

**UNDERSTAND ALZHEIMER'S
SUPPORT AUSTRALIA**



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

**UNDERSTAND ALZHEIMER'S
SUPPORT AUSTRALIA**

Alzheimer's Australia Ltd

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CHAIR'S REPORT



The year 2016-2017 will be seen as a watershed moment for us as an organisation with significant decisions made about our future direction. This financial year saw the Board of Alzheimer's Australia take the decision to become a united organisation that will ensure that we

continue to advocate and provide even better services for people living with dementia.

Unification ensures we are a united force in the aged care sector that enables us to respond to the changing nature of this sector. Moving forward we will be united under our new name, Dementia Australia. Our new structure and name will provide assurance to consumers that we are the voice of all people, of all ages diagnosed with all forms of dementia and we will continue to advocate on their behalf.

Alzheimer's Australia has had strong support from the Federal Government for this process. We thank and acknowledge them for their continued support for both unification and our organisation.

What began as a formal process progressed into functional changes within our organisation and we will continue to see more changes next year as a result of unification.

The board members, CEOs and leadership teams from around the country have been extraordinary in their support throughout the unification process and their shared vision for better services and support for our consumers. Our staff and volunteers have also shared their 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 are looking

forward to the advantages a unified organisation will bring to all of us.

Moving to a unified national body will bring substantial benefits for people with dementia, their families and carers as well as staff and volunteers including:

- capacity to deliver on the organisation's mission 'to improve the lives of people with dementia and their carers' is improved;
- improved capacity to deliver services for people with dementia their families and carers;
- a strengthened client voice and increased public profile that will maintain Dementia Australia's status as the peak charitable body for people with dementia;
- a more nimble, agile, and responsive organisation able to deal with the rapidly changing environment building long-term sustainability;
- streamlined decision-making and efficiency;
- increased capacity to secure financial support and improve financial sustainability; and,
- improved collaboration, strengthened organisational culture and development opportunities for all staff.

Importantly, the organisation will maintain a highly-visible profile to continue performing regional activities, including relationship management, media, events and bequests.

Our success in advocacy was evident in November last year when I launched the Consumer Companion Guide at the Parliamentary Friends of Dementia Forum held at Parliament House in Canberra. The Consumer Companion Guide entitled 'Diagnosis, treatment and care for people with dementia' provides a resource that sets out the level of care that people with dementia and their carers and families should expect.

This Companion Guide was developed by people living with dementia, carers, researchers and clinicians from the National Health and Medical Research Council's Cognitive Decline Partnership Centre. Consumers played a key role in the development of the Consumer Companion Guide to ensure the document is relevant to the needs of people living with dementia and their carers.

We also advocated for consumers at the highest level when in November 2016 I appeared in front of the Senate Community Affairs References Committee providing our input to the inquiry on the Future of Australia's aged-care sector workforce. We emphasised our position that as the prevalence of dementia increases in our community, it is critical that all aged care services are well equipped and motivated to provide safe, high quality care for people with dementia, as part of their core business.

In February this year I joined Professor Laurie Brown of the National Centre for Social and Economic Modelling at the University Of Canberra, and author of our report The Economic Cost of Dementia in Australia 2016-2056, at Parliament House to release the report. The report found that if nothing was done to reduce the incidence of dementia, the economic cost to Australia will be more than \$36 billion in less than 40 years as the number of people with dementia soars, from an estimated 413,000 people in 2017 to 536,000 people by 2025 and a staggering 1.1 million

people by 2056

In February, we also welcomed Maree McCabe to the position of National Chief Executive Officer. Maree had been the Interim National CEO of Alzheimer's Australia and prior to that was the CEO of Alzheimer's Australia Victoria. Maree brings with her invaluable experience and expertise, gained from working in senior roles in the mental health and aged care sectors.

During her tenure as interim CEO, Maree demonstrated outstanding work in the unification process. I am looking forward to continuing to work with Maree to advocate for those diagnosed with dementia, their families and carers.

Our achievements this year demonstrate that we are committed to achieving a dementia-friendly Australia 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 stakeholders and the continued 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.

Professor Graeme Samuel AC
Chair Alzheimer's Australia

CHIEF EXECUTIVE OFFICER'S REPORT



It is an honour to submit this report as the CEO of Alzheimer's Australia. In August, I was welcomed as interim CEO of Alzheimer's Australia and was delighted to be officially appointed CEO in February. During the year, I had the pleasure to work in both of these roles, alongside our

extraordinary staff across the country to continue to highlight the issues faced by the more than 413,000 people living with dementia in Australia, their families and carers.

It has been a year of change in which we began the process of unification, combining eight federated bodies of Alzheimer's Australia into one. I am pleased to be leading the unification process under the direction of the board and chair, Professor Graeme Samuel AC. It is an opportunity to better support and engage with our consumers, to promote prevention strategies and to elevate awareness and understanding of dementia in Australia by being bigger, bolder and stronger as a unified organisation.

This year we completed a thorough engagement and consultation process with our consumers, volunteers, board members and staff to understand how we could best leverage our expertise in dementia as a unified organisation. 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.

We also found that our consumers were very positive of the support they received from Alzheimer's Australia and would find benefit in a unified organisation. Consumers gave us positive feedback, speaking of the highly professional relationships, scope of the services and personal benefits of the support they received. Carers found value in our education and support services, areas we plan to grow under our unified organisation.

I would like to take this opportunity to recognise and thank the CEOs and management teams of the eight Alzheimer's Australia organisations. Your hard work and dedication to provide better results for our consumers provides us with a solid

foundation to build upon. Without your support of the unification process this would have not been possible.

In May this year, the World Health Organisation (WHO) endorsed a global action plan on the public health response to dementia 2017-2025. The plan called to improve the lives of the more than 50 million people living with dementia, their families and carers and to 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 national strategic plans targeting dementia.

Alzheimer's Australia has worked to align our strategic vision with that of the WHO plan, adding our own voice to the global push for action on dementia. We continue our call for a fully-funded national plan on dementia in Australia, which is essential for providing adequate, specialised support for people living with dementia.

During the year, I attended and presented at the 32nd International Conference of Alzheimer's Disease International in Kyoto, Japan. The theme of the conference was "Together towards a new era", which explored the global challenge of increasing awareness of dementia and to support improvements in treatment and care. I was encouraged by the international efforts being undertaken to create a dementia-friendly world.

I also had the pleasure of attending our Parliamentary Friends of Dementia forum at Parliament House in Canberra in November 2016, and was touched and inspired by the stories and experiences shared by our consumers. I was honoured to introduce clinicians, carers and parliamentarians who presented at this event.

Visiting our Alzheimer's Australia offices across the country in April and May and meeting those diagnosed with dementia, the carers and the families that our staff work so passionately for was humbling. All over the country our staff provide our consumers advocacy, support services, education and information. As one team it is a truly exciting opportunity moving forward to elevate awareness of dementia and transform the quality of care and lives of all people impacted by dementia.

Maree McCabe
CEO Alzheimer's Australia

OUR BOARD



Graeme Samuel AC
President

Graeme Samuel AC (Master of Laws 1977) is a Professorial Fellow in Monash University's Business School. He is also a Councillor of the Australian National University and Chair of its Finance Committee, Chair of Data

Governance Australia, President of Alzheimer's Australia, Chair of the Alzheimer's 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 Chair of the Commonwealth Government's Panel of Review of Australia's Independent Medical Research Institutes and advisor to the Commonwealth Department of Health in relation to its review of private health insurance. He was also a member of the Review Panel of Australia's Wool Selling Systems.

Professor Samuel has held a number of roles in public life including former Chairman of the Australian Competition and Consumer Commission, Associate Member of the Australian Communications and Media Authority, President of the National Competition Council, Chairman of the Melbourne and Olympic Parks Trust, Commissioner of the Australian Football League, President of the Australian Chamber of Commerce and Industry, Chairman of Playbox Theatre Company and Opera Australia, Trustee of the Melbourne Cricket Ground Trust and Chairman of the Inner and Eastern Health Care Network

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



William Bass
Secretary and Treasurer

William brings considerable corporate executive experience predominantly in the fields of strategy and commercial and financial management. He is a director, senior financial officer, company secretary and advisor to

a number of prominent Australian and international companies. Other current directorships include - China Magnesium Corporation Limited (ASX listed), Newground Capital Partners Pty Ltd (unlisted).

Responsibilities as a AA Ltd Director include Treasurer, Secretary, Public Officer and Chair of Finance Audit & Risk Management Committee. Qualifications include BEcon., CA, FGIA, FInstIB, MAICD, JP(Qual) Secretary, Treasurer, Public Officer



Tony Newman
Vice-President

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 Alzheimer's Australia holds a special place with Tony. His dad was diagnosed with Alzheimer's five years before his death in 1996. Tony is Chairman of Alzheimer's Australia SA and a board member of the South Australian Jockey Club and has an Economics degree from the University of Adelaide.



Amanda Quealy

Amanda has had an executive career in the health care industry for the past 26 years in the government, private and not-for-profit sectors. She is the President of Alzheimer’s Australia Tasmania and CEO of The Hobart Clinic a private not-for-profit

mental health service. Amanda represents Tasmania on the Australian Private Hospital Association Council, Chair, Tasmanian Alcohol and Drug Tribunal, Member of the Health Services Establishment Advisory Committee, Deputy Chair, Tasmanian Women’s Council and President, Australian College of Health Service Managers (Tas Branch). She has been recognised as a Top 100 Women of Influence, Westpac & AFR 2013 and was Telstra Business Woman of the Year (Tas) 2010.

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.



Craig Masarei

Craig Masarei is the Chairman of Alzheimer’s Australia WA Ltd, Chief Legal Officer & Company Secretary Water Corporation, Chairman Water Corporation Superannuation Pty Ltd as trustee for the Water Corporation Superannuation Plan. He currently

holds memberships at Australian Corporate Lawyers Association, Law Council of Australia, Law Society WA, Australia Superannuation Funds Association and Alzheimer’s Disease International. Craig has a Bachelor of Jurisprudence, University WA and Bachelor of Laws, University WA.



Greg Fraser

Greg had 25 years public sector management experience, with more than 16 years at chief executive and senior executive levels. Greg was Chief Executive of the ACT Department of Health and Community Care and had extensive involvement in

intergovernmental initiatives and forums and represented the States and Territories at several international Treaty meetings.

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

Greg has been involved with Alzheimer’s Australia for the last six years, including being a member of the national board for four years and chair of the ACT Board for three years. Greg holds membership with Australian Institute of Company Directors, Risk Management Institution of Australia, Centre for Strategy and Governance, Institute for Public Administration Australia



Neil Samuel

Neil Samuel is the former Managing Director of Dryen Australia Pty. Ltd., one of Australia’s largest Domestic Linen importers and wholesalers servicing Australia’s Blue-Chip retailers. Over the past 40 years he has been actively involved in

business with an emphasis on Finance, Administration, Sourcing and Procurement. Neil has travelled extensively throughout Asia and Europe for 40 years 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. Neil has 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, including two terms as Vice President. He is a member of the Finance, Audit, Risk Management committee and Chair of the Information Communication and Technology committee. He is also serving on the Board of Alzheimer’s Australia Dementia Research Foundation and Alzheimer’s Australia Dementia Research Foundation Victoria. Neil’s passion for Alzheimer’s Australia was born out of family experience with Alzheimer’s disease.



Paul Robertson AO

Paul Robertson is currently the Chair of Alzheimer's Australia (NSW). 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. He has recently been appointed as a director of the Sydney Theatre Company Foundation.



Vicki Krause

Associate Professor Vicki Krause, MD, DTM&H and FAFPHM, has served as the President of the Board of Alzheimer's Australia NT (2011-2017). She is the Director of the Northern Territory (NT) Centre for Disease Control and Head of the TB/Leprosy Unit for the NT

Department of Health and is a current member and past chair of the Communicable Diseases Network Australia (CDNA) and the National Tuberculosis Advisory Committee (NTAC). She served on the Technical Research and Advisory Subcommittee of the WHO Global TB Programme, 1995-1998 and is a current and longstanding member of the TB Technical Advisory Group, (TAG) for the Western Pacific Region. Dr Krause has edited the NT Disease Control Bulletin, a quarterly publication, for the past 20 years and has supervised postgraduate scholars since 1991. She has previously worked in PNG, as a specialist physician with a particular interest in piloting treatment protocols and in the USA with an interest in migrant and refugee health and the Indian Health Service.



Maree McCabe

Maree McCabe, PMHN, MBA, MAICD is the Chief Executive Officer for Alzheimer's Australia Ltd., appointed in February 2017. Prior to that she was the CEO of Alzheimer's Australia Victoria since 2010. A passionate advocate for not only improving the lives

and quality of care of those living with dementia and their families and carers, Maree is committed to elevating the voice of the 413,000 Australians that live with dementia. Maree drives Alzheimer's Australia's focus to raise awareness about dementia and demystify the disease and promotes the opportunity of risk reduction and for people living with dementia to stay engaged in, and with, their own community, for as long as possible.

Maree's career background has involved senior executive positions across the mental health and aged care sectors, including Executive Operations for TLC Aged Care, Director of Clinical Resources at The Melbourne Clinic, General Manager of Hospitals for St John of God Healthcare and Surveyor for the Australian Council on Healthcare Standards.

Maree 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. Maree 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.

The Financial and Risk Management Committee as at 30 June 2017

The committee consists of: William Bass, Treasurer; Neil Samuel, Board Director; Maree McCabe, CEO Alzheimer's Australia and two independent members:



Geoff Knuckley
BEc ANU, FICA, GAICD, IIAA

Geoff Knuckley had a 32-year career with major accounting firm Ernst & Young and retired as a Partner in December 2009 to pursue a new career comprising board non-executive director and Audit Committee positions in the private and public sectors. His career has included specialising in financial statements' auditing of entities of all sizes ranging from ASX-listed companies through to medium-sized and small businesses across all types of industries, including the financial services sector. His role also included advising in internal audit, corporate governance, risk management and financial statements auditing and reporting. He has operated in both the private and public sectors. He is currently Chairman or non-executive director of six private-sector companies and is also Chair or Independent Member of the Audit and Risk Committees for 12 government departments. Geoff is currently a member of the Alzheimer's Australia Financial Audit and Risk Management committee.



Tony Grieves
BA (Accounting)

Tony is a Chartered Accountant. Tony currently works in the risk assurance services practice of RSM in Canberra. Prior to joining RSM in 2012 Tony was at PwC and before that a Partner at Walter Turnbull in Canberra.

With more than 25 years' professional services experience in Sydney and Canberra, Tony has worked with not-for-profit, government-funded and private sector organisations. Tony is currently a member of the Alzheimer's Australia Financial Audit and Risk Management committee and is also a member of the Australian Council for International Development, Finance and Audit committee and the Healing Foundation, Audit Risk and Finance committee.

Professional Associations:

Associate Member, Chartered Accountants Australia and New Zealand

Associate Member, Australian Institute of Company Directors

Institute of Internal Auditors – Australia

Associate Member, Association of Certified Fraud Examiners

Financial and risk management committee

Our Finance, Audit and Risk Management (FARM) Committee was established to provide ongoing support, advice and recommendations to the Alzheimer's Australia Board on finance, audit and compliance, and risk management issues. This includes the provision of high quality financial management and reporting, as well as due care and diligence in relation to assessment, mitigation strategies and monitoring.

The FARM Committee's objectives are to:

- provide a forum for in-depth discussion and assessment of issues relating to finance, audit and compliance, and risk management
- provide greater accountability and oversight in relation to financial management, audit, compliance and accounting practices
- ensure quality and compliance of relevant reports (financial statements, audit reports)
- monitor, review and recommend budgets to the Board
- monitor compliance with relevant legislation
- monitor key corporate policies (e.g. privacy, security, records management, business continuity, liabilities, fraud control etc.) to promote an ethical culture within Alzheimer's Australia
- provide oversight of the risk management responsibilities and activities of Alzheimer's Australia
- advise the Board on emerging areas of risk and recommend mitigation strategies
- conduct such projects and/or analyses as directed by the Board

THE YEAR IN REVIEW

The 2016-2017 financial year was a year of growth and change with the appointment of Maree McCabe as interim CEO for Alzheimer's Australia and officially appointed CEO in February 2017. Dementia Awareness Month, our flagship event, carried the compelling theme 'You are Not Alone' to remind those diagnosed with dementia, their family and carers that they are not alone in their experience with dementia. Alzheimer's Australia also organised two large forums for the Parliamentary Friends of Dementia, which were held at Parliament House.

Work continued on Alzheimer's Australia support programs such as the Younger Onset Dementia Key Worker Program, National Dementia Support Program, Service Delivery Pathways Project and Dementia Friendly Communities. Multiple resources to assist the community continued to be developed such as the revised *Diagnosis, treatment and care for people with Dementia: A consumer companion guide* and the *Economic Cost of Dementia in Australia 2016-2056* report.



OUR SERVICES

Younger onset dementia

The Younger Onset Dementia Key Worker Program continued in 2016-2017 with a focus on supporting the transition to the National Disability Insurance Scheme (NDIS). The aim of this program is to improve the quality of life for people living with younger onset dementia, their families and carers, by providing individualised support to access the care and support services most appropriate for their needs, including the NDIS.

We have a number of Younger Onset Dementia Key Worker Program clients currently on active NDIS plans, and despite the challenges transition to the NDIS has presented, the Younger Onset Dementia Key Worker Program has continued to maintain a consistently high level of service with an overwhelming majority of clients reporting their goals were met or exceeded.

Some of the key achievements include:

- an increase in active clients compared to the previous financial year;
- an increase in people with dementia or suspected dementia, compared to the previous year;
- an increase in active clients who now identify as having a special need;
- an increase in the number of clients who have been supported to obtain active NDIS plans.

National Dementia Support Program

In the 2016-2017 year the National Dementia Support Program offered a suite of supports to people living with dementia, carer partners and family members that included the National Dementia Helpline, the national Alzheimer's Australia website, counselling, support groups, early intervention, carer education and social, therapeutic and outreach activities.

In the 2016-2017 year:

- thousands of carers and family members received education and training
- tens of thousands of people across Australia attended Community Information and Information and Awareness sessions and events to learn about dementia.
- tens of thousands of resources targeting special needs groups were downloaded from the national website

- tens of thousands of calls were made by people to the National Dementia Helpline
- the national website continued to provide valuable information to people all over Australia
- early intervention courses were delivered to people living with dementia and care partners all over Australia
- thousands of care partners attended education sessions to learn about dementia and how to support someone living with dementia

In the 2016-2017 year Alzheimer's Australia's National Dementia Support Program produced the following useful and informing resources:

- *Homelessness and Dementia Discussion Paper*
- *Travelling and Holidays with Dementia*
- *Living with Dementia in Retirement Villages Help Sheet*
- *Anticholinergic Drugs and Dementia Q&A sheets*
- *Benzodiazepines and Dementia Q&A sheets*
- *Younger Onset Dementia and the NDIS (A5 Booklet, A4 Checklist and Online video)*
- *Harmful Substance Use and the Brain (A5 Booklet - consumers and A4 Information Sheet - Health Professionals)*

Service Delivery Pathways Project

The 2016-2017 financial year was the closing year for the Service Delivery Pathways Project which delivered targeted services to people with special needs including people who live in rural and remote areas, people who identify as Aboriginal and Torres Strait Islander, lesbian, gay, bisexual, transsexual or intersex or are culturally and linguistically diverse or homeless. The final report found that targeted supports that build capability across special needs organisations and populations are an effective means to improve access to a timely diagnosis, early intervention and other supports.

Alzheimer's Australia engaged Hall & Partners to undertake research across Alzheimer's Australia and produce the report *Framing the Way Forward; A strategic approach to build reach and impact for special needs audiences*. The report identified several important initiatives offered by Alzheimer's Australia for special needs audiences designed to overcome challenges of access.

Dementia-Friendly Communities

In 2016-2017 Alzheimer's Australia was contracted by the Federal government to implement a national Dementia-Friendly Communities program. The program builds on dementia-friendly work already initiated in state and territory communities, pilot sites and successful overseas models. The goal of this program is to develop a nationally coordinated approach to promoting dementia-friendly communities across Australia. The program is made up of two key activities; establishment of a national Dementia Friends awareness program (designed to raise dementia awareness in the community and encourage individuals and local organisations to take up the challenge of creating dementia-friendly communities), and development of a national Dementia Friendly Community resource hub website.

Program aims include the need to increase understanding and public awareness of dementia across Australia and improve levels of active engagement with people living with dementia across the community. Consultation and engagement with people living with dementia, care partners and stakeholders, primarily via the

Dementia-Friendly Communities Dementia Advisory Group and Dementia-Friendly Communities Steering Committee, has been a key focus for year one of this three year program.

Program highlight includes the filming of national face-to-face consultations that resulted in content for both module 1 and module 2 of the online Dementia Friends awareness program. Consultations were focused on collecting individual and direct voices of people living with dementia.

Aged Care Service Improvement and Healthy Ageing Grants

The *Supporting GPs and Practice Nurses in the Timely Diagnosis of Dementia Project* was completed on 30 June 2017. The project delivered online and face-to-face training to GPs and Practice Nurses across Australia. The project was evaluated by the Australian National University (ANU) and the online training modules will remain available for future GPs and Practice Nurses.



MARKETING AND EVENTS

Dementia Awareness Month 'You are Not Alone', September 2016

During Dementia Awareness Month, Alzheimer's Australia called for greater awareness and understanding of dementia so people living with the condition could feel less isolated and alone by promoting the powerful theme of 'You are Not Alone'. The results of a 2016 survey, conducted by Alzheimer's Australia, found that people with dementia are almost twice as likely to have high rates of loneliness compared to the general public and people with dementia and carers are significantly more lonely than the general public.

International guest speaker

One of the world's leading dementia experts, Dr Ronald Petersen, the Director of the US Mayo Clinic Alzheimer's Disease Research Centre conducted a national speaking tour in September 2016, during Dementia Awareness Month. Dr Petersen visited Sydney, Brisbane, Canberra, Melbourne and Adelaide as part of his tour to discuss the latest insights and research findings about dementia and Alzheimer's disease and the US and global experiences in establishing a national dementia strategy. During his tour, he appeared on Studio 10, a Channel Ten morning show, where he joined Ita Buttrose to speak about dementia.



Above The World Alzheimer's Day Alzheimer's Australia Dementia Research Foundation panel discussion.

Dr Petersen was appointed by former US President Barack Obama's Administration to head up the Advisory Council for the National Alzheimer's Project Act (NAPA) an integrated national plan to overcome Alzheimer's disease in the US by 2025. Dr Petersen, who was former US President Ronald Reagan's personal physician and treated his Alzheimer's disease, was also appointed to the World Dementia Council in 2014 by the then UK Prime Minister, David Cameron

Below Dr Ron Petersen (centre) on the Studio 10 panel with Alzheimer's Australia Ambassador Ita Buttrose (far right).



Parliamentary Friends of Dementia Forum November 2016 and February 2017

Alzheimer’s Australia hosted two successful Parliamentary Friends of Dementia forums in the 2016-2017 financial year at Parliament House in Canberra. The first, held in November 2016, was opened by Alzheimer’s Australia CEO, Maree McCabe who introduced National President, Professor Graeme Samuel AC. The forum was used as the launch pad for the new Cognitive Decline Partnership Centre Consumer Companion Guide. The guide looked at diagnosis, treatment and care for people with dementia and it acted as a consumer companion guide to the Clinical Practice Guidelines and Principles of Care for People with Dementia 2016. The event was also attended by Conny and Bryan Gard who highlighted their personal experiences in living with younger onset Alzheimer’s disease. Shadow Minister for Ageing & Parliamentary Friends of Dementia Co-Convener Senator Helen Polley joined the event and spoke about the role of Parliamentarians in tackling the dementia challenge.

A second Parliamentary Friends of Dementia Forum was held in February and was opened by National Ambassador Sue Pieters-Hawke. The event was attended by Mr Andrew Laming MP,



Above Professor Laurie Brown

Member for Bowman and Parliamentary Friend of Dementia Co-Convener and Senator Hellen Polley. The forum was also attended by Professor Laurie Brown, National Centre for Social and Economic Modelling (NATSEM) who launched a new research report titled Economic Cost of Dementia in Australia 2016-2056 at the event. The report, commissioned by Alzheimer’s Australia and produced by NATSEM, forecasted the economic cost of dementia in Australia up to the year 2056. There were many alarming statistics included in the 84 page report including the annual forecasted cost of dementia in Australia to reach \$36.85 billion by 2056. Dawn and Glyn McKay offered the forum their personal experiences with vascular dementia and the impact it has on their lives, which was a valuable contribution towards breaking down the stigma and misconceptions often associated with dementia.



Below Attendees at the Parliamentary Friends of Dementia forum



CONSUMER ENGAGEMENT

Alzheimer's Australia Dementia Advisory Committee

The Alzheimer's Australia Dementia Advisory Committee supports people with dementia to meaningfully participate in advocating for the needs and priorities of people with dementia in relation to service provision, information, support and education.

Committee members serve a maximum term of three years and the aim of the committee is to elevate the voice of people living with a diagnosis of dementia in Australia.

The Alzheimer's Australia Dementia Advisory Committee, established in 2013, is the third of its kind in the world, and the first in Australia.

Committee membership continued to be strong this year, with the 2016-2017 recruitment round receiving 14 membership applications from around Australia. From the 14 applicants, six new members were recruited to the committee.

Alzheimer's Australia values and respects the contribution of past and current committee members.

Key achievements of the Alzheimer's Australia Dementia Advisory Committee this year included informing the Alzheimer's Australia's submission to the Australian Human Rights Commission National Consultation. Between October 2016 and March 2017 the Disability Discrimination Commissioner Alastair McEwin conducted a national consultation to help guide his priorities and sought input from the disability community on how he could effectively work to advance the rights of people with a disability.

The Alzheimer's Australia Dementia Advisory Committee also contributed to the:

- Angels in Aprons Dementia Action Plan. Angels in Aprons Dementia Pty Ltd is a Brisbane-based provider of home and hospital support, social support, family and carer support and in-home aged care;
- Substitute decision-making draft brochure;
- Alzheimer's Australia Dementia Friendly Communities Action Plan and the Centacare Dementia Friendly Action Plan;
- Be the Change, the 17th Alzheimer's Australia Biennial National Dementia Conference;
- Alzheimer's Australia submission to the review of the National Ageing and Aged Care Strategy

for People from Culturally and Linguistically Diverse (CALD) Backgrounds (the CALD Strategy) and the National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy (the LGBTI Strategy) conducted by the Australian Government.

Alzheimer's Australia National Consumer Network

The Alzheimer's Australia National Consumer Network is open to all people living with dementia and current and past care partners. There are currently 159 members in the network, with membership representing all Australian states and territories. The Consumer Network Members engage in person, over the phone and via the internet with Alzheimer's Australia and other organisations wishing to hear from consumers with a lived experience of dementia or as a care partner of a person with dementia.

Achievements of the Alzheimer's Australia National Consumer Network this year include contributing to the:

- Alzheimer's Australia submission to the review of the National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) Backgrounds (the CALD Strategy) and the National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy (the LGBTI Strategy) conducted by the Australian Government;
- Alzheimer's Australia submission to An Integrated Care at Home Program to Support Older Australians;
- Australian Commission for Safety and Quality in Healthcare's Comprehensive Care Standard Advisory Group resources.

A number of Alzheimer's Australia Consumer Network members also participated in research opportunities that were promoted through the Dementia Australia Research Fund website:

dementiaresearchfoundation.org.au

Alzheimer's Australia would like to take this opportunity to thank all the Dementia Advisory Committee and National Consumer Network members for their extensive commitment and contributions.

FUNDRAISING

This has been an amazing year and we are proud of the efforts of our fundraisers who organised and delivered a variety of fundraising activities across the country. We value the continued support of our donors, members of our community, businesses and individuals who swam, ran, walked, jogged, wrote and devoted their valuable time to raising awareness and funds for Alzheimer's Australia.

All funds raised will go towards the implementation of practical support and education programs for people living with dementia, their family and carers. Our carer education programs, for example, are designed to help family, carers and friends of people living with dementia increase their understanding of dementia and offer ideas for improving quality of life. Thank you again to all who have dedicated their time and efforts to raising money for Alzheimer's Australia.

MEDIA

Media and Social Media

Traditional Media

In the traditional media space we issued more than one hundred 2016-2017 financial year. Our interactions with the media resulted in 826 news items mentioning Alzheimer's Australia that reached a total audience of 5,820,280 and had a total advertising space rate equivalent of \$1,428,074.

Social Media

Our social media channels continued to steadily grow. At the end of 2016-2017 financial year we had more than 10,100 Twitter followers and more than 43,900 Facebook followers.

Website

During the financial year 2016-2017, our website continued to provide a vital source of dementia related information for members of the public. Visitors to our website continue to rise as we provide more evidence backed content to consumers regarding information on dementia.



POLICY

Alzheimer's Australia continues to provide a credible and recognised voice and gateway to information on dementia. Awareness of the organisation and the available dementia services and supports are promoted through our engagement with traditional and social media as well as through promotion of the National Dementia Helpline.

Over the last year Alzheimer's Australia also coordinated two Parliamentary Friends of Dementia events. In 2016, we launched the resource *Diagnosis, treatment and care for people with dementia: A consumer companion guide*. This launch was held in collaboration with the Cognitive Decline Partnership Centre and was attended by numerous parliamentarians and consumers.

At the February 2017 Parliamentary Friends of Dementia, we launched the *Economic Cost of Dementia in Australia 2016-2056*, which was prepared by Professor Laurie Brown, Eric Hansnata and Hai Anh La from The National Centre for Social and Economic Modelling (NATSEM) at the Institute for Governance and Policy Analysis, University of Canberra. This report determined the current economic cost of dementia and also projects likely to impact future direct and indirect costs of dementia over the next 40 years. The event was co-convened by Senator Helen Polley and Mr Andrew Laming MP and was also attended by The Hon. Ken Wyatt AM, MP, Minister for Aged Care and Minister for Indigenous Health, along with more than 100 people.

Alzheimer's Australia continued to develop evidenced-based policy publications over the course of the 2016-2017 financial year, including:

- Flexible Respite Resources for Consumers and Providers;
- The revised resource *Diagnosis, treatment and care for people with dementia: A consumer companion guide*;
- *Dementia and loneliness*;
- *Dementia and Your Legal Rights* resource;
- and
- A discussion paper on *Relationships and Dementia*.

This year we have continued to supplement and facilitate work on the National Quality Dementia Care Initiative (NQDCI). This has included projects progressed with the philanthropic support of the JO and JR Wicking Trust. Projects on improving dental care for people with dementia and improving allied health care were completed within the project period. Resources were also released for the projects on allied health and dental care to assist the knowledge of consumers and health professionals. These resources were released during Dementia Awareness Month in September 2016 and are available online.

Work regarding improving quality use of medicines for people with dementia has also reached finalisation over the course of this project and has resulted in the development of a new resource, *Medicines and Dementia*.

All resources developed through NQDCI will continue to remain accessible to consumers online. Alzheimer's Australia continues to pursue further philanthropic support and partnerships with the Wicking Trust and other sources.

National policy development affecting people with dementia and their families and carers was informed by quality submissions and input from Alzheimer's Australia, which consistently drew on evidence and consumer experience.

Some of the submissions we have made this year include:

- Submission to Inform Development of The New Aged Care Diversity Framework;
- Submission to the National Disability Insurance Scheme (NDIS) - Code of Conduct Discussion Paper;
- Submission to the National LGBTI Ageing and Aged Care Strategy Review;
- Submission to the National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) Backgrounds - Review;
- Submission Inquiry into Outcomes Under the National Disability Strategy 2010-2020 to Build Inclusive and Accessible Communities;
- Submission to Single Aged Care Quality Framework - Draft Aged Care Quality Standards Consultation Paper;

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- Submission to the Productivity Commission's Review of National Disability Insurance Scheme (NDIS);
- Submission to the Australian Law Reform Commission's (ALRC) Elder Abuse Discussion Paper;
- Submission to the Aged Care Financing Authority (ACFA) Discussion paper: Protection of Accommodation Bonds;
- Submission to the Productivity Commission Reforms to Human Services Stage 2;
- Submission to Human Rights Commission Consultation on Disability Rights;
- 2017-18 Budget Submission Stage 1 of a comprehensive National Dementia Strategy for Australia;
- Submission to the Digital Health Strategy Consultation;

Alzheimer's Australia also contributed to forums, consultations and key informant interviews including the following:

- NDIS Essential Briefing organised by NDIA;
- Palliative Care consultation on Evaluation of the National Palliative Care Strategy 2010 organised by Department of Health;
- NDIS ILC Consultation organised by NDIA;
- Shaping our future: Discussion on disability rights organised by the Australian Human Rights Commission;
- Advance Care Planning Advisory Committee
- Stakeholder Roundtable on 'Building Seniors' Financial Capability' organised by ASIC;
- Consultation on the Single Aged Care Quality Framework organised by Department of Health;

- Evaluation of the Regional Assessment Scheme Programme - Focus group for consumer bodies and provider peak bodies;
- Wellness and reablement Review stakeholder meeting organised by Nous Group consultants;
- Learning Design Blueprint for the National Assessment Workforce Learning Experience;
- Accelerated design workshops.

Alzheimer's Australia contributes to international awareness and work to progress issues important to people with dementia and their families and carers as a current member of Alzheimer's Disease International and the World Dementia Council. Alzheimer's Australia attended and presented at the Alzheimer's University conference and the ADI Asia Pacific Regional Office conference in November 2016 (New Zealand).

Alzheimer's Australia partnered with Wicking Trust on two lectures with Professor Harry Johns from the USA.

Alzheimer's Australia's CEO and the Executive Manager Policy and Strategy also contributed as active members of the following Ministerial committees:

- Aged Care Sector Committee
- Aged Care Sector Committee Quality Sub-Group
- ACFI Technical Reference Group
- Aged Care Quality Advisory Council
- Cognitive Impairment Advisory Group
- 2016 Ministerial Dementia Forum
- Australian Digital Health Agency Forum
- Aged Care Complaints Commissioner Consultative Committee
- Commonwealth Home Support Program Advisory Group

Alzheimer's Australia maintained and built working relationships with stakeholders to improve understanding of issues and to work collaboratively to improve outcomes for people with dementia, their families and carers.

This included:

- Membership of National Aged Care Alliance
- Liaison with other partners and stakeholders including Foundation for Alcohol Research and Education (FARE), NPS MedicineWise, Australian Dental Association, Palliative Care Australia, Associations Forum, Council on the Ageing (national), Ballarat Health Services, Aged Care Report card
- Contribution to the Aged Care Reform Stakeholder Workshop
- Participation in MyAgedCare Accelerated Design Workshops
- Participation in the development of MyAgedCare training blueprints for Carers, ATSI and CALD communities
- Expert roundtable in reducing inappropriate use of antipsychotics for people over 65
- Participation and assistance in developing the 2016 Ministerial Dementia Forum.

Alliances and partnerships with organisations that focus on preventative health including:

- Membership of Prevention 1st, an alliance of FARE, Consumers Health Forum and Public Health Association of Australia which advocates for preventive health and reduction of modifiable risk factors.
- Neurological Alliance- including MS Australia, Parkinson's Australia and MND Australia.
- Alzheimer's Australia also supported and endorsed new principles of Palliative Care in residential care developed by Palliative Care Australia.

Conference presentations supporting the agenda of Alzheimer's Australia and partner and other organisations to improve outcomes for people with dementia, their families and carers, including:

- National Standards Excellence conference – presentation on *Caring for patients living with dementia*
- COTA – Strengthening Dementia Services Conference - panel participation
- Alzheimer's University conference (NZ)- *Younger Onset Dementia advocacy*
 - Alzheimer's Disease International APRO conference- presentation on Putting dementia research into practice
 - Alzheimer's Australia participated in a Prevention 1st event held at Parliament house for the launch of a new economic report by La Trobe University's Professor Alan Shiell, *Preventive health: How much does Australia spend and is it enough?*

Alzheimer's Australia also partnered with Australian members of the Australasian Delirium Association for World Delirium Day.

RESEARCH

Research Partnerships

Research into the diagnosis, management, prevention, delay and cure of dementia continued to be a priority for Alzheimer's Australia this year. We collaborated with dementia researchers across the country in our continued effort to gain a better understanding of the disease.

Some of the partnerships we were involved in include:

- Supporting research funding through the Alzheimer's Australia Dementia Research Foundation Grants Program;
- Supporting the National Health and Medical Research Council's Cognitive Decline Partnership Centre;
- Promoting the work of researchers and new findings through our communications channels, and,
- Partnership-based research projects.

Alzheimer's Australia Dementia Research Foundation Grants Program

The Alzheimer's Australia Dementia Research Foundation (AADRF) is the research arm of Alzheimer's 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 2016, the AADRF 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.

National Health and Medical Research Council's Cognitive Decline Partnership Centre

Alzheimer's Australia continued its strong partnership with the National Health and Medical Research Council's Cognitive Decline Partnership Centre (CDPC) as one of four contributing organisations. The CDPC aims to improve the care of people with dementia and their 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 the expertise of researchers, industry, government, clinicians and consumers to address the complex issues of cognitive decline. The CDPC has a unique structure where they build national partnerships through involving consumers and partner organisations, including Alzheimer's Australia and our consumer network, at every stage of the research process.

In November 2016, Dementia Australia collaborated with the CDPC to release a Consumer Companion Guide to the Clinical Practice Guidelines and Principles of Care for People with Dementia at a Parliamentary Friends of Dementia event at Parliament House in Canberra. The consumer version of the Clinical Practice Guidelines was produced by the CDPC to support consumers to be fully informed when being investigated or treated for possible or diagnosed dementia.

THANK YOU

Strategic Partnerships

Alzheimer's Australia would like to thank the individuals and organisations that have supported the organisation over the past year. We are grateful for the generosity shown by everyone.

In particular, we would like to thank the following supporters:

The Australian Government for their support of dementia awareness and dementia services delivered through Alzheimer's Australia.

The Hazel Hawke Research and Care Fund and the family of Hazel Hawke for their continued support of dementia research.

The J.O and J.R Wicking Trust for its ongoing support of the National Quality Dementia Care Initiative.

Bupa Health Foundation for its support of the Brainy App Initiative.

The Priceline Sisterhood and Priceline franchisees for their support of Alzheimer's Australia and its community fundraisers.

Workplace Giving Partners

We are thankful for the support offered by a wide range of staff who generously provided donations to Alzheimer's Australia through their internal workplace giving schemes.

Our contributors in this capacity include:

Australian Federal Police
Alcatel-Lucent Australia
Allens Arthur Robinson
AMP Foundation
ANZ Community Giving Program
Australian Securities and Investment
Australian Unity
ASX
Attorney General's Department
Australia Post
Charities Aid Foundation
Chartered Accountants Australia & New Zealand
Dulux and Selleys
Department of Health
Department of Infrastructure and Regional Development
Department of Social Services
Department of Immigration and Border Protection
Department of Defence
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Veolia Transport
Westpac Group