

# ALZHEIMER'S AUSTRALIA ANNUAL REPORT 2015/16



**UNDERSTAND ALZHEIMER'S  
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# ABOUT THIS ANNUAL REPORT

This report outlines Alzheimer's Australia's activities and achievements during the 2015 –16 financial year. It has been developed for people living with dementia, their families and carers, our members, staff, volunteers, donors, government, corporate and community organisations.

Further information about all of the programs focused on in this Annual Report and full financial details are available at our website. Visit [www.fightdementia.org.au/annual-reports](http://www.fightdementia.org.au/annual-reports).

## WHO WE ARE

Alzheimer's Australia is the peak body representing more than 353,800 Australians living with dementia, and the estimated 1.2 million Australians involved in their care.

We are a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.

We also represent, at a national level, the interests of our federation of state and territory members on all matters relating to dementia and carer issues.

## WHAT WE DO

Alzheimer's Australia works to influence national policy and advocates for the needs of all Australians impacted by dementia.

We administer national dementia programs to deliver services such as the provision of information, support, counselling, training and education to people with dementia, their families and carers and the health care community.

We work with the health and aged care sectors to support best-practice dementia care.

We educate the community about dementia and the benefits of a brain-healthy lifestyle in working to reduce dementia risk.

Many of these programs are funded by the Australian Government and are delivered by individual Alzheimer's Australia associations in each state and territory.

## OUR HISTORY

In the early 1980s, a number of state and territory Alzheimer's Associations were established by and for the family carers of people with Alzheimer's disease and other dementias, in response to concerns about the lack of appropriate support.

Alzheimer's Australia was formed as a national federation in 1989 with membership from all states and territory organisations, with the objective of advancing advocacy for all Australians impacted by dementia.

## WHAT IS DEMENTIA?

Dementia is a disease of the brain and the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning.

It is a broad term used to describe a loss of memory, intellect, rationality, social skills and physical functioning.

There are many types of dementia including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy Body disease.

Dementia can happen to anybody, but is more common after the age of 65.

# DEMENTIA FACTS AND FIGURES

There are more than 353,800<sup>1</sup> Australians living with dementia.

Without a medical breakthrough, the number of people with dementia in Australia is expected to increase to almost 900,000 by 2050<sup>1</sup>.

Dementia is the second leading cause of death in Australia<sup>2</sup> and there is no cure.

An estimated 1.2 million Australians are involved in the care of a person with dementia<sup>3</sup>.

## VISION

Alzheimer's Australia's vision is for a society committed to the prevention of dementia, while valuing and supporting people living with the disease.

## VALUES

Respect, Collaboration, Innovation, Integrity, Quality and Professionalism.

1. Australian Institute of Health and Welfare (2012) *Dementia in Australia*. 2 Australian Bureau of Statistics (2015) *Causes of Death, Australia, 2013: Cat no. 3303.0*. 3 Alzheimer's Australia, (2011) *Pfizer Health Report Issue #45 – Dementia, Pfizer Australia*.

# STRATEGIC PRIORITIES

- Policy and advocacy
- Community awareness, understanding, attitudes and actions
- Service innovation and expertise
- Leadership in research
- Organisational sustainability and growth
- Governance and leadership

## OUR SUCCESS WILL BE MEASURED BY...

- Being recognised by our stakeholders as the key leadership organisation for dementia
- Achieving outcomes that improve quality of life for people with dementia
- Increasing the number and proportion of people with dementia who we support
- Strengthening our national footprint in dementia services and education
- Improving the extent to which we work in partnership with other national peak body organisations, Government, consumers and our state and territory members.

# 1. GOVERNANCE AND LEADERSHIP

## BOARD

Our Board is responsible for the governance of Alzheimer's Australia with the Chief Executive Officer responsible for the management of the organisation. The Board establishes the results to be achieved, and the tasks required to achieve these results are delegated to the Chief Executive Officer.

In performing their duties, the Board will:

- At all times act lawfully and consistently with Alzheimer's Australia policies
- Meet regularly to monitor the performance of management and Alzheimer's Australia as a whole
- Ensure 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 Alzheimer's Australia are protected by a suitable risk management strategy
- Honour its obligations to Alzheimer's Australia consistent with the Constitution



## THE NATIONAL BOARD AS AT 30 JUNE 2016:



### GRAEME SAMUEL AC, NATIONAL PRESIDENT

#### NATIONAL PRESIDENT SINCE JULY 2014

*"Dementia is a disease which affects so many people, whether they be persons living with dementia or those who provide the much cherished care for their loved ones. It is the mission of Alzheimer's Australia to provide advice, assistance and care for all those in the community affected by dementia. Alzheimer's Australia did this wonderfully for my family in our time of great need - my brothers and I owe it to Alzheimer's Australia to support it in all its endeavours to provide the same assistance to other families who face the same need as did mine."*

Graeme Samuel AC (Master of Laws 1977) is a Vice Chancellor's Professorial Fellow in Monash University's Business School and co-director of the Monash Business Policy Forum. He is a Commissioner of the Australian Rugby League Commission, a Councillor of the Australian National University and Chair of its Finance Committee, Chair of Data Governance Australia, Chair of the Alzheimer's Australia Dementia Research Foundation, Chair of the South Eastern Melbourne Primary Health Network, member of the National Health and Medical Research Council and Chair of its Health Innovation Advisory Committee and the National Institute for Dementia Research, and a member of the Aged Care Financing Authority.

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

Graeme 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.

Until the early 1990s, Professor Samuel pursued a professional career in law and investment banking.

He was appointed a life member of the Australian Football League and an honorary life trustee of the Committee for Economic Development of Australia.

He was awarded an Australian Sports Medal for services to sport, and a Centenary Medal in recognition of his service as president of the National Competition Council.

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



## **TONY NEWMAN** **VICE-PRESIDENT**

**VICE-PRESIDENT SINCE NOVEMBER 2015**  
**BOARD MEMBER SINCE MAY 2014**

*"I hope to make a contribution to the improved quality of life of people diagnosed with dementia and their carers, in honour of my late Dad and Mum. Dad had dementia and Mum was his devoted carer. It is a privilege to be a part of an organisation that supports and encourages efforts to find a cure."*

Tony Newman is a highly experienced senior executive with expertise in finance, supply chain, sales and marketing, and information technology. He 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 his success in a complex international environment.

The work of Alzheimer's Australia holds a special place in Tony's heart. His dad was diagnosed with Alzheimer's disease five years before his death in 1996. He is Chairman of Alzheimer's Australia South Australia and a Board Member of the South Australian Jockey Club. He has an Economics degree from the University of Adelaide.

Alzheimer's Australia was delighted to welcome Tony into his new role as Vice President of Alzheimer's Australia in November 2015.



## **GREG FRASER** **SECRETARY**

**SECRETARY SINCE NOVEMBER 2015**  
**BOARD MEMBER SINCE NOVEMBER 2013**

*"With dementia increasing rapidly, and already the second highest cause of death in Australia, Alzheimer's Australia is providing advocacy on behalf of, and a critical range of support and services to, those affected. I have a deep personal commitment to the work of Alzheimer's Australia to urgently find a cure and, in the meantime, provide the highest level of care and support to those people affected by dementia."*

Greg Fraser has 25 years of public sector management experience, with more than 16 years at Chief Executive and Senior Executive levels. He was Chief Executive of the ACT Department of Health and Community Care and had extensive involvement in intergovernmental initiatives and forums, while representing 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.

He is currently President of Alzheimer's Australia ACT and until July 2015 chaired the Risk and Audit Committee of Alzheimer's Australia.

His memberships include the Australian Institute of Company Directors, Risk Management Institution of Australia, Centre for Strategy and Governance and Institute for Public Administration Australia.

Greg has a BA from the University of Sydney and was part of the Executive Development Program at Cornell University.



## **WILLIAM BASS TREASURER**

**TREASURER SINCE NOVEMBER 2015**

**BOARD MEMBER SINCE JULY 2015**

*"Caring for a beloved aunt with Alzheimer's disease brought home to me how so many can help in so many ways. Serving on the Alzheimer's Australia national board alongside equally passionate directors, and witnessing the commitment of donors, carers, families and staff reinforces both how much is being done and still needs to be done. Together we can make a difference."*

William Bass 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.

He is currently a Director for China Magnesium Corporation Ltd, 1300SMILES Ltd, Silicon Lakes Ltd, Alzheimer's Australia Qld Ltd and Alzheimer's Australia Gold Coast Inc. He is also Treasurer and Chair of the Finance and Audit Committee for Alzheimer's Australia.

William's qualifications include a BEcon., CA, FGIA, FInstIB, MAICD and JP(Qual).



## **VICKI KRAUSE**

**BOARD MEMBER SINCE OCTOBER 2011**

*"I am very proud to be involved with an organisation whose mission is to provide the best quality services and support for all people in Australia with dementia and their families. There is a great need to skilfully plan for continued excellence in dementia care as we face future challenges. Living in the NT, the remoteness and diversity along with having the fastest growing aging population in Australia, underscores this responsibility. Additionally, I am passionate about supporting the role that Alzheimer's Australia plays in generally raising awareness and understanding about dementia and importantly in supporting the search for its cause, prevention and cure."*

Associate Professor Vicki Krause, MD, DTM&H and FAFPHM, has served as the President of the Board of Alzheimer's Australia NT since October 2011 and has lived in the NT since late 1989.

She is the Director of the Northern Territory Centre for Disease Control and Head of the TB/Leprosy Unit for the Northern Territory Department of Health. She is a current member and past Chair of the Communicable Diseases Network Australia (CDNA) and the National Tuberculosis Advisory Committee (NTAC).

Vicki has served on Technical Research and Advisory Subcommittees of the World Health Organisation's Global TB Programme and has previously worked in Papua New Guinea as a specialist physician with a particular interest in piloting treatment protocols, in the USA with an interest in migrant and refugee health and with the Indian Health Service.



## CRAIG MASAREI

**BOARD MEMBER SINCE DECEMBER 2014**

*"Since 1989 Alzheimer's Australia has been dedicated to providing help for people with dementia and their caregivers. That help comes in many ways."*

Craig Masarei is the Chairman of Alzheimer's Australia WA. He is Chief Legal Officer and Company Secretary of the Water Corporation and Chairman of the Water Corporation Superannuation Pty Ltd as Trustee for the Water Corporation Superannuation Plan. He is also Trustee for the Drysdale Family Foundation.

He currently holds memberships at Alzheimer's Disease International, the Australian Corporate Lawyers Association, Law Council of Australia, Law Society of Western Australia and Australia Superannuation Funds Association.

He has a Bachelor of Jurisprudence and a Bachelor of Laws, both from the University of Western Australia.

Prior to his most recent period on the Alzheimer's Australia Board, Craig was also involved as a Board Member a number of years ago. He then returned as Vice-President between December 2014 and November 2015, and continues to serve as a Board member.



## AMANDA QUEALY

**BOARD MEMBER SINCE NOVEMBER 2015**

*"As a Board member at Alzheimer's Australia, it is satisfying to know that my small contribution has played a part in supporting the great work that our staff do each day across the nation in providing dementia care, research and advocacy. It takes the contribution of each individual to make it happen, and I know the organisation has made a real difference in the everyday lives of people with dementia and their families, which is what it's all about."*

Amanda Quealy has had an executive career in the health care industry for the past 26 years, working in the government, private and not-for-profit sectors.

She is President of Alzheimer's Australia TAS and CEO of The Hobart Clinic - a private not-for-profit mental health service.

Amanda represents Tasmania on the Australian Private Hospital Association Council, is Chair of the Tasmanian Alcohol and Drug Tribunal and a Member of the Health Services Establishment Advisory Committee. She sits on the Board of the Tasmanian Women's Council and is President of the Tasmanian branch of the Australian College of Health Service Managers.

She was recognised as one of the Australian Financial Review and Westpac 100 Women of Influence in 2013 and was Telstra Business Woman of the Year (Tas) in 2010.

Amanda's academic background includes honours degree in Economics, Social Work degree, Post Graduate Diploma, Human Services Administration and Master's in Business Administration.

She is a Graduate of Australian Institute of Company Directors, Chartered Institute of Public Sector Finance & Accountancy and an accredited ACHS Hospital Surveyor.



## **PAUL ROBERTSON AM**

**BOARD MEMBER SINCE FEBRUARY 2016**

*"Families living with dementia experience a wide range of problems. It is wonderful to be part of an Australia-wide team that is helping those families. Like many other Australians, my wife and I have experienced the issues associated with parents living with dementia. Being involved with Alzheimer's Australia presented me with a wonderful opportunity to help other families, in memory of Rose and Betty."*

Paul Robertson is currently the Chair of Alzheimer's Australia NSW. He is also Chair of St Vincent's Health Australia and Social Ventures Australia.

Paul has extensive experience in banking, including 27 years at Macquarie Bank where he was an Executive Director, Global Treasurer and Integrity Officer of the Bank.

He is the founding Director of the Financial Markets Foundation for Children and a Director of Telco Together Foundation.

He has recently been appointed as a director of the Sydney Theatre Company Foundation.



## **NEIL SAMUEL**

**BOARD MEMBER SINCE JULY 2014**

*"Nobody deserves to die from dementia, including my mother who passed away from Alzheimer's disease. My passion for supporting Alzheimer's Australia was born from the support they gave me during that difficult time."*

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 35 years he has been actively involved in the day-to-day management of the business with an emphasis on Finance, Administration, Sourcing and Procurement.

Neil has travelled extensively throughout Asia and Europe for 30 years, and lectures at Deakin University on Trading with China.

He has served in leadership positions on numerous Boards within the not-for-profit sector for many years, specialising in governance and finance. Neil serves as Chair on the Board of Alzheimer's Australia Vic. He is also serving on the Board of Alzheimer's Australia Dementia Research Foundation and Alzheimer's Australia Dementia Research Foundation - Victoria.

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





**ACTING CHIEF  
EXECUTIVE OFFICER  
MAREE MCCABE**

Maree McCabe, RN, Post Grad Dip Adv MHN, PMHN, MBA, MAICD has a background in senior executive positions across the mental health and aged care sectors.

Since Maree's appointment as CEO of Alzheimer's Australia Vic in 2010, she has successfully overseen an 84% increase in staff and driven the development of the Perc Walkley Dementia Learning Centre, including the Virtual Dementia Experience™ - a world first multisensory environment for experiential learning in dementia care. This technology has won the state, national and

international iAwards, the Microsoft Imagine Cup in the category of Global Citizenship and the Minister for Health Public Healthcare award in 2015.

Maree has also overseen the expansion of dementia support services in regional Victoria, including the establishment of multidisciplinary regional hubs in a number of rural areas.

Maree is currently the Interim National CEO of Alzheimer's Australia.



# OUR THANKS GO TO

## OUR NATIONAL AMBASSADORS



### **ITA BUTTROSE, AO OBE**

Ita has been a great supporter of Alzheimer's Australia since her time as National President, and we are grateful for her continued contribution and involvement over the past 12 months.



### **SUE PIETERS-HAWKE**

Sue has long been involved with Alzheimer's Australia, and has now offered her support in an ongoing capacity. We thank her for the contribution she has made during the past year.

## OUR NATIONAL PATRON



### **GOVERNOR-GENERAL OF THE COMMONWEALTH OF AUSTRALIA.**

His Excellency General The Honourable Sir Peter Cosgrove AK MC (Retd).

## **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 FINANCIAL AND RISK MANAGEMENT COMMITTEE AS AT 30 JUNE 2016

The Committee consists of Treasurer Neil Samuel, Director, Alzheimer's Australia (SEE PAGE 11), Maree McCabe, Acting Chief Executive Officer, Alzheimer's Australia (SEE PAGE 12) and two independent members:



### GEOFF KNUCKEY

**MEMBER SINCE NOVEMBER 2015**

Geoff Knuckey BEc ANU, FICA, GAICD, IIAA, 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 non-executive board director and Audit Committee positions in the private and public sectors.

His career has included specialising in financial statement 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 on internal audit, corporate governance, risk management and financial statements auditing and reporting. 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 of twelve government departments.



### TONY GRIEVES

**MEMBER SINCE FEBRUARY 2014**

Tony is a Chartered Accountant and currently works in the risk assurance services practice of RSM in Canberra. Prior to joining RSM in 2012, Tony worked with PriceWaterhouseCoopers, and before that was Partner at WalterTurnbull in Canberra.

With over 25-years of professional services experience in Sydney and Canberra, Tony has worked with not-for-profit, government funded and private sector organisations. He is currently a member of the Australian Council for International Development, Finance and Audit committee and the Healing Foundation Audit Risk and Finance committee.

His professional associations include membership of Chartered Accountants Australia and New Zealand, the Australian Institute of Company Directors, Institute of Internal Auditors – Australia and Association of Certified Fraud Examiners.

Tony's academic background includes a Bachelor of Arts in Accounting.

# NATIONAL PRESIDENT'S REPORT



In this, my third year as National President of Alzheimer's Australia, I once again find myself reflecting on a year of change. During 2015 and 2016 we have seen governance changes within our own organisation, as well as aged care reforms and changes to government funding that have impacted on the way Alzheimer's Australia operates.

These changes have not come without their challenges but, as you will see throughout this report, the commitment of our Board, staff, volunteers and members has enabled us to meet these challenges with a great deal of success.

Last year, the announcement of the new National Health and Medical Research Council's (NHMRC) National Institute of Dementia Research (NNIDR) heralded a significant change to the dementia research landscape in Australia. Over the past twelve months, we have enjoyed building on our partnership with the NNIDR to prioritise dementia research and to ensure Australia continues as a world-leader in this field.

In October, we welcomed the announcement of \$43 million in funding to be shared among seventy-six dementia researchers. We look forward to seeing this crucial contribution being translated into results that will create a healthier Australia.

In addition, we have continued to hold vital, ongoing discussions with government officials to ensure the specific needs of people with younger onset dementia are met going forward. To that end, we have continued to advocate for change when it comes to the appropriateness of residential aged care homes for younger people with dementia by raising the issue during parliamentary inquiries, in public forums and the media.

During the past twelve months we have continued to ensure consumer voices are at the heart of all we do. We have used their insights to inform our advocacy work, in particular when advocating in numerous ways for a comprehensive, funded National Dementia Strategy with measurable outcomes.

A particular highlight came in March when we hosted a two-day national summit in Canberra, during which our consumers articulated their vision for dementia care in Australia. This initiative fed directly into our National Dementia Strategy blueprint which allowed us to take the unanimous voice of our consumers to the very policy makers who influence legislation with a view to improving the quality of life for all those living with dementia and their families and carers.

Our commitment to advocating for a National Dementia Strategy culminated in a campaign implemented during the lead up to the 2016 Federal Election, which saw us call repeatedly upon all political parties to commit to funding improved dementia support across a number of different areas.

Following this activity, Alzheimer's Australia welcomed new Government legislation announcing greater consumer choice and control over their aged care services and providers. We now look forward to working with the Government to see relevant supports developed and information made available to ensure consumers are best equipped to make informed choices.

I would like to take this opportunity to thank our former National CEO, Carol Bennett for her service and dedication to the organisation during 2015 and 2016. I would also like to thank retiring National Board members Jerry Ellis and Richard Cooper, both of whom brought a wealth of expertise and practical support to Alzheimer's Australia. Their contribution is greatly appreciated.

I would like to close this report by acknowledging and thanking all of our supporters, corporate partners, donors and anybody else who has made a contribution to Alzheimer's Australia during the past twelve months. I look forward to continuing our work with you in the future.

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

**Yours sincerely**  
**Professor Graeme Samuel AC**  
**National President**  
**Alzheimer's Australia**



# CEO'S REPORT



The past financial year has been a busy and exciting time for Alzheimer's Australia, with a number of activities being undertaken by the highly committed people who make up our organisation. As in previous years, they have worked with the collective focus of ensuring better outcomes for people living with dementia, their families and carers. It is this commitment that informs the areas of focus prioritised set by Alzheimer's Australia.

Our operating environment has been influenced by a number of factors including the ongoing Aged Care Reforms, the National Disability Insurance Scheme (NDIS), the introduction of My Aged Care and the new world of consumer-directed care. These changes have seen Alzheimer's Australia successfully rise to the challenge of finding new and innovative ways of undertaking our business to better support people impacted by dementia.

Throughout the year there have been a number of highlights which collectively demonstrate our commitment to meeting our strategic priorities. They include:

- Ongoing discussions with the Government to advocate for people with younger onset dementia. The work of our Younger Onset Dementia Key Worker Program in supporting people diagnosed with dementia under the age of 65 to transition into the NDIS. We are pleased that nationally 4,126 people with younger onset dementia are being supported by our Key Worker Program, which is an increase of 1,388 people since the previous financial year.
- Continued involvement with the National Health and Medical Research Council's (NHMRC) National Institute of Dementia Research (NNIDR) to ensure our consumers are involved in setting dementia research priorities for the Institute.
- Our National Consumer Summit at Parliament House in Canberra, which brought together over 70 people living with dementia and their carers to outline and communicate priorities for improving dementia care in Australia. As an outcome of this meeting the National Consumer Summit Communiqué was developed which is actively being used in our advocacy and policy work.
- A campaign in the lead up to the 2016 Federal Election calling on all parties to commit to taking action against dementia, resulting in funding pledges from the Coalition, Australian Labor Party and the Greens.
- The development of over 17 policy proposals and submissions to various Government departments aiming to improve outcomes for people living with dementia and their carers. We are pleased

our Submission to the Senate Community Affairs Reference Committee Inquiry: The Future of Australia's Aged Care Workforce resulted in a Public Hearing, allowing our National President to present our case before the Australian Parliament.

We acknowledge that this important work could only have been achieved with the invaluable contribution of our consumers. We understand the importance of having a wide range of consumer engagement mechanisms in place to enable as many people impacted by dementia as possible to inform the work of Alzheimer's Australia and drive change at the national level.

For that reason, over the past twelve months Alzheimer's Australia has been moving towards capturing a more diverse range of consumer perspectives than ever before. This has included a shift away from having various committees to the establishment of a more inclusive network, known as the National Dementia Consumer Network.

The Network aims to strengthen and promote the voices of people living with dementia, as well as the voices of their informal carers and family members. It aims to involve a diverse network of consumers in the development of dementia policy, programs and research to ensure the provision of dementia support is responsive to the priorities of consumers.

We look forward to continuing our work with consumers to drive all aspects of our efforts and performance into the future.

I would like to thank everybody who has been involved with Alzheimer's Australia over the past twelve months for their dedication and commitment to our organisation as we strive to lead the way towards a world that is inclusive of people living with dementia. In particular, I would like to acknowledge the Commonwealth Government for their ongoing support of our work. Their contribution ensures we are able to continue meeting the needs of Australians impacted by dementia through the provision of specialist support and education.

A handwritten signature in black ink, appearing to read 'Maree McCabe', written in a cursive style.

**Yours sincerely**  
**Maree McCabe**  
**Ag Chief Executive Officer**  
**Alzheimer's Australia**

## 2. POLICY AND ADVOCACY

Alzheimer's Australia is committed to ensuring the voices of people living with dementia, their families and carers are at the heart of everything we do including policy and advocacy, service provision, community awareness and research. Our aim is to strengthen consumer involvement across all areas of the organisation and to ensure their insights inform and shape national policy.

We work closely with the Australian Government and have provided input into national policy through the Ministerial Dementia Forums, the Aged Care Sector Advisory Committee, National Aged Care Alliance and national submissions on issues that are important to people impacted by dementia.

“ I have an important contribution to make to the discussion around the funding for dementia and the way in which we are supported by the Government and the Community. It's about improving the future situation for people who have been diagnosed with dementia, Mike Bryan, living with dementia.

## CONSUMER SUMMIT

In March 2016, more than 70 people living with dementia and their carers from across the country gathered in Canberra to develop and present a Communique to Parliamentarians outlining their priorities for immediate action to improve dementia care in Australia. These action priorities were informed by their experiences and knowledge of what would make a difference in their own lives.

The Communique was developed by consumers during an intensive two-day National Consumer Summit held at Parliament House, to help shape the beginnings of a National Dementia Strategy. The event was hosted by Alzheimer's Australia, in recognition of the critical role consumers should be enabled to play as the drivers of future policy around dementia.

Over the two days, consumers unanimously called for a funded National Dementia Strategy with measurable outcomes which builds on the National Framework for Action on Dementia 2015-2019 and addresses the following action priorities:

- Promote greater awareness and risk reduction
- Tackle the stigma and discrimination associated with dementia and support social inclusion and participation

- Improve access to timely diagnosis and high quality health care
- Provide care and support in the community that supports independence, social engagement and effective support for informal carers
- Ensure access to high quality residential care and publicly available information about consumer experience and quality of care
- Improve end of life care and support for people with dementia
- The implementation of Consumer Directed Care for people with dementia and their carers
- The commitment to increase investment in dementia research

The Communique can be reviewed in full at [www.fightdementia.org.au/sites/default/files/NATIONAL/documents/National-Consumer-Summit-2016-Communique.pdf](http://www.fightdementia.org.au/sites/default/files/NATIONAL/documents/National-Consumer-Summit-2016-Communique.pdf)



## DEMENTIA-FRIENDLY COMMUNITIES

Alzheimer's Australia is committed to the development of dementia-friendly communities across the nation. A dementia-friendly community is a place in which people living with dementia are supported to live a high quality of life with meaning, purpose and value. It is a place where people with dementia are enabled to remain socially engaged and to continue working, participating in volunteering, hobbies and cultural activities.

Dementia-friendly initiatives were prioritised across a number of projects funded by our National Quality Dementia Care Initiatives program. In addition to our ongoing work with Kiama in New South Wales, which commenced during the last financial year, five more pilot dementia-friendly communities have now been established across Australia. These include:

- Port Macquarie in New South Wales
- Beechworth in Victoria
- Holdfast Bay in South Australia
- Bribie Island in Queensland
- Darwin in the Northern Territory

People living with dementia and their carers have been closely involved with these initiatives, thanks to their participation in local dementia alliances.

Each community has created meaningful opportunities for people with dementia to become socially engaged through the likes of dementia-inclusive community cafés, choirs and other social groups. Businesses and other organisations in these areas including local councils, community centres, aged care facilities, retail outlets, banks and hospitality venues have also made a commitment to working towards providing dementia-friendly environments.

Alongside this, we have continued our work with the community of Kiama which has stepped up to become a leader in the area of dementia-friendly communities by partnering with Alzheimer's Australia and the University of Wollongong to create a dementia-friendly community. At the heart of the Kiama project is a local dementia advisory group, comprising people living with dementia alongside their care partners, friends and/or significant others, to help guide and inform the project.

## BUDGET SUBMISSION

Alzheimer's Australia called on the Federal Government to build on the previous year's investment of \$200 million for dementia research in its Federal Budget Submission, Towards 2020 – a Dementia Response for Australia.

To read the submission in full, visit [fightdementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Pre-Budget-Submission-2016-17.pdf](http://fightdementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Pre-Budget-Submission-2016-17.pdf)

The submission asked the Government to implement a comprehensive, funded national strategy with measurable outcomes, which builds on existing areas of success to develop a strategic, collaborative and cost-effective response to dementia.

Alzheimer's Australia called on the Government to invest \$101.6 million over three years with a view to:

- increasing awareness to reduce the stigma and social isolation associated with dementia
- developing risk reduction strategies which look to partner with other health promotion campaigns focusing on conditions with common risk factors
- enabling timely diagnosis, to connect people with dementia to the support and services they need as quickly as possible
- developing a coordinated approach to post-diagnosis care and support
- creating initiatives to improve the quality of care for people with dementia
- ensuring end-of-life care supports the choices of people with end-stage dementia
- investing and supporting consumer involvement in dementia research.

Despite our calls, the budget did not result in any new major policies or programs to support people with dementia. This was disappointing, particularly considering that dementia is now the second leading cause of death in Australia. However, this has encouraged us to advocate even harder in the future to ensure people living with dementia receive better support.

The budget did include continued funding for dementia flexible funds, initiatives to boost funding for a My Aged Care contact centre, support for regional aged care facilities and unannounced compliance visits for residential aged care facilities. These are all developments that our consumers have indicated are important.



## ELECTION CAMPAIGN

In the lead up to the Federal election, Alzheimer's Australia called on all political parties to commit to tackling the dementia challenge.


Alongside consumers, representatives from our organisation met with a number of political leaders at Parliament House in Canberra to stress the importance of a Governmental commitment to implementing a comprehensive, funded, national approach to supporting people with dementia.

Following consultation with our consumers, we identified the following three key priorities:

- tackling the stigma and discrimination associated with dementia
- developing respite services to better support people with dementia and carers in the community and
- committing to ensuring high quality care in residential care.

The campaign was followed by:

- the Coalition pledging to commit \$3.9 million to support dementia-friendly communities and \$7.5 million for specialist dementia care units
- the Australian Labor Party (ALP) pledging to commit \$5 million for a National Dementia Strategy, \$10 million for dementia-friendly communities and \$10 million for respite care trials at two important sites
- the Greens pledging to commit \$137 million in funding and support for dementia over four years.

 **We all hope to see a cure for this condition, but until meaningful research achieves a real breakthrough, we need to support the 353,800 Australians and their families currently living with the condition to ensure they have access to the best quality dementia care possible. Professor Graeme Samuel AC, National President, Alzheimer's Australia**

## MAJOR NATIONAL POLICY SUBMISSIONS AND PAPERS

**During the 2015-2016 financial year, Alzheimer's Australia developed numerous national policy submissions and papers, including:**

Submission to Productivity Commission Data Inquiry - July 2016

Submission to Integrated Carer Support Service consultation - June 2016

The Medical Research Future Fund Priorities - June 2016

The National Disability Advisory Program review - June 2016

Increasing Choice in Home Care - June 2016

ILC Commissioning Framework Submission - April 2016

Submission to the Senate Community Affairs References Committee Inquiry: the Indefinite Detention of People with Cognitive and Psychiatric Impairment in Australia - April 2016

Submission to the Senate Community Affairs References Committee Inquiry: the Future of Australia's Aged Care Sector Workforce - March 2016

Submission to the Joint Standing Committee on the National Disability Insurance Scheme: Inquiry into accommodation for people with a disability - March 2016

Pre-Budget Submission 2016-17 - February 2016

Submission to the Australian Human Rights Commission - Willing to Work - December 2015

Private Health Insurance Review - December 2015

MBS Review - November 2015

National Safety and Quality Health Service Standards Version 2: Consultation - October 2015

Australian Aged Care Quality Agency – Let's Talk Quality consultation - October 2015

Submission to the Primary Health Care Advisory Group - September 2015

Submission to the House of Representatives Standing Committee on Health - July 2015

Submission to the National Disability Advocacy Framework - July 2015



## CONSUMER GROUPS INCLUDED IN ALZHEIMER'S AUSTRALIA'S WORK

As part of our commitment to ensuring the voices of people living with dementia, their families and carers are at the core of our work, we have continued to involve consumers in our policy and advocacy work.

### National Consumer Advisory Committee

The National Consumer Advisory Committee contributes to policy, advocacy documents, submissions, publications and consultations. It also monitors the work of Alzheimer's Australia on issues of importance or concern to people with dementia, their families and carers.

Committee membership comprises people with dementia and carers.

#### Key achievements include:

- Working with Alzheimer's Australia to progress policy work around:
  - o elder abuse
  - o increasing choice in home care
  - o consumer directed care
  - o dementia and legal rights
  - o people who are homeless.
- Progressing the work on legal rights following a diagnosis of dementia, including providing input into the *Dementia and Your Legal Rights* publication, developed to help people better understand their legal rights when it comes to dementia. The publication was launched at Parliament House in March 2016.

This publication can be viewed at [www.fightdementia.org.au/Dementia-and-your-legal-rights.pdf](http://www.fightdementia.org.au/Dementia-and-your-legal-rights.pdf)

- Providing input into the development of the Support for *Carers: A practical guide to services for families and friends of people with dementia* resource, developed to provide information and support to carers who are embarking on a dementia journey with someone they care for.

This resource can be viewed at [www.fightdementia.org.au/Support-for-carers.pdf](http://www.fightdementia.org.au/Support-for-carers.pdf)

- Participation in ongoing activities to raise community awareness and understanding of dementia, including providing advice on Alzheimer's Australia's Dementia Awareness Month activities during September, participation in media interviews, and presentations at conferences and other events.
- Providing consumer perspectives and participation in external policy committees and research studies.
- Sharing consumer experiences to contribute to the Australian Commission on Safety and Quality in Health Care's Caring for Cognitive Impairment Campaign - a national campaign that recognises people with dementia as being at significantly higher risk of preventable adverse events while in hospital.

### Consumer Dementia Research Network

The Consumer Dementia Research Network enables consumers to take an active role in research and research translation. It sets priorities for funding, provides feedback on project proposals, assists on project steering and advisory committees, and contributes a consumer perspective to ongoing research. Network membership comprises people with dementia and carers.

#### Key achievements include:

- Participation on research steering and advisory committees for the Cognitive Decline Partnership Centre's knowledge translation projects.
- Working with the Dementia Collaborative Research Centres to review applications and participate in new and ongoing research and knowledge translation activities.
- Sitting on the Scientific Panel of the Alzheimer's Australia Dementia Research Foundation and the Expert Advisory Panel of the National Health and Medical Research Council's National Institute for Dementia Research.
- Participation in project advisory groups and steering committees for knowledge translation projects funded under the Alzheimer's Australia National Quality Dementia Care Initiative.
- Helping to raise public awareness and understanding of the importance of consumer input into dementia research through communications activities including promoting the work of the committee during key forums.
- Providing input into Alzheimer's Australia submissions to national consultations on research issues.

- Providing consumer perspectives during national public forums, such as the National Dementia Research and Knowledge Translation Forum 2015 and participation in external policy committees and research studies.
- Involvement as research participants in external dementia research projects.

### **National Cross Cultural Dementia Network**

The National Cross Cultural Dementia Network supports Alzheimer's Australia, its member organisations, government and peak bodies with advice and advocacy on the provision of quality dementia care for people from culturally and linguistically diverse (CALD) backgrounds.

Membership, drawn from across Australia, is multidisciplinary and represents a diverse mix of cultures and ethnicities. Members also come from a range of professions including residential aged care, education, community work, acute care, peak ethnic agencies, research and management positions.

Key achievements include:

- Advocating to peak agencies involved in research, such as the National Health and Medical Research Council, for CALD communities to be equitably represented in all aspects of research.
- Progressing work to address barriers in order to increase CALD-specific dementia research, as well as CALD participation in mainstream dementia research.
- Raising awareness of the needs of CALD communities in relation to dementia services and programs.

### **National Aboriginal and Torres Strait Islander Dementia Advisory Group**

The National Aboriginal and Torres Strait Islander Dementia Advisory Group provides advice and guidance to Alzheimer's Australia in helping to meet the needs of Aboriginal and Torres Strait Islander people with dementia. The NATSIDAG membership includes people from around the country and with diverse professional backgrounds including social work, nursing, aged care and geriatrics.

Key achievements this year included member attendance at national conferences, such as the Australian Association of Gerontology conference, as well as working with Alzheimer's Australia to review and improve Aboriginal and Torres Strait Islander content on our national website [fightdementia.org.au](http://fightdementia.org.au) and in our Help Sheets.

### **Formation of the National Dementia Consumer Network**

In early June, the National Consumer Advisory Committee, the Consumer Dementia Research Network, the National Cross Cultural Dementia Network and the National Aboriginal and Torres Strait Islander Dementia Advisory Group were amalgamated to form the Alzheimer's Australia National Dementia Consumer Network. We would like to acknowledge the invaluable contribution made by the individuals who make up these groups. Their work has made a huge difference to those impacted by dementia across these communities.

Alzheimer's Australia decided to take this new approach to strengthen consumer engagement and support consumer leadership in a more sustainable way moving forward.

The establishment of a National Dementia Consumer Network supports the involvement of a broad and diverse network of consumers in national dementia policy, programs and research, and aims to empower consumers to drive change across these areas in numerous ways, including:

- Sharing a personal story in the media
- Participating in consumer summits, workshops and forums
- Providing feedback on Alzheimer's Australia submissions and consumer publications
- Involvement in research activities
- Setting consumer priorities in Alzheimer's Australia advocacy and research work

Network membership is open to all people with dementia, their families and unpaid carers (past or current) from across the country.

Alzheimer's Australia welcomes and encourages participation amongst members from diverse backgrounds and special needs groups, including Aboriginal and Torres Strait Islander people; people from culturally and linguistically diverse backgrounds; people with younger onset dementia; people in rural and remote areas; people at risk of homelessness; people who identify as lesbian, gay, bisexual, transgender and/or intersex, and people with dementia who live alone.


## **Alzheimer's Australia Dementia Advisory Committee**

Our Alzheimer's Australia Dementia Advisory Committee was formed in 2013. All members are people with dementia, making this committee the third of its kind to be established anywhere in the world, and the first in Australia.

The committee aims to give a voice to people living with a diagnosis of dementia by incorporating their insights into advocacy and policy around the needs and priorities of people with dementia in relation to service provision, information, support and education.

### **Key achievements include:**

- Working with Alzheimer's Australia to identify and address gaps in services for people with younger onset dementia, people with dementia who are living alone, and the children of people with dementia.
- Working with Alzheimer's Australia to inform national submissions on elder abuse and increasing choice in home care.
- Members presenting at the 31st International Conference of Alzheimer's Disease International in April 2016 in Budapest, Hungary.
- Participation in ongoing activities to raise community awareness and understanding of dementia, including advice on Alzheimer's Australia Dementia Awareness Month activities, participation in media interviews and conference presentations.
- Raising important consumer issues during the Increasing choice in Home Care workshop hosted by the Department of Health.
- Working with Alzheimer's Australia to improve the access and usability of our website [fightdementia.org.au](http://fightdementia.org.au) for people with dementia.
- Providing advice and feedback to inform the Younger Onset Dementia Key Worker Program evaluation.
- Reviewing and providing feedback on resources used during the Alzheimer's Australia Living with Dementia program across Australia.
- Providing advice on Alzheimer's Australia's Community Development grants, designed to address the gaps that exist across the service delivery spectrum for people living with dementia.

 **In order to effect meaningful change, people with dementia must be front-and-centre when it comes to the issues that affect us,**  
Kate Swaffer, Co-founder, Chair and CEO of Dementia Alliance International (DAI) and Chair of Alzheimer's Australia Dementia Advisory Committee (AADAC) and living with dementia.

# COMMUNITY AWARENESS, UNDERSTANDING, ATTITUDES AND ACTIONS

## Dementia Awareness Month

Dementia Awareness Month was held throughout September 2015, with a continuation of the previous year's theme 'Creating A Dementia-Friendly Nation'. The goal was to encourage Australians to become dementia-aware, have a better understanding of what life is like for a person with dementia, and ultimately be inspired to create communities where people with dementia are supported to live a high quality of life with meaning, purpose and value.

### Media coverage

Over the 53-day period between 17 August 2015 to 8 October 2015 there were 417 media items related to Dementia Awareness Month across print, broadcast and online mediums. This coverage reached a cumulative audience of 15,068,542 people, and had an advertising space rate of AUD 3,985,087.

### International guest speaker

Alzheimer's Australia welcomed International guest speaker Gill Ayling, who conducted a national speaking tour which saw her visit every state and territory in the country.

Gill's presentation focused on examples of international initiatives to combat dementia and create dementia-friendly communities.

Gill has over 30 years of experience in the UK civil service and, in the last 15 years, has held senior roles in central government policy and operations work. She currently works in the UK Department of Health and is Head of Global Action Against Dementia (GAAD).

### Domestic lecture tour

Professor Richard Fleming conducted a domestic lecture tour during Dementia Awareness Month, visiting Port Macquarie, Adelaide and Darwin where he presented Dementia Friendly Communities need Dementia Friendly Buildings ... but how do we recognise them?

His presentation focused on what we have learned from 30 years of research on the design of residential environments for people living with dementia, the progress that has been made, the challenges we are facing and the ways we can support people with dementia to live outside of residential facilities by making our towns and cities more dementia-friendly.

Professor Fleming discussed international examples of the steps being taken to achieve this, and gave details of a new tool that aims to help recognise a dementia-friendly building when we see one, and to identify the improvements that need to be made to buildings that don't currently support people with dementia.

## Parliamentary Friends of Dementia Forum

Alzheimer's Australia hosted a Parliamentary Friends of Dementia Forum at Parliament House in Canberra, during which international guest speaker Gill Ayling addressed federal politicians, sharing some of her experiences and urging them to ensure the Australian Government follows the UK example in developing a measurable, national strategy to help tackle the growing dementia challenge.

The event was opened by consumer John Doull, a former public servant who gave an engaging address offering an honest insight into life with dementia.

The Minister for Health and Aged Care, The Hon. Sussan Ley MP attended on behalf of the then Prime Minister, The Hon. Tony Abbott, while our co-conveners The Hon. Shayne Neumann MP and The Hon. Teresa Gambaro MP and a number of other stakeholders and Parliamentarians attended.

## Diagnosing dementia - what does the future hold? ABC Big Ideas

Alzheimer's Australia teamed up with the Alzheimer's Australia Research Foundation, The Florey Institute of Neuroscience and Mental Health and the CRC for Mental Health to host a panel discussion for ABC's Big Ideas program, entitled Diagnosing dementia – what does the future hold?

During the event, which was held in Melbourne, our consumer Jenny Lloyd addressed a full house alongside ABC Big Ideas host Paul Barclay; Alzheimer's Australia National President, Professor Graeme Samuel AC; Professor Ashley Bush from the CRC for Mental Health and Florey Institute; Alzheimer's Australia Dementia Research Foundation Fellow Doctor Rachel Buckley from the University of Melbourne and Doctor Shaun Frost from the CSIRO.

The forum focused on providing an update on the very latest developments in dementia research, while examining potential areas of focus for dementia research in the future. It was later broadcast during World Mental Health Week.

## MEDIA AND SOCIAL MEDIA WEBSITE

### Traditional media results for 2015-2016

Number of news items generated by Alzheimer's Australia 929

Total cumulative audience reached **34,676,197**

Total Advertising Space Rate (ASR) AUD **\$8,235,107**

### Social media results for 2015-2016



MORE THAN **7,785** FOLLOWERS



MORE THAN **41,941** FOLLOWERS

### Join our community



@AlzheimersAus



Fight Dementia



Alzheimer's Australia



AlzheimersAustralia



@ alzheimersaus

During the financial year 2015-16, our website continued to provide a vital source of dementia-related information for members of the public.

Key highlights included:

- the launch of an automatic 'Read Aloud' service to support visitors with poor vision, by reading content aloud
- the expansion of our translated and bi-lingual content to cover more than 40 different languages, to support readers whose preferred language is not English
- the initiation of a User Research project to better understand our visitors by analysing their behaviour, needs and desires. The results of this research will inform our website strategy going forward, and assist us to meet our goal of hosting a consumer-led website
- the launch of a Video Gallery to showcase Alzheimer's Australia's large collection of education and awareness YouTube videos.

## RESULTS

### VISITORS IN 2014/15

**1.1 million**

### VISITORS IN 2015/16

**1.3 million up 21%**

### PAGES VIEWED OR READ IN 2015/16

**3.3 million**

### PAGES VIEWED OR READ IN 2014/15

**3 million up 11%**

Help Sheets read or downloaded

**349,000 TIMES**

When asked "How likely is it that you would recommend the Alzheimer's Australia website to a friend or colleague?" 75% of our website users rated us **7+ OUT OF 10.**



## DEMENTIA NEWS

Dementia News is Alzheimer's Australia's e-newsletter, which has been circulating since December 2015 to provide an effective way of disseminating information about the latest newsworthy developments relating to dementia.

Prior to the development of Dementia News, Alzheimer's Australia distributed seven different eNews updates, each catering to a different audience. Following consultation with the Australian Government Department of Health it was decided a more efficient way to manage this process would be to include all information in one universal update.

The Dementia News currently has a regular subscriber base of **12,797**.

## RESOURCES

During the 2015-2016 financial year, Alzheimer's Australia developed and launched an array of new print and online resources.

### **Dementia Friendly Communities White Paper**

This resource was developed to increase awareness about the simple steps all communities can take towards become more dementia-friendly. It also aims to educate on how the development of dementia-friendly communities around Australia will dramatically improve the lives of people living with dementia and their families and carers, as well as the community at large.

The resource can be viewed at [www.fightdementia.org.au/Dementia-Friendly-Communities-white-paper.pdf](http://www.fightdementia.org.au/Dementia-Friendly-Communities-white-paper.pdf)

### **Support for Carers: A practical guide to services for families and friends of people with dementia**

The purpose of this guide is to provide information and support to carers who are embarking on their dementia journey with someone they care for.

The resource can be viewed at [www.fightdementia.org.au/Support-for-carers.pdf](http://www.fightdementia.org.au/Support-for-carers.pdf)

### **Caring for Someone with Dementia: The economic, social and health impacts of caring and evidence based supports for carers**

This resource was developed alongside the Support for Carers resource and explores the far-reaching impacts of caring for a person living with dementia.

The resource can be viewed at [www.fightdementia.org.au/Alzheimers-Australia-Numbered-Publication-42.pdf](http://www.fightdementia.org.au/Alzheimers-Australia-Numbered-Publication-42.pdf)

### **Preventing financial abuse of people with dementia**

This resource was developed to explain how financial abuse of people with dementia can occur and outline the steps people with dementia, their families and carers can take to prevent this from happening.

The resource can be viewed at [www.fightdementia.org.au/Helpsheet-DementiaQandA22-PreventingFinancialAbuseofPeoplewithdementia\\_english.pdf](http://www.fightdementia.org.au/Helpsheet-DementiaQandA22-PreventingFinancialAbuseofPeoplewithdementia_english.pdf)

### **Brainyapp**

Our free app that can help people improve their brain health was upgraded to reflect the latest scientific research and engage more with users, while still including games and trivia for an element of fun.

A web version of the app which has also now been made available and can be synchronised with smartphones and tablets.

More information on this resource can be found at [www.brainyapp.com.au](http://www.brainyapp.com.au)

### **Dementia and your legal rights**

This resource was developed to give people living with dementia and their carers access to information that will help them better understand their legal rights when it comes to dementia.

The resource can be viewed at [www.fightdementia.org.au/legal-rights](http://www.fightdementia.org.au/legal-rights)

### **Community Café Toolkit**

This resource was designed to help community groups, organisations or individuals set up and run a local café social group for people living with dementia, with a view to helping people with the disease remain socially connected.

The resource can be viewed at [www.fightdementia.org.au/community-cafe-toolkit](http://www.fightdementia.org.au/community-cafe-toolkit)

# 3. SERVICE INNOVATION AND EXPERTISE

 The community café in our area has been a great support to both of us in so many ways. This is not just because of the special bond we have formed with people in the same boat as us, but also, because of the wonderful help we have received from our Younger Onset Dementia Key Worker, Justine, who also attends, Chris Jones, carer.

## YOUNGER ONSET DEMENTIA KEY WORKER PROGRAM

The Younger Onset Dementia Key Worker Program (YODKWP) continued in the 2015 and 2016 financial year. This flagship program provides individualised support to people living with younger onset dementia, their families and carers, which is achieved through a national network of 40 Younger Onset Dementia Key Workers.

The third operational year of this program has seen continued growth in referrals and a consequent increase in support provided to people with younger onset dementia and their families.

### YOUNGER ONSET DEMENTIA KEY WORKER PROGRAM RESULTS:

No. of people accessing program in 2013-2014	<b>1,754</b>
No. of people accessing program in 2014-2015	<b>2,894</b>
No. of people accessing program in 2015-2016	<b>4,126</b>
No. of new referrals to program in 2013-2014	<b>970</b>
No. of new referrals to program in 2014-2015	<b>1,400</b>
No. of new referrals to program in 2015-2016	<b>1,388</b>

## NATIONAL DEMENTIA SUPPORT PROGRAM – BUILDING CAPACITY IN DEMENTIA CARE:

### HELPLINE, COUNSELLING AND SUPPORT, INFORMATION, AWARENESS, EDUCATION AND TRAINING

Alzheimer's Australia provides vital support and services to assist people living with dementia, their carers, family and friends while also increasing knowledge and awareness of dementia in the community, through the National Dementia Support Program (NDSP).

Services provided under the NDSP include the National Dementia Helpline, counselling and support, information, awareness, education and training. Funded until June 2017, the program also develops innovative methods to respond to neurodegenerative disease.

#### The NDSP provides:

1. National Dementia Helpline and Referral Service - 1800 100 500
2. National website - [fightdementia.org.au](http://fightdementia.org.au)
3. Counselling and support services, including early intervention such as the Living with Memory Loss programs
4. Up-to-date information and national resources including our Help Sheets
5. Carer education programs
6. Awareness, information and education sessions
7. Promotion of awareness and increasing the understanding of dementia across the whole community

#### 2015 - 2016 statistics:

- NDSP service offerings continued to be in high demand with **195** early intervention sessions, **2,088** support group sessions and **4,322** counselling sessions delivered to consumers.
- **2,963** family members or carers participated in educational programs and **1,362** community information, education and awareness sessions were delivered.
- There were **1,113,902** visits to the Alzheimer's Australia national website, with **347,937** Help Sheets and over **23,000** website resources targeting special needs groups downloaded.
- A total of **27,876** calls were made to the National Dementia Helpline – an average of **2,323** calls per month.
- A further **1,070** people made contact with the organisation through enquiries lodged via the website.
- There were **10,849** visitors to our service centres, with the range of services offered including counselling, carer education, early intervention, education and training, support for people with special needs, libraries and resources.
- A total of **723** activities were delivered through our service centres to **13,551** participants. These activities included outreach, therapeutic and social activities. Access points and associated services continued to provide information, while linking and referring consumers to services and host activities.

## SERVICE DELIVERY PATHWAYS PROJECT

Funded until June 2017, this program provides a range of Service Access Liaison Officer projects that focus on assisting special needs groups to access services. Projects have included work with Aboriginal communities, culturally and linguistically diverse communities, the homeless and people with dementia who live alone.

## AGED CARE SERVICE IMPROVEMENT AND HEALTHY AGEING GRANTS


In 2015-2016, we continued in the delivery of two programs that commenced in March 2015 after Alzheimer's Australia worked with partner organisations to secure Aged Care Service Improvement and Healthy Ageing Grants.

The **Making Flexible Respite Care a Practical Reality Project** promoted access to flexible respite services and developed a trial and evaluation to support the successful implementation of individualised funding. For this project we collaborated with the University of Wollongong, Alzheimer's Australia NSW, Carers Australia and National Respite Australia.

The project aimed to address real and/or perceived barriers to using flexible respite service models and to promote the use of more effective respite care.

A literature review was undertaken resulting in a report that identified the key characteristics of flexible respite and provided recommendations for further research and action to improve the delivery and uptake of flexible respite. The project built on this knowledge base through expert interviews that explored key factors associated with the provision and limitations of flexible respite care.

A national consumer summit on flexible respite was held on 1 April 2016 in Sydney. The Summit was attended by 41 people comprising people with dementia, carers, respite service providers, Key Workers/Dementia Advisors, researchers and representatives from peak bodies. The summit provided the opportunity for workshop

 Sometimes people don't know how to react but if you tell them, they'll treat you really well, Dawn McKay, carer.

discussions on the key factors relating to flexible respite services and successful models of respite care. Summit participants also engaged in small workshop discussions to test the characteristics, barriers and strategies that can be used to support successful implementation of flexible approaches to respite.

Two resources were developed as a result of this project and are to be finalised:

- A service provider resource Flexible Respite Services for People with Dementia and their Carers, Information for Service Providers, which is designed to assist aged care and disability respite providers to deliver flexible services that meet the needs of people with dementia and their carers.
- A consumer resource Flexible Respite Services for People with Dementia and their Carers, Information for Consumers, which explains how people with dementia can benefit from using respite services and how these services can support carers. It will assist consumers to recognise and seek out flexible respite within the new aged and disability systems.

In addition, research and consultation with consumers, service providers and policy experts was undertaken to support the development of a proposal for the trial of individualised funded respite and an evaluation framework. The trial proposal developed presented a series of research trials in Australia to assess the degree to which consumer choice and control impact on satisfaction with respite and overall care outcomes for people with dementia and their carers.

This project is now complete.


The **Supporting GPs and Practice Nurses in the Timely Diagnosis of Dementia Project** will continue to deliver training on dementia assessment, diagnosis and management to **6,000** GPs and **2,500** Practice Nurses. **3,537** GPs and **1,433** Practice Nurses have participated in the training so far, with the project expected to be completed by 30 June 2017.

## DEMENTIA COMMUNITY SUPPORT PROGRAM

This program continues to support the ongoing collaboration, policy and advocacy activities of Alzheimer's Australia at the national level, including our work to involve consumers in shaping national policy. Funding is available to support this work until 2017.

### Key achievements included:

- contributing to the development of policy papers and submissions to government inquiries, such as:
  - o the Joint Standing Committee on the National Disability Insurance Scheme: Inquiry into accommodation for people with a disability
  - o the Senate Community Affairs References Committee Inquiry: the Future of Australia's Aged Care Sector Workforce
  - o the Senate Community Affairs References Committee Inquiry: the Indefinite Detention of People with Cognitive and Psychiatric Impairment in Australia
- A National Consumer Summit held during March 2016 which allowed consumers, carers and parliamentarians to meet and identify priorities and topics of concern to consumers.

 When you're dealing with a medical profession with your loved one, don't be afraid to ask as many questions as you want to ask. Don't be afraid to tell a medical person, this is good or this is bad or the effects are bad, because you are advocating for the person you love - they can't do it for themselves, Imelda Gilmore, carer.



# 4. LEADERSHIP IN RESEARCH

## RESEARCH PARTNERSHIPS

During the past year, research has remained a top priority for Alzheimer's Australia. As such, we have partnered with multiple dementia researchers across the country, ensuring we involve our consumers wherever possible.

### **Some of the partnerships that we have launched include:**

- Supporting research funding through the Alzheimer's Australia Dementia Research Foundation (AADRF) Grants Program
- Contributing to the NHMRC Cognitive Decline Partnership Centre
- Partnership-based research projects
- Working with researchers to promote relevant findings through our research communications channels
- Staff and consumer involvement in numerous research projects and programs through positions on advisory committees

## NATIONAL QUALITY DEMENTIA CARE INITIATIVE

The National Quality Dementia Care Initiative (NQDCI) was established in 2010 with the objective of improving the quality of dementia care across Australia, in light of areas of concern highlighted by people living with dementia and their families and friends.

Following consultation with the Consumer Dementia Research Network (CDRN) in 2014, seven projects were identified and rolled out, and commenced in 2014-2015. The projects have progressed well, and a suite of resources and initiatives have been developed for people living with dementia, their families and carers, as well as health professionals.

### **Key achievements include:**

- Communities across Victoria, South Australia, New South Wales, Queensland and the Northern Territory working towards becoming dementia-friendly, by creating opportunities for meaningful social engagement for people with dementia through community cafes, choirs, and other social groups. People living with dementia and their carers have been closely involved with these initiatives through their involvement with local dementia alliances.
- The engagement of local organisations to become more dementia-friendly by providing them with national guidelines. Twenty-eight local businesses and organisations across the country are now actively working towards becoming dementia-friendly through staff education and training, assessing their physical environments and the implementation of dementia-enabling design to create a socially inclusive and supportive environment.
- The creation of volunteering buddy programs in South Australia, Tasmania, New South Wales and Victoria, where people living with dementia are enabled to get involved with their communities by volunteering with local organisations.
- The creation of the Community Café Toolkit to help community groups, organisations and individuals establish and run local café social groups to assist people with dementia, their families and carers to remain socially connected.


- The development of the Engage, Enable, Empower online resource, specifically designed for people with dementia in consultation with consumers to provide information, recommendations and encouragement to stay active and engaged in meaningful activities.
- A partnership between the Australian Dental Association and Alzheimer's Australia to develop of a series of online professional development educational tools. These tools were developed through consultation with dentists, medical practitioners and consumers to educate dental professionals on best practice care for people living with dementia.
- A partnership between NPS MedicineWise and Alzheimer's Australia which saw the development of a national consumer awareness campaign to educate and empower people living with dementia, and help them understand their treatment rights. A suite of resources was developed to help people with dementia and those involved in their care navigate their medicine and non-medicine choices.
- A partnership between the NSW Agency of Clinical Innovation and Alzheimer's Australia to develop resources co-designed by consumers, to support people living with dementia, their families and carers to work in partnership with allied health professionals.


## NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL (NHMRC): COGNITIVE DECLINE PARTNERSHIP CENTRE

Alzheimer's Australia is one of the four funding partners for the NHMRC Cognitive Decline Partnership Centre (CDPC). The vision of the CDPC is to improve the lives of people living with dementia and cognitive decline through the co-creation and dissemination of knowledge that changes policy, systems and practices.

The CDPC is currently conducting nearly forty major activities or research projects, which are supported by seven Enabling Sub-Units, one of which is the Consumer Enabling Sub-Unit, supported by Alzheimer's Australia through the funding of the role of Consumer Investigator. The Consumer Investigator leads the Sub-Unit, which consists of approximately sixteen Alzheimer Australia consumers.

## COMMENTS FROM THE RESEARCHERS SURVEYED INCLUDED:

 The consumer representatives have been enormously beneficial by participating during teleconferences, in commenting on documents and in assisting with the direction of the overall activity.

 The consumers have been the backbone of the whole project. They've given time, they've been really, really meticulous, they've made a massive contribution ... I can't speak highly enough of the consumers."

2015 – 2016 has seen Alzheimer’s Australia consumers continuing their active voluntary involvement in all aspects of the CDPC’s work including:

- the Executive Committee
- the Scientific Sub-committee
- the Research Project Steering and Advisory Committees
- the Annual Meeting including presentations
- workshops
- evaluation processes
- periodic reporting requirements

During this period, we have experienced a continued increase in respect and understanding by researchers when it comes to the value consumers can add to their work. As part of this working partnership, consumers have continued to learn more about the processes of research and working with researchers to achieve each project’s intended outcomes.

Additionally, this year we have seen two consumers invited onto Governance structures within the new NHMRC National Institute for Dementia Research (NNIDR), of which the CDPC is now a part. Dr Jane Thompson has been appointed to the NNIDR Board and Louise Heuzenroeder to the Expert Advisory Panel.


We have also seen two consumers awarded for their extraordinary dementia advocacy work.


Christine Bryden, who is living with dementia, was awarded the Order of Australia medal for her significant service to community health through her provision of support to people living with dementia.

Former carer Dr Ron Sinclair received the Order of Australia medal for services to environmental biosecurity management, and to people living with Alzheimer’s disease. He was recognised for his advocacy work, calling for better research funding into Alzheimer’s disease and support for families, particularly in regional areas.

Continuing support from Alzheimer’s Australia for consumer involvement in all aspects of the CDPC’s work through the newly formed National Dementia Consumer Network is helping to enhance relevance in quality research, for quality outcomes which will impact the lives of people living with dementia, their families and carers.

The 2015 CDPC Baseline Evaluation Report for the Consumer Enabling Sub-Unit indicated that consumer involvement is highly valued by CDPC members. 78 per cent of survey respondents were satisfied with the Consumer Enabling Sub-Unit, which was the highest level of satisfaction of all the Enabling Sub-Units.

 The consumers have been enormously positive, useful and beneficial contributors to the project.

 Our appreciation is extended to each consumer who has generously volunteered their time, effort and energy to the work of the CDPC.

# **5. ORGANISATIONAL SUSTAINABILITY AND GROWTH**



## STRATEGIC PARTNERSHIPS

Alzheimer's Australia would like to thank everybody who has supported the organisation over the past 12 months. We are humbled by the generosity shown by individuals and organisations.

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

The **Australian Government** for their support of dementia awareness, dementia risk reduction 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. & J.R. Wicking Trust** for its ongoing support of the National Quality Dementia Care Initiative.

**Bupa Health Foundation** for its support of the BrainyApp initiative.

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

## WORKPLACE GIVING PARTNERS

We are proud to be supported by a wide range of staff who generously provide 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
- 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
- Flight Centre
- Chartered Accountants Australian & New Zealand
- Macquarie Finance
- MSS Security
- National Library of Australia
- OneSteel
- Orica Australia
- Port Stephens Council
- Quicksuper
- Steven Hallis
- Scenic Tours
- Teachers Mutual Bank
- Travelex
- Veda Advantage
- Veolia Transport
- Westpac Group

## FUNDRAISING

Our fundraisers continue to amaze us with their persistence, courage and strength in undertaking astonishing challenges. We thank everyone who has supported us over the past year. You have on many occasions gone above and beyond to raise money for Alzheimer's Australia and awareness of dementia and that means the world to us.

These fundraisers range from individuals to families, schools, businesses, community and interest-based organisations. They support us in a number of innovative ways including their participation in marathons, charity walks and other physical challenges; hosting sporting events; holding fundraising days through social and special interest events; staff morning teas; community raffles; school cake stalls; garage sales; contributions through donation programs and much, much more.

## DONORS AND COMMUNITY FUNDRAISERS

We are grateful to all donors who have assisted us in working towards our goal of a world that is inclusive of people living with dementia. Many of our donors make a contribution in memory of a loved one and wish to remain anonymous.

Some of our organisational and individual donors include:

- ANZ
- Associazione Abruzzi Del NSW
- Bequests
- Blue Illusion
- Collaborate for a Cause
- Dawn Simpson Road Trip
- Equity Trustees
- Hayden's Walk
- Hunter Hall
- Macquarie Group Foundation
- Nick Abraham "Digital Disruption in Australia"

Our fundraisers also support us by raising awareness and funds through their own social media and fundraising pages on Everyday Hero, Good2Give, Give Now, IGive, MyCause and Go Fundraise.



# 6. FINANCIALS

# TREASURER'S REPORT

The financial statements for the 2015-16 financial year have been audited by Hardwickes Chartered Accountants, who have issued an Unqualified Audit Report.

Alzheimer's Australia Ltd was incorporated on 17 September 2015, whereby the net assets of the association were transferred to Alzheimer's Australia Ltd. There was no change to the principal activities of the organisation, and the short and long term objectives remained the same.

The operations of Alzheimer's Australia Ltd for the 2015-16 financial year resulted in a surplus of income over expenditure in the amount of \$1,735,200. The Board made a strategic decision to build the capacity of the organisation to assist with achieving the long term objective of organisational sustainability and growth, via the adoption of a Reserve Strategy.

Total income for the 2015-16 financial year was \$23.9m (\$25.6m 2014-15), which represents a decrease of 6.6 per cent. This net reduction in income was a direct result of a reduction of operating grant and sponsorship income of \$2.7m, offset in part by an increase in donations and bequests of \$750K.

Total expenditure for the 2015-16 financial year was \$22.2m (\$25.2m 2014-15), which represents a decrease of 11.8 per cent. The net reduction in expenditure was due to a decrease in employee benefits expenses and program distributions in line with the reduction of operating grant and sponsorship income, offset in part by an increase in program costs and other operating expenses, including a significant investment in national information communications technology and national tender applications for future funding.

The retained earnings of Alzheimer's Australia Ltd at 30 June 2016 were \$3.6m (\$1.8m 2014-15), represented by working capital of \$3.4m (\$1.6m 2014-15), a current ratio of 1.38 (1.33 2014-15) and a quick ratio of 1.36 (1.03 2014-15). Accordingly, Alzheimer's Australia Ltd is in a position to pay its debts as and when they fall due.

Alzheimer's Australia Ltd has a number of Federal Government funding contracts that extend beyond 30 June 2017 as well as a number of other Federal Government funding contracts that conclude at 30 June 2017. Alzheimer's Australia Ltd will be actively seeking to secure additional funding contracts for the 2017-18 financial year and beyond.

The Alzheimer's Australia Ltd Board approved a responsibly small deficit operating budget for the 2016-17 financial year, exclusive of donation and bequest income. Ongoing planning and budgeting is in process to ensure that the operations of Alzheimer's Australia Ltd is financially viable and supported by appropriate structures and staffing profiles beyond the 2016-17 financial year.

The Finance, Audit and Risk Management (FARM) Committee of the Board of Alzheimer's Australia Ltd met on three separate occasions by teleconference meeting with one meeting held face-to-face at the National Office in Canberra. The FARM Committee consists of the Treasurer, Neil Samuel (Director), two independent members Geoff Knuckey and Tony Grieves and the Interim CEO of Alzheimer's Australia Ltd Maree McCabe. During the course of the 2015-16 financial year, the FARM Committee adopted a revised Charter and set annual objectives; recommended a number of policies for adoption by the Board including a Risk Management Policy and a Delegations Policy. The FARM Committee reviewed and discussed the quarterly financial management reports prepared and presented by the Consultant Chief Finance Officer. The FARM Committee reviewed and recommended the 2015-16 Draft Audited Financial Statements and the 2016-17 Operating and Capital Expenditure Budgets to the Board for approval. Risk management is a standing item on the agenda of all FARM Committee meetings to ensure that all existing and emerging risks are identified and managed.

The operating environment of the organisation is being transformed with the National Disability Insurance Scheme, My Aged Care and the new world of consumer-directed care. Our Board support these measures and is proactive in challenging how we would best operate to ensure that we can continue to provide the highest quality support to people living with dementia, their families and carers. To this end the Alzheimer's Australia Board has recommended adoption of a unified national model in 2017 to replace the current federation model, which is designed to enhance the agility, capacity and efficiency of service provision.



**William Bass**  
Alzheimer's Australia Ltd Treasurer



## STATEMENT OF REVENUE AND EXPENDITURE AND OTHER COMPREHENSIVE INCOME FOR THE YEAR ENDED 30 JUNE 2016.

	2016 (\$)	2015 (\$)
REVENUE	23,933,982	25,642,599
Employee benefits expense	(3,059,239)	(3,153,084)
Program distributions	(14,725,838)	(18,431,952)
Program costs	(2,612,345)	(2,429,655)
Administrative expenses	(1,731,112)	(1,070,528)
Depreciation expense	(70,248)	(89,916)
<b>Surplus before income tax</b>	<b>1,735,200</b>	467,464
Income tax expense	–	–
<b>Surplus for the year</b>	<b>1,735,200</b>	467,464
<b>Other comprehensive income, net of income tax</b>		
<b>Items that will not be reclassified subsequently to surplus or deficit</b>		
Revaluation changes for property, plant, equipment	–	(8,672)
<b>Other comprehensive income, net of tax</b>	–	(8,672)
<b>Total comprehensive income for the year</b>	<b>1,735,200</b>	458,792

## STATEMENT OF FINANCIAL POSITION AS AT 30 JUNE 2016.

	2016 (\$)	2015 (\$)
<b>ASSETS</b>		
<b>CURRENT ASSETS</b>		
Cash and cash equivalents	12,031,667	4,889,733
Trade and other receivables	82,451	38,085
Other financial assets	27,942	1,225,738
Current GST receivable	–	112,137
Other assets	67,427	79,280
<b>TOTAL CURRENT ASSETS</b>	<b>12,209,487</b>	<b>6,344,973</b>
<b>NON-CURRENT ASSETS</b>		
Property, plant and equipment	211,284	262,947
<b>TOTAL NON-CURRENT ASSETS</b>	<b>211,284</b>	<b>262,947</b>
<b>TOTAL ASSETS</b>	<b>12,420,771</b>	<b>6,607,920</b>
<b>LIABILITIES</b>		
<b>CURRENT LIABILITIES</b>		
Trade and other payables	2,037,658	1,586,019
Current GST liabilities	303,793	–
Provisions	110,564	79,437
Other liabilities	6,373,293	3,088,755
<b>TOTAL CURRENT LIABILITIES</b>	<b>8,825,308</b>	<b>4,754,211</b>
<b>NON-CURRENT LIABILITIES</b>		
Provisions	19,350	12,796
<b>TOTAL NON-CURRENT LIABILITIES</b>	<b>19,350</b>	<b>12,796</b>
<b>TOTAL LIABILITIES</b>	<b>8,844,658</b>	<b>4,767,007</b>
<b>NET ASSETS</b>	<b>3,576,113</b>	<b>1,840,913</b>
<b>EQUITY</b>		
Retained surplus	3,576,113	1,840,913
<b>TOTAL EQUITY</b>	<b>3,576,113</b>	<b>1,840,913</b>







For more information:

[fightdementia.org.au](http://fightdementia.org.au)

National Dementia Helpline: 1800 100 500

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**EDUCATE AUSTRALIA**  
**FIGHTDEMENTIA.ORG.AU**