



## **Dementia Australia**

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To read more about our Ambassador Program  
visit <https://www.dementia.org.au/ambassadors>

# About this Annual Report

This report highlights Dementia Australia's progress and achievements, including its financial statements, throughout 2017–18.

Dementia Australia was established on 18 October 2017 when the federation of Alzheimer's Australia became Dementia Australia Limited. During the first quarter of the 2017–18 financial year, the Federation of Alzheimer's Australia continued operation whilst in transition to forming the new national peak body. For the purposes of this document all activity is referred to as Dementia Australia activity unless reporting requirements demanded otherwise.

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

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ISSN 2652-0931

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The cover image was taken at the Dementia Australia 17th Biennial National Dementia Conference, October 2017 at Melbourne Convention and Exhibition Centre to commemorate the launch of Dementia Australia and the unification of the Federation of Alzheimer's Australia. Photo: Darren James.



Caption: The Bondi2Berry Ride to Remember, our biggest national community fundraising event, drew 60 riders in September 2017. Natarsha Belling, Channel 10 newsreader and Dementia Australia Ambassador was there to wish them luck. Natarsha is with Bondi surf lifesaver Andrew Reid (left), project leaders Pierre Sullivan and Nick Young and chef Jason Roberts.

# Bringing all the dementias together

## Who are we?

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

## What do we do?

- We represent the more than 436,000 Australians living with dementia and the estimated 1.2 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 people impacted by dementia, 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 the 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 a person's normal social or working life.

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.

Caption: The National Carillon in Canberra was lit up in teal for World Alzheimer's Day in 2017.  
Photo: Maddie Manning.

# Contents

## Key statistics

An estimated 436,000 Australians are living with dementia and nearly 1.2 million people are involved in their care.<sup>1</sup>

In the absence of a medical breakthrough, it is predicted there will be 1.1 million Australians living with dementia by 2058.<sup>1</sup>

In 2018, dementia was estimated to cost Australia more than \$15 billion. By 2025, the total cost of dementia is predicted to increase to more than \$18.7 billion in today's dollars, and by 2056, to more than \$36.8 billion.<sup>2</sup>

Dementia is Australia's second leading cause of death overall, and the leading cause of death of women.<sup>3</sup>

Dementia affects almost 50 million people worldwide, and that number is predicted to increase to 131.5 million people by 2050.<sup>4</sup>

Every three seconds someone in the world develops dementia.<sup>4</sup>

Alzheimer's disease is the most common form, but there are more than 100 diseases that may cause dementia.<sup>5</sup>

1. Dementia Australia (2018). Dementia Prevalence Data 2018–2058, commissioned research undertaken by NATSEM, University of Canberra.

2. The National Centre for Social and Economic Modelling NATSEM (2016) *Economic Cost of Dementia in Australia 2016–2056*

3. Australian Bureau of Statistics (2017) *Causes of Death, Australia, 2016* (cat. no. 3303.0)

4. Alzheimer's Disease International <https://www.alz.co.uk/about-dementia>

5. Dementia Australia <https://www.dementia.org.au/information/about-dementia/types-of-dementia>



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Caption: Students from East Brunswick Primary School with the banner they made to raise awareness during Dementia Awareness Month 2017. Photo: Darren James.

# Key achievements

- Throughout the unification process we ensured the continuity of support for people living with dementia, their families and carers.
- We secured overwhelming support from stakeholders all over Australia to change the organisation name from Alzheimer's Australia to Dementia Australia to more accurately reflect that support, advocacy, information and education is available for people of all ages living with all forms of dementia.
- We established the Dementia Australia Centre for Dementia Learning as the leading national provider of dementia practice education in Australia.
- We delivered our first national Memory Walk & Jog campaign, with 10 flagship and 34 DIY walks across the country, and more than \$1.2 million raised.
- We delivered our annual Dementia Awareness Month campaign, 'You Are Not Alone', which resulted in more than 400 media stories and 60 events around Australia.
- We developed a suite of technology using virtual reality, interactive video games and apps to transform dementia care and practice recognised by national and international awards (see page 46 for details).



Auctioneer Nigel Spoljaric from Pickles Auctions takes bids on a work at The Eclectic Perspective exhibition and auction of artwork created by people living with dementia held in Canberra in May 2018. The event features works by participants from the Dementia and the Arts program. Its aim is to provide art opportunities to every person in the ACT living with dementia.

# A message from our Chair



The year 2017–18 has been an extraordinary achievement for us as an organisation with significant decisions made about our future direction. This financial year Dementia Australia was officially launched and became a united, national peak body organisation that will ensure that we continue to

advocate and provide even better services for people of all ages, living with all forms of dementia, their families and carers.

It is fitting to celebrate our theme *Bringing All The Dementias Together*, which was the driver behind us becoming the first national dementia peak body. We have continually demonstrated throughout the year that we are a united force in the aged care sector, and this enables us to respond to the rapidly changing nature of this sector.

The Board members, CEO and leadership teams from around the country have been extraordinary in their support and adaptation throughout this year of continued transition and their shared vision for better services and support for our clients. Our staff, volunteers and Ambassadors have also shared the excitement in the changes that we are currently undertaking. Overall, we have been encouraged by the feedback we have received from all our stakeholders in this process, and we are already experiencing the advantages a unified organisation brings.

Becoming a national peak body has brought substantial benefits for people with dementia, their families and carers as well as staff, volunteers and Ambassadors including:

- building our capacity to deliver on the organisation's mission nationally 'to improve the lives of people with dementia and their carers';
- building capacity to deliver services around the country for people with dementia their families and carers;
- providing increased opportunities and platforms for a strengthened client voice and increasing our public profile that has established Dementia Australia's status as the peak charity for people living with dementia;

- being a more nimble, agile, and responsive organisation able to deal with the rapidly changing landscape, and strategically working towards long-term sustainability;
- streamlining our operations, embedding consistency, ensuring nationally informed decision-making and efficiency;
- increasing our capacity to secure financial support, inspiring increased donations and improving our financial sustainability; and,
- improving collaboration, strengthening our organisational culture and professional development opportunities for all staff.

Importantly, the organisation has maintained a highly-visible profile and while still in transition, continued to deliver services across metropolitan, regional and remote areas, maintaining and building important local and national stakeholder relationships, securing sustained media coverage, and delivering impactful and meaningful events.

Our achievements this year demonstrate that we are committed to achieving a dementia-friendly Australia, especially through the launch of Dementia Friends, where people with dementia are included, respected, supported, empowered, and engaged in community life.

I would like to acknowledge all of our donors, supporters and corporate sponsors who have contributed to the success of this financial year. I would also like to thank the Federal Government and State and Territory Governments for their ongoing support and engagement. It is our valued stakeholders' support that helps us provide the best possible outcomes for those diagnosed with dementia, their families and carers and we look forward to working with you in the future.

My sincere thanks and appreciation.

A handwritten signature in black ink, appearing to read 'Graeme Samuel'.

**Professor Graeme Samuel AC**  
Chair Dementia Australia

# A message from our CEO



It is an honour to report to you in our first year as Dementia Australia. During the year, I have had the pleasure to work alongside our extraordinary team across the country who work to make a difference to the lives of the more than 436,000 people of all ages, living with all forms of dementia in Australia, their families and carers.

It has been a year of continued transition which I have had the privilege of leading under the direction of the Board and Chair, Professor Graeme Samuel AC. It has been an opportunity to improve and increase our reach and engagement with our clients, to promote and encourage access to our services, programs and resources and, to elevate awareness and understanding of dementia in Australia by being bigger, bolder and stronger as a national, peak body.

This year, working within the first Dementia Australia Business Plan, we completed a thorough engagement and consultation process with our external stakeholders, consumers, volunteers, Board members and staff to understand how we could best leverage our expertise in dementia to develop our Strategic Direction for the next five years. In face-to-face meetings and in an online survey, we found that across the country our staff shared a sense of pride in our service delivery and were committed and enthusiastic about a continued shared culture and delivering and expanding our unique services.

At our national dementia conference in October 2017 we officially introduced Dementia Australia. It was a powerful statement for us as a new organisation, and as the theme of this report declares, we have been *Bringing All The Dementias Together*. We unveiled a ceremonial plaque with Dementia Australia Ambassador and world-renowned Dementia Advocate Christine Bryden, alongside Brett Partington who represented family carers. A replica of this plaque is now in every reception of our buildings around the country to mark the significance of the occasion. Immediately after the announcement we joined together for the photo you see on our cover. I congratulate all who participated because capturing that moment was crucial to representing the energy, the vision and the shared excitement about the future we set out to create – which we are now achieving.

I would like to share my delight that, in the middle of the photo as people grabbed the placards emblazoned with all types of dementia, we heard people claiming a type of dementia with pride. We were all part of something symbolic but also very real for so many people living with their form of dementia who were present. And I can add to the delight that when our team went to collect the placards after the photo, they couldn't – participants had taken them home. Picturing people on public transport, in taxis and walking to their cars with their placards still makes me smile and will always remind me of why we exist – to serve every person impacted by all forms of dementia.

I would like to take this opportunity to recognise and thank the Board and CEOs of the eight Alzheimer's Australia organisations who are listed on page 26. Without their support of the transition to a national peak body, Dementia Australia would not be in the position it is today.

Using the World Health Organisation's (WHO) *Global Action Plan On The Public Health Response To Dementia 2017–2025* as our guide we have focused this year on building our own, comprehensive Strategic Direction to be aligned with the WHO plan, which we believe will add our unique Australian voice to the global push for action on dementia.

The WHO plan calls to improve the lives of the more than 50 million people living with dementia, their families and carers and decrease the impact of dementia on communities and countries around the world. WHO identified seven action areas for the plan including awareness, risk reduction, research, support, and developing funded national strategic plans targeting dementia.

Visiting our Dementia Australia offices across the country throughout the year and meeting those diagnosed with dementia, the carers and the families that our staff work so passionately for has been inspiring. All over the country our staff are the back bone to our role in providing advocacy, support services, education and information. As one team we are truly empowered to elevate awareness of dementia and transform the quality of care and lives of all people impacted by dementia.

A handwritten signature in black ink, appearing to read 'Maree McCabe'.

**Maree McCabe**  
CEO Dementia Australia



# A message from the Chair of our Finance and Investment Committee



We saw a change on 29 August 2017 from Alzheimer's Australia Ltd to Dementia Australia Ltd, and the creation of a unified entity as agreed with the Australian Charities and Not-for-profits Commission (ACNC).

The results for the year ended 30 June 2018 disclosed in our financial statements compare the

unified Dementia Australia Ltd with the results of the previous year. The new combined company now has total equity of \$43.8 m (2018) compared with total equity of \$3.7m (2017). The total combined comprehensive income is \$2.3m (2018) compared with total comprehensive income of \$166k (2017).

As a result of pooling the interests of all the above named entities, Dementia Australia Ltd has become a very strong organisation. It now has cash holdings of \$27.7m, and investments of \$16.5m, which allows us to plan for the future where we can continue to serve people living with dementia, their carers, and their families.

The creation of the unified entity has resulted in a number of other changes.

Previously there had been eight separate payrolls, finance systems and finance functions. Dementia Australia has worked this year to establish one payroll system, one national finance system, and one national team.

I would like to recognise and thank the members of these finance teams who have worked towards the creation of the national payroll and national finance system. This I understand is work in progress. They have all contributed to the success of these projects and I acknowledge both current and previous staff for their commitment during this transition.

**Tony Newman**

Chair of Dementia Australia's Finance and Investment Committee – June 2018

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



Ivan and Vera are just some of the thousands of people who regularly attend Memory Lane Cafes around Australia.

# Dementia Australia Advisory Committee Report

The Dementia Australia Advisory Committee (DAAC) provides a national platform to hear the voices of people living with dementia. The aim of DAAC 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 DAAC are key participants in Dementia Australia's Dementia Advocates Program (see page 36). They are active advocates in their communities and contribute specialist expertise by providing lived experience knowledge.

The year 2017–18 was a year of change for the committee. The committee said farewell to Chair Ian Gladstone and Vice-Chair Eric Garnett, as well as founding members Kate Swaffer (inaugural chair) and Di Harris who had been on the committee since its establishment in 2013. Thank you to Ian, Eric, Kate and Di for their significant contributions to the committee's work.

In September 2017, the DAAC elected a new Chair Phil Hazell and Vice-Chair Eileen Taylor. Dementia Australia also welcomed new members Dennis Frost, Bobby Redman, Kevyn Morris, Sarah Ashton and Val Schache. Additional members of the committee will be recruited over the next year.

Highlights from this year included:

- identifying areas of priority for people living with dementia
- providing feedback for the national Dementia Australia Strategic Plan
- providing feedback into the National Institute for Dementia Research Strategic Roadmap
- providing feedback on Dementia Australia resources
- working with the consumer engagement team on the development of the national Dementia Advocates Program.

**“ The committee is acutely aware of the needs of those living with dementia and is therefore in a powerful position to recommend positive change. ”**

**Phil Hazell, Chair DAAC**



Phil Hazell, Chair Dementia Australia Advisory Committee with his assistance dog Sara.

**“ As vice-chair of the advisory committee and working with a strong group of committed people, I am looking forward to continue to review and contribute to any further important documents and decisions the committee is part of. ”**

**Eileen Taylor, Vice-Chair DAAC**

# Dementia Australia: A Business Plan

Early in 2017 the Dementia Australia business plan 2017–18 was presented to the Alzheimer’s Australia Board as an interim one-year plan to enable the organisation to continue its focus on operations, while working towards unification and developing the first strategic plan for a unified Dementia Australia.

In this report we have focused on the key milestones achieved in this business plan.

The milestones achieved are:

## Unification

Unified all functions, services and programs across Dementia Australia to increase ability to provide services across Australia and to deliver operational efficiencies.

## Centre for Dementia Learning

The establishment of the Centre for Dementia Learning (CDL) to position Dementia Australia as the

leading provider of dementia practice education in Australia. The CDL has strengthened current education programs, developed and delivered an efficient, consistent and unified approach to education, and contributed to the expansion of dementia consultancy projects.

## Strategic Partnerships

Identified, established and built on existing strategic partnership arrangements.

## Fundraising

Prioritised the establishment of unifying fundraising and philanthropy operations to accelerate fundraising capability nationally and in all states and territories.

## Strategic Plan

Developed a long-term strategic plan to identify strategic priorities, including a review of the organisational vision and purpose.

Actions and measures were identified in the business plan for each of the achievements listed above and are reported against in the following pages.



Dementia Australia is a proud charity partner of the Priceline Sisterhood Foundation. In June 2018 former cricket star Merv Hughes turned his legendary moustache pink to kick off a national drive to raise \$1 million for five Priceline Sisterhood Foundation charities that month. To mark the occasion, Merv became the first ever ‘Mister’ to join the Priceline Sisterhood Foundation, which is already proudly supported by Priceline Sister and Dementia Australia Ambassador Ita Buttrose AO, OBE, model Samantha Harris and sportswoman Ellyse Perry. Photo: Dominic Lonergan.

# Unification: A Single Entity

The launch of Dementia Australia at our biannual conference in October 2017 was the culmination of more than 12 months of negotiation, discussions and organisational change.

A variety of factors drove the need for unification. Amongst them were the increasing prevalence of dementia and the need to find effective ways to provide national support, changes in federal funding policy, and the opportunity for economies of scale in administration.

The process of unification required agreement across the national and state and territory boards as well as across the state members. This agreement was gained at a series of special general meetings that were held across the country throughout August and September, which resulted in a unified organisation with a single national board and executive team.

The impact of unification on people living with dementia, their families and carers was carefully considered as part of every decision and, wherever possible consultation and regular communication occurred.

A unification team was established to coordinate legal and compliance activity across the states and territories, to support the organisational realignment under the new executive team structure, and to develop national processes and ways of working.

Unification has already achieved substantial benefits with every aspect of the organisation seeing improvements. New national ways of working have led to improvements in quality, outcomes and reduced risks. Significantly, unification has enabled investment in both expanding the ability of Dementia Australia to reach more people living with dementia, their families and carers; and to build capacity within the aged care sector through the Centre for Dementia Learning.

## Benefits of unification

The unification process has already achieved substantial benefits with multiple reviews still in progress and more to be realised over time.

All areas of the organisation were reviewed. Existing duplications and inconsistencies in processes and practices were redeveloped in areas, for example, across finance, people and culture, administration, assets, programs, course curriculum and preferred suppliers.



Melbourne Playback Theatre captured the spirit of the Biennial Alzheimer's Australia National Dementia Conference 2017 with their interpretive performance at the closing ceremony.

The plan has focussed on growth areas and maximising opportunities to:

- expand reach and build capacity in the sector
- increase government and non-government funding
- drive the implementation of strategy and achieve further improvements
- improve governance and quality and decrease risk.

This approach has resulted in substantial gains in:

- nationally efficient and effective ways of working;
- improvements in quality in both internal and external service delivery;
- improved outcomes and increased reach; and
- a reduction in people and compliance related risks.



Dementia Advocate and Dementia Australia Ambassador, Christine Bryden presenting at the 17th Biennial Alzheimer's Australia National Dementia Conference 2017 – Be The Change

# Centre for Dementia Learning

The Centre for Dementia Learning is the home of a comprehensive suite of evidence-based learning and consultancy services to help improve the quality of support and quality of life experienced by people living with dementia.

In July 2014, based on recommendations in a comprehensive review of education by an external consultant, the then-Alzheimer’s Australia CEOs supported the establishment of the Centre. After years of planning and with the support of a two-year funding agreement with the Priceline Sisterhood Foundation, the Centre for Dementia Learning was established in October 2017.

The Centre’s dedicated focus on health professionals and the aged care sector enables it to progress a strong agenda for transforming the quality of dementia practice while drawing on more than 30 years’ experience. It achieves this by providing a comprehensive suite of evidence-based learning and consultancy services to help improve the quality of care and quality of life experienced by people living with dementia.

Our initial focus was to develop national course development standards to ensure consistencies in teaching, informed by a combination of research, practice and the experience of people living with dementia, their families and carers.

The first courses developed against these new standards were the most popular and essential workshops. Delivery of these new workshops began in 2018. These workshops were:

- Understanding dementia
- Applying a problem solving approach to behaviour
- Meaningful engagement

- Successful communication
- Enabling EDIE™

The three-hour workshops are usually delivered onsite to aged care provider staff. The table below provides a summary of the number of participants we have had in these various programs nationally since 1 July 2017.

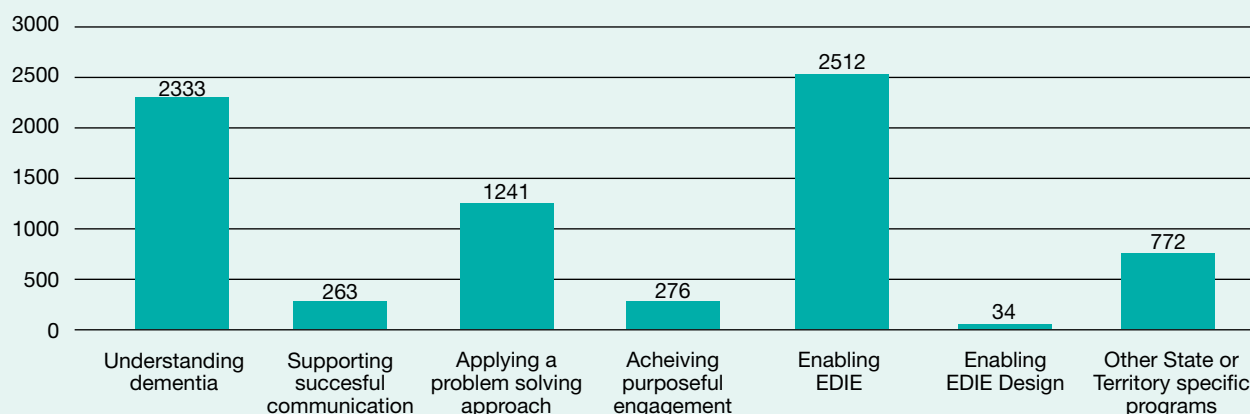
## Release of the Dementia Learning Guides

There are currently 3,223 aged care providers nationally ranging from micro-businesses to large national enterprises, with a current workforce of more than 366,000. A key aspect of the success of the Centre relies on its capacity to reach these providers. A significant amount of work was put into developing learning guides for each state and territory for release in late 2017. The guides outlined the suite of programs available through the Centre, including the workshops listed above. The guide also listed Dementia Essentials – an accredited Dementia program delivered by the Centre for Dementia Learning for Dementia Training Australia – and our online learning and consultancy services.

These guides were sent both in hard copy and electronically to every aged care provider in each state or territory to introduce them to the newly established Centre for Dementia Learning. This, together with proactive business development activities by teams and Regional Directors, has contributed to the level of engagement with the Centre’s programs in its first full year of operation.

A number of facilitators and managers attended the national Dementia Australia conference in Melbourne as part of an ongoing commitment to ensuring that our staff are across contemporary dementia practice and research, as well as being grounded in the experience of people living with dementia.

Centre for Dementia Learning Workshop Participants Financial Year 2017–18





EDIE™ immerses carers and staff in the world of someone living with dementia.

### Implementing new structures and processes

We have developed and implemented new management and staffing structures to ensure the effective and efficient operation of the Centre nationally. This is also partly a result of our unification process more broadly. We are still progressing this work, taking into account the particular needs and opportunities which exist in different parts of the country.

An initial achievement was the establishment of a single registered training organisation for the Centre, replacing the four that had previously existed. This has not only resulted in immediate savings around registration and associated costs, but has also enabled greater operational efficiency. This has been important for us to be able to deliver the Dementia Essentials program for Dementia Training Australia nationally.

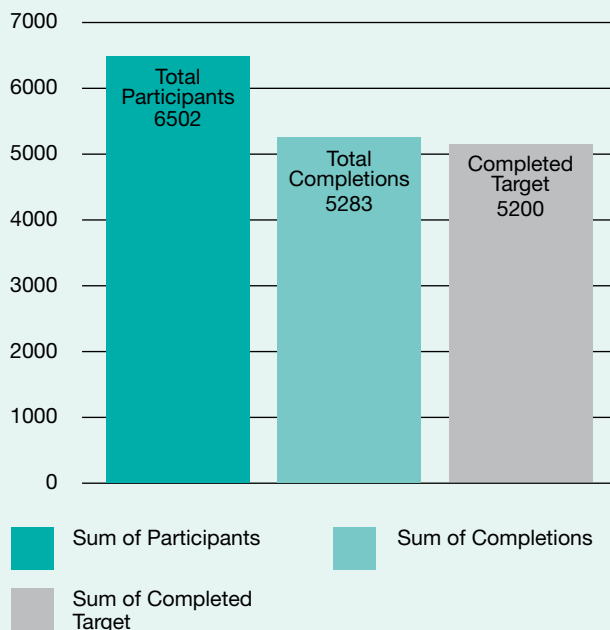
We are currently working on the implementation of a national operating system using one that has been successful in several parts of the country.

We also successfully exceeded our fee for service target, which was particularly pleasing given the period of unprecedented change for the organisation.

Staff have continued to deliver a range of existing education programs including Dementia Essentials, which is a Dementia Training Australia accredited three-day program funded by the Australian Government under the Dementia and Aged Care

Services Fund. This program was successfully delivered to 6,502 aged care workers during this period, with 5,287 successfully completing the program.

**Graph: Dementia Essentials delivery summary for 2017–18.**



# The value of strategic partnerships

Throughout the transition to a national peak body it was essential to acknowledge that for any future strategic priorities to be realised and to make a profound and lasting difference to people living with dementia, their families, carers and our communities – we could not do it alone.

The need to maintain and build relationships and partnerships across the country in the government, corporate, health, aged care, and philanthropic sectors as well as within our local communities was imperative.

A review of the more than 150 existing relationships with organisation was undertaken to ensure the years of connections with people and organisations in the states and territories did not go unacknowledged.

Key relationships were identified and strengthened, namely with major funders, sponsors, contract partners, and any existing Memorandums of Understanding were reviewed.

In addition to these Dementia Australia participates in many joint activities with multiple government, health and aged care sector advisory, research, policy and consumer bodies across state, territory and national levels.



Cathy McGowan MP, Member for Indi, Maree McCabe, CEO Dementia Australia, Christine Bolt, National GM Communications, Corporate Communications Dementia Australia, welcoming Ms McGowan as a Dementia Friend through our Dementia-Friendly Communities program.

## The outcomes of just a few of our strategic partnerships

Community organisation, CASS Care Limited in Sydney and Wollongong has partnered with Dementia Australia to deliver training which better enables staff to provide specialist dementia support to the more than 2,600 families from culturally and linguistically diverse backgrounds who access their services. In particular, people from the East Asian countries, including Chinese, Koreans, Indonesians and Vietnamese.

Queensland Police Service has partnered with Dementia Australia through our Dementia-Friendly Communities program. Members around the state have been learning how they can play an important role in building a dementia-friendly community. Senior police executives led by example by signing up as a Dementia Friend with the aim of the 10,000 members to participate in further training and sign up as Dementia Friends through 2018–19.

Lifeline Residential Care has supported various projects over many years, notably the development of The Virtual Forest™, an interactive computer game that offers an engaging, peaceful and enjoyable immersive environment designed specifically to improve the quality of life for people living with dementia. Most recently Lifeline, along with Swinburne University of Technology School of Design, has supported the development of the A Better Visit iPad app to be released in November 2018. A free app with interactive games designed with and for people living with dementia to play with friends and carers to enhance the experience of a visit.

Palliative Care Australia collaborated on a number of key end of life care projects including the development and release of a joint policy statement in May 2018. <https://www.dementia.org.au/files/documents/Dementia-Policy-Statement-2018.pdf>

The Yulgilbar Alzheimer's Research Program collaborated with Dementia Australia through the Dementia Australia Research Foundation to develop an inaugural \$1 million innovative dementia research grant to be released later in 2018.

This summary of activity is only an indication of the focus needed in this area and with the release of Dementia Australia's Strategic Direction 2018–2023, due in October 2018, reporting against this area of strategic partnerships in future will be directly aligned with the priority areas over the coming five years.



# Fundraising

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 new national organisation would not exist today without the past contributions and involvement of the many thousands of people and hundreds of organisations all over Australia.

Key to the business plan was ensuring all those who support Dementia Australia know they are valued and acknowledged especially throughout this past year of change. Maintaining and building relationships and, improving methods of communication have been a priority to ensure donors have had the opportunity to share in the vision and potential offered by unification.

A business plan priority was to establish a unified fundraising and philanthropy function to increase capability across all the states and territories. This has resulted in setting new national benchmarks and the development of the first, national, fundraising, three-year plan.

All fundraising activities have been aligned to national objectives with centrally managed systems and processes. The consolidation of multiple databases was a major achievement and essential to renewing, maintaining and improving Dementia Australia's relationships with existing donors.



Adelaide Crows AFL player Bryce Gibbs gets ready to lose his hair for dementia awareness in March 2018. Bryce raised almost \$30,000 for charities including Dementia Australia.



The Annual Collection Day occurred on World Alzheimer's Day, 21 September, with volunteers mobilised at major public transport stations and high foot traffic areas.

A new, national fundraising structure was introduced to reduce expenditure, increase efficiencies, and have a national focus while importantly enabling and retaining local connections and relationships with individuals, communities and organisations.

The expansion of Memory Walk & Jog events is a strong example of this commitment with one, national team ensuring consistency and quality control of the event program, branding and organisational approach introducing efficiencies that have increased revenue. Ten events were delivered by Dementia Australia while community leaders all over the country hosted their DIY Memory Walk & Jog events inspiring their local communities to participate, raise awareness and raise important funds.

A dedicated fundraising strategy is essential to ensure Dementia Australia has the capacity to expand services and increase the ability to reach people around Australia. Dementia does not discriminate. With more than 436,000 living with dementia in Australia and an estimated 1.2 million people involved in caring for someone with dementia, it impacts on people in major cities, in regional and remote areas, across all socio-economic levels and every different community group.

Dementia Australia is committed to working with all donors and inspiring others to join us to make a difference to the lives of Australians impacted by dementia.

# Strategic Direction – development

One of the major tasks as a unified national body as part of the Dementia Australia Business Plan 2017–18 (referred to in more detail on page 11) was to develop the inaugural Dementia Australia strategic plan to set the national vision and long-term direction for the future.

Prior to this year, as a federated structure the Alzheimer's Australia separate state and territory bodies were responsible for developing their own priorities and delivering their own plans in varying timeframes, while the former Alzheimer's Australia national entity managed a separate strategic plan. One of the benefits of unification is that this fragmentation no longer exists.

As a national peak body Dementia Australia reviewed and audited the status of older plans, combined the key messages and priorities, and then analysed them against the 2017–18 state of play. This process positioned the new organisation to be able to look back, gather what had been learned and achieved as a federation, collectively, and start to look forward. This was viewed as a once in a lifetime opportunity to really understand and tackle the biggest issues for people living with dementia.

The objective decided upon and led by the CEO, the then Unification Lead, Kate Morton and the Executive Directors was to deliver and release the new, Board approved, strategic plan by August 2018.



The team worked together to determine two questions that were then put to all stakeholders:

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

A broad and consultative approach was undertaken with the following stakeholders:

- people of all ages, living with all forms of dementia
- carers and families
- all types of donors
- contacts at leading and relevant trusts and foundations
- Dementia Australia staff
- Dementia Australia volunteers
- Dementia Australia members
- Dementia Australia Board members
- key contacts and leaders in clinical and social research around Australia and with some international contacts
- key health professional contacts and leaders across a breadth of specialist areas
- key contacts at member organisations of Alzheimer's Disease International
- former Alzheimer's Australia Board members and CEOs where possible
- members of parliaments around Australia
- key contacts and leaders in government departments around Australia
- key contacts and leaders in providers of health and aged care services
- Dementia Australia's social media audience.

Throughout our consultation and analysis process the responses were recorded, collated and analysed by the CEO and Executive Directors to guide all in determining Dementia Australia's strategic priorities.

A draft Strategic Direction 2018–2023 was presented to the Board for consideration and the approved Strategic Direction document was announced in October 2018. Next year's annual report will start the five year process of reporting against Dementia Australia's progress in delivering on the agreed strategic priorities.



Chef Jeffrey Tan launches his book *Cooking for Charity*. It shares the story of Chef Jeffrey's remarkable commitment to raising awareness and funding for Dementia Australia.

# 17th Biennial Alzheimer's Australia National Dementia Conference 2017 – Be the Change

The national conference was held in Melbourne with the theme of *Be the Change* that acknowledged the role we all play in improving the quality of dementia support and care. Attracting more than 600 delegates from across the country and internationally, the conference also achieved the greatest level of consumer involvement of any conference previously held by Dementia Australia.

An impressive line-up of local and international experts successfully engaged the audience through a range of interactive presentations across the two and a half days of the conference including for the first time a number of pre-conference workshops. The comprehensive program for the conference included 14 workshops, 10 keynote speakers, three panel discussions, 37 concurrent sessions and 51 digital poster sessions. Each day consisted of a series of keynotes, parallel sessions comprising a mix of workshops and oral presentations with a wide range of opportunities for engagement and interaction.

The conference was officially opened by internationally acclaimed Dementia Advocate and author Christine Bryden. Kate Swaffer, CEO and co-founder of Dementia Alliance International also presented as part of a number of presentations by Dementia Advocates throughout the conference, with over 70 consumers involved. A consumer participation fund was established with funding from the Department of Health, Department of Social Services and private donors to support them to become involved in the conference.

Professor Sam Gandy, from the Mount Sinai Medical Centre in New York gave the opening keynote address: *What Would It Take to Get an Effective Alzheimer's Drug?*

Naomi Feil, pioneer of the world-renowned Validation method, presented on how to apply Validation techniques to older people living with dementia who exhibit behaviours of unmet need. The feedback we received from participants was that she was one of the major highlights of the conference.

Dr Cameron Camp, Director of Research and Development at the Centre for Applied Research in Dementia in the United States of America, a leader in integrating Montessori educational methods into dementia care, was another of the popular keynote speakers at conference. The Montessori approach focusses on engaging with the person living with dementia based on their strengths and abilities.

The conference also provided the perfect opportunity to officially launch Alzheimer's Australia's new brand, logo and unification announcement as Dementia Australia. Staff from across the country were able to be part of this significant event through live video.

In another first, the conference included the 19th Annual Libby Harrick's Memorial Oration. The oration honours the memory of the first president of the Deafness Forum of Australia. The focus of the oration was on hearing loss and dementia. It followed publication in *The Lancet* of a report about hearing loss as one of nine factors that could be changed in midlife to reduce the incidence of dementia. Dr Piers Dawes from the University of Manchester discussed the possible links between hearing loss and cognitive health. The oration was supported by Audiology Australia.

The conference provided a diverse range of learning opportunities to delegates, including: film screenings over lunch, where delegates could also talk to the filmmaker; digital poster presentations; a performance by a choir of people living with dementia; a sound installation; and the *Feed your Senses* area.

*Feed your Senses* was an interactive immersive zone for delegates to experience a dementia-friendly garden which displayed edible plants, herbs and flowers that encouraged people to pick, taste and enjoy the garden. Special guest speakers explored the garden and spoke about activities that benefit carers and the person living with dementia.

Interactive sessions featured people living with dementia and carers, national and international leaders in dementia research and practice as well as change and innovation. Their authentic voices informed and inspired delegates to achieve practical change.

There was also a technology space which provided delegates with the opportunity to experience a range of different technologies that engage people living with dementia as well as improve understanding of dementia through programs like EDIE™ – Educational Dementia Immersive Experience.

The Teal Team, made up of staff and volunteers, provided important support to delegates and presenters throughout the conference. They took on a wide range of duties, including assisting delegates

to find their way to sessions and supporting consumers in dedicated rooms so they could take time out from the busy conference program. We received fantastic feedback from delegates on the value of the Teal Team.

A highlight of the final day was a panel with three inspiring young people who live with dementia in their family – *A youth perspective on dementia care*. Dr Tanya Petrovich also delivered a very powerful presentation on engaging through technology which was followed by a panel discussion.

The closing ceremony featured the Melbourne Playback Theatre doing interpretive performances to capture audiences’ perspectives and experiences of the conference. This very emotional and moving piece provided a unique opportunity to reflect on the conference experience and how it had touched, moved and inspired delegates to be the change. This was followed by CEO Maree McCabe inviting two consumers to formally close the conference.

### NHMRC National Institute for Dementia Research (NNIDR) Dementia Forum

Working together, we were able to precede the conference with the NHMRC National Institute for Dementia Research (NNIDR) Dementia Forum which was held at the conference venue. This enabled some consumers to be involved in both events and we were also able to share a keynote speaker.

The forum theme, *Involving Consumers in Research towards Better Care Outcomes*, had three key points of focus on the day:

1. Providing consumers with an overview of the current research underway and plans to improve care outcomes
2. Addressing the important question of how and when people living with dementia and their families and carers can be engaged in the design and management of research programs
3. Providing consumers with the opportunity to advise on their priorities for improving dementia care outcomes, and identifying gaps and omissions in the current research agenda

A number of delegates from this forum also went on to attend our conference.



TV gardener Vasili Kanidiadis provides some outdoor tips to delegates in the Feed Your Senses space. The space incorporated a dementia-friendly garden and technology zone.



Isao, Hamish, and Ashlyn all have a close relative who is living with dementia. With Brighid Brodie, Family Clinician Dementia Australia, they provide a young person’s perspective on dementia care.



Songbirds, the well-known choir of aged care and disability provider Annecto, performs at the conference.

# Our organisation

## Governance

The Dementia Australia Board has responsibility 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 is delegated to the Chief Executive Officer.

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 they receive 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. View the full document on the Australian Charities and Not-for-profits Commission's website.
- Board members perform this role on a voluntary basis and are not paid for their services.

### Meetings of the Board

The Board held 12 meetings during 2017–18, with attendance outlined below.

| Name                       | Total Attended |
|----------------------------|----------------|
| Professor Graeme Samuel AC | 12             |
| Neil Samuel                | 12             |
| William Bass               | 12             |
| Greg Fraser                | 9              |
| Jenna Dennison             | 10             |
| Tony Newman                | 11             |
| Amanda Quealy              | 10             |
| Paul Robertson AM          | 11             |
| Maree McCabe               | 12             |

### Board Committees

The Board had one sub-committee – the Finance and Risk Management (FARM) Committee. The purpose of the FARM Committee was to provide ongoing support, advice and recommendations to the Dementia Australia Board on finance, investment, audit and compliance and risk management issues in relation to all Dementia Australia entities and its associated research foundations. This included the provision of high quality financial management and reporting, as well as due care and diligence in relation to risk assessment, mitigation strategies and monitoring.

#### FARM Committee Members:

Chair: William Bass

Neil Samuel

Maree McCabe

Geoff Knuckey (independent)

Tony Grieves (independent to Jan 2018)

Ian Knight (independent from Jan 2018)

In June 2018 the Board resolved to split FARM and establish the Finance and Investment Committee and the Audit and Risk Management Committee.



The Hon Linda Dessau AC, Governor of Victoria, takes part in a Memory Lane café.

# Our organisation

## Board

**Professor  
Graeme  
Samuel AC**

**Chair**



Professor Graeme Samuel AC is Chair of Dementia Australia and Chair of the Dementia Australia Dementia Research Foundation, Chair of the South Eastern Melbourne Primary Health Network, Chair of Lorica Health Pty Ltd (a CMCRC company), Council member of the National Health and Medical Research Council and Chair of its Health Innovation Advisory Committee and the National Institute for Dementia Research. He was a member of the APRA Panel to conduct a Prudential Inquiry into Commonwealth Bank of Australia.

He was Chair of the Commonwealth Government's Panel of Review of Australia's Independent Medical Research Institutes. Professor Samuel was appointed an Officer of the Order of Australia in 1998. In 2010 he was elevated to a Companion of the Order of Australia.

**Tony  
Newman**

**Vice Chair**



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 a highly effective operations manager. His highly 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 dad was diagnosed with Alzheimer's disease five years before his death in 1996. Tony serves on the Board of Dementia Australia Limited, Dementia Australia Research Foundation and Dementia Australia Research Foundation Victoria.

**William  
Bass**

**Secretary,  
Public Officer  
and Treasurer**



William Bass brings considerable corporate executive experience predominantly in the fields of strategy, commercial and financial management and governance. He is Chairman of ASX listed China Magnesium Corporation Limited and a director, senior financial officer, company secretary and advisor to a number of prominent Australian and international companies.

Responsibilities as a Dementia Australia Limited Director include Treasurer, Secretary, Public Officer and Chair of Finance Audit and Risk Management Committee until June 2018. From June 2018 he was appointed Chair of the Audit Risk Management Committee.

**Maree  
McCabe**

**CEO Dementia  
Australia**



Maree McCabe is the Chief Executive Officer of Dementia Australia. Her career accomplishments include Executive Operations for TLC Aged Care, Director of Clinical Resources at The Melbourne Clinic, and General Manager of Hospitals for St John of God Healthcare and Surveyor for the Australian Council on Healthcare Standards.

Maree is also a director of Dementia Australia Research Foundation and Dementia Australia Research Foundation Victoria. She is a member of the board for the National Ageing Research Institute and a member of the Aged Care Sector Committee which provides advice to the Federal Government on aged care policy development and implementation. She is also a member of the Australian Commission on Safety and Quality in Healthcare and is on the Executive Committee of the Cognitive Decline Partnership Committee. Internationally Maree represents Dementia Australia as a member of Alzheimer's Disease International and is a member of the ADI Asia Pacific Regional Committee.

**Greg Fraser**



Greg Fraser was Chief Executive of the ACT Department of Health and Community Care and has had extensive involvement in intergovernmental initiatives and forums and represented the States and Territories at several international Treaty meetings.

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

Greg has been involved with Dementia Australia boards for more than seven years and has been a member of the Dementia Australia Board since 2013. He is also a member of the ACT Ministerial Advisory Council on Ageing.



**Jenna  
Dennison**



Jenna Dennison has served as a board member for Dementia Australia since July 2015, firstly in the Northern Territory and in July 2017 as a Director of the Dementia Australia Board.

Jenna works with the NT Department of the Attorney-General and Justice, Correctional Services and the NT Police Fire and Emergency Services on a range of projects focusing on legislative and policy reform and was the recipient of the 2017 NT Government AICD NFP Scholarship program. She is excited about the opportunities that are emerging in the Northern Territory for people living with dementia and their carers as a result of the unification and establishment of Dementia Australia.

**Amanda  
Quealy**



Amanda Quealy is CEO of The Hobart Clinic a private not-for-profit hospital and community mental health service and holds an honorary position as Adjunct Senior Lecturer at University of Tasmania. Amanda represents Tasmania on the Australian Private Hospital Association Council and Australian College of Health Service Managers. She is Chair, Tasmanian Alcohol and Drug Tribunal and Deputy Chair Tasmanian Women's Council. As a former Telstra Business Woman of the Year, she has also been recognised in the Top 100 Women of Influence.

Her academic background includes degrees in Economics (Hons) and Social Work, Chartered Institute of Public Sector Finance & Accountancy, Post Graduate Diploma, Human Services Administration, Graduate Australian Institute of Company Directors, ACHS Hospital Surveyor and Masters in Business Administration.

**Paul  
Robertson AO**



Paul Robertson has been involved in the organisation since early 2016 as previous Chair of Alzheimer's Australia NSW and continuing as a Director on the Dementia Australia Board. He is also Chair of St Vincent's Health Australia and Chair of 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 the founding Director of the Financial Markets Foundation for Children and a director of Telco Together Foundation. He is also Chair of Tonic Health Media and the Sydney Theatre Company Foundation.

**Neil Samuel**



Over the past 40 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.

Neil has served in leadership positions on numerous boards within the not-for-profit sector for many years, specialising in governance and finance. He served on the board of Alzheimer's Australia Vic since 2003, including Honorary Secretary, Deputy Chair and Chair. In 2007 he was appointed to the Board of Alzheimer's Australia, now Dementia Australia and also serves on the Boards of Dementia Australia Research Foundation and Dementia Australia Research Foundation Victoria. Neil is also a member of the Finance, Audit, Risk Management Committee and Chair of the Dementia Australia Victorian Advisory Council.

Neil's passion for Dementia Australia was born out of family experience with Alzheimer's disease.

# Our organisation Board

The following people served as Board members for Alzheimer's Australia in the states and territories and retired from these positions during the transition to Dementia Australia.

We acknowledge their commitment over many years and honour the key role they have played in our shared history. It has been a significant change in moving our organisations from a federation to a single unified organisation and this has only been made possible through their dedication and commitment during this time.

At our heart we are the same organisation, as Dementia Australia we will be bigger, stronger and bolder and we stand on the shoulders of the work they have done and the difference they have made.

Thank you for your contribution to this extraordinary accomplishment. It would not have been possible without you.

## Outgoing Alzheimer's Australia state and territory Board members and CEOs

| State/Territory | Role                         | Name                    |
|-----------------|------------------------------|-------------------------|
| <b>ACT</b>      | Vice-President               | Gayle Sweaney           |
|                 | Treasurer                    | John Barbeler           |
|                 | Director                     | John Fely               |
|                 | Director                     | Geoff Hine              |
|                 | Director                     | Camilla Rowland         |
|                 | Director                     | Sharon Winks            |
|                 | Director                     | Philip Butler           |
| <b>NSW</b>      | Director                     | Dr Richard Matthews AM  |
|                 | Director                     | Dr Jennifer Alexander   |
|                 | Director                     | Lucille Bloch           |
|                 | Director                     | Eileen Hoggett          |
|                 | Director                     | Ian Horton              |
|                 | Director                     | David Lane              |
|                 | Director                     | Dagmar Schmidmaier AM   |
|                 | Director                     | Malcolm Schyvens        |
|                 | CEO                          | The Hon John Watkins AM |
| <b>NT</b>       | Vice-President               | Lorna Maher             |
|                 | Treasurer/<br>Public Officer | Neil Von Bertouch       |
|                 | Secretary/<br>CEO            | Kylie Beard             |
|                 | Director                     | Vicki Krause            |
|                 | Director                     | Claire Bell             |

|            |                              |                                         |
|------------|------------------------------|-----------------------------------------|
| <b>QLD</b> | Director                     | Desley O'Brien                          |
|            | Director                     | Swain Roberts                           |
|            | Director                     | Peter Carne                             |
|            | CEO                          | Victoria Beedle                         |
|            | Acting CEO                   | Pat Walsh                               |
| <b>SA</b>  | Vice-Chairman                | Tim White                               |
|            | Director                     | Alan Bevan                              |
|            | Director                     | John Giles                              |
|            | Director                     | Vasilios Antoniou                       |
|            | Director                     | Jason Neave                             |
|            | Director                     | Clare MacAdam                           |
| <b>TAS</b> | Acting CEO                   | Rajiv Chand                             |
|            | Vice-President/<br>Treasurer | Richard Cooper                          |
|            | Director                     | Eric Pinkard                            |
|            | Director                     | Gillian Groom                           |
| <b>VIC</b> | Director                     | Mike Blake                              |
|            | Vice-Chairman                | Ian Knight                              |
|            | Treasurer                    | Piera Murone                            |
|            | Secretary                    | Frauke Tyrrell                          |
|            | Chief Medical Advisor        | Associate Professor Michael Woodward AM |
|            | Director                     | Helen Sykes                             |
|            | Director                     | Jerome Fahrer                           |
|            | Director                     | Ross Oakley OAM                         |
|            | Director                     | Sabine Phillips                         |
| Acting CEO | Leanne Emerson               |                                         |

## Outgoing CEOs

| State/Territory | Name                     |
|-----------------|--------------------------|
| ACT             | Rebecca Vassarotti       |
| NSW             | The Hon John Watkins AM  |
| NT              | Kylie Beard              |
| QLD             | Victoria Beedle          |
|                 | Pat Walsh (Acting CEO)   |
| SA              | Rajiv Chand (Acting CEO) |
| TAS             | Tony Reidy               |
| VIC             | Maree McCabe             |

# Our organisation

## Executive Directors



**Maree  
McCabe**

**Chief Executive  
Officer, Dementia  
Australia**



**Anneliese  
Coghlan**

**Executive Director  
People and Culture**



**Leanne  
Emerson**

**Executive Director  
Business  
Development**



**David  
Frost**

**Executive Director  
Finance and Asset  
Management**



**Kate  
Morton**

**Executive Director  
Strategy and Business  
Improvement**



**Susan  
McCarthy**

**Executive Director  
Client Services**



**Dr Kaele  
Stokes**

**Executive Director  
Consumer  
Engagement, Policy  
and Research**

# Our organisation

## Our people

Dementia Australia is making a difference to the lives of people living with dementia, families and carers all over Australia because of the strength of more than 500 extraordinary, committed people working in an array of roles. Aply supported by the People and Culture team, the majority of staff deliver counselling, education and support programs through Client Services and the Centre for Dementia Learning. They would not be able to accomplish all they do without the support of the experienced teams in fundraising, policy, research, advocacy, finance, IT, administration, marketing and communications.

The enormous transition for staff throughout 2017 and 2018 has required reviews, position description updates, changes in organisational structure, classifications and reporting lines, while internal processes, protocols and IT changes have also impacted.

The introduction of comprehensive digital communication and video conferencing tools has enabled Dementia Australia to truly be national, inclusive and no longer limited by geographical boundaries. This has resulted in the organisation being better positioned to attract the quality staff needed to fulfil on our unification objectives.



Lisa Reed, Administration Officer Client Services and Jodi Eagland, Administration Officer – Hospitality, just two of the hundreds of Dementia Australia staff making a difference all over Australia

Dementia Australia now has teams dispersed across the nation and across time zones. There are some who work in traditional office space while many others work in shared offices or remotely – all to enable the organisation to flexibly reach as many of the 436,0000 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 while 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                               | 2017–18 |
|-------------------------------------|---------|
| No of staff – full time             | 218     |
| No of staff – part time             | 246     |
| No of staff – casual                | 55      |
| Tenure rates – Less than 1 year     | 198     |
| Tenure rates – between 1 & 3 years  | 118     |
| Tenure rates – between 3 & 5 years  | 68      |
| Tenure rates – between 5 & 10 years | 99      |
| Tenure rates – More than 10 years   | 36      |

| Staff                | 2017–18 |
|----------------------|---------|
| No of staff (people) | 519     |
| No of Staff (EFT)    | 371.5   |
| WA                   | 7       |
| SA                   | 41      |
| NT                   | 14      |
| QLD                  | 85      |
| Tas                  | 43      |
| NSW                  | 142     |
| Vic                  | 143     |
| ACT                  | 44      |
| No of staff – female | 460     |
| No of staff – male   | 59      |

## Employment arrangements

Dementia Australia staff are employed under a variety of industrial agreements which will be reviewed in the next financial year or according to scheduled expiry dates. By 30 June 2018, as part of the review and legal process, staff across the country signed agreements to officially transfer their existing employment arrangements to the new entity Dementia Australia Ltd. Honouring all existing conditions in the unification process was a priority and one of the commitments made to staff at the beginning of this change, as well as a Fair Work Australia requirement.

## Professional development

Dementia Australia acknowledges that professional development is integral to personal job satisfaction, workplace productivity, reward, and recognition, and is critical to the achievement of the organisation's mission and continuous improvement in the quality of its programs and services.

Professional development can occur through a range of formal and informal work related activities relevant to the various roles.

These include:

- Attendance at:
  - conferences,
  - seminars,
  - short courses (internal or external) or
  - workshops.
- Participation in:
  - committees or working parties,
  - industry placement/visits,
  - mentoring schemes (being mentored and acting as a mentor),
  - subject or course meetings,
  - undertaking specific project/consultancy work,
  - courses or programs.
- Involvement in Work Integrated Learning:
  - critical reflection on practice,
  - professional reading,
  - focused consultation with colleagues,
  - obtaining and acting on feedback from clients and/or colleagues,
  - networking,
  - temporary performance of duties in another position.

- Formal Studies:
  - Studies for formal TAFE or higher education programs at undergraduate or postgraduate level including research activities.
- Research/Writing:
  - Obtaining a research grant or performing action research, preparing and publishing papers or books.

Staff can request these options with their manager and approval to attend is negotiated dependant on budget and relevance to the purpose of the role.

## Wellbeing

One of the other nationally consistent People and Culture services implemented this financial year has been the appointment of a single employee assistance program provider. This service gives staff, and their immediate families, 24/7 access to qualified counselling support – either face-to-face or by phone. The service provider appointed has a variety of resources to support staff – such as a manager helpline, fact sheets, a comprehensive website and a smart phone app. The service has been well used in this past year of change.

A focus on staff wellbeing will expand these services into the next financial year. Clinical supervision for front line services staff continues to be important, and will be reviewed and improved in the new year. Dementia Australia is committed to improving the wellbeing offerings for all staff to ensure the best possible working conditions, and the supporting culture, are in place for all staff wherever they are located in Australia.

# Our organisation

## Volunteers



Volunteers are central to the success of events like the Sydney Memory Walk & Jog, held at Leichhardt Oval on 6 May.

### Volunteers

We acknowledge the hard work and dedication of our volunteers across the nation to our organisation and those impacted by dementia. 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 2017–18, more than 950 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 and Younger Onset Dementia Cafes
- attending community events
- administrative support in our offices and libraries
- volunteer drivers
- 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 and awareness events such as Collection Day, fundraising evenings such as A Night to Remember Gala Ball, Dementia Awareness Month seminars and expos and 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 will assist with:

- registration desk
- raffle ticket selling
- way finding
- sweep riders
- Al the Elephant
- bump in and bump out
- fundraising
- information booth
- backstage coordination
- give-away bag packing and distribution
- start finish line marshalls.

Our volunteers have maintained their fantastic work and support throughout the recent transition from

state and territory based organisations to Dementia Australia. We are excited to explore future innovative opportunities to use volunteers well into the future to compliment 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.

### Numbers

745 Event volunteers

226 Ongoing volunteers

**Total 971 volunteers**



Volunteer Sandra Erickson demonstrates the EDIE™ technology at the Dementia Technology Showcase in Melbourne.



Volunteers around Australia regularly support our events for people living with dementia and carers.

# Our organisation

## Awareness Raising

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 this year was on internal communications, especially in relation to keeping all staff and volunteers updated on 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, 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.

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

A major achievement for the team was the development, transition and launch of Dementia Australia in October 2017 supported by the unveiling of the new name and brand.

The headline annual Dementia Awareness Month campaign in September 2017, just prior to our name change, included the release of the Dementia and Stigma report that supported the theme, You Are Not Alone.

### The key findings were:

- People living with dementia and carers experience embarrassing situations, feel strongly disconnected, feel less competent and sometimes feel useless, a new survey has found.
- 94 per cent of respondents who have a diagnosis of dementia felt that they encountered embarrassing situations as a result of their dementia.
- 60 per cent of carers who responded found themselves in embarrassing situations because they are caring for someone living with dementia.

What is encouraging is the same survey found one in two members of the general public are frustrated by their lack of understanding about dementia and want to know more about how they can help.

This survey cemented the team'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.

### Highlights included:

#### ABC Four Corners Dementia feature – Forget me not

- Episode of ABC Four Corners aired nationally in July 2017 that shared the experiences of Dementia Advocates living with dementia and their carers, Mandy and Garry Lovell, Heather and Brian Fisher and Suzie O'Sullivan.

#### Dementia Awareness Month

- Resulted in more than 400 media stories, supported by a marketing campaign and, more than 60 Australia-wide events, and hosted Dr Steven Sabat, Emeritus Professor, of Psychology at Georgetown University, USA, who delivered the public lecture, Forget Memory Loss – what about the person?

#### National Dementia Conference

- Resulted in more than 100 media mentions and stories focussing on the keynote speakers, international and local health and aged care sector experts alongside people living with dementia and carers.
- A media highlight was the national coverage of our younger onset dementia assistance dogs research project in partnership with Vision Australia and University of Melbourne.

#### Launch and unveiling of the new look Dementia Australia

- Throughout 2017 and 2018 our in-house team managed the development and design of our new branding to coincide with the official launch of Dementia Australia in October 2017.



Dementia Advocates Glenys Petrie and John Quinn with David Astle, ABC Radio National, ABC Local Radio presenter and, Ambassador Dementia Australia.



# Our organisation

## Client Services

This year, the Client Services team at Dementia Australia has delivered a large number of community awareness events, education sessions, counselling sessions, Living With Dementia programs and much needed information, support and resources for people with dementia, carers, families and health professionals.

We are always looking for ways to increase our reach and support people living with dementia, carers and families.

We have agile service offerings; truly client focused service models; service management structures which support staff; comprehensive models of support and the ability for staff to manage diverse roles and client needs.

Client Services brings together a range of support, education and information services, including

- the National Dementia Helpline
- the Library
- Counselling
- Carer and Community Education
- Younger Onset Dementia programs
- Dementia Advisory Services
- Early Intervention Services
- Social Support programs
- Respite, and
- Dementia-Friendly Communities.

We provide services in all states and territories to people living with dementia, their families, carers and the community via programs including National Dementia Support Program, Younger Onset Dementia Key Worker Program, Commonwealth Home Support Program and Dementia-Friendly Communities and various state-based funded programs.

One of the big achievements of the year was the development of a new Client Services structure designed to provide geographical support and leadership, as well as national accountability.

The Client Services General Managers have regional responsibility for various teams and programs. They also have national responsibility for different programs and elements within Client Services. This is an important step forward in truly unifying and expanding our Client Services offering.

Our appointed General Managers bring a tremendous amount of skill, passion, professionalism, expertise and integrity to Dementia Australia.

This is truly an exciting time for Dementia Australia – as a national team we are a stronger organisation, and are in a position to extend our reach to support more people living with dementia, their families and carers.



Participants at the three-day carers' retreat in Grindelwald, Tasmania were given the chance to unwind with a session of tai chi with Chris Dell of Iron Lotus Tai Chi.

The year started with a review and analysis that brought to light the outstanding work that Client Services staff achieve with the resources and funding available to them. It was a chance to identify gaps, opportunities and areas for improvement, and this process informed how we will develop and grow into a new national entity.

The analysis identified the need to increase our reach to people living with dementia, families and carers. There is also a need to develop an equitable national service offering and a robust monitoring and evaluation framework.

With the vision of increasing our reach and delivering a core suite of national services, the focus for the future will include the National Dementia Helpline, early intervention services, dementia advisors, carer education, strengthening our position as the first contact after diagnosis and other important service offerings to support people living with dementia, their families and carers.

An important initiative in December 2017 was to bring together the Client Services management team from each state and territory. The team gathered in Sydney for a two-day workshop to discuss the strategic direction for Client Services, the National Dementia Support Program consultation paper, and the ongoing delivery of the Younger Onset Dementia Keyworker Program and Dementia-Friendly Communities. The workshop highlighted the skills, expertise and passion of our staff across the country, the need to foster these skills, and to support and learn from each other.

Some highlights from the year include:

- A large number of staff were involved in the transition projects into a national client services team, and their continued efforts, enthusiasm and professionalism in driving these projects is greatly appreciated. This has truly helped prepare Client



Guests at the May Dementia Australia Memory Lane Café at Mulgrave Country Club were delighted to be entertained by 60s pop legend, Normie Rowe. Mr Rowe generously performed at the event as a demonstration of his support for one of his oldest and closest friends, Bill, who is a regular Café attendee with his wife Jo, who is living with dementia.

Services for the future, and place us in the best position to deliver quality services.

- The introduction of national service offerings meant that our teams are starting to work across different states and territories. As a result, the South Australian counselling team will now support the NSW counselling team to deliver services to waitlisted clients. In addition, we have created a national webinar for those who are recently diagnosed, available to clients no matter where they live.
- There have been a number of other projects that focused on specific elements of our service delivery including increasing reach to diverse groups, developing client pathways, reviewing carer education courses and streamlining client contributions for the Commonwealth Home Support Program. These are all important steps to

making client services the best support possible for people living with dementia.

- Another great program is the Dementia-Friendly Communities project. This year it supported the development of local dementia-friendly community activities and through an Expression of Interest process, we awarded 20 local funding grants, of \$15,000 each, to organisations and communities who want to develop local dementia-friendly projects.

To select the final list of recipients, a panel reviewed and discussed the most appropriate applications. Some of the successful grant recipients include Darwin Community Arts, Dubbo Neighbourhood Centre, Kiama Municipal Council, Dementia-Friendly Ballarat, Mercy Health and Aged Care Central Queensland Ltd, ECH Inc, Wicking Dementia Research and Education Centre, the University of Tasmania and the Shire of Manjimup Community Home Care, Western Australia. It is a diverse group of organisations and community groups, with a good geographical spread. Keep an eye out for the full details on [www.dementiafriendly.org.au](http://www.dementiafriendly.org.au).



Bernadette Milsted, Counsellor Dementia Australia enjoying a dance with a Memory Lane Café guest.

- The Younger Onset Dementia Key Worker Program supports people living with dementia under the age of 65, and their families and carers. It is a unique program which provides much needed support to those living with younger onset dementia, as they navigate the condition as well as the various personal, economic and social challenges.
- The National Dementia Support Program delivers the National Dementia Helpline, Counselling, Carer and Community Education, Early Intervention Services, support groups and many more benefits. To provide an indication of its remarkable achievements, in just a few months, it delivered a total of 22,922 contacts to the National Dementia Helpline, 644,879 visits to the national website including 447,015 Help Sheets downloaded. It demonstrates how valuable these resources are and how much dementia information is required and needed. Counselling continues to be in high demand with almost 2,500 support sessions delivered in the later part of 2017, and 900 people impacted by dementia accessing our Early Intervention services, such as the Living with Dementia program, more than 2,400 families and carers attended carer education sessions and almost 5,000 people living with dementia and carers attended support group sessions. Additionally, 28,363 people attended community education, information and awareness. This program is national and far reaching and more importantly improves the lives of people impacted by dementia.

| Key figures for Client Services |                                                                                 |
|---------------------------------|---------------------------------------------------------------------------------|
| 22,922                          | Calls to the National Dementia Helpline.                                        |
| 28,363                          | People who attended community education, information and awareness sessions.    |
| 5,000                           | People living with dementia and carers who attended support group sessions.     |
| Almost 2,500                    | Support sessions delivered.                                                     |
| More than 2,400                 | Families and carers who attended carer education sessions.                      |
| 900                             | Attended early intervention services, such as the Living with Dementia program. |
| 644,879                         | Visits to the Dementia Australia website.                                       |
| 447,015                         | Help Sheets downloaded.                                                         |

Through a year of big changes, the national Client Services team continued to deliver on all contracted outputs and provided high quality services to clients. We've discovered continued passion, commitment and expertise from all corners of the country.

We are excited to continue to make a positive difference to the lives of people affected by dementia next year with our unified support expertise and services.



Dementia Australia partnered with the International College of Advanced Education in Darwin for Dementia Awareness Month celebrations in September 2017. Our Darwin Seniors community was treated to live entertainment and dancing. Hospitality students created the menu, prepared the dishes and served people living with dementia and carers at the special luncheon celebration, held at the Greek Orthodox Community Hall, Nightcliff.

# Our organisation

## Consumer Engagement, Policy and Research

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.

Our objectives are to respond to existing and emerging challenges which people living with dementia, their families and carers face through our policy, advocacy and research agendas. We undertake the important task of promoting the voice 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.

People living with dementia and carers are invaluable in informing the work that we do. They collaborate with us, governments and the health, disability and aged care sectors on identifying pathways forward, and promote inclusive communities. By combining their insights with those of service users, providers and industry representatives, we are able to develop a wide range of position and discussion papers, as well as offering evidence-based recommendations for further action to government and other stakeholders.

### Consumer engagement

The Consumer Engagement team now has four Consumer Engagement Coordinators located across the country and is led by the General Manager Consumer Engagement. The team works closely with all areas of the organisation as well as a large number of external groups. The role of the team is to provide advice and expertise on engagement values and best practice, and coordinate advocacy opportunities through the Dementia Advocates Program. 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.

At the heart of our consumer engagement strategy is recognising the value of lived experience, acknowledging individuals as experts by experience. Through the Dementia Advocates Program and we



Dementia Advocates and Dementia Australia Executive staff met with representatives from the Federal Department of Health's Residential and Flexible Aged Care Division.

are working towards an ongoing partnership with people living with dementia, carers and former carers to share stories in such a way that they can inspire, inform, motivate positive change and reduce stigma.

Dementia Advocates are woven into the fabric of everything we do and consumer engagement is a key advocacy activity. It is central to our policy and research work.

The Dementia Australia Advisory Committee, which reported on page 10, is one component of the wider Dementia Advocates Program.

Government policy and research submissions include input from the Dementia Advocates network.

Over the past year, Consumer Engagement in partnership with Dementia Advocates has:

- built the capacity and networks of the Consumer Engagement team across Australia
- expanded the network of Dementia Advocates and enhanced the mechanisms for harnessing their voices in our systemic advocacy
- embedded supporting infrastructure to facilitate the growth of the Dementia Advocates program
- strengthened the Dementia Australia Advisory Committee as a representative voice of advocates
- consulted with advocates on a wide range of topics, submissions, projects and strategies
- created the Advocacy in Action newsletter to keep Advocates and staff across the country informed about advocacy activity, goals and achievements.

We would like to take this opportunity to thank all the Dementia Advocates for their hard work, generosity, commitment and invaluable contributions.

## Major national policy submissions and papers

Dementia Australia has continued to develop evidence-based policy publications and position statements over the course of the 2017–18 financial year, including:

- Younger Onset Dementia: Bridging the Gap – August 2017 <https://www.dementia.org.au/files/VIC/documents/AlzAus-PFOD.pdf>
- Awareness and Understanding of Dementia in Australia – October 2017 <https://www.dementia.org.au/files/media/2017-IPSO-report.pdf>
- Palliative Care and Dementia – May 2018 <https://www.dementia.org.au/files/documents/Dementia-Policy-Statement-2018.pdf>

National policy development affecting people living with dementia and their families and carers was informed by quality submissions and input from Dementia Australia, which consistently drew on the experiences and insights of people living with dementia, their families and carers.

During the 2017–18 financial year, Dementia Australia developed numerous national and state policy submissions and papers responding to the complex health, disability and aged care environment, including:

- Draft Cost Recovery Implementation Statement – July 2017
- Draft National Safety and Quality Health Service (NSQHS) Standards user guide for ATSI Health – July 2017
- Inquiry into NDIS Amendment Bill – July 2017
- Ministerial Review of National Aged Care Quality Regulatory Processes – July 2017
- Optional Protocol to Convention against Torture (OPCAT) – July 2017
- Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services – July 2017
- NDIS Costs and Productivity Commission Position Paper – July 2017
- Future reform – an integrated care at home program to support older Australians – August 2017
- Effectiveness of the aged care quality assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised – August 2017
- Australian Law Council's (ALC) Justice Project – September 2017
- Redesign of dementia consumer supports – November 2017

- Review of the National Screening and Assessment Form – November 2017
- National Museum of Australia's disability access plan 2018-2022 – December 2018
- Victorian Carers Statement- December 2017
- Future of Work and Workforce – January 2018
- Review of the NSW Guardianship Act – January 2018
- Specialist Dementia Care Units – January 2018
- Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia – February 2018
- Review of Australian Charities and Not-for-profits Commission (ACNC) legislation – February 2018
- ACT Legislative Assembly Select Committee Inquiry on End of Life Choices in the ACT – February 2018
- Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT – March 2018
- Aged care workforce strategy consultation – March 2018
- Draft Transport Plan for Brisbane: Strategic Directions – March 2018
- Aged Care Financing Authority (ACFA) Respite Care – April 2018
- Integrated Carer Support Service: Regional Delivery Partners – May 2018

Many of these submissions resulted in follow up meetings, round tables or appearances at parliamentary hearings, not least:

- Senate Select Committee into the Future of Work and Workers public hearing
- House of Representatives Standing Committee on Health, Aged Care and Sport into the quality of care in residential aged-care facilities in Australia
- ACT Select Committee Public Hearing on End of Life Choices

The organisation was represented by staff and advocates at these hearings.

## Parliamentary Friends of Dementia

The Policy, Research and Consumer Engagement team have held a number of Parliamentary Friends of Dementia events over the past year.

**September 2017**, International guest speaker Prof Steven Sabat, Professor Emeritus of Psychology at Georgetown University, presented at the Federal Parliamentary Friends of Dementia for Dementia Awareness Month supported by Co-convenors Andrew Laming MP, Member for Bowman, QLD and Tasmanian Senator Helen Polley, Shadow Assistant Minister for Ageing.



From left: NSW PFOD co-convenor Kate Washington MP, Maree McCabe CEO Dementia Australia, advocate and former care partner Imelda Gilmore, Premier Gladys Berejikian, Dennis Frost living with Dementia Advocate and co-convenor Leslie Williams MP.

**November 2017**, Hosted the South Australian Parliament's Dementia Champions Morning Tea with Co-convenors Nat Cook MP, the then Parliamentary Secretary for Housing and Urban Development and Sam Duluk MP, Member for Waite.

**June 2018**, Parliamentary Friends of Dementia presented in Federal, NSW and Victorian parliaments to launch the national Dementia Friends campaign to encourage members of parliaments all over Australia to register as a Dementia Friend. The Federal and Victorian meetings were supported by the Co-convenors as mentioned above. The NSW meeting was supported by Co-convenors Leslie Williams MP, Parliamentary Secretary for Regional and Rural Health and Kate Washington MP, Shadow Minister for Early Childhood Education, and Shadow Minister for the Hunter. In addition to the Co-convenors, a number of senior members attended and registered as Dementia Friends including The Hon Ken Wyatt AM MP, Minister for Aged Care and Minister for Indigenous Health; The Hon Bill Shorten MP, Leader of the Opposition; The Hon Gladys Berejikian, Premier of NSW and The Hon Martin Foley MP, Victorian Minister for Housing, Ageing and Disability.

It was great to hear from Dementia Advocates at all of these events. Janice Hodgson and, Peter and Ann Gill, shared their own stories at the Federal event. Theirs and all the other contributors' stories shared were timely reminders of the power in our political leaders hearing the personal experiences of those impacted by dementia, and thank you to each of them for speaking so generously and courageously.

During the event in Australian Parliament House, we also officially welcomed our latest Ambassadors, The Veronicas. Singing duo Lisa and Jessica Origliasso, whose mother Colleen is living with Lewy body disease, made their ambassadorial debut, participating in a Q & A session during the event, led by our National Ambassador Ita Buttrose AO OBE.



Evelyn Glennan, and her parents, Dementia Advocates Kerin and Karen and Kerin's assistance dog Roger attended the Victorian Parliamentary Friends of Dementia event.

# Our organisation

## Research



The Hon Ken Wyatt AM, Minister for Senior Australians and Aged Care, new ambassadors The Veronicas, Lisa and Jessica Origiasso, National Ambassador Ita Buttrose AO OBE and Dementia Australia CEO Maree McCabe.

### Research

During the past year, research and research partnerships have remained a top priority for Dementia Australia. Our partnerships include:

- supporting the work of the National Health and Medical Research Council (NHMRC) National Institute for Dementia Research (NNIDR)
- directing funding to dementia research through the Dementia Australia Research Foundation annual grants program
- contributing to the NHMRC Cognitive Decline Partnership Centre
- working with researchers to promote relevant findings through our research communications channels
- The collaboration of staff and Dementia Advocates in numerous research projects and programs through positions on advisory committees.

#### NHMRC National Institute for Dementia Research

The NHMRC National Institute for Dementia Research (NNIDR) is a key element of the Australian Government's \$200 million initiative to boost dementia research. The NNIDR, an initiative of the

NHMRC, hosted and administered by Dementia Australia, was established in 2015 to target, co-ordinate and translate the strategic expansion of dementia research in Australia.

At the halfway point, 127 grants have been awarded to 285 leading dementia researchers, working across 24 universities and research institutions through the Boosting Dementia Research Initiative. Case studies indicate significant successes in dementia research across prevention, treatment, diagnosis and care.

Through a series of forums and workshops held in 2017–18, Dementia Australia and the NNIDR brought together people living with dementia, carers, researchers and representatives from service providers, research organisations, peak bodies and government to drive conversation about how we can better involve people living with dementia, their families and carers, and the wider public in dementia research.

#### Dementia Australia Research Foundation Grants Program

The Dementia Australia Research Foundation is the research arm of Dementia Australia. It provides funding to Australian researchers who are researching in areas relating to the diagnosis,

management, 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 2017, the Foundation awarded grants to 17 individuals to undertake research into dementia. This delivered more than \$1 million in funding directly to researchers across 13 project grants and four PhD scholarships.

### **NHMRC Cognitive Decline Partnership Centre**

Dementia Australia continued its strong relationship with the NHMRC Cognitive Decline Partnership Centre (CDPC) as one of four contributing organisations. The CDPC 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 CDPC is unique in that people living with dementia, their families and carers are involved at every stage of the research process. The CDPC 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 CDPC is translating its research outcomes into practice. By June 2018, CDPC supported activities had produced more than 1,200 outputs including published academic papers, reports, conference presentations and workshops. The CDPC advocate group has played a vital role in promoting key messages, having presented its work at both national and international conferences throughout the year.



Dementia Advocates, Paul Bryden, Glenys Petrie, John Quinn, Pat Walsh, former Acting CEO Alzheimer's Australia QLD, Songwoman Maroochy Barambah, Jillian Jeffery, General Manager Operations, Dementia Advocate, Christine Bryden, Maree McCabe, CEO Dementia Australia and Professor Stephen Sabat at the 2017 Dementia Awareness Month event in Brisbane.



# Our organisation

## Business Development

Business Development is about the creation of 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. For example, leveraging current programs for expansion or income opportunities and creating new programs/products. This will allow us to become less reliant on government funding at a time when there is increased competition for the government dollar.

Some of the broad functions of Business Development are the provision of state-based relationship and partnership opportunities through the Regional Directors, establishment of the Centre for Dementia Learning (CDL), which will leverage our professional educational and consulting services for expansion nationally, sponsorships, innovation and technology, and a range of strategic projects.

During the first 12 months since unification, Business Development has focused on:

- creating a business and financial model for our commercial enterprise across Dementia Australia
- establishing 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 to 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 have been numerous. Based on our great track record, we were delighted when we were able to extend our state-based Registered Training Organisations registrations into a single national membership, enabling efficiencies and increased reach in our accredited training programs.

### Learning opportunities

Now we are one organisation, our Enabling EDIE™ workshops are available across all states and territories. Enabling EDIE™ is a three-hour workshop incorporating our EDIE™ app, which uses virtual reality technology to allow participants to explore in detail the impact a diagnosis of dementia can have. Among the target audience of health and aged care professionals (to whom the training is available as a fee-for-service offering) the objective is to deliver education in a way that prompts empathy alongside knowledge. Research has found that participants are better able to understand dementia

from the consumer's perspective, placing them in a stronger position to develop an effective support plan that enables the person with dementia to live more confidently.

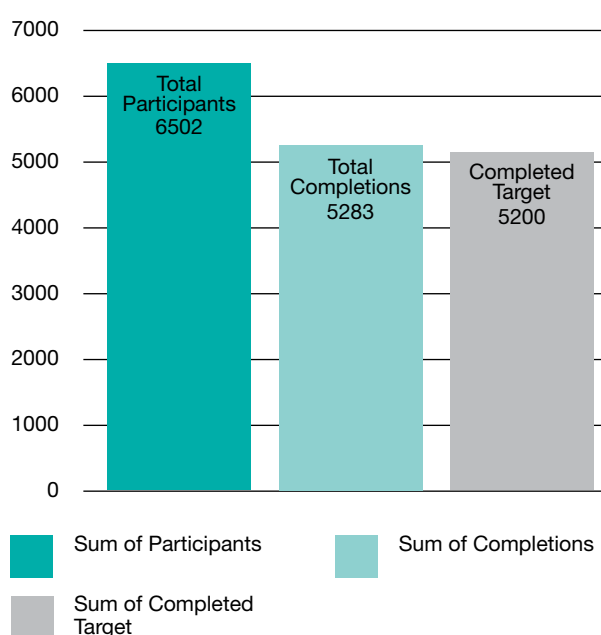
We also conducted a learning technologies showcase with a visiting trade delegation from the Czech Republic, which was facilitated by AusTrade. The fourteen delegates represented a range of aged, disability and health care providers who were visiting services and providers across Victoria, New South Wales and Queensland. They experienced some of the great examples of our innovative uses of technology in dementia care, including the Virtual Dementia Experience™, EDIE™, The Virtual Forest™ and The Dementia-Friendly Home App™.

The attendees were very interested to hear about our work and we were invited to present at their long-term care conference in Prague in late 2018.

### Centre for Dementia Learning

The aims of the 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.

### Total number of participants who commenced Dementia Essentials and total number of participants who successfully completed Dementia Essentials





The Navarra family donated \$30,000 to Dementia Australia's A Night to Remember in Sydney in February 2018. The event at Sydney's Le Montage, raised an incredible \$210,000. Channel 10 newsreader and Dementia Australia Ambassador Natarsha Belling was MC, joined by guest speakers Phil Hazell, Alex Florio, Sabrina Navarra and Silvana Zaami. Entertainers Luke McGregor, The Three Waiters and Judah Kelly ensured the guests were kept amused throughout the night.

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

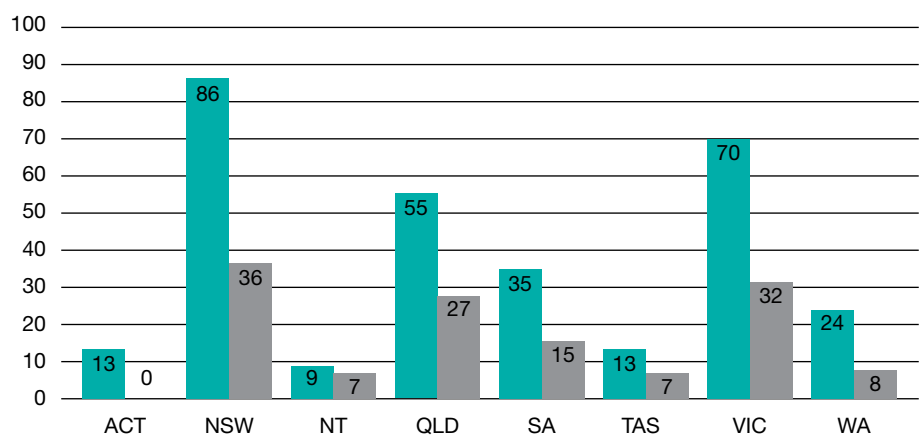
- develop career pathways for those wishing to become leaders in dementia practice
- provide ongoing opportunities for people to develop dementia knowledge and skills
- create unique learning experiences which touch, move and inspire participants to change their attitude and consequently their behaviour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

It has been established with a clear focus on sustainability through providing a number of services on a fee-for-service basis, so that there is less reliance on government and other sources. This is also seen as important in how these services are valued and the extent to which there is a commitment to change as a result.

The Dementia Training Australia, Dementia Essentials program had a significant reach nationally with a target in 2017–18 of 6,500 aged care workers being provided with this three-day accredited program. Those who successfully

### Number of metro and regional/remote Dementia Essentials courses

- Sum of Metro run courses
- Sum of Regional/Remote run courses





From left Graeme Wickenden, IT in Aged Care (ITAC) Organising Committee; Kelly Burns, Course Developer; Dr Tanya Petrovich, Manager Business Innovation and Rod Young, Chair, ITAC Organising Committee celebrate Dementia Australia's win in the ITAC awards in November 2017.

complete the workplace assessment, which provides an opportunity to apply the learnings, also receive a certificate of attainment.

The national rollout of the Educational Dementia Immersive Experience™ (EDIE™) using virtual reality provides participants with unique insights into what it might be like to live with dementia. An independent Swinburne University evaluation of the program found it not only increased participants' understanding of dementia and the importance of dementia-friendly design principles, but also increased empathy. This is critical if we are going to influence attitudes and change behaviours.

The EDIE™ program has also received recognition, winning the Simulation Australasia Project Innovation Award and the Best Aged Care Software Development and Deployment Award at the Information Technology in Aged Care (ITAC) Awards.

It was also a great achievement to have the Victorian team recognised as the 2017 Small Training Provider of the Year at the Victorian Training Awards. This was for their work in creating unique immersive learning experiences which provided participants with unique insights into what it can be like to live with dementia.

### Transforming dementia practice

While providing a comprehensive suite of evidence-based quality dementia education through a variety of formats is the central focus of the Centre for Dementia Learning, we know from the research that only 10 per cent of learning occurs through

formalised learning opportunities. A further 20 per cent occurs through coaching and mentoring staff and the remaining 70 per cent occurs on the job. Consequently if we are to transform dementia practice we also need to work with organisations.

To address this we developed our consultancy service a number of years ago so that we could work with organisations to develop improved models of care and organisational cultures which supported the ongoing learning of staff and the practices we promote through our learning programs.

Initially, we focused on improving the physical environment in aged care facilities as we know this can be a trigger to changed behaviours. We also focused on improving the engagement programs offered in residential aged care. However, increasingly our work has focused on assisting with the organisational change required to introduce a new model of care. Through effective engagement with senior leadership, managers, direct care staff, families and carers and most importantly people living with dementia, we have been able to see a significant improvement in the quality of services provided and also the levels of staff engagement and satisfaction which has had a positive impact on staff retention.

Importantly this work is funded by these organisations who have chosen to invest in building their organisational capability in a range of areas as part of their commitment to become providers of choice in dementia support and care.

### Fundraising

The national fundraising team has been focused on building stability and growing our donor base, while also seizing this opportunity to test our field and try new fundraising modalities.

Successful national fundraising initiatives have included our A Night to Remember gala dinner in Sydney, our golf day in Melbourne, Dementia Australia being named charity partner of the Brisbane Broncos, and various community fundraising events. A great example being Adelaide Crows player Bryce Gibbs' commitment to cutting off his long hair in order to raise funds for charities including us in South Australia.

We energised the public to get involved with national running events such as Run Melbourne, Sydney Half Marathon and Bridge to Brisbane Day, as well as our 2018 national challenge event A Trek To Remember that took an intrepid group of donors to Everest Base Camp for the adventure of a lifetime, while also raising funds.

Unification provided the opportunity for the Memory

Walk & Jog series to be national for the first time. Fundraising team members from across the country joined forces with human resources, marketing and communications teams to bring the series of 10 events to fruition.

Working as one national team has allowed for consistency in the event program, branding and organisational approach. It has also been a successful exercise in raising awareness, with a large amount of traditional and social media coverage resulting from these events.

It is the selflessness and generosity of our Ambassadors and volunteers, alongside the hard work of our own team that ensures these events remain a success, year after year, and continue to make a difference to the lives of people living with dementia.

In addition to the 10 flagship events, those unable to make it to one of these locations were encouraged and supported to establish their own DIY Memory Walk & Jog event in their local community. More than 50 such events were planned, with even more people signing up to participate in a solo My Memory Walk & Jog challenge.

### Partnerships

Dementia Australia is a partner in Alzheimer's Disease International's project supporting the work

of Alzheimer's associations in developing countries. Contributing to a twinning project with Nepal, we have provided staff and resources to support Nepal in its efforts to tackle dementia locally.


Dr David Sykes, our Director of the Centre for Dementia Learning, and Ann Reilly, General Manager Client Services, attended the Alzheimer's Disease International Dementia Care Skills Train the Trainers program in Jakarta, Indonesia. The program brought together potential trainers from across the Asia Pacific region to be trained to deliver an educational program locally, based on our own Dementia Essentials program. They were invited to be part of a group that assessed participants' capacity to deliver this program, with trainers from Pakistan, Nepal, Thailand, Indonesia, Tonga, India, Myanmar and Singapore.

In NSW, we delivered 38 Enabling EDIE™ workshops to Calvary, a not-for-profit Catholic health care organisation. In Queensland, we forged a partnership with Kaplan Education, which is the membership organisation for more than 33,000 financial advisors across Australia. The partnership will result in the organisation incorporating dementia information into its communications with members and, in time, dementia education into its continuing professional development programs.

## THANKS TO YOU WE'VE ACHIEVED SO MANY IMPORTANT THINGS



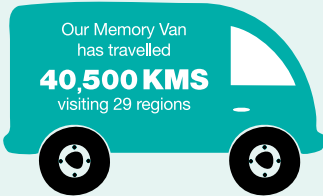
The National Dementia Helpline has dealt with  
**45,000 CONTACTS**




The library has provided over  
**13,000**  
resources for people in need



**PROVIDED 4,852 ONE-TO-ONE**  
counselling sessions and  
407 counselling groups



Our Memory Van has travelled  
**40,500 KMS**  
visiting 29 regions



**10,000 DEMENTIA KITS DISTRIBUTED NATIONALLY**

Managed **YOUNGER ONSET DEMENTIA** programs for 1,270 active clients with 1,094 new referrals this year




**\$1 MILLION** granted in 2017 to **17 NEW PROJECTS** to conduct ground-breaking dementia research

Announced jointly funded \$1 million Dementia Australia Research Foundation – Yulgilbar Innovation Grant.



Continued **ADVOCACY AND AWARENESS** including 'You are not alone', and the launch of our Dementia Friends program.

Our flagship workshop **EDIE – Educational Dementia Immersive Experience** received the **Best Aged Care Software Development and Deployment Award** at the Information Technology in Aged Care Awards



Information sent to donors about how their generosity has helped people living with dementia, their families and carers.

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## Marketing

With the launch of Dementia Australia, the new voice of Alzheimer's Australia, the marketing team undertook an extensive rebranding and awareness campaign to launch the new national organisation.

A 'Turn to us' campaign encouraged people to make contact via the National Dementia Helpline or our website.

The Dementia Friends campaign commenced in March to call on members of the community to sign up to become dementia friends. The campaign aimed to inspire people to sign-up and become Dementia Friends by June 2019, and saw the

development of the Dementia-Friendly Communities website, a resource for individuals and community groups to learn more about how they can make their local communities more dementia-friendly.

A review of marketing collateral across all states and territories commenced with a view to taking a targeted approach to ensure we continue to have the right materials for the right purposes, while filling any gaps in information identified. As much as possible, we will create national materials, recognising there are local nuances that may need to be reflected in some pieces.



Dementia Conference delegates commit to being the change in dementia care, in the conference photo booth.

# 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.

We received the Best Aged Care Software Development and Deployment Award at the Information Technology in Aged Care Awards in November 2017, and the Small Training Provider of the Year Award a month earlier at the Victorian Training Awards.

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.

The aim was to create 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.

As a result, our flagship workshop, the Virtual

Dementia Experience™ delivered in Parkville, Melbourne, has attracted 4,000 participants since its launch in October 2013.

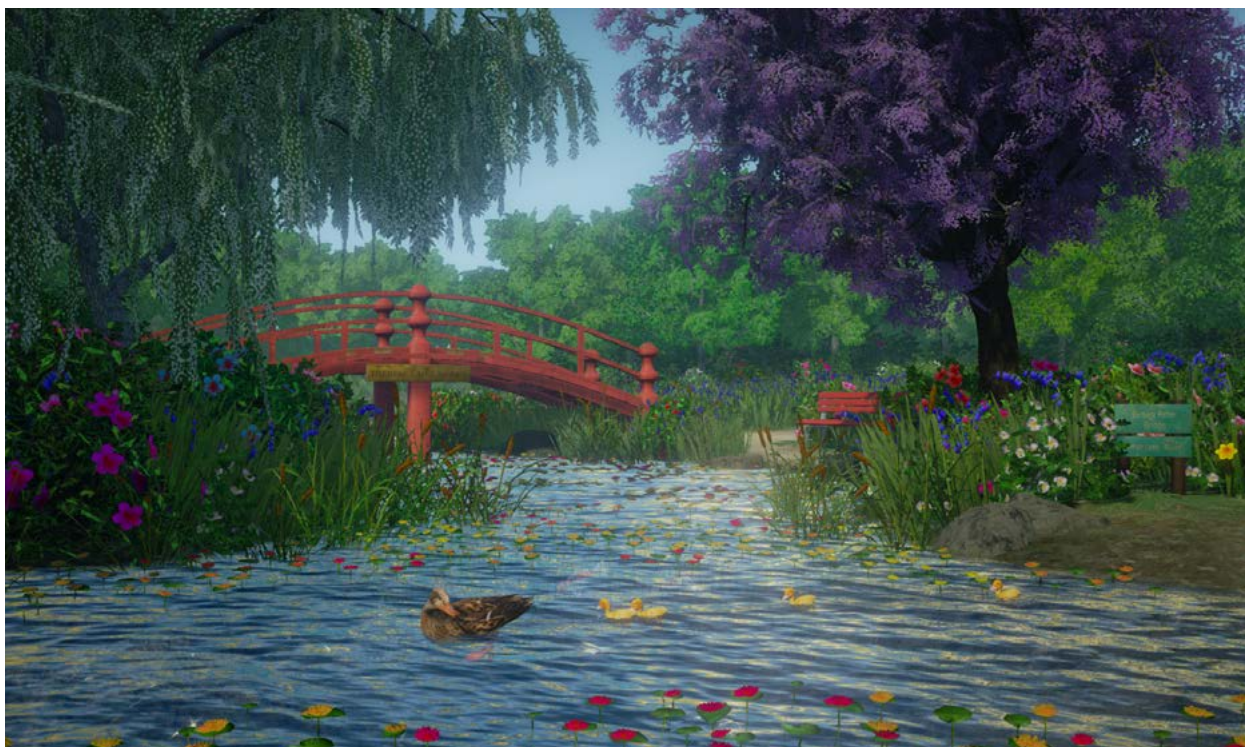
Using game technology, the workshop shifts from an information session to an experiential session and the worker is exposed to the lived experience of a person with dementia, which helps them develop empathy for that person. This has resulted in participants making changes to their work practices to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

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



The Virtual Forest™, a peaceful and enjoyable immersive environment designed specifically to improve the quality of life for people living with dementia.

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 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.



Leader of the Opposition, The Hon Bill Shorten MP experiencing EDIE™ in August 2017 after a consumer roundtable meeting.

## Dementia Australia's award-winning technology

- **2017 Winner** – Best Aged Care Software Development and Deployment Award, Information Technology in Aged Care Awards (ITAC)
- **2017 Winner** – Enabling EDIE™ Project Innovation Award, Simulation Australasia
- **2015 Gold Winner** – Virtual Dementia Experience™ Victorian Public Healthcare Award Excellence in person, family and community-centred care
- **2015 Winner – With Opaque Multimedia** Virtual Dementia Experience™, Microsoft Imagine Cup World Citizenship Award
- **2015 Finalist** – Virtual Dementia Experience™ HESTA Community Sector Awards Outstanding Organisation
- **2014 Winner – With Opaque Multimedia** Virtual Dementia Experience™ at The Perc Walkley Dementia Learning Centre, Asia Pacific ICT Alliance Awards APICTA for eLearning
- **2014 Winner – With Opaque Multimedia** Virtual Dementia Experience™ at The Perc Walkley Dementia Learning Centre, Victorian iAward eLearning
- **2014 Winner – With Opaque Multimedia** Virtual Dementia Experience™ at The Perc Walkley Dementia Learning Centre, National iAward Education Category
- **2014 Finalist – With Opaque Multimedia** Virtual Dementia Experience™, Melbourne Awards Contribution to Profile
- **2012 Gold Winner** – BrainyApp Victorian Public Healthcare Award, Healthcare Innovation Award – Optimising healthcare through e-health and communications technology

# Memory Walk & Jog

Nationally, our Memory Walk & Jog raised more than \$1.2 million from registrations, fundraising and corporate sponsorships in 2018, with 10,000 runners and walkers, volunteers and spectators taking part in 10 flagship and 34 DIY walks across the country.

Memory Walk & Jog has grown to become the largest national event raising funds and awareness for dementia.

This year, the Memory Lounge was launched at Memory Walk & Jog events to explore the importance of sharing memories and never taking your memories for granted. A total of 219 walkers recorded their personal memories in the Memory Lounge, supported by Nikon, and spoke about why it was important for them to take part in Memory Walk & Jog.



Dementia Australia Ambassadors Takaya Honda (Neighbours, Playschool actor) and Doris Younane (The Wrong Girl, McLeod's Daughters actor), front centre, leading the charge at the Brisbane Memory Walk & Jog in Rocks Riverside Park, Seventeen Mile Rocks on 3 June 2018.

**“ I saw the Memory Walk & Jog and straight away signed our family up to participate and fundraise. We are taking part as, through our experience with dementia and the effects it’s had on our family, we believe it is so important to raise awareness of the disease and the impact it has on families and loved ones of those diagnosed.**

**Actively sharing and fundraising has been very hard in many ways, and particularly emotionally for all of us. But through being a part of a community supporting Dementia Australia, in their fundraising, raising awareness, research and support, we have found something to positively focus on in relation to dementia.**

An event participant shared these thoughts on Dementia Australia's Facebook pages





More than 820 people attended the Adelaide Memory Walk & Jog at Colley Reserve, Glenelg on 18 March, raising more than \$72,500.



And they're off... Nearly 500 people took part in the Sunshine Coast Memory Walk & Jog at Kawana Surf Club, Buddina on 24 June.

# Our thanks

We would like to acknowledge those who have generously supported Dementia Australia in 2017–18. These include substantial bequests, in memoriam donations, major sponsors, philanthropic trusts, foundations and private ancillary funds, individuals, companies, organisations, community fundraisers, and volunteers. Every gift is appreciated.

## Government

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



Dementia Australia Ambassador Ita Buttrose AO OBE with guests at A High Tea to Remember, Hotel Windsor, Melbourne October 2017. Dementia Advocates, Isabelle Burke and Tara Macdonald are left and right of Ms Buttrose.



Anne Tudor and Edie Mayhew, Dementia Advocates and their younger onset dementia assistance dog, Melvin. All three are participants in a research project partnership between Dementia Australia, University of Melbourne and Vision Australia Seeing Eye Dogs Australia

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## Contact us

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**National Dementia Helpline** 1800 100 500

Funded by the Australian Government

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## Find us

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## Online resources

<https://www.dementia.org.au/resources/websites>

Online Dementia Support is available after hours at [helpwithdementia.org.au](http://helpwithdementia.org.au)

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## Regional offices

Dementia Australia has regional hubs, supporting our services in all States and Territories.

<https://www.dementia.org.au/support/in-your-region>