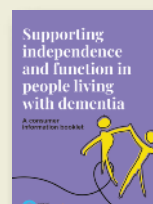
Reablement guides

HammondCare has worked with the University of NSW, Brightwater Care Group, Helping Hand Aged Care, Dementia Australia and the Australian Government Department of Health to publish a new suite of three resources on reablement for people living with dementia, all bearing the same title: **Supporting independence and function in people living with dementia**. The first is a substantial 82-page guide aimed at the aged care sector and is subtitled **A handbook of reablement programs for service providers**. The authors have attempted to translate research evidence into practical programs that can be delivered in real-world settings: as a result, the handbook outlines eight reablement programs around key areas of everyday living activities, mobility and physical function, and cognition and communication. For each program, detailed information is provided on duration, setting, who can run the program, general comments and key points.



The second guide is subtitled **A technical guide to the evidence supporting reablement interventions** and presents a detailed overview of the research evidence on reablement for people with dementia; it is aimed at health professionals delivering programs, and researchers.

The final resource, **A consumer information booklet**, is aimed at people living with dementia in the earlier stages, and covers questions such as 'What is reablement?', 'What does a reablement program do?', 'How can I help plan my reablement program?', 'How to make the most of your reablement program', and 'What else does a reablement program involve?'.



This project was funded with support from the NHMRC Cognitive Decline Partnership Centre (CDPC). The three resources are available to download for free from HammondCare's website: go to www.hammondcare.com.au/reablement-resources

Online

Deaf Services Queensland and Ozcare have teamed up to produce five short **films on dementia**, all signed in Auslan (with captions) and aimed at the Deaf community. The films look at an introduction to dementia, communication in dementia, practical suggestions for assisting people with dementia, and a film of Vera Walsh who is Deaf sharing her story of supporting her husband Keith who is also Deaf and living with dementia. Each film is about three minutes long. They are available to view via the websites for both Deaf Services Queensland (search for 'Video resources for Deaf seniors' or go to <https://bit.ly/2HlqrEp>) and Ozcare (search 'Dementia videos for the Deaf').

Bolton Clarke – the new face of RSL Care, RDNS and Rally Homecare – has worked with Dementia Australia to produce **Information on dementia in English**, a talking book on dementia aimed in particular at people with low literacy or visual impairment. Each page of the resource can be read

and/or listened to by simply clicking on an audio icon. It covers nine key areas: general information on dementia, a diagnosis of dementia, communication, dementia and behaviour, information for the person with dementia, information for families and carers, helping the person with dementia with everyday tasks, driving and travel, and dementia and planning for the future. The book was co-designed with input from Dementia Australia clients and carers, and with two Aboriginal social support services in Victoria. The book is available to download for free from the Bolton Clarke website at www.boltonclarke.com.au



The Alzheimer's Society in the UK has published a new guide, **Dementia-friendly rural communities guide**, aimed at helping anyone in a rural community to get started on becoming dementia-friendly. The 52-page guide includes a chapter looking at the particular challenges facing people with dementia in rural communities, best practice

advice on how to create a dementia-friendly community in rural areas, case studies from across the UK and links to useful resources and organisations. The guide was developed in partnership with the Prime Minister's Rural Dementia Task and Finish Group, a group of organisations, individuals and rural experts. It is available to download from the Alzheimer's Society's website.



In 2016-17, the Cognitive Decline Partnership Centre (CDPC) at the University of Sydney led a research project involving seven aged care organisations across Australia, looking at policies relating to supported decision-making in dementia in residential and community care organisations. As a result of this work, the CDPC has now published **Supporting decision-making guide: a policy development guideline for aged care providers in Australia**. The guideline describes key aspects and implications of the National Decision-Making Principles (as recommended by the Australian Law Reform Commission in

2014), provides an action plan for policy development and offers a range of practical tools, including a self-assessment tool for aged care providers to assess their current policies, a case study (including reflective questions for group discussion) and a model policy framework to assist aged care providers in reframing current policies (including key actions to be taken). The guideline is available to download from the CDPC website.



Funding from the Dementia Centre for Research Collaboration (formerly the Dementia Collaborative Research Centres) has enabled the University of Melbourne to develop and publish **Physical activity guidelines for older Australians with Mild Cognitive Impairment or Subjective Cognitive Decline**, after adapting similar guidelines from Canada. The guidelines set out the current evidence on the benefits of physical activity for older adults with MCI or SCD, and indicate what is the most beneficial type, frequency, intensity, duration and setting for the physical activity. The guidelines

also provide practical advice on enablers and barriers to older people participating in physical activity, but do not examine any chronic conditions beyond MCI or SCD. The guidelines present four recommendations: on aerobic physical activity; on progressive resistance training activity; on balance; and on the need for programs to be individually tailored, with input from health professionals. The 66-page guidelines are available in full or in a two-page easy-read version, both via the University of Melbourne's website.

Dementia UK has been expanding its range of **information leaflets** over the past year, and its collection now extends to 24 topics, grouped into six themes: 'Dementia: first steps', 'Maintaining health in dementia', 'Understanding changes in behaviour', 'Complementary therapies', 'Looking after yourself', and 'Planning for the future'. Most of the guides are 6-8 pages in length and include lots of practical tips and strategies written in easy-to-read language. The leaflets can be downloaded for free from Dementia UK's website at www.dementiauk.org

Events

■ August 2018 – WA & VIC

Introduction to the Hierarchic Dementia Scale-Revised (HDS-R) and the Possibility Oriented Approach to Care Planning

Workshop, presented by Dementia Training Australia, in Como, WA (10 August); and Kew, VIC (31 August). Details: www.dta.com.au

■ 23-24 August 2018 – NSW

Better Practice For The Future National Conference: Living The Life I Choose

Hosted by the Australian Aged Care Quality Agency, in Sydney. Better Practice Award winners to be announced at the conference dinner on 23 August. Early bird registration now open until Friday 13 July. Details: www.aacqa.gov.au

■ 3-5 September 2018 – NSW

2018 ACSA National Summit

'What's Next? Identify, Adapt, Deliver', presented by Aged and Community Services Australia (ACSA), in Sydney. Details: www.acsanationalsummit.com

■ 19-21 September 2018 – VIC

Diversional & Recreation Therapy Australia National Conference

In Melbourne. Details: <http://diversionaltherapy.org.au/>

■ 9-10 October 2018 – VIC

Embolden

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

■ 28-30 October 2018 – SA

LASA National Congress 2018

Australia's largest aged service industry event, presented by Leading Age Services Australia, in Adelaide. Details: www.lasacongress.asn.au

■ 11-14 November 2018 – NSW

11th International Conference on Frontotemporal Dementias

In Sydney. Details: www.icftd2018.org.au

■ 21-23 November 2018 – VIC

51st AAG Conference: Advancing Not Retiring: Active Players, A Fair Future

Hosted by the Australian Association of Gerontology (AAG), in Melbourne. Details: www.aag.asn.au/national-conference/2018-conference

Details of more events at www.journalofdementiacare.com

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