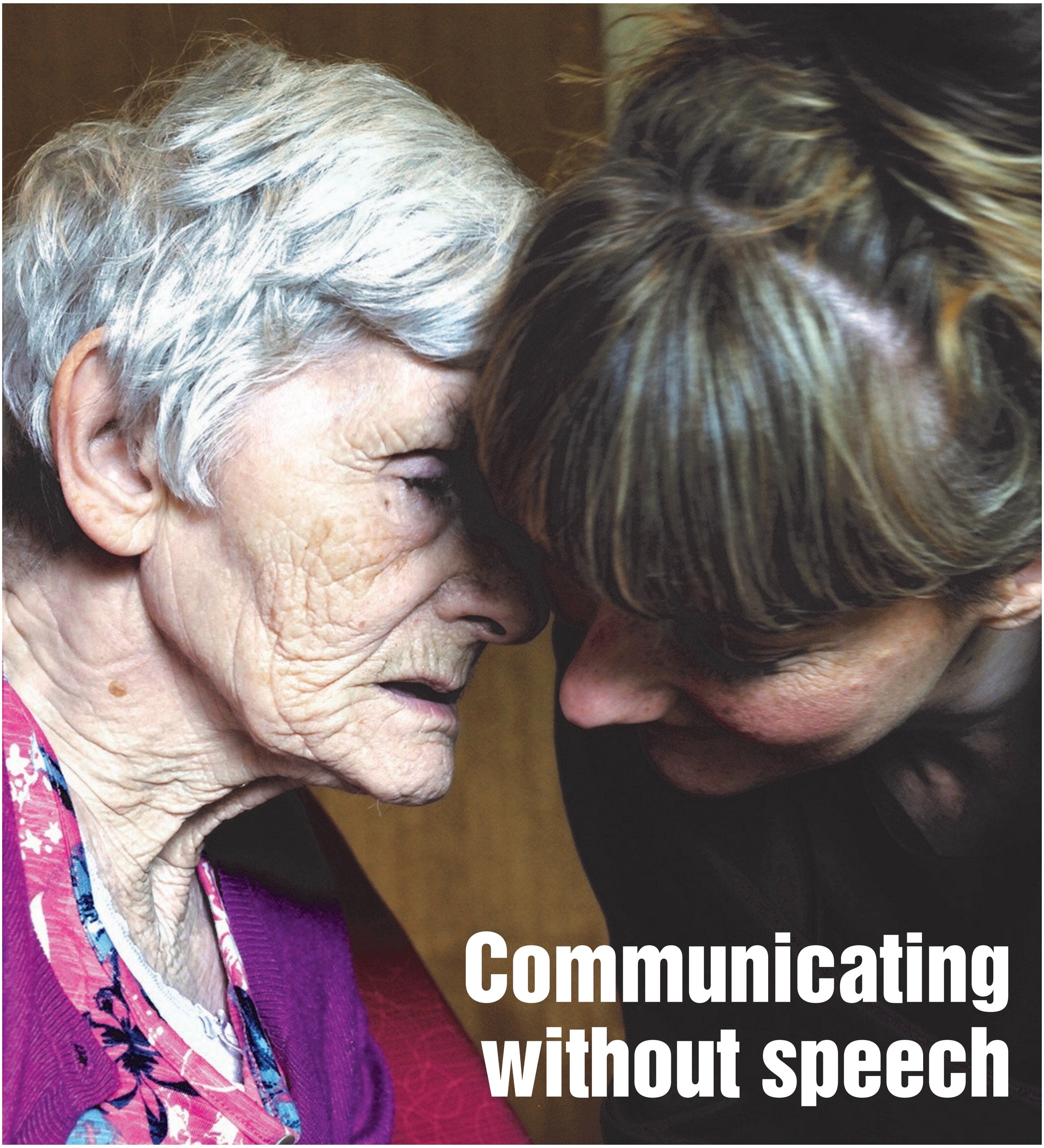
Australian Journal of Dementia Care

For all who work with people with dementia

Vol 8 No 2 April/May 2019



Communicating without speech

Also inside this issue:

- Stories from those who care
- Inroads into remote training
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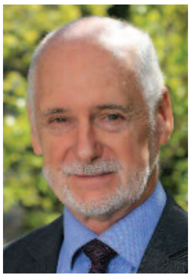
- Being a ‘disruptor’

The right people in the right place

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



I don't think I would like to be a Royal Commissioner, certainly not one dealing with the profoundly human issues that lie at the heart of caring for elderly people. They must be so much more difficult to come to grips with than the issues of good banking practice, to use the example of the recent Royal Commission. Yes, there are some things that are black and white. Physically abusing a resident in an aged care home is as clearly wrong as charging dead people fees for services, but our notions of what constitutes good care are not nearly as clearly defined as what constitutes good banking practice.

Unlike the Aged Care Quality and Safety Royal Commissioners, the Royal Commissioner dealing with banks did not have to cope with the idea of a complete paradigm shift. No one was saying that banks, per se, are a bad idea and that no-one wants to use them. However, there are many voices shouting that residential care is bad and that no one wants to use it. Residential care for people with dementia has come in for particular criticism.

What is wrong with residential care for people with dementia? Answering that question presumes a knowledge of what good dementia care looks like. As Tom Kitwood is often quoted as saying, "If you have met one person with dementia, you have met one person with dementia". It is dangerous to generalise; there is no one-size-fits-all description.

But perhaps there are some critical elements that can provide a framework for discussing what is good, and bad, in residential care for people with dementia.

I suggest that there are six such elements, with the first being that it should be driven by a vision of what a perfect day for the resident will look like. But, you may say, if everyone with dementia is different how can there be a perfect day for residents? This brings me to the second element – having the right residents. A residential care facility for people with dementia should be able to focus on the care of a defined group of people, not expected to satisfy everyone. The third element is that the staff should be the right staff, with the required values and emotional intelligence, along with sufficient training.

The fourth element is that the building should be designed to support the staff and the residents to achieve what they want to achieve, especially the simple things like finding their way around. The fifth is that the staff, and their activities, are valued by the community and this value is reflected in their numbers and pay.

The sixth is that the whole package – activities that make up a perfect day; resident focus; staff selection and training; the design of the building; and staff numbers and pay – are all regulated by standards that support the staff and the residents to strive for lives full of meaning.

Much easier said than done, but we do know how to do most of it. The most difficult bit is raising the value placed on the staff by the community. As well as the obvious obstacle of additional cost to the individual in the community, probably through increased taxation, there is the hidden issue that the community as a whole doesn't actually value old people, particularly those with dementia. In our materialistic society we haven't worked out what old people are for, so we can't put a value on them. And if we don't value them why would we value the staff looking after them?

So, the Aged Care Quality and Safety Royal Commissioners have their work cut out. The paradigm shift that they are looking for is not going to be found solely within the aged care system. It is going to have to include engaging the community with some hard questions about its overarching values. As Pearl Buck said "Our society must make it right and possible for old people not to fear the young or be deserted by them, for the test of a civilization is the way that it cares for its helpless members."

The Royal Commission is holding up a mirror to us all, not just shining a spotlight on ill-trained staff and greedy aged care providers. ■

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

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

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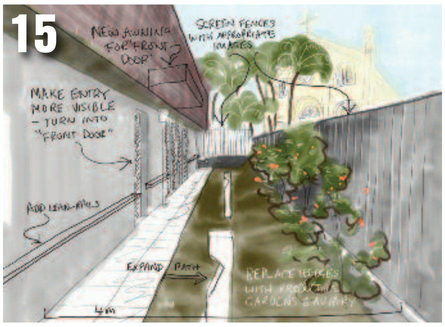


Regulars

Cover image: Dr Maggie Ellis (right) and Nancy forming a deep connection during an Adaptive Interaction (AI) session. Dr Ellis and Professor Arlene Astell's research has confirmed the potential of AI for connecting and communicating with people with dementia who can no longer use speech. See article pp30-34. Photo: Brett Housego

$40m for education, resources and innovative technology

The Australian Government is providing a further $40 million in grants to better support people living with dementia.

Applications close on 3 April 2019 under the Dementia and Aged Care Services Fund (DACS) National Dementia Support Program for funding from 2019-20 to 2021-22.

A total of $36 million will go to supporting education programs, services and resources to improve interactions between people living with dementia and those around them. The remaining $4 million focuses on the use of innovative technology for people living with dementia.

Projects eligible for a share of the $36 million could include those raising awareness and understanding about dementia, and increasing the skills and confidence of people living with dementia, their carers, families, health professionals, volunteers, and contacts within their communities.

These grants may also be used to:

- support primary health care practitioners, including GPs, to improve early diagnosis of dementia;
- reduce stigma about dementia which can exist in the community;
- support people and families at or after the diagnosis of dementia;
- provide culturally appropriate education and information on dementia and support services for people, families and carers from Aboriginal and Torres Strait Islander and culturally and linguistically diverse backgrounds.

This funding includes $5 million to Dementia Australia to enable the organisation to continue to provide its services for five months to 30 November 2019 while the grant process is undertaken.

The technology grants aim to:

- assist people living with dementia to sustain their independence and remain in their own homes for longer;
- improve the quality of life of people living with dementia in both home and residential aged care; and
- support families and carers to develop skills and strategies for caring.

Applications for the National Dementia Support Program can be downloaded from the GrantConnect website by searching for GO1777 at www.grants.gov.au.

Restraint regulations latest

The Minister for Senior Australians and Aged Care, Ken Wyatt, has promised draft changes to restraint regulations, in response to ABC coverage on this issue in January, and said that there has been "extensive examination of this important issue over the past 18 months". Glenys Beauchamp, Secretary for the Department of Health, told the Royal Commission into Aged Care Quality and Safety on 18 February that the Department was currently working on options to be put to the Minister on the matter.

In January, the Aged Care Quality and Safety Commission also released a statement saying: "The Commission has recently sharpened its focus on the use of restraints in residential aged care, and providers can now expect that they will be specifically asked about restrictive practices during monitoring visits."

The Government is also using the mandatory National Aged Care Quality Indicator Program for residential care to address the issue of restraint. "[The program] includes an indicator on the use of physical restraint in line with our commitment to better regulate chemical and physical restraint in aged care," Mr Wyatt said. The National Aged Care Quality Indicator Program started on 1 January 2016 as a voluntary program for Commonwealth subsidised residential aged care services. From 1 July 2019, all Commonwealth subsidised residential aged care homes must collect and provide clinical quality indicator data to the Department of Health.

Dementia Plan for Vietnam: Dr Tuan Anh Nguyen from the University of South Australia will lead a team of international researchers and clinicians to contribute to the development of Vietnam's first National Dementia Plan. The project has been awarded $850,705 jointly from the Australian National Health and Medical Research Council (NHMRC) and the National Foundation for Science and Technology Development of Vietnam (NAFOSTED), and will also involve Professor Henry Brodaty, Co-Director of the Centre for Healthy Brain Ageing (CHeBA) at the UNSW Sydney. Professor Brodaty said, "We know dementia disproportionately impacts low and middle income countries so it is a privilege to be involved in helping equip Vietnam to meet these challenges."

Federal funding injection for dementia supplement

The home care supplement for dementia and cognition increased from 20 March 2019. The increase is just one small part of a major new $662 million package of funding for aged care announced by the Australian Government in February – in addition to the $552 million of funding announced in December.

Nearly half of the new investment is aimed at residential aged care (a $320 million general subsidy boost in 2018-19), while $282.4 million will fund an additional 10,000 home care packages across all levels, with the hope that this speeds up access to home care for older Australians.

Other elements of the new funding package include:

- a $4.2 million mandatory national aged care quality indicator program (see story at left)
- $7.7 million to enhance the safety, quality and integrity of home care
- $35.7 million to increase home care supplements for dementia and cognition and veterans
- a $4.6 million trial of a new residential care funding tool to replace the Aged Care Funding Instrument
- a new $7.4 million business advisory service for both residential and home care providers to help them improve their operations and share best practice.

COTA Chief Executive Ian Yates said that COTA welcomed the various funding increases, but expressed concern that the Government has not tied the $320 million in extra funding for residential aged care providers to better staffing. He said, "It is disappointing there are no conditions attached to require providers to use the additional funding to increase staff numbers and/or support workforce training and development programs that will lift the standard of care in Australian nursing homes."

Mr Wyatt also announced in January that an extra $58 million a year will go towards 775 new Short-Term Restorative care places. He said 350 of the new short-term restorative care places will be allocated by July 2019, with another 425 places to be allocated in 2019-20.

Specialist Dementia Care Program

The Department of Health has presented further detail on its Specialist Dementia Care Program (SDCP), which will see the establishment of more than 30 specialist care units around Australia for people with dementia with the most complex responsive behaviours.

The Specialist Dementia Care Program (SDCP) will include:

- At least one specialist care unit in each of the 31 Primary Health Networks, generally comprising nine beds, located within existing residential aged care facilities.
- A nationally-consistent needs-based assessment framework to ensure care is delivered to those most in need.
- Person-centred and multidisciplinary care delivered in accordance with 10 Specialist Dementia Care Program service delivery principles.
- Formalised arrangements for regular specialist clinical input and review.
- Transitional support that focuses on reducing or stabilising symptoms, with the aim of enabling the person to move to a less intensive care setting.
- Regular reporting on client outcomes, independent evaluation and a focus on identifying and sharing best practice in specialist dementia care.

The Department says that the SDCP will be rolled out using a phased approach, with the first prototype service – to be run by Brightwater Care Group in Perth – expected to be operational by mid-2019. A tender process this year will result in the selection of up to 15 units to be operational by early 2020. The remaining sites will be selected in 2021, subject to an evaluation process.

The Government has committed $70 million annually to the SDCP (by full roll-out), which will operate as the ‘third level’ of Australian Government programs to assist people with dementia, alongside the existing Dementia Behaviour Management Advisory Service and Severe Behaviour Response Teams.

Dementia Australia said it welcomed the announcement of the phased approach to the introduction of the SDCP to ensure the service model can be appropriately tested, evaluated and improved before a broader roll-out nationally.

HammondCare is working with the University of NSW to develop criteria and a clinical assessment pathway to guide objective clinical decision making around entry to and exit from the program. HammondCare ran a series of roundtable discussions across Australia in February and March to inform stakeholders about its role in the project and to seek input to assist in the development and refinement of the pathway tool.

Proposed new residential care funding model: The Australian Government is seeking feedback from the aged care sector and the community on a proposed new funding model for residential aged care. A landmark University of Wollongong (UOW) study about the proposed new and improved model – the Australian National Aged Care Classification – was released in March 2019. Consultation is open until 31 May 2019 and the paper can be accessed at www.consultations.health.gov.au. Minister for Senior Australians and Aged Care, Ken Wyatt, said the research could be a “game changer” for aged care because the proposed new system is a completely different way of allocating funding for residential aged care. The proposal includes removing identified flaws in the Aged Care Funding Instrument including complex and time-consuming assessment processes and eliminating incentives found not always to be in consumers’ best interests. The sector and community feedback will inform decisions around funding reform and the design of the proposed new model. Mr Wyatt said the UOW study addresses the need for a more stable, contemporary, efficient and effective funding tool and system.

News in brief

DSDC Gold Standard for Life Care

South Australian aged care provider Life Care is the first provider in the Southern Hemisphere to be awarded Gold Standard Accreditation from the Dementia Services Development Centre (DSDC) at the University of Stirling in the UK. The accreditation has gone to Life Care’s Gaynes Park Manor residential care home, in Joslin, Adelaide. Life Care CEO Allen Candy said, “A key to Gaynes Park Manor receiving the award was our use of an innovative Real Time Location system. This removes the need for physically cordoned areas and enables people living with dementia to move around safely and with confidence within ‘virtual boundaries’.” He said Life Care was the only provider in South Australia to use the ‘House Model’ of care, where residents are grouped into small communities with unique visual cues, to help with recall and orientation.

Dementia Grants announced

Seventeen new projects are to share in more than $1 million in grants from the Dementia Australia Research Foundation, starting this year. The Dementia Grants Program will fund research into a wide range of topics – such as financial vulnerability in people with younger onset dementia, hearing-related neurocognitive impairment, and supporting expression of sexuality by older people with dementia in long-term care. The Getting Home Safe project, led by Dr Margaret MacAndrew from Queensland University of Technology (and featured on pp24-26 of this issue), was awarded the Many Miles For Mary Project Grant, which will fund research into generating agreement on national policies and procedures for reporting a missing person with dementia. Most of the projects will receive $75,000, and two recipients of Training Fellowships will receive $15,000 each per year for two years. A full list of the grant recipients is available on Dementia Australia’s website.

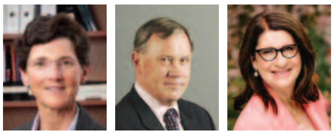
Home care staff training ‘inadequate’

Inadequate staff training in dementia care is one of a dozen issues highlighted in a new research report on home care in Australia. The report, *Older people living well with in-home support*, says that the research identified systemic problems with the home care system, and that consumers have a high level of dissatisfaction with current arrangements for home care packages. The qualitative study was conducted by Aged Care Matters’ Sarah Russell, and commissioned by Minister for Senior Australians and Aged Care, Ken Wyatt. It involved interviews with 40 recipients of home care, along with their family carers. Other issues identified in the research included insufficient numbers of staff, high turnover of case managers and support workers, poor communication, and lack of transparency about administrative and management fees. Both LASA and ACSA have responded by saying they welcome the further exploration of these issues at the upcoming hearings of the Royal Commission into Aged Care Quality and Safety.

Australia Day Honours

Three individuals who have made a significant contribution to the dementia field were acknowledged in the 2019 Australia Day Honours announcements. Professor Peter Schofield, CEO of Neuroscience Research Australia (NeuRA), Professor of Medicine at UNSW and Interim Joint CEO of the Mindgardens Alliance, was awarded an Officer of the Order of Australia (AO) “for distinguished service to medical and scientific research in the field of neuroscience, and to professional institutions”. Author and dementia advocate Tom Valenta received the Medal of the Order of Australia (OAM) in the General Division for his distinguished service to the community through charitable organisations – including Dementia Australia. In 2007 Tom published *Remember me Mrs V: caring for my wife and others*, which was a tribute to his wife, Marie, who was diagnosed with Alzheimer’s disease at the age of 54. Lynette Chester was also included in the Australia Day Honours as a Member (AM) in the General Division of the Order of Australia for her significant service to community health, particularly to people living with dementia and their families.

Royal Commission gets to work


From left: Janet Anderson, Richard Tracey, Lynelle Briggs

The particular needs of people living with dementia emerged as a key issue during the first hearing of the Royal Commission into Aged Care Quality and Safety, which saw 28 witnesses appear over the first eight days during February, in Adelaide.

The focus of the first hearing was on key features of the aged care, quality, safety and complaints system, about how that system works in practice and at a general level. Witnesses included consumer representatives, representatives from peak and professional bodies, the new Commissioner of the Aged Care Quality and Safety Commission (Janet Anderson), and the Secretary for the Commonwealth Department of Health (Glenys Beauchamp).

In summing up comments on the final day of the first hearing, Senior Counsel Assisting Dr Timothy McEvoy said that "understanding and accommodating the needs of Australians with dementia will be critical to the design of the aged care system going forward".

Dr McEvoy also remarked on the number of witnesses who had identified a need for a variety of innovative care models to be considered for future implementation to better address the needs of people with dementia. He said this would be given more detailed consideration at the May hearings.

In her appearance at the Royal Commission, Maree McCabe, CEO of Dementia Australia, raised multiple issues: community awareness, dementia diagnosis, the lack of dementia-specific staff training, the lack of dementia-specific facilities, and the need for funding for dementia-specific services.

Associate Professor Edward Strivens, president of the Australia and New Zealand Society for Geriatric Medicine, spoke about the complexities of treating people who are living with multiple illnesses and the need to be "very careful about pharmacotherapy" with older people. He commended taking a rehabilitative approach to supporting people with dementia post-diagnosis and acknowledged the "tremendous work" done by advocacy groups such as Dementia Alliance International to address issues to do with language in dementia care.

Professor John McCallum from National Seniors Australia spoke of the need for compulsory dementia-specific training for care staff.

At the conclusion of the first hearing, the Commission had received over 1200 submissions from members of the public and staff working in aged care. Most (90) of the largest 100 aged care providers who were sent information requests had responded to the Commission.

At the time of going to press, the second hearing was due to commence in Adelaide on 18 March, focusing on aged care in the home.

The Commissioners, Lynelle Briggs and Richard Tracey, will provide an interim report by 31 October 2019, and a final report by 30 April 2020.

About the hearings: The Royal Commission will conduct hearings in all capital cities and some regional locations. Hearings are due to take place in the weeks commencing: 6 May, 13 May, 17 June, 24 June, 8 July, 15 July, 29 July, 5 August, 9 September, 8 October, 14 October, 4 November, 11 November and 9 December 2019 (although dates may change). Locations will be announced closer to the time of the hearings.

The hearings are open to the public and are also streamed live through the Royal Commission's website, with full transcripts made available after the hearings also.

The Royal Commission will also undertake a series of community forums in various metropolitan and regional locations around Australia, roundtable meetings with experts, and site visits during the course of its inquiry into aged care delivery in Australia. The first community forums were held in Bankstown in Sydney on 1 March, in Bendigo in Victoria on Tuesday 5 March, and Wollongong, NSW on 13 March 2019.

Full details about upcoming hearings, along with live webcasts of hearings and video recordings and transcripts of previous hearings, are available on the Commission's website at https://agedcare.royalcommission.gov.au

Background paper: *Navigating the maze: an overview of Australia's current aged care system* is the title of the first background paper released by the Royal Commission into Aged Care Quality and Safety. The 55-page document sets out a basic explanation of the aged care system, the services currently being delivered in Australia and the areas in need of substantial reform. Prepared by the Office of the Royal Commission for the information of Commissioners and the public, the paper is the first of a number of publications to be released to the general public during the Royal Commission. It is available to view on the Commission's website: https://agedcare.royalcommission.gov.au

News in brief

Action plans for diversity

A series of four Aged Care Diversity Framework action plans have been launched by the Government to assist government and aged care service providers to address barriers and challenges faced by older people with diverse characteristics and life experiences. The action plans have been developed as part of the Aged Care Diversity Framework, and were drawn up by the Aged Care Sector Committee Diversity Sub-Group in consultation with the sector. Dementia Australia has been a part of the committee and welcomed the launch of the new resources. An action plan has been developed for each of four communities: older people with diverse characteristics and life experiences (presents action common to all older people); older Aboriginal and Torres Strait Islander people; older people from culturally and linguistically diverse backgrounds; and older lesbian, gay, bisexual, transgender diverse, and intersex elders, with the expectation of more plans to come. The Australian Government has also prepared an additional action plan outlining the actions it's taking to support the aged care sector to meet the needs of diverse groups.

The Aged Care Diversity Framework action plans are available from the Department of Health website at http://bit.ly/diversity-framework

National Aged Care Advocacy Framework

Minister for Senior Australians and Aged Care Ken Wyatt launched the National Aged Care Advocacy Framework in February. The new framework will guide the delivery of nationally consistent aged care advocacy services under the National Aged Care Advocacy Program (NACAP). NACAP is delivered by nine member organisations that are part of the Older Persons Advocacy Network (OPAN) and provides confidential advocacy support, education and information to older people receiving Commonwealth-funded residential or home support aged care services (and family carers also). The new framework outlines objectives, guiding principles and target groups for the NACAP, as well as directing NACAP to focus on people living with dementia, a disability, or cognitive decline and those from special needs groups. The framework is available on the Department of Health website at http://bit.ly/NACA-framework

Dementia service takes team approach

A team of allied health professionals, a geriatrician and carer consultants are providing holistic at-home support for people at all stages of dementia through Merri Health's innovative Specialist Memory and Dementia Service. **Daniel Calleja** reports

Merri Health's Specialist Memory and Dementia Service provides intervention and education to enhance people's independence in the home environment, as well as providing specialist input if care becomes challenging at home. **Photos: iStock**

Merri Health, a community health organisation in Melbourne's North, has established an innovative and timely program to meet the needs of people with dementia and their carers living in the community. Commencing in June 2018, the Specialist Memory and Dementia Service is funded through the Commonwealth Home Support Program (CHSP) to provide in-home support to these clients.

As a multi-disciplinary program, services are offered through occupational therapy (OT), physiotherapy, exercise physiology, speech pathology and dietetics.

In addition, clients have access to an MBS-funded geriatrician and dementia carer consultants. The service currently employs a full-time senior exercise physiologist, a full-time physiotherapist, a team leader / senior OT, a full-time senior OT, part-time dementia carer consultants, a part-time allied health assistant and a part-time geriatrician. The dementia service, in conjunction with a Rapid Reablement Service which also commenced in June 2018, forms the Aged Specialist Services Program at Merri Health.

The reablement program is a goal-focused, person-centred program to assist clients to return to their previous level of function, usually following an acute episode such as a fall. It is a time-limited program, usually up to three months in duration.

It involves the allied health team as well as the Regional Assessment Service (RAS) team supporting the client during their period of reablement.

Filling a gap

It is vital that people with dementia and their carers are provided with ongoing, holistic support at all stages of dementia while living in their own homes in the community. The Specialist Memory and Dementia Service came about through extensive consultation with key stakeholders in Melbourne's northern suburbs, including the RAS, Aged Care Assessment Service (ACAS) and Cognitive Dementia and Memory Service (CDAMS), which identified a gap in the dementia care system – specifically that a community-based dementia service was required. It was set up particularly to support clients post-diagnosis, from CDAMS and through all stages of dementia, as well as people without a formal diagnosis of dementia.

What we do

Merri Health's Specialist Memory and Dementia Service provides intervention and education to enhance people's independence in the home environment, as well as providing specialist input if care becomes challenging at home.

The service focuses on addressing responsive behaviours, environmental enhancement, carer and client wellbeing and engagement in meaningful life roles and activities. Providing support for the physical needs of a person with dementia is also of great importance. Having a physiotherapist and exercise physiologist on the team helps to meet the mobility, balance, falls management and exercise needs of the clients.

Retaining independence

A diagnosis of dementia should not mean that the person stops their meaningful activities and roles. An important aim of the Specialist Memory and Dementia Service is to assist clients and their carers to continue to engage in these activities and to help them modify tasks, based on their functional and cognitive strengths.

Many clients and carers are not aware that there are interventions which can be implemented to help the person with dementia retain their independence, life roles and leisure interests and continue to engage in meaningful activities. These interventions can include: signage and use of visual cues around the home to assist with orientation; reviewing the use of contrast and lighting in the environment; falls management strategies; support to resume or continue meal preparation, personal care and accessing the local community; education to assist carers to simplify their communication with the person with dementia; and enhancing visiting experiences with family through personalised, graded activities. Specifically, we use the Pool Activity Level (PAL) Instrument for Occupational Profiling, in conjunction with a lifestyle questionnaire and the client's goals, to grade activities and tailor them to the individual.

The service's dementia carer consultants provide emotional and strategic support for carers and family members. They support carers to learn more about dementia, understand and respond to behavioural changes and assist with navigating community services. The consultants, who are based primarily with CarerLinks North, work closely in partnership with the Specialist Memory and Dementia Service allied health team.

Environmental assessment

A unique intervention offered through the Specialist Memory and Dementia Service is environmental assessment and enhancement of the home environment. Based on the 10 dementia design principles (Fleming *et al* 2003), clients are provided with an assessment and a report to assist with enhancing their home. OT interventions also support the clients and their carers in implementing these changes in the home environment.

Having trained in environmental enhancement for people with dementia, I acknowledge it's a fine line in what we modify in a client's home. On one hand, the home environment offers a place of familiarity for a client, yet much can be done to make the environment safer, to provide opportunities for meaningful engagement, and to enhance helpful stimuli and reduce unhelpful stimuli. I am always conscious of making sure there is a balance when modifying a client's home to make it more dementia friendly. For clients with dementia living in their own home, it is so important to provide them with support to make their environment as optimal as possible to their wellbeing and safety.

Accessing the service

Referrals to the Specialist Memory and Dementia Service can be made through My Aged Care (MAC) under Specialised Support Services, and our team's geriatrician can be referred to directly through a GP. An important aspect of the service is that it is not time-limited. As long as the program continues to be funded by CHSP and a referral is received through MAC, the client can present to the service as often as required and we do not cap how many instances of care they will receive.

There is no set number of visits a client can receive per week as this is determined by their clinician. Given the nature of dementia and the changing needs of clients and carers, some of our original cases are still open.

Initial assessments generally take 1.5 hours and review visits generally last 45-60 minutes. For some disciplines such as OT, there is quite a lot of work outside of these times, for example sending clients resources, reports and recommendations to implement between visits.

Some of our clients do not have a formal diagnosis, or have just been diagnosed, while others are more advanced in their dementia. Not all clients wish to pursue a diagnosis, however we can support them in this process if required. After assessment by an OT, cognitive screening and a history from the carer and the client, we write to the client's GP requesting follow up. Follow up can either be through CDAMS or our service's geriatrician, who will then contact CDAMS if a dementia diagnosis is required.

As a general rule, clients who are pensioners will pay $9.90 for a home-based consultation through the Aged Specialist Services Program. We also work with clients on home care packages and these clients are charged at full cost recovery as per the home care package and CHSP guidelines.

Our geriatrician is MBS-funded and therefore bulk bills, which means there is no cost to the client. Clients are currently also seeing a geriatrician within one to two weeks of receiving the referral from their GP. While the demand for the geriatrician will increase with the growth of the service, it is likely that the waitlist for our geriatrician will still be considerably shorter than often is the case with other services.

Conclusion

Merri Health's Specialist Memory and Dementia Service is certainly the only one of its kind in Melbourne and, in the 17 years that I have been practicing as an OT, I am not aware of any other services in Victoria that offer what our program does – a full allied health team and a bulk-billed geriatrician service, providing support for people at all stages of dementia and cognitive loss in the client's home.

Since the service began in June 2018 we have seen 192 clients. Demand is such that we're now planning to increase our staff numbers so we can expand beyond Merri Health's traditional service area in Melbourne's northern suburbs. We're also looking to include nursing support. Once the team grows we will have the capacity to visit clients in their homes within a 30km radius of our office in Glenroy. ■

Reference

Fleming R, Forbes I, Bennett K (2003) *Adapting the ward for people with dementia*. Sydney: NSW Ministry of Health.

For further information contact Daniel Calleja, Team Leader and Senior Occupational Therapist, Aged Specialist Services, at Merri Health, on 1300 637 744 or email Daniel.Calleja@merrihealth.org.au

Experiences of dementia: stories from those who care

A recent symposium in Sydney for family carers and friends of people living with dementia was an opportunity for participants to share their stories and ideas, and access support from each other. The stories also offer valuable insights for professional carers. **Katherine Guinane, Jane Mears** and **Gaynor Macdonald** report

Caring in the context of dementia is unlike any other experience. Carers can learn so much from those who have walked similar paths. In September 2018 a one-day symposium, *Experiences of dementia: stories from those who care,* brought together over 50 familial carers (family members and friends) to do just that. It was an event of the Dementia Reframed project, which we launched in 2016 to examine ways of looking at dementia beyond the medical understanding of cause and treatment. The symposium, at the University of Sydney, provided a unique opportunity to hear from those with first-hand experience of the day-to-day of 'living with dementia' as a carer – those who are the experts in what it means to care at home for someone with dementia.

Co-author Dr Gaynor Macdonald's husband Charlie Eldridge didn't let advanced Alzheimer's stop his enjoyment of family photos and the company of his granddaughter, Natalie Anderson, who has just begun her nursing training. **Photo: Gaynor Macdonald**

Stories and their value to carers

Stories are an important way for carers to access ideas and support. We put out a call for informal carers to 'tell their own story'. We asked people to focus on their personal experiences of caring at home rather than institutionally-based care, or work done with care organisations. We were delighted to have people with dementia share their strategies for remaining independent as well as being cared for. Some participants used PowerPoint or notes, others spoke more informally.

Stories are not like 'advice': as one listens, one can imagine, reflect, work out what is and is not like one's own experience. As one of the symposium participants said: *"I liked the idea that experiences are often more helpful than blanket advice"*. So when we listen to someone explaining how she helped her father come to terms with the fact that he couldn't drive anymore, it isn't exactly our situation but we recognise parallels, see things that might work, because we're about to confront a similar issue. So stories help us imagine our own possibilities. *"So much of what was talked about really resonated with me in relation to both my father's situation, as well as the stories of many families that I have worked with over the years."*

A universal concern expressed by those at the symposium was that skills and insights acquired by carers are overwhelmingly undervalued, particularly in an arena dominated by biomedical models and the expertise of professionals. The stories shared made clear that there is no 'one size fits all' but that sharing experiences does communicate a range of strategies as well as being emotionally supportive. *"I learned so much and was particularly interested in the different ways different people dealt with the issues as they arrived,"* explained one participant.

"It was a most enjoyable and stimulating day – the problems and issues are all similar and there is a common thread," said another. These threads included:

- the need to understand the importance of supporting familial carers
- ways to involve the wider community in support
- developing effective advocacy (both at the level of individual cases but also at the level of government planning)
- awareness of the importance of self-care and what this means in practice.

What really stood out were the amazing ways in which people had been able to turn around very burdensome, negative experiences with the support and insights of others. For some, this meant relationships with other carers, or engagement with carer networks; for others there had been transformative educational experiences – including two great stories about the positive impact of doing the courses offered through the Wicking Dementia Research and Education Centre (University of Tasmania).

The importance of 'home care' and support for carers

The stories were also ways to see what is needed to make our society one that really does care for its most vulnerable members. The carers told us that too little attention is given to people being cared for in the familiarity and safety of their own home, by people who know the person requiring care. They felt excluded and devalued. It is not hard to understand how a person may like the comfort of their own bed and bedding, as well as surroundings they are familiar with, particularly when they are experiencing the anxiety and uncertainty that dementia can bring.

New website, resources for carers

The *Experiences of Dementia* Symposium was an event of the Dementia Reframed project (see *AJDC*, Aug/Sept 2018, pp22-24, *Reframing dementia: the challenge to change*). The Project's revamped website (www.dementia-reframed.com.au) will be available soon.

This project has two foci: changing social attitudes to allay fears and ignorance about dementia; and providing resources for informal carers that are grounded in the experience of those who care. This is an initiative of carers, for carers.

We are committed to bringing the needs of dementia carers to the fore, providing ways to learn from each other, letting them know they are not alone, and pointing them to resources that are not always easy to find. With this in mind, participants to the symposium were asked to contribute their stories in written form. These will form the core of a publication for dementia carers (working title: *Stories from dementia carers: learning through sharing*).

They will also contribute to a new website for dementia carers, Dementia Carers Australia, which we will launch by mid-2019 (www.dementiacarers-aust.com.au). It will include insights from experienced carers, enriching stories, and links to useful resources and organisations.

We are planning another workshop for carers in late 2019/early 2020, titled *Dementia carers supporting each other: a knowledge and skills exchange*.

To join the Dementia Reframed project mailing list to receive future updates, email Gaynor Macdonald at gaynor.macdonald@sydney.edu.au.

Katherine Guinane, Jane Mears, Gaynor Macdonald

Similarly, it is more likely that familiar people will understand the personality and needs of the person for whom they are caring, the things and forms of care this person enjoys – like wanting their scrambled eggs soft – and even the types of things that annoy. Passing on such understandings to a professional carer can risk locking a person into an idea of them that doesn't adjust over time. Several presentations indicated that knowing a person in such a way as to develop a level of intuitive understanding lessens anxiety for both carers and those being cared for.

All the speakers were concerned about how little support there is for home carers – except providing professional carers if they are eligible. It was not uncommon for carers to be told, 'you've used up all our services'. There is little community and educational support for familial carers. Presenters spoke of the need for support from a wide range of people in the community if they are to effectively provide care: this is not something any single individual can provide.

Participants had lots of ideas to encourage better understanding of dementia across the community, including: children's books about people with dementia; involving schools in changing attitudes towards dementia; and dementia-friendly cafés where people can feel safe and understood. One participant spoke of what it had meant to her to receive support from a local surf life saving club.

Some carers had supportive workplaces that provided flexible hours, while others felt they needed to give up working, sometimes because of unsympathetic employers, or to move to a different area to gain access to services. But the benefits of carers being able to stay in their chosen field of work were also evident.

A wonderful treat on the day was the specially-created performance of *Don't knock your granny*, by the Older Women's Network (OWN). They had us laughing, crying and thinking hard – all at the same time!

Relationships and networking

These carer stories indicated that, in most cases, current systems (medical, government) failed them and were ill-equipped when it came to providing support on how to care. They talked of the stress and confusion of navigating a complex and incoherent 'system'. *"Even with my background I had such a hard time getting my father's needs recognised and was minimalised* [sic] *at every turn by health professionals."* Presenters remarked on the lack of collaboration between service providers, and too little attention given to involving family.

While some spoke of the helpfulness of professional workers, others spoke of feeling powerless in the face of what they were 'told to do' by experts. They spoke of how difficult it was to deal with 'professionals' whose (usually biomedical) understandings of illness often meant they were not insightful in communicating how to care for someone with dementia, or they made well-meaning but onerous suggestions. One participant commented, *"There are lots of ideas and activities 'out there' but what do we actually know about carers' perceptions of the practicalities and the payoff for what these involve?"*

The need for effective advocacy was a strong theme. Comments included: *"There is an ongoing need to be vocal in opposition to government policies which further disadvantage the vulnerable"* and *"There must be an equal focus/inclusion on home care compared to residential care"*.

Stories highlighted the critical importance of effective self-care. Perhaps the strongest theme to emerge was the need for effective ways to network – to share knowledge and gain support; for instance, more community-run workshops providing opportunities to learn from other carers. Carers need to be able to communicate the difficulties of caring and explore ways these might be overcome.

The act of sharing the stories was clearly a source of comfort and was inspirational – with lots of excellent, practical ideas for dealing with the emotional experiences of care. One

Co-author Katherine Guinane made this tree for the symposium and distributed paper leaves on which participants could write their ideas and comments. These were then added to the tree during the day

person described having felt “trapped in someone else’s disease”; others spoke of powerful feelings of guilt as they negotiated the tensions between their own needs and those for whom they cared. They shared feelings of isolation and loneliness as intimacy in a relationship changed. Learning that one was not alone, even if there were no easy answers, was a support in itself. Caring involved learning to “let go of what you thought life would be like”, to “roll with the punches”, and accepting there “is no right way”, one does what one can.

“*It was a very moving experience to listen to the stories of many other caring women and men … my own caring journey has changed my life in so many ways, so many stories resonated with my own and in particular the refusal to be defined or stigmatised by the unexpected changes*”. “*I cherished the insight [from another participant], ‘You don’t know how strong you are until strength is the only way forward’* ”.


■ From left: Katherine Guinane is a Research Assistant in the Department of Anthropology, University of Sydney; Dr Jane Mears is an Associate Professor in the School of Social Sciences and Psychology at Western Sydney University; Dr Gaynor Macdonald is a Senior Lecturer and Consultant Anthropologist in the Department of Anthropology, University of Sydney. To follow up on this article, contact Gaynor at gaynor.macdonald@sydney.edu.au

Many attendees said how moved they were by the stories, finding them emotive and informative: “*I found today an awesome experience – listening, hearing the voices of carers and those with experience of this challenging illness*.”

Conclusion

The voices heard during this symposium are important because the majority of people with dementia (70%) are living in their own homes in the community and rely on familial carers – family members, neighbours and friends (Alzheimer’s Australia 2013). Of the 1.2 million Australians involved in caring for people with dementia (Dementia Australia 2018), an estimated 500,000 are informal carers, including over 350,000 primary carers.

Most older Australians prefer to stay in their homes, in the communities where they have lived for decades (Department of Health 2017). That means we will be forced to rely on our family and friends to support us as we grow more dependent and vulnerable. Many are prepared to do so, but need to be recognised, supported and equipped to make this happen. ■

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Inroads into rural and remote area dementia training

Dementia Training Australia staff took to the road (and the sky) to discover the specific training needs and challenges facing health professionals working in some of Australia's most remote areas. **Liz Miles**, **Sandra Jeavons**, **Catherine Wyles** and **Elizabeth Beattie** report

Dementia Training Australia (DTA) staff recently drove some 7500km to conduct workshops in 34 towns in rural and remote areas of all states and territories as part of DTA's commitment to bridging the gap in dementia training between health professionals working in urban areas and their rural and remote counterparts.

The Rural and Remote Field Trip (RARFT) Project was developed as a way to engage with rural and remote health providers and workers involved in dementia care to determine and better understand their specific training needs. RARFT also provided a means to establish and grow relationships with key contacts in residential aged care, community care and hospitals in the areas visited. These project goals align with DTA's vision that all people with dementia, *regardless of service type and location*, receive high-quality, evidence-based care that supports and enhances their wellbeing.

Places visited

DTA staff from Queensland University of Technology (QUT), the University of Wollongong, La Trobe University and the University of Western Australia hubs embarked on 14 field trips between June and September 2018, reaching 480 people. Towns visited were selected on the basis of having a hospital and/or aged care service, other towns within a 200km radius to maximise potential reach, and degree of remoteness (see map p13).

DTA team members Terri Preece (Senior Environmental Design Consultant) (left) and Shiralee Birnbacher (State Training Coordinator for WA and SA), flying the DTA banner at Coonalpyn SA during the RARFT Project. Photos: DTA

Town workshops

The half-day workshops held in the 34 towns were designed as information exchange meetings. They included a two-hour dementia education session and a discussion of training needs. The range of topics covered in the training session included: what makes a building helpful to people with dementia and to the staff caring for them; a wellbeing approach to dementia; positive approaches to responsive behaviours; optimising antipsychotic medication use in dementia care; and younger onset dementia. The discussion of training needs was started by DTA staff explaining the services on offer and encouraging participants to describe their dementia education needs and how the DTA services might need to be modified to meet them.

It was clear to the DTA staff who conducted the workshops how appreciative the participants were that they had taken the trouble to visit their communities. Many workshop participants commented about the importance of seeing DTA staff face-to-face:

"It sends a message to us that DTA takes us, out here, seriously…"

"It makes a difference when you have people with a lot of knowledge come and sit around and talk things over, recommend ways of managing things… and also for us to tell you what we do and some of our issues… ."

People also mentioned how important it is to build these relationships – expressing the hope that, having visited once, DTA staff will continue to return:

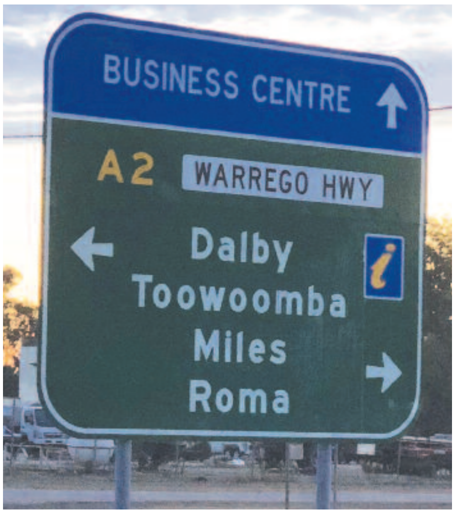
"It would be great if these things weren't one-off events but were regular and we knew that we'd be seeing the same people again, building on what we've done today… ."

DTA Training Consultant Dr Christine While was staggered by the 49 health professionals, care workers and service providers who attended, in their own time, a workshop she delivered in eastern Victoria. "Their commitment to delivering great dementia care was evident, as was the desire for more dementia education in their area," she said.

Participants commented on how important it is for DTA to understand what their work involves in rural and remote services. DTA Director Professor Elizabeth Beattie, who went to Darwin and Alice Springs with RARFT, said that participants described the pressing health issues they faced and the challenges of covering huge geographical areas, for example:

"There are so many other issues for people that they are more worried about out here […] dementia isn't a big priority, you know, because diabetes and kidney disease and substance abuse are right in front of us… So more training about dementia risk factors and also about knowing how to recognise when a person is having issues that might signal dementia would be really helpful".

One workshop attendee told of driving 10-12 hours, each way, to take a client home to country. He said that while he is prepared to travel vast distances because of the importance of the land for the wellbeing of his Indigenous clients, he would



The RARFT Project team covered 7500km visiting 34 towns in rural and remote areas of Australia


Towns visited by DTA during the Rural and Remote Field Trip, grouped by itinerary

NSW	QLD	SA	WA	VIC	NT	TAS
Griffith	Goondiwindi	Mount Gambier	Kalgoorlie	Mildura	Darwin	Launceston
Deniliquin	Charleville	Bordertown	Esperance	Swan Hill	Alice Springs	Burnie
Narrandera	Roma	Murray Bridge	Bunbury	Horsham		Devonport
Narrabri	Chinchilla	Port Lincoln	Margaret River	Leongatha		
Moree	Dalby	Whyalla	Albany	Bairnsdale		
		Port Pirie		Traralgon		
				Warragul		
				Ararat		

welcome dementia-specific training to enable him to provide better care and education for family carers.

Survey results

In addition to the discussions, surveys of attendees captured rural and remote area training needs, priorities and preferences, as well as current dementia training practices of participants.

How participants access training

The majority of respondents (83%) reported having adequate technological capacity, bandwidth and equipment for staff to access online training, however limitations identified included the lack of appropriate spaces for training and limited internet access. Comments about accessing online training included:

"Slow and unpredictable internet."

"Poor internet and expensive."

"Not all staff live in town and have access to good internet."

"Staff use their own devices to access training."

When asked to indicate which modes of training they preferred, 88.7% of participants selected face-to-face training, and 66.3%selected online learning. In reality, respondents described accessing training in a range of ways, the majority (72.7%) online (including, webinars and MOOCs), but also, for example, face-to-face (24%) and by external providers (conferences, seminars and workshops) (16.5%). The participants were concerned about the lack of training opportunities and described many obstacles to accessing training, eg the distance to travel for training and the time it takes, being able to release staff and find a replacement, the cost of the training and the payment of the staff for their time. Comments included:

"Need to travel long distances."

"Face-to-face usually includes travel but staff shortages limits time off."

"Travel approx. 2-5 hours."

"Difficult to release staff to travel."

There were also comments on the reluctance of some staff to attend training and the expectation that staff access training in their own time:

"Not all staff are willing to train in their own time – [they] often want to be paid for training time."

"Most staff [are] reluctant to attend training even when offered in-house, free and paid. The same staff attend and those that really need to attend don't."

Priority education topics

Education priority areas were examined by asking participants to rate a list of 30 dementia topic areas by perceived level of staff training need – high, medium or low priority. Based on the 218 responses, the following topics have the highest priority:

1. Behaviours and indicators of unmet needs (53%)
2. Pain (45%)
3. Person-centred care and other approaches (44%)
4. Expressions of anger or aggression (44%)
5. Creating opportunities for engaging in personally meaningful activity (43%)
6. Delirium (41%)
7. Knowing and responding to how the person communicates (40%)
8. Beliefs or attitudes toward dementia (39%)
9. Expressions of anxiety or worry (37%)
10. Hallucinations or delusions (37%).

Specific learner needs and diverse populations

Almost all respondents (99.6%) indicated that they had specific education needs related to at least one diverse population group in their area. This was most frequently Indigenous populations (36.8%), and Culturally and Linguistically Diverse (CALD) populations (33.7%) (see Table 1, p14).

Specific education needs identified in the 'Other' category related to a range of characteristics of clients, often compounded by issues of isolation. For instance, issues unique to farmers and people living on the land in rural/remote areas were raised. One person observed: *"Country people are independent and are reluctant to seek assistance until dementia is well advanced"*.

Single people/people living alone, financially disadvantaged/lower socioeconomic status, travellers/grey nomads and people with acquired brain injury were all identified as groups with specific needs that presented specialist training requirements for health professionals. Training in how to engage with the community, such as *"raising awareness amongst shopkeepers"* was also identified.

What else does DTA need to know?

In response to the question, "Is there anything else we need to know specific to your geographic location and size?", the diversity of the population was again raised. Groups specified were Indigenous and farming communities, an ageing population and multicultural communities.

Respondents talked about the large geographical areas that they had to cover. Some who worked in community-based care used the term ‘spread-out’ to refer to the health service (*“a large area with a spread-out health service”*) and to the location of clients. With spread-out health services it was observed that there are limited professionals available for advice and visits. Another commented that they *“Cover half of NT remote communities – some with phone access, some not”*.

Challenges accessing training because of the distance to travel were exacerbated by insufficient staff numbers and, in some cases, size of facilities or capacity of providers to provide cover:

“Low staff numbers – rostering needs to allow staff to attend.”

“Stand-alone community organisation – limited funds.”

AJDC and the Journal Club

As part of the RARFT project, DTA also contacted 172 of the most remote services in Australia, identified from Department of Health records, and provided them with a complimentary 12-month subscription to the *Australian Journal of Dementia Care*, along with a Journal Club Discussion Guide. The guide was designed to encourage team discussions about the needs of people with dementia and care practice, using ideas raised in key articles in each issue of the journal. DTA also invited these services to complete its training needs questionnaire on their special circumstances and needs.

Table 1: Training needs specific to diverse population groups (DTA RARFT Project Survey)

Population group	*%*
ATSI	36.8
CALD	33.7
Veterans	29.1
Younger onset	28.8
LGBTI	13.7
Homeless	11.2
Other	7.7

Learnings and outcomes

The RARFT project brought DTA closer to rural and remote audiences, raising awareness of DTA as an organisation and promoting DTA’s dementia-specific services. As a result, a number of organisations are entering into DTA Tailored Training Packages (TTPs) and more DTA workshops are being scheduled in rural areas, including some already held in a number of the towns visited. DTA will continue to communicate with more than 600 rural and remote health professionals, care workers and service providers reached through the promotion of the trips and the connections made with those who attended the workshops.

For RARFT Project Manager, Sandra Jeavons, the opportunity to travel to rural and remote western Queensland and talk to health professionals in their environment provided many insights. “Getting out there and hearing the stories about how they provide care for people with dementia and the barriers they face each day has been invaluable.” What DTA learnt through the three months on the road will inform future strategies and has already made some inroads into bridging the rural-metropolitan gap in dementia education. ■

Acknowledgment

The RARFT project was a national DTA collaborative project led by the QUT team who would like to thank everyone involved in making the project a success.

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See Research News p36 about a new study on support needs in rural dementia services.

A salutogenic retrofit

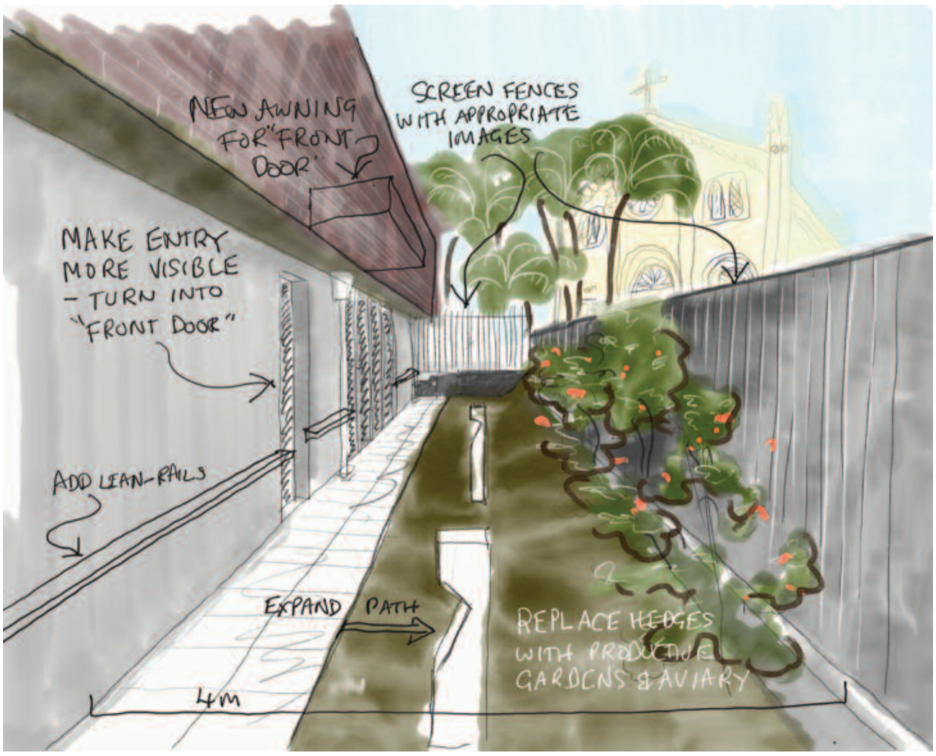
Architect **Jan Golembiewski** explains how to retrofit salutogenic values and vision to an existing unit for people with dementia. Salutogenics improves the lives and outlook for residents and makes staffing and visiting easier

The brief our architects' office received was written by people who knew dementia care well enough to distil everything into just a few words: "We want people [who don't have dementia] to visit the Memory Support Unit (MSU) (residence for dementia care) and think; 'Hey, when can I move in?'."

The problem was that the MSU had already been designed and built by others, and although it was still unoccupied, the management realised it had been built to a dated (staff-centred) model of care. The new unit was smart looking, designed to fill a site (less setbacks) in a busy urban area. The plan had a central courtyard, the MSU bedrooms were on the ground floor, on the outside of a spinal corridor, so the bedroom windows looked into the 4m deep setbacks, and beyond these, onto the surrounding streets. Shared spaces were on the inside of the spine, looking into the courtyard. One side of the building was a large dining hall and kitchen, and the opposite an entry foyer, which was out of bounds for residents, except when coming or going with staff or family.

As smart as the unit was, it could be far better – not only for residents, but also for staff. The nurses' station would become an unwanted focus for residents, a place for staff on duty to retreat to, and would also create an institutional feel. The dining room would set an undesirable tone with harsh lighting and shiny surfaces that absorb little ambient noise. The corridors and other spaces were all stylish, but identical, and therefore confusing for residents with dementia. The courtyard was also a problem. It was divided into three areas using sharp, palisade fences: one area for MSU residents, one for other residents and the last (for visitors) was out of bounds for residents, but had the only feature worth noting – a fountain that was clearly visible when entering the building through the foyer doors.

Beyond these concerns, the management had no idea what to do but suspected their insights were just a start, so they contacted Psychological Design and asked how the unit could be improved quickly and inexpensively. We are architects, but also world-leaders in understanding how people respond to architecture, drawing on non-architectural knowledge of neuroscience and psychology.



This drawing shows recommended solutions to improve the unit's walking path, including screening the fences and replacing hedges with a garden and aviary. Image: Psychological Design

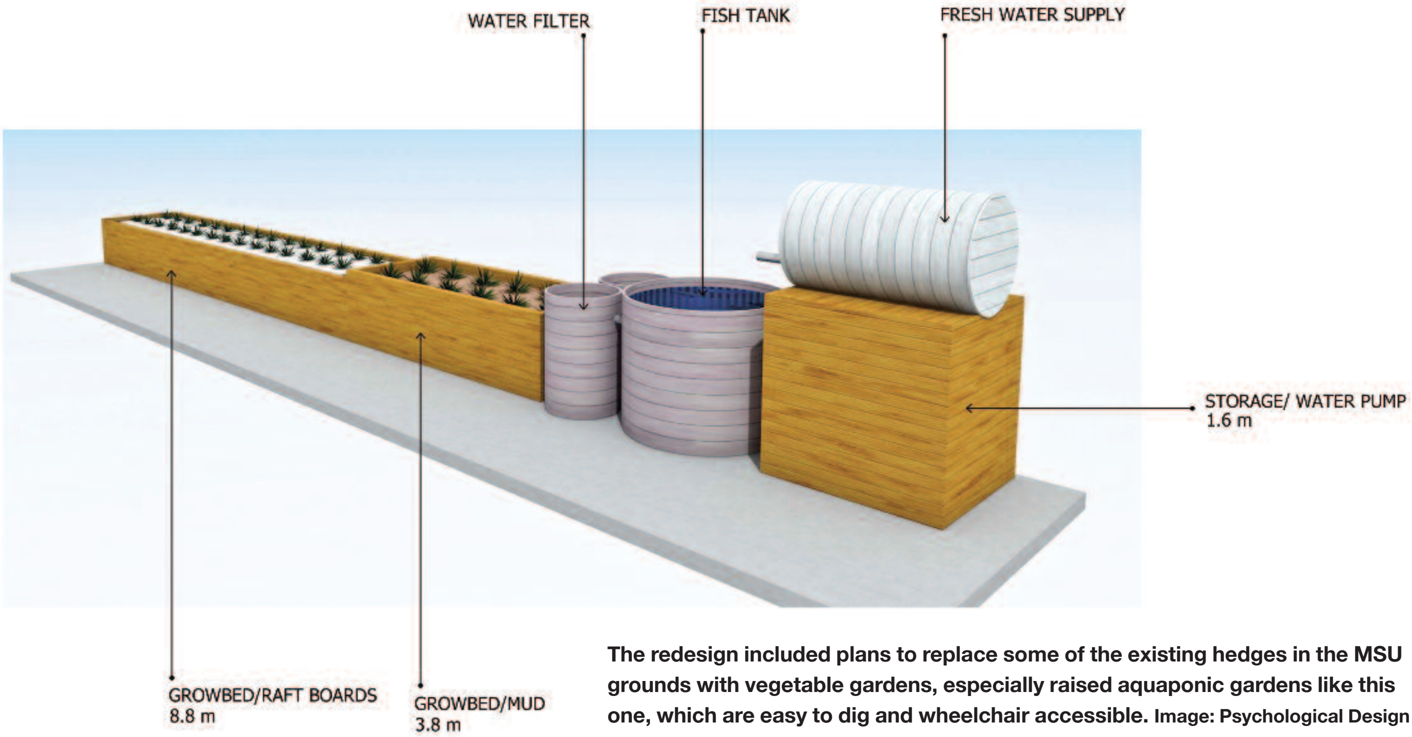
Using a salutogenic design model

When designing for dementia there are four primary objectives:

- To make clients happier.
- To assist in the treatment, management and recovery from illness, pain, breakages and symptoms (such as loss of appetite, sleeplessness, wandering*, anger, confusion and anxiety*).
- To improve clients' interactions (in regard to client/client interactions, client/staff interactions and client/visitor interactions).
- To promote and maintain functional and social independence.

To address these objectives, Psychological Design audited the environment using a range of lenses adapted from Zeisel (2000b), Zeisel (2000a), Zeisel *et al* (2003), Perkins (2013), Ulrich and Simons (1986) and Gawande (2014). We also used a salutogenic framework (Golembiewski 2009). Salutogenic design is a methodology that enables people to help themselves by addressing three engines that combine to provide "the confidence that, as in the past, things by and large, work out well" (Antonovsky 1987). The engines are manageability, comprehensibility (a capacity to understand and use one's circumstances) and meaningfulness.

But salutogenics isn't ideal for identifying specific stressors and deficits (Mittelmark & Bull 2013). Instead, salutogenics will point to and help find solutions to systemic issues like boredom and loneliness, both of which are caused by meaninglessness; frustration and



The redesign included plans to replace some of the existing hedges in the MSU grounds with vegetable gardens, especially raised aquaponic gardens like this one, which are easy to dig and wheelchair accessible. Image: Psychological Design

anger, which are products of poor comprehensibility; or bad hygiene and diet which are typical outcomes of inability to manage. The other models mentioned above are more specific, and helped us to identify specific problems that would otherwise remain latent.

Once problems and opportunities had been identified, we addressed them using a salutogenic method, as described in a previous issue of the *Australian Journal of Dementia Care* (Golembiewski 2017). By promoting manageability, comprehensibility and meaningfulness, designers and carers make it easier for ageing residents to manage their lives themselves, to understand and negotiate the circumstances they find themselves in (comprehensibility) and to rediscover and nurture meaningful lives (meaningfulness).

Salutogenic renovation

The idea of a salutogenic renovation is to make changes to improve meaningfulness, comprehensibility and finally manageability, in that order. Once a care home serves these needs, one can rest assured that it is doing all that is currently possible to make the lives and circumstances as good as they can be for residents, and that these changes will improve behaviours also, thereby making the unit more harmonious and improving the lives of staff and others. But how do we do this using architecture? It's difficult enough to design to help people with simple self-sufficiency (manageability), much less comprehensibility. How can architecture stretch to address psychological abstractions to foster meaningfulness? And how can salutogenesis be retrofitted?

Perhaps the most important key to enable the physical architecture to translate into bespoke psychological outcomes involves dispelling the myth that most behaviour is premeditated and rational (Bargh *et al* 2001). The environment affects behaviour, thoughts and emotions directly: there is no time for conscious cognition before reactions commence. In dementia, and a number of other mental disabilities, it isn't the impulse to act which is lacking, but the ability to reject the impulse, thereby giving rise to disinhibited behaviours, thoughts and emotions (Lhermitte *et al* 1986). Put simply, people *act* on opportunities to act – and it is the ability to *react* that is hampered by dementia. A seat triggers the impulse to sit, as insults trigger anger, but it is a far more complex cognitive process that suppresses impulses.

Action opportunities are called 'affordances' (Gibson 1979). If designers learn to predict them, they have a direct handle on the brain and behaviour. Salutogenics is an exceptional language for this purpose, because it exerts a constant, passive and positive inhibitory influence.

The audit

Over several visits, Psychological Design identified many things within the MSU that could be improved – some critical, others less so. We recommended they be actioned according to best value for cost. (This article doesn't list all the options because many are prosaic and uninteresting.)

The first step of the proposal was to identify overt stressors which may resonate with a sense of meaninglessness, and therefore sap meaning from life. We also identified details that were confusing, thereby eroding the salutogenic sense of comprehensibility. Other features we challenged would make normal activity difficult, compromising simple self-sufficiency. Golembiewski (2012a, 2012b) describes how these and other poor design choices cause symptoms, trigger undesirable behaviours and confuse vulnerable people.

Overt stressors

One of the obvious problems we identified is ubiquitous in aged care facilities: the new MSU was designed with outward-looking views. Ulrich (1979) discovered that views of 'nature' encouraged healing and improved recovery rates for a range of illnesses, and similar studies have replicated this discovery many times. But these studies never considered views onto attractions that are unavailable, such as landscapes and streetscapes that are out of bounds. As this MSU celebrated its views onto interesting and activated streets, we knew that the views would become problematic rather than beneficial. The main exit was also plainly visible from the central courtyard, but the path to reach all these enticing public places was beyond high, sharpened steel fences and locked glass doors – as if residents were prisoners. To use analogy, the brand-new MSU was effectively bringing children into a toy store with no possibility to buy a gift.

Similarly, the unit was designed with four fake bus stops around the periphery, looking out onto the surrounding streets through more unpassable barriers. The bus stop concept, whilst dated, has a good pedigree. Bus stops give the sitting and waiting behaviours* (which people with dementia tend to develop) a context, so bus stops are known to be useful for keeping residents self-contained. But imagine the frustration residents feel if ever a real bus passes? Waiting behind bars when this happens is an absurdist torture. The walking paths had the same problem. Contemporary dementia care units provide closed walking circuits. In this case, the circuit surrounded the building. But the path looked out onto interesting streets through prison-like bars. Residents would see buildings, transport and civic attractions. It's easy to predict them grabbing the bars and yelling out to passers-by: "Help me. They're holding me in prison!"

Proposed solutions

As the MSU was already built, these overt problems required sophisticated design solutions to mitigate. Short of knocking down the building (or surrounding ones), we recommended screening the fences and planting fast-growing vines. The screens would assist meaningfulness by preventing the opposite – meaninglessness. Scented flowers could assist with manageability, as the fragrance may counter negative olfactory delusions (ideas about being smelly).

We designed the screens with distinct colours and themes for each face to assist with orientation. These matched interior redecorations, so that way-finding could become more intuitive and easier. The most important of these contextualised the tall and attractive buildings that couldn't be hidden even with screens. But screening the streets is only a partial solution. Without the affordance of the street, the walking circuit and bus stops would become dangerously meaningless and wouldn't serve comprehensibility. Therefore, the screens needed to be offset with enriched spaces to turn attention inward – into the 4m-deep setback strips – before they could be used as a walking trail.

The proposed enrichment involves many features including giving greater emphasis to entry doors to aid comprehensibility. These currently are camouflaged and are virtually invisible, even to young, sighted visitors. We proposed fitting handrails to the building's exterior to improve manageability and prevent falls. To keep people's interests within the setbacks, we proposed that generic hedges be replaced with scented plants for the potential psychological benefits mentioned earlier. We went further by suggesting that some hedges be replaced with vegetable gardens, especially raised aquaponic gardens which are easy to dig, produce a lot, and are wheelchair accessible (Baldwin 2012). Most importantly, vegetable gardens mean that residents can give fresh produce to visitors, so that they feel that they are still contributing meaningfully to the community (Golembiewski 2017).

The addition of a sauna (with showers) was proposed as an alternative to residents' showering in their own bathrooms. **Image: Psychological Design**

Along the walking trail, construction codes meant we had to maintain compulsory (but locked) emergency exits (to the streets). These were a real problem because it's bad enough having a fence between a resident and the street, but locked doors are worse still. These needed to be disguised as weatherboard sheds. On one side, the sheds have purpose, such as real tools or a real chicken coop, and on the other an obscured emergency exit.

Chickens and other animals make wonderful affordances and are known to lift the moods of residents and reverse entrenched behaviours (Gawande 2014). As such, in addition to the exit-hiding coops, our redesign included wild bird-feeders and cages for song birds in both the courtyard and periphery walk. This involves a 10m-long walk-through aviary, to be filled with colourful canaries. Chase Memorial Nursing Home in New York famously (and very successfully) defied the codes to install 100 birds, two dogs and four cats in its aged care facility. One caged budgie went into each resident's room and the dogs and cats were let to roam free – wherever you go, there is the chatter of birds and the flutter of wings. This became a world-famous precedent, as it increased visitor numbers hugely (thereby doubly assisting with meaningfulness). We also suggested a couple of well-trained Labrador dogs to live outside, along with doves.

Laundry

At the last point of the walking trail, outside the residents' laundry, we recommended installing waste-height clothes-lines and comfortable seating to make these spaces more communal and manageable. In a MSU, a laundry not only assists with self-manageability, but also improves community interaction.

The central courtyard

As mentioned earlier, the courtyard was divided into three parts in order to separate the users of the unit. The management readily agreed to our recommendation to remove all the courtyard fencing. Other recommended changes for this area included the addition of a pizza oven outside a new residents' kitchen, a children's play area, and a scale-model town for children to play in and residents to reminisce about. We recommended the other side of the courtyard be set up as a market, with canvas marquees and a knick-knack shop, and a coffee shop and a deli to create delicious smells to stimulate appetites and mask any unpleasant odours. At first it was proposed that the courtyard would be for the MSU residents only. However, once these other changes were detailed, it was agreed that the courtyard should be opened to all residents and guests to become the most appealing part of the unit, and really live up to the promise of our brief – that other residents and visitors should be encouraged to visit and enjoy the MSU so they could fantasise about ending up there themselves!

Dining room

The MSU dining room was built as a large and institutional space with harsh lighting and reverberant acoustics. Elderly people often lose their appetites and need encouragement to eat, and while an environment like this is considered 'normal' in aged care, it's designed so that staff can easily see the residents (who's eating, who needs assistance). The bright lights are installed to decrease the risk of falls – but from a psychological perspective the opposite is more likely. Bright 'short wavelength' light is useful during the day, but at night is likely to interrupt circadian rhythms (Figueiro *et al* 2014), and the institutional environment created by such lighting is therefore likely to cause far more problems than it solves. Instead we redesigned a smaller space (thereby finding the room for a sauna and a massage room). We also proposed breaking up the dining room into booths and nooks, with some soft day-bed seating to absorb sound, and replacing the ceiling panels with sound-absorbing material. We proposed mood lighting on each table and fitting dimmers for the existing lights.

Nurses' station

We recommended removing the nurses' station altogether to make a residents' kitchen and home-like living space, complete with sofas, cooking facilities and homely lighting. We have previously (successfully) trialled having no nurses' stations at all by moving all clinical and administrative spaces out of the residential area and into a hidden administration zone. In this model, staff can sit at a table (perhaps with the residents) to write up their observations and notes (Smith *et al* 2015; Golembiewski 2014).

Not only is our proposed renovation salutogenic, but so too is the new model of care. Traditional models of care have residents visiting the clinic in a constant and efficient stream. Patient-centric models, such as the one we proposed, reverse this paradigm by having clinical staff visit the residents in their rooms for clinical procedures.

Inaccessible doors

Throughout the MSU there are locked doors – many of which are unnecessary. There are also service bays which we recommended be walled off. Any doors not for regular use by residents were to be camouflaged against the corridor walls – that is, virtually invisible with no noticeable frames, handles etc. Wherever possible these doors were to be papered over with wallpaper and hidden behind planters, following guidance tested by Zeisel *et al* (1994).

Ensuites

The audit noted that the ensuites are clinical and functional but not comfortable and homely. We decided that it would be too costly and disruptive to change them all, so the addition of a sauna (with showers) was proposed as an alternative to showering in residents' own spaces. We also recommended installing bidets in the ensuites. Bidets improve manageability for many aged-care residents because it makes cleaning up after incontinent mistakes easier. There are a range of bidet options available from stand-alone French bidets to devices that attach to the toilet seat, or separate water hoses. These are especially useful for Middle-Eastern and Asian cultures that sometimes have rules about washing rather than wiping.

The ensuites were originally built with mirrors. These needed to be covered with curtains because mirrors can frighten or distress people with dementia who may not recognise their reflection. Other mirrors in the unit needed removing or similar treatments.

Sauna and massage suite

Our proposed changes involved taking part of the dining hall and designing drainage modifications and a couple of water-tight rooms, one of which was to be fitted with a steam-maker and underfloor heating to make it into a wet-sauna. The other space would be a dry changing room and massage area / antechamber. These additions would greatly assist with meaningfulness, comprehensibility and manageability as they would encourage visitors, keep people clean, and be a good place to socialise, thereby promoting community and social networks. Massage would become an integral and useful part of the experience, as even short massages assist with agitation and other symptoms of dementia (Hicks-Moore & Robinson 2008).

Ceilings

Elderly people often spend long periods in bed. Sometimes they hardly get out – but it doesn't mean they're always asleep. We recommended that ceilings be regarded as important elevations – perhaps with illuminated pictures, TVs facing down or hanging mobiles (choices to be made by the families or residents themselves). If nothing else, lighting has to be sensitive, and there should be something to look at other than functional services. In this instance, we recommended warm-spectrum light fittings to improve sleep.

Conclusion

As well as being a useful guide for other facilities on retrofitting, the recommendations described in this article demonstrate the importance of getting the details right in the first place. However, we recognise that when this facility was being designed and built, the designers were working with good precedents, but it was almost a decade ago and current models of care were barely on the horizon, much less current ideas about salutogenics, person-centredness or neuro-design.

Also, there are few architects with the knowledge to understand the nuances of this specific typology of design and, right now there are no design courses available in any Australian university to address this problem. So even if the aged care industry is prepared to shift paradigms and to be fully resident-centred and world-leading, the supporting industries such as architectural and interior design still lag behind. So as you commission a new unit, take care and be prepared to leave some budget aside to update even brand new units before they open. ■

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* Editor's Note: The *Australian Journal of Dementia Care* (AJDC) acknowledges there is ongoing debate over the use of terms such as 'wandering' (along with others such as BPSD or 'behavioural and psychological symptoms of dementia', and 'managing behaviour') in relation to people living with dementia. The *AJDC*'s editorial policy is to use the term 'responsive behaviour/s' to underline the importance of seeing agitation, calling out, aggression,

wandering and disinhibition primarily as expressions of real needs, which require individual responses. However, we do publish articles that include these terms when it is clear they are used in the context of the research or practice being described and the author's intent is to promote person-centred care.

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Dementia-friendly Memory Lounge

People with dementia are invited to explore the Queensland State Archives (QSA) under the leadership of a trained staff member during sessions to be held throughout 2019 in the QSA's new Memory Lounge (pictured).

The Memory Lounge was launched in November 2018 and is designed to be a welcoming and accessible space within QSA's Reading Room for people with dementia to explore the QSA collection. Visitors will be accompanied by a trained staff member to explore archival photos from the records, and enjoy morning tea.

The design of the Memory Lounge was inspired by mid-century interiors, to invoke memories of times past. Decisions about the room's colourings, textures and custom-made furniture were based on Dementia Australia's dementia-friendly environment guidelines. There are blocks of pop colours, simple textures and strong, dark shades in primary colours. Distinct colours are used for differentiation, patterns are limited and reflective surfaces avoided. QSA was recognised as a dementia-friendly organisation in November 2018.

The 2019 sessions are open to people with dementia living in the community or in aged care facilities, and will take place on the last Tuesday of the month during April, May and June, and then on 6 August and 12 November at 10.30am, followed by morning tea. The Memory Lounge is at 435 Compton Road, Runcorn in Brisbane.

For more information, and for session bookings, contact Elysha.Rei@archives.qld.gov.au or 07 3037 6721.

QSA is also hoping to establish partnerships with care facilities interested in using the space for their own independent visits. Use the above contact details to find out more.

Being a disruptor in deme

Disruptors are innovators but not all innovators are disruptors. In what he describes as a relatively conservative care home sector, **David Sheard** argues that there is a need for more disruptive innovation because disruption is the 'new normal'

Dr David Sheard is the founder of Dementia Care Matters

If we are to better the future we must disturb the present.
Catherine Booth, co-founder, The Salvation Army

In the worlds of information technology, architecture, electric cars and space exploration the age of disruption arrived many years ago, but the relatively conservative care sector has a lot of disruptive catching up to do.

Disruptive individuals are usually the starting point. Steve Jobs, Mark Zuckerberg, Tracy Chou, Bill Gates, the late Zaha Hadid, and Elon Musk are recognised as disruptors in their fields. From these individuals and their game-changing concepts, large disruptive organisations grew.

Financial journalist Martin Vander Weyer says that, if we define a disruptor as an "entrepreneurial business that radically changes its own marketplace, numerous examples spring to mind, from the low-cost no frills airline to the flat pack home assembly bookcase" (Vander Weyer 2018).

We must never doubt the case for disruption in the care home sector and I can think of no better reason for it than the example of Inga Cherry, someone I know who sat for hours at the end of a long hallway in a locked dementia 'unit' crying out "I'm in a cage, I'm in a cage." (Welsh M 2018).

Dementia care disruptors

It can be difficult to name game-changing disruptors in the care home sector. Certainly, Professor Tom Kitwood was a disruptor with his seminal work on person-centred care and his groundbreaking book *Dementia Reconsidered*, but whether this radically changed the care home marketplace is a matter of debate. Dr Bill Thomas, founder of the Eden Alternative and the Green House Project, also immediately comes to the fore as a disruptor with his Age of Disruption Tour in 2016. In 'The Fix', a series on disrupting the care home sector published by the *Toronto Star* this year, Thomas writes in true disruptor fashion that the newspaper…

"…could do a story, a terrible, terrible heart-rending story about long term care 365 days a year. That's actually not the most dangerous story. What's most dangerous to the status quo is that it can be different. That there can be joy, that there can be dignity, love, and privacy. To the degree that the public sees and understands that then it undermines the entire 'poor me' argument of the industry that 'oh we are doing the best that we can and what can we expect'. They're not doing the best they can and we should expect better."

Is the care home sector ready for disruption, however, and what are the conditions for disruptive forces to thrive?

Fear of disruption

In the Melrose Film Productions training DVD *Days of change*, the statement is made that "the greatest paradox of our lives today is that the only constant is change and yet in the workplace it scares us witless".

There can be a problem with the term disruption if it is seen to imply disorder, turmoil, interruption and breaking apart, with the emphasis on the destructive.

The care home sector can justify its resistance to disruptive change by misjudging it as a negative thing. That is not what is meant by disruption. Disruption is listening to your intuition, not your ego or your mind. It is a process of disrupting yourself first so as not to play safe. Disruption is a force for good; being disruptive is not for its own sake but in order to make things better.

A disruptor is defined by the Cambridge Dictionary online as "a person or thing that prevents something, especially a system, process or event from continuing as usual or as expected". Katie McBeth (2017) describes a disruptor as someone "who transforms what the rest of the world accepts as normal and eschews the rules of your industry".

Harvard Business School professor and disruption guru Clayton Christensen says that "a disruption displaces an existing market, industry or technology and produces something new and more efficient and worthwhile. It is at once destructive and creative" (Christensen 1997). So the first condition for disruption in the care home sector is the desire for positive disruptive innovation.

Disruptive innovation

Is all positive innovation disruptive or not? Innovation and disruption have similarities but essential differences. Not all innovations are disruptive. An innovation can change a practice without affecting the core product or market. The care home sector is full of innovation layered on to models of care that remain undisrupted, which has been the biggest stumbling block to real implementation of person-centred care.

Rather than person-centred care as a disruptive force changing the whole care home market, it was turned instead into an innovation which has then struggled to change the market. Instead of person-centred care being a disruptor, it ended up as an innovation. As Whitney Johnson says: "Disruptor is a popular term these days to describe anyone appearing to offer innovation. But a real disruptor is more than an innovator, it's someone who is truly changing the landscape of the industries they are working in" (2015).

Just as an innovative product requires mass

ntia care

production to be a disruptive innovation, we are still waiting for the innovation of person-centred care to mass-produce a radically changed care home market. The second condition we need for the care home market to embrace disruption is for the larger care home organisations to realise that they need to plan now for tomorrow, they need to behave more like their disruptive smaller care home competitors of today.

Smaller disruptors

Smaller care home organisations can more easily have the abundance of raw nerve needed to be a disruptor. As Christensen notes about larger organisations, "the reason why it is so difficult for existing firms to capitalise on disruptive innovations is that their processes and their business model, that make them good at the existing business, actually make them bad at competing for the disruption" (Morris 2011).

Larger care home groups seem uncertain about or resistant to oncoming disruption for these very reasons, yet they need to realise how effective disruptive smaller organisations can be. The care sector should be mindful that a range of smaller organisations can be, as Johnson puts it, "foolishly and easily dismissed as a 'silly little thing', [but they] are gaining a foothold on the low rung of the market ladder that no larger competitor bothers to challenge – until it's too late" (2015).

Many smaller care home organisations are disruptors that are leading by being outstanding. Dementia Care Matters has 12 Butterfly Homes in smaller organisations rated as outstanding by the Care Quality Commission in the UK and we would suggest that they are templates for the disruptive care homes of the future. Their characteristics can be summarised as:

- love – returning a care home to Being Loving
- family – creating a sense of "We Are Family"
- feelings – really evidencing Feelings Matter Most
- spirituality – giving meaning to A Person's Core Spirit
- vulnerability – focusing training on Our Own Vulnerability
- attachment – supporting Past Attachment Matters
- living – coming Alive Again Inside
- inclusion – ensuring People's Mutual Regard
- households – feeling At Home Inside Ourselves.

This is disruption to the core business of larger care home organisations and our advice would be that they would benefit from taking heed of it.

As I state in a new film *We are family*, produced by Fire Films and launched at the UK Dementia Congress in November 2018, we are locked in a care sector which is largely driven by business and by models that have been taken from the healthcare system of hospitals and clinical efficiency, or by a vision of what four star hotel care looks like.

The characteristics of Butterfly Homes like Landermeads in Nottingham, in the UK – love, feelings-based care, vulnerability – "are templates for the disruptive care homes of the future".
Photographs of residents and staff by Emma Bailey

Yet we know in our own lives that the greatest thing in helping us survive and giving us a sense of wellbeing is being loved. I think that the idea of love as being the core of what transforms lives can come across as a huge threat to a detached professional sector and to some senior managers of the larger care home groups.

For larger care home organisations to grasp that such considerations are not "silly little things", they have as the third condition of successful disruptive innovation to commit to it at board level.

Disruptive organisations

Johnson describes seven key features of a disruptive organisation (2015):

- taking the right risks
- playing to distinctive strengths
- embracing constraints
- battling misguided entitlement
- stepping down, back or sideways to grow
- giving failure its due
- being driven by discovery.

In other words, for care homes to become disruptive organisations, it is about adopting a new care model, taking risks, and working on innovation. Constantly driving disruptive innovation as the organisation's core force is the way to meet regulations, while never over-promising on the potential results nor always expecting to succeed. Disruptive organisations realise that their current delivery of core business will not be the place to create their future; they understand that disruption takes longer to develop than sustaining the norm. They invest in disruption knowing "an innovation that creates a new market provides a different set of values which ultimately and unexpectedly overtakes an existing market" (Brands 2013).

Where are the disruptive care home organisations that have realised this and are investing in a disruptive future? Disruptive innovations tend to be created by certain people with naturally disruptive qualities about them, so the fourth condition in achieving disruptive innovation is that an organisation should find disruptive innovators and place them centre stage. It will require appointing more than one to create support and momentum, with the power and authority invested in them to change the organisation. ➤

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Disruptive innovators

Disruptive innovators are the explorers and dreamers in life. Constantly looking for a new way, they have vision, tenacity, and never deviate from their aspiration to change the world. They are who they are on the outside as well as the inside, they have a human transparency. In being real, authentic and a truth seeker they have a 'Marmite effect', but they don't care whether they are loved or loathed, they just keep on going, determined to stay in for the long haul, determined to win.

People like this are in short supply and not usually attracted to staid sectors unless the scope for disruption is exciting enough to entice them in. Disruptive innovators realise that the success of today will stifle the future, they expect that quality delivered now will be being copied by competitors and improved. They also know how to quit a successful market while they are ahead and invest in a new disruptive set of ideas and path for the future. They take a left turn while the rest of the sector is looking right.

The greatest companies are willing to disrupt themselves and this springs from "their unique capacity to dream, to imagine, to change, to create, to improve, to win, and ultimately in the business context to profit and make money" (Forbes 2013). Yet John Burton has noted that, in a care sector faced with deep systemic failures, dominated by the demands of regulation and inspection where it is bad care that makes the headlines, "for many managers work becomes merely a matter of obeying the rules and they spend more and more time in the office instead of where they are needed, ie with people living and working together. This is a universal problem and it can only be tackled by disrupting the system" (Burton 2015).

So, the fifth condition for disruptive innovation has to be freeing up the care home sector, not only to attract disruptive innovators but to prevent them from drowning in 'malignant' forms of care.

Residents and staff at Landermeads care home, and David Sheard (above right). Photographs by Emma Bailey

Innovation in care

In the past 20 years the story of dementia care has not just been one of malignant cultures of care remaining in place. Many disruptive ideas in person-centred care have led to significant innovations in dementia care homes with improvements in people's quality of life. Innovative ideas first seen as disruptive are now considered best practice, such as:

- emphasising the experience of living with dementia
- hearing people's voices and inclusive practice
- valuing and maintaining people's life history
- focusing on people's strengths and abilities
- seeing 'behaviour' as the expression of feelings
- showing people visual choices is the only way
- providing meaningful occupation as activity
- measuring people's wellbeing and ill being
- observing people's quality of interactions
- compensating in design for people's disability.

Yet many ideas in dementia care are still viewed by the sector as too disruptive, a step too far. Removing uniforms, turning hotels in care into real homes, developing staff teams to practise a family model, addressing the concept of emotional labour, and bringing the word 'love' back into care are all often seen as a disruptive threat.

The care sector embraces innovation that does not disrupt. It often reacts strongly and defensively to disruptive innovation. Like a manufacturer of petrol-driven cars, it refuses to believe that the day of the electric car will come. The sixth condition for disruptive innovation to thrive is for a sector to shed the past and be prepared to let go of a self-serving system designed for professionals who think they know best.

Disrupting matters

Dementia Care Matters' mission is to be an innovative disruptor of all care. For 23 years we have tried to adopt a model of disruption with varying degrees of success and challenge. If we were to identify eight of our key disrupting pieces of culture change work, they would be:

- Merevale House – a new disrupting model of care working with Anne Fretwell (Sheard 2017a)
- Feelings Matter Most – a series of resources shifting from task to emotional care
- Butterfly Homes – a challenge to the sterility of the hotel model of care homes (Sheard 2017b)
- *Can Gerry Robinson fix dementia care homes?* – a reality TV series to shake up the sector (Open University 2009)
- Emotional Intelligence Training – a learning initiative from doing to 'being' person-centred (Sheard 2008)
- *Dementiaville* – a TV series shown on Channel 4 in 2015, recreating people's past reality as a way to reconnect
- The Fix – the newspaper series in Canada disrupting complacency in long-term care
- All Care Matters – a transfer of the Butterfly model into a model of care for all (Sheard 2018).

What we have learnt from trying to be a disruptor is that you make friends and enemies, that the followers of disruption do so with a heartfelt passion while the resistors fight back hard. If you are a relatively small disruptor, there is danger your

disruption is turned into fringe innovation – you need to think bigger and eventually be bigger to affect a marketplace.

By practising what we preach we have recognised the need to harness larger disruptive forces behind our mission by becoming part of a worldwide organisation. What we have learnt is that the failures of disruption occur when the forces of resistance have no compelling requirement on them to change. Why would a care home organisation with good occupancy levels and positive regulatory ratings see the need to disrupt itself?

Of course, this flies in the face of all the evidence from other sectors that stood back in the belief that disruptive innovation would not impact on them but which then found that they were eventually overtaken by competitors they had not anticipated. Where now is Nokia, the original distributor of mobile phones, as Apple soars worldwide?

The seventh condition for disruptive innovation to break into a market is that those at government, commissioning and regulatory level who support innovation but don't drive disruption should have their processes disrupted too.

Nursing homes next?

Perhaps the greatest legacy from two decades of innovation in dementia care is its potential to disrupt the whole care sector. Are nursing homes in need of disruptive innovation? Some of them have much to learn from outstanding examples of dementia care about disruptive innovation that works. Now that dementia care has moved from being a Cinderella service to being its own specialism, it has the potential to disrupt the whole future of long-term care. As reported in The Fix series in the *Toronto Star:* "One nursing home took a gamble on fun, life and love. The most dangerous story we can tell is how simple it was to change."

Change is simple but hard in complex organisations which are afraid of disruption. The essence of an outstanding dementia care home ought now to be available to everyone living in a care home regardless of whether they have dementia or not. Great dementia care can be great care for everyone and yet traditional nursing homes are now lagging behind the innovative disruption which some outstanding dementia care homes have achieved.

As the managing director of both a dementia care home and a nursing home, Charlie Hoare acknowledges that "much of the stigma attached to nursing homes is fear of institutionalisation – a loss of independence and having decisions made for you". The disruptive innovation he implemented first in his dementia care home is now being transferred equally to the nursing home he manages (Hoare 2018).

We have decided that our next disruptive innovation is in launching All Care Matters – The Butterfly Model. It includes the lessons we have learnt from disrupting dementia care, which we believe provide the answer to the dilemmas, challenges and culture of long-term care. Our conviction is that if we get outstanding dementia care right, with adaptation to the model we can get all care right. The eighth and final condition for disruptive innovation to have impact is that "it takes a left turn by literally uprooting and changing how we think, behave, do business, learn and go about our day to day" work (Howard 2013).

Disruption is coming

Renowned investor Warren Buffet puts it well:

"*Should you find yourself in a chronically leaking boat, energy devoted to changing vessels is likely to be more productive than energy devoted to patching leaks.*" Or, as Dementia Care Matters' new CEO Peter Bewert notes, "*innovation and disruption go hand in hand. By disrupting our present day thinking we ensure our tomorrows are better*".

Which prompts the questions, who are the disruptors in the care sector, which are the disruptive care home organisations, and who will emerge as the next guru of disruptive innovation in care homes? Will the care sector keep relying on innovation that tinkers around its edges but never disrupts the core? If so, what will come along to truly disrupt the sector once and for all?

Eden Alternative and Green House Project Founder Dr Bill Thomas believes the answer to all these questions is on the horizon:

"I see the freight train coming, I see millions of people born after World War 2 who have very different attitudes to what they will accept. The demographic freight train is coming down the track and they are my allies. These are people who are going to demand something better. They're not going to accept a 19th century model of care in a 20th century building.

"We've seen across the history of the baby boomer generation they make change when they arrive on the scene and they're coming. So here I am standing on the track saying 'so you don't believe me? – just wait'. The power of that generation in terms of economics, culture, society and politics is tremendous. It's never yet been focused on long-term care but it will." ■

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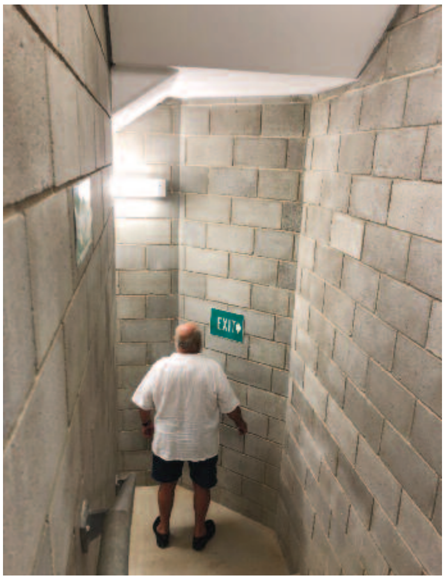
Towards autonomy and safety for people with dementia

Margaret MacAndrew, Elizabeth Beattie, Linda Schnitker, Deborah Brooks and **Nicole Shepherd** summarise their research on people with dementia getting lost and interventions to improve the safety of people with dementia while maintaining their autonomy and dignity. The research is a contribution to the ongoing debate about risk and freedom of movement for people with dementia as exemplified by the *AJDC* article 'Taking the risk: strategies to support getting out and about' (April/May 2017 issue) and the *AJDC* editorial 'Unlocking the barriers' by Professor Joseph Ibrahim (August/September 2018)

Our recent review of online news reports has revealed that between 2011 and 2015, 132 Australians with dementia were reported missing (MacAndrew, Schnitker, Shepherd, Beattie 2018). Ninety-two of these reports included details on outcomes related to those who became lost. Alarmingly, 20% of these people were found seriously injured and 20% were found dead. These unacceptable findings have prompted our research team to explore how to improve the safety of people with dementia while maintaining their autonomy and dignity.

Getting lost is defined as being "away from their expected location and unable to return independently, no matter how long or where they were lost" (Tsoi *et al* 2018 p3355). When dementia impacts the areas of the brain responsible for navigation – the hippocampus, the parietal cortex, and the anterior basal forebrain – there is a greater risk that the person with dementia will not be able to independently navigate to a desired destination.

Internationally it has been estimated that between 30% and 70% of people with dementia will experience at least one getting lost event during their disease trajectory (Pai & Lee 2016). While this risk increases as the disease progresses, people in the very early stages of dementia can experience navigation problems and subsequently are at risk to become lost. Recent evidence suggests that increasing difficulties building cognitive maps of new surroundings may be an early preclinical sign of Alzheimer's disease, with people at risk of, and becoming lost very early on (Allison *et al* 2016). The most reliable predictors that a person with dementia will experience a getting lost event are: 1) a previous getting lost event, and 2) failure to implement safety measures after the first getting lost event has occurred (Pai & Lee 2016).



Common features

Using the findings of the reported outcomes of getting lost events in Australia involving a person with dementia, common features of these events have been highlighted:

- The average age of the person was 75 years old.
- More men than women were reported missing. More women experienced serious injury, while more men were found dead.
- For most, the last known location of the missing person was their home or residential aged care facility and most people left that location on foot.
- Most people were found just 1km from their last known location and those who were found deceased were frequently under thick vegetation.
- Missing for more than 6-12 hours increases the risk of finding the person dead (MacAndrew *et al* 2018).

Recommendations

These findings were almost identical to those from a comparable study conducted nearly 20 years ago in the US (Rowe & Bennett 2003). As a result of these and other international findings related to the characteristics of a getting lost event involving a person with dementia (Tsoi *et al* 2018) the following recommendations were made:

- Carers need a current photo of the person with dementia.
- Family, neighbours and the broader community should be aware of the risk.
- In the event that a person with dementia becomes lost, this should be reported immediately to the police.
- When police receive a missing person report involving a person with dementia a coordinated search protocol that includes an intense search of the immediate area where the person was last seen to a radius of 5km is initiated.
- The search includes looking under vegetation and inside outdoor structures (eg garden shed).
- The general public are informed and provided with identifying details and a photo so they can assist with the search effort (Tsoi *et al* 2018).

While in Australia the recommendations related to the police search protocol have been implemented by the Search and Rescue Unit throughout Australia, the similarity in findings 20 years later suggests that not all these recommendations have been adopted in the Australian context. In addition, Australian carers have reported that they

Getting home safely

Safely Home is a program available in NSW with a similar program, Safe Return, offered in South Australia and the Northern Territory. The programs are joint initiatives between Dementia Australia and the respective state police services and offer some peace of mind to anyone who cares for a person living with dementia.

A carer is able to confidentially register the person in their care with the programs. The person who is registered then wears a stainless steel bracelet that has an engraved personal identification number and toll free police phone number. If someone finds the person confused or seemingly lost they can call the phone number to initiate the safe return process with police. Police will access the program's database, accurately identify the person and support them safely back to their home.

Carers may also find the service useful if they need to report someone missing, as police will already have key information to be able to start their search.

Information about the programs can be found on the Dementia Australia website at www.dementia.org.au.

There are other options that may support a person living with dementia to maintain their independence. Dementia Australia's National Dementia Helpline staff can provide information about assistive technology programs and products for safe walking. Dementia Australia staff do not endorse any individual products or services, instead they aim to provide a broad picture of the options available so carers can explore what might work best for their situation. More information is also available at: https://www.dementia.org.au/files/resources/GPS-tracking-and-monitoring-devices.pdf.

Resources

Safer walking for people with dementia
Four-page help sheet with practical information from Dementia Australia on safer walking for people with dementia. Available at: https://bit.ly/2RNa0el

Alzheimer's Society's view on safer walking technology
This detailed position statement sets out the issues facing people with dementia and their supporters when it comes to considering GPS systems to support safe walking in the community. Available at: https://bit.ly/2RMARrH

Systematic literature review
Neubauer NA, Azad-Khaneghah P, Miguel-Cruz A, Liu L (2018) What do we know about strategies to manage dementia-related wandering? A scoping review. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*. Available at: http://bit.ly/2ENacrc

find balancing safety and autonomy for the person with dementia challenging and some reported using extreme measures, such as locking the person within their home or using chemical or physical restraint, to provide the level of security they perceived as necessary (Beattie & MacAndrew, in review).

Considering the known risk of becoming lost for people with dementia, we recommend three key approaches that aim to maintain safety while promoting autonomy and dignity: 1) Be aware of the risk and prepare for a getting lost event; 2) Implement evidence-based strategies to prevent a getting lost event; 3) Initiate a rapid response to a getting lost event.

Prevent a getting lost event

While the available evidence for interventions to prevent a person with dementia from leaving a safe environment is of low quality, some guidelines related to non-pharmacological interventions are available. A review of the literature related to interventions to support safer walking revealed two approaches: environmental modifications and Smart Home Technology (MacAndrew, Brooks & Beattie 2018).

Environmental modifications
Environmental modifications that were found to be effective in reducing the number of attempts to leave a safe environment included camouflaging the door using material of the same colour as the wall (Feliciano *et al* 2004), and discouraging entry through a door using a rubber mat (Moore 2014) or black stripes (Padilla *et al* 2013).

Smart Home Technology
Smart Home Technology, such as the use of motion detector alarm systems to alert carers that the person is out of bed or approaching the exit (Evans *et al* 2011; Orpwood *et al* 2008), were also found to be effective in reducing unsupervised exits and falls. However, this evidence needs to be taken with caution as the testing has relied mainly on single case studies. There is also strong evidence that alarm systems can be disarmed by the person being monitored and false alarms can result in carers becoming desensitised and therefore failing to respond (Aud 2004; Aud 2013). Consequently, preparing for the possibility that a person with dementia could become lost is important.

Prepare for a getting lost event

Maintaining autonomy and dignity are fundamental to achieving optimal quality of life for all humans. However, due to the potential for a person with dementia to become lost, putting mechanisms in place to help the person to navigate successfully, or to be found if they do not make their intended destination when expected, could reduce the risk while enabling the person to remain independent for as long as possible.

Strategies such as raising awareness in the broader community that the risk exists for an individual, carrying an ID card in the wallet or wearing an ID bracelet/necklace (Dementia Australia 2019) and using tracking technology (eg wearable GPS devices) can promote autonomy and safety when applied appropriately (White *et al* 2010).

However, tracking technology is only effective if used correctly, if it has adequate battery life and is continuously worn by the person with dementia (MacAndrew *et al* 2018). In addition, there is still conflicting opinion from people with dementia regarding the benefits of such devices versus the right to privacy as these devices identify where the person is at all times (MacAndrew *et al* 2018).

Rapid response to a getting lost event

As there is currently no fail-safe means to ensure that a person with dementia does not leave a safe environment alone and that they will return home safely, evidence from previous getting lost events involving a person with dementia can be used to develop strategies for reporting a missing person with dementia and directing the search that then follows.

In Australia there is currently no standardised approach to reporting a missing person with dementia. According to the Queensland Search and Rescue Unit, the coordinated search that is known

From left: Dr Margaret MacAndrew is Lecturer at the Queensland University of Technology (QUT) and Knowledge Translation Research Fellow at the Dementia Centre for Research Collaboration (DCRC); Professor Elizabeth Beattie is the Director of the Queensland hub of the DCRC; Dr Linda Schnitker is a Lecturer at QUT; Deborah Brooks is a PhD Candidate at QUT; and Nicole Shepherd is a Lecturer at the University of Queensland. To follow-up on this article contact Dr MacAndrew at margaret.macandrew@qut.edu.au.

to be effective is often delayed because the police call centre is not informed of the diagnosis of dementia or carers delay informing the police. Delaying the initiation of a coordinated search for the missing person with dementia reduces the likelihood of finding the person alive.

Internationally, programs have been implemented to address this issue and include the Silver Alert System in the US and two new systems in Scotland and Canada which use a phone app to disseminate vital information about the missing person to the general public. These systems also raise awareness of the potential risk of people with dementia getting lost.

Getting Home Safe Project

While it is not clear if systems such as these would be effective in Australia, we aim to explore this further through the Getting Home Safe Project. The Getting Home Safe Project aims to improve the safety of people with dementia through the development, trial and implementation of a national approach to rapidly reporting a missing person with dementia to police so that a search can begin, thus improving the likelihood of finding the person alive and well. Phase 1 of this project, which has received funding through the Dementia Australia Research Foundation, began in Brisbane in March 2019 and runs until March 2021.

In Phase 1 we will work with our Project Ambassador, John Quinn, and co-investigators Dubhglas Taylor and Senior Sergeant Jim Whitehead to identify national and international approaches to reporting a missing person with dementia. We will then consult with the experts (carers of people with dementia, people with dementia, emergency services and health professionals) to propose recommendations for a standardised approach to reporting in Australia.

With informed collaboration we can prevent injury and tragedy and help people with dementia to continue to enjoy their community.

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Personho

Over the last 20 years there has been a move towards a positive and person-centred approach to dementia care underpinned by the concept of personhood. This was defined by Tom Kitwood (1997) as "a standing or status that is bestowed upon one human being by others in the context of relationship and social being".

Before Kitwood wrote his trailblazing book, people with dementia had often been regarded as being consumed by their condition with their personality, roles and attitudes being eroded and lost (Ray 2016). But if such views are now considered misleading, what does it mean to maintain personhood in dementia?

As one possible answer to this question we present the case of Helen (not her real name), a doctor who developed early onset Alzheimer's disease, to examine how far identity and a personal narrative can be maintained in the face of dementia (see case study on pp28-29). Our commentary on the case study aims to cast light on how the relationship between Helen and her husband / caregiver helped her to maintain that identity.

Former French president François Mitterand said at the end of his life: "I am beginning to understand the pleasure that the old experience when they sit for hours on a bench in the shade of a plane tree, doing nothing, gazing into the distance, silent, motionless, their hands folded." This is a positive depiction of fulfilment in later life after previous roles and physical strength have been lost.

Achieving this state, however, requires a sense of personal continuity and intact psychological resources (de Hennezel 2011). In contrast, people with dementia experience a progressive diminution of psychological function and find themselves excluded from participation in mainstream social activities (Thomas & Milligan 2015). This exclusion may be unintentional and arise from the failure to communicate with people with dementia whose language skills are reduced, or failure to recognise and respond to non-verbal ways in which people with dementia communicate.

The 17th century philosopher John Locke argued that personal identity extends only so far back as one's consciousness and memories of one's own past. Holton (2016), however, disagrees by stressing the importance of social relations in maintaining the personal characteristics of the person

od in dementia: a case study

What is personhood and how can it be maintained in someone with dementia? Commenting on a case study of 'Helen', written by her husband and caregiver 'David' (pp28-29), **Ilina Singh** and **Philip Wilkinson** argue that supporting relationships is key, both for the person with dementia and, crucially, their caregiver

with dementia. Combining these two perspectives, it might be claimed that loss of self in people with dementia can arise both from the direct impact of disease and the behaviour of those regularly involved in their lives (Sabat & Harré 1992).

Holton also points out that the types of memory (semantic and procedural) that embody identity tend to be preserved in the earlier stages of dementia, even after impairment of episodic memory sets in. For this reason, Helen "…remembered odd episodes from her school days," as the case study tells us. Helen's caregiver David (not his real name) took many active steps to maintain her status and identity, making sense of the different feelings she exhibited including loss of enthusiasm, pleasure, anxiety, and frank fear.

Accepting and adapting

David helped others to know her and accepted the new relationships that her dementia brought. He helped to preserve her previous activities as far as possible while acknowledging her emerging preference for less complex and non-verbal activities. He also recognised that the decline she experienced was not linear: "There were flashes of the old Helen which came through".

Early in her dementia, Helen experienced persecutory thinking, then frank paranoid psychosis which had a greater negative impact than her early cognitive impairment. Not surprisingly, psychotic symptoms in dementia are known to be associated with increased caregiver burden (Tampi *et al* 2011) and reduced wellbeing (Lethin *et al* 2017). Helen was prescribed antipsychotic medication, which is known to carry medical risks in people with dementia (Corbett *et al* 2014).

In Helen's case, however, this treatment brought about relief of distress, both for herself and David as her caregiver, allowing her to return home from hospital, restoring positive relationships, and helping her to engage in activities that would become important to them both. The progression of dementia, particularly that of early onset such as Helen's, brings a loss of the skills and roles that have previously defined the person, and these losses have an increasing impact on caregivers.

Implications for practice

- A focus on personhood can help to prioritise participation in activities and bolster positive relationships for the person with dementia
- Appropriate use of psychotropic medication in dementia can help to sustain personhood
- In making the transition to becoming a caregiver, the partner of the person with dementia can also make positive changes in his activities and relationships
- In the later stages of dementia, however, the caregiver may experience loss of agency and self-esteem
- While personhood in people with dementia has been widely discussed in the literature, personhood in caregivers has been largely overlooked

Both Helen and David eventually had to give up their careers. Later, Helen's identity as a doctor was still apparent, however, in shaping the content of her delusions during her period of psychosis. Her participation in two clinical research studies, instigated by her caregiver, was congruent with her previous professional values and priorities.

Creative ways to communicate

Reciprocity in interactions with carers, family and others is important in maintaining wellbeing for all involved in the dementia journey (Ray 2016). As Helen's communication and practical skills declined, her paid carers and family members found creative ways to communicate with her, particularly through music therapy, which is said to access underexploited abilities by bypassing inhibitions and distractions.

Music therapy has also been observed to alleviate agitation, depression and anxiety (Guétin *et al* 2009, Raglio *et al* 2008) and to have specific effects on working and short-term memory (Särkämö *et al* 2013). Emotional reactions to music are preserved even in the later stages of dementia (Johnson *et al* 2011) and in Helen's case, despite her apparent loss of awareness, this provided some connection with other people and reassurance for her caregiver.

Helen's caregiver benefited from the support of the Young Dementia UK worker and care home staff in sharing responsibility for care and activities. They gave helpful feedback on the approaches he was taking. Caregivers find the need to provide positive interaction at all times to be burdensome but enabling them to recognise their own strengths and vulnerabilities can enhance their sense of agency and satisfaction (Chung *et al* 2017). Clinicians play an important role in supporting the caregiver in this way, as they do by fostering relationships in the dementia community.

Impact of loss over time

Perhaps the biggest impact over time is on a caregiver who has known the person before the onset of dementia and who accompanies them through the slowly progressive illness. Caregivers make the journey despite the fact that the person who is known and loved gradually recedes from them, becoming someone whose mind and sense of history share few common roots with the caregiver.

David was left to carry their memories which, 10 years after diagnosis, might also have been experienced as a burden, given the loss of their future together. As Helen reached the later stages of her dementia, her personal memories, connection with loved ones and previous activities were lost to her, but they remained alive for David. The gradual shift from the role of husband in a mutually loving relationship to caregiver for a person who viewed him as a stranger much of the time was profound, particularly given that his wife's understanding would not improve.

While there are recognised ethical and legal obligations on a lifelong partner or family member to provide care for a loved one during the dementia decline, little attention has been paid to the needs of the carer over the long course of dementia. Are there obligations to care for the carer beyond occasional respite care? If so, on whom are those obligations conferred? These questions will become all the more important in the light of medical efforts to slow the dementia decline. While this is likely to have important benefits for the healthcare system and for people with dementia, we need to recognise that it could inadvertently increase the burden of caregiving on family members and other carers.

Until there are biomedical advances in the prevention and treatment of dementia it will remain a progressive disorder with a considerable impact on people with dementia and those close to them. As stated by Holton (2016), "keeping a personality going in dementia, demanding as that is, is a job for us all". We argue that approaches arising from the concept of personhood have contributed much to the care of people with dementia and, as our case study demonstrates, they can at the same time help caregivers re-shape their skills, status and relationships.

Benefits for caregivers do not endure, however, once the dementia has reached its later stages and the paths of the person with dementia and the caregiver have diverged. Further understanding of how to foster a caregiver's sense of identity and self-esteem in these later stages of dementia is therefore required. ■

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This article and the case study below were first published in the UK *Journal of Dementia Care* 26(5) 30-33.

Early-onset Alzheimer's disease: David's story

An account by David, Helen's husband and caregiver*

At the age of 54, my wife Helen wasn't quite right – not as on the ball as others of her age. She seemed to be losing her characteristic enthusiasm and drive. She could not manipulate the spreadsheets she used to or complete her tax return, and she spent long hours playing solitaire on-screen, which now seemed to be the peak of her achievement even though previously she had enjoyed doing cryptic crosswords. She would buy dozens of garden plants in pots that lay outside unplanted, dying for lack of water.

Helen seemed very stressed at work – she was a doctor - and complained that her colleagues were ganging up on her. I got very angry with her sometimes because she seemed almost wilfully stupid. It was all out of character, so I began to wonder if it may be an illness. Surely it would be treatable? Helen herself felt something to be wrong; she knew she had good days and bad. Her GP and family thought it was stress-related and she was started on an antidepressant. But the bad days steadily increased.

Two years after her problems started, Helen became seriously lost on familiar roads and was driving erratically. One evening she left from work, about 30km away, but did not get home till three in the morning. I was frantic, but she could not explain where she had been and it did not seem to worry her. Nonetheless, she sought further help from her GP and was referred for neuropsychology tests.

In the tests, she could not draw a clock face, getting all the numbers bunched up in one place, and failed catastrophically on all the spatial skill tests – matching blocks, copying line drawings etc. This was our first formal and objective evidence that Helen was truly unwell and it was hard to take in. She was put on long-term sick leave with a provisional diagnosis of potentially treatable depressive pseudo-dementia and we hoped that a different antidepressant would work.

But it didn't, and Helen never returned to work. She was then referred to an old age psychiatrist who diagnosed early onset dementia of the Alzheimer's type. Her particular problem was not so much memory loss as loss of executive function – organising and managing tasks. Helen was upset by the diagnosis. I was still working full-time but Helen now stayed at home. She started to tell me things that I knew not to be true – that her business colleagues were having an affair and that her best friend had married our son. She drove to her previous workplace and told her colleagues that I had died.

By the age of 57, Helen's ideas were more and more far-fetched. She believed she had been appointed as chief executive of the organisation she had worked for, and she was convinced that I had AIDS and was trying to poison her. She was physically violent towards me and her delusions and hostility became so intense that she was admitted as a psychiatric inpatient for assessment under the Mental Health Act. She stayed in hospital for three months and, after treatment with an antipsychotic drug, she was discharged and seemed improved, although I took partial retirement to spend more time with her. She could not make her own lunch, so I left a sandwich on the days I went to work.

At this time, we had our first contact with the charity Young Dementia UK. Helen was assigned a support worker to take her out once a week. They found fun things to do, visiting gardens and museums, going for long walks and always ending up with tea. The support worker's visits, when I was at work, made a big difference to Helen. Gradually she was weaned off the antipsychotic and was able to make her own lunch again.

Things seemed to improve but, sadly, this was only temporary. Helen could not now do any gardening. She could not work out the dead-heading or the weeding, and if she dug a hole to plant something she filled it right up with soil again instead of the plant. One dark wet winter evening she went missing from home when I was at work. I called the police who mobilised a helicopter and found her a few hours later. She was 6km from home, believing she was to attend a wedding reception.

When she was 57, Helen stood for hours in the cold and the dark outside the house waiting for taxis she believed she had ordered. When they did not come, she tried to steal my car keys. I could not now go to work as it was unsafe to leave her on her own. I locked us in the house together, but she got physically violent when contradicted or restrained. The GP prescribed the antipsychotic again, but Helen refused to take it so she was again detained under the Mental Health Act in a psychiatry inpatient unit for her own safety. At this point I was relieved, but also realised that I had lost for good the old Helen – it was a tearful time for me.

Helen at first believed she was in the inpatient unit to monitor the performance of staff. Eventually, she accepted a long-acting antipsychotic injection and began to calm down. She took part in ward-based gardening and swimming activities and seemed to gain some understanding of her illness. She was prepared for discharge and I had her at home on occasional afternoons or took her out for longer and longer periods. After discharge, Helen was calm but unable to do anything she used to do, such as wash herself or go to the toilet unaided.

Helen now had places at two day centres, which enabled me to go to work just half a day a week and gave her the stimulation of mixing with other people. She started one-to-one music therapy, which seemed to tap into something she still enjoyed. She loved to sing along with familiar music, and we were able to go out to concerts as we had once done. She was quiet and had little conversation, although she understood that she could not do her past activities. But she had no insight into why.


Helen and David

When she was 59, Helen entered a year's drug trial of memantine, which had positive effects. I was sure she was not on the placebo! She became more alert, less stressed, smiled a lot more and was an easier, friendlier, person to have around. Just occasionally there were flashes of the old Helen which came through – she would laugh at some punning word play, for instance. She became more aware of her environment, noticing flowers, birds and sunsets.

At 61, Helen had her first week in residential respite care while I went away on my own. Later we had a week away visiting friends and relatives and she coped pretty well, but without any conversation or real connection to anyone. Over the next three years she needed gradually more help with eating; she walked more slowly and managed steps less easily.

Helen was recruited to a positron emission tomography (PET) study for detection of amyloid plaque in the brains of living subjects which meant a couple of long sessions at the hospital. She coped well and managed to lie still for the crucial 30 minutes while the scan was done. It was good that we could contribute by taking part in such things – as a doctor this is what Helen would have wanted.

By the time Helen reached 66, I had been caring for her for 10 years. She no longer engaged significantly with me, with friends or family, or with her home environment. She enjoyed music and her one-to-one music therapy sessions, but she no longer liked the crowded environment of concerts and I felt there was little more I could do for her. I felt worn out by being on duty 24 hours a day. It seemed to me that Helen would be as happy in a care home as she was with me, and we have a high-quality dementia home not far away.

The family encouraged me to take this route. Helen settled happily in the home, but even months later I was still finding it hard to come to terms with. The 'ambiguous loss' and the guilt at being inadequate remained with me – irrationally, I felt that if only I had worked harder as a carer, I could have made Helen better. I was pleased, therefore, that the care home offered me support and counselling.

I visited Helen frequently and helped her eat at mealtimes, which was maybe more for my benefit than hers, though she smiled and laughed occasionally, apparently at what I had to tell her. So maybe she took in more than I realise? I like to think Helen's quality of life was now better than it would have been just staying with me at home. There were kind people with her all the time and she definitely responded well to the care home staff.

For my part, I needed to re-invent myself in the outside world as a 'real person' with an identity of my own and no longer as simply 'Helen's carer'. Who indeed was I now? After 10 years, this would be a challenge.

Helen is now 68 years old and it is hard now to think of her psychotic days 10 years ago. In some way, she seems to have been through all that and come out the other side as a much more relaxed person. In that regard, she is more reminiscent of when I first knew her exactly 50 years ago, except that she has lost all her energy and enthusiasm and initiative, of course. I am sure the psychotic phase was in some way an interaction between that energy and enthusiasm and the dementia.

Two years after she moved to the home, I am gradually reaching an accommodation with my situation. In many ways these two years have been harder than the previous 10. Watching Helen decline is the saddest part. Our plans for what we might do in our later lives have not been realised – no holidays abroad together, few trips out, no big household projects engaged and completed.

There is an almost total loss of meaningful shared companionship and friendship. Helen could not help at all with house and garden projects which she once initiated and enjoyed. It is hard to stay enthusiastic about things when there is nobody else around to appreciate or share them. ■

** Names have been changed.*

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.

Communicating without speech

Adaptive Interaction (AI) is a non-verbal communication tool for people with dementia who can no longer speak. In this article, **Maggie Ellis** and **Arlene Astell** briefly describe the genesis of AI, its development over a number of years and how they see its future

Adaptive Interaction (AI) was born through synchronicity. A coffee-break conversation at a research meeting in 2002 between the Universities of St Andrews and Dundee planted the seeds that were to become AI.

Dr Suzanne Zeedyk (www.suzannezeedyk.com), a developmental psychologist from the University of Dundee, was drawing together researchers and practitioners from Scotland and Scandinavia to investigate using imitation as the basis for communication. This wide-ranging group worked with newborn infants, people with profound and multiple learning disabilities (PMLD), autism spectrum disorder (ASD), congenital deaf-blindness and severely neglected children.

Chatting in the coffee-break, Suzanne asked if imitation was used with people with dementia. At the time, we (Maggie and Arlene) were working on a project to support social interactions between people living with dementia and caregivers for which we were video-recording all interactions. Examining our recordings, we found examples of spontaneous imitation, for example harmonising movements when singing together, where people with dementia and caregivers 'connected'. Suzanne invited us to present these examples and our initial ideas about imitation in dementia at a small gathering entitled 'Promoting Social Interaction for Individuals with Profound Communication Needs', and to join the Scottish-Scandinavian Imitation Network (SSIN).

Dr Maggie Ellis initiating a connection with Vera during an Adaptive Interaction (AI) session. Photos: Brett Housego

Between 2004 and 2007 the SSIN explored the role of imitation as the basis for communication for individuals who do not have speech. We were aware that a similar technique known as 'mirroring' (in which communication attempts are reflected back to the initiator) had previously been used as a means of interacting/resolving conflict within this population (Feil 1993, Killick & Allan 2001, as cited in Henwood & Ellis 2015). However, this work lacks empirical evidence and differed from our approach in terms of theoretical origins. Our prior work was based on supporting conversation between people living with dementia and their caregivers and we were excited, but also apprehensive, about applying a non-verbal approach with individuals who had previously been able to speak. We have always been conscious that this was a major difference with the other populations in SSIN who have never learnt to speak. However, we also knew from our work in care homes that many people with dementia reach a point where they can no longer use speech, which makes it difficult for them to be involved in social activities. As such, we joined SSIN with an open mind and optimism that the work being carried out with these other populations without speech would lead us to a communication tool for people with dementia who can no longer speak.

Intensive Interaction (II)

SSIN was built on imitation and the principles of Intensive Interaction (II) (Hewitt 1996; Nind 1996), a technique developed in the 1980s to facilitate communication between people with PMLD and their caregivers. People with PMLD experience extreme communication difficulties, with many never developing speech. However, all humans have the desire and urge to communicate, and individuals with PMLD are no exception. From this premise II seeks to uncover each individual's personal repertoire of communicative actions which provide the means to connect and interact with others (Caldwell & Horwood 2007). This starts with imitation.

Maggie and Jim: behaviour matching in action

Close behaviour-matching and imitation of sounds between parent and baby is the key to the development of speech in infants (Meltzoff & Moore 1983). II uses these fundamental interactions as a basis for connection and, although the structure and contents of these exchanges are non-verbal, it is difficult to argue that they are without meaning or emotion (Papousek 1995). It is important to note that these basic non-verbal communicative skills such as facial expressions, eye gaze and movements, are not limited to infants or to people with learning disabilities. All humans, regardless of age or cognitive status, use this type of communication every day but once we have speech we are mostly unaware of it. As such, we are not equating people without speech with infants, nor suggesting that they should be regarded as such.

Getting started: adapting II to dementia

Intrigued by the possibilities of using the principles of II with individuals with dementia who can no longer speak, we embarked on the first of our studies. This involved working with Jessie, a lady with dementia who could still produce words but not connected speech, to examine the role of imitation in her communication (Astell & Ellis 2006). Jessie's urge to communicate and participate in social interactions through turn-taking, facial expressions and imitation was clear (Astell & Ellis 2006; Ellis 2009). She and her communication partner spontaneously imitated verbal and non-verbal behaviour to keep the interaction going over two sessions each lasting roughly 30 minutes.

Inspired by these initial findings, we were ready to take the next step of working with someone who no longer had any speech. Edie was an 80-year-old woman who had been resident in a care home for six years when we first met her. She was unable to walk or to take care of personal needs without assistance and to the untrained eye appeared to be completely non-communicative. However, observation over two days in her care environment revealed that Edie *did* make attempts to engage with others but that these were not recognised as such and so were largely ignored. For example, Edie made a very loud sound that most staff and residents found to be disturbing and as a consequence she was confined to her bedroom for most of the day.

Before commencing our work with Edie, we were extremely fortunate to spend two days with Phoebe Caldwell (www.phoebecaldwell.co.uk), another member of the SSIN, learning techniques for connecting with people who are non-verbal. Phoebe is a world-renowned expert in II and non-verbal communication with people with PMLD and ASD and she shared her philosophy and practical skills with us. Imitation in the form of matched responsiveness is central to Phoebe's work and is the basis for connecting with people who are non-verbal (Caldwell 2005). Phoebe taught us how to identify communicative actions and reflect them back to the individual to make a connection. We found that by reflecting instead of ignoring Edie's distinctive sound we afforded her the opportunity to engage with another person using elements of her *own* language (Ellis & Astell 2008). Over multiple sessions Edie engaged with Maggie as her communication partner demonstrating turn-taking, sounds, movements, facial expressions, touch and perhaps most surprisingly, smiling and laughter (Ellis & Astell 2008).

Adaptive Interaction is born

An important aspect of II is that once a connection is made between a non-verbal individual and an interaction partner, this is built on over time into a communication model for each individual (Caldwell 2008). This demonstrates learning and expansion of non-verbal techniques into each person's unique communication style. As a progressive neurological disorder characterised by longitudinal impairment in memory and other cognitive processes, dementia is distinct from other conditions where people never develop speech. If individuals with dementia reach the point of being non-verbal, they will have experienced pronounced changes in memory and other aspects of cognition. As such we could not presume that we could involve people with dementia who could no longer speak in learning activities to build up their communication skills. Rather, we decided to focus on connecting with the person, uncovering their individual communication repertoire and adapting our response to whatever they are doing at any given point. This approach requires the communication partner to meet the person where they are and to adapt their interaction accordingly. As such, we named this variant of II Adaptive Interaction (AI).

Building out from our initial success with Edie, we expanded AI through a small group study exploring the effectiveness of imitation in revealing individual communication repertoires (Ellis & Astell 2017). Working with this varied group of individuals confirmed the potential of AI for both connecting and communicating with people with dementia who can no longer use speech. Some of the group made no sounds at all but communicated through eye gaze, small movements and changes in their breathing (Ellis & Astell 2017). In all cases there was increased communication behaviour during AI sessions compared to usual (speech-

Maggie and Joan developing their connection during AI based) interactions. The Table (right) illustrates AI behaviour modalities and some of the communicative behaviours used by individuals in the group.

AI training

All of this work was conducted in care homes, where there was initial scepticism followed by shock and realisation as we demonstrated that individuals who had been written off as communicators were still eager to participate in the social world. Our next step was to develop training for care staff which we initially tested in one care home where we had more families than staff willing to participate (Astell & Ellis 2011). Faced with anxiety and low expectations from those around us, we set about equipping four staff with the skills to identify and reciprocate communicative behaviours of four residents they were partnered with. This four-session program saw a major shift in both interactions between staff and residents and in staff attitudes towards both AI and the residents. Staff were extremely proud of their achievements when the results were presented to the residents' families and they had overcome their initial reluctance and embarrassment at using non-verbal communication.

From these initial pieces we consolidated our training model and started to raise awareness of how AI can benefit people with dementia who can no longer speak and those who care for them. For example, a training program run in Brighton in the UK showed that training caregivers with the skills to both recognise and use communicative action in the individuals for whom they care:

- Increased positive communication behaviours in people with dementia when compared to those in the control group.
- Decreased the amount of communicative behaviours that hinder and express displeasure in interactions for residents in the intervention home, while they remained stable in the control group.
- Improved Quality of Life for residents cared for by staff who were given training, while it remained stable in the control group (Dampney-Jay 2015).

Examples of Adaptive Interaction

The following table lists the communication modalities and some of the communicative behaviours used by people with dementia during Adaptive Interaction sessions conducted by the authors (Ellis & Astell 2017).

Modality	**Communicative behaviour**
Eye gaze	Looking at the other person
	Eyes closed
	Eyes closed tight
Sound	Coughing
	Yawning
	Speech sounds
	Clearing throat
	Heavy breathing
	Laughing
	High-pitched sound
	Growling sound
	Clicking tongue
	Sighing
	Singing
	Tutting
Movement	Pointing
	Nodding
	Shaking head
	Finger in/on mouth
	Looks at/plays with hands
	Lifting head off bed
	Shrugging shoulders
	Wringing hands
	Licking lips
	Head side to side
	Touching the other person
	Poking out tongue
Facial expression	Eyebrows raise
	Smile
	Frown
	Surprise
	Blowing kiss
	Winking

Reference: Ellis M, Astell A (2017) Communicating with people living with dementia who are nonverbal: the creation of Adaptive Interaction. *PLOS ONE* 12(8): e0180395

We gave presentations at national and international conferences including in Germany, Norway, and the US and gradually received invitations to deliver training. To accommodate demand, we developed a one-day AI taster workshop to accompany our hands-on four-session training.

In addition to care homes, we have trained family caregivers and hospital nurses (Astell *et al* 2015) and in 2017 our book *Adaptive interaction and dementia: how to communicate without speech*, describing the principles and practice of AI, was published by Jessica Kingsley Publishers (see John Killick's review in Resources on p37). In 2017 we also established Astellis (www.astellis.co.uk) as an independent entity and have delivered our training programs in the UK, Bulgaria and Canada. We are able to deliver the training anywhere in the world, including Australia.

AI and person-centred care

The question we are most commonly asked is "isn't imitation infantilising?" This concern reflects the power and reach of Kitwood's tenets of person-centred care in which he defined 17 'personal detractors' or negative modes of behaviour towards an individual with dementia (Kitwood 1990). Personal detractors take away from the personhood of the individual with dementia and 'infantilisation', where a caregiver treats a person with dementia as if they were a very young child, is one of these negative behaviours. Over the many years we have worked in this field we have witnessed infantilisation, along with other personal detractors, primarily when a caregiver did not know how to interact with a person with dementia and wanted to distance themselves from their apparent incompetence. In contrast, imitation as taught in AI is a tool for connecting with an individual, attuning ourselves to their communicative behaviours and following their lead to build up a meaningful interaction. AI respects the personhood of the individual with dementia and reflects Kitwood's observation that: "In the course of dementia a person will try to use whatever resources he or she still has available. If some of the more sophisticated means of action have dwindled away, it may be necessary to fall back on ways that are more basic, and more deeply learned; some of these were learned in early childhood" (Kitwood 1997 p75).

What have we learnt along the way?

AI started out as a research topic and our findings include that the urge to communicate is retained even when speech has gone, that AI can uncover the communication repertoire of people who cannot speak, and that interactions based on AI increase indicators of wellbeing such as smiling and laughter. Additionally, over the years we have discovered a number of issues of relevance not just for AI but also for care of people with advanced dementia as a whole. Although AI is focused on creating connection above facilitating message-based communication, this aim does not necessarily preclude the exchange of more complex information. For example, an AI communication session may well illuminate the existence of pain or discomfort in a person with dementia. Such insight is likely to have implications for care provision.

First, when we train caregivers in AI, we initially ask them to engage with an individual with dementia as they 'normally' would. In this initial interaction, caregivers bring along a prop, typically food or drink. We realised quite quickly that this is because their normal interactions with non-verbal individuals take place during the course of routine care activities such as giving someone food or drink. They do not just have social interactions. Reassuringly, once caregivers have the opportunity to focus solely on communication and getting to know the individual, they find it increasingly easy to communicate with people with advanced dementia on their own terms.

Second, considering the questions about infantilisation, we initially wondered if discussion of the developmental underpinnings of AI might not sit well with our trainees. However, our research into this (article in preparation) has shown that it is most effective to face this theoretical point head on. Indeed, developmental theory is crucial for explaining AI and enabling caregivers to understand its basis.

Third, we have found that attitudes towards using the principles of II with people with dementia have changed markedly since we started our journey with AI. To begin with, care staff thought we were 'kidding ourselves', some family members thought it was 'pointless' and there was widespread scepticism. At the start of training, caregivers are extremely self-conscious about being observed interacting and applying non-verbal means. However, once they are equipped to take the first steps, their whole focus shifts to the interaction and learning the language of their partner with dementia.

We believe for the most part that *witnessing* the impact of AI on people with advanced dementia and their caregivers changes people's perspectives. It would appear that the notion of using AI is more challenging than actually watching or participating in it. This perhaps seems counterintuitive as one might expect discussion of the approach to be less controversial than seeing it in action. However, we have consistently found that people develop a deeper understanding of AI and the reasons why it is important when they witness or take part in it as opposed to hearing or reading about it. We maintain that this change of heart occurs largely in response to the affective nature of taking part in AI rather than just watching video footage of it in action. This emotional quality is far easier to feel than to explain; a point often echoed by trainees.

Challenges of implementing AI

Sadly, the challenges of implementing AI in everyday care are no different to any other person-centred intervention. Care facilities are short on time, money and often, knowledge of how to make life better for their staff and residents. In order to facilitate person-centredness in dementia care, we need to 'care' as much about people at the end of their lives as we do about those at the beginning. The blatant irony here is that AI is based on developmental psychology and our understanding of how infants learn to talk. As a society, we are extremely invested in how our infants develop and as such devote a significant amount of resources to facilitating this process. For under two-year-olds in nursery care, the recommended staff-infant ratio is one carer to three infants. There is no equivalent framework in place for dementia care facilities and as such this population typically receive care that is rushed, functional and perfunctory. We pay little heed to the psychosocial needs of people with dementia who can no longer speak. What's worse, we are often unaware that these individuals indeed *have* such requirements.

Going forward

We continue to research and advance knowledge about communication beyond speech. This includes looking for ways to enhance caregivers' abilities to recognise communicative behaviour in people with dementia who cannot speak as well as exploring the impact of AI through physiological measures including salivary cortisol and oxytocin (the so-called 'love' or 'cuddle' hormone). We supervise students and deliver presentations and remain engaged in the II and dementia care communities. Interest in our training is growing, although we recognise the financial climate in both health and social care is challenging and likely to remain so. However, we remain optimistic that the synchronous coffee-break discussion in 2002 will continue to benefit people living with dementia who cannot speak long into the 2020s and beyond. ■

Nancy and Maggie forming a deep connection during AI

Resources

For information on Adaptive Interaction communication and training, visit the authors' website at www.astellis.co.uk/.

Their book, *Adaptive Interaction and dementia: how to communicate without speech* (Jessica Kingsley Publishers) (see p37, this issue), includes free downloadable resources available at: http://bit.ly/jkp-AI

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Maggie and Vera laughing together during AI

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Research updates

Abnormal prescribing patterns

A new Australian study published this year in the *Journal of Pharmacy Practice and Research* has revealed that nursing home residents living with dementia are more likely to be prescribed medications for treatment of responsive behaviours, pain and urinary tract infections than those without dementia. The Flinders University study, working with the NHMRC Cognitive Decline Partnership Centre at the University of Sydney, investigated dispensing data from the individual pharmacy records of 541 residents at 17 Australian not-for-profit nursing homes; 348 (64.3%) had dementia and 193 did not have dementia. They found that a quarter of people with dementia living in nursing homes were prescribed the antipsychotic drug risperidone (suggesting this is likely to be overprescribed) while people with dementia were generally less likely to be given prescribed cardiovascular or respiratory treatments. Differences in over-prescription and under-prescription may reflect reduced awareness of, or ability to communicate, symptoms by those residents living with dementia, researchers at Flinders and Sydney University say. The paper, *Patterns of medication prescription by dementia diagnosis in Australian nursing home residents: a cross-sectional study*, is available at: https://onlinelibrary.wiley.com/doi/10.1002/jppr.1457

Drug trial discontinued

Pharmaceutical company Roche has discontinued early its phase III clinical trials of the potential Alzheimer's drug, crenezumab (referred to as CREAD 1 and CREAD 2), which was designed to treat people in the early stages of Alzheimer's disease. Sandra Horning, Roche's Chief Medical Officer and Head of Global Product Development, said that while the results were disappointing, they still contribute to an understanding of Alzheimer's disease. She said Roche remains committed to ongoing clinical studies in Alzheimer's disease, including phase III trials with gantenerumab, its phase II anti-tau trial (TAURIEL), and its Alzheimer's Prevention Initiative (API) study of crenezumab in familial Alzheimer's disease.

Cognitive reserve and dementia

A new study published in *Neurology* has concluded that education does not play a role in when dementia starts or how fast it progresses. Rush University Medical Centre in Chicago conducted the study which investigated the contribution of education to cognitive reserve by analysing information from two long-term studies involving 2899 participants. Commenting on the findings, lead study author Dr Robert Wilson said, "It's possible that the contribution of education to cognitive reserve depends on other factors, such as life experiences or biological factors, but these results did not show a relationship between a higher level of education and a slower rate of decline of thinking and memory skills or a later onset of the accelerated decline that happens as dementia starts." The researchers did identify an association between having a higher level of education and higher thinking and memory skills at the start of the study, decades after formal education had ended.

Alcohol and dementia risk

A systematic scoping review has attempted to clarify the conflicting evidence about the relationship between alcohol and dementia risk – and concluded that reducing heavy alcohol use may be an effective dementia prevention strategy. It also says future studies need to address the limitations of the research to date. The review, published in *Alzheimer's Research and Therapy*, identified 28 systematic reviews published between 2000 and 2017. Light to moderate alcohol use in middle to late adulthood was associated with a decreased risk of cognitive impairment and dementia (causality could not be established). Heavy alcohol use was associated with changes in brain structures, cognitive impairments and an increased risk of all types of dementia.

RESEARCH NEWS

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

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How can carers 'live well'?

Researchers from the UK explored the factors associated with living well among carers of people with mild-to-moderate dementia.

Data were analysed from 1283 carers of people with mild-to-moderate dementia living in the community. The researchers generated a 'living well' factor from measures of quality of life (assessed with the World Health Organisation (WHO) Quality of Life-BREF), satisfaction with life (assessed with the Satisfaction with Life Scale) and well-being (assessed with the WHO Five Well-Being Index).

The association between seven domains and living well were examined using structural equation modelling. These domains were:

- Social capitals, assets and resources (SCAR) – reflecting social resources, networks and participation in social activities.
- Social location – reflecting socioeconomic status and perceived social standing.
- Psychological characteristics and psychological health – reflecting personality characteristics, optimism, self-esteem and depression.
- Physical fitness and physical health – reflecting physical activity, lifestyle and health conditions.
- Managing everyday life with dementia – reflecting perceived severity of, and distress at, dementia symptoms.
- The relationship with the person with dementia – reflecting current and past relationship quality.
- Experiencing caregiving – reflecting both positive and challenging aspects such as competence, coping, stress and social restriction.

Psychological health was most strongly related to living well (2.53), followed by physical health (1.48) and experiencing caregiving (1.34). SCAR (0.68) and the relationship with the person with dementia (-0.22) had smaller associations with living well. Social location and managing dementia were not significantly associated with living well.

Limitations of this study include using self-reported, cross-sectional data and only including carers of people with mild-to-moderate dementia. These limitations mean that the causal relationship of the domains with living well cannot be determined and the associations are unknown for carers of people with advanced dementia.

Overall, the findings demonstrate the importance of supporting the psychological and physical health of carers of people living with mild-to-moderate dementia.

Clare L, Wu Y-T, Quinn C *et al* (2018) A comprehensive model of factors associated with capability to 'live well' for family caregivers of people living with mild-to-moderate dementia: findings from the IDEAL study. *Alzheimer Disease & Associated Disorders*. Published online 5 December doi: 10.1097/WAD.0000000000000285 (Epub ahead of print).

Effectiveness of DementiAbility methods

Researchers from Hong Kong examined the effectiveness of the DementiAbility Methods: The Montessori Way (DMMW) intervention on agitation in people with dementia living in long-term residential care.

A total of 46 people with dementia were randomly allocated to receive the DMMW (n=23) or structured social activities as the control condition (n=23). Each participant in the DMMW group received six intervention sessions of 45 minutes within a two- week period. Frequency and disruptiveness of agitation (assessed using the Chinese Cohen-Mansfield Agitation Inventory) was compared before and after the DMMW intervention.

Overall, the researchers found that in comparison to the control group, DMMW significantly reduced overall frequency and disruptiveness of agitation, including verbal aggression, physical non-aggression and physical aggression.

Yuen I, Kwok T (2019) Effectiveness of DementiAbility methods: the Montessori way on agitation in long term care home residents with dementia in Hong Kong. *International Journal of Geriatric Psychiatry.* Published online 29 January doi: 10.1002/gps.5063 (Epub ahead of print).

How often is dementia misclassified?

Researchers from the UK and US were interested in predicting misclassification of dementia by three common cognitive assessments: the Mini-Mental State Examination (MMSE), the Memory Impairment Screen (MIS) and the Animal Naming Screener (AN).

A total of 824 older adults with a dementia diagnosis based on two versions of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R and DSM-IV) were included in the study.

Predictors of false-negative (dementia positive), false-positive (dementia negative) and overall misclassification by the MMSE, MIS and AN were analysed separately in multivariate bootstrapped fractional polynomial regression models.

Misclassification by at least one assessment occurred in 36% of participants and 2% of participants were misclassified by all three assessments. The researchers found that increased years of education predicted higher false-negatives (odds ratio [OR] 1.23) and lower false-positives (OR 0.77) of dementia by the MMSE. Living in residential care predicted lower false-negatives (OR 0.15) and higher false-positives (OR 4.85) of dementia by the AN.

False-negatives were most consistently predicted by absence of carer-rated poor memory in the person with dementia. False-positives were most consistently predicted by age, residential care status and non-Caucasian ethnicity. The only consistent predictor of overall misclassification across all three assessments was absence of carer-rated poor memory in the person with dementia.

Overall, this study suggests that dementia is often misclassified when using brief cognitive assessments and this is largely due to test-specific biases.

Ranson JM, Kuzma E, Hamilton W, Muniz-Terrera G, Langa KM, Llewellyn DJ (2019) Predictors of dementia misclassification when using brief cognitive assessments. *Neurology: Clinical Practice* 9(1) 1-9.

Support needs in rural dementia services

Australian researchers aimed to identify and prioritise the needs of people with dementia and their carers living in rural Victorian communities.

Phase one involved focus groups in a rural region of Victoria with representatives from organisations that provide services for people with dementia, including the rural health service, local government and the local Alzheimer's Australia (now Dementia Australia) service (n=5), as well as with people living with dementia (n=3) and their carers (n=13). The second phase was conducted with the same participants and used a survey to prioritise the dementia service needs and gaps identified in phase one.

Respondents identified 12 service needs for people with dementia living in rural Victoria, with three a high priority. The first priority was improving early diagnosis of dementia so that appropriate services can be accessed. The second was providing more training to health professionals in rural areas to facilitate dissemination of current best practice. The third priority was to increase community awareness about dementia in order to reduce stigma for people living with dementia and their carers.

The researchers note that the identified service needs align with previous studies, however applicability of the identified priorities to other rural regions in Australia should be investigated in future research.

Bauer M, Fetherstonhaugh D *et al* (2019) Identifying support needs to improve rural dementia services for people with dementia and their carers: a consultation study in Victoria, Australia. *Australian Journal of Rural Health* 27(1) 22-27.

Challenges and solutions to medication management

Researchers from the UK conducted a systematic review to identify medication issues and coping strategies used to manage these issues by people with dementia and their carers.

Twenty-one studies in which people with dementia and/or a carer of a person with dementia were interviewed were included in the review. Only four studies interviewed both the person with dementia and their carer.

The researchers identified four domains that influence the use of medication:

- Cognitive impairment, typically related to memory.
- Medication issues relating to obtaining medicine, concerns about medication safety and the complexity of the medicine regimen.
- Social and cultural factors such as lacking appropriate support, poor carer availability and living alone.
- Knowledge and communication factors, such as gathering information from health care professionals and recognising adverse effects.

People with dementia reported challenges in all four domains, while family carers reported issues related to the medication and knowledge and communication domains.

People with dementia reported three practical solutions to these issues: accepting assistance in medicine management; using medicine aids (eg pill boxes); and using memory reminder strategies (eg taking medicine with breakfast).

Family carers used more coping strategies for medicine management. These strategies included memory reminders (eg diary or alarm), establishing a routine for buying and administering medicine, optimising medication types (eg liquids), simplifying the dose regimen, building a relationship with health care professionals, developing contingency plans and preparing for adverse situations.

Overall, the researchers found that the 'voices' of people with dementia were largely missing from the reviewed studies. Health practitioners and researchers should actively involve people with dementia in conversations about medication management to improve uptake of coping strategies.

Lim RH, Sharmeen T (2018) Medicines management issues in dementia and coping strategies used by people living with dementia and family carers: a systematic review. *International Journal of Geriatric Psychiatry* 33(12) 1562-1581.

Anxiety and risk of dementia

Australian and Spanish researchers conducted a meta-analysis of studies that investigated the association between anxiety and dementia.

Prospective cohort studies reporting relative risks (RRs) for the association between anxiety and dementia, adjusted at least for age, were considered eligible for the meta-analysis. A total of six cohorts, reporting on 10,394 participants from Europe, the US and Mexico were included.

Overall, anxiety was associated with a 29% higher risk of dementia (pooled RR 1.29).

This increased risk occurred regardless of the cohort's percentage of females, average age at baseline, duration of follow-up, study location, depression status or cardiovascular risk factors. The adjusted RR varied between 0.81 and 1.77, with three cohorts showing a significant association and three showing a non-significant association. One study was found to have a medium risk of bias, while all remaining studies indicated a low risk of bias.

Future research is needed to determine the underlying mechanisms by which anxiety may promote dementia and whether medication may affect the association.

Santabarbara J, Lipnicki DM, Villagrasa B, LoboE, Lopez-Anton R (2019) Anxiety and risk of dementia: systematic review and meta-analysis of prospective cohort studies. *Maturitas* 119 14-20.

Perspectives on advance care planning and end-of-life care

Researchers from Advance Care Planning Australia (ACPA) conducted a systematic review and thematic analysis to describe the perspectives of people with dementia and their carers on advance care planning and end-of-life care. Eighty-one articles involving 389 people with dementia and 1864 carers from various countries including Australia, the US and the UK were included in the review.

The researchers found that people with dementia and their carers had to confront emotionally difficult conversations and navigate existential tensions (eg accepting incapacity and death) during advance care planning. Many voiced a sense of distrust and a lack of confidence in the information and support available to them in healthcare settings.

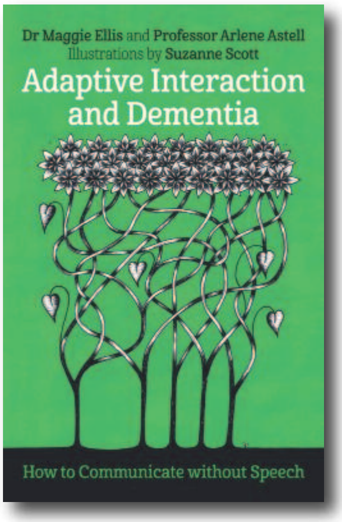
Barriers to discussing advance care planning and end-of-life care included general anxiety about death, reluctance to confront inevitable cognitive decline associated with dementia and fear of being locked into an inflexible pathway of care.

The researchers conclude that advance care planning strategies that attend to people's uncertainty in decision-making may help to empower people with dementia and their carers when planning end-of-life care.

Sellars M, Chung O, Nolte L, Tong A, Pond D, Fetherstonhaugh D, McInerney F, Sinclair C, Detering K M (2018) Perspective of people with dementia and carers on advance care planning and end-of-life care: a systematic review and thematic synthesis of qualitative studies. *Palliative Medicine* 33(3) 274-290.

Adaptive Interaction and Dementia: How to Communicate Without Speech

Dr Maggie Ellis and Professor Arlene Astell, Jessica Kingsley Publishers, ISBN 9781785921971, $37



This book confronts head-on what is undoubtedly the most profound challenge in communicating with people with dementia: that of effective interactions with those lacking verbal ability. Such individuals tend to be dismissed as non-communicators or as having 'gone away'. The co-authors reject these reactions and propose an alternative intensive approach.

Their method is called 'Adaptive Interaction' (AI) and the term indicates the two-way nature of what is envisaged, and the flexibility necessary for success. They disclaim any attempt to provide a 'how to' text, preferring to see the book as an introduction to the theory and research of AI. It is true that anyone wishing to practise the technique would need to supplement the volume with videos and a training course; these are available.

If you buy this book, how convinced are you likely to be of the effectiveness of this innovation? The answer in my case is 'wholly', but that may be partly based on my own experience of trying to confront the problems on my own without benefit of any underlying code of practice. But it is also partly based on the evidence of these pages.

It is not a long book – less than 200 pages – and the first 80 pages are a kind of laying of the groundwork for what is to follow. Some of this material is pretty basic, and I wasn't convinced of its necessity in a work which is proposing a ground-breaking approach. And some of it does not seem to me relevant, and in any case is easily obtainable elsewhere (the complete set of Kitwood's 'personal detractors' for example).

Where the authors present the case for AI they do so briefly and clearly. But it is the section of three case studies which is the clincher: they are the core of the book and occupy pages 101 to 169. They are detailed and thought-provoking. I defy anyone not to be moved by them. They should be essential reading for all care staff, managers and commissioners of services.

John Killick, writer and poet

This review first appeared in the UK *Journal of Dementia Care* 26(5) 37

Dementia activity Scarf-e

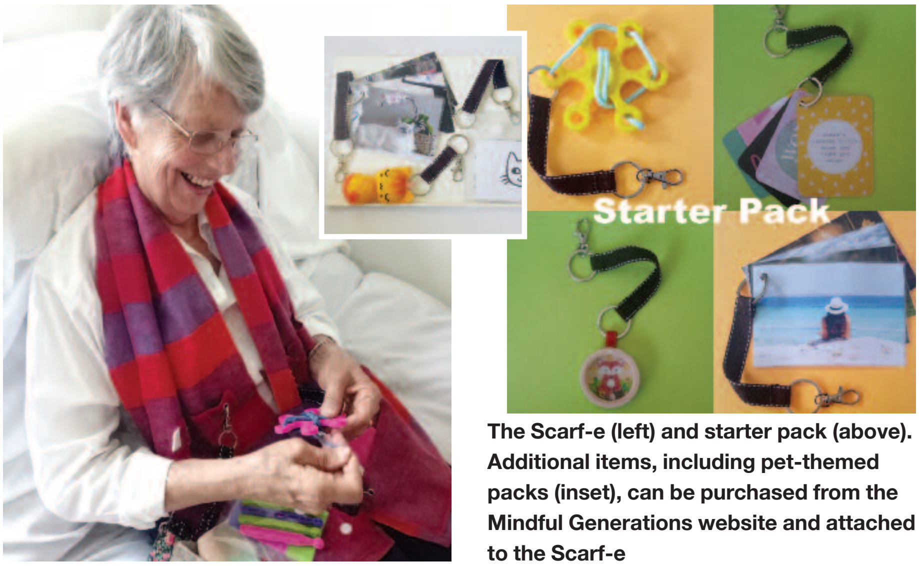
Aged care diversional therapists Marina De Freitas and Gayle Langston have used their experience working with aged care residents to create a 'self-supporting' activity scarf designed to give comfort, support, dignity and enjoyment to people living with dementia. The **Scarf-e** (pictured) is handmade in the Illawarra, NSW, and sold online through their newly-created company Mindful Generations.

The dementia activity Scarf-e comes with a starter pack of four clip-on activity items (tactile, cognitive, visual and reminiscence), plus six clasps/tethers which are attached to the Scarf-e to keep the activity items from dropping to the ground.

"Unlike other fiddle/activity resources that have permanent attachments, our activity Scarf-e allows all activities to be unclipped for easy washing and also for ease of changing activity attachments daily," Gayle said. "The activity Scarf-e also has pockets where glasses or other important items can be kept close by to help make life easier for people living with dementia.

"The activity Scarf-e can be worn around the neck or across the person's lap, whichever gives greater comfort, and enables the wearer to access and engage with the activities when they choose to, without having to wait or rely on someone to help, giving greater independence and empowerment," Gayle said.

Some of the Scarf-e activity items available include sensory bags, a peg board, art therapy, photos, objects to promote reminiscence, tactile fabric, cognitive puzzles, fiddle items, handmade felt and material-comfort animals/birds/fish. Personal interest activity packs, with themes including travel, pets, fishing, cooking and family, for example, and new activity packs are offered for sale each month on the website. Carers can also add personal items to the Scarf-e that they know are special to their loved ones.



The Scarf-e (left) and starter pack (above). Additional items, including pet-themed packs (inset), can be purchased from the Mindful Generations website and attached to the Scarf-e

The activity Scarf-e comes in a choice of four fabrics: recycled '70s blankets, cotton denim, Fair Trade yak wool or polyester/cotton. It costs $109 for the Scarf-e and four-activity starter pack, with a portion of each sale being donated to Dementia Australia for research and education.

An information sheet is provided with each activity Scarf-e. Marina and Gayle are also offering a free user workshop for aged care facilities or associations buying 10 or more dementia activity Scarf-es. For information and orders, visit www.mindfulgenerations.com.au or email Marina and Gayle on info@mindfulgenerations.com.au

Online

The Aged Care Quality and Safety Commission has launched a new **Self-Assessment Guidance Tool** to assist providers of Commonwealth funded aged care services to understand and self-assess their performance against the new Aged Care Quality Standards, which commence 1 July 2019. The self-assessment template and guidance was developed in consultation with stakeholders and has been tested with aged care service providers. The new Self-Assessment Guidance Tool will replace existing guidance on self-assessment once the new Standards come into effect. Providers are not required to submit self-assessment information against the new Aged Care Quality Standards before 1 July 2019, however the Commission is encouraging providers to use the new resource in preparation for the introduction of the new Standards, to identify and address areas for improvement. The tool is available to access via www.agedcarequality.gov.au

The Royal College of Psychiatrists in the UK has published consensus guidelines on **Driving with dementia or mild cognitive impairment** to offer guidance to clinicians who work in the assessment and management of people with cognitive impairment who drive. Although UK-specific, the resource provides a framework for thinking about the management of driving safety which is still relevant beyond the UK and includes links to useful resources from around the world on this topic also. The resource is available to download for free from the British Geriatrics Society website at www.bgs.org.uk

Dementia Training Australia (DTA) has launched a new tool to help residential aged care providers to monitor antipsychotic usage. The **Antipsychotic Tracking Tool** (APTT) can be used to generate regular audit reports and graphs and to determine the prevalence of use of antipsychotic medications. The tool allows staff to follow changes in the use of antipsychotic usage over time for all residents within an aged care setting (not necessarily only those living with dementia), and make comparisons with state-based benchmark percentages (that come from the RedUSe national study). The resource includes a comprehensive instruction manual, two Microsoft Excel files (the APTT itself and an antipsychotic medication list), and instruction videos to guide users in how to set up and use the APTT. The APTT can be used by any health professional with experience and familiarity with antipsychotic medications within a residential aged care setting, for example, a clinical nurse or pharmacist, as a quality improvement activity. The resource is available to access for free from the DTA website, at www.dta.com.au

The **International Dysphagia Diet Standardisation Initiative (IDDSI) Framework** is to be implemented in Australia from 1 May 2019 after agreement in 2016 from Speech Pathology Australia (SPA), the Institute for Hospitality in Healthcare and Dietitians Association of Australia. The IDDSI Framework is considered best practice for professionals and will support safety in the management of dysphagia. IDDSI introduces standard terminology to describe texture modification for food and drink, and has a continuum of eight levels covering both food and fluid textures and includes descriptors, testing methods and the evidence base for its recommendations. A suite of **five webinars** is now available to view on the website for the Institute for Hospitality in Healthcare (www.ihhc.org.au) that introduces IDDSI and explains the initiative. Further information about IDDSI is also available on the SPA website at www.speechpathologyaustralia.org.au

Armchair Gallery is the name of a new app aimed specifically at people with dementia, which is promoted with the tagline, 'We can't all get to the gallery…'. Instead, Armchair Gallery 'brings world-class art and culture to you'. The app features artworks and artefacts from major UK galleries and venues, including the Yorkshire Sculpture Park, Dulwich Picture Gallery, and Chatsworth House. It encourages active engagement with the artworks (by adjusting the digital images) and also gives instructions for a wide range of creative activities relating to the arts. The app is available to download from the App store or Google Play; find out more also at http://armchairgallery.co.uk/

Dementia Australia has published **Transport for NSW Older Persons - Transport and Mobility Plan 2018-2022: a response from Dementia Australia**. This state-specific submission is an important document given the sparsity of resources on dementia-friendly transport in Australia. Dementia Australia applauds the inclusion of people with dementia in the NSW draft transport plan, and notes that the NSW Government considers dementia a priority. The response from Dementia Australia presents 15 recommendations for how Transport for NSW can provide and/or support dementia-friendly transport initiatives and strengthen its support for people living with dementia, their families and carers. It is available on Dementia Australia's website (www.dementia.org.au). Go to 'About us', then 'Publications' then 'Government submissions'.

RemindMeCare has launched a new free app aimed at offering a central support hub for people with dementia and their wider circle of support. The **ReMe** app can be used in conjunction with Amazon Alexa, enabling people with dementia to interact with it verbally, and to respond to verbal prompts from Alexa. ReMe can be used to facilitate communication (with family and friends, and health and care networks), to capture and store a life story, for reminiscence, games and activities, music and entertainment, as well as help with day-to-day diary management and health monitoring and support (for example by prompting a person to take medication and drink water, or by linking with a GP surgery). RemindMeCare has associates working in Australia who can offer a webinar and other support to people living in Australia who would like to initiate a trial of the ReMe app. For more information, go to www.remindmecare.com

A chapter on 'Dementia and cognitive impairment: special considerations' features in a newly published second edition of **Pain in residential aged care facilities: management strategies**, from the Australian Pain Society. The book is aimed at helping the multidisciplinary residential aged care workforce, from personal care assistants, through to allied health professionals and pharmacists, to identify, assess and manage pain by addressing various pain management strategies. The book includes revised content and two new chapters (on 'Pain at the end of life' and Pain and nutrition'). The new edition (the first update since the 2005 original) is being prompted as user-friendly, with new supporting resources. The book costs $99 per copy (including P&P) and is available to purchase from the Australian Pain Society. Go to www.apsoc.org.au/publications

International Research Network on Dementia Prevention (IRNDP) has launched a new website (**coghealth.net.au**) to promote its work and events. IRNDP is a multinational network launched in 2017 which brings together researchers who are working to reduce the risk of dementia across the world. It is governed by a leadership committee and an independent advisory group, and is a project of the Dementia Centre for Research Collaboration. A two-page fact sheet on **Physical activity and brain health** is now available on the new website, and is available in multiple languages (English, Spanish, Italian, Chinese, Arabic and Greek). The fact sheet is aimed at older people and sets out the case for how much and what type of exercise might support brain health, explains how it does so, and gives tips for staying motivated. You can also use the website to access IRNDP's newsletter, find out about the work of different working groups within the IRNDP, and check upcoming events.

A new suite of resources on the topic of learning disabilities and dementia is available to download from the Pavilion Publishing website. The resources are linked with a training program on this topic, and while the substantial **Training Pack** does involve a cost, others are available for free, such as **Supporting people with learning disabilities and dementia: practice development guide** written by Karen Watchman, Heather Wilkinson and Philly Hare. The 36-page guide presents an accessible introduction to this topic, and covers a wide range of subject matter such as understanding behaviour, environments, pain, activities, communication, eating and drinking, night-time care and advanced dementia. A **Training pack resources** document includes helpful resources to use in training sessions, such as a quiz on Down's syndrome and one on dementia. There's also a link to the well-received **Supporting Derek** film, produced by Nine Lives Media in 2010 with the University of Edinburgh and Joseph Rowntree Foundation on this same topic, and now also available for free. To find out more, go to https://bit.ly/2DXho2p

Accessible Telecoms is a new nationwide disability telecommunications service that aims to provide free, independent, up-to-date information on mainstream and assistive telecommunication products that are suitable for people with disabilities, including people with a cognitive impairment. The service also provides referrals for training, set-up, ongoing support and equipment provision, and is available to anyone: people with disability, their family and carers, service providers and advocates. The Information on Disability Education and Awareness Service (IDEAS) organisation is delivering the information through its website and call centre. To find out more, go to www.ideas.org.au/telecom/category or phone 1800 029 904.

The **Moving Pictures** multimedia project – the joint work of the National Ageing Research Institute and Curtin University – has launched 15 short films, aimed at improving the understanding of dementia and access to care for people in Chinese, Indian and Arab communities in Australia. Three films (**Detection and Diagnosis**, **Navigating Care**, and the **Carer Journey**) have been made in five languages: Tamil, Hindi, Cantonese, Mandarin and Arabic. The films are based on interviews with carers in Perth (from the Chinese community), Melbourne (Indian) and Sydney (Arabic) and with service providers. Comic strips promoting dementia awareness in the five different languages are also available. To access the films, go to www.movingpictures.org.au

Events

- 2019 – national
  Preparing For The New Standards
  The Aged Care Quality and Safety Commission is planning a series of dates for standalone public workshops for aged care providers to assist with preparing for the new Aged Care Quality Standards. Details will be released on the Commission's website: https://bit.ly/2CWw4zB

- Starting April 2019 – QLD, NSW, VIC, WA
  Culture Change in Dementia Care Course
  Presented by Dementia Care Matters, in Brisbane (from 2 April); Sydney (from 8 April); Melbourne (from 11 April); and Perth (from 11 April). Details and bookings: www.dementiacarematters.com

- 16 April 2019 – national
  Time Travelling With Technology For People With Dementia
  Webinar, presented by Professor Kate Stevens and hosted by Dementia Training Australia. Registration and details, including times for each state: http://bit.ly/2ELNuOW

- 8 May - 28 June 2019 – SA, QLD, NSW, TAS, VIC, NZ
  Dementia Fundamentals Symposium
  Intensive one-day seminar, designed to empower carers and practitioners with vital expertise and capability across the core areas for day-to-day care in aged care settings, the community and homes. Each topic is evidence-based and proven in clinical practice. Register up to four weeks prior to each event for an early bird discount at https://bit.ly/2DTnp08 or visit www.dementiacentre.com/events

- 15-16 May 2019 – VIC
  10th Annual National Dementia Conference
  Premier national event for medical professionals, carers, researchers, aged-care workers and policy makers involved in the diagnosis, treatment and care of people living with dementia. Presented by Informa, in Melbourne. AJDC readers receive 30% off by quoting promo code P19A04AJDC30 at the time of booking, or book via this link which has the discount automatically applied: http://bit.ly/Informa-conference. Conference details: http://bit.ly/2GZMN8g

Details of more events at www.journalofdementiacare.com

- 22 & 23 May 2019 – NSW
  International Design School
  Learn the fundamentals of designing for dementia in this interactive and intensive two-day workshop in Sydney. Perfect for architects, designers and dementia care decision makers – this innovative course will be led by experts from the International Design School. You'll learn the principles of designing for dementia, strategies for successful design and the tools to turn your design concept into reality. Details and bookings: https://bit.ly/2BJbtOk or visit www.dementiacentre.com/events

- 5 June & 17 July 2019 – NSW & VIC
  Dementia Cottage Experience Workshop
  The Dementia Cottage Experience is an invaluable experience for architects, designers, service commissioners and managers, and direct care staff. In this 3-hour workshop you'll learn about the HammondCare design story and model of care, have an introduction to dementia design principles and a guided tour of a HammondCare site and dementia-specific cottage with a Dementia Consultant. In Cardiff, NSW (5 June) & Caulfield, VIC (17 July). Details and bookings: https://bit.ly/2XlRzSB or visit www.dementiacentre.com/events

- 13 June 2019 – WA
  Dementia Information Session: Music and Communication, and Supports Available
  Free session for family carers in the community, presented by Alzheimer's WA and the Australian Red Cross, in Bunbury WA. To register phone 1300 66 77 88 or email support@alzheimerswa.org.au

- 13-14 June 2019 – Tasmania
  Australian Dementia Forum 2019: Shining A Light On The Impact of Dementia Research
  Presented by the NHMRC National Institute for Dementia Research, in Hobart. Details: https://nnidr.eventsair.com/australian-dementia-forum-2019/

- 5-8 November 2019 – NSW
  52nd AAG Conference
  Coming of Age Together: New Ways of Knowing and Acting, Now and Beyond, in Sydney. Presented by the Australian Association of Gerontology (AAG). Details: www.aag.asn.au

Australian Journal of DementiaCare
For all who work with people with dementia
Vol 8 No 2 April/May 2019
Communicating without speech
Also inside this issue: ▪ Stories from those who care ▪ Inroads into remote training ▪ Towards autonomy and safety ▪ Being a 'disruptor'