

Dementia Australia Annual Report 2018–19

Designing
a new future



Dementia Australia

is registered as Dementia & Alzheimer's Australia Limited
ABN 79 625 582 771
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To read more about our Ambassador Program visit
<https://www.dementia.org.au/ambassadors>

Dementia Australia would like to acknowledge the Aboriginal and Torres Strait Islander people as the traditional custodians and carers of the country of Australia.

We acknowledge and respect the Aboriginal and Torres Strait Islander people of Australia's relationship with country and their cultural and spiritual beliefs.

About this annual report

This report highlights Dementia Australia's progress and achievements throughout 2018–2019, including links to its financial statements. The Dementia Australia financial statements are listed on the Australian Charities and Not-for-profits Commission website.

Dementia Australia was established on 18 October 2017 when the Federation of Alzheimer's Australia became Dementia Australia Limited.

This report and previous years' reports for Dementia Australia and Alzheimer's Australia are available online at <https://www.dementia.org.au/annual-reports>.

We welcome your feedback on this report and any of the activity reported.

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Cover photo: People living with dementia, families, carers and Dementia Australia staff at Dementia Australia's Quality Care Initiative National Consumer Summit held in Canberra, June 2019.
Photo: Andrew Taylor



Attendees at Dementia Australia's South Australian Parliamentary Friends of Dementia event held in Adelaide, November 2018.
Photo: James Elsby

Designing a new future

Who are we?

Dementia Australia is the national peak body and charity for people, of all ages, living with all forms of dementia, their families and carers.

What do we do?

- We represent more than 447,000 Australians living with dementia and the estimated 1.5 million involved in their care.
- We work with individuals and families, all levels of government, and other key stakeholders to ensure that people of all ages with all types of dementia, as well as their families and carers, are appropriately supported – at work, at home (including residential aged care) or in their local community.
- We are an important advocate for those impacted by dementia and, due to our close engagement with consumers, we provide input on policy matters and identify service gaps.
- We draw on our expertise to collaborate with a wide range of stakeholders including researchers, technology experts and providers.
- We provide support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.

Our history

Dementia Australia was officially launched in October 2017 as the new voice of Alzheimer's Australia, a unified, national, peak body for people of all ages, living with all forms of dementia, their families and carers.

From a grassroots community of passionate carers around Australia we have evolved into the leading organisation providing a voice for people impacted by dementia. We have offices in regional and rural Australia, as well as in all capital cities.

Our vision

An inclusive future where all people impacted by dementia receive the care and support they choose.

Our purpose

To transform the experience of people impacted by dementia by elevating their voices and inspiring excellence in support and care free from discrimination.

Our values

- Diversity and Equality
- Respect and Inclusiveness
- Integrity and Accountability

Dementia facts and figures

What is dementia?

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease.

Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person's normal social or working life.

There are a number of conditions that produce symptoms similar to dementia. These include some vitamin and hormone deficiencies, depression, medication clashes or overmedication, infections and brain tumours.

It is essential that a medical diagnosis is obtained at an early stage when symptoms first appear, to ensure that a person who has a treatable condition is diagnosed and treated correctly.

If the symptoms are caused by dementia, an early diagnosis will mean early access to support, information, and medication should it be available.



Key statistics

In 2019, there are an estimated 447,115 Australians living with dementia.¹

Without a medical breakthrough, the number of people with dementia is expected to increase to 589,807 by 2028 and 1,076,129 by 2058.²

Currently an estimated 250 people are joining the population with dementia each day. The number of new cases of dementia will increase to 318 people per day by 2025 and more than 650 people by 2056.³

Three in 10 people over the age of 85 and almost one in 10 people over 65 have dementia.⁴

1. Dementia Australia (2018) Dementia Prevalence Data 2018–2058, commissioned research undertaken by NATSEM, University of Canberra
2. Dementia Australia (2018) Dementia Prevalence Data 2018–2058, commissioned research undertaken by NATSEM, University of Canberra
3. The National Centre for Social and Economic Modelling NATSEM (2016) Economic Cost of Dementia in Australia 2016–2056
4. The National Centre for Social and Economic Modelling NATSEM (2016) Economic Cost of Dementia in Australia 2016–2056

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(L–R) Neil Samuel, Board Director, Dementia Australia, Glenn Rees AM, Chair, Alzheimer's Disease International, Anthony Boffa, Executive Director, Corporate Services & Governance, Dementia Australia attended the NHMRC National Institute for Dementia Research Australia Dementia Forum in Hobart, June 2019. Photo Loic Le Gully

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The Bell Tower in Perth turned teal for World Alzheimer's Day, 21 September 2018.

Key achievements

- Development and implementation commenced for the Strategic Direction: Designing a new future 2018–2023
- Quality Care Initiative commenced with the focus on the National Consumer Summit
- Successfully positioned Dementia Australia as a key contributor to the development of the terms of reference, and as a trusted and informed source for the Royal Commission into Aged Care Quality and Safety
- Dementia Australia and 76 Dementia Advocates contributed to Terms of Reference for the Royal Commission into Aged Care Quality and Safety, attended community forums and appeared as witnesses
- Released the A Better Visit™ free tablet app to encourage engagement and activity when visiting people living with dementia



A Melbourne LifeView resident enjoyed the launch of Dementia Australia's A Better Visit app held at Lifeview Willow Wood in Cranbourne, November 2018. The development of A Better Visit was sponsored by Lifeview Residential Care. Photo: Arsineh Houspian



Ita Buttrose AC OBE, long-term Dementia Australia Ambassador was awarded a Companion of the Order of Australia (AC) in the Queen's Birthday 2019 Honours for eminent service to the community through leadership in the media, the arts and the health sector, and as a role model. Ms Buttrose has a long history of advocating for people living with dementia and has contributed to Dementia Australia over several years in many different roles, including as President of Alzheimer's Australia, as a member of the NSW Advisory Committee and now as an Ambassador.



Dementia Australia Ambassadors, Dementia Advocates and stakeholders gathered together for the 2018 Dementia Awareness Month Small Actions Big Difference Roadshow event in Adelaide in September. (L–R) Ian Gladstone, Dementia Advocate, Doris Younane, Ambassador, Dementia Australia, Bronwyn Lee, Dementia Advocate, Mike Lee, Dementia Advocate, Sue Pieters-Hawke, Ambassador, Dementia Australia, Dr Faizal Ibrahim Consultant Geriatrician, Central Adelaide Local Health Network South Australia and Port Lincoln Geriatrics Clinic Services. Photo: Kelly Barnes



Comedian Denise Scott visited Dementia Australia staff and Dementia Advocates in March 2019 after her appearance on reality television program Dancing with the Stars. Denise danced for Dementia Australia after selecting our organisation as her charity of choice.

A message from our Chair



It is with immense pride that I share with you Dementia Australia's first full financial year annual report on our achievements and the commencement of our **Strategic Direction: Designing a new future 2018–2023**.

Dementia Australia's strategic direction is underpinned by a vision and purpose that speaks to

who we are: an organisation that stands for the rights of people impacted by dementia to receive early supports and high-quality services throughout their lives and to be respected, valued and included in their communities.

We will take on the biggest issues facing those living with dementia, their families and carers through the three lenses of service delivery, capacity building and advocacy.

We provide information, education, counselling and support services. As active advocates, Dementia Australia is tackling these issues as a united organisation, in partnership with government and other stakeholders, and most significantly, in collaboration with people living with dementia, their families and carers.

Our achievements this year demonstrate a commitment to the three strategic priority areas of improving access to timely diagnosis and ongoing support, increasing the quality of dementia care and reducing discrimination.

The board members, CEO and leadership teams from around the country have been integral to the development and extensive consultation process that has guided us to identify these priorities as a focus for the next five years.

I would like to acknowledge our donors, supporters and corporate sponsors who have contributed to the success of this financial year. I would also like to extend a thanks to the federal, state and territory governments for their ongoing support and engagement. Our stakeholders provide us with invaluable support in our commitment to provide the best possible outcomes for people living with dementia, their families and carers.

My sincere thanks and appreciation.

Professor Graeme Samuel AC
Chair Dementia Australia

A message from our CEO



Dementia Australia has continued to cement its position as the national peak body for people of all ages, living with all forms of dementia, their families and carers. We are going from strength to strength thanks to the commitment and passion of an extraordinary team of professionals who are working to make a difference to the lives of all

people impacted by dementia.

A major focus of the year has been the Royal Commission into Aged Care Quality and Safety. In September Dementia Australia was called upon to provide input into the draft terms of reference that were later released with dementia as a central focus of the investigations.

I was honoured to represent Dementia Australia as a witness at the Royal Commission and we have regularly been consulted by the Commission in its research and to ensure the voices of advocates have been included.

The organisation's **Strategic Direction: Designing a new future 2018–2023** was developed over twelve months as part of Dementia Australia's Business Plan reported in last year's annual report. This year it is exciting to report on the launch and commencement of the plan, especially on our progress with Strategic Priority Two: Quality Dementia Care. There is more detail about the strategic direction on pages 12–17.

Supporting and in addition to the strategic direction our teams across Australia have continued to deliver:

- on our counselling and support services
- the Centre for Dementia Learning training, education courses and consultancy
- contributions to ongoing development of policy and research, as advocates to governments, media, and the health, aged care, disabilities, social services and community sectors
- on providing opportunities for Dementia Advocates in policy development, research and spokesperson roles
- successful business development and fundraising activity
- and continually raising awareness and the profile of dementia and Dementia Australia.

I acknowledge and thank our board, our honorary medical advisors, ambassadors, Dementia Advocates, volunteers, staff and all external stakeholders for their contribution to the achievements shared in this annual report and throughout the year.

In this, the first stage of our five-year strategy for the future, in partnerships with government and other stakeholders and, most significantly, in collaboration with those impacted by dementia, we will work together to create a profound and lasting difference for people living with dementia and those impacted by dementia.

Maree McCabe
CEO Dementia Australia

A message from the Chair of our Finance Audit and Risk Management Committee



In 2018–19 Dementia Australia continued to invest significantly to further develop infrastructure and systems to underpin the strength and success of our new national organisation, which was formed in 2017 with the unification of state and territory organisations around the country.

The result for the year ended 30 June 2019, disclosed in our financial statements, are compared to the unified entities' results from the previous year. Total equity for the organisation was \$43.8 million (2019) compared to \$43.8 million in the previous year (2018). The total combined comprehensive loss was \$27,000 (2019) compared to total comprehensive income of \$2.4 million in the previous year (2018). The reduction was primarily due to \$1.7 million in expenditure attributable to unification costs.

At the end of the year the organisation had cash holdings of \$22.7 million and investments of \$17.7 million (2019) compared to \$27.8 million and \$16.5 million (2018). These funds are being managed to

support the future growth of the organisation in order to continue supporting those who are living with dementia and their carers.

Some of the key initiatives undertaken during the year include creation of a national intranet portal for staff to access key organisational resources, consolidation of student administration data for the provision of training services, assessment of new useful technologies and innovations for people living with dementia and their carers and implementation of a consolidated national IT network. This work is ongoing, and the organisation will continue to streamline systems and processes to compliment the consolidated entity.

I would like to recognise the work of the Finance team and other staff involved in these activities. I thank them for their efforts through the course of the year.

Ian Knight

Chair, Finance Audit and Risk Management Committee

You can view our full 2018–19 financials here: <http://bit.ly/DAFinancialStatements>

Dementia Australia Advisory Committee Report

The Dementia Australia Advisory Committee provides a national platform for the voices of people living with dementia. The aim of the committee is to work with Dementia Australia to ensure the insights and wisdom of people living with dementia are included in policy, program and service development. Members of the committee are key participants in Dementia Australia's Dementia Advocates Program. They are active advocates in their communities and contribute specialist expertise by providing lived experience knowledge.

It is my pleasure as Chair of the Dementia Australia Advisory Committee to provide an update on our achievements.

We would like to express our sincere gratitude to John Hiller who stepped down from the committee in July. John was one of the founding members of the Committee and provided significant contributions to the committee's work during the past five years. John lives in Hobart with his wife and four adult children, and has been an essential voice in representing Tasmania. John continues to be passionate about breaking down stigma. We wish John all the best for his future endeavours.

In September, following the announcement of the Royal Commission into Aged Care Quality and Safety, the committee held an urgent meeting to provide input into Dementia Australia's submission on the terms of reference.

It was decided by the committee to focus on the call for the Royal Commission take a human rights-based approach to dementia, which frames substandard care, neglect and abuse as human rights violations and provide opportunities for meaningful involvement and leadership by people living with dementia and disability. We are keeping a close eye on this space.

In early December the committee met at a two-day, face-to-face meeting in Sydney. It was the first time some of us had met in person and it provided an opportunity to strengthen our work and discuss what we want to achieve in 2019.

This was followed by a focus on Dementia Australia's Strategic Priority 2, which aimed to create baseline and best-practice standards for quality dementia care.

The committee's work on this has included:

- Providing feedback on the Quality Dementia Care focus group plan and briefing paper
- Working with Dementia Australia on planning for the National Consumer Summit



Phil Hazell
Chair,
Dementia
Australia
Advisory
Committee

- Member Dennis Frost travelled to Canberra to undertake a venue assessment, with Canberra Advocate Dawn McKay, to recommend possible locations for the summit

As a result Mr Frost developed an excellent toolkit and guidebook for assessing venues to be dementia-friendly which has now been introduced to Dementia Australia practice nationally

Committee member Sarah Ashton and other committee members provided feedback on the development of the draft Dementia Australia client services survey and the Younger Onset Dementia Hub Project, and have been involved in the planning of the National Consumer Summit.

In other news, the committee updated the 'Talk With Me' brochure. Created by the committee when it was known as Alzheimer's Australia Dementia Advisory Committee, the brochure sets out good communication tips for talking with people living with dementia.

The Quality Care Initiative National Consumer Summit took place in Canberra on 26 June, 2019 and committee members were table facilitators. The Summit provided important input into the Summit Communique that was then presented to Senator the Honourable Richard Colbeck, Minister for Aged Care and Senior Australians.

Also in June 2019 was a productive face-to-face Canberra meeting which included:

- The CEO of Dementia Australia, Maree McCabe, and the chair of the committee, Phil Hazell, signing the updated committee terms of reference
- Guest speakers Leanne Wells, CEO Consumer Health Forum of Australia, and Alice Tibbits, Director Engagement and Funding National Disability Insurance Agency
- Attendance by Professor Graeme Samuel AC, Chair Dementia Australia and Greg Fraser, Board Director Dementia Australia.

Phil Hazell

Chair, Dementia Australia Advisory Committee

Strategic Direction

The big issues for people impacted by dementia



Timely diagnosis and support



Diagnosis takes on average

3
years

Consumers tell us **accessing support services early improves their understanding** of dementia, their relationships and planning for the future



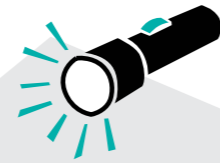
Quality care



NO
dementia-specific care standards in aged care facilities



50%
of people in aged care facilities have dementia



Reduce discrimination



63%

of people say they **know very little** about dementia

41%

feel **confronted** when talking to someone with dementia

Dementia Australia aims by 2023



To significantly reduce the time it takes to diagnose dementia and increase the number of people accessing support.



To create baseline and best practice standards for quality dementia care and advocate for these standards to be implemented into aged care facilities across Australia.



To tackle discrimination head on so that no-one with dementia feels isolated.

Strategic Direction: Designing a new future 2018–2023

This is the first year reporting to the outcomes of our **Strategic Direction: Designing a new future 2018–2023**. This five-year plan will guide us to achieve our vision of an inclusive future where all people impacted by dementia receive the care and support they choose.

Strategic Direction: Designing a new future 2018–2023 outlines our strategic priorities focusing on the three key issues of greatest need:

- Improving access to timely diagnosis and ongoing support
- Increasing the quality of dementia care
- Reducing discrimination.

When Dementia Australia was formed in 2017, bringing together our state and territory organisations to create the national peak body, we committed to becoming a bigger, stronger and bolder voice for people living with dementia, their families and carers.

To understand how best to achieve this we undertook extensive and rigorous consultation with our community to identify the focus areas that will deliver the greatest benefit for those living with dementia, their families and carers.

Strategic Direction: Designing a new future 2018–2023 is the result of that consultation and highlights the issues that our stakeholders identified as areas of greatest need. We are committed to focusing on the priority areas that will achieve the most significant outcomes for all people impacted by dementia. We will implement and report on this strategy over the next five years.

To identify the priorities and throughout the consultation we asked two key questions:

- What are the biggest issues for people living with dementia, their families and carers?
- How can Dementia Australia have the biggest impact?

Following is the result of this consultation work.



Dementia Advocates and other Dementia Australia stakeholders gathered together in Canberra, June 2019 to attend Dementia Australia's National Consumer Summit. Photo: Andrew Taylor

Strategic Direction: Designing a new future 2018–2023

1

Timely diagnosis and support

It can take up to three years for someone to receive a diagnosis of dementia and up to seven years for a person with younger onset dementia. This is unlike any other chronic disease.

Aim

Significantly reduce the time it takes to diagnose dementia and increase the number of people accessing support.

Achieving our aims

- Initiative 1: Barriers to diagnosis**
Consultation process with all stakeholders* to determine barriers and propose solutions.
- Initiative 2: Direct Referral Model**
To develop with general practitioners, diagnosing clinics and specialists.
- Initiative 3: Dementia Care Navigator Model**
Trial the Dementia Care Navigator Model.

*Stakeholders are primarily, always, people living with dementia, their families and carers and secondarily, tailored to the objectives such as researchers, clinicians, government departments, politicians, aged care sector, local government, GP, allied health and other specialists and the broader community.

Positive outcomes

Access to the services and supports needed; empowered to advocate for their needs, exercise choice in their lives and manage changes; an ability to live well with dementia; the care relationship is supported; ability to implement relevant strategies for individual circumstances and reconnect with supports as needed; improved psychological wellbeing and coping strategies.

2018–2019 progress

A national client and community education suite of approximately 25 products (for example, workshops and early intervention programs) rolled out on 1 July, and monitoring and evaluation framework in pilot. Trial of the Dementia Care Navigator Model commenced in Perth and Dubbo funded by Department of Health.

2

Quality care

The majority of providers strive to provide high quality dementia care but need support in bringing about practice that is evidence-based, client-centred and sustainable.

Aim

To advocate for the baseline standards, which will include provisions for dementia specific training, to be mandatory and implemented into aged care facilities across Australia.

Achieving our aims

- Initiative 1: Baseline standards of care**
Work with stakeholders to define standards in quality support and care to be implemented into aged-care facilities across Australia.
- Initiative 2: Best practice of care**
Establish a best practice model of care in partnership with the sector to achieve excellence in dementia practice.
- Initiative 3: Create 1,000 Dementia Practice Leaders – Certificate IV Dementia Practice**
Train a target of 1,000 aged-care workers in the Certificate IV in Dementia Practice.
- Initiative 4: Community of Practice**
Dementia Australia's Centre for Dementia Learning will support a Community of Practice.
- Initiative 5: National Dementia Learning Program**
Develop a complete suite of online and face-to-face dementia learning programs.
- Initiative 6: Unique learning experiences which touch, move and inspire participants**
Continue to explore technology options, working with leading universities, clients and providers to develop new and innovative programs.

Positive outcomes

National quality standards in dementia care are practiced; Minimum education levels are achieved across the sector; providers strive to achieve the best practice in care; people living with dementia, their families and carers report a significant improvement in the quality of support; an increase in dementia knowledge and confidence; dementia practice is a career that attracts and inspires the workforce.

2018–2019 progress

Extensive stakeholder consultations from January to June
Quality Care Initiative National Consumer Summit held in Canberra on 26 June and Communicate **Our Solution: Quality Care for People Living with Dementia**, developed, ratified and distributed to federal, state and territory governments, relevant government departments and aged care sector.
Planning underway of the next stages for delivery of the Quality Care Initiative.
National Stakeholder Round Table and key attendees scheduled for Melbourne on 12 November 2019 and Dementia Australia National Symposium – Dementia Care is Quality Care in Sydney on 24 March 2020; Introduction of A day in the life – mealtime experience™ workshop and roll-out partially funded by partnership with Nestle Australia.

Strategic Direction: Designing a new future 2018–2023

3

Reduce discrimination

Social isolation, stigma and discrimination are common for people living with dementia with research telling us that 63 per cent of people say they know very little about dementia.⁶ This demonstrates the need for an attitudinal shift.

6 Ipsos research for Dementia Australia on Perceptions and Understandings of Dementia, 2015

Aim

To tackle discrimination head on so that no-one with dementia feels isolated.

Achieving our aims

Initiative 1: Measure discrimination
Undertake research using existing measures of stigma and discrimination. Target reach 1,000 people living with dementia, their families and carers, and 1,000 professional workers in the community.

Initiative 2: Movement of change
Deliver a call-to-action campaign to create a more aware and inclusive Australia.

Initiative 3: Dementia-friendly programs
Continue focus on the Dementia Friends and Dementia-Friendly Communities programs.

Positive outcomes

People living with dementia are empowered and engaged in local community, increasing participation and social inclusion opportunities; awareness, understanding and positive attitudes towards people living with dementia are increased in the community; communities make a long-term commitment to being dementia-friendly and develop community initiatives that are informed by people living with dementia; stigma towards dementia is reduced

2018–2019 progress

Funding of Dementia-Friendly Communities extended by Department of Health to June 2022; launch of new online resources hub for Dementia-Friendly Communities; target of 20,000 Dementia Friends reached by June 2019. Planning underway for September 2019 Dementia Action Week with all activity and objectives to focus on reducing discrimination. Reporting on this activity will be included in 2019–2020 annual report.

Advocacy will be a key driver to the success of the strategic plan

The proposed advocacy strategy for the plan period consists of two main elements:

- Continued response to contemporary, relevant issues for people living with dementia, their families and carers, with messaging focusing on the fact that dementia is not yet core business for the majority of providers and consumer-directed market drivers are not yet sophisticated enough to enforce service excellence.
- A proactive advocacy campaign that focuses on the three priority areas articulated in Dementia Australia's strategic plan and positions Dementia Australia as leaders in driving systemic change.

The first element will continue to span our existing advocacy platforms, build in consistent messaging around making dementia core businesses and potentially narrow our submission activities to a smaller, more targeted range of topics.

The second element will explore each of the three priority areas (noting that underpinning policy research is required for each priority area, including consumer engagement, statistical research and other stakeholder engagement).

In the interim there is a third element reflecting a more immediate priority: sustainability of Dementia Australia's government funding for National Dementia Support Program, Younger Onset Dementia Key Worker Program; and Dementia Training Australia.

Partnerships are fundamental to achieving the strategic plan

The implementation of the strategic plan will require a substantial role for partnerships. Dementia Australia has always been an organisation that views partnerships as an essential component to growth and service delivery and has more than 150 partnerships already in place.

An assessment of these partnerships has been undertaken to identify those that are aligned with the strategic priorities to provide an insight into where further growth and opportunities lie.



Professor Graeme Samuel AC, Chair, Dementia Australia, spoke at a Federal Parliamentary Friends of Dementia event in Canberra, November 2018. A memorandum of understanding between Dementia Australia and Dementia Alliance International was signed at the event. Photo: Irene Dowdy

Our organisation Board

Professor Graeme Samuel AC
Chair

Appointed July 2014*



Graeme Samuel AC is a Professorial Fellow in Monash University's Business School and School of Public Health and Preventative Medicine. He also chairs the Dementia Australia Research Foundation, Lorica Health Pty Ltd, Airlines for Australia and New Zealand and the National Health and Medical Research Council National Institute for Dementia Research. He was a member of the Australian Health Practitioner Regulation Agency panel that conducted a prudential inquiry into the culture, governance and accountability of the Commonwealth Bank and chair of the panel that conducted a capability review of the agency. He recently conducted a review for the Commonwealth Government of the Food and Grocery Code of Conduct and is undertaking a government independent review of the *Environment Protection and Biodiversity Conservation Act*.

Professor Samuel chaired the Commonwealth Government's panel of review of Australia's independent medical research institutes and was adviser to the Commonwealth Department of Health's review of private health insurance. He was also a member of the review panel of Australia's wool selling systems.

Professor Samuel's roles in public life include former Chairman of the Australian Competition and Consumer Commission, Associate Member of the Australian Communications and Media Authority and President of the National Competition Council.

He was appointed an Officer of the Order of Australia in 1998. In 2010 he was elevated to a Companion of the Order of Australia for "eminent service to public administration through contributions in the area of economic reform and competition law, and to the community through leadership roles with sporting and cultural organisations".

Tony Newman
Director

Appointed May 2014



Tony Newman is a highly experienced senior executive with expertise in finance, supply chain, sales and marketing and information technology. Tony is a strategic thinker and leader and an effective operations manager. His well-developed skills in negotiation, collaboration, relationship management and delivery of customer satisfaction and his coaching and mentoring approach with staff have contributed to Tony's success in a complex international environment.

The work of Dementia Australia holds a special place with Tony. His father was diagnosed with Alzheimer's five years before his death in 1996.

Tony also serves on the board of the Dementia Australia Research Foundation and Dementia Australia Research Foundation Victoria and is a member of Dementia Australia's Finance Audit and Risk Management and Governance committees.

William Bass
Director

Appointed February 2014*



William brings considerable corporate executive experience, mainly in the fields of governance, strategy and commercial and financial management. He is a director, senior financial officer, company secretary and adviser to a number of prominent companies.

William's involvement in Dementia Australia arose out of family experiences with various types of dementia. His responsibilities have included Treasurer, Secretary, Public Officer and Chair of the Audit and Risk Management Committee.

Jenna Dennison
Director

Appointed July 2017



Jenna has served as a board member for Dementia Australia since July 2015, firstly in the Northern Territory and from July 2017 as a director of Dementia Australia. She is also Chair of the Dementia Australia Governance Committee. Her commitment to the organisation began when her father was diagnosed with younger onset dementia in early 2015 and she brings this experience and insight to the board.

After a brief period of working in Sydney, Jenna moved to Darwin in 2012 to work with the Solicitor for the Northern Territory. Jenna has worked with the Northern Territory Department of the Attorney-General and Justice, Northern Territory Correctional Services and the Northern Territory Police Fire and Emergency Services on legislative and policy reform projects. She has also worked as a public prosecutor and is currently the Secretary of the Northern Territory Parole Board. In 2017 Jenna received a Northern Territory Government Australian Institute for Company Directors not-for-profit scholarship.

Jenna grew up in rural New South Wales. She is an enthusiastic road cyclist, traveller and adventurer and serves as Secretary of the Darwin Cycling Club.

Greg Fraser
Director

Appointed November 2013



Greg has 25 years' public sector management experience, with more than 16 years at chief executive and senior executive levels. Greg was Chief Executive of the Australian Capital Territory Department of Health and Community Care, where he had extensive involvement in intergovernmental initiatives and forums and represented the states and territories at several international treaty meetings.

Since 1996, Greg has consulted to public, private and not-for-profit bodies on corporate governance, risk management, program evaluation, strategic and business planning and change management. He works independently and with PricewaterhouseCoopers, RSM Bird Cameron and Directors Australia. He specialises in public sector and not-for-profit governance and risk management.

Greg has been involved with Dementia Australia boards for more than 10 years and has been a member of the Dementia Australia board since 2013. He is also a member of the board of Marymead and serves on the National Blood Authority's Audit and Risk Committee.

Greg is a Fellow of the Australian Institute of Company Directors, a Fellow of the Governance Institute of Australia and a member of the Risk Management Institution of Australia and the Centre for Strategy and Governance.

Ian Knight
Director

Appointed November 2018



Ian is Executive Chairman of Axsia Group, a boutique advisory group. He sits on a number of not-for-profit, private and public company boards. Ian has had an extensive career in investment banking for more than 40 years and was a partner at KPMG from 1995 to his retirement in June 2012. Ian has served on the board of the Dementia Australia Research Foundation since 2018 and on the Dementia Australia Research Foundation Victoria board since 2012.

Ian was a member of Dementia Australia Finance, Audit and Investment and Audit and Risk Management committees. Following his appointment to the Dementia Australia board in 2018 he became the Chair of Dementia Australia's combined Finance and Risk Management Committee.

*All dates marked with an asterisk reflect Board members who were on the Alzheimer's Australia National Board when the organisation transitioned to Dementia Australia in October 2017.

Our organisation Board

Amanda Quealy

Director

Appointed November 2015



Amanda has had an executive career in the health care industry for the past 27 years in the government, corporate health, private and not-for-profit sectors. She has held a number of CEO roles, including her current position with the National Institute of Integrative Medicine. Amanda holds an honorary position as Adjunct Senior Lecturer at University of Tasmania, School of Medicine.

Amanda has served on the Dementia Australia board since November 2015 and was Chair of the Dementia Australia Governance Committee.

Amanda is a Fellow and National Board director of the Australian College of Health Service Managers. As a former Telstra Business Woman of the Year, she has also been recognised in the Top 100 Women of Influence.

Paul Robertson AO

Director

Appointed February 2016



Paul Robertson has been involved in the organisation since early 2016 as previous Chair of Alzheimer's Australia New South Wales. He also chairs Goodstart Early Learning and Social Ventures Australia.

Paul has extensive experience in commercial and investment banking including 27 years at Macquarie Bank where he was an executive director and Global Treasurer. He is a former Chair of St Vincent's Health Australia. Paul is the founding director of the Financial Markets Foundation for Children, a director of Telco Together Foundation, Chair of Tonic Health Media and a director of Sydney Theatre.

Neil Samuel

Director

Appointed December 2014*, retired November 2019



Over the past 45 years Neil Samuel has been actively involved in business with an emphasis on finance, administration, sourcing and procurement. Neil has travelled extensively throughout Asia and Europe enabling him to become a regular guest lecturer at Deakin University. He is currently CEO of Golden Wrap Pty Ltd.

Neil has served in leadership positions on numerous boards in the not-for-profit sector for many years, specialising in governance and finance. Neil served on the board of Alzheimer's Australia Victoria since 2003, including as honorary secretary, deputy chair and chair. In 2007 he was appointed to the board of Alzheimer's Australia, now Dementia Australia, and he retired from this board role in November 2019. Neil continues to serve on the boards of the Dementia Australia Research Foundation and Dementia Australia Research Foundation Victoria and is now also an independent member of the Finance and Risk Management Committee.

*All dates marked with an asterisk reflect Board members who were on the Alzheimer's Australia National Board when the organisation transitioned to Dementia Australia in October 2017.

Maree McCabe

Director/ Company Secretary

Appointed September 2016



Maree McCabe is the Chief Executive Officer of Dementia Australia and a member of the organisation's board. In August 2016, Maree was appointed as the interim Alzheimer's Australia National CEO; in February 2017 Maree was officially appointed to the role. Maree led the unification process from the federation of Alzheimer's Australia to the creation in October 2017 of Dementia Australia as a unified national organisation. Within the federation Maree served as CEO Alzheimer's Australia Victoria from October 2010 to August 2016. A recognised leader in the health and aged care sector, Maree brings to the role more than 20 years' experience across the health, mental health and aged care sectors.

Maree's career accomplishments include the roles of Executive Operations for TLC Aged Care, Director of Clinical Resources at The Melbourne Clinic, General Manager of Hospitals for St John of God Healthcare and Surveyor for the Australian Council on Healthcare Standards. Maree has a post-graduate Diploma in Mental Health Nursing, a Master of Business Administration and is a graduate of the Oxford University Leadership Program and the Australian Institute of Company Directors.

Maree is a director of the Dementia Australia Research Foundation and serves on the board of the National Ageing Research Institute. She is a member of the Aged Care Sector Committee, which provides advice to the Federal Government on aged care policy development and implementation, and the Aged Care Quality Advisory Council. Maree is on the Executive Committee of the Cognitive Decline Partnership Committee. Internationally Maree represents Dementia Australia as a member of Alzheimer's Disease International (ADI), chairs the ADI Nominations Committee and is a member of the ADI Asia Pacific Regional Committee.

A passionate advocate for improving the lives and quality of care of those living with dementia and those who love and support them, Maree is committed to elevating the voice of the 459,000 Australians who live with dementia and their families and carers. Maree drives Dementia Australia's focus to raise awareness about dementia, to demystify the disease and deliver on the priorities of timely diagnosis, quality care and reduced discrimination.



(L-R) Isabelle Burke, Dementia Advocate, William Bass, Board Director, Dementia Australia, Ann Pietsch, Dementia Advocate enjoyed a high tea get-to-know you event with the Dementia Australia Board in Hobart, June 2019. Photo: Loic Le Guilly

Our organisation

Governance

The board is responsible for the governance of the organisation with the Chief Executive Officer responsible for the management of the organisation. The board establishes the results to be achieved and the task of achieving these results are delegated to the Chief Executive Officer.

Under the terms of the Constitution, the board comprises of the chair and directors.

In performing their duties, the board will at all times act lawfully and consistently with Dementia Australia policies and meet regularly to monitor the performance of management and Dementia Australia as a whole.

The board is expected to:

- act lawfully and consistently with Dementia Australia policies at all times
- meet regularly to monitor the performance of management and Dementia Australia as a whole
- ensure that it receives regular and accurate reporting on financial and service provision matters
- regularly review its own performance as a basis for development and quality assurance
- carry out its meetings in such a manner as to ensure fair and full participation of all board members
- ensure the assets of Dementia Australia are protected by a suitable risk management strategy
- honour its obligations to Dementia Australia consistent with our constitution.

Board members perform this role on a voluntary basis and are not paid for their services.

Board meeting attendance

Board member	12 July 2018	9 Aug 2018	13 Sept 2018	11 Oct 2018	AGM 24 Nov 2018	15 Feb 2019	1 Mar 2019 SGM Name change	5 Apr 2019	10 May 2019	14 Jun 2019	Total attended
Graeme Samuel	1	1	1	1	1	1	1	1	1	1	10
Neil Samuel	1	1	1	1	1	1	1	1	1	1	10
William Bass	1	1	1	1	1	1	1	1	1	1	10
Greg Fraser	1	1	1	1	1	1	1	1	1	1	10
Jenna Dennison	0*	0*	0*	0*	1	1	1	1	1	1	6
Tony Newman	1	1	1	1	1	1	0#	1	1	1	9
Amanda Quealy	1	1	1	1	1	1	1	1	1	1	10
Paul Robertson	1	1	1	1	1	1	0	1	1	1	8
Maree McCabe	1	1	1	1	1	1	1	1	0	1	9
Ian Knight	n/a†	n/a†	n/a†	n/a†	n/a†	1	1	1	1	1	5

Notes/changes: *Leave of absence Jul–Nov 2018. #Proxy for 1 March 2019 SGM. †Appointed following Nov AGM.

Meetings of the board

During 2018–2019 the board continued its commitment to take the opportunity to meet with stakeholders and staff across the country. These visits coincided with the scheduled monthly meetings as an opportunity to speak about unification and the vision of the strategic direction and informally meet with a large range of stakeholders and partners. Since the start of this program visits included:

- March 2018, Adelaide – met with Dementia Advocates, members of the Rosemary Foundation and staff.
- June 2018, Sydney – met NSW ambassadors, Dementia Advocates and staff. This event included the announcement of The Honourable John Watkins AM as a Dementia Australia Ambassador and introduction of the dementia-friendly garden at the Dementia Australia North Ryde office.
- November 2018, Brisbane – met with Brisbane and Gold Coast staff and researchers and included a tour of the Queensland Brain Institute.
- April 2019, Melbourne – met with donors, philanthropic stakeholders, sponsors and staff, and included a showcase of technology tools for awareness and education. This featured the virtual reality tool EDIE (Educational Dementia Immersive Experience)™.
- June 2019, Hobart – met with Dementia Advocates and coincided with attending the National Institute for Dementia Research – Australian Dementia Forum 2019.

Board committees

In June 2018 the Finance Audit and Risk Management Committee, chaired by William Bass, was split into two subcommittees: the Finance and Investment Committee, chaired by Tony Newman, and the Audit and Risk Management Committee, chaired by William Bass. Following the annual general meeting in November 2018 both committees were folded back into the Finance Audit and Risk Committee and Ian Knight was appointed as chair.

The purpose of the committee is to provide ongoing support, advice and recommendations to the Dementia Australia board in relation to all Dementia Australia entities and its associated research foundations on finance, budgets and investments, and audit, compliance and risk management issues, as it relates to risk assessment, mitigation strategies and monitoring of organisational activity.

In April 2019 the board agreed to establish a subcommittee known as the Governance Committee. Its focus is to support the board on governance activities in particular effective succession planning and renewal for the board and board committees as well as review and recommendations around the Dementia Australia ambassador program.

Thank you to the following committee members: Tony Newman, Neil Samuel, Ian Knight, Paul Robertson, Maree McCabe, William Bass, Greg Fraser, Ian Knight, Maree McCabe, Geoff Knuckey (independent)*, Amanda Quealy, Greg Fraser and Jenna Dennison.

*Dementia Australia has a history of seeking independent expertise for advice on specific areas to the board and sub committees. Geoff Knuckey has offered his guidance in the area of audit and risk management for the past three years Mr Knuckey had a 32-year career with major accounting firm Ernst & Young. He is currently chair or non-executive director of six private-sector companies and is also chair or independent member of the audit and risk committees for twelve government departments. Geoff is a Fellow of the Institute of Chartered Accountants in Australia and has been a Registered Company Auditor since 1995. He is Graduate Member of the Australian Institute of Company Directors, a member of the Institute of Internal Auditors and a member of the Australian Institute of Management.



A Walk to Remember

Board Director Jenna Dennison took a leave of absence from the board from July to November 2018 to undertake 'A Walk to Remember'. Over 145 days Jenna and her partner Neil walked 4,264kms along the Pacific Crest Trail from Canada to Mexico raising \$12,000 for Dementia Australia.

As part of the hike, Jenna and Neil walked through the Cascades, the Sierras and the Californian deserts. The walk also included cliff climbs, camping in snow blizzards and being off the grid for the majority of the trip.

Our organisation

Executive directors



Maree McCabe
Chief Executive Officer, Dementia Australia



David Frost
Executive Director Finance and Asset Management – until April 2019



Anthony Boffa
Executive Director Finance and Asset Management – from May 2019



Kate Morton
Executive Director Strategy and Business Improvement – until May 2019



Anneliese Coghlan
Executive Director People and Culture



Susan McCarthy
Executive Director Client Services



Leanne Emerson
Executive Director Business Development



Dr Kaele Stokes
Executive Director Consumer Engagement, Policy and Research

Our organisation

Our people

Dementia Australia's People and Culture team works with teams across the organisation to help recruit, retain and develop staff. It provides specialist human resource and industrial relations advice to executives, managers and team leaders, and advises staff on employment-related issues. The People and Culture team is also responsible for supporting the recruitment, engagement and coordination of volunteer involvement across all teams in the organisation. The team's programs align with the Strategic Direction Enablers.

Throughout 2018 and 2019, work continued to unify functions across the organisation. Members of the People and Culture team have undertaken projects such as coordinating and implementing changes in organisational structure, with a focus on aligning roles to be consistent nationally and reviewing all roles to ensure current and objective award level evaluation has been conducted and recorded and pay rates are correct.

We have also:

- Developed and implemented a national online exit interview portal.
- Supported the launch of DAISI, the staff intranet, by building our own content and collaborating closely with the IT team and internal communications to ensure staff directory details were comprehensive and correct.

We continued to refine and add to our list of documented internal processes and protocols including:

- The national induction procedure.
- A central recruitment function.
- Onboarding and offboarding procedures that need to flex frequently in order to reflect improvements to process in our partnering teams such as IT and Facilities.

The introduction of comprehensive digital communication and video conferencing tools has continued to enable Dementia Australia to truly be national, inclusive and no longer limited by geographical boundaries. With the People and Culture team taking ownership of coordinating staff meeting events both locally and nationally, this has ensured that the leadership team has consistent and varied ways of communicating with staff.

Dementia Australia now has teams dispersed across the nation and across time zones. There are some who work in traditional office spaces, while many others work in shared offices or remotely – all to enable the organisation to flexibly reach as many of the more than 447,000 people impacted by dementia as possible.

The board, CEO and executive directors wish to acknowledge and extend their gratitude to all Dementia Australia staff for their patience and willingness to work with and through the changes, and, most importantly, not missing a beat when it comes to supporting and advocating for the many thousands of people living with dementia, their families and carers.

Staff	2018–2019
WA	13
SA	43
NT	10
QLD	82
Tas	45
NSW	157
Vic	158
ACT	40
Average tenure	3.94 years

Our organisation

Our volunteers

We acknowledge the hard work and dedication of our volunteers across the nation. Volunteers are an integral part of the organisation and the contributions they make in all areas are appreciated and valued. We are truly grateful for their support.

Throughout 2018–2019, around 900 volunteers assisted in a wide variety of ways, supporting Dementia Australia through administrative and Client Services support, community engagement and many more activities that shape our services. These generous people can be found working with Dementia Australia staff across metropolitan and regional communities.

These ongoing and vital roles exist in many locations and include:

- assistance with and facilitation of social support groups such as Memory Lane Cafes
- attending community events
- administrative support in our offices and libraries
- helping prepare information kits.

Roles vary across the nation, with some states having highly embedded client support volunteering programs, making the range of volunteering activities in some locations more extensive than is listed above.

In addition to the regular and ongoing roles, volunteers have been absolutely integral to fundraising events such as Collection Day, Blackmores Sydney Running Festival and the Tulip Time festival, the Dementia Australia National Consumer Summit, Dementia Awareness Month forums and most significantly to our flagship fundraising event, the Memory Walk & Jog series. These events have raised vital funds for Dementia Australia as well as increasing community awareness. Much of the success of the Memory Walk & Jog series has been due to our hardworking volunteers who enthusiastically turned up in the early hours of the morning, rain hail or shine, always with a smile on their face, to ensure a safe and successful event. At these events volunteers assist with:

- the registration desk
- raffle ticket selling
- way finding
- sweep riders
- Al the Elephant
- information booth
- start and finish line marshalling.

We are always open to innovative opportunities to utilise volunteer assistance to complement the work of all Dementia Australia teams. Dementia Australia sincerely thanks all volunteers for their commitment, enthusiasm, and willingness to take on new volunteering initiatives.

National volunteer numbers
675 event volunteers
225 ongoing volunteers
Total 900 volunteers

Our organisation

Client Services

Dementia Australia's Client Services programs are aligned with all three of the Strategic Direction Priorities: timely diagnosis and support, quality care and reducing discrimination.

National services and programs

The National Dementia Helpline, 1800 100 500, is a telephone information and support service. The service can be accessed by email or webchat from 9am to 5pm Monday to Friday excluding public holidays. A message service is available so if you call outside operating hours, we'll call you back the next working day.

The National Dementia Helpline provides:

- information about dementia and memory loss
- information on how you may be able to reduce the risk of getting dementia
- information about government support services (including My Aged Care, the Carer Gateway and Centrelink)
- information about services in your area
- emotional support to help you manage the impact of dementia

The helpline service is private, confidential and for anyone interested in dementia, concerned about their memory, anybody who has been diagnosed with dementia or who works with people with dementia, or anybody who simply wants to know more.

Help sheets

Our help sheets provide advice and practical strategies on a range of commonly raised dementia topics.

Help sheets are available for free on the Dementia Australia website as PDF files which can be read online, downloaded or printed. There are more than 130 Help Sheets with the most popular files available in more than 30 languages.

Counselling

Dementia Australia provides a counselling service for people with dementia, their carers, families and friends to discuss any issues related to dementia. Dementia Australia counsellors are skilled professionals who are trained to provide support, advice and practical assistance.

Living With Dementia Series

The Living With Dementia Series provides people in the early stages of dementia, along with their families and carers, with a program of information, advice and peer support to help them to come to terms with their condition and plan for the future.



Dementia Australia clients and carers danced together at the 2018 client and carer end-of-year party held at Nerang Bicentennial Hall, Gold Coast, Queensland.

National Younger Onset Dementia Key Worker Program

This program provides customised information and support, to improve the quality of life for people with younger onset dementia.

Carer support groups

Our carer support groups provide an environment in which carers of people with dementia can discuss issues with other people in a similar situation.

Family carer education

Our highly skilled educators offer specialised dementia education, sessions, and programs for family members and carers of people living with dementia.

Public awareness activities

Throughout the year Dementia Australia delivers a range of seminars and other presentations to the community on memory loss and dementia-related subjects.

Peer support

Dementia Alliance International offer peer-to-peer support programs to people with dementia so that they can access small groups of people with a diagnosis of a dementia.

Our organisation

Client Services



Visitors from St Lukes ElderCare, Singapore enjoyed morning tea with clients at Dementia Australia Gold Coast respite facility; Rosemary House. The group from St Lukes ElderCare visited Rosemary House in September 2018 to learn more about community and residential care in Australia.

In 2018–2019 the Client Services team has achieved significant growth in services, the introduction of new partnerships and the first submission to the National Dementia Support Program tender as a single, national, peak body.

Highlights include:

- The merging of the Australian Frontotemporal Dementia Association frontotemporal dementia carer support groups to Dementia Australia under the agreement of a new memorandum of understanding that commenced on 1 November 2018.
- Team member conference abstracts accepted for the Alzheimer's Disease International Conference, Chicago, July 2018 and the 11th International Conference on Frontotemporal Dementia Conference, Sydney, November 2018. The papers shared the learnings of a very successful frontotemporal dementia carer support service model, originally delivered in Geelong and now a model integrated around Australia.
- Another year of younger onset dementia funding was secured to assist the program's transition to the NDIS and secured two national Information Linkages and Capacity Building younger onset dementia grants totaling \$1.5 million.
- A single national dementia library service was developed.

- Dementia Australia was recognised as a provider for the National Disability Insurance Scheme.
- A national client services contracts and milestone register was developed and implemented.
- The tender submission for the deliverables under the National Dementia Support Program was led by the Client Services team with extensive collaboration within and across all of Dementia Australia's departments.

Snapshot from around the country:

- In the Australian Capital Territory an LGBTIQ Inclusive Practice review was completed, and a successful auction of works of art created by people living with dementia was held. These art works are now on display at many different public places in the ACT such as the Tradies Club, funded and conducted by the AIDS Action Council ACT between July and September 2018.
- In New South Wales the first government-funded EDIE™ for Family Carers Program was launched with three-year funding from the NSW Department of Family and Communities.
- In the Northern Territory a local NT ILC grant was secured to deliver younger onset dementia activities.
- In Queensland Eden validation for Gold Coast respite centres was secured. The team is on track

Key figures for Client Services 2018–2019

47,299	Contacts were made to the National Dementia Helpline
34,577	People who attended community education, information and awareness sessions.
6,166	People living with dementia and carers who attended support group sessions.
2,201	Support sessions delivered.
3,342	Families and carers who attended carer education sessions.
1,794	Attended early intervention services, such as the Living with Dementia program.
1,549, 801	Visits to the Dementia Australia website.
843,353	Help Sheets downloaded.

* Founded by Dr William Thomas, the Eden Alternative Philosophy provides a framework to provide person centered care.

** The Nightingale Program is a palliative model of care, provided by specialist nurses, under the auspices of Dementia Australia, Adelaide, South Australia. It provides strategies and advice to support people living with dementia, their families and care providers with a focus on promoting choice and well being during all stages of diagnosis. The program is funded by The Rosemary Foundation for Memory Support.

to achieve the full validated Eden Alternative Organisation*, which is expected to happen in 2019 and will make Dementia Australia the only community care organisation validated in Queensland.

- In South Australia funding was secured for three years to continue and expand the much-needed Nightingale Nurse program**.
- In Tasmania our North West premises was moved from Ulverstone to Devonport providing the opportunity to expand the team to provide more services across the North West region of Tasmania.
- In Victoria the specialist dementia clinician role was developed which focuses on supporting people living with other forms of dementia and creating dementia-specific support groups. Staff developed and presented 'Dementia and Parkinsons' and 'Down Syndrome and Dementia' presentations for particular groups and we are looking to expand these programs nationally.

- The Western Australian team has increased from one staff member to seven in less than a year and has continued to deliver services and expand Dementia Australia's profile all over the state.
- Most importantly, the Client Services team provided much-needed support, information and education to tens of thousands of people of all ages living with all forms of dementia, their families and carers.

There has been an increase in the level of satisfaction recorded in the Younger Onset Dementia Key Worker Program

- 92 per cent of clients were satisfied with their Key Worker.
- 82 per cent have a better understanding of dementia and have the help and supports they need (up from 75 per cent last year).
- 77 per cent said they had social contact with people other than family/paid staff and participate in activities out of the house at least once a week. This is compared to only 36 per cent of participants in the NDIS who stated that were actively involved in community, cultural or religious groups in the past year.
- When asked whether they agreed with the statement 'I would recommend support from Dementia Australia to another person in my situation', 77 per cent said they completely agreed.

Our organisation

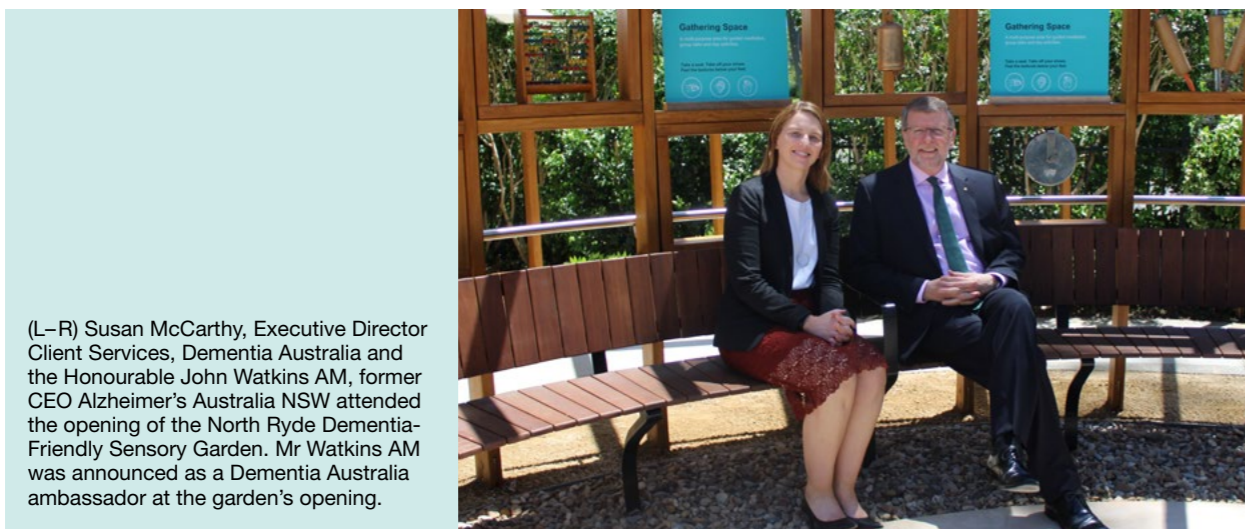
Consumer engagement, policy and research



Susan McCarthy, Executive Director Client Services and Lucille Bloch, former Alzheimer's Australia NSW Board Director, cut the ribbon to officially open the Dementia-Friendly Sensory Garden at Dementia Australia's North Ryde office, November 2018.



Features of the Dementia-Friendly Sensory Garden in North Ryde designed to create a therapeutic space for people living with dementia, their families and carers.



(L-R) Susan McCarthy, Executive Director Client Services, Dementia Australia and the Honourable John Watkins AM, former CEO Alzheimer's Australia NSW attended the opening of the North Ryde Dementia-Friendly Sensory Garden. Mr Watkins AM was announced as a Dementia Australia ambassador at the garden's opening.

Dementia Australia's consumer engagement, policy and research teams elevate the voices and experiences of people impacted by dementia through policy, system design, service delivery and research aligned with all three of the Strategic Direction Priorities; timely diagnosis and support, quality care and reducing discrimination.

Responding to existing and emerging challenges which people living with dementia, their families and carers face are the key objectives. These are achieved through the policy, advocacy and research agendas. An important task is to promote the voices of people living with dementia and carers to the policy makers who influence legislation to improve the quality of life for all those living with dementia, their families and carers.

Dementia Australia Quality Care Initiative – National Consumer Summit

A key strategic priority for Dementia Australia in the next five years is to work with people living with dementia, their families and carers to define standards of quality dementia care, and work with government and industry to promote the adoption of those standards.

To achieve this objective, we established the Dementia Australia Quality Care Initiative, an organisation-wide project group which will work to ensure the need for quality in dementia care is articulated, understood and applied across the sector, with measurable outcomes.

Dementia Australia seeks to clearly define what quality dementia care is and embed these principles consistently into practice in partnership with the industry, regulators, people living with dementia, their families and carers, and link them with the new Aged Care Quality Standards which will come into effect on 1 July 2019.

In preparation for the Consumer Summit on Quality Dementia Care was held in Canberra on Wednesday, 26 June 2019. The development and planning consisted of three months travelling around Australia, listening to people with dementia and carers articulate what quality aged care to people

living with dementia can be and should be.

The Consumer Engagement team facilitated 25 face-to-face focus groups and six video conference, attracting people from every state and territory across metropolitan, regional and remote Australia. The 137 participants came from locations as far afield as Cairns in Queensland, Port Lincoln in South Australia and Darwin in the Northern Territory.

This national consultation enabled Dementia Australia to hear the stories of a diverse range of people living with dementia, as well as current and former carers.

The results of the consultations were put forward at the summit as a set of recommendations against each of the eight Aged Care Quality Standards in a draft communique.

At the summit, Dementia Advocates ratified the communique written from the perspective of people with lived experience. Entitled **Our Solution: Quality Care for People Living with Dementia**, the communique outlines what quality aged care means to people living with dementia, their families and carers.



Members of the Dementia Australia Advisory Committee (DAAC) together with Maree McCabe, CEO, Dementia Australia (third from left) and Greg Fraser, Board Director, Dementia Australia (far right) at Dementia Australia's National Consumer Summit held in Canberra, June 2019. DAAC members include (L-R) Kebyn Morris, Bobby Redman, Eileen Taylor, Val Schache and Dennis Frost. Photo: Andrew Taylor

Recommendations within the communique include: dementia-specific training; decision-making centred on the person with dementia; flexibility and continuity of care; meaningful activities to maintain a sense of community connectedness; and



A Trek to Remember

A group of fundraisers, including Amanda Allen, National Manager Planning & Performance, Dementia Australia, undertook a trek to Everest Base Camp in October 2018 to raise more than \$50,000 for Dementia Australia.

Our organisation

Consumer engagement, policy and research

Other advocates appearing before the Royal Commission during the 2018–2019 reporting period include:

- February (Adelaide) – Barrie Anderson cited staffing levels in residential aged care as a critical area that needed attention and highlighted the need for specialist training for aged care workers.
- March (Adelaide) – Lynda Henderson and Veda Meneghetti – Lynda spoke about her experience caring for Veda, and described the six-month wait for the delivery of higher-needs home care. During this time Veda suffered immense fear and anxiety as well as sleeplessness.
- May (Sydney) – Trevor Crosby described his experience of being diagnosed with dementia, and the need for supports for carers as well as people with the diagnosis. Trevor also raised the need for research, and a cure.



(L–R) Liz Keating, Facilitator, Centre for Dementia Learning, Tara McDonald, Dementia Advocate, Maree McCabe, CEO, Dementia Australia, Senator Derryn Hinch, Donna Mercier, Customer Service & Reports Officer, Centre for Dementia Learning together during Senator Hinch’s visit to Dementia Australia’s Parkville office.



Maree McCabe, CEO, Dementia Australia, was interviewed by the media before appearing as a witness at the Royal Commission into Aged Care Quality and Safety in Adelaide, February 2019.

transparent accountability for quality dementia care with key performance indicators that are specific, clear and measurable. Dementia Australia will deliver the communicate to Senator the Honourable Richard Colbeck, Minister for Aged Care and Senior Australians, early in July. Delivering the communicate marks the first milestone in Dementia Australia’s Quality Care Initiative.

The full communicate, **Our Solution: Quality Care for People Living with Dementia**, is available at dementia.org.au/files/documents/DAConsumer-Summit-Communique.pdf

Royal Commission into Aged Care Quality and Safety

Following the announcement of the Royal Commission into Aged care Quality and Safety in September 2018 and the appointment of the Commissioners, hearings began in Adelaide in February 2019.

During the past 12 months advocates have informed our submission to the commission’s terms of reference, provided witness statements and shared stories at the hearings, roundtables and community forums. Six advocates appeared as witnesses. Ten advocates attended the Bankstown forum. Elaine Todd spoke at the Wollongong community forum and Kirsty Cappellano appeared

at the Adelaide community forum, while James Nelson attended a Royal Commission roundtable in March and Rae Telfer attended a workshop by the Commissioner for Senior Victorians, Gerard Mansour, in April.

Maree McCabe, CEO of Dementia Australia, appeared as a witness in Adelaide. Dementia Australia’s submission called for dementia to become core business for the aged care sector – not just in principle but in practice. It also called for legislative changes to address the over-use and inappropriate use of medications and restraints, a focus on quality dementia care through the new Aged Care Quality Standards, and a focus on a call for mandatory dementia training for the entire aged care workforce.

Dementia Australia’s Honorary Medical Advisor, Professor Henry Brodaty AO, appeared at the May hearing held in Sydney. Among the topics he discussed were the need for a service pathway following a dementia diagnosis and the importance of person-centred care in residential care facilities.

Dementia Advocate Kate Swaffer, Chair and CEO of Dementia Alliance International, spoke about her diagnosis of early onset dementia, the stigma she and others have faced, the importance of early diagnosis and the benefits of implementing good design principles in aged care facilities.



Attendees of Dementia Australia’s November 2018 New South Wales Parliamentary Friends of Dementia event listened to a series of speakers as at Parliament House, Sydney. Photo: Adam Hollingworth

Our organisation

Consumer engagement, policy and research

Major national policy submissions and papers

During the 2018–2019 financial year, Dementia Australia developed numerous national and state policy submissions and papers responding to the complex health, disability and aged care environment, including:

May 2019

Dementia Australia response to the proposal for a new residential aged care funding model

Dementia Australia response to Voluntary Assisted Dying in Western Australia

April 2019

Dementia Australia response to Queensland aged care and end of life inquiry

Senate Committee questions on notice

March 2019

Australian Digital Health Agency: Digital Medicines Program Blueprint

2019–2020 federal pre-budget submission

2019–2020 state and territory pre-budget submissions

February 2019

Streamlined Consumer Assessment for Aged Care 2019–2020 New South Wales pre-budget submission

January 2019

Transport for New South Wales Older Persons – Transport and Mobility Plan 2018–2022

2019–2020 Pre-budget Submission

December 2018

Supplementary Inquiry into effectiveness of aged care quality

October 2018

Aged Care Amendment Staffing Ratio Disclosure Bill 2018

Draft Charter of Aged Care Rights

August 2018

Consultation on Australian Medical Research and Innovation Priorities for 2018–2021

Government relations

Advocacy is a key driver of the delivery of the strategic plan and its success. The proposed advocacy strategy for the plan period consists of two main elements:

- **Continued response** to contemporary, relevant issues for people living with dementia, their families and carers, with messaging focusing on the fact that dementia is not yet core business for the majority of providers and consumer-directed market drivers are not yet sophisticated enough to enforce service excellence.
- A **proactive advocacy campaign** that focuses on the three priority areas articulated in Dementia Australia's strategic plan and positions Dementia Australia as leaders in driving systemic change.
- Timely campaigns and activity for budgets and elections in federal, state and territory calendars.

Senator Anne Urquhart moved a motion in Federal Parliament to remind MPs to consider the needs of people living with dementia over the festive season.

It's very encouraging to hear dementia being spoken about in this way in our Federal Parliament.

Parliamentary Friends of Dementia events

Dementia Australia delivers a Parliamentary Friends of Dementia program to regularly engage with all members of all state and federal parliaments.

In November 2018, we hosted parliamentary friends events in federal parliament, South Australian and New South Wales parliaments to launch Dementia Australia's Strategic Direction to key MPs and Senators.

At the federal event speakers were Professor Graeme Samuel AC, Chair Dementia Australia, Parliamentary Friends of Dementia co-convenors Member for Bowman Andrew Laming MP and Senator Helen Polley, Shadow Assistant Minister for Ageing, and Dementia Advocates Bryan and Conny Gard and Kevyn Morris. In addition the event recognised and acknowledged the formal signing of a memorandum of understanding with Dementia Alliance International. This was the organisation's first memorandum with a national dementia peak body, which signals an exciting development for both bodies.

In South Australia speakers were Dr Kaele Stokes, Executive Director Consumer Engagement, Policy and Research Dementia Australia, Parliamentary Friends of Dementia co-convenors Sam Duluk MP,

Member for Waite and Nat Cook MP, Shadow Minister for Human Services, Member for Hurtle Vale, with guest speaker the Hon Stephen Wade, Minister for Health. Dementia Advocate speakers were Ian Yates, Jennie and Amy Aikman.

In NSW speakers were Maree McCabe, Parliamentary Friends of Dementia co-convenors, Leslie Williams MP, Parliamentary Secretary for Regional and Rural Health, Member for Port Macquarie and Kate Washington MP, Shadow Minister for Early Childhood Education, and Shadow Minister for the Hunter, Member for Port Stephens. Dementia advocate speakers were Linda Bryan and Trevor Crosby.

Where face to face events were not conducted engagement included Dementia Australia magazines, e-news and media releases distributed to all parliamentarians around Australia; invitations to parliamentarians to attend Memory Walk & Jog events; and invitations to other significant events and meetings during sitting weeks or at Dementia Australia offices. Wherever possible Dementia Advocates are included in all meetings.

Consumer engagement

The Consumer Engagement team works together with Dementia Advocates (people living with dementia and their carers) to raise awareness of dementia, to tackle stigma and discrimination, and to influence decision-makers in government and service providers.

The Dementia Advocates Program supports people living with dementia, carers and former carers, who have a genuine interest in wanting to make a difference, to be involved in meaningful advocacy activities.

Activities include:

- Providing profiles and stories for Dementia Australia's publications including the national member magazine, social media, e-newsletter; participating in briefings with state and federal politicians including attending Parliamentary Friends of Dementia events; providing input for Dementia Australia's response to an Australian Government discussion proposal aimed at streamlining the current assessment process for aged care; providing witness statements and appearing at the Royal Commission into Aged Care Quality and Safety.
- Providing input into Dementia Australia's response to three diversity action plans: CALD, LGBTI, and Aboriginal and Torres Strait Islander groups; reviewing the client services new monitoring and evaluation framework; sharing their experience

with members of the banking sector to support Dementia Australia's project aimed at improving banking experiences for people living with dementia; participating in consultations to investigate options and make recommendations to improve the coordination of brain donation in Australia; reviewing new Dementia Australia 'Safe Walking' online resource; panel members on Dementia Australia interview panels; featuring in Relationships Australia's National Neighbour Day campaign initiative; participating in feedback session with Department of Health on new My Aged Care website.

- Regularly speaking to the media.

Dementia Awareness Month

Advocates played a key role in the success of Dementia Awareness Month, held in September 2018.

Throughout September, Dementia advocates from around Australia were involved as speakers and on panel discussions for the national Small Actions Big Difference roadshow, attended events, helped to organise regional events and were interviewed for media stories.

The roadshow then traveled to Darwin, Hobart, Sydney, Melbourne, Perth, Adelaide and Canberra. These events were supported by both our advocates and ambassadors.

Advocates in the media

The Consumer Engagement team supported Dementia Advocates in responding to multiple media requests. Highlights include:

- Sydney Morning Herald feature on research into frontotemporal degeneration and daydreams
- ABC RN program 'All In The Mind' looking at frontotemporal degeneration sleep and daydreaming
- Interviews on Channel 9 and ABC radio following the announcement of the Dementia Australia Research Foundation and Yulgilbar Alzheimer's Research Program inaugural \$1 million Innovation Grant
- ABC 7.30 to discuss the issues people living with dementia face with federally-subsidised home care packages
- 9 News Adelaide coverage on funding for a trial to improve services for people with young onset dementia
- International Women's Day social media campaign
- ABC news online about the unexpected challenges with younger onset dementia and promoting Dementia Australia resources booklet

Our organisation

Consumer engagement, policy and research



Jessica Marshall, PhD Candidate, Baker Institute and the Florey Neuroscience and Mental Institute, won the 2017 Scientia Professor Henry Brodaty PhD Scholarship. Thanks to the scholarship Ms Marshall spent 2018 researching into the effects of overexpressing Heat Shock Protein 72 on the cognitive decline and disease progression of Alzheimer's disease, as a potential therapy.



Dr Michele Callisaya, Postdoctoral Research Fellow, Monash University and University of Tasmania, winner of the 2018 Dementia Advocates' Award. Dr Callisaya will use her award funding for a project focused on a cognitive-mobility stress test to detect mild cognitive impairment and the risk of developing into dementia.

to better support people living with dementia who are LGBTI

- An article in the Sunday Telegraph on Alzheimer's disease and Macquarie University scientists growing brains for dementia cure.

Research

As well as funding high-quality, innovative, Australian dementia research, through the Dementia Australia Research Foundation, the research team also coordinates Dementia Australia's involvement in research more broadly, through participation in various research initiatives and projects.

Some key research initiatives include:

- Supporting the administration of the National Health and Medical Research Council, National Institute for Dementia Research.
- Governance and Executive Committee representation on the Cognitive Decline Partnership Centre.
- Membership of the Melbourne Ageing Research Collaboration.

NHMRC National Institute for Dementia Research

The NHMRC National Institute for Dementia Research is an initiative of the National Health and Medical Research Council. The institute is governed by a board of directors and Dementia Australia provides administrative support. The institute is based in Canberra, ACT, and is a key element of the

Australian Government's \$200 million investment to boost dementia research, which targets, coordinates and translates the expansion of dementia research in Australia.

In 2018 the institute reviewed its Strategic Roadmap for Dementia Research and Translation, which outlines the priorities for dementia research in Australia and the vision, objectives and principles that underpin the institute's activities. The priority areas highlighted in the revised Roadmap are:

- Diagnosis and prevention
- New targets, new technologies, new drug candidates
- Improving quality of life and provision of care
- Dementia and Aboriginal and Torres Strait Islander Australians
- Retaining and building Australia's dementia research capacity.

Dementia Australia Research Foundation Grants Program

The Dementia Australia Research Foundation provides funding to Australian researchers with areas of focus relating to the diagnosis, treatment, care, prevention, and delay of dementia.

The foundation funds researchers at any stage of their career but there is a focus on capacity-building of new and early career researchers. In 2018, the foundation awarded grants to 20 individuals to undertake research into dementia. This delivered

more than \$3 million in funding directly to researchers across 20 project grants.

The highlight of the year was an announcement by the Dementia Australia Research Foundation and Yulgilbar Alzheimer's Research Program that a total of three grants would be awarded for research ideas that advance dementia research.

The inaugural award provided for a \$1 million grant to be bestowed on Professor Perminder Sachdev, of UNSW Sydney's Centre for Healthy Brain Ageing, while two new \$500,000 grants have been awarded to Professor Simon Bell at the Centre for Medicine Use and Safety, Faculty of Pharmacy and Pharmaceutical Sciences, Monash University, and Professor Chennupati Jagadish AC from the Australian National University.

NHMRC Cognitive Decline Partnership Centre

Although the NHMRC Cognitive Decline Partnership Centre is due to conclude in December 2019 due to the cessation of funding, Dementia Australia continues its strong relationship with the centre, as one of four contributing organisations. The centre

aims to improve the care of people living with dementia and carers by providing better evidence and information about best practice in dementia care.

The centre facilitates more than 30 research activities across Australia and brings together the expertise of researchers, industry, government, clinicians and consumers to address the complex issues of cognitive decline. The centre is unique in that people living with dementia, their families and carers are involved at every stage of the research process. The centre is a great example of sustained and active public engagement in research and is a huge credit to all the advocates who have been involved in the centre over many years.

With the completion of a number of projects, the centre is translating its research outcomes into practice. By June 2018, activities supported by the centre had produced more than 1,200 outputs including published academic papers, reports, conference presentations and workshops. The centre's advocate group has played a vital role in promoting key messages, having presented its work at both national and international conferences throughout the year.



Dr Cindy Jones, Associate Professor of Behavioral Sciences, Bond University was awarded a \$75,000 Dementia Australia Research Foundation Project Grant. She will use the funding to develop the facilitation of care environments that are supportive of the verbalisation and expression of sexual preference, need and desire by people living with dementia.

Our organisation

Business development

Dementia Australia's Business Development team creates short- and long-term value for the organisation, people living with dementia, their families and carers. This is achieved through developing and bringing in new markets, partners, products, technologies, and services, with the aim of creating additional income to achieve financial sustainability. These aims are in line with all three of the Strategic Direction priorities; timely diagnosis and support, quality care and reducing discrimination.

Business development has focused on:

- executing a business and financial model for our commercial enterprise across Dementia Australia
- growing the Centre for Dementia Learning to elevate our education and build capacity across the sectors
- creating new products and services, including expanding our work in cutting edge innovation and technology; and building relationships and partnerships across community, government, trusts and foundations, and corporate industries
- attracting large organisations to partner with us and to invest in our products and services.

Business Development highlights from the last 12 months include:

Partnerships

More than 50 partnerships were established with businesses, councils, primary health networks, and a wide variety of other community organisations. Extensive partnerships have been established with organisations and councils to support and expand our Dementia Friends program, including Queensland Police Service, Leading Age Services Australia, Australian Strength and Conditioning Association, Kaplan Professional, Board of Melbourne, Brisbane Airport, Victoria Police, Lendlease, Priceline Pharmacies, Australia Post, Heathcote Dementia Village, Commonwealth Bank, Qantas and Darwin Airport.

The partnership with the Queensland Police Service is a result of their commitment to working with non government agencies and community groups to maximise community safety and improve policing responses for vulnerable persons. This includes welcoming opportunities to better engage with organisations such as Dementia Australia to build the capacity of the Queensland Police Service to understand and assist people with disabilities, their

families and carers. The Queensland Police Service has indicated its intention to throw its full support behind the Dementia Friends initiative, with the potential for its messages to reach up to 11,000 members.

Marketing

This year, we developed a Marketing team structure that will comprise the specialised skills Dementia Australia needs across marketing strategy, campaigns, digital, web and events.

Dementia Awareness Month was a huge success, with the theme 'Small Actions. Big Difference'. We worked with our ambassadors to generate an advertising campaign calling on the public to get involved in Dementia Awareness Month and become a Dementia Friend.

A national speaking tour, aligned with the Dementia Friends campaign, visited each capital city during the month with each event featuring a presentation from a research scientist and a panel discussion involving our ambassadors and advocates. Around 40 local events, ranging from morning teas to large seminars, were hosted at this time, with a range of promotional materials and tactics developed.

The brand project kicked off, an important next step for Dementia Australia's evolution. The brand project is about understanding and articulating who we are, and developing a strategy to create an emotional connection with Dementia Australia. This project has multiple phases and will continue in to the next financial year.

We launched a social media campaign on 18 March with the aim of continuing to grow our Dementia Friends community – successfully achieving our goal of 20,000 Dementia Friends by June 2019.

Our organisation

Centre for Dementia Learning

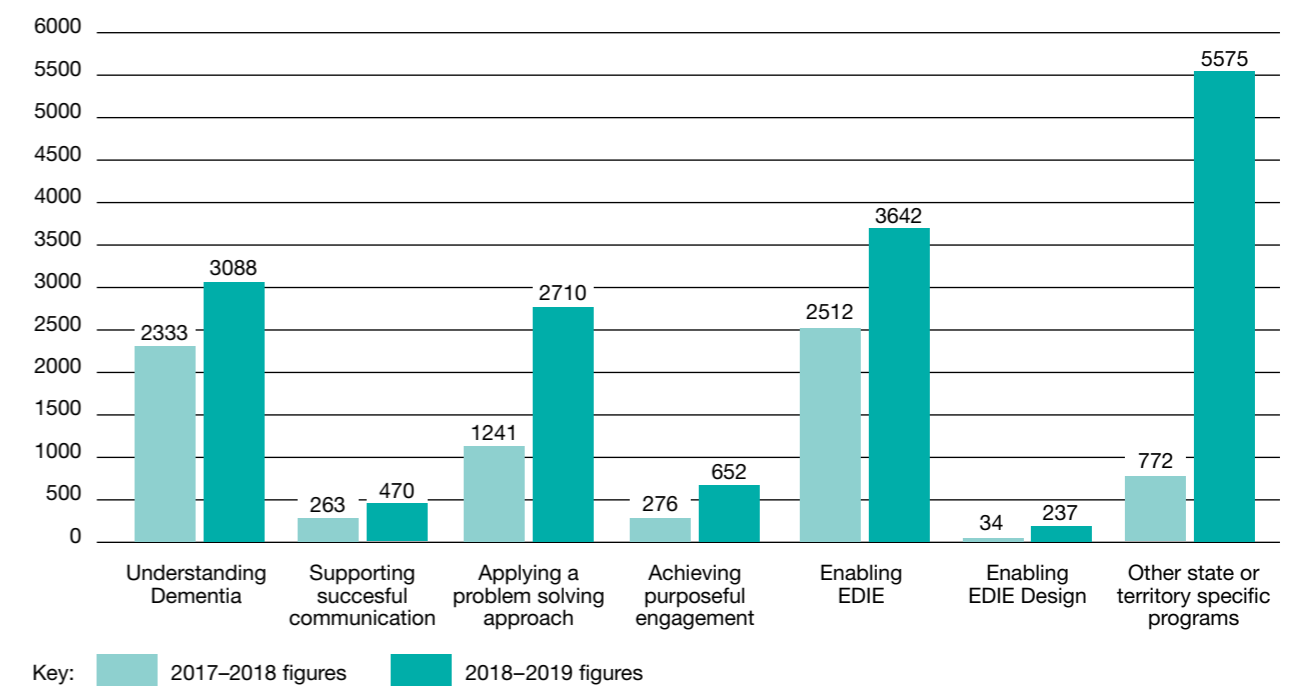
The aims of Dementia Australia's Centre for Dementia Learning are to define standards in quality support and care and build the capacity of the health and aged care sector to achieve clear, measurable outcomes that enable people living with dementia to live engaged and empowered lives. Dementia Australia works to ensure all those living with dementia receive quality support and care which maximises their quality of life through building the capacity of aged care providers.

The centre has four objectives for the comprehensive suite of evidence-based learning and consultancy services it provides:

- Develop career pathways for those wishing to become leaders in dementia practice
- Provide ongoing opportunities for people to develop dementia knowledge and skills
- Create unique learning experiences which touch, move and inspire participants to change their attitude and consequently their behaviour
- Transform the culture of care through consultancy work with providers.

The Centre for Dementia Learning is aligned with all three of the Strategic Direction Priorities; timely diagnosis and support, quality care and reducing discrimination.

Centre for Dementia Learning Workshop Participants Financial years 2017–2018 and 2018–2019



Highlights of the year include:

EDIE™ on a roll

A focus of the 2018–2019 financial year has been the continued national roll out of EDIE (Educational Dementia Immersive Experience™). This world-leading and innovative virtual reality tool used in the Enabling Edie Workshops continues to generate national and international interest in our education programs.

The licensing of Enabling EDIE Workshops to Singapore and the Czech Republic was finalised in 2019 with staff conducting train the trainer sessions in both countries.

Our organisation

Centre for Dementia Learning

The Dementia Australia Northern Territory Roadshow July 2018

A standout activity for the year was the Northern Territory roadshow to ensure all communities are aware of and have access to information about dementia.

Travelling 4000 kilometres and visiting remote Northern Territory centres including Hermannsburg, Alice Springs, Tennant Creek and Katherine, the roadshow exhibited at the Alice Springs, Tennant Creek and Katherine shows and concluded with a three-day exhibition at the Royal Darwin Show.

Over 600 people visited the Dementia Australia stand between 6 and 28 July 2018 of which over 66 per cent were given leaflets and help sheets about dementia.

Dementia Australia appreciates the support given by Neil Scriven of Scriven Exploration.



Judy Kay, Social Support Facilitator, Dementia Australia and Klem Hedenig, Education Officer, Dementia Australia attended the 2018 Royal Darwin Show as part of the 2018 Dementia Australia Northern Territory Roadshow.

	Alice Springs Show	Tennant Creek Show	Katherine Show	Royal Darwin Show	Totals
Date	6–7 July	13 July	20–21 July	26–28 July	
Visits (people)	107	52	153	289	601
Verbal info	70	37	64	173	344
Leaflets/help sheets	68	38	60	230	396
Merchandise	57	14	81	260	108
Just looking	13	11	39	66	129

Supporting industry and government

During this reporting period the Centre for Dementia Learning had the opportunity to work with My Aged Care, and deliver 27 Enabling EDIE™ sessions (1.5 hour) over nine full days to over 400 staff across the agency's sites in Box Hill, Wollongong and the Gold Coast.

We have also been delivering Understanding Dementia programs to 658 staff across 27 Lendlease retirement villages and will develop a bespoke program which we will deliver to all 71 Lendlease sites.



Representatives from the Royal Commission into Aged Care Quality and Safety (RCACQS) visited Dementia Australia's Parkville office in March 2019 for a demonstration of our technology designed to improve the lives of people living with dementia. (L–R) Paul Bolster, Counsel Assisting, RCACQS, Peter Gray QC, Senior Counsel Assisting, RCACQS, Commissioner Lynelle Briggs AO, Commissioner, RCACQS, Maree McCabe, CEO, Dementia Australia, Dr David Sykes, Director, Centre for Dementia Learning Dementia Australia, Dr Tanya Petrovich, Manager Business Innovation, Centre for Dementia Learning Dementia Australia.

Dementia Australia would like to acknowledge the support received from the Priceline Sisterhood Foundation, which has been a key supporter.



A group of Priceline Pharmacy staff were recognised by Dementia Australia in March 2019 after taking steps towards making their pharmacies dementia-friendly. The Priceline Sisterhood Foundation has been a key supporter of Dementia Australia during the establishment of the Centre for Dementia Learning.

Dementia Training Australia

Dementia Australia continues as a member of the Dementia Training Australia consortium. Dementia Training Australia is funded by the Australian Government to provide nationwide education on the support and care of people living with dementia. Dementia Training Australia offers a range of courses and resources including e-learning, workshops, webinars and nationally accredited vocational training. The vocational training is delivered by Dementia Australia to 6,500 people every year through the Dementia Essentials courses.

The consortium is made up of Dementia Australia and five universities – the University of Wollongong, La Trobe University, Queensland University of Technology, Wicking Dementia Research and Education Centre (University of Tasmania) and the University of Western Australia

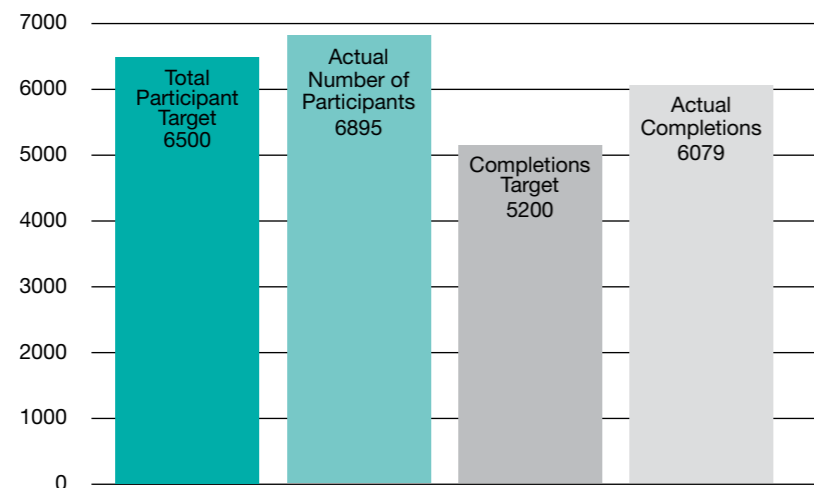
Our organisation

Centre for Dementia Learning

The Centre for Dementia Learning was also successful in securing an extension of an additional contract with Dementia Training Australia until 30 June 2021, to develop a training program for staff at the Australian Aged Care Quality Agency. The development of tailored training packages is an encouraging extension of Dementia Australia's role as a consortium member of Dementia Training Australia. There has been a significant growth in the work directed from Dementia Training Australia to Dementia Australia, which reflects the strength of the relationship. This includes Enabling Educational Dementia Immersive Experience (EDIE™) workshops, online learning and other services.

The centre has demonstrated an improved benefit to Dementia Training Australia through the successful work we are doing in other program delivery by tailoring training packages and developing courses for the Australian Aged Care Quality and Safety Commission.

Dementia Essentials delivery summary for 2018–2019



Making visits better

In November 2018, Dementia Australia launched A Better Visit™ app. Comprised of a series of interactive games designed to assist families to re-connect and communicate with family members whose cognitive function has been affected by dementia, the app was developed in partnership with the Centre for Design Innovation at the Swinburne University of Technology, and is the latest example of our commitment to using technology to improve the lives of people impacted by dementia.



Award for The Virtual Forest™

At the annual Information and Technology in Aged Care conference, held in November, Dementia Australia's The Virtual Forest™ was awarded High Commendation (Runner Up) award in the Best Solution that Provides Ongoing Consumer Independence category.



Left: A Lifeview Residential Care resident interacting with The Virtual Forest™. The Virtual Forest, developed thanks to sponsorship from Lifeview Residential Care, was awarded High Commendation in the Best Solution that Provides Ongoing Consumer Independence category at the 2018 Information and Technology in Aged Care conference.

Right: A screen shot of The Virtual Forest™.

Conference successes

In raising the profile of the centre both nationally and internationally, team members represented Dementia Australia at a number of conferences presenting on the innovative use of technology in the learning space. This included the Alzheimer's Disease International Conference in Chicago, and the LASA National Congress in Adelaide.

Improving training

Dementia Australia's Centre for Dementia Learning played a key role at the first meeting of the Aged Services Industry Reference Committee which will be an important vehicle for progressing changes and improvements to both the Vocational Education and Training (VET) and university sectors. Work has commenced on the development and the national implementation of VETtrak, a single student management system. This will assist with streamlining our systems and also provide us with a more comprehensive data to inform our program decisions.

As part of a review commenced by the Australian Skills Quality Authority into the Certificate III in Individual Support, a range of issues including problems with course packaging which often results in an absence of dementia education, were identified.

We are currently doing work to demonstrate how our programs support the various new aged care standards.

New certificate

The Centre for Dementia Learning signed a Memorandum of Understanding with the University of Tasmania in September 2018 to work towards the Certificate IV in Dementia Practice crediting towards a degree course. This will enable us to achieve our long-held goal of creating an accredited career pathway to become a dementia specialist.

Empowering masterclass

In March 2019, Dr Cameron Camp, Director of Research, Centre for Applied Research in Dementia, Ohio USA, a world leader in innovative approaches to dementia practice delivered Masterclasses in Brisbane and Sydney. His Montessori approach focuses on capabilities rather than inabilities to empower both staff and clients, to help improve service support for people living with dementia while at the same time inspire powerful changes within the workplace.

Our organisation

Fundraising

Dementia Australia's Fundraising team raises much needed funds to ensure Dementia Australia and our services can continue to develop and grow in line with Strategic Direction priority, timely diagnosis and support.

Dementia's Australia's donors are committed to making a difference to the lives of people living with dementia, their families and carers and are often driven by wanting to give back or bring about change to help others. The Fundraising Team works tirelessly to increase this support.

Core areas of responsibility:

- Memory Walk & Jog – DIY Memory Walk & Jog, MY Memory Walk & Jog and flagship events
- Appeals and campaigns
- Community fundraising events
- Donor related enquiries
- Special events
- Gifts in wills
- Corporate partnerships and workplace giving.

Highlights

A number of fundraising bike rides took place this year. Bondi2Berry was established in 2016 by Nick Young and Pierre Sullivan and is Dementia Australia's biggest national community fundraising event. It returned for another year with 80 cyclists taking off on 8 September 2018 from the North Bondi Surf Life Saving Club in New South Wales on their way to their final destination of Berry on the New South Wales south coast. Riders raised an amazing \$130,000 in this event.

A Ride to Remember – Uluru to Ballarat, Victoria was organised by Nick Locandro to raise funds for Dementia Australia. After 14 days on the road and 2,200 kilometres they were greeted in Ballarat by Leanne Emerson, Executive Director of Business Development and other Dementia Australia representatives.

A national membership program to ensure a consistent approach across all states and territories was established with the intent of supporting our peak body and advocacy activities and allowing us to harness the support of more than 100,000 members.



A group of riders from the 2018 Bondi2Berry fundraising event cycled 155km from Bondi, Sydney to the town of Berry on the NSW South Coast on 8 September 2018. The group of 80 riders raised \$131,000 for Dementia Australia. Photo: Paul McMillan



(L-R) Colin Munro, Memory Walk & Jog participant and Jessica Redmayne, actress and MC for the 2019 Hunter Memory Walk & Jog.



Volunteers helped collect funds at Macquarie University train station, Sydney for Dementia Australia's 2018 Collection Day, held 20 September. Approximately \$15,000 was collected for Dementia Australia nation-wide during the day.

Our organisation

Awareness Raising



(L-R) Amy Jackson, Nicola Stevens, Ben Crocker and Takaya Honda, all Dementia Australia ambassadors, attended a reception to honour Their Royal Highnesses the Duke and Duchess of Sussex at Government House Victoria in Melbourne, October 2018.

The Dementia Australia Marketing and Communications teams play a key strategic, advisory role supporting the delivery and implementation of the organisation-wide objectives.

Across Corporate Services, People and Culture and Finance, the focus continued to be on internal communications, especially in relation to keeping all staff and volunteers updated on the progress with national changes.

Externally, to continually raise awareness about dementia and the services we provide multiple communications and marketing campaigns were implemented, including the development of key resources, management of multiple websites, publications, social media strategies, video production and promotion, multimedia advertising and management of events for our Client Services, Centre for Dementia Learning, Fundraising and, Consumer Engagement, Policy and Research teams.

The teams delivered on strategies across traditional and digital marketing, social media, public relations activity, brand strategy, stakeholder and government relations, ambassador management, speech writing, award submissions and the development of a new intranet.

The headline annual Dementia Awareness Month campaign in September 2018, focused on the theme **Small actions Big difference** supported by a national Roadshow, featuring local Dementia Advocates, Dementia Australia Ambassadors and some of Australia's leading researchers.

Our capital cities Roadshow events were complimented by an array of locally-based activities in regional areas and many other locations.

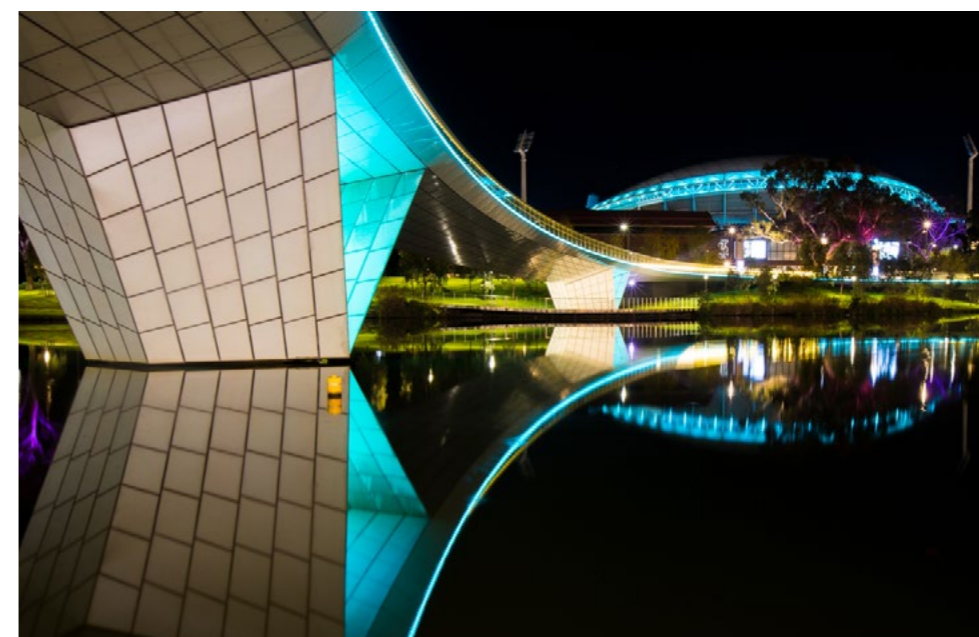
The campaign highlighted the small actions people can take to create a big difference for people living with dementia, their families and carers.

The community were invited to pledge their support by becoming a Dementia Friend to make a positive difference to the lives of people living with dementia, their carers and families, through increased awareness and support.

Through the Dementia Friends program, we aim to transform the way we, as a community, think, act and talk about dementia. To read more about the Dementia Friends program visit dementiafriendly.org.au.

The campaign cemented the Dementia Australia's commitment to raising awareness about dementia, and to position Dementia Australia as the leader in providing support, education, information, programs and resources for the whole community.

Cities lit up in teal, in the lead-up to World Alzheimer's Day on 21 September. As such, we took over iconic landmarks in Adelaide, Melbourne, Brisbane, Canberra, Perth, Sydney, Darwin and Hobart creating a wonderful talking point, and encouraging people to take photos and spread the word via social media.



Adelaide Oval was one of the nation's architectural icons lit up in Dementia Australia teal for Dementia Awareness Month 2018. Photo: Kelly Barnes

Dementia Awareness Month



Brisbane's Story Bridge was lit up in Dementia Australia teal in celebration of Dementia Awareness Month 2018. The Story Bridge was among a number of Australian architectural icons lit in teal to help mark Dementia Awareness Month. Photo: Glenn Hunt



Dementia Awareness Month Small Actions Big Difference Roadshow event in Sydney, September 2018. (Back row, L-R) Sebastian Caruso, Dementia Advocate, Professor Sharon Naismith, MAPS CCN, Associate Professor Michael Woodward AM, Honorary Medical Advisor, Dementia Australia, Scientia Professor Henry Brodaty AO, Honorary Medical Advisor, Dementia Australia, Jeff Thurlow, Dementia Advocate. (Front row, L-R) Mark Seymour, Ambassador, Dementia Australia, Maree McCabe, CEO, Dementia Australia, Phil Hazell, Chair, Dementia Australia Advisory Committee and his assistance dog Sarah. Photo: Adam Hollingworth



A panel discussion was held in Brisbane during Dementia Awareness Month to help mark Queensland Police Service's commitment to encourage its staff to participate in Dementia Australia's Dementia Friends program. The panel included Alistair Dawson, Acting Deputy Commissioner, Queensland Police Service, Jessica and Lisa Origliasso (The Veronicas), Ambassadors, Dementia Australia, Eileen and Dubhglas Taylor, Dementia Advocates and host, Maree McCabe, CEO, Dementia Australia. Photo: Glenn Hunt

Memory Walk & Jog

Memory Walk & Jog has become Dementia Australia's largest fundraising community engagement campaign.

Nationwide, the 2019 series attracted close to 1,000 participants and raised a total of \$950,550 for Dementia Australia. The events have also resulted in a huge amount of awareness being raised, with over 150 media items, reaching an estimated three million people. In addition, widespread social media through Dementia Australia channels and participants' accounts has helped to spread event messages even further.

Aside from the commitment shown by the general public, the 2019 Memory Walk & Jog season also enjoyed the support of a number of high profile figures, including ambassadors Ita Buttrose AC OBE; Neighbours actor Takaya Honda, who also MCed at multiple events; gamer and TV presenter Stephanie Bendixsen; Collingwood FC's Ben Crocker; Melbourne City's Amy Jackson; Hawthorn FC Assistant Coach, Sam Mitchell; Adelaide Seven News Senior Reporter Andrea Nicolas; Giants Netball's Sam Poolman; AFLW Carlton FC's Nicola Stevens; Brisbane Seven Sports Editor Pat Welsh; Five Bedrooms actor Doris Younane; radio personalities David Astle and Denis Walter, and internationally renowned pop duo, Lisa and Jessica Origiasso, The Veronicas.

Other supporters who attended various events included comedian Denise Scott, the Honourable Nick Wakeling MP, Victorian Parliamentary Friends of Dementia co-convenor and The Voice contestant Oskar Proy attended events. Actress Jessica Redmayne and fitness guru Jamie Milne also attended and assisted in MC roles at numerous events.

The incredible support and commitment demonstrated by our ambassadors was extraordinary and contributes enormously to the profile and awareness raising value of these events.

More information about the program is available at www.memorywalk.com.au



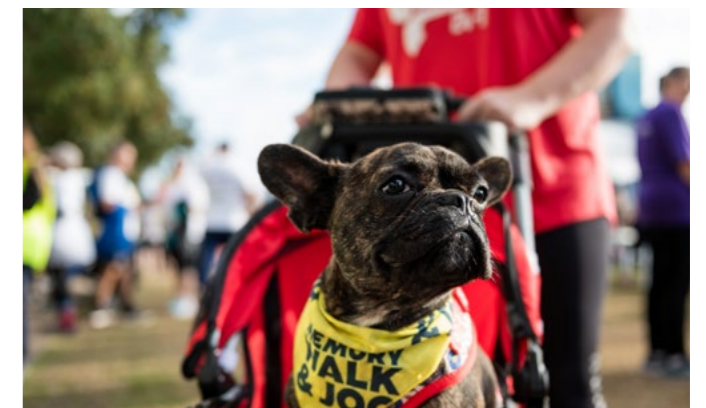
The 2019 Illawarra Memory Walk & Jog participants celebrated their achievements together at the finish line. Nationwide, the 2019 Memory Walk & Jog series attracted nearly 1,000 participants and raised \$950,550 for Dementia Australia.



Adelaide participants reached out to each other for a helping hand to cross the finish line.



Brisbane participants enjoyed a sunny Memory Walk & Jog held alongside the Brisbane River in May 2019. The Brisbane 2019 Memory Walk & Jog attracted record numbers with over 1,000 people in attendance.



For the first time dogs were allowed to be officially registered for Memory Walk & Jog 2019.

Our technology

Dementia Australia's leadership in the development of virtual reality, interactive video games and apps continues to transform dementia care and practice.

This work has been recognised by the technology and training sectors, receiving a number of awards over the years. The awards are a recognition of our vision to create unique learning experiences which touch, move and inspire our sector colleagues to improve dementia practice.

A number of years ago we identified the potential of exploring opportunities with emerging technologies such as virtual reality and computer games.

As a result, in November 2018, we launched the A Better Visit™ app. Often, family members struggle to interact and engage with a family member who no longer recognises them. The app is designed to help families have a 'Better Visit' with their family member living in residential care.

A Better Visit features a range of two-player games that a person living with dementia and a family member or carer can enjoy as a shared experience. The games include Tic Tac Tango, Marble Maze and Gone Fishing and are designed to enhance communication and facilitate positive social interactions between people living with dementia, their carers and families.

We have continued our focus on delivering immersive and impactful experiences to build empathy and to prompt new thinking and discussion in the workplace and sector about how, as care providers, we can improve communication and the environment around a person living with dementia.

Our flagship workshop, the Virtual Dementia Experience™ delivered in Parkville, Melbourne, continues to attract participants.

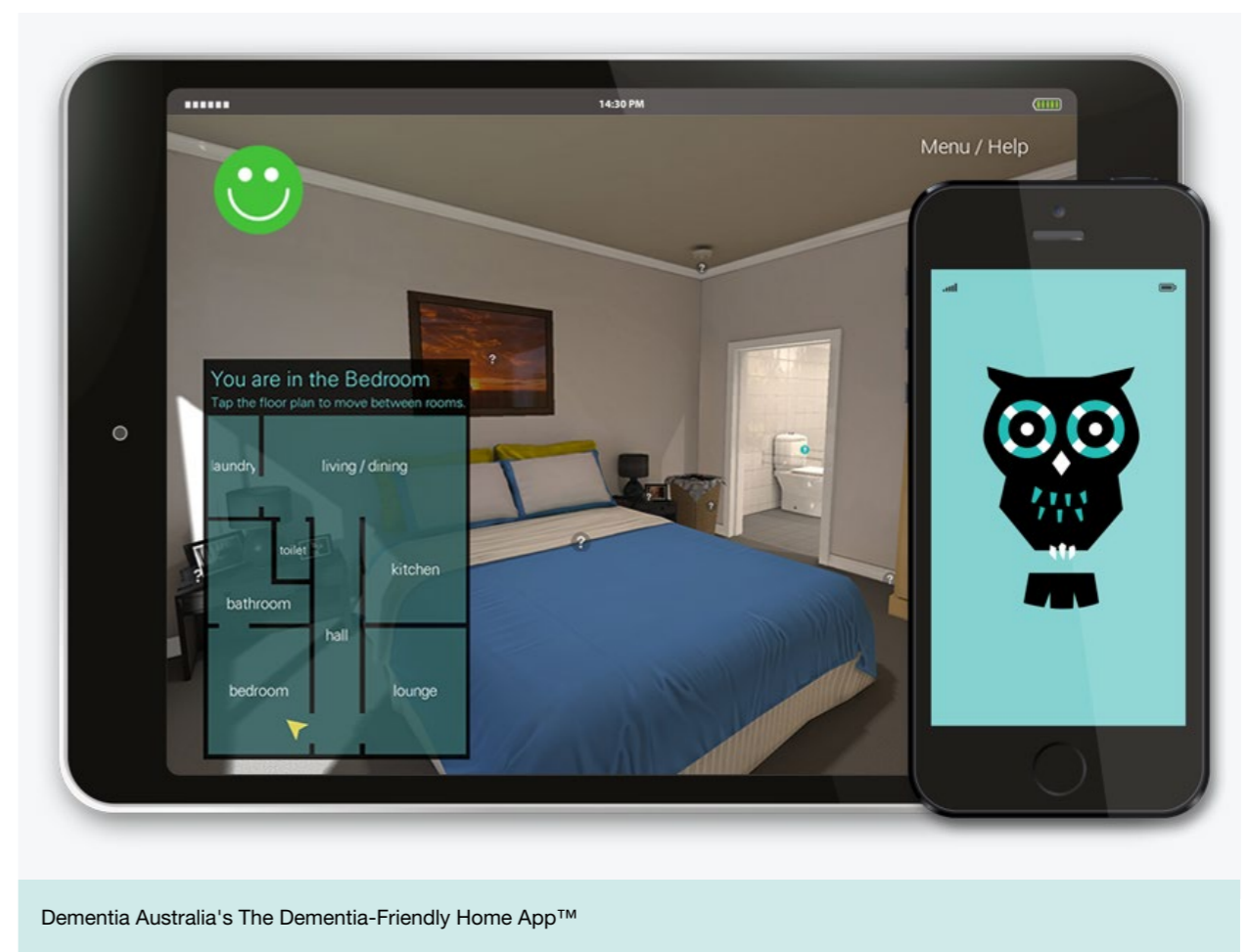
Using game technology, the workshop shifts from an information session to an experiential session and the worker is exposed to the lived experience of a person with dementia, which helps them develop empathy for that person. This has resulted in participants making changes to their work practices to ensure better results for people living with dementia.

With the emergence of virtual reality headset technology, Dementia Australia developed a more comprehensive and mobile offering – the Educational Dementia Immersive Experience (EDIE™) – which has been in constant demand.

EDIE uses Samsung Gear VR to give participants a high quality virtual reality experience that enables them to see the world through the eyes of a person living with dementia. This portability means that training can take place anywhere in the country.



International visitors from the Gwangju Public Health Care Centre in South Korea tried on EDIE headsets during a June 2019 visit to Dementia Australia's North Ryde office.



Dementia Australia's The Dementia-Friendly Home App™

Both workshops provide an immersive experience of what it might be like to live with dementia.

Through ongoing independent evaluation and consumer consultation we know that our technology is influencing change in residential and community care that improves the lives of those living with dementia.

Along with these experiences, we also offer The Dementia-Friendly Home App™, a mobile application that provides simple ideas to enable people living with dementia to remain in their homes for longer.

Another technology, The Virtual Forest™, does not require headsets, but allows people living with dementia and others to use gaming technology to create a sensory experience. Using a large interactive screen, it is designed to immerse the user in a peaceful and enjoyable virtual environment for people living with dementia.

The Virtual Forest creates a beautiful nature setting which is calming as well as engaging and enjoyable. With just a wave of their hands, interaction with

animals such as ducks, fish, a dragonfly, a Monarch butterfly and flowers in the forest is possible. It is theirs to enjoy and experiment with.

Designed to give back some control to people living with dementia, The Virtual Forest uses the Orbbec motion sensor to recognise natural, easy motions that control interactive elements in the forest.

Our thanks

We would like to acknowledge all those who have generously supported Dementia Australia in 2018–19. These include substantial bequests, in memoriam donations, major sponsors, philanthropic trusts, foundations and private ancillary funds, individuals, companies, organisations, community fundraisers, and volunteers.

We thank the following organisations for their support and generosity.

Every gift is appreciated.

Aurizon Community Giving Fund
 Australian Communities Foundation
 Australian Philanthropic Services
 Australian Unity Trustees Foundation
 Bell Charitable Fund
 Collier Charitable Fund
 Cranwell Family Trust
 Equity Trustees
 Fitzpatrick Sykes Family Foundation
 Fonda Family Charitable Foundation
 Frances Jane Edwards and Martha Elizabeth Sirovs Foundation
 Gandel Philanthropy
 Gaudry Foundation
 Geoff and Helen Handbury Foundation
 Hopetoun Fund
 Isabel & John Gilbertson Charitable Trust
 La Manna Foundation

Mr Rodney Dux
 O'Sullivan Family Gifts
 Perpetual
 Priceline Sisterhood Foundation
 Stuart Leslie Foundation
 Sunrise Foundation
 Support was provided by several charitable fund accounts of Lord Mayor's Charitable Foundation
 TasCOSS
 The Douglas & Phillip Young Charitable Trust
 The Elizabeth & Barry Davies Charitable Foundation
 The Gloria and Douglas Mathews Endowment
 The Madeline Crump & Madeline Williams Trust
 The Yulgilbar Foundation
 William Angliss Charitable Fund
 Wood Family Foundation
 Woodend Trust

Government

Dementia Australia acknowledges the support of the Commonwealth Government and all State and Territory Governments.



(L–R) Dennis Frost, Dementia Advocate and Scientia Professor Perinder Sachdev AM FAHMS met after Professor Sachdev won one of three Dementia Australia Research Foundation – Yulgilbar Innovation Grants in December 2018. Professor Sachdev will use his grant to help fund study into nanotechnology for the diagnosis and treatment of neurodegenerative disorders.



SOME OF WHAT YOU'VE HELPED DEMENTIA AUSTRALIA ACHIEVE THIS YEAR

2019

The Dementia Australia Memory Van raises awareness of the impact of brain health and provides information on dementia for people living with dementia and their families, service providers and the community.

The Memory Vans have travelled **OVER 15,046 kms** this year.

They have visited **42** locations:



The National Dementia Helpline contact numbers **EXCEEDED 40,000**



with **99%** positive client satisfaction

OVER 7,247 DEMENTIA KITS were distributed nationally



349,083 Help sheets downloaded and distributed

We have delivered:



OVER 5,000 counselling sessions



OVER 2,500 support group and activity sessions

OVER 150 Living with Dementia Programs



OVER 3,000 family care reduction sessions



OVER 1,000 community information and awareness sessions



RISK REDUCTION PROGRAMS across regional Victoria



EXPANSION OF THE YOUNGER ONSET DEMENTIA VOLUNTEER PROGRAM in Victoria



Further development in THE USE OF TECHNOLOGY in our education programs



We have run **12 YOUR BRAIN MATTERS** rural sessions with over **450** participants



ENABLING EDIE INTERACTIVE WORKSHOPS have been made available in all States and Territories with a roll out of **283** workshops with **3,396** participants



LIBRARY

The Dementia Australia library provides access to a vast range of dementia-related information for people living with dementia, family, carers, friends and people working in dementia care and health. The library team loves speaking with people and helping them find the information they need.

Has lent **OVER**

9,934 resources

500 e-resources



Has had **OVER**

5,290 renewals

477 new resources

“When I first visited the library, based on the challenges I was experiencing at the time, the librarian directed me to resources and information that I had no idea existed.”

Contact us

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This is an initiative of the Australian Government

Find us on social media at



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