

Australian Journal of DementiaCare

For all who work with people with dementia

Vol 1 No 1 June/July 2012



SMILES improve life in residential care

**Also inside
this issue:**

- Environmental design in the heart of Australia
- The harsh reality of pain
- Understanding neighbourhoods

A message from the minister

It gives me great pleasure to contribute to the inaugural edition of the *Australian Journal of Dementia Care*. I understand this is the sister publication to the *Journal of Dementia Care* that has been published in the United Kingdom for the last 19 years.

I commend the New South Wales and Australian Capital Territory Dementia Training Study Centre for launching this journal.

Dementia is one of the two emerging epidemics in Australia – the other being diabetes. Currently, there are almost 300,000 Australians living with dementia. Without a significant medical breakthrough, this number will double every 20 years.

There have been giant strides taken in recent times in talking publicly about a condition that for too long was invisible. We recognise now that dementia is not simply

a natural part of ageing. Research is crucial if we are to reduce the number of people with dementia and ensure that people living with dementia have a better quality of life.

This is why the Australian Government will provide \$268.4 million over five years to tackle dementia, as part of the \$3.7 billion *Living Longer, Living Better* aged care reform package announced on 20 April 2012.

Funding will be available to support GPs to make a more timely diagnosis of dementia, expand the scope of the Dementia Behaviour Management Advisory Services, improve the care of people with dementia in hospitals, and to enable younger people with dementia to access better coordinated care and support. In addition the package will provide funding for a new Dementia Supplement for eligible Home Care package recipients and funding to improve the quality of care in aged care homes for residents who have severe behavioural and psychosocial symptoms of dementia.

In recognition of the importance of having a health and aged care system that responds to emerging challenges such as the increase in the number of people with dementia the Government will recommend to Health Ministers that dementia be recognised as the ninth National Health Priority Area, to focus attention on dementia at national, local and state and territory level.

Publications such as the *Australian Journal of Dementia Care* help us effectively share information on developments in the care of people with dementia. This publication will play an important role in the dissemination of research findings and will assist in translating research into practice.

I have seen clearly the benefits of promptly translating research outcomes into better clinical practice. For example, pain management research carried out by the Australian Government-funded Dementia Collaborative Research Centres, will inform the development of a new training package for staff in aged care facilities, assisting them to better identify and manage pain in people with dementia. The NSW Dementia Collaborative Research Centre and the Victorian Dementia Training Study Centre are jointly developing this training package and are working closely with aged care facilities to help them more effectively manage behavioural and psychological symptoms of dementia, which may be associated with untreated pain.

The good work being undertaken by these Study Centres, for example, includes the development of evidence-based competencies for registered nurses engaged in the care of people with dementia. This New South Wales Dementia Training Study Centre project will establish a competency framework that will inform the education, recruitment and the clinical practice of registered nurses providing specialist care for people with dementia. The project is due to be completed later this year.

It is important that we continue and further improve the good work being undertaken to ensure people living with dementia and their family and carers receive the best care possible. I am confident that this publication will make a significant contribution to ensuring the dissemination of information to a range of health care practitioners.



Mark Butler MP
Minister for Mental Health and Ageing

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This is the first of a series on communication and relationships specially written for AJDC by well-known author, John Killick. They are based on John's experiences of talking with and working alongside people with dementia over two decades in the UK and abroad, including Australia. The views are John's own and some of them may be considered controversial.

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Introducing our Advisory Board members

The AJDC is proud to have the support of 12 eminent people from a wide variety of areas in the dementia care field, including research, policy, advocacy and service delivery. Each has accepted a two-year appointment to the Advisory Board, which will guide the strategic direction of the AJDC. We will introduce them over the first four issues.

Professor Rhonda Nay



Professor Rhonda Nay has been involved in the teaching, research and practice of aged care for over 30 years. She is the Director of TIME for Dementia, the Victorian and Tasmanian Dementia Training Study Centre, and also serves the Australian Centre for Evidence Based Aged Care. She is Foundation Professor of Interdisciplinary Aged Care, Director of the Institute for Social Participation, and of the Australian Institute for Primary Care and Ageing at La Trobe University.

Rhonda has chaired the Minister's Awards for Excellence in Aged Care, and has been a judge for the ACSAA Awards. She has been a Director on the Aged Care Standards and Accreditation Agency Board since 2002. In her academic role, Rhonda has led numerous research projects related to aged care and has supervised over 20 doctoral students from nursing, medicine, sociology, education and business.

Rhonda has been a member of numerous government and professional committees including the Commonwealth Aged Care Workforce Committee, the AHCA Reference Group on Continuum of Care, the National Advisory Committee on Ageing and was

an Expert Advisor to the International Council of Nurses. Rhonda's passion is person-centred care for older people, especially those living with dementia. Her research focuses on getting evidence-based, interdisciplinary, relevant findings on staff-family relationships, person-centred care, pain assessment and management into practice.

Glenn Rees



Glenn Rees has been CEO of Alzheimer's Australia since 2000, during which time dementia has been made a National Health Priority. He is an active member of the National Aged Care Alliance and has been a member of many ministerial and official advisory committees on aged care.

Glenn has worked at senior levels in the British and Australian public services. In Britain he worked as Private Secretary to senior ministers and in the Cabinet Office. In Australia since 1976, he has worked in program and policy areas including Prime Minister and Cabinet, Employment and Training, Aged Care, Disabilities, Housing and the Aboriginal and Torres Strait Islander Commission. He was Chair of the Nursing Homes and Hostels Review in 1986 and was involved in implementing the first wave of aged care reforms.

His passion is to ensure that policy and service development is driven by consumers and is sensitive to the needs of diverse communities. Recently his focus has been the establishment of the Consumer Dementia Research Network and the

National Quality Dementia Care Initiative. This approach seeks to empower consumers to identify concerns in dementia care, to match these concerns to the evidence base and then to fund national knowledge translation projects to achieve change.

Sue Pieters-Hawke



The daughter of Hazel Hawke and former Prime Minister Bob Hawke, Sue Pieters-Hawke is a tireless advocate for people with dementia. Sue has a lifetime of involvement in social change and personal development technologies. She co-chairs the federal Minister's Dementia Advisory Group, an expert body advising the federal Minister for Mental Health and Ageing, Mark Butler, on dementia in the context of significant proposed aged care reform. Sue was appointed the inaugural National Ambassador for Alzheimer's Australia, and campaigns extensively throughout Australia for increasing understanding, changing attitudes, and supporting funding and services for people living with dementia and their families and carers.

Sue has enjoyed a diverse career – she's studied law, history, complementary health and preventive medicine, yoga, qigong and Tibetan Buddhism; been an activist for progressive social issues, an artists' model and rock'n'roll barmaid. While raising her two children, she worked part-time as a PR advisor, fundraiser and small business manager, and established a clinic and school with two Chinese qigong masters. She managed Hazel

Hawke's office from 1995 until 2008, and cared for her during her illness with dementia.

Professor Henry Brodaty



Professor Henry Brodaty has served on several New South Wales and commonwealth committees related to ageing and dementia. He has been a member of the reference group for the NSW Action Plan for Dementia since its inception and serves on the Commonwealth Dementia Task Force for the Minister for Ageing. He is the past chairman of Alzheimer's Disease International, representing 75 national Alzheimer's Associations, and is past president of Alzheimer's Australia.

He has served in various Australian commonwealth and state committees, advising on services for older people in general and for dementia in particular. Professor Brodaty has been co-chairman for the NSW Task Force on the Mental Health of Older People (1997). He is the author of over 200 scientific papers, has served on the editorial boards of 10 scientific journals, and has won numerous awards, including the New Zealand College of Psychiatry's Senior Organon Research Award in 2003.

Professor Brodaty's research interests include the effects of dementia on family carers and on how best to help them; trials of new drugs for Alzheimer's disease; the causes and management of behavioural and psychiatric complications of dementia; the role of nursing homes, and late-life depression, suicide and self-destructive behaviour among older people.

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Welcome to AJDC

By **Professor Richard Fleming**, University of Wollongong, Executive Editor



The discussion of research findings and their application to practice is very limited in Australia. There has been no readable and lively publication that reports on current research, showcases good practice and attracts the attention of a wide range of professionals. This is not the case in the UK where the *Journal of Dementia Care*, guided from the start by key thinkers such as Tom Kitwood, has for 17 years provided a means of sharing research, practice and views between a very wide range of people engaged in the care of people with dementia.

While the idea of establishing an *Australian JDC* was first raised by Vicky Traynor, Associate Professor in the School of Nursing at the University of Wollongong, back in 2009, the opportunity to do it had to wait until re-focussing of the Dementia Training Study Centres. Five of these centres have been established by the Department of Health and Ageing and in 2010 a new strategic plan resulted in them being given three National Priority Areas each. The priority area most relevant here is Knowledge Transfer, assigned to the NSW Dementia Training Study Centre based in the University of Wollongong.

The transfer of knowledge from its generator and its user has been described as following four stages: awareness, agreement, adoption and adherence (Davis *et al* 2003). This simple model highlights the fact that the adoption of new, and better, ways of doing things depends on the awareness of the potential user and his/her agreement with the new approach. If there is no channel of communication providing the potential user with the opportunity to become aware of the new information, and to decide whether or not they agree with it, then there will be no change.

The NSW / ACT Dementia Training Study Centre is working with the publishers of the UK Journal of Dementia Care to establish this channel of communication by launching the *Australian Journal of Dementia Care (AJDC)*. The *AJDC* will contain a balance of home-grown articles and UK articles of relevance to Australians. An Advisory Board comprising the people driving the transfer of knowledge through the Dementia Training Study Centres, the generators of knowledge in the Dementia Collaborative Research Centres and champions of better care for people with dementia, has been established to guide its activities. The success of the *AJDC* will be determined by the ability of its advisors, editors and writers to attract and engage a large body of practitioners in the consideration of new approaches. I hope that you will join us in this endeavour by reading and thinking about this issue, discussing it with your colleagues, telling us what you think about it and providing us with ideas for the next issue. You can contact us at dementia@uow.edu.au. ■

Davis D *et al* (2003) The case for knowledge translation: shortening the journey from evidence to effect. *BMJ* 327 33-35.

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 on dementia@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.

News in brief

Global awards ceremony to be in Australia

Australia is to host the International Dementia Excellence Awards for the first time, as part of the Risky Business conference in Sydney in June. The international judging panel includes Australian dementia advocate Sue Pieters-Hawke and CEO of Alzheimer's Australia, Glenn Rees. This year there will be three Australia-specific awards: Team of the Year, Employee of the Year and Volunteer of the Year. Previous award winners include HammondCare and the Royal Hobart Hospital. Professor June Andrews, Director of the Dementia Services Development Centre (DSDC) at the University of Stirling in Scotland, will be one of the international judges. Speaking about the awards, Professor Andrews stated: "We often hear about the growing challenge of dementia for both the developed and developing world; we should not forget the outstanding work already occurring to meet this challenge. It is vital that we raise awareness regarding innovation and good practice in dementia care, as well as highlighting those who, through passion and commitment, make a real difference in the lives of those living with dementia".

Raising undergraduates' awareness

More than 1,500 undergraduate students across schools of Nursing, Nutrition, Psychology, Medicine, Occupational Therapy, Physiotherapy and Exercise Physiology at three universities – Wollongong, Canberra and Tasmania – are being invited to participate in the NSW/ACT Dementia Training Study Centre Essay Competition, now in its third year. The Essay Competition is the first of three stages in a project designed to provide opportunities for undergraduate students to 'bump into' dementia during their 2nd, 3rd and 4th years of study. The 3rd year opportunity involves placements with aged care providers and the 4th year provides the opportunity of honours scholarships. The 2011 essay prizes were \$300 gift vouchers, which were awarded to 16 students in schools of medicine, nursing, nutrition, physiotherapy and pharmacy. The 2012 essay prizes will be \$500 each and work has already commenced on involving more universities in the project.

NHMRC Partnership Centre joins fight on dementia

Researchers, policy makers and healthcare workers will jointly establish Australia's first Partnership Centre for better dementia and aged health outcomes, with the potential for \$25 million in funding to be allocated over five years. The Partnership Centre's research activities will be headed by an investigation team from Sydney, who won the contract in March of this year.

The National Health and Medical Research Centre (NHMRC) is funding six partnership centres each focused on a different health issue. The first Partnership Centre, entitled 'Dealing with Cognitive and Related Functional Decline in the Elderly', will focus extensively, but not exclusively, on dementia. The funding is being provided by the NHMRC, Alzheimer's Australia, Brightwater Care Group, HammondCare and Helping Hand Aged Care.

The Minister for Mental Health and Aging, the Hon Mark Butler MP, affirmed that dementia is one of the fastest growing sources of disability

for older people, and the third leading cause of death after heart disease and stroke. He stated: "To improve clinical interventions, social care and community support for dementia and related functional decline, we need to support better collaboration between those working in the health system and researchers. This is exactly what the new Partnership Centre will do.

With a heavy emphasis on knowledge translation projects, the primary strength of the Partnership Centre will be the active collaboration between researchers, community care practitioners, consumers and health care staff. A significant part of the Partnership Centre team's work will be developing policy and regulation to drive practical change, removing obstacles to successful knowledge translation and improving health care outcomes for people with dementia. The core focus of the team will be on investigating supportive care in the home, the community and long-term care facilities.

Experience of a lifetime

The McCusker Alzheimer's Research Foundation, in conjunction with the Lions Club of Claremont Nedlands, WA is organising the inaugural 'Ants Across America' 10-day motorcycle ride to raise money for Alzheimer's research. Billed as a 'Corporate Network Challenge', the project aims to attract one hundred participants from major Australian companies to take part in the ride. Individuals are also welcome. The ant was chosen as the group's symbol to reflect the group's strength, courage and determination. Participants will get the chance to network, while also helping to provide vital funds and publicity for research. The dates for this adventure are September 13-24, 2012. Video footage and photographs of the ride will be uploaded to Facebook and YouTube daily, ensuring a fantastic amount of exposure for Alzheimer's awareness, companies and individuals. For more information, contact Jenny Gill on 0459147474.



WHO and ADI: dementia is a global health priority

In a major step towards increasing awareness of the impending impact of dementia, Alzheimer's Disease International and the World Health Organization have published *Dementia: A public health priority*, a major report outlining the scope of the dementia epidemic and asserting the urgent need for national health strategies to combat dementia around the world.

"The report provides the knowledge base for a global and national response to facilitate governments, policy-makers, and other stakeholders to address the impact of dementia as an increasing

threat to global health," writes Dr Margaret Chan, general-director of the World Health Organization.

"I call upon all stakeholders to make health and social care systems informed and responsive to this impending threat."

Dementia: A public health priority finds that the predicted trebling of the prevalence of dementia from 35 million people to more than 115 million people by 2050 will exert enormous economic and social pressure on health systems around the world. Every week in Australia, approximately 1600 people are diagnosed with dementia. This

figure is set to rise to 7400 new cases each week by 2050.

The report has several Australian contributors, including Pamela Nichols, who helped co-ordinate the international project, and Professor Henry Brodaty, who assisted in research on caregivers. There are a number of key messages within the report, which includes recognition of the burden placed on caregivers of people with dementia and also a recognition of the unique perspectives of caregivers and of people with dementia themselves. It is suggested that caregivers and people with dementia must play a stronger

role in determining the ways in which care programs are formed.

Issues covered in the report include: the impact of dementia around the world, the prevalence across different national income levels, predictions of the burden on international healthcare systems, and suggestions for confronting the scale of the epidemic. "Countries must include dementia on their public health agendas. Sustained action and coordination is required across multiple levels and with all stakeholders – at international, national, regional and local levels."

Australian research is awarded ADI prize

An Australian research team based at the University of Technology Sydney has won the 2011 Alzheimer's Disease International Psychosocial Research prize for best evidence-based psychosocial intervention. Lead by Professor Lynn Chenoweth, the project, Person-centred Environment and Care for Residents with Dementia: A Cost-effective Approach to Improving Quality (PerCEN), was a large three-year study, covering 38 residential care homes and involving close to one thousand participants.

"Our study (PerCEN) was a clustered randomised controlled trial looking at a person-centred approach to the care environment and care practices to improve outcomes for persons with dementia," Professor Chenoweth said. "The research focused on the psychological well-being, reduction in agitated, distressed behaviours and depression that can occur in people with dementia."

The research prize included €18000 (Euros) to be used to promote the project and

further its outreach, with the money being put towards a dissemination plan which will improve the understanding of the project's goals, outcomes and implications.

This plan will support practical solutions, implementation of the project's results, and sustainability for Australian programs based on the new information.

Professor Chenoweth has said: "Sharing the project's findings and recommendations with key stakeholders and implementing strategies to disseminate the project's outputs through communications, social exchange, education and training are paramount in the interdisciplinary learning and research process."

Professor Chenoweth, a prominent and celebrated researcher who is known for her achievements in aged care and dementia-focused research, accepted the prize on behalf of the PerCEN research team on the 9 March 2012 at the ADI conference in London.

Research indicates the need for knowledge translation

Professor Andrew Robinson from the Wicking Dementia Research and Education Centre in Tasmania has described levels of knowledge about dementia among care staff and family carers as "problematic" and "frightening".

Speaking at the National Dementia Congress in February in Melbourne, Professor Robinson shared findings from a study involving the assessment of the knowledge of 315 staff in

aged care facilities and 163 family carers in three states.

In particular, he said it was alarming that over 40 per cent of registered nurses, over 50 per cent of unregistered carers and 60 per cent of family carers do not consider dementia to be a terminal condition.

He suggested that this should be addressed by a full-scale knowledge translation programme as the provision of education in isolation does not produce changes in service delivery.



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An ongoing program at the Bupa Bellarine residential facility has seen 70 older people with dementia walk 20 000 kilometres in 16 months, covering almost the entirety of Australia's coastline. Beginning their travels in Geelong, Victoria, the residents have hiked along the Great Ocean Road to South Australia, then walked to places as far off the beaten track as Coober Pedy, Alice Springs, Darwin and Cairns – without ever once leaving the nursing home.

The Walk Around Australia program was born in a focus group run at Bupa Bellarine, based in Geelong, in January 2010. At the meeting, staff and residents discussed the importance of staying fit. Though residents understood that exercise was important, they reported that they generally didn't enjoy exercising and were sometimes unmotivated to start and continue any activities.

The residents wanted a goal-orientated, positive relationship with exercise, instead of pursuing fitness out of obligation to their health. General Care Manager Heather McKibbin and her team rose to the challenge, and the Walk Around Australia program was born. One of the main goals of the program has been to place less emphasis on notions such as 'exercise is good for you', and instead promote exercise as a desirable, goal orientated activity.

'Wandering' and restless pacing are generally considered to be difficult behaviours for staff to respond to. According to Heather, another goal of the Walk Around Australia program has been to turn 'wandering' into something positive.

Prior to the program, residents who were inclined to walk persistently were generally steered into sedentary activities or repeatedly told to sit down, but of course the walking continued. Now, rather than staff considering walking a problem behaviour, the program gives them a reason to encourage and reward residents to walk around the grounds of the nursing home.

How the program works

The staff of Bupa Bellarine measured the distance around three walking trails in the grounds of the nursing home – two around buildings and one around the garden. They developed a scoring sheet that residents could use to check off each time they completed a lap of a trail.

Participation in the program is voluntary, and residents are given a comprehensive physical assessment prior to commencement to assess if they are physically capable of participating. Then – on their own or with help – they walk

One step at a time

The Walk Around Australia program has motivated long-term care residents with dementia to trek the total distance of Australia's coastline – over 20 000 kilometres – in a 16-month collaborative effort. By **James Baldwin**



Residents' journeys are marked onto a large map of Australia displayed in the facility

around the paths when they want to exercise. Residents who cannot walk the trails are able to join in by exercising with the help of an arm-peddling machine which is set on a table.

Every fortnight, the total distance covered by all of the participants is added up and drawn on a large map of Australia. The residents 'walk from town to town' with this method.

When they are close to reaching a milestone or a major location, Heather contacts a community leader in that town and requests a letter of welcome for the residents. The mayors of various cities and towns and other community representatives have been very enthusiastic, and sometimes go the extra mile to celebrate the achievement. The mayor of Coober Pedy sent a letter along with a number of opal chips, which were given out to the residents as a token of their visit.

Every 'arrival' in a location is marked by a celebratory party, themed for the point of arrival. When the residents

reached Darwin, they celebrated with beer and crocodiles; in Cairns, it was lollies shaped like fish, tropical fruit and punch. The letters are framed and displayed on the wall alongside the map, reminding residents of their achievements and their future goals.

Results

Before starting on the program, the residents are given a six-minute walking test which allows a physiotherapist aide to measure the distance that a resident can walk. After two months of participation, the walking test is given again. Bupa Bellarine has kept record of the changes in fitness and walking distance, and the results showed demonstrable improvements in distance covered by individuals between the first and subsequent tests. Overall, the results have shown that residents are able to walk further and have increased levels of physical fitness due to their participation in the program.

Published research in Australia,

America and Sweden indicates that exercise in cognitively intact older people may slow the onset of Alzheimer's disease, and that fitness past the onset of dementia is valuable in slowing the progression of dementia.

The research showed statistically significant differences between test populations who engaged in moderate exercise (around three times per week) versus those who got little exercise (Andel *et al* 2007; Larson *et al* 2006). In a separate study which used data from 18,766 women aged 70 to 81 years, Harvard researchers Weuve *et al* (2004) also found a positive association between physical activity and better cognitive performance. Women who walked at least 1.5 hours per week had less cognitive decline than those who walked less than 40 minutes per week.

There is anecdotal evidence that the Walk Around Australia program can be beneficial for the mood and memory of people with dementia.

A family carer at Bupa Bellarine noted a great difference in his mother, and reported that prior to the program, his mother was sedentary and often seemed to be just 'biding time'. After she had begun

participating, he observed that she was noticeably fitter, happier and more alert.

For care staff, the program means more positive engagement with residents, as well as changing the way they think about walking and people with dementia. It was recorded in an improvement log at BUPA Bellarine that staff are not telling the residents to sit down as often as they did before. The staff have an active role in facilitating the program: contacting the representatives of various townships, walking and spending time with residents, reflecting on their achievements in their company, and participating in the celebrations once a goal is reached.

Future roads

The Walk Around Australia program is ongoing. As of March 2012, the residents were about to reach Bendigo before marching forward to Tasmania. There's no sign of them finishing there, either: some are looking forward to returning to towns where they were born, while others wish to return to countries they visited when they were younger. "I don't think the residents want to finish," said Heather, "They are looking to Tasmania, and after that, it's the world."

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James Baldwin is Contributing Editor of the Australian Journal of Dementia Care. He can be contacted at: james@mjblood.com.

Residents are finding they can walk further and faster after involvement in the program



What a difference a day makes

In September 2004, the coalition announced during that year's federal election campaign that they would allocate additional funding over four years to make dementia a national health priority. Subsequently, in the 2005 budget the coalition government implemented the *Dementia initiative: Making dementia a national health priority*, allocating \$320 million over five years to support high care dementia community packages, expanded dementia training, funding for dementia care research and additional funding for Alzheimer's Australia through the National Dementia Support Program. This was a landmark decision, not only in Australia, but world-wide. Australia in 2005 was the first country to recognise dementia as a major issue in that way.

The current government's package *Living longer, living better*, announced on April 20 this year by the Prime Minister, Julia Gillard, and the Minister for Health and Ageing, Mark Butler, signals another red letter day for people with dementia and their family carers. There could be no better way to celebrate the first issue of the *Australian Journal of Dementia Care* than with the announcement that with these aged care reforms, dementia will once again be made a national health priority subject to the agreement of Australian Health Ministers. The Fight Dementia Campaign and the courage of people with dementia and their family carers in telling their stories during the consultations on the Productivity Commission's *Caring for older Australians* report (2011) have made an impact on the government.

Good policy is the pre-condition for the implementation of effective programs. Many stakeholders

Alzheimer's Australia has long championed the cause of people with dementia and their carers. In this article **Glenn Rees** celebrates the impact of the Fight Dementia Campaign on the government and welcomes the release of the 'Living longer, living better' reform package



Campaigners from Alzheimer's Australia marching in October 2011 at Parliament House, Canberra

in the aged care sector may have been surprised by the comprehensive nature of the government's response to the Productivity Commission's report at a time of such economic uncertainty. At the policy level, *Living longer, living better* lays the basis for reforms that complement the advocacy of Alzheimer's Australia in five important ways.

Community care

First, the reforms hold out the promise of strengthening the community care system to make it possible for people with dementia to stay at home longer. There will be more community care packages that will better service varying levels of need and more funding for respite care. In

many ways, this is not new, but rather the fulfilment of the aged care reforms that were introduced in the mid-1980s.

Doubts remain about whether the reforms still go far enough. Today only 113 people per 1000 aged over 70 are able to access care. Over 10 years that number will increase to 125 and the number of community care packages will be 45. The government's commitment stops far short of making aged care a universal entitlement – the system will still be rationed. Nonetheless we are heading in the right direction.

Consumer-directed

Second, the reforms will empower consumers through adopting consumer-directed

care in all care packages, which will allow all consumers to have more say over their services: what they need, when they need them and who delivers them. Alzheimer's Australia first began advocating for consumer-directed care in the aged care system in 2002. Ten years on, consumers have got their message across – services must meet the needs of consumers and particularly those of diverse communities.

The cultural change involved in consumers being more assertive in saying what they want and service providers responding to these demands is huge. It is not just a question of funding, but a deeper question of mutual respect and, according to people

Australian Institute of Health and Welfare on a project that estimates the economic costs on hospitals associated with poor quality dementia care through analysis of data they have collected in their Hospital Dementia Services program.

In Australia an assortment of small projects have focused on improving the quality of dementia care in hospitals. These have included dementia education programs, a Cognitive Impairment Symbol, a dementia volunteer project, a Dementia Champions project and education around delirium. Most of these have been implemented in only a few hospitals and some have shown benefits for people living with dementia in hospital. E-Health may also offer potential for the future in identifying people with dementia at risk. It is clear that, without coordinated action by the commonwealth and states and territories, hospitals will continue to be dangerous places for people with dementia.

Future campaigns

The government's plan to tackle dementia does not have a vision for reducing the future number of people with the disease either through dementia risk reduction or investment in research. These are issues that will be at centre stage in the advocacy work of Alzheimer's Australia over the coming months.

The benefits of even a short delay in the onset of dementia will be substantial. It has been estimated that if the onset of Alzheimer's disease (50-70 per cent of all cases of dementia) could be delayed by five years, it would reduce the numbers of those with Alzheimer's disease by half between 2000 and 2040 with significant savings to the health and aged care systems. Further investment in research into the causes and prevention of dementia is key to reaching this goal.

There is now good evidence

that we can reduce our risk of dementia by taking control of alcohol use, blood pressure, body weight, cholesterol, depression, diabetes, diet, head injury, mental activity, physical activity, smoking and social activity. Yet only 50 per cent of Australians believe that it is possible to reduce the risk of developing Alzheimer's disease and other forms of dementia. Even among those who are aware there is something they can do to reduce risk, most are only aware of the benefits of staying mentally active. Approximately 80 per cent of Australians are not aware of potential benefits of reducing high blood pressure, cholesterol and avoiding head injuries. It has been estimated that half of all cases of Alzheimer's disease could be attributed to modifiable risk factors.

Dementia research is grossly underfunded in relation to health and care costs, disability burden and prevalence compared to other chronic diseases. In the 2011-2012 financial year, the National Health and Medical Research Council's research funding for chronic diseases was \$159.2 million for cancer, \$92.4 million for research on cardiovascular disease, \$71.2 million for diabetes and \$53.6

million for research on mental health. Alzheimer's disease and other types of dementias received only \$24 million.

Where to now?

The government has indicated that at the end of five years there will be a review of the progress made in implementing Living longer, living better. From the consumer point of view, there will be major issues to explore – the extent to which community care has been expanded, improvements in flexible respite, the adequacy of the new funding model and transparency in quality of care. The government is right to take the view that the successful implementation of the ambitious policy reform contained in Living longer, living better will take a decade to achieve. Unfortunately, that will mean that many people with dementia and their family carers will continue to struggle to access good quality dementia care and support when they need it.

■ Glenn Rees has been CEO of Alzheimer's Australia since 2000 and was influential in making dementia a National Health Priority. He has a degree in economics and a long history of public service at the highest levels in the UK and Australia. He

was Chair of the Nursing Homes and Hostels Review in 1986 and was involved in implementing the first wave of aged care reforms in Australia.

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Alzheimer's Australia campaigners in action

Removing the walls of fear

This is the first of a series on communication and relationships specially written for *AJDC* by well-known author, **John Killick**. They are based on John's experiences of talking with and working alongside people with dementia over two decades in the UK and abroad, including Australia. The views are John's own and some of them may be considered controversial.

Fear is something we all have to overcome when we encounter someone with dementia for the first time. It can take a number of forms:

- fear of the unknown, where we come up against situations we have never encountered before
- fear that we may be hurt physically and/or emotionally by the other person
- fear of powerlessness: that we will be found wanting, that we will fail in the task with which we are confronted
- fear that what is happening to the person before us may happen to ourselves in course of time.

We may not be fully aware of the cause of our fear – it may be a mixture of these and other anxieties. It may not be possible for us to allay fully any of these fears. There are strategies we can adopt, though, which may help us with each of them to a greater or lesser degree.

Familiarity

First, and most importantly, it is certainly true that familiarity can lessen the anxiety state. I don't mean that we can ever reach the situation of being able to take dementia for granted, but it can begin to seem less strange in course of time.

It is natural to be afraid of anyone who acts differently from ourselves. If we do not understand why they act as they do, it becomes difficult to feel empathy for them. They challenge our view of the world as a place that functions according to a set order, and change it into something incomprehensible and hostile. Here, surely, is the basis for the stigma that people with dementia have to endure, a situation made worse by the way we talk about the condition and how the media exploit it. It is important to recognise that just as we are challenged by dementia, so are those who are going through the experience and their struggle to make sense of it can be even more stressful than our own.

My own introduction to people with dementia was dramatic. I was pushed into a unit with thirty residents, told I would get nothing from any of them, and the door was locked behind me. I knew nothing about the subject, and had never

before met anyone with the diagnosis. At first I was bewildered and felt alienated; I really thought I would not survive the experience. But I learned quickly and became more confident. Tom Kitwood spoke of seeing the person, not the disease, and I understood this before I ever heard him say it. At the end of a week every person was clear to me as a unique and lovable individual.

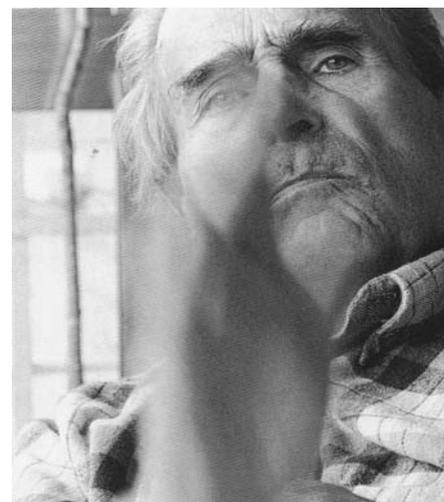
The fear of being hurt is again lessened by the number of occasions when it has not occurred. In my work I have had the privilege of interacting with hundreds of people with dementia in many different situations (in day centres, nursing homes, hospital wards, and in their own homes), and with different degrees of communication difficulty, and no assault has ever occurred.

Respite and reflection

It is true, however, that after about five years of one-to-one encounters, the emotional effect gradually crept up on me. One day I found I could not go through the nursing home front door. I went to a counsellor. I thought I was having a 'breakdown' but she said I was having a 'breakthrough'. The experience of encountering so many different persons struggling with the changes they must come to terms with had changed me too: my emotions were nearer the surface, and this was something I must plan for in my subsequent work. I paced myself, and took time for reflection. I am sure this applies to all who work in this field: respite for the carer is an important principle.

Fear of failure is without doubt the most likely to be realised of all these fears: there is no way that any one individual can give the perfect answers to all the questions that will be raised by communication and relationship. The best you can hope for is that you will become more assured, and that the success rate, insofar as it can be measured, will improve. A certain humility is necessary, and the bar should not be set too high in the first place, so that when the special moments occur, you can take strength from them.

Deborah Everett, a chaplain in Canada, has written: "The powerlessness that may



Photograph by Carl Cardonnier from *Openings* (Hawker Publications)

occur when caring for a person with dementia has a lot to do with the caregiver's inability to value other means of communication than just words... When we see only meaninglessness, commitment is often lost. Surrender to the mystery of the future means admitting the possibility of suffering. Real care for those affected by dementia only takes place when the walls of fear have been removed."

Preparing for the future

No one can be sure that dementia does not lie in wait for them. Concentration on the positives will erase parts of the bleak picture which other people and the media will paint. Rather than push this fear under, it is better to bring it out into the open. One of the best things we can do is to make plans for how we wish others to behave towards us if we were to develop the symptoms; in particular, what we would like carers to know about our likes and dislikes in case we are not in a position to tell them. 'Be Prepared!' is not just a motto for British Boy Scouts!

In general terms, some factual knowledge of dementia (all the medical matters) can be helpful, but it is unlikely to affect the situation in a major way. For that to happen there is no substitute for the access of awareness that accumulated experience brings.

Kahlil Gibran offers understanding of the process we must undergo in the following lines taken from his book *The Prophet*:

"Your pain is the breaking of the shell that encloses your understanding.

Even as the stone of the fruit must break, that its heart may stand in the sun, so you must know pain.

And could you keep your heart in wonder at the daily miracles of your life, your pain would not seem less wondrous than your joy."

Trial iPhone app helps to extend environmental design consultancy



Professor Richard Fleming is the Director of the NSW/ACT Dementia Training Study Centre. For further information send an email to dementia@uow.edu.au.

Richard Fleming writes about an innovative approach to design consultation for aged care facilities: an iPhone App based around the principles of the Environmental Audit Tool (EAT) which aims to make designing for dementia more accessible

Reading a good article or attending a good presentation on environmental design for people with dementia may be useful, but nothing beats having an opportunity to discuss your own facility with an expert at exactly the time you need to firm up your ideas. The NSW / ACT Dementia Training Study Centre (DTSC) is well on the way to providing a nationwide service for people engaged in refurbishing or planning new facilities for people with dementia. An iPhone app based on the Environmental Audit Tool (EAT) is helping them reach people they cannot visit in person.

There are more than 90 000 people with dementia in residential aged care facilities across Australia and the demand for these places is estimated to grow at 4 per cent per annum between now and 2029 (Access Economics 2009). Many of the facilities in which these people live are being refurbished. Unfortunately, these refurbishments often occur without the work being guided by the knowledge gained from the last thirty years of research into designing environments for people with dementia. The result

is a missed opportunity for improvement.

The NSW / ACT DTSC provides a Department of Health and Ageing-funded service to encourage aged care providers planning refurbishments to take advantage of available research information. This service is currently being delivered by NSW / ACT DTSC consultants in NSW, Victoria, Tasmania and Western Australia. It usually involves a one-day site visit by the consultant. The day begins with an exploration of the philosophy of care of the facility. Once that idea has been developed, effective principles of design can be applied to modify the facility while supporting the managers and staff in delivering the type of service that they value.

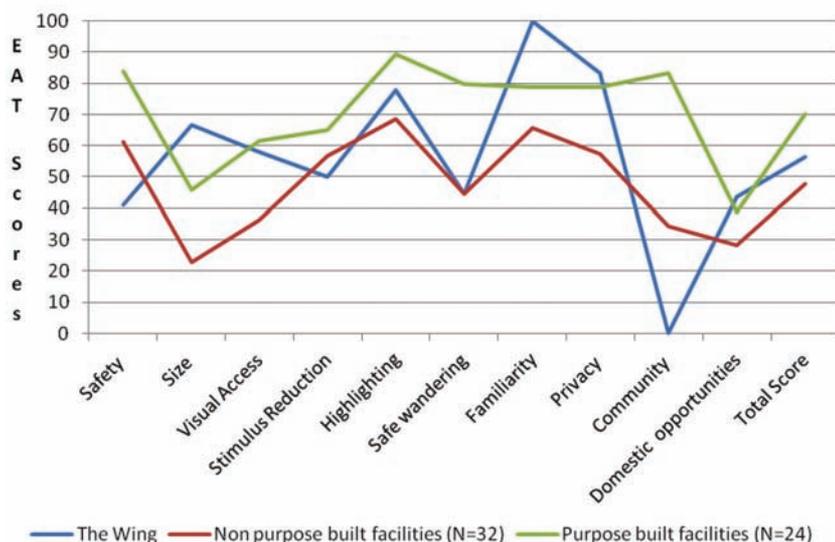
Evaluation

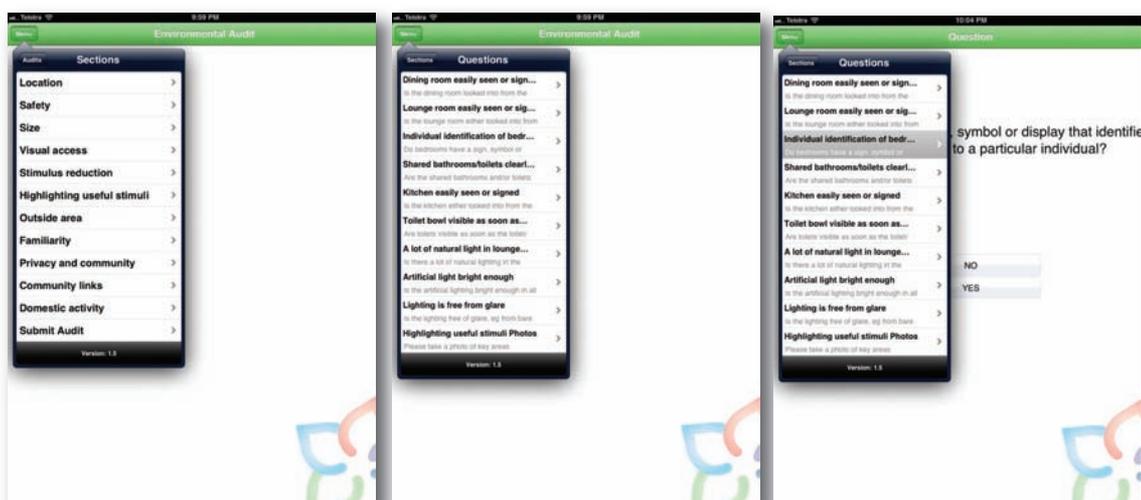
Once the available knowledge has been described, the facility that is about to be refurbished is evaluated using the EAT. This tool was first used in a NSW Health project aimed at improving the wards used for people with dementia in rural and regional hospitals. Details of this project are available in a NSW Health report, *Adapting the ward: For people with dementia*, which can be found on the NSW Department of Health website. Whenever possible this evaluation is conducted with key staff from the facility. When the audit is completed, the visiting expert enters the results into a spreadsheet that provides two things which will be the basis of a discussion in the afternoon.

The spreadsheet generates a graph (see left) that compares the facility with a number of other facilities, including those purpose-built for residents with dementia. In this example, The Wing – a facility that has been audited and is in blue – compares favourably with other purpose-designed facilities in size, the provision of familiar furniture and fittings, and in providing opportunities for privacy as well as being with others. It doesn't do well on providing links to the community, that is, making it easy and pleasant for family and friends to visit.

The second outcome of the visiting expert's spreadsheet is a table in which the items in the Environmental Audit Tool are ranked in order of the size of the difference between the actual score and the maximum score, or in other words, the room for improvement. The table prioritises items

Comparison with
56 facilities reported in Smith, R., R. Fleming, et al
(2011)





The iPhone app is based on the EAT

for which there is a lot of room for improvement at the top.

The afternoon begins with a discussion of the strengths and weaknesses of the current facility as shown by the graphical comparison with other facilities. This leads on to a detailed discussion of the items in the audit tool that have the greatest room for improvement. In other words, the discussion starts with the items at the top of the list and works down, the idea being to come up with ideas for improvement that fall into three categories: those that can be done immediately using existing resources; those that will take a little longer and may require modest expenditure; and those that will have to be put into the maintenance or capital works schedule. By the end of the afternoon the key staff have begun, if not completed, a systematic plan for improvement.

Shortly after a consultation, Vicki Simpson, the manager of a UnitingCare Ageing facility in Tamworth, NSW, emailed with the following feedback:

“Our aged care service recently enlisted the support of the environmental design consultancy service to review the dementia areas and the links with the general aged care sections. Richard’s ideas were well received (because they were underpinned by strong research), were practical because most did not require major building changes, challenged staff ideas and led to a flurry of creativity on the ground – all of which are proving positive for those who live in the facilities. As a result agitated people are becoming less so, and some of those who were not eating have warmed to the changes, recognise their dining room and are now happy to stay and eat.”

The service began operating in November and forty consultations will have been provided by June. While the service will be extended to Queensland, South Australia and the Northern Territory in the coming financial year, travelling time, travelling expenses and the availability of time from the experts will always restrict the number of visits that can be made.

To solve this problem, an iPhone app based on the EAT is being trialled to guide the facility manager through the audit process without a consultant actually being present. The app, called

‘Built Environment Assessment Tool – Dementia’ (BEAT-D), is available through the Apple App Store. The user downloads the app which then requests some basic information, including an email address. When the app sends this information to the computer in the NSW / ACT DTSC Centre, a unique User ID and Password is sent to the user who is then able to access the full app.

When the user is ready they use the app to complete the audit tool. It presents questions in ten sections, each one corresponding to a principal of design, for example safety, visual access, and stimulus reduction.

At the end of each section, the user is asked to take a photo or two to illustrate the main points of their assessment. They can illustrate good or bad parts of the environment. When the user has completed all of the sections they have the opportunity to send the information and the photographs to the computer database at the NSW / ACT DTSC. When it is received, the beginnings of a report are automatically generated. This includes the graph comparing the user’s facility with other facilities and the ‘Room for Improvement Report’. The photographs are also placed in their correct positions in a report template that is structured on the ten principles of design.

This report is then sent back to the user along with information on good design for people with dementia and an invitation to set up a one-hour teleconference with a NSW / ACT DTSC design expert. During the course of this teleconference the strengths and the weaknesses of the facility will be discussed; the report with the photographs is fleshed out, and a beginning made on the development of the short-, medium- and long-term plans for the facility.

While this approach does not offer the same level of personal interaction as the site visits, it does offer the opportunity for a very detailed, systematic discussion of ways to improve a residential aged care facility. It is most useful to people who are actively engaged in planning a refurbishment and will provide them with timely information that will help them to make the best of the opportunity that refurbishment offers.

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How ventriloquism is helping people to speak for themselves



James Baldwin is Contributing Editor of the Australian Journal of Dementia Care

James Baldwin writes about the Melbourne-based Baptcare Strathalan initiative, the Ventriloquist Dolls in Music Therapy Program, which brings accessible, interactive comedy to people with dementia

If you go to Baptcare Strathalan Community on a Wednesday, you might notice something... unusual. Namely, people with dementia, care staff and the odd nurse laughing along with a gentleman named Marty, sitting on the lap of a man named Peter Coughlan. Marty is one of five ventriloquist dolls puppeteered by Peter at the Victorian aged care residential home as a part of the Ventriloquist Dolls in Music Therapy Program, an ongoing on-site program that now runs across five long-term residential facilities in Melbourne. Possibly the first of its kind in the world, the program was the recipient of an Aged Care Standards and Accreditation Agency Better Practice Award in 2011 for its role in enriching the lives of people with dementia in long-term care.

Peter Coughlan, the man behind the initiative, is a music therapist who has worked with older people and people with dementia for over a decade. He developed an interest in finding other ways to engage people, in addition to music. His initial programs at Strathalan included one-on-one, small and large group music therapy sessions, static displays of toys and objects, and later, electronic toys which he used in performances to entertain residents of the home.

A display of plastic 'rubber duckies' turned out to be very successful and lead to much laughter and humour around the nursing home. This incident sparked his interest in the ability of objects such as toys and dolls to stimulate people with dementia, and he went on to expand his repertoire into objects that move, such as a singing toy dog, a singing lobster and a recordable parrot which plays back sound in a higher pitch, just like the real thing.

The seeds of the Ventriloquist Dolls in Music Therapy Program were planted during a visit to Baptcare Strathalan by the iconic Australian entertainer Ron Blaskett, who performed at the home with his famous ventriloquist doll, Gerry Gee, in 2010.

"I heard a big commotion coming from the common room, so I stuck my head in. I saw Ron sitting there giving a performance with his ventriloquist doll, Gerry Gee," Peter said. "And the residents were reacting very well to the doll.

They were laughing... there were residents elbowing each other and saying things like 'Did you see that? The doll just talked!'"

Peter had a broken ventriloquist doll at home, but had no idea where to have him fixed. After talking to Ron Blaskett, he got the name and number of Gordon Ross, a man who specialised in making and repairing dolls for ventriloquist performances.

Ross was also making reproductions of Gerry Gee. Peter got his doll repaired, but after much deliberation, bought himself one of the superior, but costly Gerry look-a-likes. After witnessing the reaction at Strathalan, he wanted to know if working with a ventriloquist doll could help residents become more engaged, alert and connected.

As it turned out, the residents loved the doll and continue to respond positively to ventriloquist performances. The pair move around the facility during the day, with Peter and Marty integrating their show into the fabric of day-to-day care at Strathalan. A constant role play occurs with residents, visitors and staff, encouraging laughter, humour and fun interaction with the doll. The process is very different to standard implementations of doll therapy for people with dementia – the ventriloquist dolls are not left in the complex for the residents to pick up as and when they choose, and Marty and the other ventriloquist dolls are only used in active performances which engage residents individually.

Drawing out responses

One of the most remarkable results of the program has been to observe the way in which the use of a ventriloquist doll opens up residents, particularly those who are withdrawn or depressed. People with dementia, who may fear talking about their situation, emotions and difficulties to care staff, will often open up to a ventriloquist doll. Peter Coughlan related that one woman who had not spoken for around two years opened up dramatically when introduced to the doll. "She kissed his cheeks, gave him a two-armed hug, and then she grabbed his collar. He had a sheepskin

collar on, and she said: "That'll keep you warm for winter!"

Another resident who rarely communicated with her family or care staff also opened up to the doll, engaging with it where she would not engage with people.

Peter became interested to find out more about ventriloquism and dementia. He began asking other ventriloquism performers from around Australia for their thoughts on why residents might open up to a doll instead of a person. The general conclusion was that the doll is a surrogate, non-threatening entity, who evokes Vaudevillian images of humour and light-heartedness which makes communication easier. Ventriloquism is associated with a kind of 'truth-telling' – the dolls are typically not constrained by the same social mores and restrictions which people are pressed into, and so, communication with them is easier and freer.

Scoring system

Peter went on to contact Dr Bruce Barber, a researcher and lecturer in Melbourne University's National Aging Research Institute (NARI), to get his advice on research methods to probe this question more systematically. The Bapcare Strathalan team, with Dr Barber's advice, developed a scoring system for testing whether or not residents showed higher degrees of interaction and engagement with the doll versus listening to music or interacting with a member of staff. Each session was conducted with an observer in attendance.

The interactions were scored under three conditions: one with questions to the resident by a member of staff (the control group), one with music and questions, and one with the doll talking and asking questions. The study revealed a 28 per cent increase in engagement when the doll was used compared to the other two types of interactions.

Performing with the dummy takes a flair for comedy, a gregarious personality and a lack of fear. "It's not for the faint-hearted," Peter reports, "You have to be able to get a doll, you have to be outgoing, you have to be able to role play and develop a character." He noted, however, that the performer does not necessarily need to know how to perform closed-mouth ventriloquism. Peter also adds that, "I'd love to see other aged care workers embrace this phenomenon, and use it daily. It's a winner."

The program started in 2010 and continues to develop. The next step will be to combine the ventriloquism performances with music to offer residents the opportunity to engage with the doll in song as well as conversation. It is hoped that this will bring the benefits associated with music therapy into the interactions. There is clearly an opportunity for further research into the effectiveness of this approach.

Bapcare operates eight aged care homes across Victoria and Tasmania. To find out more about Bapcare's services, visit www.bapcare.org.au



Peter with Marty and another of his ventriloquist dolls

Doll therapy in dementia care

Dolls have been observed to have a generally positive effect as a form of therapy with people who have dementia. A pilot study in 2006 based in the University of Newcastle in England (Mackenzie *et al*) questioned care staff about the use of dolls in a high-level residential care facility. The dolls were left in visible locations, such as tables and hobby niches, where the residents were able to find and collect them.

The study found that the overwhelming response was positive, with care staff reporting that residents who made use of the dolls were less agitated, more engaged and more likely to communicate with staff.

Despite its effectiveness, this approach has triggered ethical and moral debate over the

suitability of using dolls as therapy for older residents on the grounds that it is potentially infantilising. Infantilisation refers to the treatment of old age as being a second childhood, with accordingly diminished respect for the adulthood and history of an older person. Problems associated with doll therapy include the risk of over-investment in the dolls, overstimulation and criticism from family and other residents of people who use the dolls.

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Mackenzie L, James I, Morse R, Mukaetova-Ladinska E, Reichelt K (2006) A pilot study on the use of dolls for people with dementia. *Age & Ageing* 35(4) 441-44.

Designing for dementia: key design principles in Indigenous settings

How do we design appropriate facilities for Indigenous people with dementia? As an architect, I find that one of the most fascinating things in any new project is getting to know the client. What is important to them? What are their dreams? What are their values? How do they wish to live? What are they able to do? When designing for older Indigenous people with dementia it is no different. These questions can be asked in any setting. It is the answers and the meaning of the responses that will differ according to the place and people, however the answers can be understood with reference to a set of key principles.

This article will illustrate the application of a set of principles to the design of an aged care facility for Indigenous people with dementia and their application in the development of an audit tool for measuring the strengths and weaknesses of these specialised facilities.



Kirsty Bennett is an architect who has specialised in designing for older people and people with dementia for over 15 years. She is currently Manager of Major Projects and Architecture for the Uniting Church in Australia, Synod of Victoria and Tasmania. She is also Manager, Environmental Design Education Services at the NSW/ACT Dementia Services Training Centre at the University of Wollongong.

Architect **Kirsty Bennett** discusses the application of design principles to a long-term residential care facility for older Indigenous people with dementia

Key design principles

The late 1970s and early 1980s saw the beginnings of interest in the building of specialised units for people with dementia. Purpose designed cottages were built in Aldersgate in South Australia, designed by the architect Brian Kidd. The CADE units were established in NSW (Fleming & Bowles 1987) and the Lodge Programme started in Victoria (Marshall & Eaton 1979).

As a result of this work and that undertaken in other parts of the world, a number of key design principles have been identified as important (Fleming & Bowles 1987, Fleming & 1994, Kidd 1988, Calkins 1988, Cohen & Weismann 1991 and Marshall 2001). In 2003, Richard Fleming, Ian Forbes and I identified 10 key design principles for people with dementia, and developed the Environmental Audit Tool (EAT) to measure these principles in practice (see Fleming, Forbes & Bennett 2003):

- Be safe and secure.
- Be small.
- Be simple and have good 'visual access'.
- Reduce unwanted stimulation.
- Highlight important stimuli.
- Provide for planned wandering.
- Be familiar.
- Provide for opportunities for privacy and community.
- Provide links to the community.
- Be domestic.

While these are design principles for people with dementia, they are also design principles which are of benefit to the whole community. All of us, for example, would like to know where we are, where we can go and what we will find when we get there.

Applying key principles

It is vital to recognise that these are principles of design. They are not a checklist of items, simply to be ticked off one by one. They are not rules to be applied in the same way to every situation. They are principles to be

understood and interpreted in each particular setting to determine what they mean. The principles are the start of a conversation. The responses to the principles can be very different, depending on where the project is and who will live there. The key design principles can be applied effectively in very different cultural settings. This is clearly seen in their use in the design of Tjilpi Pampaku Ngura (TPN), on the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands, in the north western part of South Australia near the border of the NT, WA and SA.

In this context it is also vital to note the importance of undertaking meaningful conversations and consultation. There will be things when working with Indigenous communities that as non-Indigenous people we are not told. There will be a reason for something being the way it is that we are not told about or simply do not understand. Gender and skin groups will determine who can talk to whom among Indigenous and non-Indigenous people. The way consultations are held will be particularly important and cultural matters will influence where meetings are held and who is present. It will also impact on the time needed to make decisions and the way decisions are made.

Design principles at Tjilpi Pampaku Ngura

Tjilpi Pampaku Ngura (meaning 'old man, old woman') is an aged care facility which is home to up to 16 Anangu either for respite or a longer stay. Three architects worked on the project: Adrian Welke of Troppo Architects who has experience in designing and building in remote areas, Paul Pholeros, an expert in Indigenous housing who has worked on the APY Lands for many years, and I contributed my experience in designing for people with dementia. It was opened in 2000 following a long consultation process which considered the needs and hopes of the people of the APY Lands. It comprises a series of separate bedroom

buildings, each containing two bedrooms (which can have three or four people living in them) and an ensuite bathroom. These units are placed in the landscape and connected by open walkways to a central building which contains a lounge / dining area, staff facilities and communal toilets and bathrooms.

TPN is not like a residential aged care facility in a city or suburb of Perth, Melbourne, Adelaide or Hobart, but the process for its design was not dissimilar to that in other places. Here too, the architects met with Anangu and aged care workers and explored what the design principles could mean in that place. The first things to consider were questions which focused on what older Anangu want and are able to do, what is important to them, their experiences and their expectations. Anangu said that they want to participate in cultural business, travel, hunt and gather, teach young Anangu, visit their traditional country, attend funerals and conduct sorry business. They wish to maintain family and community links, socialise, practice traditional arts (such as making artefacts, basket weaving and painting), sing, dance and tell stories, and sit by the fire with other Anangu. It is important that they have shelter from the elements (of extreme heat extreme cold, dust and rain), have sheltered shady places to sit with a view, have good food including bush tucker, feel safe and have secure storage for their belongings.

Many Anangu come from homes where good housing is defined by the availability of running water, a functioning toilet and a place to cook. Anangu will expect to go outside no matter how sick they are, and will want to lay near fires and live close to or on the ground. Anangu can live happily with very limited belongings. While everything comes and goes from the building it is not the feature but rather a place for retreating in times of bad weather and storing things. It will be important that there can be separation between men and women and that family / social relationships that require distance between people can be respected. It will also need to be possible to make a sorry camp, a place where people can move to and from when a person dies. It was apparent that while Anangu are more agile than other frail older people (seen for example in the way they climb into the back of vehicles and sit on the ground for hours) they are chronically ill with diseases such as



View to country at TPN

diabetes, kidney, respiratory, skin, eye and heart disease and mobility problems.

Having gained a greater understanding of these 'big picture' questions, it was then important to determine which of the design principles are most relevant when designing for older people on the APY Lands and what the most appropriate response to these principles was. These are now described and illustrated below.

Be safe and secure

TPN is surrounded by a high wire fence. It is easy to see and is an obvious barrier. In this setting, however, this is an entirely appropriate response.

Fences are seen as a positive thing on the APY Lands, perhaps in a similar way people from other cultures may view the wall of a lounge room. The fence serves a number of purposes. One is to prevent residents at TPN leaving. Another is to prevent non-residents coming to TPN uninvited. Another is to identify this place as the older person's place, thereby offering them peace and security.

Be small

Anangu have an interesting appreciation of scale as they live with the vastness of the landscape and the smallness of a wiltja (traditional outdoor shelter). The TPN is a small facility that has then been broken up into a number of small buildings. Bedroom units are separate

buildings that are distant from communal areas. All the buildings are placed in the landscape and this vastness is reinforced by the buildings' separateness. The buildings are designed to be small objects in a vast landscape, rather than be a significant presence.

Be simple and have good 'visual access'

When the Anangu sit in or leave the lounge / dining room at TPN they see the sheltered path which leads to the bedroom units and the surrounding landscape. When the Anangu leave their bedroom unit they see the lounge / dining room and the landscape. In this way Anangu have a clear view of the places that are of interest and importance to them and so can choose where they wish to go.

Reduce unwanted stimulation

At TPN the kitchen and laundry are placed away from resident areas and away from the view. There are two circulation systems: a 'front of house' way for residents and a 'back of house' route for staff. This allows

residents to be undisturbed by the servicing and operation of the building and instead to focus on the areas that are of interest to them such as a bedroom unit and the lounge / dining room.

Highlight important stimuli

For many Anangu it will be the outdoor environment which will offer the most meaningful stimulation and cues. Rocks,



TPN offers a place to be on one's own or with others outside

Indigenous Aged Care Design Guide

The relevance of key design principles in different cultural settings has also been seen in the development of an Indigenous Aged Care Design Guide for the Department of Health and Ageing. Led by Paul Pholeris, Kirsty Bennett, Adrian Welke and Maureen Arch, the project took the key principles of the EAT and examined how these are relevant to Indigenous people. This has resulted in the development of an Indigenous Environmental Audit Tool (IEAT). The IEAT is designed to be used in Indigenous settings across Australia in locations as geographically and climatically different as Boroloola, Brunswick and Pukatja. It is organised around the ten design principles of the EAT, but questions have been reviewed and revised to respond to Indigenous settings.

A number of additional questions have been added to the principle of 'Be safe and secure' and it has been renamed 'Safety, security and health' to reflect the need for greater emphasis on designing for health in many Indigenous settings. Over 90 per cent of the failures of health hardware in Indigenous housing are due to poor initial construction or lack of routine maintenance (Dept Family Community Services 2007). As a result, Indigenous people do not have the ability to carry out the most basic healthy living practices: the ability to wash people, particularly children; the ability to wash clothes and bedding; to be able to remove waste safely from the house and immediate living environment; the ability to store, cook and prepare food (Dept Family Community Services 2007).

views, mountains and fire are all likely to assist wayfinding and orientation. As a person moves around TPN there are constant views and engagement with the outdoor environment. Anangu are directed toward bedroom units and the lounge/dining area by the covered pathway.

Internally, a large painting by local Anangu marks the approach to the lounge room. Otherwise, internal finishes are durable and simple in response to the harsh demands of the environment.

Provide for planned wandering

There are many ways people can move about at TPN. The outdoor environment is deliberately free from paths and instead remains in a more natural state. People are able to move about outside from place to place as they wish, following their own routes and creating new ways as appropriate.

Circulation between buildings is clearly defined by covered walkways. A simple path is laid under the walkway. This is designed to be easy for people to move about on in wheelchairs, on foot or by crawling.

In remote locations, aged care facilities can face difficulties in providing functioning health hardware due to the harsh environment, lack of available tradespeople and poor design and maintenance. The IEAT therefore asks a number of additional questions to determine whether kitchens, toilets, bathrooms and ensuites are functioning in the aged care facility.

The principles of 'Visual access' and 'Privacy and community' include a greater emphasis on outdoor living. 'Privacy and Community' also includes this emphasis and the questions also explore group sizes in more detail. In Indigenous settings, much of life can be lived communally and so there are times when large groups are very desirable.

'Domestic activity' identifies a number of other things that would be specifically appropriate and desirable for Indigenous residents to be involved in, including access to clean sand for sitting and dancing, being able to enjoy views to country, sleeping or resting in a cool (or warm) place outside and being able to make spears, create artefacts and or brew a cup of tea.

The IEAT also introduces another principle, 'Creating an enabling environment – Accessibility'. This is in response to the greater level of physical impairment that many Indigenous residents are likely to have as a result of chronic illnesses such as diabetes and eye disease. It also recognises that Indigenous people are likely to want to be outside no matter how frail they are.

Be familiar

For Anangu, outdoor shelters (wiltjas) are a very familiar part of their lives. The outdoor environment was designed for these to be introduced and removed as appropriate over time.

Rooms have been designed to be of a size that is familiar to Anangu, recognising that they are used to being inside in a

small space or outside in big country.

The en suite layout is similar to the layout of bathrooms in houses on the APY Lands. Even if the older people have not lived in a house they may have visited one and so the design could be familiar.

Provide for opportunities for privacy and community

Much of life in Indigenous communities is lived in public. On the other hand, privacy between different skin groups and genders is very important.

There are many ways people can be with others or alone at TPN. The lounge/dining room is a place for people to gather and be together in small or large groups. It is important, however, not to assume that all things are done in public. Privacy in bedrooms is a big issue at TPN. Visitors are not allowed in residents' bedrooms. Bedrooms are seen as private secure places rather than as meeting places. Outdoors, verandahs, wiltjas and trees provide many opportunities for people to sit (or lie) and be with others or be alone.

Provide links to the community

The relationship between TPN and the community is best reflected in the selection of the site itself. Despite older Anangu's strong desire to take part in the life of the APY Lands, it was seen as very important that older people were given a quiet place to live, away from the noise and humbug (or bother) of the community. This is entirely consistent with the way older people choose to live in tents on the edge of the town centre so they are away from the noise and any trouble.

The selection of the site and its cultural and spiritual significance was seen as much more important than the design of the facility itself. It was important that the site was a place where all Anangu could



Anangu sitting in a wiltja at TPN

feel welcome, recognising that people will come from all parts of the APY Lands and so for many people TPN will be on someone else's country. The importance of site selection is reflected in the time taken to choose a site: three years. This included an extensive process of visiting all parts of the APY Lands to talk through the issues. Many Anangu travelled great distances to take part in these meetings. It also included making an inventory of all the things that were required to make the facility work in each community, such as good power supply, good water supply, access to a health clinic, staff, good roads, a (food) store and an airstrip.

Be domestic

For Anangu a 'domestic' environment would mean having easy access to the outdoors and being able to sit around, eat outside, sleep outside, and see the surrounding country with adequate shade and shelter. It means having access to fire to make a cup of tea, make a spear, to cook, to make artifacts, to keep spirits away, to provide warmth and to dance and sing. (All of these activities and tasks require different sorts of fires.) It means having a fire that can be moved during the day to suit the sun and wind.

Older people at TPN are able to continue to do much of what they would like to do. This includes painting, sitting outside under a wiltja, looking out long way to country and watching the path of the moon and the stars.

Conclusion

It is apparent from this brief review of the design of Tjilpi Pampaku Ngura and the development of the IEAT that the key principles of designing for people with dementia are relevant when designing for older Indigenous people. It is vital to recognise the strength of Indigenous culture and the influence this can have on design of settings for older people. The key design principles offer a way to explore this by using a design approach which has been widely recognised.

The key lies in exploring the principles and starting afresh with every project. Let us not assume we know how older people wish to live. Let us not presume to know what is important to them. Let us consult meaningfully and take time to sit with older people and hear their stories. And then let us apply the key design principles in an imaginative way that creates inspiring environments for people with dementia.

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Above: the covered walkway. Below: a painting by Anangu marks the approach to the lounge.



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How to raise a SMILE: the Sydney Multi-site Intervention of LaughterBosses and Elder Clowns



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Dr Peter Spitzer, aka Dr Fruit-loop, explains the work of Elder Clowns and Laughter Bosses in dementia care, while Dr Lee-Fay Low shares some of the early findings from the world's largest study into the effects of humour therapy on people with dementia

There's nothing like a good laugh, and they can be hard to find in residential aged care. In New South Wales, the Humour Foundation has introduced two interlinked collaborative programs – Elder Clowns and LaughterBoss training – that have been bringing humour and joy into the lives of people with dementia with a unique collaboration between residential aged care facility (RACF) staff and specially trained Elder Clowns from the Australian Humour Foundation. A study of the two programs – the Sydney Multisite Intervention of LaughterBosses and Elder Clowns (SMILE) – is the largest study into the effects of humour therapy on people with dementia in the world.

The benefits of laughter for people with dementia

Gelotology is the study of humour and its effect on the human body. The Association for Applied and Therapeutic Humor (AATH), founded in 1988, defines therapeutic humour as "... any intervention that promotes health and wellness by stimulating a playful discovery, expression, or appreciation of the absurdity or incongruity of life's situations. This intervention may enhance health or be used as a complementary treatment of illness to facilitate healing or coping, whether physical, emotional, cognitive, social or spiritual" (AATH 2001).

On the physiological level, laughter stimulates respiration, relaxes arteries and improves blood flow as well as oxygen saturation of peripheral blood. Positive effects of laughter on hypertension and diabetes – common co-morbid conditions accompanying dementia – have been noted. Laughter has been researched in the field of psychoneuroimmunology, with studies showing a drop in serum cortisol ('stress hormone') levels and the enhancement of immune system function. People with dementia often experience degrees of chronic pain, which may be undiagnosed and untreated, and laughter is beneficial as a non-pharmacological tool to help manage pain. Gelotological interventions have shown positive effects on performance, mood, optimism, anxiety and depression.

Older persons who have a better sense of humour and use humour as a coping mechanism are more likely to live longer (Svebak *et al* 2006), age well (Solomon 1996), and be more satisfied with their physical health and life in general (Celso *et al* 2003).

The ability to experience the positive benefits of



Doris enjoying a dose of bubbles

humour does not diminish over the course of dementia. People with dementia may lose the ability to communicate clearly through use of smiling and laughter at a relatively early stage of the condition, but despite the lack of physical cues, they demonstrate the associated health and mental health benefits of laughter and humour from onset through to late-stage dementia (Tadaka *et al* 2010).

The same study, based in Japan, goes on to note that: "Dementia patients are usually under considerable strain, at least at the beginning of their illness. Patients' families are placed under even more stress because of the burden of care. A positive emotion, together with laughter, may enable dementia patients to cope with their illness better, improve immune function, increase pain tolerance, and decrease the stress response. When a positive attitude is shared by patients and staff, it can have a positive effect on the emotional-affective and cognitive functioning of the patients" (Tadaka *et al* 2010, p5).



The LaughterBoss SMILE graduates, with Professor Henry Brodaty at the top left

The art of clowning

Clowning has a long history as a performing art form that invites play, interaction and laughter. The internationally renowned 'Father of Clown Doctors' is Patch Adams, a doctor based in New York City. As a young doctor in the 70s, Patch Adams began clowning for hospital patients. Big Apple Circus established the Clown Care Unit in New York City in 1987, and was the first structured hospital clown program with frequent and regular visits to host hospitals. There are now many hospital clowning programs around the world where hospital clowns work in partnership with other health care providers. Professionalism of the hospital clowns and the programs they deliver are high priorities, with regular training, program and scheduled quality assurance reviews. Clowning in hospital addresses the psychosocial needs of patients as well brightening the atmosphere of the facility as a whole.

It was a very natural progression for this art form to spread from paediatric hospitals into other areas, partnering with healthcare professionals working in adult medicine, rehabilitation and palliative care. Regular programs have been delivered to aged care facilities by overseas clown doctor units for the past 10 years. These include the Big Apple Circus Clown Care Unit Vaudeville Caravan in the USA; the Hearts&Minds Elderflowers in Scotland; and Fools for Health Familial Clowns, who operate in Canada.

Programs for older people with dementia differ from clown doctor programs used with cognitively intact patients. Although these programs operate independently, a number of common themes have emerged and these include: avoiding the hospital/doctor persona of the performer as used in hospitals; avoiding stethoscopes and medical schticks; more detailed briefing by staff; sensitive tailored interactions based on individual needs;

flexibility in delivering multiple art forms; and the toning down of costumes and characters. However, all performers continue wearing the traditional red nose.

A healthcare-arts partnership

The Humour Foundation has been delivering humour therapy to paediatric hospitals, general hospitals and palliative care facilities since 1997. Visits to residential aged care facilities (RACF) were initially irregular, and as a result impact and connection with everyone in the facility was limited. The comment "Why don't you come more often?" signalled an inadequately met need.

In my capacity as co-founder of the Humour Foundation, I developed a new program model in

Introducing more humour into daily aged care

It will make a big difference if the culture of the facility, including management, is welcoming of humour, play and creativity. This can also make a difference to staff, improving staff satisfaction, decreasing stress, and reducing turnover.

Any humour intervention will involve some risk, a performance or a joke can sometimes 'fall flat'. This risk is lessened through training, experience, trust and good communication with the resident. So, take the risk with good heart, handling humour slowly and sensitively. Being alert for signs that today is not the day for joking. Here are some ideas for bringing laughter to any facility:

- Put up a humour notice board. This doesn't take a lot of management and

becomes a constantly changing façade. Only funny (constructive) material can be posted.

- Transform a stainless steel trolley into a humour cart. Use creativity to dress it up – a mobile giraffe, perhaps? Leave room for props that can be available for play. Over the course of a busy day, brief humour and play interventions are the way to go.
- Similarly a wicker play basket sitting in the corner can be loaded with great period hats, scarves and other objects, which can be picked up by residents or carers on the way from A to B.
- Take photographs. Many residents have photos of the past. How about a photo in the present?

About the SMILE Study

The Sydney Multisite Intervention of LaughterBosses and Elder Clowns (SMILE) study is the biggest study of humour therapy anywhere in the world to date.

Researchers wanted to find out whether the anecdotal reports of the benefits of humour therapy for older aged care residents could be substantiated with hard evidence. The aim of the study was to examine the effects of humour therapy on resident mood, social engagement, quality of life, agitation and behavioural disturbance.

406 residents from 36 residential aged care facilities were involved in the study. Researchers blind to whether residents were in the usual care control group or humour therapy intervention group collected data using well-established assessment tools such as the Cornell Scale for Depression in Dementia (CSDD). Dementia-related quality of life was measured with the DEMQOL resident and proxy versions, the social engagement subscale of the Multidimensional Observation Scale for Elderly Subjects (MOSES), the Cohen-Mansfield Agitation Inventory (CMAI), and the Neuropsychiatric Inventory Nursing Home version (NPI). Demographic, clinical and observational information were also collected at baseline (that is, before the intervention), after the 12-week intervention, and again at 26 weeks.

Residential aged care facilities were randomly allocated to either humour therapy or control groups. The humour therapy intervention comprised one-day training on how to incorporate humour into daily care for a staff

member nominated by the facility to act as their LaughterBoss. Elder Clowns (performers experienced in using humour in health care settings) visited once per week for 12 weeks, engaging in two-hour humour therapy sessions to engage residents through music, conversation, props and other techniques. LaughterBosses partnered with Elder Clowns during these visits, providing information which allowed for tailoring of interactions about resident history, personality and function. LaughterBosses were encouraged to continue use humour techniques between Elder Clown visits and after these sessions had ceased.

The first papers from the SMILE study have been submitted for publication. Observational data and staff reports show that residents enjoyed the humour therapy sessions and were happy and engaged during the sessions. The results also suggest that humour therapy decreased agitation compared with controls. LaughterBosses also reported benefits of participating in the program, including increased staff morale, more laughing and better communication at work between staff, and better knowledge of residents. Researchers were also told anecdotal stories of individual resident responses to the program, such as residents beginning to talk again, or residents whose depression lifted significantly during the program. Researchers are using the results to improve our knowledge of how to administer humour therapy and how to judge its effects on people with dementia.

Dr Lee-Fay Low

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which staff members attend training in humour intervention skills with a visiting professional ClownDoctor. This became known as the LaughterBoss model and was introduced at The First National Conference on Depression in Aged Care: "Challenging depression in aged care" hosted by HammondCare at the University of NSW, Sydney, Australia in June 2003.

The LaughterBoss is a modern day court jester. The main role of the LaughterBoss is to bring play, humour and laughter into the residential facility. The LaughterBoss aims to reduce staff stress and improve morale as well as assist staff to enhance quality of life for people with dementia, reduce depression and meet the psychosocial needs of the residents. This is done through assisting communication, increasing emotional support, giving residents cognitive control, providing positive diversion and generally improving the mood around the nursing home. While the main focus of the LaughterBoss is on the residents, staff, visitors and the general community have often reported a positive impact.

The ideal candidates for LaughterBoss training are RACF staff members who have an intimate knowledge of the people (residents, staff and families) and a thorough understanding of the environment and culture of the facility. The LaughterBoss is not a specific member of staff – they can be a registered nurse, an assistant in nursing, a diversional therapist, an activities co-ordinator or a member of the care staff. LaughterBosses completing training receive a certificate stating that they are now 'certifiable'.

Training does not make the LaughterBoss a professional performer. They keep their 'day job' as well as emerging as a new identity in the facility,

which not only reduces costs, but which also addresses and enhances recommended multi-disciplinary interventions. They should be easily recognisable and be available to do their work as the need arises. They also lead the way in introducing humorous themes, special days and events. Importantly, to do their job well, the facility LaughterBoss requires the support, acknowledgement and blessing from management.

Complementary to the LaughterBoss role is the position of Elder Clown. Working in partnership with LaughterBosses, Elder Clowns are skilled professional performers auditioned, trained and experienced with clowning in care settings where people have different levels of physical, emotional and cognitive abilities and needs. The Elder Clown and LaughterBoss play off each other non-threateningly while building rapport and trust with residents within and across visits. Humour intervention techniques include story-telling, mime, song, magic and slapstick. The Elder Clown is an improviser who uses the LaughterBoss to help gather information regarding the residents' abilities, previous history and interests. They then use their own experience and intuition to create tailored interactions, or 'plays' that better connect with the resident.

For people with dementia these plays may allow them to act out old scripts from their past. The Elder Clown and LaughterBoss keep notes after each visit to facilitate the continued development of these interactions over time. These notes can be used in nursing and medical reviews, and may also be of benefit in case management reviews. The LaughterBoss and Elder Clown are unique and new healthcare-arts partners.

This model of partnership is unique to Australia.

In overseas models, clowning performers work in pairs, but they don't have the kind of working partnership with health staff that exists between the LaughterBoss and Elder Clown. The LaughterBoss receives weekly input from visiting Elder Clown as they work together. During the rest of the week the LaughterBoss works alone, implementing their own new humour therapy interventions and/or building on interventions initiated by their Elder Clown partner. This means that for an RACF, there is not only the occasional visitation by a pair of performers, but rather, that humour-based therapy is integrated into the RACF and the lives of the residents.

For optimum results, and to maintain humour, fun, creativity and some mischief around the nursing home, the Elder Clown visits should take place once a week for three months, and then fortnightly. This model helps to make the program more financially viable for aged care facilities.

The partnership in action

On arrival at the RACF, the Elder Clown meets with the LaughterBoss before they start their rounds together. This time is used to discuss the profile and get an update of the resident with dementia they will be visiting. Entries about humour therapy interventions made in the resident's notes will also be reviewed. Choice of plays, music, costuming and other factors will be discussed. The Elder Clown is generally the principal performer in the session, with the LaughterBoss assisting and joining in the interaction as appropriate. There are opportunities for the LaughterBoss to take the lead role. De-briefing, including note taking, takes place at the end of the session. Concepts for taking the humour

therapy forward for the next week are proposed. The practice is co-operative and reflective.

Pairing the Elder Clown with the LaughterBoss has multiple benefits:

- for the LaughterBoss, this will reinforce and augment their humour training, and give them ideas to try when the Elder Clown is not present
- for the Elder Clown, they will be working with a staff member who knows the residents well and whom the residents trust, facilitating building of a relationship with the Elder Clown
- for the resident, it means that the Elder Clown interventions are sustained by the LaughterBoss.

Conclusion

From the point of view of the Elder Clowns the benefits of laughter and humour on people with dementia are clear. Caring for people with dementia is stressful and demanding, and as aged care in Australia continues to move towards person-centered care, there is an increasing appreciation of the role of humour in improving the lives of people with dementia. SMILE is a three-year NH&MRC funded study, and is a world first randomised control trial looking into the effects of humour, laughter and play on people with dementia in RACFs. The results of the research are being brought to the attention of practitioners across Australia in a series of knowledge transfer workshops being presented by the Dementia Training Study Centres and the UNSW Dementia Collaborative Research Centre. Together, professional performers, partnering and working together with health care staff, will make a palpable difference to the difficult journey for residents, families and staff – the 'Art of Medicine' at work. ■



Above: Professor Richard Fleming (holding rubber chicken). Right: Care Manager Mark



Pushing past the pain barrier

Under-assessed and under-treated: chronic pain management of people living with dementia has a troubled history. Studies tell us that somewhere between 18 per cent and 89 per cent of those with dementia experience chronic pain (McAuliffe *et al* 2009). The imprecise nature of those figures is in itself concerning, but accurately assessing the extent of the problem is very difficult due to the symptoms of dementia itself. What we do know for certain is that the risk of pain increases as we age, and that people with dementia remain extremely vulnerable to misdiagnosis. Too often, pain goes undetected or is inadequately managed in people with dementia.

The problem is that someone with dementia is less likely to be able to articulate the location, type or degree of pain. This alone demands a fundamental rethink in the way care is provided. The reliance on non-verbal cues to assess pain requires a high level of appropriate skills and knowledge related to noticing and accurately interpreting these cues.

A recent development is challenging the status quo via a series of targeted training modules aimed at better assessment of pain in people with dementia. The genesis of the initiative was a literature review conducted by Professor Rhonda Nay, Dr Deirdre Fetherstonhaugh, Megan O'Donnell and Linda McAuliffe from the Victorian Dementia Collaborative Research Centres (DCRC). Pain assessment in older people with dementia: literature review was published in 2009, and highlighted the complexities associated with treating pain in older people with cognitive impairment. In particular, it identified the obstacles to effective pain assessment and management, as well as the strategies needed to overcome those obstacles.

Towards the end of 2010, 'Pain assessment in older people with dementia: literature review' (PAD) was nominated by Professors Elizabeth Beattie and Rhonda Nay for Knowledge Translation (KT) by the DCRC team, led by Dr Tom White. The aim was to equip staff on the front line of dementia care with the latest research on pain prevalence in people with dementia and the treatment of pain, using a format most likely to bring about changes in practice. The result has been that 18 months down the track, the pain assessment and management learning modules are being rolled out across the country. Using the PAD review as a



Kathy Stone reports on new training modules designed to improve identification, assessment and treatment of chronic pain in people with dementia

springboard – and incorporating a combination of power point slides, photos, handouts and presentation notes – the training modules have been shaped to meet the needs of nursing and health practitioners working across the full range of dementia care settings.

An updated dementia e-learning program is currently being implemented in acute care hospitals in NSW, integrating the best resources from across the country with the aim of creating a comprehensive national e-learning package. At the same time, an in-service course designed for the eight-member network of Dementia Behaviour Management Advisory Services (DBMAS) is focused on helping their staff improve pain assessment in the nation's residential aged care facilities (RACF).

The emphasis is on creating practical outcomes in regards to pain management, which in itself has demanded widespread consultation. The program designers talked individually with each DBMAS, and through those conversations, decided on what best suits their particular circumstances. When asked about the breadth of the undertaking, Dr White said: "We needed to think in terms of the people using the research, find out what their needs were and put it in a form that was usable. Each DBMAS is different and there needed to be flexibility so that the presentation could be adjusted to fit any setting. In a sense it was being customised for every situation."

Recognising pain

Both the PAD review and KT project acknowledge one of the key obstacles facing dementia care is recognising the existence of pain. Evidence suggests that nursing staff may be predisposed by their training to attribute distressing behaviour by people with dementia to psychological symptoms rather than look for alternative causes.

The danger of this default position was underlined by a joint British-Norwegian study (Husebo *et al* 2011) which suggested that agitation in non-verbal people with dementia, often attributed to Behavioural

and Psychological Symptoms of Dementia (BPSD), might in fact be an expression of undiagnosed pain.

Reported by the BBC in July last year, the study was conducted across nursing homes in Norway and raised serious questions about the reliance on anti-psychotic drugs in treating people with dementia. Importantly, the study found that the use of simple painkillers reduced agitation symptoms by as much as 17 per cent over an eight-week period and could significantly reduce the dependence on anti-psychotics which exacerbate pain and carry the risk of serious side-effects.

With an estimated 150,000 UK patients needlessly prescribed anti-psychotics, it is perhaps not surprising that the Chairman of the National Care Association, Nadra Ahmed, described the recognition of the link between pain and agitated or aggressive behaviour in people with dementia as a "major breakthrough".

Certainly those behind the DCRC KT project are acutely aware of the problem of unnoticed pain in people with dementia. This is illustrated in a series of troubling photographs of injuries, incorporated into both the e-learning and in-service programs. Taken by Cathy Edgar, a Clinical Nurse Consultant specialising in pain assessment, the photos capture severe ulceration on dementia patients where pain was clearly present but not recognised or treated.

According to Tom White such oversight demonstrates a fundamental misunderstanding of both pain and dementia, which enables trained staff to observe serious wounds and yet conclude that no pain exists. Nurses questioned about the lack of pain assessment for a patient pictured, characterised the presence of "moaning" as a symptom of dementia rather than a response to some underlying cause.

Tom White added: "In one of the photos a person's heel is entirely gone, yet they were never assessed for pain. As a result of that wound they died a fortnight later. So the question is, how long were they in pain?"

"I think we have to consider the fact that because these people are non-verbal, staff may assume there is no pain. That the UK study showed agitation decreases with use of painkillers should be a huge flashing sign about the importance of assessing pain before undertaking BPSD treatment."

Overcoming the barriers to pain assessment

There are several key obstacles to effective pain assessment detailed in the PAD review and taken up by the KT project. These are divided into two sub-groups: those barriers pertaining to staff – for example the inability to recognise pain, insufficient training, misdiagnosis or late diagnosis and failure to use appropriate assessment tools – and those barriers particular to older people with dementia, such as difficulty in differentiating between types of pain and a desire not to complain.

The strategies for overcoming these problems are often deceptively simple. For example, taking the time and getting to know a non-verbal person with dementia increases the likelihood of recognising their pain cues. Other strategies include: applying intuitive knowledge derived from a diversity of clinical experience; improving staff education and training; using a combination of pharmacological, cognitive, physical and alternative therapies; and implementing objective pain assessment tools. The PAD review concluded that comprehensive education and training in detecting pain was a priority, along with effective pain assessment tools specifically developed to deal with all stages of dementia.

Older people with dementia may express discomfort through facial expressions, body movements,

verbalisations, changes in interpersonal interaction, alteration in normal routines and change in mental status. Frowning, grimacing, grunting, fidgeting, changes in sleep patterns, crying and irritability are some of the pain behaviours commonly observed by staff. Early recognition of these behaviours and signs is crucial in identifying instances of chronic pain.

Critically, there are no quick fixes when it comes to assessing pain in a person with dementia. Opinions vary as to the length of time (from one week to three months) a nurse may need to become sufficiently familiar with a person to recognise pain signals. Thereafter, regular reassessment and evaluation is required until the pain is effectively treated.

While it takes time to know a person well enough to feel confident in detecting subtle changes in behaviour or personal habits which may be symptomatic of underlying pain, the use of skilled observation and an understanding of non-verbal communication will improve pain recognition and treatment in those settings where the length of stay is short, such as emergency departments and acute care.

A key factor in achieving successful outcomes is the use of pain assessment tools. The KT learning modules take participants through the range of pain measurement scales available, including dementia-specific assessment tools that have been shown to enhance pain management for people who are non-verbal.

Clearly, though, this is a time intensive approach that faces challenges in the way it is implemented. The move towards temporary and agency staff in RACFs coupled with significant levels of staff turnover are likely to hinder successful pain assessment programs. The PAD review notes: "Greater workforce stability is therefore required for staff to be able to know and work consistently with individual persons so that they can increase the success of the detection, assessment and ultimately the treatment of pain in older adults with dementia."

"The critical success factor, based on the research, is knowing the person well," Tom White said. "Some RACFs allow eight days to assess for pain and hospitals are not set up for that. On the other hand, the high turn-over of staff in RACFs presents its own barriers to successful pain assessment."

Many of the questions surrounding pain assessment tools concern the length of the process. The usual response to the presentation of assessment tools is: "Did

I hear that right? Do you really have to assess every four hours after pain is detected until it goes away?" There is always that element of surprise. Nevertheless, making the effort upfront can save a lot of distress and time spent in responding to behavioural and psychological symptoms of dementia caused by untreated chronic pain further down the track.

Towards pain free care

Translating the latest dementia-pain research into focused learning is by no means the end game, but it is a vital intermediary step towards the development of care practices that honour the dignity of each person with dementia.

Growing awareness of the prevalence of pain in people with dementia is an excellent first step, and the level of interest in the training programs gives cause for hope. It is early days yet for implementation of the pain research findings, but there is strong focus on creating a greater appreciation of how pain impacts on people with dementia.

The obvious winners from embarking on effective pain assessment and management are those living with dementia and their families, though the ripple effect extends much wider. Tom White believes that, at the very least, it will result in more positive end-of-life experiences for people with dementia, reducing the trauma on patients, and the burden of care on families and professional carers.

About 24 per cent of people admitted to acute care in NSW hospitals have dementia, and many of those people are experiencing undiagnosed chronic pain. Ultimately, this is an issue that engages every level of the health care system – from questions of staffing levels to matters of workplace morale – but at its heart, it remains a question of human rights and the obligation on every society to seek the pain-free care of its most vulnerable citizens.

Please contact your DBMAS to inquire about the in-service course, or direct your queries to Dr Tom White at tom.white@unsw.edu.au

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Acknowledgments

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Appetite for life: what can help improve the mealtime experience?

Lynn Malloy is an occupational therapist currently working as Acting Manager of the Haringey Memory Service, Barnet, Enfield and Haringey Mental Health NHS Trust, London, UK

Lynn Malloy describes her review of studies on the mealtime experience for people with dementia in formal care settings. She focuses especially on what can help mealtimes to provide ‘food for the soul’ as much as they provide fuel for the body, and the importance of guidance and emotional support for care staff

Mealtimes mark the rhythm of each and every day and can be the time of greatest contact between resident and care worker. If *Living well with dementia*, the English Department of Health’s 2009 National Dementia Strategy, is to be realised in care settings, mealtimes seem a very good place to direct some attention.

In 2010 I carried out a review of studies that had taken place over the previous ten years on ‘mealtimes for people with dementia living in care settings’. This was the final part of an MSc programme at City University. Also, as an occupational therapist working in mental health services for older people, I was interested in finding out what evidence there was from around the world.

Being able to feed and eat independently can be one of the last activities of daily living that is lost with the progress of dementia (Manthorpe & Watson 2003). Nevertheless there are risks of malnutrition (Berry & Marcus 2000), weight loss and dehydration (Castellanos *et al* 2003), and being in formal care does not necessarily lessen these risks.

I would suggest that just as important as these outwardly observable signs or symptoms are the ‘under the surface’ consequences of not taking into account the emotional and relational aspects involved in taking food with others.

Not only does food provide strong, pleasurable sensory experiences, but most of us also have

strong associations and memories of sharing food with others, with specific meanings varying to some degree from individual to individual and across cultures. Food and sharing a meal is used for example to celebrate, commemorate, mourn, build and foster relationships and cope with feelings (Fjellstrom 2004).

Often, for an individual with dementia living in care, these connections to past and current life expressions are lost. Eggers *et al* (2005) looked at ‘fragmented experience’ and how care staff counteracted or inadvertently contributed towards a fragmented experience for the person with severe dementia. They describe how connections between experiences in the present, past and future become increasingly difficult to make.

In this article I will focus on the five categories of interventions that emerged from the thirteen studies reviewed. I am particularly interested in mealtimes being a time where people come together – around a table or when a care worker sits with an individual. And in discussing the five themes, I will be keeping in mind this relational aspect to mealtimes and highlight aspects of the studies that care settings in the UK might want to consider putting into practice.

The thirteen studies I looked at fall into five categories:

- making changes to the environment (Altus *et al* 2002, Cleary *et al* 2008, Mc Daniel *et al* 2001, Nolan *et al* 2004)
- the use of music at mealtimes (Richeson *et al* 2004, Thomas *et al* 2009)
- education and training of care staff (Chang & Lin 2005, Suominen *et al* 2007)
- finding out more about the experience of mealtimes (Chang & Roberts 2008, De Bellis *et al* 2003, Gibbs-Ward *et al* 2003, Pasman *et al* 2003)
- a combined study looking at meal time routines, how mealtimes were experienced and care staff education (Mamhidir *et al* 2007).

Changes to the mealtime environment

Four studies looked at the dining room environment or how meals were served and whether changes made a difference to how much food was eaten, interaction levels and/or levels of agitation. The interventions were:

Search strategy

Electronic databases CINAHL, PsycINFO, British Nursing Index, MEDLINE and AMED were systematically searched for primary studies which reported on mealtimes, eating and feeding difficulties for people with dementia living in formal care settings, specifically in order to understand the mealtime experience from the perspective of the person with dementia and/or staff member, or to report the findings from an intervention aimed at improving the mealtime experience

Once the databases had been searched, the abstracts were read and assessed. The reference sections of these papers were then hand searched to identify further studies missed in the electronic search. The time scale of the study meant that there was no searching of grey literature such as conference papers and PhD theses.

The time period 2000-2010 was chosen to capture literature subsequent to a previous literature review with a time period of 1993-2003 (Watson *et al* 2006).



Directly helping a resident with dementia to eat presents challenges for staff, both with the physical task and relational aspects.

- a change in how meals were served, from pre-plated meals to self service serving bowls
- a change from individuals deciding on a day-to-day basis where they sat, to having a routine seating plan
- the introduction of a clock and a written wall-mounted notice in the dining room of when meals would be served
- a reduction in noise and an increase in lighting levels.

All these studies reported positive outcomes: on participation and communication (Altus *et al* 2002), on food and fluid intake (Cleary *et al* 2008, Mc Daniel 2001) and a reduction in repetitive questioning about food and mealtimes (Nolan *et al* 2004).

The mealtime experience

Four studies set out to find out more about the experience of mealtimes from the perspective of the individuals with dementia and the care staff (Chang & Roberts 2008, De Bellis *et al* 2003, Gibbs-Ward *et al* 2005, Pasman *et al* 2003). The chosen research methods included participant and non-participant observation, which aimed to capture the complexities of mealtimes.

These four studies were all carried out in settings where it was reported the majority of individuals required assistance to eat. As will be familiar to readers of this article, this situation immediately brings the care staff and resident into a closer relationship. These studies suggest that directly assisting a resident to eat presents two main challenges for care staff. Firstly, how to balance the 'task' of assisting someone to eat with that of 'relating' to another human being. Secondly, the care staff's knowledge and skills about dementia and the associated eating and feeding difficulties. All but Chang & Roberts

(2008) present findings that indicate how difficult it can be to achieve a balance between the task and relational aspects of mealtimes.

Music at mealtimes

Two studies explored the use of listening to music during mealtimes and the impact on calorie intake or the percentage of food eaten (Richeson *et al* 2004, Thomas *et al* (2009)). The former study was also interested in exploring the use of music on agitation levels in residents and to explore a possible correlation between agitation and the amount of food consumed. This study developed from a concern expressed by staff at the levels of agitation at mealtimes.

The two studies contrasted in how they chose the music to be played. Richeson *et al* (2004) played 'soothing music' chosen by the staff. Thomas *et al* (2009) played music that reflected favourite music styles of the residents. Both studies report positive findings and aimed to build on previous studies into the use of music at mealtimes. These earlier studies, Goddaer *et al* (1994), Ragneskog *et al* (1996) and Denny (1997), were preliminary and invited further investigation.

Education and training

Two studies looked at the effects of staff education: a feeding skills training programme (Chang & Lin 2005) and the nutrition education (Suominen *et al* 2007). Both studies collected data to show the effects on the staff involved in the study and on the individuals with dementia. The results regarding food and calorie intake are different for each study. Chang & Lin found no difference before or after the intervention. Suominen *et al* report a sustained increase in calorific intake at one year post intervention. There are a number of possible reasons for this different outcome including the level of difficulty individuals experienced at mealtimes and how much assistance they required. Also Suominen *et al* report that they employed an education theory and reflective practice model. There are clear differences between these two studies in education style and emphasis on peer learning, multidisciplinary discussion and reflection. Embedding of the learning in the Suominen *et al* study may be reflected in their study outcome of a sustained increase in calorific intake.

Combined study

The final study in the review explored weight increase, an alteration in meal routine and an 'integrity promoting care' educational element (Mamhidir *et al* 2007).

The study reports an increase in residents' weight following the education programme and a correlation between weight increase and improved intellectual functioning. It is difficult to separate out whether the change in intellectual functioning might in fact be due (or partly due) to the different care culture. Mamhidir *et al* (2007) also report increased interaction between staff and residents following the education programme which

Mealtimes are a multilayered experience, for the individual with dementia and the care staff. How care homes or dementia units establish a culture which supports staff will significantly impact on how effectively mealtimes enhance well-being for the residents with dementia

possibly lends credence to the suggestion above that the change in care culture has an impact on aspects other than a resident's bodily weight. This study also incorporates the change from individually plated meals to 'help yourself' serving bowls on the dining tables, similar to Altus *et al* (2002).

This environmental change immediately provides the setting for more interaction in the act of sharing and possibly cooperating. The serving bowl seems to symbolise an act of faith on the part of the staff that residents (with support where required) will know how to respond. To make this leap from serving plated food to a more facilitative style requires the staff to change their perspective and approach.

Strength of the study results

Overall the strength of the evidence from the studies reviewed was variable. Some used very small sample sizes, limited statistical analysis and/or consideration of confounding variables. There was however a significant number of studies that collected qualitative data as recommended in an earlier literature review (Watson & Green 2006).

Implications for practice

Changes to the dining room environment

The findings of this literature review suggest that there are environmental interventions that can make a contribution to creating a better mealtime experience for people with dementia:

- listening to music
- displaying a clock and orientation notice board
- having a routine seating plan
- using serving bowls in place of pre plated meals.

None of these interventions require significant sums of money, so in terms of resources they should be within reach of the majority of settings. However, what this review has also found is that interventions can be more effective when staff are appropriately supported in implementing change.

Care staff can express frustration with the status quo of their work settings, but there may also be an unspoken, perhaps unacknowledged, ambivalence about changes which increase interaction between residents and care staff.

The task and relational elements

Although feeding and supporting a person with dementia to eat is a concrete task, it takes place within the context of a relationship – the person with dementia who is increasingly challenged by the effects of dementia on their comprehension and engagement with the world and the care worker who is spending time with someone who is going through this experience. Under these conditions, the way in which the care worker manages their emotions will have a psychological impact on the person with dementia.

In previous UK JDC articles, Morton proposes a model which builds on Kitwood's interpersonal, person-centred approach by introducing the 'third dimension' of intrapersonal dynamics (Morton 2007a). This model refers to the emotional level of experience and communication; some of which can be put into words and some of which remains 'under the surface'. For someone with dementia who is finding it increasingly difficult to verbally communicate, a psychodynamic understanding suggests that there is increased reliance on non-verbal communication (Bender *et al* 1997, Davenhill 2007, Malloy 2009). To stay 'in relationship' with the other person, the care worker is therefore challenged on an emotional level. This needs to be acknowledged and supported by the workplace.

Providing containment

Clear leadership in both modelling good practice and in creating a particular culture within a setting was also noted as significant in some of the studies. Supporting good practice and initiating change requires management skills. There is a knowledge and skills element, a social element and an emotional/relational layer. To hold all these in mind is challenging, and 'containing' leadership and management is key. Containment is a concept from psychodynamic theory and has been discussed in the context of dementia care by a number of clinicians including Balfour (2007) Morton (2007b; 2008) and Waddell (2002).

For a care worker in a dementia care setting, a sense of containment can be provided by:

- a manageable work load, with a clear role and the necessary skills and knowledge training
- having their needs as a care worker understood, on emotional, physical and psychological levels
- having a sense that their manager/supervisor is thoughtful about their work and holds the 'bigger picture' of the care setting over time.

The more contained a staff group, the more capacity they will have to work sensitively and thoughtfully with the individuals with dementia in their care.

Structures and interventions for care staff, to keep the right balance between a task orientated and a relational approach, can include clinical supervision and group reflective sessions, as described by Davenhill (2009), which places an emphasis on the emotional aspects of working with individuals with dementia.

My review suggests that practice development training and education specifically around eating

and feeding is enhanced through a reflective element provided by keeping diaries and /or small group discussion. Leadership and structures to support reflective practice can all contribute to containing the inherent anxieties that staff will inevitably be exposed to in their work. Lintern *et al* (2000) put forward a strong argument that "training is not enough to change care practice".

Assessment of eating and feeding difficulties

This review identified a tendency to not formally assess eating and feeding difficulties. This both reinforces a generalised attitude to individuals with dementia and means that interventions, a particular approach or the need for a referral for a specialist assessment (to occupational therapy or speech and language therapy) is not considered. The whole area of maintaining an individual's skills through adapting the immediate environment, diet, seating, eating utensils and

approach requires a multidisciplinary approach which settings need to know how to access.

Conclusion

In the combined study by Pasma *et al* (2003) outlined above there is a quote from a member of the care staff who describes how she "takes to heart" whether a resident eats or refuses the food that she is offering. I think this offers another insight into the emotional and relational layer of mealtimes, which can become obscured by an over emphasis on eating and feeding being purely functional tasks.

Mealtimes are a multilayered experience for the individual with dementia and the care staff. How care homes or dementia units establish a culture which supports staff will significantly impact on how effectively mealtimes enhance 'well-being' for the residents with dementia.

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Book review

■ Maintain your brain: What you can do to improve your brain's health and avoid dementia

Dr Michael Valenzuela • \$27.99 • 2011 • ISBN 9780733330223

A book written by a researcher recognised as the top-ranked NHMRC Research Fellow in 2010-11 by the Australian Government National Health and Medical Research Council might well be expected to be a heavy read. However, Dr Michael Valenzuela explores the complexities of the causes of dementia in a way that clarifies the issues, informs us of current debates and conveys an excitement about the field that leaves the reader feeling refreshed.

Having reviewed the definition of dementia and the characteristics of Alzheimer's disease and vascular dementia, Valenzuela lays a firm foundation for the advice he provides on how we can reduce the chances of developing dementia. He leads the reader to an understanding that the distinction between Alzheimer's disease and vascular dementia may not be a clear cut as was once thought. He describes the revolutionary ideas of Dr Karen Cullen of the University Sydney, which explains the plaques associated with Alzheimer's disease as being the result of microbleeds. If this idea turns out to be

correct, the traditional beta-amyloid cascade hypothesis will no longer be tenable and the focus of anti-Alzheimer's disease drugs will need to turn to combating microvascular disease rather than plaque formation.

The book continues with a range of well explained, evidence-based suggestions for maintaining healthy blood circulation. These include eating the right foods prepared in the right way and managing cholesterol levels.

Valenzuela then takes up the old adage that we need to 'use it or lose it'. Drawing on 40 years of evidence from behavioural science, he explains the benefits of an enriched sensory environment and goes on to link this with practical advice on exercising our minds and bodies.

This book pulls together a wealth of research findings and practical advice. It offers something of interest to everyone interested in reducing their own chances of developing dementia or in caring for others who need advice and support.

Richard Fleming
Professorial Fellow,
University of Wollongong

Resources

Frontier Services NT Dementia Behaviour Management Advisory Service (DBMAS) has developed **Dementia: Things to do**, a new resource that provides activity ideas for carers of Indigenous people with dementia. It was developed after consultation with cultural advisors and feedback from focus groups held in remote communities where care was already being provided. The resource is appealing and full of bright, colour photographs taken in Wugularr. It explains the symptoms of dementia, the importance of providing activities for people with dementia, and offers communication tips and ideas for carers. Some of the hands-on activities listed include going back to Country, collecting bush tucker, bush aromatherapy, painting and weaving, storytelling and physical activities and games such as chair football and boomerang golf. The resource was funded by the Department of Health and Ageing Dementia Community Grant 2009, and it should go a long way in helping carers in remote Indigenous communities improve the quality of life for people living with dementia. Judy Ratajec, DBMAS Program Manager, said: "We all need to have purpose and meaning in our lives. Providing activities for a person with dementia gives them back some meaning; to actually be involved in something gives them that purpose back." For more information contact www.frontierservices.org or tel 1800 699 799.

The Dementia Training Study Centres (DTSC) are in the process of establishing a national website. When completed it will provide access to all of the resources developed by the five DTSCs. At the moment there are DVDs, workbook and manuals available on caring for Indigenous people with dementia in remote areas, person-centred care, general dementia knowledge, palliative care and living with dementia. Access these and more at: www.dtsc.com.au/category/resources/

The Dementia Foundation for Spark of Life has launched a new website at www.dementiafoundation.org.au. The Foundation is now actively fundraising to offer grants for practitioners to train in the Spark of Life approach.

FinerDay, a new reminiscence therapy-based website, has been launched. The site offers free reminiscence and activity resources, as well as a hub for recording life history and communicating with friends and family online. The site is set out in an easy to use format and can be used in individual or group sessions. View FinerDay at: www.1finerday.com

The new I CAN! I WILL! website (see: www.alz.co.uk/icaniwill) hosted by Alzheimer's Disease International, aims to be an 'ideas library' for dementia. The site is aimed at everyone with an interest in dementia – people living with dementia, family carers, campaigning groups and professionals – and invites anyone to contribute ideas on raising awareness and care and support for people with dementia.

The Bradford Dementia Group has posted a video on YouTube which explains about dementia care mapping (DCM) and how Bradford Dementia Group training is able to help improve dementia care in the UK and beyond. View the video at <http://tinyurl.com/6ganm4>

Events

■ 29-31 May

Spark of Life Practitioners Course Three-day course to become a Spark of Life practitioner (one-day introduction also available on 29th) in Sydney. Sponsored by and held at the Kirribilli Club. For details: info@dementiacareaustralia.com

■ 5-7 June

Behavioural and Psychological Symptoms of Dementia: Using Evidence to Inform and Lead Change

One-day Knowledge Transfer Master Class. Brisbane (5 June) and Cairns (7 June). Joint initiative between the Queensland Dementia Training Study Centre and Dementia Collaborative Research Centre: Carers & Consumers. For details, email: jennifer.henderson@qut.edu.au or call (07) 3138 0071.

■ 13 June

Person-centred care

One-day Master Class in Sydney. Presented by the Aged Care Standards and accreditation agency. To register, visit: <http://www.accreditation.org.au/education/person-centredccare/>

■ 14 June

Knowledge Transfer workshops

One-day involved workshops on pain management, humour, assessing dementia in people with a CALD background and understanding dementia amongst indigenous Australians. Presented by leading researchers, hosted by the WA Dementia Training Study Centre in Perth. For details, email: dementia@uow.edu.au

■ 27-29 June

Risky Business 2012: International Dementia Partnership

Three-day conference in Sydney. Hosted by the International Dementia Partnership of The Dementia Centre, HammondCare and the Dementia Services Development Centre, University of Stirling. To register, please visit: <http://dementiaconference.com/>, call Michelle Andrew on (02) 8788 3081, or email: conference@hammond.com.au

Australian Journal of DementiaCare Research Focus

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

What does 'neighbourhood' mean for carers of people with dementia?

Richard Ward, Andrew Clark and Matthew Hargreaves outline the findings of a study that looked at how carers of people with dementia relate to their neighbourhood, and the implications for improving local support

Looking and thinking locally is a valuable exercise if we want to better understand the everyday lives of people with dementia and their carers and the kinds of help and support that they draw on. In this article we outline the main findings from a study *A place called happiness? Networks, neighbourhoods and informal dementia care* that investigated the role neighbourhoods play in the lives of carers and former carers of people with dementia. The research was conducted in Salford in the north west of England. In this project we focused our attention on carers of people with dementia and set out to answer two main questions:

- How do carers make use of their neighbourhood and what does it mean to them?
- How are carers and people with dementia supported locally, and what can be done to improve this support?

We began by holding three discussion groups with over 30 carers from across Salford, recruited through carer support groups. These groups helped us to familiarise ourselves with the

neighbourhood-related issues that were important to carers. We then worked more closely with 14 carers and former carers to better understand the significance of neighbourhoods for them. These 14 participants each completed two tasks:

- Social network 'mapping': each carer was given a large piece of paper and asked to depict in whatever way they wanted all the people who were important to them. This was then used to guide a later interview.
- Walking interviews: we asked the carer to take us for a walk around their neighbourhood to the types of places that they visit and use in their everyday life, or Mobility diaries (carers who chose not to do a walking interview kept a record of their trips outside the home over one full week. We then interviewed them about this record).

Our findings reveal three overarching themes regarding the importance of neighbourhoods for dementia care:

- the changing meanings of home
- being able to get out and about
- proximities.

The changing meanings of home

Carers' feelings about the home change as opportunities to maintain outdoor activities become more challenging. Much existing research on dementia and the outdoor environment tends to overlook the home. In contrast, our work reveals a dynamic relationship between the domestic sphere and the world beyond the front door.

Carers talked of a number of ways in which their feelings of home have changed as a result of the presence of dementia: of the ways in which the illness has altered future plans, such as decisions to move house or even emigrate. The meaning of the home also changes for friends and relatives. Some carers talked about how they sensed a reluctance in friends and family to call round as frequently as they had previously, especially if unannounced, and of not staying for as long when they did visit. While this may be because of ►

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This 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.

Each Research Focus will include a comprehensive review by a leading expert of significant research in a subject area.

We would like to hear from you, specifically with the following:

- 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.

➤ difficulties in accommodating visitors when caring for someone with more severe dementia, carers also sensed that, for some visitors, the house has become associated with stigmatised illness that they perhaps choose to avoid.

Some carers felt isolated within the home, in part because of difficulties of getting out, but also because of a lack of social interaction with visitors to the home.

It's when you go home. Then you feel isolated and you think there's no one but you that's in this situation and you've got to keep telling yourself 'Oh no, I was out this afternoon', or 'I was out yesterday' or 'I'm going out tomorrow or the day after and am meeting people who are in the same situation.' (Carer at discussion group)

Such experiences suggest that for some the home can take on potentially discomfiting meanings. However, carers and people with dementia can, and do, leave the home, and place great importance on these trips, however brief.

Being able to get out and about

Leaving the home is crucial for well-being Having a set routine of visits to particular places is one way of maintaining a sense of familiarity and comfort: of feeling 'at home' away from home. Some carers recalled incidents when they have felt uncomfortable in unfamiliar places, having to explain the behaviour of those they care for, or where difficulties had arisen with access or travel arrangements. Consequently, places frequented outside the home tend to be those considered 'safe':

If she sees it's nice and sunny she might want to go out for something to do... There's a coffee shop where we go in and the girls make a big [fuss], they love [her] you know, they think she's great you know, always seeing to her, and she wouldn't know them in the street. (Male carer)

This ability to get out and about represents an ongoing connection with a wider world that becomes increasingly important to maintain, given the potential challenges presented by a shrinking world and the changing meaning of the home.

However, leaving the home requires planning. Here, our analysis suggests two important ideas: 'organised spontaneity' and taking 'planned risks'. Outings demand considerable 'effort' in terms of cost, time and energy to arrange and complete. Carers talked of the difficulties of undertaking a seemingly

What does existing research say about neighbourhoods and dementia?

Getting lost: Much early research looking at people with dementia outside their home is concerned with the risk of getting lost. For instance, McShane et al (1998) described this risk as substantial – affecting about 40 per cent of those who took part in their study. That research found a strong association between getting lost and a subsequent move to institutional care, while many carers responded to such episodes by keeping the person they cared for at home, sometimes under lock and key.

Creating dementia-friendly environments: As thinking about dementia has evolved, so research has started to look beyond symptoms and their effect on people's lives to consider the wider environments in which people live. Mitchell et al (2003) introduced the idea of dementia-friendly cities and looked at how different features of the urban landscape might support people with dementia to get out and about. The findings showed that for people with early stage dementia sometimes small alterations to things like signage and street furniture could make a big difference in maintaining independence.

Experience of a 'shrinking world': Duggan et al (2008) found people experience a shrinking world when they have dementia. This is often because they lose the confidence to venture too far from home and feel safest when they're close to home. Many people have their driving licence removed as a result of receiving a diagnosis and find the prospect of travelling longer distances on public transport quite daunting. Consequently, neighbourhood boundaries can constrict as dementia progresses.

straightforward outing; for example arranging alternative care if going alone or ensuring the needs of the person with dementia are met if being accompanied. Consequently, while carers embark on spontaneous trips, these tend to be to places previously visited, or to meet friends or relatives, often at specified times in order to make planning easier.

Carers are acutely aware of the potential risks facing those they care for when leaving the home and sought to reach agreement with those they care for about how to manage this. Often, trips taken independently of the carer involve visits to local shops or to neighbours' homes – to locations where carers feel support would be provided in an emergency. In this way, local places become vital in enabling carers to limit, to a degree, the risk of the home becoming a prison and maintaining both

their own independence and that of the person they care for.

Recognising the potential to get out and about may be as important as actually doing so

Maintaining opportunities to get out and about is important for both the carer and the person being cared for. For instance, one carer discussed the importance of a local venue:

We've got the cricket club further up which is very functional, very good. Dave is still a member because he enjoyed cricket. He's not able to go up, but he likes to be a member still, so it's there in his mind that when he feels like it he can go. (Female carer)

It is not necessarily actually going to these places (which, practically, may be difficult) that matters here, but rather the possibility to do so. For carers and people with dementia it is important that the world does not just exist as a series of physical spaces, but also as imagined and remembered places that could be visited. Our findings suggest that the potential to visit such places can be equally important. This is particularly the case in respect of open, green spaces and the value to carers of knowing that they are nearby.

The scope of neighbourhood living is shaped by questions of mobility

Having the means to travel is important therefore not just for getting out, but also for maintaining the opportunity to do so. It is also important when carers have less time because of caring responsibilities:

Without the car I think I would have killed him or walked out... I've got the relief of being able to say, 'Fancy going out? Come on, let's get in the car and go for a ride'. And I think, 'I've left the house, I've left the washing and the ironing, especially the cleaning.' It didn't mean you were a prisoner in your own home, it didn't make it so that 'You've got dementia. You can't go out. You don't know where you're going'. (Female carer)

The car in particular is seen as a symbol of autonomy: a vehicle of opportunity as well as movement. Carers reliant on public transport felt limited in the scope and times they could travel, especially given the amount of work that went into organising trips. Even so, carers without a car frequently rely on friends and other carers to help with travel, so that mobility itself creates opportunities for sociability.

Proximities

The study identifies complex associations between physical and social proximity in how carers and people with dementia foster relationships over time

For carers and people with dementia the experience of a shrinking world means that the people in closest proximity often take on particular importance. Staying local means bumping into people who are familiar and who recognise them:

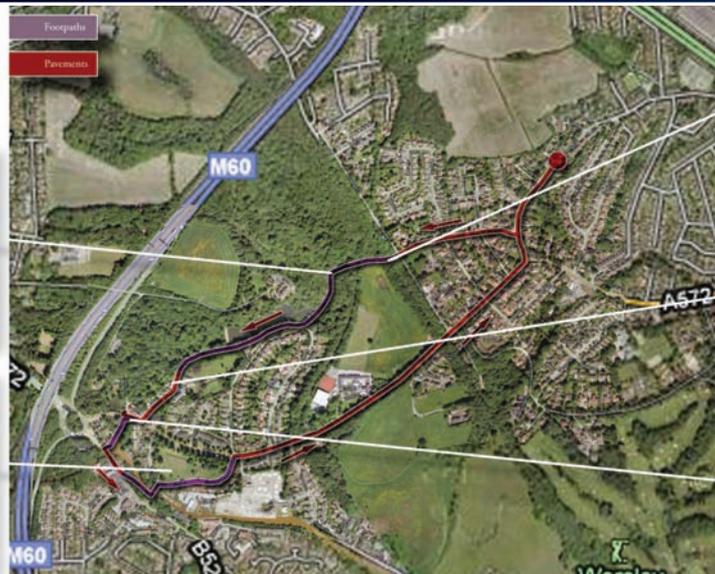
I used to walk round with (the person with dementia) and he got to know people. He can't remember them now, but he does know they're familiar and they'll say 'hello', and he knows then he's safe, because they're familiar looking... so that's his security.
(Female carer)

Seeing familiar faces maintains a sense of comfort and acts as a reminder to this person with dementia that he is not straying too far from home. This link between proximity and a sense of safety underlines the value of local connections and demonstrates the importance of face-to-face contact when it comes to understanding the type of help and contact that people value the most. Such contact doesn't have to be close or prolonged, for even fleeting exchanges of greetings are important in helping someone to feel safe.

The role of neighbours: maintaining a polite distance

A central aspect of the research is the importance of neighbours. While some carers know their neighbours 'well', these tended to be relationships of acquaintance rather than intimacy. The issue of disclosing the diagnosis of dementia revealed much about such relationships. Carers often stopped short of telling their neighbours about the diagnosis, in part because of the intimacy of disclosure, but also because of a fear of gossip:

Carer: Yes his sister knows [about having dementia]... and my friend... that's it.
Interviewer: Okay but that's it... so you've



Above: Walking interview route with images taken by carers along the way. **Left (and front cover):** This contoured neighbourhood representation was designed by one of the researchers and used to facilitate discussion with two carers about places of local significance.

not told your neighbours?

Carer: No not really no, no actually.

Interviewer: I know it's a personal question but can I ask you why you've...

Carer: Well, the reason why is because I don't want them to spread it all over the place. Just leave him as he is.

However, despite differing depths of intimacy with neighbours, and attempts to maintain relations at a distance, neighbours do become important for maintaining a 'watchful eye' and in times of emergency. As well as providing the security of a 'background presence', such neighbourly relations are important sources of support:

We're all very friendly but not imposing, we've all had sort of jobs and work, so we've learnt that yes we're here for each other, but not always bopping in and out of each other's houses as such, we've got our own privacy which is a good thing, but if any help is needed then they're there for you... There's a lot of older people who have been here for many, many years, so those again are always the caring people because they know your history, and they've known our children, and they ask about them and they understand the situation. (Female carer)

Neighbourhoods have a collective capacity to help and support carers and people with dementia

A further aspect of note is the type of help that often remains hidden and/or

undocumented in the lives of people with dementia and their carers.

These were the kind of encounters that were unplanned and difficult to anticipate but nonetheless demonstrate that support and help exist in unexpected places such as cafes, restaurants and supermarkets. This suggests that a broader awareness and understanding of dementia can make a positive difference to those affected by it:

He used to go to Tesco's a little distance from where we are and various members in Tesco got to know him and of course, if they saw him getting his shopping they'd make sure he'd put it in the bag and sort his money out and send him back home again...
(Discussion group participant)

Carers spoke about their anxieties of becoming separated from the person they cared for when out and about but, by staying local and visiting familiar places, they rely on support from familiar people such as shop-workers:

...and you would turn around and he'd disappeared, you wouldn't know where he was and I found that going to all the same shops, I could say to the people 'Has my husband been in?' Because they were used to it and they'd say, 'Well, if he turns up, we'll send him to the car park.' So I always knew, most of the time, when I got to the car park he was there.'
(Discussion group participant) ▶

► Carers surround themselves with people who understand dementia

Many carers we interviewed had been surprised by how many people they had encountered who had experience of dementia in their own families. Often these individuals took on a more active role supporting carers. However, carers also described friends and family becoming distant, losing contact, or avoiding them after the diagnosis. One carer described how well-meaning friends who didn't understand dementia would offer unhelpful advice: she found herself having to explain things to them or defending the person she was caring for against criticism:

I've got other friends, they do understand to a point that I am busy and my lifestyle has changed, that I've got a commitment to [the person with dementia] but they don't understand the dementia. So, they're response is... a sort of hard factual approach to it but that is the lack of understanding of the dementia mind. (Female carer)

A clear message emerging from the research is that, while friends and family are loved and are cherished for their help and support, the most valued support often came from other carers with shared experiences:

We've all got... there's something that binds us one way or the other and if one hasn't been through it then the other one has. So that's quite special that. (Female carer)

This also highlights the role played by formal support services, and those who work in them, in facilitating contact and ultimately friendship between carers:

[Support group workers] interacted with everybody, joined everybody in and they always found time to come and speak to you individually within the groups at the time... the discussions we were having, the information we were getting, that was good and then they always say, don't forget afterwards, we've got the quiet room if anybody wants to speak to us one-to-one. (Female carer)

Conclusion

Although the participants in this study lived in the same city and were of a similar age, their experiences of their neighbourhoods varied a great deal. Some had quite extensive support networks with a diverse mix of family, friends and acquaintances, others had a more limited number of contacts. Some had networks that stretched nationally and internationally while others had a

closely knit group of friends and family mainly clustered nearby. Such variety means we must not make assumptions about the type of help or support that is available to individual carers. However, we have been able to outline commonalities in the nature and experiences of support that carers found most helpful and meaningful.

Our findings reveal the importance of face-to-face contact for carers as a means of maintaining a sense of independence, sociability and freedom, enabling them to feel like individuals above and beyond their duties and identities as a carer. While welcome support was received from various sources, the most valued support often came from fellow carers who repeatedly provide vital information and emotional support based on experience. The study also revealed the importance of the organisations and agencies that facilitate the coming together of carers and former-carers.

Our research also implies a cautious optimism. Beyond formal services and specialist resources, those carers we spoke to described a web of support that helps them in their daily struggle to care and maintain some semblance of a life beyond their front door. It is clear that wider awareness of dementia and the challenges it creates underpins a network of often hidden support, reassurance, and assistance in times of need. Neighbourhoods have the capacity to collectively support carers and people with dementia in ways that we are only just beginning to understand. ■

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We would like to acknowledge the support of the Manchester Interdisciplinary Collaborative for Research on Ageing (MICRA) which funded the study and Age Concern Salford for help with recruitment. We would especially like to thank the 14 carers and former carers who generously agreed to take part in the research.

This article was first published in the UK Journal of Dementia Care 20(2) 33-36.

Cognitive stimulation 'is beneficial in dementia'

Cognitive stimulation therapies have beneficial effects on memory and thinking in people with dementia, according to a systematic review by Cochrane researchers. Despite concerns that cognitive improvements may not be matched by improvements in quality of life, the review also found positive effects for well-being.

There is a general belief that activities that stimulate the mind help to slow its decline in people with dementia. Cognitive stimulation provides people with dementia with activities intended to stimulate thinking, memory and social interaction, in order to delay the worsening of dementia symptoms. In 2011, the World Alzheimer's Report recommended that cognitive stimulation should be routinely offered to people with early stage dementia. However, increased interest in its use in dementia in recent years has provoked concern about its effectiveness and potential negative effects on well-being.

The review, published in The Cochrane Library, included 15 randomised controlled trials involving 718 people with mild to moderate dementia, mainly Alzheimer's disease or vascular dementia. Participants were treated in small groups and involved in different activities, from discussions and word games to music and baking. All activities were designed to stimulate thinking and memory. Improvements were weighed against those seen without treatment, with "standard treatments", which could include medicine, day care or visits from community mental health workers, or in some cases alternative activities such as watching TV and physical therapy.

Those who received cognitive stimulation interventions scored significantly higher in cognitive function tests, which measure improvements in memory and thinking. These benefits were still being seen one to three months after treatment. In addition, positive effects on social interaction, communication and quality of life or well-being were observed in a smaller number of the trials, based on self-reported or carer-reported measures.

In one trial, family members were trained to deliver cognitive stimulation on a one-to-one basis, with no additional strain on burden on caregivers reported. "Involving family caregivers in the delivery of cognitive stimulation is an interesting development and deserving of further attention," said lead author Professor Bob Woods of Bangor University.

Woods B, Aguirre E, Spector AE, Orrell M. Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database of Systematic Reviews* 2012, Issue 2. Art. No.: CD005562. URL upon publication: <http://doi.wiley.com/10.1002/14651858.CD005562.pub2>

Cancer drug and Alzheimer's

Human trials are about to start on the skin cancer drug Bexarotene after a lot of publicity about the results of American studies on its effects on mice. After 72 hours of the drug's administration, the mice showed a significant reduction in the amount of amyloid beta-a protein, and, when tested, showed a marked improvement in their mental function.

However, the researchers warn against calling it a cure. Trials in mice do not necessarily equate to success in humans. According to statistics, since 1995 there have been approximately three hundred reports of treatments for Alzheimer's

that work in mice, none of which have proved successful in humans. One of the difficulties is that scientists use young mice with genetically modified brains, which are very different to an adult human brain. If Bexarotene is found to work in humans, the researchers also warn that while it reduces the amount of damage causing protein, it does not reverse any brain cell death.

Cramer PE, Cirrito JR, Wesson DW *et al* (2012) ApoE-directed therapeutics rapidly clear β -Amyloid and reverse deficits in AD mouse models. *Science*, published online Feb 9.

Cerebral cortex cells created

Researchers from Cambridge University in the UK have made an exciting breakthrough which may aid in the research of neurological conditions, such as Alzheimer's, by growing brain tissue from a sliver of human skin. Scientists have previously struggled to acquire cerebral cortex tissue and have relied on the controversial embryonic stem cell usage. Now, by using engineered skin cells the scientists have been able to reproduce brain development and therefore facilitate the testing of new treatments on human tissue. In a statement, Dr Rick Livesey of the Gurdon Institute and Department of Biochemistry at the University of Cambridge said, "This approach gives us the ability to study human brain development and disease in ways that were unimaginable even five years ago."

Brain cells created from patients' skin cells. Retrieved March 19, 2012 from University of Cambridge website: www.cam.ac.uk/research/news/brain-cells-created-from-patients-skin-cells/

Cognitive decline can start at the age of 45

A study which looked at the aging and deterioration of mental function, states that changes can start to occur at the age of 45, increasing in later life. Archana Singh-Manoux at INSERM, France analysed data collected over 10 years on over 10 000 people. His findings suggest that the common assumption that deterioration occurs in old age is wrong. The study also says that deterioration occurs in every area of brain function except vocabulary.

An editorial written by Francine Grodstein states, "...Singh-Manoux and colleagues have set a new benchmark for future research and, eventually, clinical practice. That is, efforts to prevent dementia may need to start in adults as young as 45 years."

Singh-Manoux A, Kivimaki M, Glymour MM *et al* (2012) Timing of onset of cognitive decline: Results from Whitehall II prospective cohort study, *British Medical Journal* 344 d7622.

Anti-depressant medication raises risk of falls

Results of a study conducted at Erasmus University Medical Centre in Rotterdam, published in the *British Journal of Clinical Pharmacology*, state that nursing home residents with dementia, who are on average doses of a type of anti-depressant medication-Selective Serotonin Re uptake Inhibitors (SSRIs), are up to three times more likely to fall than similar people who are not on the medication. The findings also stated that the risk of injurious falls increased if the residents were also prescribed hypnotic or sedative agents, such as sleeping tablets.

A randomised controlled trial of more than 300 older patients with probable or possible Alzheimer's disease in the UK, found that after a 3-month period of anti-depressant medication, no significant reduction in depressive symptoms when compared with a placebo group were found. "Depression is the leading co-morbidity in dementia. It is a cause of great distress yet the treatments we use are not proven," said Dr Banerjee, Professor of Mental Health and Aging at Kings College, London.

Lead author of the study, Carolyn Shanty Sterke, said that treatment protocols need to take into account the increased risk of falling when SSRI's are being used.

Professor Henry Brodaty, of the Primary Collaborative Research Centre, UNSW, in an accompanying editorial to the study stressed that the trial did not advocate the abandonment of anti-depressants in these patients. Rather, "...it raises questions whether there are different pathogenic mechanisms at play in depression in Alzheimer's disease," he said.

Sterke CS, Ziere G, van Beeck EF *et al* (2012) Dose-response relationship between Selective Serotonin Reuptake Inhibitors and injurious falls: A study in nursing home residents with dementia, *British Journal of Clinical Pharmacology* 73 1-3.

Genetics may play a role in cognitive decline

A study conducted by Ian Dreary at the University of Edinburgh, UK and Peter Visscher at the University of Queensland identified changes to certain genetic markers that correlated to cognitive changes in one quarter of the study group. Environmental factors were also taken into consideration. Perminder Sachdev, at the University of New South Wales states "The

study confirms what he have suspected – that cognitive aging is partly genetically determined – but we did not have the data previously to demonstrate this".

Deary IJ, Yang J, Davies G *et al* (2012) Genetic contributions to stability and change in intelligence from childhood to old age, *Nature* 482 212-15.

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Memory boost possible by stimulating key brain gateway

UCLA neuroscientists have shown that they can strengthen human memory by stimulating a critical junction in the brain. The findings, published in February, could lead to a new method for memory in patients with early Alzheimer's disease.

Dr Itzhak Fried, Professor of Neurosurgery at the David Geffen School of Medicine at UCLA and senior author stated, "The entorhinal cortex is the golden gate to the brain's memory mainframe. Every visual and sensory experience that we eventually commit to memory funnels

that doorway to the hippocampus. Our brain cells must send signals through this hub in order to form memories that we can later consciously recall."

The study involved monitoring seven patients with epilepsy who already had electrodes implanted in their brain. The researchers monitored the electrodes to record neuron activity as memories were being formed. When stimulation of the nerve fibres in the entorhinal cortex during learning occurred the patients demonstrated better memory recall and cognitive ability.

"Losing our ability to remember recent events and form new memories is one of the most dreaded afflictions of the human condition," Fried said. "Our preliminary results provide evidence supporting a possible mechanism for enhancing memory, particularly as people age or suffer from early dementia."

Suthana N, Haneef Z, Stern J *et al* (2012) Memory enhancement and deep-brain stimulation of the Entorhinal area, *New England Journal of Medicine* 366(6) 502-10.

Hearing loss linked to dementia

Research has shown a link between hearing loss and dementia, though the exact pathway is unknown. Researchers at John Hopkins School of Medicine and The National Institute on Aging in the United States have stated that the findings could help in the fight against dementia.

Dr Frank Lin, MD PhD, Associate Professor in the Department of Otolaryngology at the John Hopkins University Medical School recognised a gap in research about how hearing loss could affect brain cognition. The study proposed that there is a possible link between the two, and that the brain of those with hearing loss may

become "overwhelmed" by the constant need to strain and decode sounds.

Dr Lin utilised data available in the Baltimore Longitudinal Study on Aging (BLSA) and specifically 639 volunteers who were tested every one to two years. At the start of the study 25 per cent of volunteers had some degree of hearing loss, but none had dementia. By 2008, 58 volunteers had developed dementia, and within that group, 37 had significant hearing loss.

Lin FR, Metter EJ, O'Brien RJ *et al* (2011) Hearing loss and incident dementia, *Archives of Neurology* 68(2) 214-20.

Dementia screening tool links families and doctors

A project based at the University of Alberta in Canada has designed a new diagnostic tool, the Dementia Pocket Card, which allows family carers and medical professionals to collaborate on faster, more accurate diagnoses of early-stage dementia.

Led by Dr Belinda Park, the project outlined critical factors in translating research on dementia into applicable outcomes, tools and knowledge for family members of people with dementia and medical professionals. The aim was to develop an easy to use diagnostic tool for general practitioners. As the project progressed, the team recognized that family members play an essential role in the identification of early signs of dementia, and involving family members became a key outcome.

The Pocket Card Tool design drew on two studies: the Registered Nurses Association of Ontario (RNAO) Best Practice Guideline: Screening for Delirium, Dementia and Depression in Older Adults and the Deterioration Cognitive Observée (DECO), an informant questionnaire. Combining them, Dr Park's team created the expanding card-sized document with simplified case-finding tools and information, including the DECO.

Assessments are conducted over a year by family members using the tool, and the results are used by a GP who refers the family on for specialist assessment. The Dementia Pocket Card provides an easy and accessible method for family and medical professionals to speed diagnosis of early-stage dementia, leading to better treatment and higher quality of life.

Parke B, Woo TKW, Cruttenden KE, Sapergia S & D'Hondt A (2012) The challenge of dementia care knowledge exchange: Key factors in a national approach. *Dementia* 11 253.

Walking speed and hand grip predict dementia risk

Research has shown that simple testing could indicate the likelihood of developing dementia or stroke. The study involved more than 2,400 people with an average age of 62+ over an 11-year period. Tests included in the study looked specifically at walking speed and hand grip. Results showed that those with a slower walking speed were 1.5 times more likely to develop dementia. Those with a stronger hand grip had a 42 per cent lower risk of stroke. Results are to be presented at the 64th annual meeting of the American Academy of Neurology, New Orleans, on April 21-28.

How fast you walk and your grip in middle age may predict dementia, stroke. Retrieved March 19, 2012 from American Academy of Neurology: www.aan.com/press/index.cfm?fuseaction=release.view&release=1027

Pain management linked to reduced aggression

A team of researchers in the University of Texas led by Dr Andrea Bradford have reviewed the non-pharmacological approaches to behavioural disturbance in people with dementia.

The study concluded that pain management is an evidence-based, feasible, and underused, strategy that may be incorporated with other behavioural interventions to help prevent aggression in people with dementia. They describe a home-based intervention that targets community-dwelling older adults with dementia and their home-based caregivers.

Bradford A, Shrestha S *et al* (2012) Managing pain to prevent aggression in people with dementia. *American Journal of Alzheimer's Disease and Other Dementias* 27(1) 41-47.



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