

**UNDERSTAND ALZHEIMER'S
SUPPORT AUSTRALIA**



**ALZHEIMER'S
AUSTRALIA NSW
ANNUAL REPORT
2016-2017**

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SUPPORT AUSTRALIA**

Alzheimer's Australia NSW

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CHAIR MESSAGE



Having had the privilege of being Chair of this remarkable organisation for almost two years and, with the pending nationalisation and official change of name to Dementia Australia, it seems timely to reflect upon my time with the organisation, how far we have come and what the future looks like.

Throughout my time as Chair, I have worked with countless numbers of dedicated staff which has been truly inspiring, particularly in this recent period of transition during which they have worked hard to maintain continuity and quality of service above all else.

Alongside our staff, the overwhelming support offered by our amazing volunteers has also been a pleasure to witness.

Meanwhile, the loyal support of the donors and fundraisers who help us ensure we meet the ever-increasing demand for our services has been steadfast and has continued to enable us to achieve great things, many of which you will read about in this Annual Report.

I would like to acknowledge my fellow Board members for the enthusiasm and commitment they have shown for this important cause, selflessly offering their time and experience to further the success of this organisation.

It is the selfless giving of all these people, during the past financial year and in every previous year, that has helped us to make an immeasurable difference to the lives of people living with dementia, their families and carers, right across New South Wales. We should all be very proud.

And now, we enter a new chapter in our organisation's history. I have no doubt that the nationalisation will strengthen dementia advocacy and service-delivery in Australia long into the future.

Joining with our colleagues around Australia in becoming a unified organisation will result in improved outcomes for all people affected by dementia, particularly as our population ages and dementia prevalence continues to increase.

Equally, as dementia is the umbrella term used to describe a wide range of illnesses, Dementia Australia is a far more inclusive name for our organisation, and one which we believe will encourage more people to seek out our services.

As I officially sign off as Chair, I would like to thank everybody who has contributed in any way to the success of our organisation during my time here, and all those who came before us. Together, we have created something truly special that will continue to support people impacted by dementia long into the future.

Paul Robertson AM

Chair, Alzheimer's Australia NSW

CEO MESSAGE



The 2016-2017 financial year at Alzheimer's Australia NSW was a time of change, as we laid the groundwork for the unification of the Alzheimer's Australia federated organisations, including Alzheimer's Australia NSW, to one unified body known as Dementia Australia.

I believe these changes were essential for placing us in the strongest position to face the growing dementia challenge and provide the best support for people living with dementia, now and into the future.

As one unified body, we will be more efficient, professional and focused in delivering services, and remain up-to-date and responsive.

When you consider that there will be more than one million Australians living with dementia within 40 years, it is clear that reform was essential. Putting it bluntly, we have never faced a health and social challenge like the dementia epidemic. Dementia changes individuals, affects families and communities, and will change the face of Australia.

Alzheimer's Australia NSW was created almost 35 years ago when carers and loving family members came together to speak up for those with dementia. They called for better information, improved diagnosis, high-quality services and increased understanding.

We have never lost sight of this commitment, as you will see throughout this Annual Report, which provides a snapshot of our activities during the last financial year, including many achievements and highlights. As Dementia Australia, this commitment will only be strengthened as the different state and territory bodies combine their expertise and resources.

This is my last official communication as the CEO of Alzheimer's Australia NSW, and I would like to express my thanks to our members, supporters and donors for everything they have given us over the years, as well as our hard-working staff, dedicated Board, incredible volunteers and committed Ambassadors.

I hope you will enjoy reading about the many successes Alzheimer's Australia NSW has enjoyed during its final year, and that you will join me in wishing Dementia Australia every success as it continues its vital work in supporting all Australians living with dementia, their families and carers.

The Hon. John Watkins AM
CEO, Alzheimer's Australia NSW

SUPPORT SERVICES AND EDUCATION

It has been another positive and dynamic year for the Client Services team at Alzheimer's Australia NSW.

The team delivered a high number of community awareness events, education and counselling sessions, living with dementia programs and supplied much needed information, support and resources for people with dementia, their families and carers, and health professionals.

This activity included a number of new initiatives, demonstrating our commitment to continually seeking ways to increase our reach and support people living with dementia, carers and families.

National Dementia Helpline

During this reporting period we saw a significant increase in Helpline calls and contacts. Our contractual target has been achieved, and we are on track to over-achieve on our annual target of contacts.

The increase in contacts has been the result of a dedicated marketing and media campaign focusing specifically on the Helpline service and the value of it, and an emphasis on the ongoing need within the community for easy access to dementia information and support.

Dementia Essentials

Dementia Essentials is a Commonwealth funded initiative delivered by Alzheimer's Australia, offering fully funded education to direct care staff who provide support to people living with dementia. It is aligned to a nationally recognised unit of competency from the Community Services training package.

The program commenced in NSW for the first time in October and is progressing well, with our annual target achieved for 2016/17, high satisfaction scores from participants and bookings now being accepted for the next financial year.

Commonwealth Home Support Program (CHSP)

In February, we implemented the client contribution fees for the majority of our CHSP services, which includes our dementia advisory service, mobile respite and telephone support. This has been well received by existing and new clients, and the client contribution fees have helped to emphasise the value of the work we do.

Webinars

Technology will continue to provide another modality for delivering our services. Over this reporting period, we have started to implement additional carer education webinars including one targeted specifically at people who have been recently diagnosed. These webinars complement our face-to-face courses and provide an opportunity for clients who cannot physically attend sessions.

Introduction of technology-based services

Recognising the opportunities associated with technology in accessing information, we completed our first evening session webinar for the families and friends of people living with dementia. The event was very successful, attracting significant interest and is now being delivered more broadly.

The success of this webinar and the lessons learned through running it led us to develop a plan to deliver our Recently Diagnosed forum via webinar. This is a significant change to our traditional delivery model, and with the appropriate promotion we are confident this could present a viable option for increasing our reach.

As part of our technology-based services, we have continued to deliver the Better Life program, which aims to improve access to our services for people with dementia across NSW who may be geographically and socially isolated. Coaching was delivered via telephone and video communications affording a more accessible, flexible and individualised program option, tailored according to each client's personal goals for wellbeing. The program reached people who were not otherwise engaged with our services and linked them with community and social supports.

Enabling EDIE™ interactive workshop

The past financial year saw the introduction of EDIE™ to the Alzheimer's Australia suite of educational programs, including in NSW.

The series of three-hour workshops for professionals is for those who work with people impacted by dementia, incorporating virtual reality smartphone app EDIE.

The ground-breaking technology uses Samsung VR Gear to offer a high quality virtual reality experience that enables participants to see the world through the eyes of a person living with dementia, with a view to enhancing dementia knowledge, understanding and empathy.

Participants explore what it might feel like to live with dementia, care for somebody with dementia and work in partnership with those impacted by the disease to identify support needs and develop a plan that enables them to live more confidently.

Coupled with input from expert facilitators, the technology leaves participants with the skills and knowledge required to enhance the care they offer through increased levels of engagement, support and empowerment.



CORPORATE SERVICES

Enabling Alzheimer's Australia NSW to meet and plan for expanding community needs and expectations has remained a key focus of the Corporate Services function. The team provides a range of services covering financial, quality, technology, compliance and risk management.

Our current focus is on being responsive to change and ensuring the organisation is well positioned to meet the challenges and opportunities that arise within the communities we service.

Financial capacity

Maintaining a strong balance sheet has contributed to the financial stability of Alzheimer's Australia NSW, providing valuable assistance with our ongoing funding requirements. In 2016-2017 we continued to strengthen this position, with reserves increasing.

During 2017, the initiation of the Dementia Australia unification project, bringing eight Alzheimer's Australia state and territory bodies together to form one nationalised organisation, became an important focus for the Corporate Services teams.

Building capacity

The process of unification has increased the collective capacity of the Dementia Australia group with projects being implemented to realise and enhance our capacity to deliver services. As part of the change process, we also commenced the integration and alignment of our systems within a unified structure.

Managing quality and risk

Throughout the unification process, we continued to underpin our services with a strong commitment to quality. We recognise that in the rapidly changing aged care environment, flexibility, adaptability and efficiency are key to ensuring we are able to continue delivering positive outcomes to all those who engage with us.

We maintain accreditation in line with the Quality Improvement Council's Health and Community Services Standards and a number of funding body and program specific standards.

POLICY AND RESEARCH

Policy and Research is an important function for Alzheimer's Australia NSW, contributing to increased awareness and knowledge of dementia, and improved quality of care and support for people living with dementia, their carers and families. This year saw the dissemination of discussion papers and reports, evaluation projects, resources, and presentations and conferences. Highlights for 2016-2017 include:

- August 2016 – Living Well with Dementia Conference
- August 2016 – Living Well with Dementia discussion paper
- August 2016 – paper presented at the International Association for the Scientific Study of Intellectual and Developmental Disabilities Conference in Melbourne
- September 2016 – Dementia and Loneliness report prepared for Dementia Awareness Month
- November 2016 – Driving and Dementia discussion paper launched at Parliamentary Friends of Dementia
- November 2016 – two papers presented at the 19th Asia Pacific Regional Conference of Alzheimer's Disease International in Wellington, New Zealand
- June 2017 – Relationships and Dementia discussion paper launched at Parliamentary Friends of Dementia (attended by the NSW Premier)
- June 2017 – Evaluation of Liveable Communities – Dementia Friendly Communities completed
- 'Dementia in Retirement Villages' training delivered for the Property Council of Australia's Village Management Advanced Courses Sydney and Perth and the Aged & Community Services Australia (NSW) Retirement Village Management
- Co-authored a book chapter 'Person-centred Care and Cultural Safety: The Perspectives of Lesbian, Gay and Trans (LGT*) People and their Partners on Living with Dementia' in the 2016 edition of Lesbian, Gay, Bisexual and Trans* Individuals Living with Dementia by Sue Westwood and Elizabeth Price.
- Submissions and consultations for the Review of NSW Guardianship Act by NSW Law Reform Commission
- Development of the NDIS Participant Readiness Resource for People with Younger Onset Dementia with funding from NSW Government (FACS)
- Development of National Help Sheets including My Aged Care; Residential Aged Care; Home Care; and The NDIS YOD Booklet.
- Represented the organisation on sector networks and committees including:
 - Guardianship Division Consultative Forum
 - Carers NSW Strategic Carers Action Network
 - Older People's Mental Health Working Group
 - NSW Ageing Alliance
 - Futures Alliance
 - UNSW research advisory committee: LGBTIQ people with dementia and BPSD eLearning resource project.
 - UNSW research advisory committee: Collaboration between family care staff in quality improvement of RAC
 - NSW supported decision-making interest group

Discussion papers are available online at <https://www.dementia.org.au/nsw/research>

Help Sheets are available online at <https://www.dementia.org.au/about-dementia/resources/help-sheets>

MARKETING, MEDIA AND COMMUNICATIONS

Throughout our activities over the past twelve months, people with dementia, their families, carers and friends, have remained at the heart of everything we do. We are fortunate to have so many consumers who are passionate, ready and willing to share their own stories so generously with the media and the wider community. Telling such powerful stories helps us to make a real impact as we advocate, raise awareness and work to improve understanding of dementia.

2017 Memory Walk & Jog

During 2016-2017, we supported the Fundraising team to publicise yet another successful Memory Walk & Jog series. The series commenced in Wollongong on 26 February, before heading to Penrith, Sydney, Hunter and Port Macquarie.

Almost 6,000 participants turned out across the five events, raising an impressive total of \$700,000. This money will go towards funding services for people living with dementia, their families and carers, in the communities local to each event.

Aside from raising funds, events like Memory Walk & Jog play an important role in raising awareness of dementia amongst the general community and starting a conversation in the media.

As well as creating widespread discussion across our social media platforms, our team generated more than 130 print, radio and television items, reaching an approximated audience of more than 4.5 million people. In partnership with our Alzheimer's Australia colleagues in other States and Territories, we also contributed to the generation of more than 250 national media items, with an approximate audience reach of more than 6.5 million people.

Dementia Awareness Month 2016



During Dementia Awareness Month, which runs each year throughout September, Alzheimer's Australia NSW called for greater awareness and understanding of dementia, to help people living with the condition feel less isolated and alone.

Public lecture

One of the world's leading dementia experts, Dr Ron Petersen, spoke in Sydney at NSW Parliament House as part of a national speaking tour for Dementia Awareness Month.

Dr Petersen presented on the latest insights and findings in dementia research, the importance of an early diagnosis, as well as current diagnostic techniques, how the diagnosis is made, treatment options and future directions.

During his presentation, Dr Petersen also publically supported our call for a fully-funded, national strategy to tackle the growing challenge of dementia.

Dr Petersen is the director of the US Mayo Clinic Alzheimer's Disease Research Center and was appointed by US President Barack Obama's Administration to head up the Advisory Council for the National Alzheimer's Project Act (NAPA), which is an integrated national plan to overcome Alzheimer's disease in the US by 2025.

Below Participants enjoy our Memory Walk & Jog events





Above Professor Henry Brodaty, Alzheimer's Australia CEO Maree McCabe, Dr Ron Petersen and The Hon. John Watkins AM at the Dementia Awareness Month Public Lecture

Dementia and loneliness

In partnership with our national Alzheimer's Australia colleagues, we released the results of a survey to coincide with the start of Dementia Awareness Month, which revealed that people with dementia are almost twice as likely to have high rates of loneliness compared to the general public.

The research generated a widespread media conversation on this issue, and sparked calls for greater awareness and understanding of dementia by the general public.

Other Dementia Awareness Month events

- A regional lecture tour by Australian dementia expert Professor Jacqui Close
- Still Dementia in a Changing World: A free public forum that talked about consumer directed care, and assistive technology and dementia
- Healthy Ageing and Dementia forums: Free public brain health information sessions held across the state, including forums tailored to Culturally and Linguistically Diverse Communities through bilingual workers

Communicating the economic costs of dementia

Our report entitled *The Economic Cost of Dementia in Australia 2016-2056* revealed the number of people with dementia in Australia has soared to more than 400,000 – with almost 139,000 in NSW - meaning an estimated cost to the community of more than \$14 billion in 2016 alone.

The research also found that if nothing is done to reduce the incidence of dementia, the cost will increase to more than \$18 billion by 2025, in today's dollars, and more than double to \$36 billion in less than 40 years.

The media campaign to support the release of this research included NSW consumer and Dementia Advocate Phil Hazell, who is living with younger onset dementia. Phil participated in a number of national media opportunities, helping us to significantly further the reach of the report's messages.

Promoting our National Dementia Helpline

In terms of marketing and communication activities, our vital resource the National Dementia Helpline became a real area of focus during the past twelve months. We developed a number of radio advertisements and social media posts, featuring consumers telling their own stories, the signs of dementia and links to information and support.

The campaign ran over six months and was a great success, with the online campaign alone reaching 1.76 million people and generating hundreds of requests for Dementia Kits, several Helpline call back requests and Helpline calls.

FUNDRAISING

Thanks to all the generous supporters who have donated to our cause this year. We really appreciate your support, which helps us to continue to deliver vital services to more clients across NSW.

Individuals and organisations have generously donated via our four direct mail appeals and through our Regular Giving program, as well as via:

Bequests

We would like to wholeheartedly thank all the wonderful people who remembered Alzheimer's Australia NSW in their Wills during 2016-2017. Whether small or large, a gift in your Will makes a difference to the lives of those diagnosed with dementia and their families. It assists necessary research and a variety of dementia projects that will help meet the challenges facing us as a community in the years to come. These gifts help us build a better future for people impacted by dementia.

Corporate partnerships

We would like to thank all our generous corporate partners from 2016-2017, including:

- Opal Aged Care
- Eli Lilly
- Elder Abuse Hotline
- Day by Day Art Therapy
- Yours Magazines
- Navarra Venues
- Lovatts Crosswords and Puzzles

Workplace giving

Throughout the year, several corporate supporters have given their staff the opportunity to donate a portion of their monthly wage to support Alzheimer's Australia NSW. In some cases, these corporate supporters have also chosen to match the donated amount.

Below A participant enjoys one of this year's Memory Walk & Jog events



Thinko!

A new multi-platform fundraising campaign was launched at a celebrity trivia night in September, to coincide with Dementia Awareness Month. Thinko! allows families, corporate groups and individuals to take part in trivia and brain training games while raising funds for Alzheimer's Australia NSW. The launch event, held at Le Montage in Lilyfield, made a profit of \$230,000.

Below Alzheimer's Australia NSW Ambassador Natarsha Belling at the launch of Thinko!



Below Attendees enjoy the Thinko! launch event



Memory Walk & Jog

The latest Memory Walk & Jog series saw five events across NSW, which were attended by nearly 6,000 participants and raised \$700,000.

Many people who couldn't attend one of the five events chose to hold their own DIY Memory Walk & Jog events across the state. A total of 19 of these events saw 800 more people become involved with Memory Walk & Jog, raising \$25,000.

Twenty individuals also took part in a personal MY Memory Walk & Jog challenge, raising an additional \$8,000.



Above Participants trekking Mt Kilimanjaro to raise funds for Alzheimer's Australia NSW

Challenge events

2016 saw our first annual overseas challenge event which took 18 participants to Tanzania to climb Mt Kilimanjaro – Africa's largest mountain. The team trekked for a week through varying conditions to reach the summit at nearly 6,000 metres above sea level, raising \$60,000. The next challenge events are planned for Kokoda in September 2017 and Everest in 2018.

Community fundraising

Community fundraising is a vital means of helping to raise funds for people living with dementia, their families and carers. A few of the many highlights for 2016-2017 include:

- Bondi2Berry cycling event – with high profile participants and attracting good media coverage,
- Love Cannot Be Forgotten afternoon tea
- A motorcycle group held The Dementia Ride,
- A community-run golf event
- A photo exhibition
- A community day in Cabra Vale
- Judd Farris corporate touch football tournament
- Collection Day on World Alzheimer's Day, with match funding from one corporate group

Below Alzheimer's Australia Ambassador Ita Buttrose joins participants at the starting line of Bondi2Berry



Below Our fundraisers, out in force on Collection Day



VOLUNTEERS

Sporting events

Sporting events are another great way of raising awareness of dementia and highlighting the need for funds. This year more than 120 runners participated various sporting events, including Blackmores Sydney Running festival and City2Surf participants.

In Memoriam

Our sincere appreciation to the families who chose to collect donations to Alzheimer's Australia NSW at a loved one's funeral this year, in-lieu of flowers. Donations in memory of someone special are such a personal way to support the wishes and values of your loved one, and we are truly grateful for the support of these families.

Trusts and Foundations and Club Grants

We received many generous donations from established Trust and Foundations for the development and distribution of resources to support people living with dementia, along with more than \$93,000 from clubs across NSW to support the following projects:

- The Port Macquarie dementia-friendly sensory garden - \$20,000
- The North Ryde dementia-friendly sensory garden - \$18,700
- CALD Healthy Brain Ageing seminars in the western region of Sydney and other educational support services - \$9,500
- Set-up of the e-book service for the library - \$10,750
- Queanbeyan Carers Support Group - \$3,600.

Thanks again to everyone who has supported us throughout this year.

The Memory Walk & Jog Series was the primary volunteering program for us in 2016-2017. A total of 345 fantastic volunteers turned up in the early hours of the morning, to ensure that five successful Memory Walk & Jog events took place across the state.

Volunteers have been integral to events such as Collection Day and gala balls, administrative and library support roles at North Ryde and our regional offices, assisting with a wide variety of social and support groups in areas throughout NSW, and providing information at our Memory Vans.

A volunteers and supporters thank you event was held at North Ryde in December to celebrate and acknowledge these achievements, and we would like to take this opportunity to send out a special message to all of our fabulous regular volunteers to say thank you.



Above Volunteers at sunrise at the Illawarra Memory Walk & Jog 2017