

# Australian Journal of **DementiaCare**

For all who work with people with dementia

Vol 8 No 1 February/March 2019



## **Reconnecting with families**

**Also inside  
this issue:**

- Toilets: no laughing matter
- Meeting Centres trial
- Frontotemporal dementia: the real lived experience

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

**Managing Editor** Kerry Schelks  
kerry@australianjdc.com

**Contributing Editor** Catherine Ross

**UK Editor** Mark Ivory

**Production Editor** Andrew Chapman,  
andrew@hawkerpublications.com

**Website Manager** Emma Paul

**Publisher** Dr Richard Hawkins

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

Printed by iPS, Sydney.

© Hawker Publications Australia Pty Ltd 2019  
ISSN 2049-6893

**Advertising** Kerry Schelks  
kerry@australianjdc.com

**Address** Building 233 (ITAMS), 113,  
Innovation Campus, University of Wollongong,  
NSW 2522

www.journalofdementiacare.com

**Subscriptions** \$99 per annum (see  
page 40 for details) from DCA,  
www.journalofdementiacare.com

#### **Australian Journal of Dementia Care Advisory Board**

**Professor Elizabeth Beattie**, Professor of  
Aged and Dementia Care, Queensland  
University of Technology (QUT); Director,  
Dementia Training Australia, QUT; Director,  
Dementia Centre for Research  
Collaboration, QUT

**Professor Henry Brodaty AO**, Director,  
Academic Department for Old Age  
Psychiatry, Prince of Wales Hospital;  
Director, Dementia Centre for Research  
Collaboration, UNSW Sydney

**Marilyn Cintra**, Executive Director, Health  
and Arts Research Centre, Inc, Canberra

**Dr Penny Flett AO**, Pro-Chancellor  
University of Western Australia

**Emeritus Professor Rhonda Nay**,  
La Trobe University

**Kathryn Quintel**, CEO / Founder  
Preventing Dementia

**Tara Quirke**, Dementia consultant and  
educator

**Margaret Ryan**, Head of Dementia  
Services Group Development, Bupa Care  
Services, Australia

**Dr Andrew Stafford**, Director, Dementia  
Training Australia, University of WA

**Dr Margaret Winbolt**, Director, Dementia  
Training Australia, La Trobe University

#### **Disclaimer**

The opinions expressed in the *Australian Journal of Dementia Care* are those of the authors and are not necessarily those of the publisher. Furthermore the publisher and authors do not assume and hereby disclaim any liability to any party for any loss, damage, or disruption caused by errors or omissions, whether such errors or omissions result from negligence, accident, or any other cause.

# The importance of spiritual care

By **Ilsa Hampton**, CEO Meaningful Ageing Australia

**W**ith the Australian aged care system on the brink of landmark reform (a Royal Commission into Aged Care Quality and Safety underway and the introduction of a new set of Aged Care Quality Standards from July this year), I'd like *AJDC* readers to consider one aspect of quality care that can be overlooked or misunderstood by aged care organisations, but has powerful relevance for the wellbeing of older people, particularly those with dementia. As Australia's peak body for spiritual care and ageing, we believe that spirituality is an essential aspect of holistic care and a great asset when working with people living with dementia.

The importance of this approach was recognised when the Federal Government funded the development and launch of the National Guidelines For Spiritual Care In Aged Care. The guidelines are a key resource for the new Aged Care Quality Standards as they include practical outcomes and actions that are expected of organisations to achieve high-quality, integrated spiritual care that is relevant to older people from all backgrounds. (For details see p36 of this issue of *AJDC*).

So what is spirituality? We know it can come as quite a surprise for people to learn that spirituality is more than religion. Our role at Meaningful Ageing Australia is to help organisations understand and respond to the spirituality of older people, however it is expressed.

In 2014 an international consensus conference defined spirituality as "the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred" (Puchalski *et al* 2014\*). The international literature describes healing, guiding, reconciling, sustaining and empowering people in whatever circumstances they find themselves.

A spiritual care approach is a great asset for someone who lives with dementia as it never assumes a person is 'gone' or 'lost', regardless of diagnosis. For example, do we talk about an 86-year-old man with dementia who has trouble with activities of daily living; or Giovanni who is passionate about growing tomatoes for his community, sings light opera, was a high school teacher, needs assistance in the shower and is living with dementia? Spiritual care assumes meaning is present and focuses on a person's assets.

If our spirituality is the essence of who we are, then the experience and expression of someone living with dementia becomes our great teacher. To offer spiritual care we need to become expert at tuning in, at being present, at paying attention to the heart of the matter. The further someone's experience of dementia progresses, the more we need to learn to stay present, to find ways to connect personally and to facilitate connection with what is meaningful for this person. High-quality spiritual care never assumes what something means in the life of another, but rather offers invitations.

We know that spirituality (meaning, purpose and connectedness with ourselves, others, creativity, nature and something beyond our selves) is core to being human, that this is expressed in different ways by different people, and indeed that its meaning may change over time. Spiritual care never starts with a diagnosis but instead starts with careful listening. Its response may be practical, it may include religion and ritual, it may be about developing the courage and groundedness to keep paying attention in the face of challenges.

Cognitive decline does not equate to spiritual decline. This also triggers the importance of the spirituality of staff, as our own spirituality is what will sustain us and enable us to stay present in times of challenge.

In the words of Larry, living with dementia: "I'm a spiritual person who lives and it reflects in what you do...Not only preach what they are but do they love people?... [Spiritual care is] to help everybody I can...and teach and talk to and love" (Carr *et al* 2011 p7\*). ■

\* For reference details, email admin@meaningfulage.org.au



**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.

### ■ Project updates & viewpoints

#### Meeting Centres: an Australian trial 8

Dragana Bozinovski and Amal Madani report on the first Meeting Centres Support Program in Australia. Pioneered in the Netherlands, it offers an integrated program of recreational, social and creative activities for people with mild to moderate dementia

#### Toilets: no laughing matter 12

Toilets as a subject of conversation may raise a smile, but when it comes to dementia they are no laughing matter. Mary Marshall explains why

#### CALD dementia research action plan 14

Bianca Brijnath, Stephanie Ellis and Samantha Croy outline plans to develop a roadmap for dementia research and translation for culturally and linguistically diverse (CALD) communities

#### My wish: diversity in dementia research 15

Danijela Hlis is among the consumers, researchers and service providers contributing to the dementia research action plan for CALD communities in Australia. Here she gives a consumer perspective on why it's crucial to include CALD participants in dementia research

#### Little changes can make all the difference 16

Alison Schmidt explains how staff at Yathong Lodge worked together to devise a simple but powerful solution to improve the quality of life for a woman who was experiencing severe trauma during personal care

#### Fellowship program supports lasting change 18

Christine While explains how the Dementia Training Australia Fellowship program helps build capacity within organisations to improve the delivery of dementia care

#### Reconnecting with families 19

Julie Gray reports on one of the DTA Fellowship projects – a successful initiative at Homestyle Aged Care to facilitate more meaningful long-distance connection and engagement between residents living with dementia and family members who are unable to visit

### ■ Features

#### Residential care – but not as we know it 21

Denise Edwards describes her vision of an ideal integrated residential aged care village, designed to support a life that is manageable, understandable and meaningful

#### Death and dying in dementia care: a good end? 24

Rosalie Hudson explores a range of issues that shape care practices to support a person dying with dementia, including ethical decision making, language, pain management and the place of hope, and offers some guidance in response

#### 'But I just want to go for a walk': different approaches to risk and freedom 27

Following a three-month study trip to Australia, German Registered Nurse, PhD student and Nursing Scientist Anne Bleckmann reflects on the significant differences she discovered in how German and Australian aged care organisations deal with risk and freedom

### ■ Research Focus

#### Frontotemporal dementia: the real lived experience 31

Severe symptoms are to be expected in people with behavioural variant frontotemporal dementia, at least according to the official diagnostic criteria. But is this always the lived experience? Reinhard Guss and colleagues conducted interviews which told a different story



8



14



27

## Regulars

■ **Comment** 2  
by Ilsa Hampton

■ **News** 4

■ **Research News** 34

■ **Resources** 36

■ **Events** 39

Cover image: Homestyle Aged Care Sea Views Manor resident Elizabeth with lifestyle assistant Alana O'Keefe. Elizabeth and other residents in the dementia unit are now using video calls to reconnect with family members who are unable to visit. See article pp19-20. Photo: Homestyle Aged Care

# Quality and Safety Commission launches

The Aged Care Quality and Safety Commission has begun operations under the leadership of its inaugural Commissioner, Janet Anderson.

The launch of the independent Commission is seen as a landmark aged care reform, and a key outcome from the Carnell-Paterson Review, which followed the events at South Australia's Oakden aged care facility.

Minister for Senior Australians and Aged Care Ken Wyatt said the new independent Commission would better target sub-

standard care and ensure the safety and security of senior Australians.

"With the motto 'Engage, Empower and Safeguard', the Commission flags a new beginning for aged care quality and safety," Mr Wyatt said. "A single Commissioner overseeing compliance monitoring, complaints and customer service means no more silos.

"The Commission will also be empowered by the new aged care Charter of Rights and will implement the new, stronger set of Aged Care

Quality Standards, the first upgrade of standards in 20 years," he said.

The Commission has a budget of almost \$300 million over four years, with more than \$48 million to continue ramping up compliance checks and risk management, including the employment of dozens of new compliance officers and developing options for a Serious Incident Response Scheme.

Ms Anderson said that unannounced re-accreditation audits of aged care homes will triple in 2019, compared with

2018, and there will be an increase in unannounced inspections, to more than 3000 this year.

The Commission's new website at [www.agedcarequality.gov.au](http://www.agedcarequality.gov.au) has easily searchable information for consumers and providers on aged care consumer rights, free advocacy services to support senior Australians, Consumer Experience Reports about individual aged care services, audit reports on aged care homes, complaints, and new resources to help providers meet the Standards.

## EU funding for dementia research

The EU Joint Program on Neurodegenerative Disease Research (JPND) has awarded nearly \$28 million in total in funding to 10 multinational research teams – with Australian researchers involved in four of the 10 teams.

The EU JPND is a global research initiative aimed at tackling the challenge of neurodegenerative diseases, in particular Alzheimer's disease. A total of 21 countries have contributed towards the latest EU JPND funding round, including \$3 million from the Australian National Health and Medical Research Council, under the \$200 million Boosting Dementia Research initiative (Priority Round 4).

The four research projects involving Australian researchers are:

- **HOMESIDE:** A HOME-based Spousal caregiver-delivered music Intervention for people living with Dementia: A Randomised Controlled Trial, coordinated by Professor Felicity Baker from the University of Melbourne.

- **COGNISANCE:** CO-designing dementia diagnosis AND post-diagnostic care, coordinated by Professor Henry Brodaty from the University of NSW, with Associate Professor Lee-Fay Low from the University of Sydney as a team partner. This will involve developing international toolkits co-designed with people with dementia and clinicians to facilitate high-quality post-diagnostic care and a positive quality of life.
- **SHAPE:** Self-management and Health Promotion in Early-stage dementia with e-learning for carers – a randomised controlled trial, with Professor Kaarin Anstey from the University of NSW as a team partner.
- **SHARED:** Social Health And Reserve in the Dementia patient journey, with Professor Henry Brodaty from the University of NSW as a team partner. This project aims to understand the link between socialisation and lower risk of dementia.

**Dementia and sexual assault:** Women with dementia made up nearly three quarters of the 28 victims of sexual assault in Victorian nursing homes between 2000 and 2015, according to a new study reported in the journal *Legal Medicine*. The study is based on data from the Victoria Institute of Forensic Medicine. The researchers say that the actual number of sexual assaults during this period may be masked by under-reporting and lack of identification by nursing home staff.



**Korongee build begins:** Site work is now underway and final plans have been revealed for the Korongee dementia village in Tasmania (see artist's impression above). The village is a partnership between HESTA, not-for profit aged care provider Glenview, the Federal Government, and Social Ventures Australia. It will include 12 eight-bedroom houses, as well as a retail area with a café, supermarket, beauty salon and gardens. Glenview CEO Lucy O'Flaherty said Korongee is drawing on innovative national and international examples to change how care is provided for people living with dementia. "Residents at Korongee will live in small houses with others whose values they share." Korongee is due to be completed in late 2019.

### Gains for aged care

The Australian Government has announced it will inject \$552.9 million into aged care funding and \$512 million into primary care.

The new funding has made possible the release of 10,000 high-level home care packages in early 2019: 5000 level 3 packages and 5000 level 4 packages. The latest quarterly report on home care packages, released in November, revealed that while the number of people receiving home care packages had increased, the waiting list had continued to grow, by over 5000 for the past quarter alone.

The new funding will support many other new initiatives, including:

- the reduction of the daily maximum fees payable for level 1, 2 and 3 packages
- the viability supplement for eligible residential aged care providers (to offset higher care costs in regional areas) to be increased by 30%
- \$98 million to fund increased payments to GPs to attend residential aged care homes to treat patients
- \$5.8 million to trial a new network of community-based specialised nurses to care for people living with neurological conditions, including Parkinson's disease.

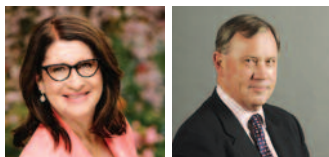
Dementia Australia welcomed the funding announcements, but said dementia was still not embedded as core business for aged care. Dementia Australia CEO Maree McCabe said that, "any discussion around aged care must include a focus on dementia".

## Royal Commission underway

Australia's Royal Commission into Aged Care Quality and Safety has begun under the direction of Commissioners Lynelle Briggs and Richard Tracey QC. It opened with a preliminary hearing on 18 January, ahead of public hearings starting in Adelaide on 11 February. The Commission's terms of reference include inquiring into how best to deliver aged care services to the increasing number of Australians living with dementia.

Submissions to the Commission will be accepted from the public and institutions until at least the middle of this year, with a closing date to be announced in the second half of 2019.

Senior Counsel Assisting the Commission, Peter Gray QC, told the Commission's preliminary hearing in Adelaide that in the responses from aged care providers to date, the highest reporting of complaints and incidents related to residential care. He said incidents being reported included elder abuse, medication mismanagement, overuse of psychotropic medication, not responding in a timely manner to residents requiring assistance and inadequate wound management leading to death. Record keeping and record



Lynelle Briggs and Richard Tracey

management was also an issue for some providers.

In her opening statement at the preliminary hearing, Commissioner Briggs said that it was "important to recognise that there are many positive examples of high-quality care within the aged care sector" but that "there has been a rising torrent of concern that the aged care system is faltering in certain areas of safety and quality and that it may not be fit for purpose".

She said the "likely major themes" to be addressed by the Royal Commission include "quality and safety, access and inclusion, young people with disabilities, interfaces and transitions, future challenges and opportunities, and how to deliver quality care in a sustainable way".

The Commission will submit an interim report by 31 October 2019 and a final report by 30 April 2020. Information about the hearings, including live streaming and transcripts of the hearings, and how to make a submission, is available at [www.agedcare.royalcommission.gov.au](http://www.agedcare.royalcommission.gov.au)

**New funding for QBI:** The Clem Jones Centre for Ageing Dementia Research at the Queensland Brain Institute (QBI) will be the first to receive new funding of \$10 million from the new 10-year Dementia, Ageing and Aged Care Mission, through the Medical Research Future Fund. The Australian Government announced in December that \$185 million will be given to the new research program, which will focus on dementia (diagnosis, treatment and prevention), fall prevention and avoidable hospitalisations, and assistive technology. The initial funding will go to the QBI team which is investigating the use of ultrasound to remove Alzheimer's disease pathology and restore memory function. To date the research has been conducted on animal models only, but QBI says that the launch of a phase 1 trial is planned for late 2019. The trial will involve a small number of people and will explore whether the technique developed at QBI is safe to use with humans.

**Global dementia profile:** The number of people living with dementia worldwide more than doubled from 20.2 million in 1990 to 43.8 million in 2016, mainly due to increases in population ageing and growth. The findings come from a study reported in the *Lancet Neurology* and are the first detailed analysis of the global prevalence, mortality, and overall burden of dementia as captured by the Global Burden of Diseases, Injuries and Risk Factors (GBD) Study 2016. Only four risk factors were found to have enough evidence for a causal link to Alzheimer's disease and other dementias: high BMI, high fasting plasma glucose, smoking and high intake of sugar-sweetened beverages.

## News in brief

### Specialist Dementia Care Program

The Department of Health has invited WA aged care provider Brightwater Care Group to apply for a non-competitive grant of up to \$5.6 million to test what is now called the Specialist Dementia Care Program (SDCP) – specialised, transitional residential support for people with very severe responsive behaviours associated with dementia who are unable to be cared for by mainstream aged care services. It is anticipated that the prototype service will operate within Brightwater The Village in Inglewood within the Perth North Primary Health Network region. The department said it would advertise grant opportunities for 14 specialist dementia care units in early 2019, with the first units operational in 2020, and that a second funding round for 20 units will follow in 2021-22. The full rollout of the program is expected in 2022-23, with at least one specialist dementia care unit operating in each of the 31 Primary Health Networks.

### New aged care restraint regulation

Chemical and physical restraint in aged care homes will be better regulated, with draft changes to regulations expected to be released by February 2019. Minister for Senior Australians and Aged Care, Ken Wyatt, announced the move on 17 January, saying incidents of over use of physical and chemical restraint would not be tolerated. "The use of antipsychotic medicines must be a clinical decision made by medical practitioners with the care recipient, and their carer or family involved at all times," Mr Wyatt said.

### CHeBA funding

The National Health and Medical Research Council (NHMRC) has awarded a \$649,205 grant to the Centre for Healthy Brain Ageing (CHeBA) to support the work of CHeBA's Stroke and Cognition Consortium (STROKOG). STROKOG is an international collaboration of researchers from around the world, established in 2015. CHeBA Co-Director Professor Perminder Sachdev said, "The successful grant will allow STROKOG the opportunity to address important issues relating to vascular cognitive disorders and help propel our international-first and ambitious efforts of this consortium."

### NARI researchers' awards

Two researchers from the National Ageing Research Institute (NARI) have been honoured for their work – including their research on dementia. NARI research fellow Dr Anita Goh has won NARI's annual Professor Robert Helme Research Award. Dr Goh was recognised for her research across several fields including her work with Dr Anita Panayiotou in developing and delivering a new half-day training program about assessment and management of cognitive decline, called 'Thinking about Thinking'. In addition, Associate Professor Bianca Brijnath, NARI's Director of Social Gerontology, has won a Tall Poppy Award in Victoria for her work in mental health and culture. Her research currently focuses on increasing awareness and understanding around depression and dementia to improve mental health among older Australian migrants. **Associate Professor Brijnath writes for AJDC on p14.**

### DA and DAI to work together

Dementia Australia (DA) and Dementia Alliance International (DAI) have signed a memorandum of understanding (MOU) to formalise their relationship. DA is the first national organisation to partner with DAI, the peak body internationally exclusively for people with a confirmed diagnosis of dementia. It now has members in 48 countries, and is a registered charity in the US. DAI Chair and Co-founder, Kate Swaffer, said the organisations would advocate together to expand the awareness and understanding of dementia across the aged care, disability and health care sectors in Australia and on the world stage.

# Life with frontotemporal dementia in focus

The two photographs featured here are from the 'Life with frontotemporal dementia' photographic exhibition which was part of the Art Show for the 11<sup>th</sup> International Conference on Frontotemporal Dementias (ICFTD2018), held in Sydney in November 2018. The show also included a series of paintings by well-known Australian artist Ann Cape who generously lent some of her portraits on the theme of dementia.

The biennial conference, held in 2018 for the first time in Australia, was organised in collaboration with Frontier – the Frontotemporal Dementia Research Group in Sydney, the Brain and Mind Centre at the University of Sydney and the International Society for Frontotemporal Dementias.

Frontier Co-Director Professor Olivier Piguet said 13 entries on the theme of dementia were submitted for the photographic exhibition by people diagnosed with dementia or their carers and family members and included portraits or activities involving the person with dementia.

The Art Show aimed to raise awareness of and highlight



**'Kell' and friends:** Greg Kelly was diagnosed with younger onset dementia at the age of 59. Now, he's challenging the stigma and raising awareness of a disease which affects over 60,000 people in New Zealand by riding a Harley Davidson the length and breadth of Australia, New Zealand, and the US. Greg is passionate to complete the rides despite the adversity he faces with his diagnosis of frontotemporal dementia. Photographer: E McLeish

the human stories behind frontotemporal dementia (FTD), a form of dementia that affects behaviour, language skills and movement.

Professor Piguet said this was the first time that the conference had featured an art exhibition and it had been well received by the 670 delegates. "The organisers of the 2020 conference in Minneapolis, Minnesota, US are interested in having an art component, which we hope will become a tradition and a

highlight of this conference."

The photographic exhibition was organised, coordinated and financially supported by Don Dickins and Alastair Griffin, who each have a wife diagnosed with FTD and are carers.

All the photos from the exhibition can be viewed on the Brain and Mind Centre's website at <http://bit.ly/life-with-FTD> and will be displayed permanently in the centre's clinic at 100 Mallett St, Camperdown, Sydney.



**Caring for one another, no matter the age or diagnosis:**

"This is a photo of my husband Michael (who has frontotemporal dementia) and our granddaughter Chloe, walking home from Chloe's day care together in Brisbane. I think it is a gorgeous photo of Michael and Chloe together. Michael happily carrying Chloe's backpack, both walking together, both comfortable in each other's company but neither actually sure exactly which way to go. The photo depicts the love, kindness and caring they have for one another, with them both trying to help one another. It is so sad when Michael gets Chloe's name mixed up, or is unable to recall her name, but Chloe chooses to ignore this little error. 'It's just part of Poppie being Poppie'." Photographer: D Saladine

## Desert Rose takes second place:

Desert Rose – a student-designed and -built house to support people living with dementia and other age-related conditions – has won second place in the Solar Decathlon Middle East 2018 international sustainable design and building competition, held in Dubai in late 2018. Desert Rose was a joint entry from a team of more than 40 students from the University of Wollongong (UOW) and TAFE NSW, known as Team UOW Australia-Dubai. The team has worked together for two years to prepare for the competition, including working with Dementia Training Australia (DTA), local care providers, community groups and people with dementia to design the house. Upon its return to Australia, the house will be located permanently at UOW's Innovation Campus.

## Three projects chosen for Innovation Grant

The Dementia Australia Research Foundation, together with the Yulgibar Alzheimer's Research Program (YARP), have announced that there are three successful applicants for its inaugural \$1 million Innovation Grant – rather than one as anticipated. A \$1 million grant has been awarded to Professor



Permindar Sachdev (left), Co-Director of the Centre for Healthy Brain Ageing (CHeBA) at the University of NSW, who

will be investigating the use of nanoparticles to move across the blood brain barrier with a view to targeting amyloid and tau.

In addition, the judging panel and funders decided to award a further \$1 million in funding, with a \$500,000 grant going to each of two runner-up projects led by Professor Simon Bell at Monash University and to Professor Chennupati Jagadish AC from the Australian National University. Professor Bell will work with researchers in the US, UK and Hong Kong to evaluate health data from hundreds of

thousands of patients, exploring which drugs to use to support people with dementia. Professor Jagadish will combine technologies in stem cell research with artificial intelligence (AI) to develop 'brain organoids' or 'mini-brains' from stem cells taken from people living with Alzheimer's disease as well as individuals unaffected by the disease.

The Dementia Australia Research Foundation says that people living with dementia and carers will be involved throughout all stages of the research process.

# THE RED CONFERENCE

28-29<sup>TH</sup>  
MARCH  
2019



## Explore innovative, hands-on, practical approaches to living well with dementia.

Be inspired by expert and internationally renowned speakers Dr Cameron Camp and Lesley Palmer DSDC; and Australian Professor Joseph Ibrahim and people living with dementia and their carers.

### Register Now

Visit [red.omnicare.org.au](http://red.omnicare.org.au)



PROUDLY PRESENTED BY

**Omnicare**

Supported by



Event Strategic Partner

# Meeting Centres: an Australian trial

**3**Bridges Community is a not-for-profit organisation located in South East Sydney that provides a wide range of programs to support vulnerable people from early years to their older and more frail age. One of its main strategic directions is to reframe ageing in a way that challenges society's negative attitudes and enables older people, including people with dementia and their carers, to stay well at home and to connect with purpose to their community

In 2015, 3Bridges Community consulted with its service users and other aged care providers on the current deficiencies in service responses to people with mild to moderate dementia and their families. This confirmed the need to 'rethink' the services offered by 3Bridges Community and to shift to locally-based programs delivered in a non-clinical environment that reduces the stigma of dementia while offering person-centred programs for people in the early stages of diagnosis and treatment.

In our search for an innovative program that produces best outcomes for people living with mild to moderate dementia and their family carers, we at 3Bridges found the Dutch-based Meeting Centres Support Program to be the answer to the fragmented support currently provided to people with dementia and their family carers in South East Sydney. Aligned with Australia's National Framework for Action on Dementia 2015-2019 (Department of Health 2015), the program reinforces the



**Members of the Meeting Centres Support Program run by 3Bridges Community in South East Sydney. Photo: 3Bridges Community**

rights of people with dementia to dignity, safety (physical, emotional and psychological), to have a choice, to be respected and valued, and to have quality of care for themselves and their family carers.

In 2017 we successfully applied for funding through the Department of Health's Dementia and Aged Care Services Fund to evaluate the effectiveness of implementing this European program in Australia, particularly in the Australian dementia care and community care sectors. We engaged Professor Yun-Hee Jeon from the University of Sydney to carry out the research. The trial period ran from November 2017 until the end of October 2018 with members attending the 3Bridges Community Carrs Park Centre in Sydney. The report will be submitted to 3Bridges Community and the Department of Health by the end of February 2019.

This article outlines the Meeting Centres Support Program (MCSP), provides an overview of the Australian trial and an update on the program to date, including successes and challenges.

3Bridges Community was guided in its implementation

of the program by the designer of the concept and coordinator of the MEETINGDEM network (see box next page), Professor Rose-Marie Drees from the Department of Psychiatry, VU University Medical Centre, Amsterdam.

## The Meeting Centres Support Program

The MCSP is a person-centred, evidence-based, comprehensive and integrated program offering support to people with mild to moderate dementia and their family members, enabling them to adjust and cope with the condition.

It is underpinned by the theoretical framework of the Adaptation-Coping model (Drees *et al* 2017) which recognises that people with dementia and their carers have to deal with adaptive tasks such as coping with disabilities, changes in behaviour and mood and maintaining a positive self-image. When the MCSP model was trialled in the UK the research team, led by Professor Dawn Brooker, chose to adjust the terminology used by the Dutch initiators into more suitable language using the overarching term 'Adjusting to Change' (Brooker *et al* 2017)

**Dragana Bozinovski** and **Amal Madani** report on the first Meeting Centres Support Program in Australia. Pioneered in the Netherlands, it offers an integrated program of recreational, social and creative activities for people with mild to moderate dementia, as well as advice and support for their families

which is more in line with the Australian terminology.

The Adaptation-Coping model recognises the changes or adjustments needed by the person and their family after diagnosis. These changes are conceptualised as adaptive tasks. How the person living with dementia and their carer deal with these tasks is based on their cognitive appraisal of them. Due to differences in personality, family history and the condition itself, these adaptive tasks will be appraised differently. For some people this will be a continuous progression and others will develop new coping strategies and behaviours (Brooker *et al* 2016).

MCSP offers an integrated package of care for the person with dementia and for the family members in one setting. For the person with dementia or members of the MCSP, a social club or group is organised for up to three days per week where they can participate in recreational, psychosocial and psychomotor therapy (Drees *et al* 2017).

For carers, there are psychoeducational meetings or information sessions every six weeks and discussion groups or carer support groups each fortnight and in accordance with carers' needs. For both the person living with dementia and the carer there are social activities, a weekly



consultation hour and regular monthly centre meetings where members, carers, staff and volunteers can share experiences, discuss any issues of concern, and suggest changes. Centre coordinators can provide assistance with My Aged Care, the National Disability Insurance Scheme (NDIS) or other help that may be required.

MCSP is a person-centred approach tailored to each person's specific needs. An individual support plan is set up based on their experiences with adjusting to life after diagnosis. The plan is evaluated regularly and adjusted when needed (Droes *et al* 2017). Practical, emotional and social support strategies aimed at helping people to adjust to changes in their life are offered to the members and their carers.

MCSP integrates several support activities that have evidence in research or practice to be effective for people with dementia or their carers, such as cognitive stimulation, psychomotor therapy, music therapy, activity groups, family support, psychoeducation and counselling (Droes *et al* 2017). In accordance with the recommendations from the

## Meeting Centres international network

The MEETINGDEM NETWORK project is aimed at implementing and evaluating the Meeting Centres Support Program (MCSP) for people with dementia and their carers living in the community.

It was launched in June 2018 in Amsterdam and consists of Meeting Centres in Australia, Italy, the Netherlands, Poland, Spain and the UK, and the universities and care and welfare organisations involved in developing or implementing these Meeting Centres.

Its aims are to: disseminate the Meeting Centres concept; exchange knowledge on effective post-diagnostic care and support for community-dwelling people with dementia and their carers via the website, newsletter and conferences; and promote international collaboration in applied research in post-diagnostic interventions in dementia. Details: [www.meetingdem.eu](http://www.meetingdem.eu)

Clinical Practice Guidelines and Principles of Care for People with Dementia (NHMRC 2016) 3Bridges MCSP encourages its members to participate in one hour of physical exercise, healthy meal preparation including set-up and clean-up, and to do as much for themselves as possible while fostering their independence at the centre and in the community. Carers are welcome to stay and participate as active members or they can use the program as respite.

MCSP is offered at an

accessible location that facilitates social inclusiveness and community integration (Droes *et al* 2017). 3Bridges Community currently offers two locations, one at Carss Park and the other at Summer Hill, in Sydney. Both run at established community centres. This enables social participation with other non-MCSP staff and centre users including visitors to the community garden and parks, as well as different generational groups such as childcare and local primary and high schools. This inclusion is supported by 3Bridges Community being a dementia champion and actively engaged in raising dementia awareness in the local area and ensuring communities are developing a dementia-friendly attitude.

### The MCSP team

MCSP is provided by a small, professional team and volunteers. The 3Bridges MCSP consists of five part-time professionals working across the two sites: two dementia care specialists, one social worker, one exercise physiologist and one diversional therapist. Professional staff are supported by volunteers and university students from social studies, creative music therapy or therapeutic recreation courses on

practical experience.

For Program Leader (and co-author here) Dragana Bozinovski, it was a dream come true to have the opportunity to be involved in implementing the MCSP soon after graduating with a Bachelor of Dementia Care from the University of Tasmania.

Despite the number of challenges initially encountered, the benefits and the positive impact for the members and their families were evident very soon after launching the first centre at Carss Park. The main ingredient for that was the camaraderie amongst the members. Meal preparation and having lunch together has become a focal point and many members are referring to the group as a 'new family'. This enables members to take these new friendships outside the centre and continue to support each other in the community.

MCSP Centre Coordinator Melissa has seen how the program supports the family as a whole. "We get to know the individuals better through our connection with their family and can help respond to issues as they arise before they become a crisis," she said. "The transparency of our monthly meetings where we talk openly about what is or is not working well with the program has really helped us to develop a comprehensive and responsive program that is always adapting to the group dynamics. Our members feel they come to the group to help others and this sense of purpose is so important to maintaining their emotional wellbeing."

As a recreational therapist at MCSP, Connie ensures that all the members get the opportunity to socialise, enjoy physical activities and express their uniqueness in a very friendly, inclusive environment. "It is a place where people with dementia and their carers regain the sense of belonging and enablement," she said.

MCSP exercise physiologist



Members of the Carss Park Meeting Centres Support Program enjoy a game of bowls during an outing. Photo: 3Bridges Community

Michael said the program has given him the opportunity to see the members improve in so many different ways. "Physically, the members are building muscle mass and bone density, are more confident with their gait and balance and in turn they walk through our front doors looking fitter and stronger. Noticing positive changes in members is the exact reason that inspires me to work in this field."

### European research

Previous studies by Professor Droes have found that when compared to regular psychogeriatric day care, MCSP proved to have a more positive effect on mood, behaviour, self-esteem and delayed premature placement into long-term residential facilities (Droes *et al* 2004; Droes *et al* 2006). A majority of MCSP carers (82.1%) experienced less burden and more professional support (Droes *et al* 2006). Despite the increase in behavioural and psychiatric problems in the people with dementia, the emotional impact of these problems on the carers remained stable (Droes *et al* 2006). As a result of this support, significantly fewer people with dementia participating in MCSP were placed into long-term residential care (4%) during the period of seven months when compared with regular psychogeriatric day care (29%). At the same time, people with dementia attending MCSP participated in the community for a longer period before being placed into long-term residential care (Droes *et al* 2006).

### Australian experiences

From September 2017 until the end of October 2018, 3Bridges Community received 106 referrals for the MCSP. Most of these came from the St George and Sutherland Dementia Advisory Service provided by Dementia Australia. A few came from My Aged Care, while some families self-

referred after learning about the program through local media.

Eligibility criteria set by the University of Sydney for participation in the MCSP trial were: official diagnosis of dementia – mild to moderate; have a carer living with them or provide support for a minimum of seven hours per week; have conversational English language; not be participating in any other structured dementia program; be willing to participate in a research study and provide consent; able to provide their own transport and not participate in any other current research. Most people who inquired either decided not to participate in the research or were ineligible, and as a result were referred to other community care programs.

There were a few other challenges for the implementation team that will be included in the final report, such as securing an appropriate venue that was available three days a week in which to deliver the program; establishing and maintaining the advisory group; and recruiting the required number of dyads for the control group.

Currently there are 42 active participants across the two sites. Feedback from members and carers has been overwhelmingly positive, especially from people diagnosed with Younger Onset Dementia (YOD) and their carers. The practical engagement with activities and meal preparation seems to be supporting their need for purpose and meaning. Some of the feedback below, from members and carers, reflects their experiences at MCSP:

"Since joining your dementia program I have seen profound changes in my husband's behaviour, temperament, communication skills and, most importantly, his ability to recall. Where he once needed encouragement to eat, shower, shop, socialise or engage in conversation he now needs much less motivation. He is up in the morning,

showered and dressed before 9am eagerly awaiting the time to leave home and join his new support community. The team at 3Bridges are more than a service providing activities, meals and fun, you have become his new family."

"My husband is doing okay. His doctor is happy with his progress. His memory has improved by two points. His anxiety level seems to be lower. He seems to enjoy attending 3Bridges with his mates on Tuesday."

"He thoroughly enjoyed the group, the company of the members, [and] the lovely friendly caring ladies who look after them so well. He felt that he is well respected, the lovely ladies have made him feel at home. He decided not to go to the Men's Shed on Mondays as he enjoys the MCSP a lot more. This also gives me, as his carer, a great peace of mind that he is happy at the centre so I can focus on my job and what I need to do. I expected that he would enjoy the program before he joined, but after a few days he enjoyed it more than I expected, which is such a relief for me."

### Conclusion

The MCSP Australian pilot study finished at the end of October 2018 but the program is continuing at the Carss Park and Summer Hill centres. Summer Hill MCSP operates on a fee-for-service basis and the Carss Park program is funded by the Department of Health until the end of June 2019. However, due to the positive feedback from participants, 3Bridges Community will introduce a fee structure in 2019 at Carss Park to ensure existing and future participants can continue to attend beyond the funding period. ■

**3Bridges Community won the 2018 ACSA NSW/ACT Aged Care Award for Innovation in Service or Design and was a finalist in the 2018 HESTA national aged care awards for its pilot of the Meeting Centres Support Program.**

**For more information on the 3Bridges Community MCSP program, visit <https://youtu.be/pzf7Baux11E>**



■ Dragana Bozinovski (left) is the MCSP Program Leader, has a Bachelor of Dementia Care and provides counselling for people diagnosed with dementia, their carers and families; Amal Madani is Director of Reframing Ageing at 3Bridges Community where she leads community programs designed to support vulnerable people including people with dementia and their family carers. Contact her at: [amal.madani@3bridges.org.au](mailto:amal.madani@3bridges.org.au)

### References

- Brooker D, Droes RM, Evans S (2017) Framing outcomes of post-diagnostic psychosocial interventions in dementia: the Adaptation-Coping Model and adjusting to change. *Working With Older People* 2113-2121.
- Droes RM, Meiland F, Schmitz M, van Tilburg W (2004) Effect of combined support for people with dementia and carers versus regular day care on behaviour and mood of persons with dementia: results from multi-centre implementation study. *International Journal of Geriatric Psychiatry* 19(7) 673-684.
- Droes RM, Meiland FJM, Schmitz MJ, van Tilburg W (2006) Effect of the Meeting Centres Support Program on informal carers of people with dementia: results from a multi-centre study. *Aging and Mental Health* 10(2) 112-124.
- Droes RM, Meiland FJM, Evans S, Brooker D, Farina E, Szczesniak D, Van Mierlo LD, Orrell M, Rymaszewska J, Chattat R (2017) Comparison of the adaptive implementation and evaluation of the Meeting Centres Support Program for people with dementia and their family carers in Europe; study protocol of the MEETINGDEM project. *BMC Geriatrics* 17 79.
- Guideline Adaptation Committee (2016) *Clinical practice guidelines and principles of care for people with dementia*. National Health and Medical Research Council.
- Patterson C (2018) *World Alzheimer report 2018. The state of the art of dementia research: new frontiers*. London: Alzheimer's Disease International.



# centre for dementia learning

transforming dementia practice

## Courses

Dementia Australia offers a wide range of courses and workshops for health professionals and workers providing support to people living with dementia

## Consultancy

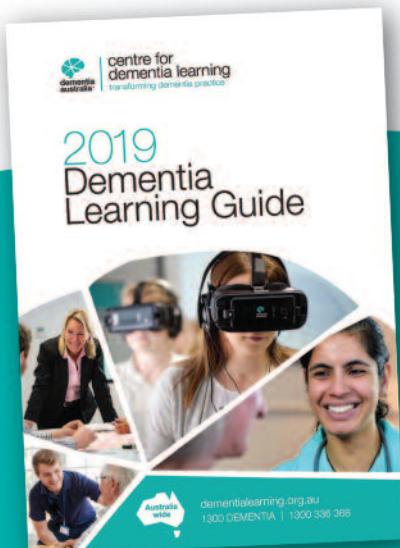
Dementia Australia provides a flexible range of consultancy support uniquely tailored to assist organisations in achieving their specific goals

## Online Learning

You can access our range of free modules or purchase individual modules of interest that can be completed in your own time and at your own pace

## Subscription

Accessing current dementia articles, podcasts and video resources couldn't be easier with our new dementia learning subscription for individuals or organisations



To request your copy of the 2019 Dementia Learning Guide, register at [dementia.org.au/DLG](https://dementia.org.au/DLG)

For more information call  
**1300 DEMENTIA | 1300 336 368**

# Toilets: no laughing matter

Invariably, when the topic of toilets comes up, people laugh. We all have deep-seated attitudes and inhibitions about the use of toilets, and for good reason. It is a private space. However, the laughing should not be allowed to conceal the importance of usable toilets for people with dementia.

Wheelchair users have succeeded, to a great extent, in ensuring that there is usually a toilet available that enables them to use it. But no such priority has been given to the needs of people with dementia. Being able to find, and then safely use, a toilet is crucial if people with dementia are to participate in society and use public spaces such as bus and train stations, museums, cinemas, concert halls, service stations, hotels and so on.

Article 29 of the UN Convention on the Rights of Persons with Disabilities asserts the right to participation in political and public life, while article 30 sets out the right to participation in cultural life, recreation, leisure and sport. If people with dementia are effectively prevented from participating in these ways – because toilets are inaccessible – their human rights have been infringed.

There is a clearly observable trend, increasingly mentioned in the media, for ever more incomprehensible signage and equipment for toilets. The reasons for this are debatable, but the impact is devastating for people who are struggling to make sense of it.

To take one example, Morag Dunning (not her real name) had to accompany her mother to the toilet in the club they went to regularly because her mother was unable to use the taps, soap dispenser and hand drier. Morag was outraged because her mother could cope independently with the toilet at home, yet she had to seek the help of her daughter if they

Toilets as a subject of conversation may raise a smile, but when it comes to dementia they are no laughing matter.

**Mary Marshall** explains why

went out together.

Many public toilets are not even age-friendly, let alone suitable for people with dementia. It is not difficult to work out what is needed if we start with the impairments most common for older people and then carry on to those of people with dementia.

Most older people will have some deterioration of their muscles; the ones often neglected in design are those of the neck and shoulders (signs need to be lower down) and those of the wrist and hands (flush buttons are really

difficult). Most older people will have a degree of impaired sight so need good contrast and at least double the levels of light necessary for younger people.

Hearing usually deteriorates and is often accompanied by hypersensitivity, which means noisy driers are hard to tolerate. Balance is often affected as proprioception and the labyrinth of the ear are less effective, meaning that cramped and crowded spaces are increasingly tricky. An often unmentioned impairment is the need to get to the toilet quickly as a consequence of either

prostate problems or weaker pelvic floor muscles. This often causes high levels of anxiety.

If we combine these normal impairments of ageing with those common for people with dementia, we can begin to understand why so many public toilets are a problem. If you have an impaired memory, you are often making sense of the world using past experience. But many modern toilet signs bear no relation to past experience and are therefore incomprehensible.

These signs should either be familiar from the past or at least very obvious. If you combine poor sight with a loss of recent memory, stick figure signs are often meaningless. An impaired ability to learn will mean that people may not remember where



**Far left: Bad – mirrors and stainless steel predominate, causing confusion for people with dementia**

**Left: Good – simple colour contrasts work well at Monkwearmouth acute dementia unit in the UK**

**Below: Bad – toilet sign is too high**



**Above: Bad – the only easily visible features to the ageing eye are the toilet roll holders, brush holder, toilet paper tube and the emergency pull!**



**Above: Good – toilet sign leads the way. Credit: StudioLR**



**Above: Bad – this frequently used toilet sign sows confusion**



Professor Mary Marshall is a senior consultant at The Dementia Centre, HammondCare. She is the author of *Toilet talk*, a free e-book on accessible design for people with dementia. It can be downloaded from The Dementia Centre website [www.dementia-centre.com/resources](http://www.dementia-centre.com/resources)

the toilet is, even if they have used it before. Perhaps the most profound impairment is that of reasoning. If you struggle to work things out, much modern signage and equipment is impossible.

Many people with dementia have sensory challenges (Houston 2015), especially perceptual problems. This can result in seeing a step when there is a change in floor tone or a contrasting threshold strip, or perceiving specks in the floor covering as litter. Elaborate patterns can seem as if they are moving.

Finding the toilet is the first challenge if you have dementia. My father walked straight past the toilet door in the airport and got lost because he failed to understand the sign which was both too high and too abstract. Here are some rules for signs:

- They may need to be high in big spaces but there should also be low ones on the door itself (1.2 metres from the floor).
- There should be colour contrasts both within the sign

itself and between the sign and what it is fixed to.

- They should have words and a meaningful picture or diagram.

There are several entertaining (and worrying) web pages of funny toilet signs, all requiring a degree of reasoning to work out.

Entering the toilet cubicle is often off-putting for people with dementia who can neither see nor understand the engaged/vacant signs. The standard issue is a small red and white indicator which is meaningless, even if someone can see it. Many people with dementia wait until someone comes out so they know the cubicle is vacant.

Once in the toilet, it can be difficult to see anything because the whole place is white. Unless the seat, the paper dispenser and the cistern contrast with the wall and floor, they can be invisible to the ageing eye. There are then further challenges. Is the toilet paper reachable and in a container that makes sense? Is the flush a

normal lever? Is the lock to get out easy to understand and use?

Here is another example from real life. Ann Bennett (not her real name) got stuck in the toilet because she could not work the lock. A caretaker managed to break the lock but not before a great deal of distress was caused, to the consternation of her daughter and other people present. Once outside, the taps often provide the next hurdle. It can be very entertaining watching people trying to work out how to use a tap (the comedian Michael McIntyre does a wonderfully funny dance in his YouTube film on "public toilet technology") but it is very humiliating if you have dementia and very little confidence. We need straightforward, easy to understand taps with blue and red on top.

Soap dispensers get more complex every day. Increasingly they are movement operated which makes no sense to someone who struggles with the simplest press-button version. Taps and soap are important if

we want people to leave the toilet with clean hands. Modern hand dryers are wholly non-intuitive as well as noisy.

Finally, getting out of the toilet can sometimes be remarkably complicated with several doors looking the same. People with dementia can be very distressed if they feel trapped (Tales *et al* 2017).

There are numerous other problems, but my intention here is simply to draw attention to the fact that they are solvable. With greater awareness, and a little extra expenditure, we can ensure the provision of toilets which enable people with dementia (and many others with similar impairments) to join us fully as fellow citizens. ■

#### References

- Houston A (2015) *Dementia and sensory challenges*. Glasgow: Life Changes Trust. Download at [www.lifechangestrust.org.uk](http://www.lifechangestrust.org.uk).  
Marshall M (2017) *Toilet talk*. Sydney: HammondCare Media.  
Tales A, Burholt V, Nash P, Richard JA, Clayton-Turner A (2017) Dementia-friendly public toilets. *Lancet* 390(10094) 552-553.

# Dementia Fundamentals Symposium

## Greater capability, better care

The Dementia Centre, recognised as a leading dementia practice, resource and research centre, is now offering for the first time an intensive one-day seminar.

This event aims to empower carers and practitioners with vital expertise and capability for day-to-day care.

Leading sector experts will cover proven and latest thinking on key topics. Each topic is comprehensively evidence based and proven in clinical practice.

Join us at one of the following locations

ADELAIDE | AUCKLAND | HOBART | MELBOURNE | SYDNEY

Book now or learn more at [dementiacentre.com/events](http://dementiacentre.com/events) or contact us at [events@dementia.com.au](mailto:events@dementia.com.au)

The Dementia Centre.

HammondCare 

# CALD dementia research action plan

**Bianca Brijnath, Stephanie Ellis and Samantha Croy** outline plans to develop a roadmap for dementia research and translation for culturally and linguistically diverse (CALD) communities in Australia

Culturally and linguistically diverse (CALD) Australians make up nearly 30% of the nation's population but are represented in less than 10% of dementia research studies (Low *et al* 2009). The NHMRC National Institute for Dementia Research (NNIDR), established in 2015 to target, coordinate and translate the strategic expansion of dementia research in Australia, has partnered with the National Ageing Research Institute (NARI) and key stakeholders to develop a five-year action plan aimed at increasing the representation of Australians from CALD backgrounds in dementia research, as well as:

- Identifying specific dementia research priorities, and any gaps, for CALD communities and how these can be translated into policy and practice initiatives.
- Facilitating collaboration across CALD dementia research and between researchers and CALD communities.

The plan will be based on consultations with researchers, consumers, service providers and established and emerging migrant communities. The development of the plan is guided by a steering committee of expert stakeholders comprising dementia researchers, representatives from peak ethnic organisations, and consumer representatives.

A CALD dementia research consultation workshop, hosted by NARI and the NNIDR, was held in Melbourne on 20 November 2018, bringing together researchers, consumers and service providers across the priority areas of prevention, assessment and diagnosis, treatment, and care.

NNIDR Director Janice Besch and NARI Director



**Professor Dimity Pond, from the University of Newcastle, and Dr Kim-Huong Nguyen, from the University of Queensland, at the CALD dementia research consultation workshop in Melbourne discussing how researchers and CALD communities can work together.**  
Photo courtesy NARI

Associate Professor Briony Dow opened the workshop, which was facilitated by Associate Professor Bianca Brijnath. In her opening remarks, Ms Besch reinforced to workshop participants that the under-representation of CALD communities in research is a fundamental gap that characterises much Australian research on dementia.

The outcomes of the workshop will be incorporated into the draft action plan which NNIDR and NARI will take to key migrant communities across Australia over the next few months for further input and refinement. The final action plan will be launched in mid-2019.

The action plan will provide a five-year framework for policy and strategy to address the multidimensional challenges dementia represents to CALD communities in Australia – people currently living with dementia in and from these communities and their families and carers.

The reality is that many research findings translated into clinical practice and social policy are culturally inappropriate, disregard differences across Australia's

multicultural groups, and perpetuate social inequalities.

## Why the need for an action plan?

NNIDR and NARI have presented the following key points to support the need for an action plan:

- The prevalence of dementia among older CALD Australians is projected to increase more than threefold from about 35,000 in 2010 to 120,000 by 2050 (Access Economics 2009).
- Communities and care providers must better understand, plan and develop services and supports for dementia prevention, diagnosis, treatment and care from a CALD perspective (Federation of Ethnic Communities Councils of Australia 2015).
- A 2015 review by FECCA found that while there is a substantial body of research evaluating culturally sensitive tools for diagnosing dementia and increasing understanding of dementia among people from CALD backgrounds, little is known about the experiences of older CALD Australians with dementia.

- Research has shown that poor understanding of dementia combined with the stigma attached to dementia in CALD communities can lead to denial of the condition and delayed diagnosis for older people from CALD backgrounds (FECCA 2015).
- Neuropsychological tests of cognitive impairment designed for English speakers have been shown to be unsuitable for diagnosing people from non-English speaking backgrounds (Low *et al* 2012).

For more information on the CALD dementia action plan, contact Dr Samantha Croy at S.Croy@nari.edu.au.

**The consumer perspective: see next page**

## References

- Access Economics (2009) *Keeping dementia front of mind: incidence and prevalence 2009-2050*. Alzheimer's Australia.
- Federation of Ethnic Communities Councils of Australia (FECCA) (2015) *Review of Australian research on older people from cultural and linguistically diverse backgrounds*. Low L-F, Draper B, Cheng A *et al* (2009) Future research on dementia relating to culturally and linguistically diverse communities. *Australasian Journal on Ageing* 28 144-148.
- Low L-F, Harrison F, Kochan NA, Draper B, Slavin MJ, Reppermund S, Sachdev PS, Brodaty H (2012) Can mild cognitive impairment be accurately diagnosed in English speakers from linguistic minorities? Results from the Sydney Memory and Ageing Study. *American Journal of Geriatric Psychiatry* 20(10) 866-877.



■ Associate Professor Bianca Brijnath (pictured) is Director of Social Gerontology at the National Ageing

Research Institute (NARI); Stephanie Ellis is Assistant Director of the NHMRC National Institute for Dementia Research (NNIDR); and Dr Samantha Croy is an NNIDR Project Officer and Research Assistant based at NARI

# My wish: diversity in dementia research

**Danijela Hlis** is among the consumers, researchers and service providers contributing to the dementia research action plan for CALD communities in Australia. Here she gives a consumer perspective on why it is crucial to include CALD participants in dementia research

**M**y wish for 2019 is to increase participation in research for people living with dementia and carers from culturally and linguistically diverse (CALD) and Aboriginal and Torres Strait Islander (ATSI) backgrounds in order to improve their quality of life and care. It's a wish I have had since I became involved in dementia research more than 10 years ago. The discussion of improved inclusion and participation of all Australians in dementia research was first voiced at the inaugural meeting of the former Consumer Dementia Research Network (CDRN), under the umbrella of what was then Alzheimer's Australia (now Dementia Australia) nearly a decade ago.

People living with dementia and their carers in the CALD communities represent a large part of our population, but their diverse needs are being ignored. I believe that to obtain accurate findings, research must be conducted with participants from all Australian communities and not state that "Participants must be proficient in English", which is current practice among researchers.

How can we work towards inclusive, respectful, dementia-friendly communities by continuing to discriminate? How can we hope for efficient knowledge translation if a person living with dementia and their carer and/or support worker are not driving the research according to their everyday needs?

My fellow participants of a recent CALD-specific dementia research workshop hosted by the National Ageing Research Institute (NARI) and the NHMRC National Institute for Dementia Research (NNIDR) in Melbourne (see article p14) shared my views, which are that:



The author, Danijela Hlis (third from left), with some of the other participants at the NARI/NNIDR CALD dementia research workshop in Melbourne at the end of 2018, (from left) Helena Kyriazopoulos, Tina Karanastasis (both from Greek backgrounds), Cristina Giusti (from an Italian background) and Ada Cheng (from a Chinese background). Photo: NARI

- All organisations dealing with dementia, research and care and the government policy makers need to collaborate.
- Competitiveness in the research funding process should not be a deterrent for such collaboration.
- Cultural and linguistic challenges and the associated additional cost for researchers are only seen as barriers because the benefits of inclusive research are difficult to show in dollars and have not been looked at. Similar applies to knowledge translation. Tonnes of multicultural facts sheets, videos, booklets, bicultural posters and apps about dementia have been created *but* have we ensured their dissemination into hospitals, residential care facilities, respite day centres, bicultural clubs, even churches? Have we trained health professionals, carers, support workers, occupational therapists and lifestyle and leisure coordinators to know how to use them? SBS radio and TV should be advertising them too.

It is a step forward for the Government to give us programs like Speak My Language (2017) in which I am involved as a bilingual facilitator for the Slovenian, French and Italian languages, and where I will try to raise awareness of the importance of dementia research.

To increase the involvement of CALD Australians in research we need to accept that with the progression of dementia, thousands of people living with the condition cannot speak up. They are forgetting English or they cease being verbal, so family carers and interpreters are of utmost importance to them and we need to respect their right to be involved. Some current dementia publications, pamphlets and brochures, containing sentences like "Please talk to me, not my carer" (Dementia Australia) need to be redesigned to be *people friendly*. Yes, for people with certain types of dementia, in certain stages of dementia, their right to be involved and included, listened to and engaged in communication is paramount. But for others, a

sentence like this, for example, would be more appropriate: 'My English is fading due to dementia. Please engage my carer and an interpreter to be my voice'.

To embrace human rights, we need to (a) raise awareness of the importance of dementia research, and (b) enable all people willing to participate to do so by providing training and support.

We know that CALD carers cannot find ethnic-specific respite, are not well educated about dementia and are not able to access bicultural tools and resources; so we need to reach out to them and get them involved. If knowledge translation about the use of bicultural tools does not improve, if participation of CALD clients in dementia research is not increased, people of CALD background face very sad lives. To be included, irrespective of our diverse cultural background, is our human right.

Reaching these types of individuals to volunteer to participate requires improved awareness among the general public and among the medical community about dementia and dementia research. Cultural and linguistic differences do affect awareness and participation. For example, in some cultures the word 'dementia' is not used; the word 'carer' does not apply, as partners and adult children are deemed responsible for assisting a family member; and questions such as 'who is the head of the family?' are important.

Cultural and linguistic challenges and possible additional cost for researchers are nothing compared to the benefits of inclusive research: increased human rights, a decrease in discrimination, improved person-centred care

and quality of life, decreased carer stress and illness and improved working conditions for staff. Let us not forget the worker in aged care/dementia – the least respected, and poorly rewarded – many of whom are of CALD background. They need education and support to start being involved and to participate. There is not enough research dealing with the importance of improved understanding of the needs of people with dementia, triggers for responsive behaviours, and possible enablers/tips for support workers of CALD clients in residential care facilities.

The management and staff at my mother's facility, where she spent the last two years of her life because I was too ill to have her at home with me, were so grateful when I gave them free culture awareness workshops. I did this not just to show them how to better care for their client (my mother) who was diagnosed with dementia and spoke no English, but how to actually enjoy their work more by getting to know her and learning a few words in her mother tongue.

When my mother was upset about something and, according to staff, "difficult to manage" and I was not nearby, I told them to give her a hug and say, in Slovenian, "kako lepa si" ("you look so beautiful"). This would often resolve the issue and a smile would return to her face. An Italian resident, who sometimes hit his head against the wall repeatedly, was fond of Italian songs. We had a Talking Photo Album in the care home

and the staff would play him the song *O sole mio* from the album. Soon he was at peace, sitting and listening to the song. The French lady screaming all the time "Je veux rentrer chez moi" ("I want to go home") was reassured and calmed once staff could understand what she was saying. Antipsychotics were no longer needed.

I am sure any researcher would feel great pride knowing that by embracing diversity and inclusion our understanding and ability to meet the needs of different groups of people improves and so does the opportunity to find the cause and cure for dementia.

May 2019 bring us a clear vision to embrace diversity in dementia research. ■

■ Danijela Hlis was born in Slovenia and is a writer, an advocate for people with dementia and volunteers with people living with dementia who are of CALD background. She has also been involved with the former Alzheimer's Australia's Consumer Dementia Research Network, the Migrant Resource Centre and Multicultural Council in Tasmania, the Federation of Ethnic Communities Councils of Australia Inc and Council on the Ageing (COTA). Contact her at: [bonjourjoie@netspace.net.au](mailto:bonjourjoie@netspace.net.au)

#### References

- Dementia Australia website (no date) *Talk to me! Good communication tips for talking to people with dementia*. Available at: [www.dementia.org.au/resources/talk-to-me](http://www.dementia.org.au/resources/talk-to-me)
- Speak My Language (2017) *Radio conversations about ageing well in Australia*. Commonwealth Government. Available at: [www.speakmylanguageradio.com](http://www.speakmylanguageradio.com)

# Little changes

**Alison Schmidt** explains how staff at Yathong Lodge worked together to devise a simple but powerful solution to improve the quality of life for a woman who was experiencing severe trauma during personal care

The experience of dementia is vastly different for each individual. No two people will respond the same to a particular stimuli, and what works for one person may be a trigger, and counterproductive for another. We see repeatedly in practice the value of non-pharmacological interventions, small details that make a world of difference; a little bit of time for meaningful engagement, a comfortable and homely environment, and care being provided that is aligned to each person's preferences (Soril *et al* 2014).

To decipher how this may look for an individual, staff need to take the time to get to know the person, speak with their loved ones, and try to understand what the person might be thinking or feeling, and why they may be reacting in a particular way. This is often easier said than done, and is the challenge of providing quality, person-centred care in dementia.

#### Uncomfortable memories

For people with traumatic memories, as dementia causes them to lose touch with reality the impact of these can become more and more evident from day to day. As dementia progresses, uncomfortable memories often resurface as a person becomes less able to use learned cognitive strategies for managing them (Flannery 2002).

For one particular woman with dementia admitted to our unit, Yathong Lodge, who we will call Mary, this had become her reality. Yathong Lodge is a 16-bed unit within Wagga Wagga Base Hospital, and part of its Mental Health Service.

Eight of the beds are specifically devoted to people with dementia experiencing responsive behaviours. People are admitted to Yathong Lodge from across the health district who are unable to be supported or cared for within their environment due to the severity of their symptoms. The length of stay varies significantly – from a week to months, depending on the person's needs and housing situation.

Mary had grown up in England during the war and it was suspected that she had been sexually abused as a child. For Mary, taking her clothes off had become so traumatic that she had not showered in six months. Following admission to our unit Mary's incontinence became nightly, making a morning shower unavoidable. However, every shower triggered traumatic memories and Mary reacted aggressively, making it increasingly difficult for the staff who were supporting her, and leaving Mary in an unhappy mood for the rest of the day. After a traumatic morning there was very little that could be done to bring a smile to her face, and the things that she usually loved, such as listening to Slim Dusty or Shirley Temple music, her stuffed animals, or books with colourful pictures, did little to improve her mood.

#### Trying different strategies

Staff experimented with using different strategies for approaching Mary when providing personal care, including the use of a 'dignity gown' to make her feel less exposed, playing her favourite music, and a friendly, slow



**NARI Director Associate Professor Briony Dow speaking at the CALD dementia research consultation workshop in Melbourne**



# can make all the difference



Staff at Yathong Lodge turned an unused staff bathroom into a space just for Mary where she would feel comfortable. They placed a clearly labelled 'Ladies Toilet' sign on the door and pictures of her favourite pink flowers and baby animals on the walls

approach from our nursing staff. This made little difference to Mary's quality of life, and it appeared there was little that could be done to ease the daily trauma she experienced around showering.

An attempted discharge to a residential aged care facility lasted only five days and Mary returned to our unit. Reports from the care home of Mary's severe aggression during personal care, and an incident where five staff members were called to restrain her during a shower made it clear that something needed to change.

During her time in our unit we had noted that Mary always reacted negatively to male co-patients and quickly became defensive as soon as anybody came near her. As our unit is located in an old building, it has only two communal bathrooms for the eight-bed dementia wing. As

with most hospital bathrooms, these are non-gender specific, and present as being sterile and uncomfortable. The environment alone was enough to terrify Mary.

## A new idea

After many staff meetings to discuss possible strategies to help Mary, we came up with a new idea; what if we found a bathroom for only Mary to use? If the bathroom and the task of getting undressed was something she associated with a traumatic past, how might she react if the bathroom was a space just for her? We trialled turning an unused staff bathroom into the safe space she needed. Mary loved animals and anything pretty and feminine, so we worked to turn the spare bathroom into an environment that she would like to be in. We placed a clearly labelled 'Ladies Toilet'

sign on the door and covered the walls with pictures of pink flowers and baby animals.

When she first walked into 'her' bathroom, Mary's reaction changed immediately, with her focus shifting to the pictures on the walls. The result was that instead of being overwhelmed by dread at the thought of going to the bathroom, it became a place where Mary felt comfortable. Because she felt comfortable there, she began to identify the urge to use the toilet, which we had not seen from her in the months she had been in our care. Mary started opening her bowels on the toilet there, rather than being incontinent regularly, and this had a huge positive impact on her care.

Now that she was using the toilet throughout the day, her overnight faecal incontinence dramatically reduced, meaning those morning showers were no longer a strict necessity.

This has made a world of difference to Mary, with a significant improvement in her state of mind, meaning she is able to interact more positively with the people around her, and spend her time doing the things she enjoys.

## Take-away learning

The take-away learning from Mary's story is the value of the little things. Gathering information about a person's life on admission is crucial to providing person-centred care, and it is often in this that hints and clues of what might work for somebody can be found. In our unit we do this by engaging with the person's family, talking to them about their relative's history and their life. On admission we ask each patient's family to complete a

Top5 form\* and a life story book, as well as list the person's music preferences.

Mary's family, whilst limited in the time they could spend due to distance, were very happy to share stories of her life, revealing her suspected trauma, as well as clues for engagement with her now based on her younger life.

## A holistic approach

By consulting the family and gathering information we can use the person's history and personal preferences to engage them in meaningful activity and develop strategies to prevent responsive behaviours from escalating. Some of the strategies we have found to be extremely beneficial are music therapy and the use of a robotic tiger, purchased from a local toy store, which individuals can engage and interact with. We also have psychiatrists who assess the medications a person is taking and modify these as appropriate.

As a vital part of this process we hold regular meetings as a whole team to discuss responsive behaviours and collectively problem-solve a consistent approach. This enables the team to share strategies, ideas and to learn from each other's successes and mistakes. As many staff as possible, including nursing, allied health and management staff, at all levels, attend these meetings. Even the regular cleaners on our unit get to know the patients, and will feed anything of note back to clinical staff.

## Never give up

As Mary's case has highlighted, the solution is rarely straightforward, but

\*The Top5 form can be used by multiple service providers in hospitals, aged care facilities and the community to promote person-centred care in people with dementia and communication problems. Carers share up to five essential strategies or care tips that would assist staff in supporting the person. This information is written onto the Top5 form. The template form is freely available to download at: <http://bit.ly/TOP5form>

trying to view the situation from the perspective of the person and problem solving why somebody might be acting in a particular way can be a good place to start. There were many times as a team that we felt defeated and helpless working with Mary. During the seven months she was with us the team felt we had tried everything. Creating the special bathroom was one of many strategies we had worked through and trialled, with others seeming hopeful one day, and being counterproductive the next.

Whatever a staff member's position, they have a vital role to play in the quality of care an individual receives, and have valuable insight into the approaches that may work. The key is to not give up on a person and it is always worth trialling strategies that may seem 'outside of the box' because it is often these little changes that make all the difference. ■



■ Alison Schmidt is an Occupational Therapist at Yathong Lodge in Wagga Wagga, NSW. Contact her at [alison.schmidt@health.nsw.gov.au](mailto:alison.schmidt@health.nsw.gov.au)

#### References

- Flannery RB (2002) Addressing psychological trauma in dementia sufferers. *American Journal of Alzheimer's Disease and Other Dementias* 17(5) 281-285.
- Soril LJ *et al* (2014) Effective use of the built environment to manage behavioural and psychological symptoms of dementia: a systematic review. *PLoS ONE* 9(12): e115425. doi:10.1371/journal.pone.0115425.

# Fellowship program supports lasting change

**Christine While** explains how the Dementia Training Australia Fellowship program helps build capacity within organisations to improve the delivery of dementia care

In 2017, Victorian aged care organisation Homestyle Aged Care Services became early adopters of the Tailored Training Package service offered by Dementia Training Australia (DTA). They were particularly interested in participating in the Fellowship program.

The focus of the DTA Fellowship program is to build capacity within change-ready organisations to improve the delivery of care. This is achieved by supporting leadership-ready individuals to implement knowledge into practice within the workplace. The Fellowship program uses a knowledge translation framework (Goodenough *et al* 2017) that increases the dementia care workforce's awareness of best practice dementia care; encourages their agreement and readiness for change; enhances practical skills through the adoption of the new practice; and supports lasting change.

The Fellowship program is led by the DTA team at La Trobe University in Melbourne. As the program leaders, myself and DTA Director Dr Margaret Winbolt work closely with the Fellows over nine to 12 months to undertake a project that is directly related to dementia care, informed by research evidence and aligned to their organisation's strategic direction or model of care. Through regular monthly meetings and brief coaching sessions the Fellows develop or enhance their skills to lead staff through the steps associated with practice change.

The Fellows are supported to:

- access the best evidence in dementia-related practice and speak to topic experts;
- learn how to plan and manage a project;
- put systems in place to drive sustainable practice change; and
- provide evidence through evaluation that the new intervention makes a difference to the lives of people with dementia.

#### Homestyle Fellows

Homestyle Aged Care Services has provided residential aged care and services in the greater Melbourne metropolitan and Geelong areas for almost 30 years. A number of its pioneering directors of nursing and facility managers stepped forward to participate in the Fellowship. They became our Homestyle Fellows.

The four Fellows' projects were innovative and inspiring and included: establishing a consistent staffing model for residents living in the dementia unit, which resulted in a team of skilled and knowledgeable staff with a shared vision for dementia care; improving the way in which the residents' life story was incorporated into direct care, which enabled the team to use lifestyle patterns to inform personalised care plans and understand responsive behaviours; and the introduction of the CAUSED problem-solving tool (O'Toole 2017) and concept mapping (Aberdeen 2015) into assessment and care planning

activities, enabling a preventative rather than a reactive approach to responsive behaviours.

The fourth Fellow, Julie Gray at Homestyle's Sea Views Manor care home, wanted to facilitate a meaningful connection between residents and families who were separated by distance. Her project is described on the next page.

#### The role of the Fellowship

Reflecting on the Fellowship experience, Julie said that the support from the DTA team was "incredibly helpful and empowering [and] essential for us being able to deliver real, tangible results for our residents."

DTA staff supported Julie in developing leadership skills, which clearly reaped rewards: "Engagement, enthusiasm, adoption and adherence from staff within the unit enabled this project to be successful," she said. ■

#### References

- Aberdeen S (2015) Concept mapping: a tool for improving patient care. *Nursing Standard* 29 (48) 49-58.
- Goodenough B, Forbes F, Fleming R (2017) KT workshops support shift from 'thinking' to 'doing' in dementia care. *Australian Journal of Dementia Care* 6(1) 29-31.
- O'Toole G (2017) CAUSED: effective problem solving to support well-being. *Australian Journal of Dementia Care* 6(1) 15-16.

■ Christine While is a Learning Consultant, Research Fellow and RPN at Dementia Training Australia. For information about Tailored Training Packages and the Fellowship program visit [www.dta.com.au](http://www.dta.com.au)

# Reconnecting with families

**Julie Gray** reports on one of the DTA Fellowship projects – a successful initiative at Homestyle Aged Care to facilitate more meaningful long-distance connection and engagement between residents living with dementia and family members who are unable to visit

**P**hone conversations with family members are not always easy for people with dementia who may find it confusing hearing a disembodied voice without being able to see the person's face. Meanwhile, relatives can often feel frustrated and disappointed at the lack of engagement from their loved one during the call. This was the experience of many family members of residents in the dementia-specific unit (DSU) at Homestyle Aged Care's Sea Views Manor in Victoria.

To improve engagement, Alana O'Keefe, a personal care attendant and lifestyle assistant in the unit, suggested introducing a program to support residents with advanced dementia in the unit to make video calls with their family members via Skype using an iPad, mobile phone or computer.

In 2017 a Fellowship Program as part of Homestyle's Tailored Training Package with Dementia Training Australia (DTA) (see story previous page) gave me the impetus to implement Alana's idea.

The six-month project, which we called Families Reconnecting and Embracing Dementia (FRED), ran from March 2017 until the end of August 2017 in Sea Views Manor's 15-bed DSU.

In the early stages of the project a literature review of Australian and international studies on the use of Skype to support people with dementia, provided by DTA Learning Consultant Christine While, showed that, despite advances in technology, this was a relatively unexplored area for researchers.

The aim was to provide a more meaningful long-distance connection and engagement



**Sea Views Manor resident Elizabeth with lifestyle assistant Alana O'Keefe. Elizabeth and her family loved the option of using video calls to keep in touch. Elizabeth is now in contact with three family members who live interstate and overseas that she was previously unable to speak to over the telephone. Photo: Homestyle Aged Care**

between residents living with dementia and their families who were unable to visit, leading to a better sense of self and decreased feelings of isolation and abandonment for the residents. We hoped that we might see an improvement in the quality of conversation between families and residents, but were unsure if the use of technology would be too confusing for residents with dementia.

The objectives were to:

- Increase residents' verbal communication through positive face-to-face interaction.
- Increase their wellbeing and sense of self by providing an

opportunity to reminisce and spend face-to-face time with families who were unable to visit.

- Provide an environment and tool which enabled residents to communicate without confusion or stress.

The project involved five residents, all from the facility's DSU and one interested family member for each resident (up to three for each resident were invited to participate).

However, as the project gained momentum, further members of two families became involved. One of the residents started touching base with her daughter in

Queensland, but over time grandchildren and great grandchildren (born during the project) also became involved in video calls, at their request.

The project was limited to the DSU to ensure a closed group of staff from the unit (23 in total).

Residents who participated in the trial were chosen because they had:

- a documented diagnosis of dementia, in its advanced stages
- adequate sensory and language capacity to participate in video calls
- at least one family member who – due to distant living arrangements – was unable to visit regularly, but continued to remain in contact via telephone and was willing and able to participate in the video chat.

## Project implementation

Initially family members 'booked' times for the video calls to reduce any possible anxiety or stress for residents. As the project progressed calls became less scheduled and the presence of staff was reduced to create a more natural process of conversation and communication. Staff would set up the call and then observe quietly from a distance, returning only to assist when the call was finished.

All staff working in the dementia unit were briefed before the project started so they could note any changes in residents' responses to the calls. At Sea Views Manor the majority of staff in the DSU are dedicated unit staff who work closely with these residents during multiple shifts per week and therefore know their personalities, likes and dislikes.

We also communicated and discussed the project at resident

and relative meetings, as well as during staff meetings before and during the project.

## Evaluation

At the outset of the project we gathered baseline data before, during and after regular telephone calls between the five residents and their relatives. We observed and recorded the amount of time these calls lasted as well as the residents' ability to communicate and understand the calls. This was later compared with data collected before, during and after each of the Skype video calls over the six-month project.

Nursing, care and diversional therapy staff collected the data. This included observations and assessments of residents' wellbeing, sense of self and ability/desire to communicate before, during and after the telephone and video calls. Residents' own observations and self-reports were also documented.

Family members completed a simple questionnaire before and after the project, and willingly gave regular feedback throughout. Participating families were asked how they felt the calls using a regular telephone were received/understood by their loved ones. At the end of the project the family members were again contacted and asked the same questions in relation to the Skype video calls.

All DSU staff were involved in discussing and reporting any changes noted in resident wellbeing or communication with other residents after the video calls.

## Findings

In their initial observations of regular telephone calls, staff saw that residents were often confused by being handed a cordless phone – out of which a 'disembodied' voice could be heard. Residents would put the telephone down and walk away, or hand it back to staff, unsure what to do with it. Family members reported their loved one "drifting off" mid-call and losing interest in the conversation.

Most families stated that they often felt frustrated and disappointed at the lack of engagement they received from their loved one with dementia during the calls. Some wondered if their relative even knew who they were talking to.

Very early on in the project it became evident that residents were more able and willing to communicate with family members when they could see the person they were speaking with on a screen. Their confusion was lessened greatly by visual cues from the screen.

Telephone and video calls were timed. Telephone calls lasted an average of four minutes, while video calls lasted on average 18 minutes, as residents became engaged with their family members.

As the project progressed, facilitating the resident-to-family conversations required less prompting and supervision from staff. By the end of the project two residents were able to be left unsupervised and unassisted for the duration of the video call.

Staff reported that residents were more conversational with other residents in the hour following a video call, and appeared to be more in touch with their sense of self. Residents would often initiate sharing personal information with others, saying things such as, "My daughter lives in Queensland" or "When the babies were born everyone was sick".

Following video calls, staff would often prompt residents to share information about themselves and their families. Residents were enthusiastic and more able to share pieces of their life stories that the call had triggered. This helped staff to learn more about the resident as a person and, in turn, may keep residents connected with their sense of self for longer as the calls trigger memories and offer reminders of who they are.

Feedback and satisfaction from family members about the quality of communication and apparent lack of confusion associated with video calls was also positive from the outset.

While initially there were a few problems relating to internet connection, or family members forgetting to call at a specific time, relatives said they preferred video calls to telephone calls.

Towards the end of the project one resident was transferred from the DSU into another area of the facility due to complex health reasons. Family members supported the relocation only on the condition that the Skype video calls would continue weekly in the new unit.

One family member who visited daily used video calls to remain in close contact while travelling overseas for three weeks. The video calls enabled both parties to connect daily, thus decreasing the resident's sense of isolation and abandonment during that time.

## Gains made

Families definitely found the video calls useful over the longer term. They are able to watch the progression of dementia through these calls and find it less confronting when they do visit their loved ones. Video calls have allowed staff to capture the resident when they are engaged with activities or others – families have seen their loved ones singing or reminiscing – and the relatives have loved being able to see these moments that they thought never occurred.

## Challenges

Due to a lack of equipment and internet access (our facility is large and the Wi-Fi signal does not reach all areas of the home), Alana donated her own iPad and mobile phone for use during the project. This limited the days and times that calls could be made and was the reason why call times were initially 'booked'. On occasions, due to the success of the video calls, Alana would come in on her own time to enable families to connect during special events, for example Mother's Day.

One family member forgot about the call on one occasion, leaving the resident upset and

confused as to what was happening. On another occasion, family attempted to call while a resident was in some distress and the call had to be rescheduled.

## The scene now

Nearly two years on, due to its success and positive feedback from all parties, video calls have continued within the DSU and two residents elsewhere in the facility – in the higher dependency units – are now using this form of communication with their relatives. We also now have the use of a computer in a meeting room at the front of the facility for residents to make video calls.

With more iPads, more staff learning how to make and facilitate these calls and improved Wi-Fi service we would love to eventually open this up to the entire facility as there would be many more residents and families willing to participate if offered.

The project details have been uploaded to the Homestyle website and Facebook pages and there has been some positive feedback and questions from care service managers at our other homes as a result. Alana and I are also willing to advise other aged care organisations interested in implementing this form of communication for residents. ■

## Acknowledgments

Thanks to Dementia Training Australia (DTA) for the opportunity to undertake the project. Support provided by DTA Director Margaret Winbolt and DTA Learning Consultant Christine While has been incredibly helpful and empowering. Thanks also to Alana O'Keefe for her ongoing commitment and attention to make this project work. Without Alana, The FRED Project would never have existed.



■ Julie Gray is a Registered Nurse and Clinical Services Manager at Homestyle Sea Views Manor, Ocean Grove, Victoria. Contact

her at care5@homestyleagedcare.com.au

# Residential care – but not as we know it

**Denise Edwards** describes her vision of an ideal integrated residential aged care village, designed to support a life that is manageable, understandable and meaningful for people with and without dementia. Her hope is that it will inspire policy makers, aged care providers and others to think more creatively about residential care

This is about my desire to change the way the aged care sector delivers residential care in the future by using a salutogenic approach, where lifestyle is the key component and where excellent health care is delivered discreetly.

## So what is salutogenesis?

'Salutogenesis' was developed by Aaron Antonovsky, and derived from the Latin term 'salus' meaning health and 'genesis' meaning origin. His concept is based on a health continuum where wellness is more than just the absence of an illness or disease (Hyatt-Burkhart & Owens 2016). Antonovsky studied the influence of stress on health and discovered that people with minimal stress in their life experienced better health outcomes, which he referred to as a 'sense of coherence' (SOC.) He believed that a SOC is only achieved when the person's world is understandable, manageable and has meaning. He also discovered a direct relationship between the strength of someone's SOC and the person's ability to employ cognitive, emotional strategies that are likely to improve coping which results in wellbeing (Stickley & Hoare 2015).

## For someone with dementia

Antonovsky's first belief, that the world is understandable, is about the person's ability to make sense of their life history, their context and their current circumstances. He believed that without this fundamental understanding people are not able to make the most of circumstances or negotiate life's challenges. He believed that an environment that is designed to enable



The author, Denise Edwards, with her father. He is not living with dementia, but has inspired her to articulate her vision for a different style of residential care

the person rather than disable the person will help make the context more understandable, which in turn will alleviate the stress caused when the person can't find familiar areas or does not know what to do at certain times of the day (Jonas *et al* 2014).

Antonovsky's second point, that the world is manageable, is about the person's ability to manage activities of daily living and focus on physical aspects of their lives. In my experience physical care in a residential setting is often identified as the priority area and lifestyle is often under resourced.

His third point, that the world has meaning, is about the foundation of the desire and motivation to live. Whilst this can be difficult to define, as everyone experiences meaningfulness differently, research tells us that meaningfulness is found in personal connections, responsibilities and making a

contribution to a person's community (Jonas *et al* 2014).

It is therefore important that we strive to provide a model of care that focuses on health and wellbeing, where the emphasis is on enabling the person living with dementia to make the most of their life, where the environment in which they live is enabling, where their world is manageable by providing the components described in Maslow's hierarchy of care (Hagerty 1999) and where meaningful relationships and opportunities to contribute to their community are encouraged.

## Comprehensible, manageable, meaningful

So, what can an aged care service do to strengthen the sense of comprehensibility, manageability

and meaningfulness for the people who live there? Transferring Antonovsky's salutogenic model to aged care requires us to think outside the box and move away from the medical model that is delivered in the majority of aged care residential services in Australia and around the globe.

How can we deliver residential care for someone living with dementia that provides them with opportunities to be the best they can be, live in an environment that enables them to have a good life where their human rights are respected, their individuality is embraced, they are empowered and where the people who support them can enable them to make choices and have meaningful relationships? It's my experience that whilst this is still achievable in a mainstream residential care home it is much more challenging when you are constantly battling against

an environment that has an institutional feel to it as it is all too easy to become task-focused.

### The ideal village

The ideal 'salutogenesis' village I am going to describe is designed for people living with dementia and those who do not live with dementia, which enables couples to stay together and does not segregate. It is multicultural, embraces diversity and breaks the mold by focusing on one important question for the people who live there: 'What matters to me?'

Let's use my own father as an example. My father needs his correct medications, assistance with activities of daily living and a clean and safe environment, but what matters to him is that his iPad is charged so he can make contact with his friends in the UK and he has enough dog biscuits to make sure my dogs have their daily treats. If those small tasks are not attended to, his day will go from bad to worse and if this continues he could become withdrawn, even depressed, as the important things in his life have been taken away. Too often we consider people's needs above what really matters to them.

### How does it look, feel and sound?

The village adjoins a regular housing estate in the suburbs. When you approach and walk up the entry path you will be greeted by the resident dog that leads you to a reception area where you are welcomed by a lovely lady who alerts the manager. You later learn that this lady also lives in the village and volunteers on reception two days a week, along with four other residents who cover the other days. She lives with dementia and now has a very important role to play that has improved her self-esteem and provided her with a sense of purpose.

There are over 100 volunteers at the village, some living with dementia, who all have a very specific role based on their life skills and knowledge. There is also a volunteer advocacy service for people who do not have any family or support. People living with dementia are employed to manage the 'Dementia Hub' where volunteers visit people living with dementia in the community from early diagnosis to end-of-life, providing advocacy support and liaison with health care professionals and appropriate services.

There are 20 six-bedroom houses, all with individual designs and names, painted different colours and with different front doors, and a post box outside. Each has a small front garden



**The De Hogeweyk dementia care village in the Netherlands, where three-wheel bikes are used for transport**

and a large yard area which is dog friendly and ideal for many of the residents who have dementia dogs to assist them.

There is no need for signage in the houses as they are small and easily navigable, with no possibility of getting lost. All bedrooms have different coloured doors and the interior has different colour schemes to aid wayfinding. The ensuites feature contrasting toilet seats, walls and floors. All the drawers in the bedrooms are labelled and the wardrobe has a glass window so residents can view their clothing. Lighting meets best practice guidelines, lamps provide a calming effect and smart lighting is timed to come on at specific times to assist people to find the toilet at night. Residents have individualised music playlists which can be piped into their bedroom.

The kitchen is the hub of the home, with a large table where residents can sit and talk, watch others cook, stir the cake mix or use the blender. Staff, who don't wear uniforms, are known as Lifestyle Partners and support the residents to prepare meals and use the dishwasher.

There is a lovely smell of freshly baked cakes and bread. Meals are often eaten in the dining room adjacent to the kitchen or outside when the weather is not too hot. The garden is inviting and sensory, with lots of edible things to pick and make jams and cakes with. Flowers are collected and used for table decorations and everyone has a role to play in making the home as beautiful as possible. They also have a part to play within their community, whether it is feeding the dog,

cat or birds, laying the tables, collecting the eggs, chopping vegetables, dusting, watering the garden, raking the leaves or cleaning.

Volunteers are specifically trained to support people to continue to care for their pets. There's also a Pet Day Care centre for staff and residents' pets. Residents can visit, even if they don't own a pet, to help with grooming and feeding.

There are information stations around the village where residents can press a button for assistance and someone will walk with them to help them find their way. Some residents also carry GPS trackers.

There are trips to the village shop and into the local community to buy the supplies for the day. Intergenerational programs have been developed and there is a child care centre on site where residents visit and assist with the programs.

The village has a hydrotherapy pool with disabled access, a cinema, village shop, hairdresser, barber, allied health services, GP, dentist, café, a small chapel, remembrance garden and pet cemetery, children's playground, a petting zoo, hen house, men's shed, barbecue area and a recreational room that's also hired out to the community.

A shop run by the residents sells things that are made on the premises. All the village shops use real money as this can assist with longer-term memory and a sense of familiarity (Mendes 2015). The home has three-wheel bikes, like those used at the De Hogeweyk dementia care village in the Netherlands, that staff, volunteers and families can use to take residents for a ride around the village.

The village doesn't have a minibus. Instead, the money that would have been spent buying and maintaining the bus is used to pay for taxis to take residents and volunteers to appointments and clubs in the community. There is also an electric car programmed to take people to various areas of the village.

There is a museum that is used for reminiscence therapy and a music and therapy room where residents and members of the community can enjoy tai chi, yoga and exercise classes. There is even a gym with equipment designed specifically for older people to improve muscle strength and mobility.

All areas in the village are well signed and there is a village green where the local schools play cricket at the weekend. There is a miniature golf course and a bowls club which is also used by the community.

Each resident has access to a number of

'Friends' who are volunteers and assist them to make the most of their day, whether it is going for a coffee, to appointments, taking them to the chapel, for a ride around the village to meet their friends, or looking after their dog.

Each resident is encouraged to spend time outside and feel the sun on their face, not only to encourage wellbeing but also to boost vitamin D required for bone, muscle and overall health.

### Meaningful and engaging lifestyle

Montessori principles for older people are adopted (Ducak *et al* 2018), where every person living in the village is assessed for what they can do rather than what they can't. The Lifestyle Partners know the people in their home well and support them to take on a role in their community. There is no distinction between lifestyle and care roles; everyone is a Lifestyle Partner who supports the person to be the best they can be. Staff are creative and innovative and build good relationships with family members. The Lifestyle Partners always try to find a solution to any challenges, working in partnership with the person, their family and friends.

Everyone is enabled to continue with their hobbies and interests, both within the home and in the community. Intergenerational programs happen regularly, with local schools hosting morning teas and residents teaching the children skills like crocheting and knitting. In turn, the children teach the residents how to use iPads and tablets to access games and activities, as well as Facebook and WhatsApp to keep them connected to their families.

### Health care delivered discreetly

All residents are regularly assessed for pain, mobility, infections, depression, delirium, anxiety and weight loss as well as other health issues that are common in older people living with dementia. Registered Nurses (RNs) concentrate on the residents' health issues and provide health care discreetly from an on-site village clinic where residents access their medications so the dining room experience is not interrupted. If residents cannot attend the clinics the RNs will visit them at their bedside or their choice of venue. The RNs do not have to answer general inquiries, fill shifts etc; they are responsible only for providing the best quality health care without any unnecessary interruptions. At night they monitor the residents from the clinic via cameras in communal areas and sensors in private areas such as bedrooms, bathrooms and toilets.

Nursing staff work with the GP to

ensure that medication is written up at the time that the person requires it so if someone always has a sleep-in they can continue to do so and still receive the correct medication and dose.

Antipsychotic, psychotropic and sedatives are rarely given to residents at this village as there is no need.

Physiotherapists provide excellent mobility and fall prevention programs and everyone is encouraged to be as mobile as possible with individual aids prescribed to support independence. There is a 'Life is for Living' program where residents and their family and friends are assisted to skydive, scuba dive, jet ski, travel and enjoy other activities that are usually deemed 'too risky' and not age appropriate.

Residents are able to stay in their home in the village until they die as 24/7 nursing care and excellent palliative care is available. Volunteers and staff also care for the families when the person is sick or dying and families and pets are able to stay with their loved ones.

### Providing the best day possible

In this village residents living with dementia are able to call each staff member and other residents by name as they all wear large-print, colour-contrasted name badges. Technology is used to support the residents and some wear glasses that identify the name of the person they are speaking with.

Staff speak clearly and slowly, and always in a caring and compassionate manner, so the person living with dementia is able to process the information and have enough time to make the choice asked of them. Lifestyle Partners work at a pace that the residents are comfortable with. Assessments are strength-based and concentrate on what the person can still do rather than what they can't do. The resident's extended family becomes the staff's family and excellent relationships are fostered.

All staff, no matter what their role, are trained in basic dementia care. Staff are given the opportunity to enroll in the Diploma in Dementia Care, the Bachelor of Dementia Care and Dementia Essentials courses, and Montessori Environments to support older people living with dementia are developed and implemented. Staff receive regular in-house training on lifestyle, health needs, Montessori principles and how to prevent responsive behaviours. Property services staff are educated and knowledgeable in contemporary dementia care practice and understand how a dementia-friendly environment should function.

### An achievable dream

This model of care is achievable, and some providers are already incorporating some of these features into new developments. This model provides an environment where people feel safe, can remain well both psychologically and physically, where there is limited stress, where human rights are respected, people are empowered to make choices, and meaningful relationships are fostered and encouraged and where people living with dementia can be all they can be.

This is salutogenesis in practice. Now let's build it! ■

■ Denise Edwards is studying a Bachelor of Dementia Care at the University of Tasmania and works full-time in aged care. Contact her at [edwards.dg@bigpond.com](mailto:edwards.dg@bigpond.com)

**This article is an edited version of Denise Edwards' essay, *Residential care but not as we know it: a salutogenic approach to caring for people living with dementia, and how residential care can support a life that is understandable, manageable and meaningful*. The essay won 2<sup>nd</sup> prize (2<sup>nd</sup> Year Category) in the Dementia Training Australia (DTA) National Storytelling Competition 2018. Details: [www.dta.com.au/storytelling-comp/#denise](http://www.dta.com.au/storytelling-comp/#denise)**

**For more information on the salutogenic approach in dementia care, see *Salutogenics and residential care for people with dementia* by Jan Golembiewski which appeared in the June/July 2017 issue of *AJDC*, pp 25-28.**

### References

- Ducak K, Denton M, Elliot G (2018) Implementing Montessori methods for dementia in Ontario long-term care homes: recreation staff and multidisciplinary consultants' perceptions of policy and practice issues. *Dementia* 17(1) 5-33.
- Hagerty MR (1999) Testing Maslow's hierarchy of needs: national quality of life across time. *Social Indicators Research* 46(3) 249-271.
- Hyatt-Burkhart DH, Owens EE (2016) Salutogenesis: using clients' strengths in the treatment of trauma. *Counselling Today* 58(11) 50-55.
- Jenkins C, Smythe A (2013) Reflections on a visit to a dementia care village. *Nursing Older People* 25(6) 14-19.
- Jonas WB, Chez RA, Smith K, Sakallis B (2014) Salutogenesis: the defining concept for a new healthcare system. *Global Advances in Health and Medicine* 3(3) 82-91.
- Mendes A (2015) Vintage sweets and nostalgic villages for people with dementia. *Nursing & Residential Care* 17(8) 450-453.
- Stickley T, Hoare M (2015) Notes from the field: a review of the concept of salutogenesis and its significance for promoting mental health recovery through participatory arts. *Journal of Applied Arts & Health* 6(1) 63-75.

# Death and dying in dementia care: a good end?

Many health professionals are unaware that dementia results in death. Failing to acknowledge it as a life-threatening condition results in sub-optimal support for the dying person and their family. Families may also have limited awareness of dementia's outcome, reducing their preparedness for death. When general practitioners (GPs) show a limited understanding of dementia as a terminal illness, their care of people in the advanced stages is compromised. Medical undergraduates may receive a one-hour lecture on dementia, hardly equipping them for exposure to the disease in hospitals, residential aged care homes or the community.

Dementia is the second highest cause of death, next to heart disease, and for women it is the most common cause of death (Dementia Australia 2018). What does this significant knowledge deficit mean for the person dying with dementia and their families? What kind of care and support will they receive? This article raises some of the urgent issues needing to be addressed and offers some guidance in response.

## Diagnosis

One way of introducing appropriate care and support for a person dying with dementia is for professional carers to note what constitutes their diagnosis of dementia. When and by whom was this diagnosis made? Has the diagnosis been confirmed and by what means? What type of dementia is it? What information has been given to the family? Do staff understand the significance of the different types of dementia and the associated prognoses?

In a recent interview, the co-chair of the US Alzheimer's Association Diagnostic Evaluation Clinical Practice Guideline workgroup noted, "...there is data to show that upwards of half the people who end up in nursing homes that are in later stages of dementia actually have never been given a formal diagnosis. That's not right," (Medscape website 2018). Unless these discussions are initiated by health professionals, many people with dementia and families miss the opportunity to recognise the dying trajectory and to plan for a dignified death.

On the other hand, knowing the facts about each person's specific dementia diagnosis and type can influence a more comprehensive process, particularly in residential aged care homes where many people with advanced dementia are cared for. Families can be educated, with written material provided in their own language if relevant. Regular education sessions may be offered to staff and families. This is not to suggest the focus should be on death from the time of the person's admission. However, if opportunities for timely discussion are missed, families may remain uninformed about options for end-of-life care. Without such information comments such as the following may be heard:

- "You don't die of dementia."
- "She's no longer a person."
- "She'd be better off dead."
- "His life's not worth living."
- "For me, she died many years ago, when she lost her mind."
- "Shoot me if I ever get like that!"

What is conveyed by these statements? For example, how would the last statement affect the care of a frail older person with dementia? If I think this person would be better off dead, would I be prompted to provide the very best care possible, or would I begrudge the effort?

Does the plea, "Shoot me if I ever get like that!" really mean I would prefer to be murdered than cared for? Similarly, if I think such a person should be shot, there is no allowance for compassion or holistic end-of-life care.

When an elderly female partner of a person with advanced dementia says: "He's no longer a person", what does this convey? How may she be encouraged to consider him, not as inhuman, but still a person despite his deficits? What remains? How does she know he cannot hear her, or know she's there? What prompts may she be given to reassure her that her presence may still have meaning, particularly at the end of his life?

I know of a gentleman who had been caring for his wife at home for many years, as her Alzheimer's disease slowly progressed to the stage where there was no alternative to aged care home admission. The nurse checking the admission details

**Rosalie Hudson** explores a range of issues that shape care practices to support a person dying with dementia, including ethical decision making, language, pain management and the place of hope, and offers some guidance in response

asked the gentleman about visiting his wife, suggesting that he must now be exhausted after his years of care. "It's time for you to have a break now", she said, hoping to be reassuring. "Your wife won't know whether you've visited or not, she no longer knows who you are, so why don't you come less often?" His response was to remind the nurse very gently, "She may not know who I am, but I know who *she* is."

## Language for death and dying

The commonly used term 'pass away' is often shortened to 'pass' or 'passed' or 'passing'. "I'm ringing to tell you your father has just passed," said the night nurse to the nursing home resident's son. "Passed *what*?" he replied, not understanding the ambiguous message. Or, using another euphemism, a nurse with no knowledge of the family circumstances said to the patient's wife: "I'm so sorry to be ringing you at this hour, but your husband has *gone*". "Gone *where this time*?" was the frustrated response from the person who had lived with her husband's "wanderings" for more than 10 years. While society in general appears reluctant to speak of 'death' or 'dying' or 'died', the use of various euphemisms by professional staff can easily lead to misunderstanding. Such outcomes are compounded when there has been no attempt to prepare families for the person's death. As death for a person with dementia seldom occurs suddenly, opportunities should be given for careful planning, including frank discussion of death and dying.

## Palliative care

Palliative care, when understood in its entirety, has hopeful connotations for those dying with dementia. When



palliative care was first introduced, it only applied to people with cancer; it now encompasses people living with any incurable illness, including dementia (van Riet Paap *et al* 2015). Furthermore, it is not generally understood that people dying with dementia have symptoms similar to those dying with cancer (Cole *et al* 2006). The result of this misunderstanding is that many people die without hope, their basic needs unmet. Similarly, families are not always informed about the terminal nature of dementia and the benefits which can ensue from palliative care (Hudson & O'Connor 2007). For example, such discussion may include the issue of inappropriate admission to hospital and the use of other overly aggressive or futile treatment.

Palliative care is often regarded as care in the final days or hours of life ("We'd better call in the palliative care team. She looks as though she won't last the weekend!"). With thoughtful, comprehensive planning a palliative approach to end-stage dementia care can be offered well before the dying phase. Such an approach, which may include pain relief, how or when to offer food and fluids and other issues of palliation, does not necessarily involve a specialist palliative care team – it is the *approach* that counts.

This approach asks: what are the goals of this person in this situation? It is an approach that prepares families for the uncertainties of prognosis and empowers them with knowledge of what is available. What preferences are outlined in this person's Advance Care Plan? Rather than wait until death is imminent, it is good practice to involve the family in a meeting to discuss the goals of care, in enough time for effective planning. If this is well documented, commonly heard disputes can be avoided, such as: "I think mum

should go to hospital." "Well, I don't! I know she'd much rather stay here!"

Palliative care does not mean ceasing all treatment, as some believe, or the excessive use of opioids. Families need education about the inclusive nature of palliative care which focuses on the holistic needs of the person, including psychological and spiritual care as well as physical.

### **Pain management**

Prominent in the research literature is the lack of adequate pain management for people with end-stage dementia. It is frequently undetected or inaccurately assessed, particularly in those who cannot verbally report their pain or point to its intensity on a visual analogue scale. While people with dementia have similar painful comorbidities as an older person without dementia, their pain is not readily acknowledged because they have no words to describe it. Does this mean they have less pain? Failure to adequately address pain management in end-stage dementia care is an urgent ethical issue. While it is difficult to assess the level of pain in a person without speech or with seriously impaired cognition, it is unethical to ignore it. One way of addressing this issue is to use readily available assessment tools designed especially for those with poor cognition or no speech (The Australian Pain Society 2018).

### **Family involvement**

Verbal reports I've received indicate that some families of people with dementia are not receiving enough relevant information. One person had the courage to articulate her anger when she realised what she had *not* been told, relating to the imminent death of her father. Sadly, this lack of knowing the facts and lack of

involvement in decisions resulted in a less than optimum dying process for her father. Who is responsible for these discussions? If nobody is responsible then, more than likely, there will be no discussion. Consequently, more and more families are left with no opportunity to ask questions, let alone receive answers. A key point in any context where a person with dementia is being cared for is to raise the question: 'Who will speak with the family, and when?'

### **Quality of life**

"She's got no quality of life" is a judgment frequently made not only by family members but also by some staff in hospitals or aged care homes. Families may be told there is little or no hope for improvement in quality of life. "She can't do anything for herself" may belie the truth that this person, albeit with end-stage dementia, may still be able to turn the pages of a magazine, or lift a glass of brightly coloured drink to her lips, or respond to music using headphones. With comprehensive information from family members and imaginative care planning, many against whom this judgment is made may exhibit surprising signs of remaining 'quality' in their lives.

### **Person or non-person**

Sabat (in Sabat & Harre 1992, p444) questions whether a person with dementia can be described as someone who has suffered 'loss of self' or personhood. He maintains, "...there is a self, a personal singularity, that remains intact despite the debilitating effects of the disorder...". In other words, the social and publicly presented person can be 'lost' but only *indirectly* because of the condition. Sabat believes one of the main problems is with those who do not have dementia, who generally regard the person with dementia as 'helpless' or 'confused'. He says that we place the person with dementia in jeopardy when we 'label' them according to our criteria. For example, why do we describe a person with dementia as 'wandering aimlessly'? If the same person chose to sit and flip through a magazine would she have been described as being engaged in 'irrational or aimless reading'? Sabat maintains that the self of personal identity "remains intact even in the face of quite severe deterioration in other cognitive and motor functions" (1992, p459). This distinguished dementia researcher counsels his readers not to make assumptions about quality of life or loss of personhood or general incapacity based on our own criteria. We should not, therefore, assume the person with dementia has 'lost their mind'.



Photo: Shutterstock

# Palliative care resources

**Palliative Care Needs Round Checklist** (Palliative Care Australia 2017) is a simple, easy-to-use checklist for palliative care needs rounds that can help improve the quality of life and death for nursing home residents. The evidence-based checklist was based on data, descriptions and interviews which captured what occurred during monthly palliative care needs rounds. Available at: <http://bit.ly/roundchecklist>

**The Palliative Care Evaluation Tool Kit** (Centre for Health Service Development, University of Wollongong 2004) is a compendium of tools to aid in the evaluation of palliative care projects. Available at: <http://bit.ly/evaluationtoolkit>

**End of Life Directions for Aged Care (ELDAC)**, a government-funded initiative that aims to connect people working in aged care to palliative care and advance care planning information, resources and services, has developed five online toolkits providing the latest clinical evidence, learning opportunities and tools to support palliative care and advance care planning. Available at: [www.eldac.com.au](http://www.eldac.com.au)

**palliAGED** provides links to palliative care evidence and resources for aged care professionals which may inform discussions and practice around decision-making, communication and assessment for people with dementia approaching the end of their life. Available at: [www.palliaged.com.au/tabid/4248/Default.aspx](http://www.palliaged.com.au/tabid/4248/Default.aspx)

**CareSearch Palliative Care Knowledge Network:** provides information about palliative care for patients, carers and families as well as for health professionals. Topics for health care staff include common care issues at the end-of-life and communication skills for end-of-life discussions. Available at: [www.caresearch.com.au](http://www.caresearch.com.au)

**Advance care planning in aged care: a guide to support implementation in community and residential settings** (Advanced Care Planning Australia April 2018): free to download at: <http://bit.ly/acpaguide>

**Palliative Care NSW** has online resources to educate and equip professionals, volunteers and the community about palliative care. Available at: [www.palliativecare.nsw.gov.au/new/get-equipped/resources/](http://www.palliativecare.nsw.gov.au/new/get-equipped/resources/)

Many readers will be familiar with the writing of Tom Kitwood, with his specific emphasis on the *personhood* of the human being with dementia. In one of his earlier articles he states: "The presence of dementia on a large scale in contemporary society, and the dire process which it often entails, raises very deep questions about what it means to be a person" (Kitwood & Bredin 1992, p270). According to this account, the personhood associated with dementia is deeply paradoxical. On one view, he or she is and will remain a person while many factors indicate their personhood is diminishing. According to Kitwood and Bredin the answer lies in relationships, for, they say, "...interdependence is a necessary condition of being human" (p284).

Christine Bryden, speaking from first-hand experience as a person living with dementia, raises questions about death and dying from the depth of her own existential crisis. On the question of dying with dignity she asks: "Will I have any personal resources left within me to deal with it?" (2016 p273). In this text and several others, Bryden emphasises the need for people with dementia to have their personhood sustained by

relationships with others. "Like you", she says, "we are human beings with emotional and spiritual needs. We are more than mouths to be fed, bodies to wash and clothe... Help us find meaning and affirm our humanity as death approaches" (p190).

## Who is this person?

To emphasise person-centred care it may be helpful for aged care homes to provide a short, well-written profile of each resident with dementia, accessible to all staff members. Examples abound to demonstrate how knowing the person's background can help staff to understand that person's behaviour. Staff at one aged care home had no idea a resident whose obsession with managing/organising was related to her academic doctorate in public policy; she had been a distinguished people manager. Another resident panicked when he heard the meal bell – staff had not realised he'd been a fire fighter and he assumed this was his call to action. Another resident was labelled as cantankerous and loud-mouthed until it was explained she had been a prominent civil rights activist, often using her loud voice at protest rallies. Such narratives are

important in helping to craft a person-centred care plan which acknowledges the uniqueness of each person's life. Here's another example:

A former professor of music, Frank's favourite instrument was the flute. He now lay in his care home bed with no speech, little independent movement and his hands always tightly clenched, fingers separated by carers with great difficulty. His wife had an idea! She brought him his beloved flute and placed it on his chest. Slowly, but very purposefully, Frank uncurled his fingers and caressed the flute. Would this action have been an appropriate inclusion in his daily care plan?: 'Spend a few minutes several times per day encouraging Frank to hold his flute'. Unfortunately, this expectation was beyond the capacity of the care home's routine. Fortunately, his wife had access to a musician who would visit regularly and play the flute for Frank, encouraging him to hold it afterwards. Frank remained connected to his flute until close to the time of his death.

These examples indicate the scope of imaginative, personalised care that can be offered to a person dying of dementia. However, the move from ideas to everyday care requires sensitive leadership from those who have a comprehensive knowledge of advanced dementia and the difference such knowledge can make for the dying process.

## Leadership in dementia care

Poor leadership in dementia care results in increased stigma, lack of attention to detail and lack of sensitivity to the unspoken and therefore unmet needs of people with dementia in any care setting. Lack of appropriate leadership also results in poor decisions at the end of life, and little understanding of a palliative approach for end-stage dementia. When the management team pay little regard to education, careful recruitment and identifying and correcting shortcomings in care, the result can be devastating for the person dying with dementia and their family.

On the other hand, when continuous education is the focus, such knowledge can translate into comprehensive, person-centred care. Most relatives have had little education in the complex nature of dementia. When, for example, the aged care home takes proactive steps to address this anomaly, there is increased potential for excellence in end-of-life care, both for residents and their families.

When staff are valued, incentive is accentuated: "Marj, I noticed how kind you were when speaking to George this

morning. Even though he may not understand I'm sure he appreciates that you care about him." Alternatively, when poor care is identified: "Marj, I heard you refer to George in rather derogatory terms. You may assume he does not understand, but to respect his basic human rights, you should always speak kindly to him and about him."

### Lingering memories

Dame Cicely Saunders, founder of the modern hospice movement, knew better than most of her medical colleagues the qualitative difference humane bedside care could produce. She had, personally, kept vigil at hundreds of bedsides, leading her to observe: "How people die remains in the memory of those who live on" (cited in *BMJ* 2013).

In whatever role we undertake we have the capacity to focus on important ethical issues, doing all in our power to influence a dignified death and dying for those in our care. While people dying with dementia suffer significant memory loss, carers whose memory is intact can influence the memories of those who live on. ■

■ Associate Professor Rosalie Hudson is a Registered Nurse, Honorary Senior Fellow in the School of Nursing and Social Work at The University of Melbourne, Adjunct Associate Professor, Charles Sturt University, and a consultant educator in palliative care, aged care, dementia and spirituality. Contact her at: rehduson1938@gmail.com

### References

- The Australian Pain Society (2018) *Pain in residential aged care facilities: management strategies*. Sydney: APS.
- British Medical Journal (BMJ) (2013) *Helping patients die well* 346 f2656.
- Bryden C (2015) *Nothing about us, without us! 20 years of dementia advocacy* London and Philadelphia: Jessica Kingsley Publishers.
- Cole L, Farrell M, Duff E, Barber J, Egan GF, Gibson SJ (2006) Pain sensitivity and fMRI pain-related brain activity in Alzheimer's disease. *Brain* 129 (Pt 11) 2957-2965.
- Dementia Australia (2018) *Dementia statistics*. Available at [www.dementia.org.au/statistics/](http://www.dementia.org.au/statistics/)
- Medscape website (2018) *First Alzheimer's guidelines for clinical practice released*. Available at: [www.medscape.com/viewarticle/899674](http://www.medscape.com/viewarticle/899674)
- Hudson R, O'Connor M (2007) *Palliative care and aged care*. Melbourne: Ausmed Publications.
- Kitwood T, Bredin K (1992) Towards a theory of dementia care: personhood and well-being. *Ageing and Society* 12 269-287.
- van Riet Paap J, Mariani E, Chattat R *et al* (2015) Identification of the palliative phase in people with dementia: a variety of opinions between healthcare professionals. *BMC Palliative Care* 14 56.
- Sabat S, Harre R (1992) The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society* 12 443-461.

# 'But I just want to go for a walk': different approaches to risk and freedom



Following a three-month study trip to Australia, German Registered Nurse, PhD student and Nursing Scientist **Anne Bleckmann** reflects on the significant differences she discovered in how German and Australian aged care organisations deal with risk and freedom for residents

The positive impact of a well-structured environment that enables people with dementia to use the abilities they still have has been shown in research during the past two decades (Fleming *et al* 2016). Tools like the Environmental Audit Tool (EAT) (Fleming 2011) and the Environmental Audit Tool – High Care (EAT-HC) (Fleming & Bennett 2015) have been used in Australia to assist aged care providers recognise the strengths and weaknesses of their environments and to improve the support they provide to people with dementia. There is no equivalent tool available in German so, as part of my Masters Degree in Nursing Science at Witten/Herdecke University, Germany, I have undertaken to adapt the EAT-HC to the German aged care setting. To generate a good culturally-adapted German tool version, I visited the developers at Dementia Training Australia. There we discussed the main issues I had found with understanding the Australian concepts of caring for people with dementia.

As Germany and Australia have similar issues of an ageing society with relatively few human resources to care for the elderly, I thought there could not be so many differences in dementia care, especially in the long-term residential care setting. But on taking a closer look, I found there is a big difference in what is understood by security and safety for

those residents. German and Australian aged care staff have very different ways of dealing with natural or constructed borders between an aged care facility and the outside area.

This article presents an overview of how aged care organisations in Germany accommodate people living with dementia and examples of ways to provide freedom of movement despite the difficulties in wayfinding and the verbalisation of needs associated with the progression of dementia.

### Similar demographic changes

The populations of Australia and Germany are both facing a change in their structure; 21% of Germans (2015) and 15% of Australians (2017) are 65 years and older, and already in need of care or at a high risk of needing care in the future (Statistisches Bundesamt 2018; Australian Bureau of Statistics 2018). Furthermore, the baby boomer generation will increase the need for professional aged care. Table 1 (see p28) shows figures for the Australian and German populations, the current number of people living with dementia and the number of residential aged care places.

### Points of difference

The demographic background of both countries is similar and suggests that the requirement for well-designed and



Residents at a German aged care home taking part in a local community event

sustainable aged care facilities addressing the needs of people with dementia is as strong in Germany as in Australia. However, my translation of the EAT-HC into German revealed some differences in approach. The starting point for this translation was a focus group with German aged care staff and nursing science students. The EAT-HC questions that provoked the most discussion were those about security and safety, especially locked doors and access to outdoor areas (see Figure 1 below).

In Germany, only a few aged care homes have secured areas. In all other areas residents are allowed to leave the facility when they want. This realisation led me to look at the aged care setting and the general conditions for caring for people with dementia in Australia to understand how things function in the tool's country of origin.

### The rights of people with dementia in Germany

To understand the confusion of German care staff and the research team working on the German version of EAT-HC, it is helpful to know about the German legal context of caring for people with dementia. There are different acts that have an influence on the rights of people with dementia. First of all, there is the United Nations Convention on the Rights of Persons with Disabilities that tells us to treat people with dementia as equals (United Nations 2006). Even the first article of the German Constitution, the Basic Law, says: "Human dignity is inviolable" and further, that everyone can choose for themselves where they want to stay. Even if people are at the onset of a cognitive impairment or already have

severe dementia, these laws are still valid.

Of course, there has to be a regulation that helps with decision-making for people with dementia if they are not able to make decisions for themselves. If this becomes necessary, a relative or an official guardian has to take out a guardianship for them. The areas covered by this guardianship are strictly regulated and are restricted to things that the person with dementia has decided on in the past

or those which a judge has ordered. If there is no legal document about this but there is a demand for a guardian, the guardianship court has to appoint someone to take on this role. The important condition is that a person takes decisions according to the will of, and on behalf of, the one who cannot decide any longer (Bayerisches Staatsministerium für Gesundheit und Pflege 2018). This method perhaps seems a little complicated, but helps avoid undermining the will of those who need help in daily living and can no longer verbalise their wishes.

The accommodation of people with dementia is another special topic which the guardian is only partially responsible for. That means they are not allowed to decide that a person living with dementia is to live in a secured area in residential aged care. In general, no resident can be locked up simply because they want to go outside the care home.

These methods also apply to other ways of restraining people in their freedom: in a pharmacological way or with mechanical restraints and even locked (front) doors that cannot be opened by the residents.

With this knowledge of the German legal system, it is perhaps easier to understand why the German aged care staff and nursing students had

UNOBTRUSIVELY REDUCE RISKS	
1	Can people who live in the unit be prevented from leaving the garden/outside area by getting over or under the perimeter? (NA = no outside area)
2	Can people who live in the unit be prevented from leaving the garden/outside area through the gate? (NA = no outside area)
3	Can the front door leading out of the unit be secured?

Figure 1: The questions above, from the Environmental Audit Tool – Higher Care (EAT-HC) relating to one of the Key Design Principles 'Unobtrusively reduce risks' (Fleming & Bennett 2015), provoked the most discussion among German aged care staff and students

	Australia	Germany
<b>Inhabitants</b>	24.9 million	82.7 million
<b>People (65 years and older)</b>	3.8 million (15%)	17.5 million (21%)
<b>People with dementia</b>	298,000	1.4 million
<b>Nursing homes</b>	2,760	13,596
<b>Care places in long-term care</b>	182,302	928,939

Table 1: Overview of aged care in Australia and Germany (AIHW 2017; ABS 2018; Statistisches Bundesamt 2018)

reservations about the 'safety and security' questions in the EAT-HC.

### Responsibility and risk

In general, there is no obstacle to a resident in an aged care home in Germany going for a walk outside, enjoying the sun in the garden or just walking to the nearby cemetery to visit the grave of their spouse, for example (see box on p29). But of course care staff feel responsible for the residents and want to care for them, so these situations can be quite stressful for staff and families. One way to ensure safety would be to prevent the person going outside the home on their own, even to a secure garden. But there are real problems with this so-called 'solution' – for example, the fall rate can increase when people are restrained (Möhler *et al* 2012).

The challenge is multidimensional. First of all, care staff may not know where the person wants to go and if there are potential risks that can hurt them. They may not trust the resident's capabilities, even if they are in the early stage of dementia. They may assume that people with dementia cannot make their own way to a familiar place outside the care home or ask for directions. Another problem is the misunderstandings about the quality of life of people with dementia living in aged care homes. Family members are happy if they see their mum or dad sitting in a chair, watching birds through the windows and get a smile when they come to visit. But even sitting in an armchair from which you cannot stand up by yourself can be a type of restraint. The physical safety that can be provided in moments like this is not matched with emotional safety.

### Dealing with the consequences of freedom

In Germany it is not permitted to restrain people living with dementia, to place



As not every resident is able or wants to join the group outside, they can watch from the balconies of the aged care home

## A plan for getting out and about

Mr Becker\*, 82, has lived in the community aged care home of a small town with 3000 inhabitants in the north-west region of Germany for two months. He has been diagnosed with early stage dementia and has diabetes. His old friends from school also live in the facility and he feels well here spending time with them, remembering their shared past or playing cards in the evening. Up until recently he was able to go for a walk outside on his own, using a walking aid. Mr Becker's wife died two years ago and he liked to visit her grave every day at the cemetery that is just five minutes away from the nursing home. He also liked to walk to the grocery shop. When his wife became ill he had loved doing the grocery shopping, showing her that he could also cook for her as she has done for him.

Unfortunately, as his symptoms of dementia worsened, Mr Becker's ability to speak decreased and he didn't know the way back to the aged care home when he went to the shop on his own. The primary nurse now caring for Mr Becker held a case conference with him, his son Michael, the social worker and other team members to talk about the worries they had with this situation and to find a common solution.

They were able to make some suggestions that enabled Mr Becker to continue many of the daily activities he was used to, but also provide security in moments when he might not remember where he was or where he wanted to go. So, for example, one of his friends, who isn't cognitively impaired but could also use this daily exercise, agreed to accompany him to the shop and the cemetery.

In the case conference the primary nurse also asked Mr Becker about his former hobbies and if he had attended a club. This knowledge gave the staff a broader base from which to draw information about the reasons why Mr Becker might react in a certain way or how they might respond more appropriately to his needs when he can no longer verbalise these in the later stages of dementia.

*\*Not his real name*

them in dementia special care units without legal approval or lock the front doors of aged care homes, even at night. But there are other measures used in Germany to provide for the security and safety of residents while supporting their right to self-determination.

Some of these are common to the Australian aged care setting, but perhaps just have different names:

- Guidelines like the *Werdenfelser Weg* to enable aged care staff to avoid restraining residents and checking the options for accommodation if it is

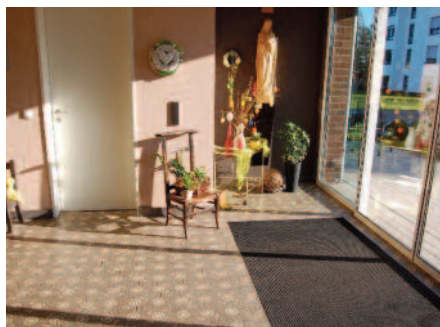
necessary (Bayerisches Staatsministerium für Gesundheit und Pflege 2018).

- Using alarm systems that ring when a resident is standing at the main door of the facility.
- Sensor mats that alert the staff at night when a resident leaves their bed.
- GPS-trackers for a person who wants to go for a walk and may not find their way back (however, this can only be used with the permission of the person or their guardian).

### Challenges with freedom of movement

While these measures give people living with dementia freedom they can also result in high stress levels for staff. In the unlikely event that a resident does not return or is not brought back by a member of the community, the police need to be informed and bring them back if there is danger in delay. Sometimes residents' relatives do not understand the legal reasons that explain why the care staff have not prevented their mother or father from going outside and they reapproach the care staff.

There is a narrow margin between the ethical principle in respect of the autonomy of a person and the safety from



The front door of this aged care home in Germany is made of glass and opens automatically so residents can see the outside and can go there without help or in a wheelchair



**The kitchen and lunch area in an integrated aged care unit in Germany. Residents with and without dementia help to prepare meals and decide what will be cooked each day**

danger that care staff want to provide. But despite the difficulties and the stress, in my opinion, it is good to provide open doors and an outside space with no borders to the community to maintain the human rights of freedom of movement. It also helps residents maintain a sense of meaning and connection in their daily lives, even after moving into an aged care home.

### Conclusion

From my experience of Australian aged care homes and my knowledge as a Registered Nurse in the German care setting, I believe that there is a big difference between the countries in terms of seeing and defining safety and security in residential aged care. It seems to be based on different legal regulations regarding the accommodation of people with dementia in aged care facilities and the difference in the general conditions of rights for people with cognitive impairment.

This experience, based on the different understanding of the 'simple' question of safety for people living with dementia, reinforced in my mind how important it



**A homelike atmosphere also includes items that provide the opportunity to do something alone such as reading books, listening to music, or looking at old photos of the local community**

is to reach a common international definition of dementia as a disability so that those concerned get the same rights as everyone else who wants to live a meaningful, self-determined life. ■

### References

- Australian Bureau of Statistics (2018) *Population*. Available at: <https://aifs.gov.au/facts-and-figures/ageing-australia/population>.  
 Bayerisches Staatsministerium für Gesundheit und Pflege (2018) *Verantwortungsvoller Umgang mit freiheitsentziehenden Maßnahmen in der Pflege*. München: Bayerisches Staatsministerium für Gesundheit und Pflege.  
 Deutscher Bundestag (2007) Grundgesetz.

- Australian Institute of Health and Welfare (2017) *Australia's welfare 2017*. Canberra: AIHW.  
 Fleming R (2011) An environmental audit tool suitable for use in homelike facilities for people with dementia. *Australasian Journal on Ageing* 30(3) 108-112.  
 Fleming R, Bennett K (2015) Assessing the quality of environmental design of nursing homes for people with dementia: development of a new tool. *Australasian Journal on Ageing* 34(3) 191-194.  
 Fleming R, Goodenough B, Low FL, Chenoweth L, Brodaty H (2016) The relationship between the quality of the built environment and the quality of life of people with dementia in residential care. *Dementia* 15(4) 663-680.  
 Möhler R, Richter T, Köpke S, Meyer G (2012) Interventions for preventing and reducing the use of physical restraints in long-term geriatric care: a Cochrane review. *Journal of Clinical Nursing* 21(21-22) 3070-3081.  
 Rothgang H, Iwansky S, Müller R, Sauer S, Unger R (Eds) (2010) *BARMER GEK Pflegerreport 2010*. St Augustin: Asgard-Verlag.  
 Seidl U, Lueken U, Volker L, Re S, Becker S, Kruse A, Schröder J (2007) Nicht-kognitive Symptome und psychopharmakologische Behandlung bei demenzkranken Heimbewohnern. *Fortschr Neurol Psychiatr* 75(12) 720-727.  
 Statistisches Bundesamt (2018) *Staat & Gesellschaft: Pflege*. Available at: <http://bit.ly/2UX62TA>  
 United Nations (2006) *United Nations Convention on the Rights of Persons with Disabilities*. Available at: <http://bit.ly/2ECcuul>
- To follow up on this article, contact the author at [anne.bleckmann@uni-wh.de](mailto:anne.bleckmann@uni-wh.de)**

## Risk and dementia: resources

**Supported decision making and risk** is a new six-minute film developed as part of the Cognitive Decline Partnership Centre's project on supported decision making. The film looks at what is supported decision making and why it is important, and how to enable choice in the context of risk. The video includes contributions from a person with a diagnosis of dementia (Theresa Flavin), family carers (Ron Sinclair and Karine Shellshear), a geriatrician (Professor Susan Kurlle) and an aged care facility manager (General Manager, HammondCare residential care, Angela Raguz). The film emphasises the importance of knowing the individual: as Raguz says, "Knowing and understanding the person is key to looking at what risk does mean for the individual, as one person's risk is another person's life." The film is available on the CDPC website (<http://sydney.edu.au/medicine/cdpc/>) or via [bit.ly/2s4Fov4](http://bit.ly/2s4Fov4)

Monash University Professor Joseph Ibrahim is touring Australia with his award-winning short film, **Dignity of risk** (2016). The 15-minute animation features an encounter between geriatrician Prof Joe and a patient, Mr Jones, who has recently been diagnosed with dementia. The film raises questions relating to protecting Mr Jones from harm vs intruding on his enjoyment and quality of life. The film has screened at six international film festivals, including winning the category of Best Narrative Film at the Global Impact Film Festival 2017. Professor Ibrahim is available to host screenings of the film, which are followed by an informal lecture (45 minutes) with an opportunity for questions from the audience to explore the notion of dignity of risk for older people, how living with the impact of dementia is constructed, the role of aged care facilities, and the complex interplay between individual, family and organisational requirements to manage risk. For more information, go to Professor Ibrahim's website where he discusses ageing issues, including risk, at [www.profjoe.com.au](http://www.profjoe.com.au)

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.

## Frontotemporal dementia: the real lived experience

Severe symptoms are to be expected in people with behavioural variant frontotemporal dementia, at least according to the official diagnostic criteria. But is this always the lived experience? **Reinhard Guss** and colleagues conducted interviews which told a rather different story

**D**iagnostic criteria for behavioural variant frontotemporal dementia (bvFTD) give a rather disturbing list of symptoms. Yet there is limited research on the experience of living with this form of dementia and how it impacts on aspects of everyday life such as relationships, sociability and wellbeing. In the research reported here, we wanted to find out to what extent the lived experience fitted with the diagnostic criteria.

It is no surprise that the diagnostic criteria (Alzheimer's Society 2017) for bvFTD have led to a somewhat negative portrayal which can be daunting for someone newly diagnosed with the condition, especially while they are coming to terms with their diagnosis and learning strategies to live well with it. Moreover, it affects others' perceptions and expectations of them.

Frontotemporal dementia is an umbrella term for a varied group of progressive neurological disorders, including bvFTD, which affect

the frontal and temporal lobes of the brain causing atrophy and deterioration of function (Mayo Clinic 2016). People with FTD can undergo changes in their personality and behaviour, some of the most prevalent behavioural changes including an absence of basic and social emotions, disinhibition, decline in grooming and hygiene, generalised apathy, hyperorality, gluttony, altered preference for sweet foods and stereotypical utterances (Snowden *et al* 2001).

More specifically, bvFTD itself results in dysfunction in portions of the brain that regulate socioemotional behaviour such as the orbitofrontal cortex and amygdala (Scherling *et al* 2017, Kipps *et al* 2009). Diagnostic literature lists symptoms such as making inappropriate jokes and comments, impulsive and rash behaviour, and atypical emotional expression (Alzheimer's Society 2017; Dementia UK 2017).

Additionally, some accounts focus on antisocial and criminal behaviour such as



■ Reinhard Guss is a clinical psychologist at Sussex Partnership Foundation Trust and the dementia workstream lead for the British Psychological Society's Faculty of the Psychology of Older People; Chris Norris (left above) is Kent and Medway NHS and Social Care Partnership Trust (KMPT) service user envoy; Chris Ryan (right above) is a member of the Dementia Engagement and Empowerment Project (DEEP) network; and Morgan-Wallis Egremont and Megan Roby are psychology students at the University of Kent, on placement in KMPT Psychology Services for Older People. All are based in the UK.

theft, trespassing, public urination, violence (Liljegen *et al* 2015, Miller *et al* 1997), aggression, obsessive and compulsive behaviour (Alzheimer's Society 2017, Dementia UK 2017) and

sociopathic acts (Mendez *et al* 2005). Further research has shown links with hypersexuality, sexually disinhibited behaviour (Alzheimer's Society 2017, Mendez & Shapira 2013, Liljegen *et al* 2015, Mendez *et al* 2005, Miller *et al* 1995), and sexual attraction to minors and animals (Boutoleau-Bretonnière *et al* 2015).

In our research, two people with a diagnosis of bvFTD took part in semi-structured interviews to explore how their personal experience of the disorder corresponded with the diagnostic criteria, which were formalised in 2011 under an agreement known as the international consensus. We wanted to generate a better understanding of bvFTD among those with a new diagnosis, their families and friends, healthcare professionals and the wider public.

Our interviews challenged misconceptions and stereotypes. We were able to explore behavioural and cognitive presentations of symptoms, how our

## Chris Norris: my views on the project

The more that Chris Ryan and I discussed things with Reinhard and the students, the greater the realisation dawned on all of us that although Chris and I had many of the characteristics of bvFTD, neither of us had behaviour patterns at the extremes outlined in the textbooks such as throwing our clothes off or making untoward advances/comments to or in front of the general public.

Neither of us shout, scream and swear at others or have become violent. It's said that people with FTD don't have awareness or insight around what we say and do but, for us, that wasn't the case. On the majority of occasions we displayed that we had insight into what we were saying or doing at the time or were able to reflect on what had occurred afterwards and realise/remember what had happened when things were outlined to us.

Sometimes we could be a bit snappy with others and, when the words were out, mostly we realised what we had said. If this was not at the time, then when someone immediately afterwards pointed it out, we were able to recognise that what we had said,

or done, was maybe outside the parameters of normal acceptable behaviour. We both agreed that although these things were normal when living with FTD, neither of us would want to use this excuse for bad behaviour and we generally pay extra attention to keeping things in check.

We realise this is our condition currently and that changes are likely and are occurring gradually to us. Both of us are past the five-year point since diagnosis and, although our behaviour filters are gradually deteriorating, we are by and large aware of what we say or do.

We also established that the textbooks stated that memory loss was not a real factor of FTD but that we both have difficulty with the memory and recollection of recent events and facts etc, contrary to what is taught around FTD.

There were other aspects around the condition of FTD that we appeared to experience differently from that stated in the textbooks but, as the article is concentrating on behaviour and insight, I will not go into them here. I hope what I have written above will go some way towards making the article a success for this journal.

interviewees interpreted and perceived these symptoms, what impact the symptoms had on their everyday lives, what emotions they felt, how they were treated by others and what they found beneficial and therapeutic.

## How did we prepare?

In preparation for our workshop at the UK Dementia Congress in 2017, we researched bvFTD, exploring journal articles, dementia educational websites, textbooks and the clinical features set out in the international consensus criteria (Rascovsky *et al* 2011). As a result of this research we drafted semi-structured interview questions, shaped in part by the following six clinical features:

- early behavioural disinhibition
- early apathy or inertia
- early loss of sympathy or empathy
- early perseverative, stereotyped or compulsive/ritualistic behaviour
- hyperorality and dietary changes
- neuropsychological profile changes, i.e. executive/generation deficits with relative sparing of episodic memory and visuospatial skills (Rascovsky *et al* 2011).

## What did we find?

There were some surprises in our key findings from the semi-structured interviews, arising from the fact that some of the cognitive and behavioural symptoms were presented in a way that contrasted with the diagnostic criteria and the research literature. The surprises we have chosen to focus on are insight, socially disinhibited behaviour and memory.

Past research has tended to give precedence to the carer's perspective rather than that of the person with bvFTD (Goldsmith 1996). The common assumption has been that people with bvFTD lack insight into their behavioural presentation and difficulties (Bozeat *et al* 2000) and that their experience is consequently without much value to researchers (Rankin *et al* 2005). Our interviews, in contrast, indicate that both participants were able to acknowledge how their behaviour had changed and recognised when it was offensive, inappropriate or harmful to themselves and others.

One of our interviewees, Chris Norris (co-author), said:

*We think we've got insight – me and Chris [fellow interviewee]. Because we can see what's*

*happening and tell what's happening and stuff like that, but they say we can't. And we can. We want to prove to them that you can have insight. Because we know what's going on – but we're not meant to know all that. So it's yeah, we've definitely got insight.*

Chris N also talked about his reaction to the condition:

*The apathy has got worse, I just feel like sometimes I can't be bothered, I think "why do I have to do this?" I deliberately do not watch daytime television; if I do I could just sit there for hours. Because of this, I try to keep myself busy.*

Socially disinhibited behaviour was described by both interviewees as speaking out of turn, becoming agitated with others and talking to strangers with familiarity. But neither was comfortable with some of the standard examples given in the literature. Our second interviewee, Chris Ryan (co-author), commented:

*We deviate from the standard description of FTD; especially socially inappropriate behaviour. It is suggested that people with FTD run around naked without clothes on – we shout, scream and swear at everyone, but that is not the case. We do show socially inappropriate behaviour, but it's*

*more like sometimes we say things that could be considered rude or should not be said.*

Chris N was concerned about how his behaviour would be perceived by others:

*I do feel worried about how people feel and think about my behaviour. When it comes to jokes, I sometimes feel like people do not think I'm joking and this worries me. I don't want to be somebody people pick their words around or avoid certain topics as they may fear my reaction and, in turn, my behaviour.*

In relation to episodic memory, both participants commented on how their short-term memory had worsened and made everyday tasks increasingly difficult. For Chris N, some of the claims made in the literature were mistaken:

*I feel like my memory has worsened, so I feel like to say FTD doesn't affect your memory is wrong. For example, if I go to a meeting, I don't tend to remember much of it afterwards. Also, my writing skills have worsened so now I don't tend to take notes because it takes too long for me to formulate words to paper.*

Chris R gave an everyday example of a memory lapse



familiar from his own experience:

*My wife will say "I want to go to the post office" and I'll get in the car to go to the post office and I'll go straight past it. She'll go "Post office?" and I'll go "oh, Christ" and I'm already going onto Sainsbury's or Canterbury or wherever, you know. I forgot the post office. It happens quite a lot.*

## Conclusions

From these interviews we were able to draw a number of inferences, at least some of which contradicted the prevailing view in the literature about bvFTD.

Among our conclusions, several of which are indicated by the quotes given above, were:

- Socially disinhibited behaviours were far less extreme than the examples given in the bvFTD literature.
- At times, our interviewees had insight into how they behaved, how their behaviour affected others and why people might behave differently towards them because of their diagnosis.
- Memory deterioration has more of an impact on everyday life than the diagnostic criteria and literature suggest.
- Psychosocial interventions

are therapeutic and beneficial, allowing individuals with bvFTD to learn from others with dementia

- An understanding of dementia among family members and the wider public was seen by the interviewees as important for communication with these groups.
- While there were similarities between the two interviewees, there were also distinct differences in their behavioural symptoms, i.e. how bvFTD manifests itself is dependent on the individual.

We believe our research is another example of why it is so important to listen to people with dementia themselves. By doing so, we often cast a very different light on the experience of dementia and challenge some of the orthodoxies that have come to dominate the thinking of professionals. ■

## Acknowledgments

The researchers are extremely grateful to the two interview participants and co-authors, Chris Ryan and Chris Norris.

**This article was first published in the UK *Journal of Dementia Care* 26(5) 28-30.**

## References

Alzheimer's Society (2017) *Symptoms - Frontotemporal*

*dementia*. Alzheimer's Society website [www.alzheimers.org.uk](http://www.alzheimers.org.uk). Boutoleau-Brettonnière C, Evrard C, Hardouin JB, Rocher L *et al* (2015) DAPHNE: a new tool for the assessment of the behavioural variant of frontotemporal dementia. *Dementia and Geriatric Cognitive Disorders extra* 5(3) 503-516. Bozeat S, Gregory CA, Ralph MAL, Hodges JR (2000) Which neuropsychiatric and behavioural features distinguish frontal and temporal variants of frontotemporal dementia from Alzheimer's disease? *Journal of Neurology, Neurosurgery & Psychiatry* 69 178-186. Dementia UK (2017) *Frontotemporal dementia*. Dementia UK website at [www.dementiauk.org](http://www.dementiauk.org). Goldsmith M (1996) *Hearing the voice of people with dementia: Opportunities and obstacles*. Readers Digest. Griffin J, Oyeboode JR, Allen J (2016) Living with a diagnosis of behavioural-variant frontotemporal dementia: The person's experience. *Dementia* 15(6) 1622-1642. Kipps CM, Nestor P J, Acosta-Cabrero J, Arnold R, Hodges JR (2009) Understanding social dysfunction in the behavioural variant of frontotemporal dementia: the role of emotion and sarcasm processing. *Brain* 132(3) 592-603. Liljegren M, Naasan G, Temlett J, Perry DC *et al* (2015) Criminal behavior in frontotemporal dementia and Alzheimer disease. *JAMA Neurology* 72(3) 295-300. Mayo Clinic (2016) *Frontotemporal dementia*. Mayo Clinic website at [www.mayoclinic.org](http://www.mayoclinic.org). Mendez MF, Chen AK, Shapira JS, Miller BL (2005) Acquired sociopathy and frontotemporal dementia. *Dementia and Geriatric*

*Cognitive Disorders* 20(2-3) 99-104. Mendez MF, Shapira JS (2013) Hypersexual behaviour in frontotemporal dementia: a comparison with early-onset Alzheimer's disease. *Archives of Sexual Behaviour* 42(3) 501-509. Miller BL, Darby AL, Swartz JR, Yener GG, Mena I (1995) Dietary changes, compulsions and sexual behavior in frontotemporal degeneration. *Dementia and Geriatric Cognitive Disorders* 6(4) 195-199. Miller BL, Darby A, Benson DF, Cummings JL, Miller MH (1997) Aggressive, socially disruptive and antisocial behaviour associated with fronto-temporal dementia. *British Journal of Psychiatry* 170(2) 150-155. Rankin KP, Baldwin E, Pace-Savitsky C, Kramer, JH, Miller BL (2005) Self awareness and personality change in dementia. *Journal of Neurology, Neurosurgery & Psychiatry* 76(5) 632-639. Rascovsky K, Hodges JR, Knopman D, Mendez MF *et al* (2011) Sensitivity of revised diagnostic criteria for the behavioural variant of frontotemporal dementia. *Brain* 134(9) 2456-2477. Scherling CS, Zakrzewski J, Datta S, Levenson RW *et al* (2017) Mistakes, too few to mention? Impaired self-conscious emotional processing of errors in the behavioral variant of frontotemporal dementia. *Frontiers in Behavioural Neuroscience* 11 189. Snowden JS, Bathgate D, Varma A, Blackshaw A *et al* (2001) Distinct behavioural profiles in frontotemporal dementia and semantic dementia. *Journal of Neurology, Neurosurgery & Psychiatry* 70 323-332.

## Overuse of antipsychotics

The newly published *Third Australian Atlas Of Healthcare Variation* says that the current use of antipsychotic medicines as a form of restrictive practice to manage responsive behaviours in people with dementia is "a matter of grave concern". The overuse of antipsychotics was identified as a problem in the 2015 *Atlas*, and consequently the 2018 *Atlas* chose to revisit the issue. It reports that this continues to be a problem, with little change in the overall amount of use from 2013-14 to 2016-17 for people aged 65 years and over. In the *Atlas*, the Commission sets out detailed recommendations for regulatory strategies to tackle the issue, including changes to prescribing, recording, monitoring and public reporting of the use of antipsychotic medicines. The *Atlas* is produced by the Australian Commission on Safety and Quality in Health Care in partnership with the Australian Institute of Health and Welfare. It's available at: <https://bit.ly/2rxms7H>

## Polypharmacy report

A new report brings together the efforts of multiple stakeholders across Australia over the past three years to address the issue of polypharmacy among older people – and sets out detailed recommendations for a strategic plan to reduce the harms of polypharmacy. *Quality use of medicines to optimise ageing in older Australians* is published by the Cognitive Decline Partnership Centre (University of Sydney), in collaboration with the Australian Deprescribing Network and NPS MedicineWise. It makes seven recommendations aimed at halving harmful or unnecessary medicines use by older Australians within five years, and details actions to achieve the recommendations. NPS MedicineWise CEO Steve Morris said two out of three Australians over 75 take five or more medicines, and about half of all older adults take a medicine that is harmful or unnecessary. Find the report at: <https://bit.ly/2CYVqwG>

# RESEARCH NEWS



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

Briana Lees is a PhD candidate and research assistant at the University of Sydney. Contact her at: [admin@australianjdc.com](mailto:admin@australianjdc.com)

## Engagement in dementia research

Researchers from Canada, Norway and the UK have explored research participation among people with dementia. In this scoping review of 54 research articles mostly published after 2010, they describe the extent and nature of engagement in the research process.

Overall, people with dementia were generally involved in clinical, health services, cultural, environmental and population health research. The majority of engagement involved people with dementia along with their care partners. The types of research engagement included focus groups, interviews, surveys and serving on committees or advisory groups.

Factors that enabled the engagement of people with dementia and carers in the research process included:

- Early planning on the part of the researcher.
- Having appropriate and adequate resources (eg time

and funding).

- Careful consideration of consent and capacity of involvement.
- Building relationships between researchers and people with dementia.
- Taking into account individual strengths, skills, preferences and needs.
- Ensuring clear and jargon-free communication that is supportive of people with dementia.
- Offering regular updates on study progress, results and outcomes.
- Maintaining a flexible attitude and approach to research.

Barriers and enablers to engagement were explored. From the researchers' perspective the challenges included the extra time and costs associated with engagement activities, adapting to sharing control with participants over decision-making, negotiating research ethics boards and

difficulty identifying a 'representative' group of people with dementia. From the perspective of the people with dementia and carers, the challenges included experiencing distress when addressing certain topics, the complexity of research and the research process as well as the lack of research training and experience.

A limitation of this study was that there was no assessment of the quality of the research or depth of engagement by people with dementia, which likely varied among the studies. Future studies should also aim to evaluate the impact of participatory engagement by people with dementia and their carers in research.

Bethell J, Commisso E, Rostad HM, Puts M, Babineau J, Grinbergs-Saull A, Wighton MB, Hammel J, Doyle E, Nadeau S, McGilton KS (2018) Patient engagement in research related to dementia: a scoping review. *Dementia* 17(8) 944-975.

## Self-efficacy among carers

Researchers in the US have conducted focus groups and interviews to understand ways to target carer self-efficacy through the Care Ecosystem model, which provides information, support and resources for people with dementia and their families.

At baseline and at six- and 12-months following the Care Ecosystem program 780 carers of people with dementia completed the Care Ecosystem Caregiver Self-Efficacy Scale. Based on these scores, the researchers identified three cases where self-efficacy had improved markedly (from 7 to 14) and contacted seven care team navigators who worked with these carers to explore the intervention strategies used.

Following a focus group with these navigators, the researchers identified three intervention strategies from the Care Ecosystem model which positively impacted self-efficacy in carers:

- Emotional support: building rapport, encouraging carers to take care of their own wellbeing.
- Informational support: providing education to prepare carers to handle current and future challenges.
- Instrumental support: helping create linkages to supportive services.

These findings reinforce that care team navigators rely on multiple psychosocial support strategies targeting education, links to community resources and emotional support to improve self-efficacy among carers.

Merrilees JJ, Bernstein A, Dulaney S, Heunis J, Walker R, Rah E, Choi J, Gawlas K, Carroll S, Ong P, Feuer J, Braley T, Clark AM, Lee K, Chiong W, Bonaera SJ, Miller BL, Possin KL (2018) The Care Ecosystem: promoting self-efficacy among dementia family caregivers. *Dementia*. Published online 29 November doi: 10.1177/1471301218814121 (Epub ahead of print).

## Evaluation of Kids4Dementia program

Australian researchers have evaluated the effectiveness of the Kids4Dementia program in improving students' attitudes towards people with dementia as well as the acceptability of the resource for teachers and students.

Kids4Dementia is a teacher-led multimedia dementia education resource for 9-12 year olds which runs for about 2.5 hours.

A non-randomised, waitlisted-controlled, mixed-methods design was used. A total of 203 students and two teachers evaluated the program. Students who completed Kids4Dementia (n=136) showed improved scores on the Kids Insight into Dementia Survey, and the effect was strongest for students who had not heard of dementia before.

The resource also improved students' empathy and behavioural intentions towards people with dementia. Qualitative reports indicated that the program was acceptable and engaging for both teachers and students.

These findings provide preliminary evidence for the efficacy of Kids4Dementia as an engaging resource to improve young people's attitudes towards people with dementia.

Baker JR, Goodenough B, Jeon Y-H, Bryden C, Hutchinson K, Low L-F (2018) The Kids4Dementia education program is effective in improving children's attitudes towards dementia. *Dementia*. Published online 23 October doi.org/10.1177/1471301217731385 (Open access).

# Measuring goal setting and attainment

Researchers in the US have investigated the process of goal-setting and measurement of goal attainment using goal attainment scale (GAS) in a dementia care management program.

Phase 1 of the study involved training five nurse practitioner dementia care managers in GAS and refining the goal setting process with 32 dyads of people with dementia and their caregivers. Phase 2 involved the dementia care managers leading 101 dyads of people with dementia and their caregivers through the process of goal setting using GAS and their goal attainment was measured after six and 12 months.

At baseline, 84% of the dyads' goals were non-medical, 47% were related to quality of life and 29% were

caregiver support goals. Of the participants, 87% felt that the goal they set was meaningful, 85% found the process helpful in planning for future care and 74% found that the goal-setting process captured something different from usual care.

At the follow-up visits the dyads reviewed the goals identified at baseline and rated their goal attainment using a five-category response scale. At six- and 12-months follow up 74% of dyads had achieved or exceeded their expected level of goal attainment. About 10% revised their goals as the person with dementia's disease had progressed.

Dementia care managers felt that the goal-setting process improved their understanding of what was most important to the person with dementia,

helped set expectations about disease progression and care needs, provided positive reinforcement when goals were accomplished and provided an opportunity for revision when goals were not met.

The researchers concluded that goal setting using GAS can be incorporated into the care of people with dementia to establish and attain person-centred goals. Research is needed to further develop personalised goal attainment as an outcome measure for dementia care.

Jennings LA, Ramirez KD, Hays RD, Wenger NS, Reuben DB (2018) Personalized goal attainment in dementia care: measuring what persons with dementia and their caregivers want. *Journal of the American Geriatrics Society* 66(11) 2120-2127.

# Levels of pain in people with dementia

Researchers from Turkey assessed pain and its consequences in 75 people with dementia living in residential care.

Presence of pain was assessed using the Pain Assessment in Advanced Dementia (PAINAD), the Discomfort Scale for Dementia of the Alzheimer's Type (DS-DAT), the Pain Assessment for the Dementing Elderly (PADE) and the Wong-Baker Faces Pain Rating Scale.

The average age of people with dementia in this study was 81. The severity of dementia varied among participants: 32% were at early stage, 24% were at moderate stage and 44% were at the severe stage of dementia.

In this study 31% of people with dementia declared pain, however scores of pain on the PADE, PAINAD and DS-DAT were similar between people declaring and not declaring pain. The number of people who declared pain varied by dementia stage: early (49%), moderate (22%) and severe (27%). Despite a lower number of people in the severe stage declaring pain than in the early stage, their scores on PADE, PAINAD and DS-DAT were the highest.

Higher levels of pain were associated with poorer mental state, an inability to perform basic daily activities, poorer nutrition, depression, agitation and immobility.

Results of this study confirm that self-report alone is not sufficient for pain assessment in people with dementia. Therefore, objective pain assessment scales developed for people with dementia should be used.

Agit A, Blaci C, Yavuz BB, Cankurtaran E, Kuyumcu ME, Halil M, Ariogul S, Cankurtaran M (2018) An iceberg phenomenon in dementia: pain. *Journal of Geriatric Psychiatry and Neurology* 31(4) 186-193.

# Characteristics of home care services

Australian researchers investigated the characteristics and use of home care services for older people living with and without dementia. A retrospective data analysis was conducted using routine data collected from a community home nursing service in metropolitan Melbourne in 2014.

Data from 11,927 people was included in the analysis, of which 2703 had dementia. The mean age of participants was 84 years. Overall, people with dementia were more likely to be born outside of Australia

(RR 1.10), require an interpreter (RR 1.41) and live with others (RR 1.09).

Compared to people without dementia, people with dementia were less likely to achieve goals they set in home care (RR 0.91), were more likely to experience deterioration in home care (24% vs 19%) and have a subsequent unplanned discharge from home care services and require admission to hospital or permanent care (RR 1.46).

Limitations of this study include using a database of

routine data from a single community nursing provider which has no measures for the degree of cognitive impairment. Future studies would benefit from using a clinical cognitive assessment with established reliability and validity to determine if the degree of cognitive impairment influences service use.

van Weel JM, Renehan E, Ervin KE, Enticott J (2018) Home care service utilization by people with dementia – a retrospective cohort study of community nursing data in Australia. *Health and Social Care in the Community* 1-11.

## Can antidepressants help treat Alzheimer's?

Canadian researchers have studied the effect of selective serotonin reuptake inhibitors (SSRIs), which are antidepressant drugs used to treat depression, on people with Alzheimer's disease.

The researchers investigated five SSRIs over a series of aggregation kinetic, transmission electron microscopy and dot-blot experiments. The SSRIs were: fluvoxamine, fluoxetine, paroxetine, sertraline and escitalopram. Fluoxetine and paroxetine were identified as the most promising SSRIs for people with Alzheimer's disease. At 100  $\mu$ M concentration these SSRIs were the most potent inhibitors of  $\beta$ -amyloid 42 (A $\beta$ 42) fibrillogenesis (75% for fluoxetine and 76% for paroxetine) which is known to be toxic and a major component of A $\beta$  plaques in the brain. To a lesser extent, sertraline (47%) and escitalopram (21%) inhibited A $\beta$ 42 aggregates. This study demonstrates that four SSRIs directly interact with A $\beta$ 42 aggregates and reduce fibrillogenesis. Fluoxetine and paroxetine may be beneficial as an adjunct therapy to decrease levels of A $\beta$  plaques in the brains of people with Alzheimer's disease.

Tin G, Mohamed T, Shakeri A, Trinh Pham A, Rao PPN (2018) Interactions of selective serotonin reuptake inhibitors with  $\beta$ -Amyloid. *ACS Chemical Neuroscience*. Published online 11 September doi: 10.1021/acscemneuro.8b00160

# Dancewise training for care home staff

Following the successful introduction of the Dancewise program to Australia in 2015, the Dance Health Alliance (DHA) is now running national workshops to teach care home staff how to deliver the dance and movement-based program for people with dementia in their facilities.

DHA CEO and Co-founder Gwen Korebrits said DHA recognised the growing need for care facilities to provide cost-effective activities that engage residents and enthuse staff.

"This year we have been training in care homes all over NSW, and so far the feedback has been incredibly positive as it's not only professional development for the staff but also personal development and a great team-building exercise. The training program is practical and available to all care facilities in Australia, wherever they may be located."

Ms Korebrits said the Dancewise sessions, designed specifically for people with all types of dementia and their carers, include brain training, memory stimulation, creative inclusion, physical activity and social interaction for residents, "all neatly packaged under the umbrella of dance".

"All the movements can be done whilst seated and/or standing, making the program suitable for all levels of mobility and people at all stages of dementia. No



**The two-day Dancewise training course is available for physical therapists, nurses, movement therapists, diversional therapists and activity coordinators working in aged care organisations Australia-wide. Photo: Dance Health Alliance**

dance experience is necessary. The aim is to get people moving and stimulate them physically," Ms Korebrits said.

The two-day Dancewise training course is available for physical therapists, nurses, movement therapists, diversional therapists and activity coordinators working in aged care organisations Australia-wide.

Ms Korebrits said the workshops are run on site by two DHA professional trainers and equip staff to run a 30-minute Dancewise class in their own facility as many times a week as the residents request. Trainees learn to create music playlists, design classes and incorporate rhythm and movement games. Online

support is provided post-training and master classes can be organised throughout the year with a DHA dance professional, depending on location.

Staff at The Whiddon Group have completed the training and are now running Dancewise classes for residents. Whiddon's Executive General Manager Strategy and Innovation, Karn Nelson, said the program has been a huge hit with residents and staff.

"It has been proven to be safe, fun and effective, with some residents and their allied health specialists reporting significant improvements in balance and coordination," Ms Nelson said.

"It is also a great social opportunity and is currently one of our most popular programs. Staff too, have really appreciated the training and additional skills and it has increased job satisfaction amongst our leisure and lifestyle teams," Ms Nelson said. "The fact that staff can be trained to run the program makes it sustainable and means, for an organisation like Whiddon that delivers services to regional, rural and remote areas, that we can offer this great program to all of our residents."

For more information on Dancewise and the cost of the training course for aged care staff, email [info@dancehealthalliance.org.au](mailto:info@dancehealthalliance.org.au) or visit [www.dancehealthalliance.org.au/care-homes](http://www.dancehealthalliance.org.au/care-homes) ■

# National guidelines for spiritual care

The **National guidelines for spiritual care in aged care** is an important resource to help residential aged care and home care organisations meet the expected outcomes in the new Aged Care Quality Standards coming into effect from 1 July 2019. According to Meaningful Ageing Australia, which helped develop the guidelines, a spiritual care approach connects at numerous points with the Standards, for example: maintain an older person's identity and make connections with others (Standard 1); create a sense of belonging, safety and comfort (Standard 5); and understand each person's needs, goals and

preferences (Standards 3,4). The guidelines are the first in the world focusing specifically on the spiritual needs of older people and are intended to support organisations to embed spirituality into key systems and processes with the goal that all older people (and their loved ones) are offered best-practice in spiritual care.

The guidelines include five domains: organisational leadership and alignment; relationships and connectedness; identifying and meeting spiritual needs; ethical context of spiritual care; and enabling spiritual expression. Each domain has 10 practical outcomes/actions



that are expected of organisations to achieve high-quality, integrated spiritual care that is relevant to older people from all backgrounds.

The guidelines were developed with funding from the Australian Government following a literature review to establish an evidence-based framework and consultation with the aged care sector including Aged and Community Services Australia, Leading Age Services Australia, the Quality Agency, plus an expert advisory panel with 28 members from Australia, the US and UK.

The guidelines, along with resources, suggestions and ideas for their implementation, and background information, are freely available on the Meaningful Ageing Australia website [www.meaningfulageing.org.au](http://www.meaningfulageing.org.au)

Aged and Community Services Australia (ACSA) has launched **Humans of Aged Care**, a storytelling online platform to celebrate and demonstrate the human elements of care at the heart of aged care services. ACSA says it hopes that the website will help balance the public portrayal of the aged care industry by highlighting the positive aspects of aged care. ACSA is encouraging nominations of anyone involved in delivering care, on a paid or unpaid basis, or from those receiving care or their family members, with a view to encouraging them to share their positive stories about aged care. To find out more, go to [www.humansofagedcare.com.au](http://www.humansofagedcare.com.au)



Dementia Australia has launched a new, free iPad app called **A Better Visit** which it hopes will assist family and friends when visiting a person living with dementia. It includes a range of two-player games, such as co-colouring, marble maze, washing windows, bowling and tic-tac-toe. The app is designed to be interactive, stimulating and fun, and to bring together people across generations by encouraging conversation and joint activity. The development of A Better Visit was sponsored by Lifeview Residential Care which involved residents as part of a consultation process in the development of the app. Technical input came from a team at Swinburne University's Self and Design Living Lab. Lifeview Residential Care CEO Madeline Gall said the app is different from other products in the market because of this consultation with residents: "[the developers] were able to tailor certain elements such as adjustable speeds, include classic songs to prompt toe-tapping and singalongs, and

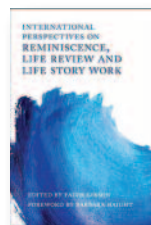
The OECD has published a policy briefing to coincide with the December summit of the World Dementia Council (WDC), titled **Renewing priority for dementia: where do we stand?** The OECD report concludes that while dementia has stayed high on the policy agenda, progress in addressing dementia has not kept up with the scale of the challenge. It says that despite progress in identifying people with dementia, the diagnostic process is still poor, diagnosis rates are too low, and that poor-quality care persists. The OECD calls on policy makers to strengthen the transparency and monitoring of the effectiveness, safety and patient-centredness of dementia care; to harness the power of data available across health care settings to improve research and the quality of life for people with dementia; and to strengthen collaboration between stakeholders and increase public investment in dementia research. The briefing can be downloaded from [www.oecd.org](http://www.oecd.org). Presentations from the WDC summit are available to view at [www.worlddementiacouncil.org](http://www.worlddementiacouncil.org). The council has also published a report on its website to coincide with the December meeting, called **Defeating dementia: the road to 2025**, which reviews progress across four areas – a disease-modifying therapy, living well, better care, and reducing the impact of dementia.



design clear buttons and uncomplicated instructions." A Better Visit is available for iPad only and can be downloaded for free at the App Store. Details: [www.dementia.org.au/abettervisit](http://www.dementia.org.au/abettervisit)

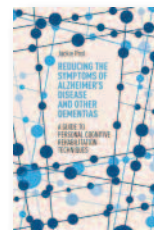
### International perspectives on reminiscence, life review and life story work

is a new substantial book edited by Faith Gibson, Emeritus Professor of Social Work at Ulster University in Northern Ireland, and associate consultant with HammondCare in Sydney. The 20-chapter book includes contributions from an international line-up of academics and practitioners, with some having a specific focus on dementia. Professor Bob Woods from the University of Wales writes about the Cochrane review of reminiscence interventions with people with dementia, for example, and Christine Bryden writes a chapter titled 'The narrative self in the lived experience of dementia'. Adjunct Professor Elizabeth MacKinlay writes about spiritual



reminiscing in later life, and Professor Assumpta A Ryan looks at the contribution of information technology to reminiscence, life review and life story work among people with dementia. The Jessica Kingsley Publishers book is available in Australia via Footprint Books for \$62 (go to [www.footprint.com.au](http://www.footprint.com.au)).

Jackie Pool is the author of a new book, **Reducing the symptoms of Alzheimer's disease and other dementias**, subtitled 'A guide to personal cognitive rehabilitation techniques'. The 176-page book is aimed at people with dementia and their family and friends, and covers topics such as nutrition, stress, communication, cognitive rehabilitation, memory and sleep, as well as other tools and information to help readers develop a self-care plan. Jackie Pool is a UK-based occupational therapist who has worked in dementia care for many years, and is best known for her work in developing the Pool Activity Level Instrument



for Occupational Profiling (PAL). The Jessica Kingsley Publishers book is available in Australia via Footprint Books for \$32.99 or \$26.99 as an e-book (go to [www.footprint.com.au](http://www.footprint.com.au)).

Betsi Cadwaladr University Health Board in North Wales is understood to be the first in the UK to develop guidelines for staff when caring for transgender people with dementia. **Supporting me to be the person I want to be** includes advice on how to deal with the sensitivities that can arise when dementia develops and transgender people may become confused between their gender preference and their gender of birth. It also offers suggestions for how to work with the families and carers of transgender people affected by dementia, and how to help assist a transgender person with dementia to maintain their preferred appearance when they can no longer do it themselves. The booklet presents discussion questions for staff alongside each of five practical dilemmas, as well as several personal stories from transgender people. The guidance was co-produced with activists from within the transgender community and is now available via [bit.ly/2s7pQGO](http://bit.ly/2s7pQGO)

The Pharmaceutical Society of Australia (PSA) has set out six new recommendations for Australians to consider around medicines use – including prescription, over-the-counter and complementary medicines. The **6 recommendations**, published by the Choosing Wisely Australia initiative, are aimed at health professionals and patients, and are intended as a guide to discussions around medication. The recommendations tackle common issues arising in medication management such as repeat prescriptions for antibiotics, the hazards of polypharmacy, and the lack of evidence for homeopathic products. The fifth recommendation relates to older people in particular: 'Do

not continue benzodiazepines, other sedative hypnotics or antipsychotics in older adults for insomnia, agitation or delirium for more than three months without review.’ The recommendations are available online and as a downloadable PDF: go to [bit.ly/2LNwjQp](http://bit.ly/2LNwjQp)

In June 2018, the University College of London (UCL) and Vision UK held a **Dementia and Sight Loss conference**, and videos of each of the 17 conference presentations are now available to view on YouTube. The conference aimed to raise awareness and educate attendees on the issues affecting people with dementia and sight loss, as well as discuss strategies for care. Presentations include topics such as ‘The neuropsychology of dementia-related visual impairment’, ‘Dementia and low vision’, ‘The social and psychological consequences of dementia-related visual impairment’, and ‘Preparing the workforce to recognise and meet the needs of people living with sight loss and dementia’. The videos are available to view via the Vision UK website ([www.visionuk.org.uk](http://www.visionuk.org.uk)) or go to [bit.ly/2LQ8Ttt](http://bit.ly/2LQ8Ttt)

**Sensory changes and dementia: sense of taste and smell** is a new booklet published by Scottish charity,

Outside The Box and the Life Changes Trust. The booklet is a follow-up to **Dementia and sensory challenges**, the resource developed by Agnes Houston in 2015 which has gone on to be republished by HammondCare in Australia. The latest booklet is also the work of Houston, again collaborating with other people living with dementia to share their experiences and suggestions, but this time focusing on the senses of taste and smell. The booklet shares responses to questions such as ‘When did you first notice the changes?’, and ‘How do these changes impact your life?’ and goes on to share suggestions for ‘Living well with sensory changes’, and ‘Hints and tips’. The booklet is available from the Outside The Box website ([www.otbds.org](http://www.otbds.org)) and an associated seven-minute film, introduced by Houston, called **Sense of taste and smell: hints and tips** is available on YouTube at [www.youtube.com/watch?v=4DZe2e8Eq3c](http://www.youtube.com/watch?v=4DZe2e8Eq3c)

Mental Health First Aid Australia is currently promoting 12-hour courses on **Older person mental health first aid**. The course covers how to assist a person aged 65+ who may be experiencing a mental health problem or mental health crisis until appropriate professional help is received or the crisis

**We are family** is a new 28-minute film by Professor Cathy Greenblat and Corinne Maunder in the series, **Side by side: love and joy in dementia care**. The film, introduced by Professor Greenblat, focuses on the UK care facility Landermeads and shows how the facility has been transformed by adopting the Dementia Care Matters’ Butterfly Model™. David Sheard, founder of Dementia Care Matters, and many of the staff at Landermeads, are featured in the film, explaining how the model works in practice, and what the changes have been since the facility went through the culture change process. Producer Corinne Maunder explains the thinking behind the content presented in the film: “Two of the things people most commented on after watching our previous films were the financial viability of the models as well as wanting to know more about how to implement the ideas from a staff training perspective. In **We are family** we made sure we covered those crucial points so that other people could put these ideas into action in their own environments, whether that’s in residential care, a day program or a family home.” The film is available to view at [www.sidebysidedementia.com/films](http://www.sidebysidedementia.com/films)



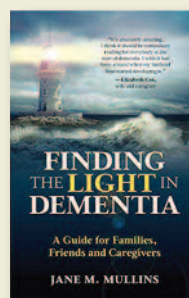
A scene from the film *Side by side: love and joy in dementia care*. Photo: Cathy Greenblat

resolves, using a practical, evidence-based action plan. The course is usually delivered as either a two-day training package (six hours per day), or as four separate modules (three hours each). The course is suitable for anyone who lives with or cares for an older person, and includes content that relates to people living with dementia. To find out about where the Older Person MHFA

courses are available locally, go to [www.mhfa.com.au/courses](http://www.mhfa.com.au/courses)

Alzheimer’s Disease International (ADI) is hosting a series of webinars on involvement in dementia research, and the first in the series is now available to view online. **Let’s talk about dementia research: demystifying trials, access and understanding** was held in November 2018. It presented an overview and discussion on what dementia research is, why clinical trials and research are needed, the practicalities for clinicians, and the lived experience for families taking part in trials. The webinar involved people living with dementia and their care partners, as well as representatives from the pharmaceutical industry, researchers and clinicians, and health professionals. In future webinars in 2019 (dates yet to be announced) ADI is hoping to cover issues such as the divide of research opportunities between lower- and middle-income countries vs higher income countries. ADI is inviting anyone with an interest in

Dr Jane Mullins is a UK-based dementia nurse consultant, researcher and author who has devoted more than 25 years to the study and practice of dementia care. She has distilled that knowledge and practice experience into a new book titled **Finding the light in dementia: a guide for families, friends and caregivers**. It’s easy to read and offers practical information and advice, interspersed with individuals’ stories, presented simply and compassionately, to help readers learn to care for and maintain a connection with their family member or friend with dementia, while also taking care of themselves. Knowing that carers are often tired and stressed, with limited free time, Mullins has written the book in short, easy-to-read chapters, summarised the main points at the end of each chapter and provided space to write notes and question sheets to use when speaking with doctors or legal professionals. Topics covered include: understanding what the person with dementia is experiencing and how to communicate more effectively; practical ways to stimulate memories and life histories; tips for sleeping, eating and drinking; understanding mood and behaviour and ways to respond to changed behaviours; approaches to avoid distress caused by hallucinations, delusions and misperceptions; self-care tips; creating a calm, safe home; how to maintain your loved one’s dignity and help with their appearance; and what to look for in choosing caregivers, respite and care homes. The book is published by DUETCare and is available to purchase online for \$14.32. Details: [www.findingthelightindementia.com](http://www.findingthelightindementia.com), where Mullins also writes the blog **Finding the light in dementia**, about ways to live well with dementia.



joining the webinars to sign up for email updates: to access the webinar and to sign up for updates, go to [www.alz.co.uk](http://www.alz.co.uk)

Dementia UK has produced a new three-minute film, **Let's talk about dementia**, aimed at children aged 8-12 to help them understand what having dementia means. The film aims to help children understand some of the changes in their relative's memory and behaviour, as well as giving practical tips for communicating with someone with dementia and continuing to enjoy time together with them. The film is available to view on YouTube at: [www.youtube.com/watch?v=3kpD-Uykmww](http://www.youtube.com/watch?v=3kpD-Uykmww)

The Older Persons Advocacy Network (OPAN) has launched the **National Elder Abuse Prevention and Advocacy Framework**, to bring together the efforts of the nine organisations delivering advocacy services to older people across Australia. The two goals of the framework are to develop and deliver a national elder abuse prevention and advocacy program, with consistent service delivery and standards across all Australian jurisdictions; and to inform, develop and deliver a best evidence, best practice national

model of elder abuse prevention and advocacy response. After reviewing the policy landscape, the framework document presents the philosophy and principles that will guide the work of OPAN service delivery organisations. The framework also sets out direction for preventing, responding to, and quantifying elder abuse, as well as guidance on building capacity. It is available to download from the OPAN website at <https://opan.com.au>

The Older Persons Advocacy Network (OPAN) has also launched a new training resource aimed at the aged care workforce, called **Talk to us first**. The series of films was developed by Altura Learning for OPAN, and focuses on explaining the role of advocacy in aged care, on the importance of raising and rectifying concerns early, and on increasing awareness of how to access advocacy services through OPAN. People who take up the opportunity to do the training are invited to complete a questionnaire both before and after watching the videos – these must be completed in order to obtain a Certificate of Completion. The resources are available on OPAN's website at <https://opan.com.au>

A new website **Music for Dementia 2020** has been launched by the UK campaign with the same name. The website is being promoted as the first of its kind: a central information hub for advice, evidence-based research, and expertise on why music, in all its forms, is essential for people living with dementia and their carers. The website shares information on a wide range of musical activities available for people living with dementia, some of which are particular to the UK, but much of the information is relevant beyond the UK: for example, from how to compile a playlist through to how to make music part of an everyday routine. The website is aimed at people living with dementia and family carers, health professionals, practitioners, musicians and volunteers, academics and researchers. It incorporates case studies, blogs, interactive short films, and advice and guidance from across the health, care, dementia and music sectors. The UK campaign, led by The Uteley Foundation, is working to make music available for everyone living with dementia by 2020. The campaign has come about following the Commission into Dementia

and Music, conducted by the International Longevity Centre UK in 2017, and the recommendations of its final report, 'What would life be – without a song or dance, what are we?' which came out in January 2018. The website can be found at [www.musicfordementia2020.com](http://www.musicfordementia2020.com)

To encourage fair and well-informed journalism when dealing with stories about dementia, Alzheimer's Society in the UK has produced a media toolkit called the **Dementia-friendly media and broadcast guide**. Produced in consultation with people affected by dementia and media representatives, it provides helpful guidance and tips on how to ensure dementia is accurately and fairly reported and portrayed. It includes the views of people with dementia on how the condition is portrayed in the media, tips on how to interview someone with dementia, language to use and avoid, guidance on how to portray dementia in documentaries, drama and comedies, and examples of good and bad practice. It is available to download from the Alzheimer's Society website at [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

## Events

- 14 Feb-3 April 2019 – all states  
**Preparing For The New Standards**  
 One-day workshop for aged care providers to assist with preparing for the new Aged Care Quality Standards, presented by the Aged Care Quality and Safety Commission in each state and Territory. Details: <https://bit.ly/2CWw4zB>
- Feb-June 2019 – WA  
**Dementia Information Sessions**  
 Free sessions on a range of topics relating to dementia, for family carers in the community, presented by Alzheimer's WA and the Australian Red Cross. Details: [www.alzheimerswa.org.au](http://www.alzheimerswa.org.au)
- 22-23 February 2019 – QLD  
**Occupational Therapy Australia National Aged Care Symposium: Respect: Relate: Renew**  
 Presented by Occupational Therapy Australia, in Brisbane. Details: [www.otausevents.com.au/agedcare2019](http://www.otausevents.com.au/agedcare2019)
- 5-6 March 2019 – NSW  
**Quality in Aged Care**  
 Conference: Preparing for the new Quality Standards, responding to the Royal Commission, building trust and engaging with consumers. Presented by COTA and ACSA, in Sydney. Details: <https://bit.ly/2sgLvwu>
- 28-29 March 2019 – NSW  
**The RED Conference: A Regional Experience in Practical Dementia Care**  
 Presented by Omnicare, in Port Macquarie. Details: [www.red.omnicare.org.au](http://www.red.omnicare.org.au)
- 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](http://www.dementiacarematters.com)
- 15-16 May 2019 – VIC  
**National Dementia Conference**  
 Presented by Informa, in Melbourne. Early bird closes 1 March 2019. Details: <https://bit.ly/2TulBAK>
- 5-8 November 2019 – NSW  
**52<sup>nd</sup> AAG Conference**  
 Coming of Age Together: New Ways of Knowing and Acting, Now and Beyond, in Sydney. Details: [www.aag.asn.au](http://www.aag.asn.au)

Details of more events at [www.journalofdementiacare.com](http://www.journalofdementiacare.com)

# Australian Journal of **DementiaCare**

We publish what you need to know:



**News • Best care practice**

**Clinical Updates**

**Training • Technology**

**Research • Resources**

**Promoting excellence  
in dementia care**

**SUBSCRIBE FOR LESS**

**THAN \$2 A WEEK**

**ONLY \$99 per year**

**SAVE \$40: Subscribe for two years for only \$158**

**ALL PRICES INCLUDE GST & POSTAGE**

**USE PROMO CODE BPG/FM19 WHEN YOU SIGN UP AT**

**WWW.JOURNALOFDEMENTIACARE.COM**

**For offline subscriptions (\$99 per year) call 03 8317 8163  
or email [dementiajournal@data.com.au](mailto:dementiajournal@data.com.au)**

**Or write to: Australian Journal of Dementia Care subscriptions, DCA, Locked Bag 1235, North Melbourne Vic 3051**

**BACK ISSUES ALSO AVAILABLE**

**SUBSCRIBE NOW AT**

**WWW.JOURNALOFDEMENTIACARE.COM**