ANNUAL REPORT 2010-11



MISSION STATEMENT

Our mission, as the National peak body for people living with dementia, is to provide leadership in advocacy, policy, services and research. Alzheimer's Australia is the charity for people with dementia and their families and carers. As the peak body, it provides advocacy, support services, education and information. Alzheimer's Australia is committed to:

Respect for all individuals and communities Co-operative working relationships Integrity Innovation, creativity and flexibility Valuing the contribution of all people involved with our work Strength and unity with respect for diversity

OUR NATIONAL PHILOSOPHY

- People living with dementia, their families and carers have the right to access high quality support services which uphold all their rights.
- People living with dementia, their families and carers have the right to access flexible, responsive and timely support services.
- People living with dementia, their families and carers have the right to be treated with dignity, courtesy and respect, to have their feelings validated and their choices and individual beliefs respected. This includes sensitivity to culture, age, language, location, educational background, and level of impairment of the person using the service.
- People living with dementia, their families and carers have the right to services that support both the person with dementia and their families individually and together provided always that serving the best interest of the person with dementia be the overriding aim.
- Whenever possible, services will be provided free and no person with dementia or their family or carer will be denied access due to their inability to pay.



Patron
Her Excellency Ms Quentin Bryce AC
Governor-General of the Commonwealth of Australia

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Dannie Ouyang – Assistant Accountant

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Sandra McPherson - Finance Officer (until March 2011)

Kathleen Stark - Finance Officer (until December 2010)

Quality Dementia Care Initiative

Chris Hatherly – Project Manager, National Quality Dementia Care Network

Ellen Skladzien – Coordinator,

Consumer Dementia Research Network

Katherine Bowditch - Research Manager (from January 2011)

Dinusha Fernando – Research Development Manager (until January 2011)

Ashley Lamont - Project Support Officer (until July 2011)

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Alzheimer's Australia is grateful for the awareness activities of both Hazel Hawke and Sue Pieters-Hawke and their continuing support in advocating for people with dementia, their families and carers.

Payroll Giving Partners

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REPORT FROM THE PRESIDENT



I was pleased to accept the position as President of Alzheimer's Australia in February this year. I've had a long-standing interest and concern about ageing issues, particularly about the care of people with dementia.

One of the first opportunities I had to be involved in the life of Alzheimer's Australia was the 14th National Conference in Brisbane in May.

Most importantly for me in a personal sense was the opportunity the conference gave me to meet people with dementia and family carers. It was a powerful reminder of the emotional commitment and physical effort that family carers make in caring for the person they love at home. As the principal carer for my father, who had dementia, I understand this well. I know the tears, the laughter and the mixed emotions that experiencing the journey of dementia brings with it.

We were delighted that the Governor General, Quentin Bryce, and the Minister for Mental Health and Ageing, the Hon Mark Butler, were able to attend the conference. What they had to say got the conference off to an excellent start.

In his address Minister Butler emphasised the importance of telling the stories of people with dementia and carers in order to help the general community get a better understanding about the need for action on dementia.

We have taken the Minister's suggestion seriously and in the last few months of this financial year have been working hard on the Fight Dementia Campaign. We intend to continue to drive home this message in the months leading up to the 2012 Budget.

Our plan is to combine this campaign with the new marketing and branding strategy developed for Alzheimer's Australia by the Sydney agency, Interbrand. This will give us the perfect opportunity to refresh our image in the community and to better position Alzheimer's Australia as an organisation committed to improving the quality of life for people with dementia.

There have been frustrations in getting a policy focus on dementia in the last few years. However, it is also true that in the last 10 years an essential part of our organisation's success has been in partnering with successive Ministers and the Department of Health and Ageing in the development of policy and new services.

The challenge is to focus political attention on dementia in order to ensure that dementia issues are centre stage in the current difficult economic and political climate.

While this attention has waxed and waned in recent years, dementia itself will remain a pressing issue, and one that will not go away as the numbers of those with dementia are set to increase to more than half a million within 20 years.

I am determined during my time as President to break new ground so that we can say with confidence at the end of my three-year term that we have greatly improved the quality of life of people with dementia and are looking forward to beating this awful disease.

Ita Buttrose

REPORT FROM THE CEO

The last year has seen the organisation mature and develop in many significant ways.

Important work has been done on branding and marketing with a view to better promoting the work of the organisation. This has been led by Alzheimer's Australia NSW and as the year closes the entire organisation is close to implementing a strategy developed by Interbrand.

The year has also seen the development of the National Quality Dementia Care Initiative which has the objective of improving the quality of dementia care by getting research into practice. The first two projects have been approved and processes are in place for a new round of funding later in 2011.

A successful workshop is planned jointly with the National Health and Medical Research Council on Knowledge Translation. This will be attended by 80 participants including researchers, service providers and consumers.

As a complement to the Initiative, the 25 members of the Consumer Dementia Research Network came together in September, 2010 and again in May, 2011. They have set priorities for new projects under the Initiative and have been involved in the consideration of project applications. Relationships have been also established between the new network and research institutions with the aim of increasing consumer involvement in research. The network has also developed a relationship with Alzheimer's Australia Research and has provided priority areas for one grant in the next funding round.

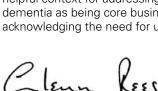
Major new additions were made to the intellectual capital of the organisation in publications on dementia and sexuality and two crucial publications on planning and decision making at end of life. Alzheimer's Australia can be proud of tackling sensitive issues of this kind.

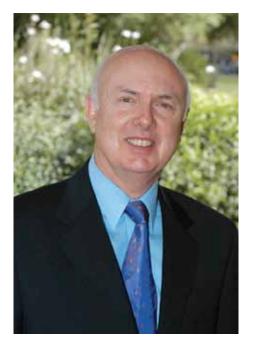
If the organisation has achieved a great deal in those ways it remains a disappointment that there has been no recognition by the current Government of the impact of dementia on the health and care system now and into the future in the context of the health and hospital reforms, in the 'Building a 21st Century Primary Health Care System' or 'Taking Preventative Action' reports.

Worse still, the Federal Government terminated the Dementia Initiative - Making Dementia a National Health Priority, in the 2011-2012 Budget. This means the loss of a policy focus on dementia, of guaranteed funding of valued services and of the capacity to plan scarce resources.

It remains of great concern that in areas such as primary care, acute care and medical research there appears to be so little interest in dementia among health policy makers.

As the year closes we await the final report of the Productivity Commission on aged care and hope this report sets a more helpful context for addressing dementia by recognising dementia as being core business in aged care and acknowledging the need for urgent action on dementia.





NATIONAL CONSUMER ADVISORY COMMITTEE CHAIR REPORT

2010-11 marks the fifth year of operation of Alzheimer's Australia's National Consumer Advisory Committee. The consumer voice has been heard, particularly through meetings on issues of concern with the Minister for Mental Health and Ageing, representatives of the Productivity Commission and a number of key federal politicians.

The focus has continued to be to contribute to national advocacy efforts particularly through the current Productivity Commission inquiries into Care of Older Australians and Disability Care and Support, and the development of the Alzheimer's Australia's 2011 Federal Budget submission.

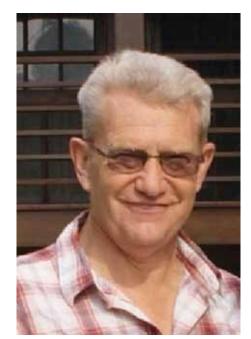
Separate working groups have continued to progress work this year around ethical and end-of-life issues and income support concerns of people with dementia and their family carers. Members have contributed significantly to papers on the end of life authored by Professor Colleen Cartwright. The relationship with Centrelink is positive and ongoing, focusing on ways to ensure that the needs of people with dementia are better understood. In 2010-11, this included piloting staff training on dementia.

This year has also been marked by a number of members leaving the committee and the new faces that we have welcomed. I would like to acknowledge the contribution of Phillip Alderton (member 2006-2011) and Annette Altree-Williams (2008-2010). We celebrate the past and continuing advocacy of all members to ensure that the voice of people affected by dementia is heard and understood.

We thank all committee members for their interest and their efforts, and the boards and staff from state and territory Alzheimer's organisations for their continued support to both individual committee members and local advisory groups.

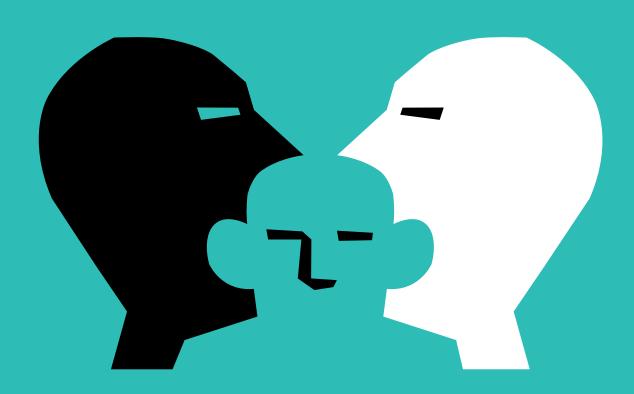
The National Board and Alzheimer's Australia staff have continued to support the committee to effectively achieve the outcomes that we seek and have a real impact on the national dementia agenda.

Consumers attended the National Conference in May 2011 in increasing numbers. They contributed their stories in both plenary sessions and through individual papers. We acknowledge the efforts of Alzheimer's Australia Old to encourage regional participation and the support of government and corporate sponsors who helped people with dementia and family carers to participate. The consumer voice in dementia continues to grow.



Tony Ramshaw

Chair, National Consumer Advisory Committee





MAJOR ACTIVITIES

NATIONAL QUALITY DEMENTIA CARE INITIATIVE

The National Quality Dementia Care Initiative was established to promote consumer involvement in dementia research and research-related activities, and to improve the quality of dementia care in Australia by translating the outcomes of existing research into better practice. The Initiative has been funded by the J.O. and J.R. Wicking Trust and Bupa Care Services Australia, with additional financial support provided by the Dementia Collaborative Research Centres, as part of the Commonwealth Government's Dementia Initiative.

In its first full year of operation, the National Quality Dementia Care Initiative has seen some exciting developments:

- The 25 members of the Consumer Dementia Research Network (CDRN) comprising people with dementia and family carers from a range of backgrounds right across Australia met on two occasions: the first at the inaugural National Quality Dementia Care Summit in Sydney, on 6-7 September, 2010, and again for a two day meeting prior to the Alzheimer's Australia National Conference in Brisbane in May, 2011.
- Members of the CDRN established six key priority themes in dementia care on which to focus the funding available through the Initiative. These were:
 - 1. Person-centred care;
 - 2. Advance care planning;
 - 3. Support for carers of people with dementia;
 - 4. Timely diagnosis of dementia:
 - Non-pharmacological approaches to responding to behavioural and psychological symptoms of dementia; and
 - Palliative approaches to caring for people with dementia.
- An initial funding round was launched with a general call for expressions of interest in October 2010. 44 applications were received, covering a broad range of innovative ideas. After a comprehensive assessment process, applicants on the shortlist were invited to supply more details, before members of the CDRN selected two projects of \$250,000 each for funding. These projects are:

- An innovative project training family members of people with dementia living in nursing homes to interact with their loved one using Montessori-based activities.
 A program will be developed during 2011-12, and workshops will be held around Australia in 2012-13. This project is being led by a team from Monash University, in partnership with Alzheimer's Australia Victoria.
- 2. The Dementia Enabling Environments Project, led by Alzheimer's Australia WA in partnership with the NSW/ACT Dementia Training Studies Centre. This project will develop and deliver a range of interactive and in-person training materials focussing on designing better outdoor and built environments for people with dementia.
- A second and larger funding round is due to commence in late 2011.

PRODUCTIVITY COMMISSION INQUIRY INTO CARING FOR OLDER AUSTRALIANS

This year has been an important one in terms of the reform of aged care and disability services. Alzheimer's Australia provided an initial submission to the Productivity Commission on their Inquiry into caring for older Australians in July 2010. This submission outlined the need for dementia to be centre stage in reform of aged care. We made specific recommendations on the need for separation of accommodation and care, increased focus on community care, the need for more flexible respite services, funding which recognises the extra costs associated with dementia, expansion of services for younger onset dementia (YOD) and those with behavioural and psychological symptoms of dementia amongst others recommendations.

The Draft report of the Productivity Commission's Inquiry was released on 21 January 2011. The recommendations broadly responded to consumer demands for reform and greater choice.

Many of the key elements of the recommendations in the draft reflected the advocacy of Alzheimer's Australia over a number of years including:

- Greatly expanded access to services based on assessed entitlement
- Greater emphasis on community care
- Better access to information for consumers
- Models of consumer directed care that empower older people and their family carers to decide when, where and how the services they need will be delivered.

However, the draft report was a disappointment in its failure to recognise dementia as core business in aged care. Indeed, none of the proposed recommendations explicitly address dementia nor was there any recognition of the need for a comprehensive plan to combat the dementia epidemic.

Alzheimer's Australia identified six priority areas in its formal response to the Productivity Commission that need attention in the final report:

- The impact of dementia not only on aged care but on all parts of the health system including primary care, acute care, prevention and medical research
- The need for a funding model that recognises the extra costs involved in care of people with dementia
- Attention to the interface of the mental health sector, disability and aged care in respect of individuals with younger onset dementia and those with severe behavioural and psychological symptoms of dementia

- An information and assessment network that builds on existing networks including those of non-government organisations
- The need to make reform of respite a priority in the first stage of reforms because it is so critical to support family carers looking after a person with dementia at home
- A reform agenda that includes an emphasis on prevention and wellness, including new lateral thinking in linking physical health to brain health.

The full submission can be found at: www.fightdementia.org.au/research-publications/submissions-to-australian-government. aspx.

The Minister for Health and Ageing has committed to utilising the National Aged Care Alliance as the primary means for consulting the aged care sector on the report. Alzheimer's Australia is well placed to have a role in these consultations as it is a sponsor member of the Alliance.

We are awaiting the final report of the Commission and are hopeful that dementia will feature more prominently in the final recommendations.

Inquiry into Disability Care and Support

Alzheimer's Australia provided an initial submission to the Productivity Commission Inquiry into Disability Care and Support in August 2010. This submission focused on the need to recognise that dementia was not a natural part of ageing and should be seen as a disability in its own right. There was limited experience of dementia within the disability sector and a need to develop better services for the 16,000 Australians with younger onset dementia. The submission recommended that individuals should be able to have access to services that best meet their needs, regardless of age. In some cases this may be disability services; in others it may be aged care services where staff have more experience with dementia.

The Draft Report of the Inquiry was released on 28 February 2011. Alzheimer's Australia made a second submission to the Productivity Commission Inquiry in May 2011. This submission argued that need, not age, should determine access to services and that support should be available from the best placed source. The submission stressed the need for improved access to assessment services, integration across the disability and aged care sectors, and increased training and other support for disability service providers in supporting people affected by younger onset dementia and those with a disability who later develop dementia.

There was a major difference between the two Inquiry reports in the approach to providing greater choice for purchase of services. The Disability report acknowledged that in many cases providing a cash option would lead to better outcomes for individuals as they would be able to purchase the services they required. In the aged care report, choice was limited to choosing amongst approved providers.

It is unclear why older Australians should not have access to a similar model of 'consumer choice' with the same protections and accountability recommended in the disability report. As the Commission indicates in the disability report there is good evidence of the benefits of a system of greater choice.

In the case of people with younger onset dementia who may be covered by the disability system until they turn 65, it seems odd that in the early stages of their disease they would have the option of cashing out their entitlement and employing friends and family if they wished, but once they reached the age of 65 they would be constrained to services they were assessed as needing, and providers which had been 'approved'.

ALZHEIMER'S AUSTRALIA NATIONAL WEBSITE

Alzheimer's Australia successfully launched a redesigned National website in December 2010. This work was possible due to funding from the Department of Health and Ageing as part of our National Dementia Support Program Grant and we thank the Department for their continued support.

As the peak organisation in Australia on Dementia, the website is critical to our role in enhancing access to information on dementia and services when needed. The website now provides online access to people living with dementia, educators, health care professionals, organisations and the general public.

Some key features of the website include:

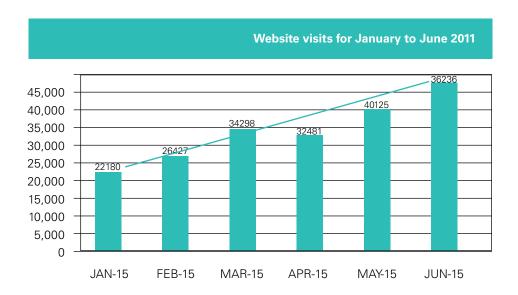
- Contact number for The National Dementia Helpline and Referral Service 1800 100 500
- Information on how to access service in each State and Territory
- Email system to 'contact us' with enquiries
- Information and resources including help sheets, publications and an online library
- Online registration for events training, education and special events
- Available to all Australians with internet connection in urban, regional, rural and remote areas

We know from talking to people with dementia and with their carers, that Alzheimer's Australia performs an invaluable role. Services such as the National Dementia Helpline and Referral Service, website and local support groups mean that we are now able to be there 365 days a year, often when nobody else can be reached.

The success of the website continues to grow. In the first six months more than 191,747 visits were recorded on the website as shown in the table below. For the same period, the number of visitors increased by 66% which resulted in increased viewing of pages on the website. The most popular website pages are the Home Page and the Understanding Dementia pages.

The majority of our visitors arrive from search engines – Google being the most common access point. With further enhancements planned, access and usage of the Alzheimer's Australia website will continue to increase to reach and help more Australias, wherever they live.

Website: www.fightdementia.org.au



TAKING A DIFFERENT VIEW... ALZHEIMER'S AUSTRALIA 14TH NATIONAL CONFERENCE BRISBANE 17 - 20 MAY 2011

"The dinner was wonderful, everyone was up dancing and it didn't matter who you were - a Rhodes Scholar, a nurse, a person with dementia or the janitor, everyone was the same on the dance floor and the energy was just electric". Conference Speaker

Organisers of Alzheimer's Australia 14th National Conference challenged attending delegates to *Take a different view*. More than 800 delegates, including consumers (people with dementia, their families and carers) from Australia and Asia attended the four day conference. The conference was a thought provoking forum putting into question society's current approach to Alzheimer's disease.

Event Profile

The conference is a biennial event with a 28 year history, which was held in Brisbane this year.

Nine keynote speakers including three from overseas headlined the daily conference program which included five breakout sessions, three workshops an exhibition and poster displays. The conference received widespread exposure though the attendance of high profile dignitaries including, Australia's Governor General Quentin Bryce, Federal Minister for Mental Health and Ageing, Hon Mark Butler MP and Alzheimer's Australia President, Ita Buttrose.

Principle Objectives

The principle purpose of the national conference is to stimulate discussion and debate in order to provide a broader view of dementia and its social, health and economic impact on society.

The conference aims to engage those with a diagnosis of dementia and their carers, to ensure they are included in planning for the future in the areas of research and services. The conference provides a platform to raise awareness about dementia and its effect on so many Australians.

Overall Summation and Outcomes

It was agreed by those attending that the message from the 14th National Conference was one of the strongest to come out of any conference so far. There was particularly strong









discussion centred around personhood, identity and consumers' rights, ethics and decision making in dementia care and best practice. There was a strong contribution by speakers who had been diagnosed with younger onset dementia telling their stories. This conference also had the most consumers in attendance of any Alzheimer's Australia conference ever held.

Delegates have the last word

"The Brisbane conference outdid the last conference. The presentations and depth of material presented was of the same high standard. The venue was by far the best I have ever been to and the food was amazing. The social events were a highlight, just amazing. The service at the conference dinner was exceptional as was the food, let alone the entertainment. The assistance for participants and presenters was of a very high standard every day." Pam Hegarty, Victorian delegate.

Top left: Minister Mark Butler Top right: Governor General Quentin Bryce Bottom left: Ita Buttrose, President of Alzheimer's Australia Bottom right: Professor Raymond Tallis



PUBLIC POLICY

END-OF-LIFE DECISION-MAKING

Alzheimer's Australia National Consumer Advisory Committee (NCAC) decided in 2009-10 that there was an urgent need to provide information on end-of-life decision-making for people with dementia and their families.

Professor Colleen Cartwright, Director of the Aged Services Learning and Research Centre at Southern Cross University, kindly agreed to work with a group of consumers to put together two very different but related publications. This two part publication was released in the first half of 2011.

Part One of *Planning for the End of Life for People with Dementia* provides a guide for people with dementia and their families and carers about the current legal options for recording wishes for end-of-life care. The publication discusses many issues including palliative care, refusal of treatment, pain control, resuscitation, residential care, advance financial planning and enduring power of attorney.

Most people say they want to make their own decisions rather than leave them to their family or doctor. However, only a minority of Australians actually take any action to prepare for an event where they may lose the ability to make decisions.

Part Two of *Planning for the End of Life for People with Dementia* looks at the issue of euthanasia and explores the arguments on both sides of the debate including particular issues relevant to people with dementia. The NCAC took the view that even though this issue is controversial it is important that the wider community have the information necessary to reach views about the complex issues that dementia raises in respect of euthanasia.

Part Two does not support a particular view in respect of euthanasia but rather seeks to inform an important debate.

The overriding objective of these two publications from a consumer perspective is to make planning for end-of-life care less confusing and challenging. End-of-life issues are complex, personal and sensitive and they are made all the more difficult if the wishes of the person concerned are not properly understood or set out, especially where the person has dementia.

By releasing these publications, Alzheimer's Australia hopes that there will be a greater willingness in the community to discuss end-of-life issues and that more people will plan properly for the end of their lives within the current legal options.

In May Alzheimer's Australia was successful in securing a Bupa Health Foundation Grant to continue important work on end-of-life planning and decision-making.

ACCESS ECONOMICS REPORTS

To inform the Productivity Commission's inquiry into Caring for Older Australians and the Federal Government's reform agenda, Alzheimer's Australia commissioned Access Economics to project the growth in demand for, and costs of aged care that could be expected between 2010 and 2050.



Above: Ms Sophie Pieters-Hawke, Ms Sue Pieters-Hawke and Mr Glenn Rees, CEO Alzheimer's Australia, at the Alzheimer's Australia NSW fundraiser and launch of the Access Economics Caring Places Vol 2 report

Below: Mr Glenn Rees, CEO, Alzheimer's Australia, Sir Michael Parkinson CBE, Ms Ita Buttrose AO OBE, President, Alzheimer's Australia and Mr John Watkins, CEO, Alzheimer's Australia NSW, at the Alzheimer's Australia NSW fundraiser and launch of the Access Economics Caring Places Vol 2 report

The report *Caring Places: Planning for Aged Care and Dementia 2010-2050* was delivered in two parts. Volume 1, released on 2 August 2010, showed that without a change in the current aged care planning policies, there would be an estimated 279,000 older Australians without access to needed aged care by 2050; the shortfall driven largely by increasing numbers of people with dementia. Along with projections, the report discussed a variety of policy options to help deal with increasing demand, such as adjusting the ratio of residential to community care and increasing program flexibility and consumer choice, as well as financial options such as Medicare-style entitlements, long-term care insurance and healthy ageing savings accounts for meeting the estimated \$80billion annual cost of aged care in 2050.

The release of Volume 1 generated significant media coverage with an advertising equivalent value of \$450,000. Print media consisted of articles in The Sydney Morning Herald, The Age, The Canberra Times and The Herald Seniors while ABC, Seven and Ten News all covered the report on television. ABC Radio highlighted the report in the news headlines in every major capital.

Volume 2 of the report broke down the projected demand for aged care places into Aged Care Planning Regions and Federal Electoral Divisions. This volume was released on 25 February 2011, in conjunction with a fundraising lunch in Sydney presented by Sir Michael Parkinson, and accompanied by a letter to every Federal MP and Senator outlining the projected increase in dementia prevalence and demand for aged care in their jurisdiction. The release of the report in conjunction with the Michael Parkinson presentation also generated media attention with reports on Channel Ten News and ABC Television, The Age and Sydney Morning Herald, The Canberra Times and AAP Newswire as well as many radio stations across the country.

Both volumes of the report are available on the Alzheimer's Australia website.



DEMENTIA CARE AND SEXUALITY IN RESIDENTIAL FACILITIES

In November 2010 Alzheimer's Australia released Understanding Dementia Care and Sexuality in Residential Facilities.

Subsequently this publication was the subject of seminars across Australia given by Associate Professor Sally Garrett, the publication's author, and by Associate Professor Susan Koch.

The publication explores the ways in which those who provide care for people living with dementia can enable meaningful sexual expression for that person without discrimination, a loss of dignity or self esteem. The publication discusses human rights and the complex issues of duty of care.

The publication makes it clear that there are no easy solutions in this complex and difficult area. There is no "one size fits all" to the issues that arise. Two essential points are made in the publication.

First, no matter what our age or disability, we need sexual expression in some form.

Second, that the art of good care is to enable sexual expression for individuals in a meaningful way without discrimination and/or loss of dignity or self esteem.

To help the reader better understand the issues that arise and how they might be approached, case studies are presented. These illustrate the requirement for staff to be able to handle complex issues and balance human rights and issues of duty of care.

Issues relating to sexuality are confronting and often not handled very well. The publication is a valuable addition to the intellectual capital of Alzheimer's Australia and consistent with the important role of the organisation, promotes public discussion of sensitive issues.



DEMENTIA AWARENESS

ALZHEIMER'S DISEASE INTERNATIONAL

Alzheimer's Australia has continued to play an active role in the life of Alzheimer's Disease International (ADI).

The 26th International Conference of ADI was held on 26-29 March in Toronto, Canada. The Alzheimer Society of Canada put together an impressive conference program. Particularly interesting papers were presented by:

- Professor Serge Gauthier on the ways in which amyloid imaging may be used in the revised criteria for the diagnosis of Alzheimer's disease. He maintained a careful balance between the positives of pre-clinical identification of Alzheimer's disease and the ethical risks in terms of false positives, catastrophic reactions, no proven treatments, additional costs of tests and the implications for primary practice.
- Monique Breteler spoke about the links between sub cortical vascular dementia risk factors and dementia. She suggested that only about one third of brain pathologies are pure Alzheimer's disease, others have a lot of vascular pathology and others without dementia have the vascular pathology. In the absence of the likelihood of effective treatments in the short term, she advocates that tackling hypertension and vascular issues in mid age is a strategy to be pursued in reducing the risk of dementia.
- There were interesting presentations on what is being learnt in the national dementia strategies being pursued by other countries. While comparative country assessments are always difficult, Australia seems to be doing as well as any other country other than France.

As always, the main benefit of being at ADI is to network with other organisations. The key meeting was between the ADI Board, Alzheimer's Europe, Alzheimer's Australia and the Alzheimer's Association (USA) to discuss regionalisation of the ADI structure. The meeting resulted in agreement to further pursue a regional structure to work out the business model and regional groupings to make it happen.

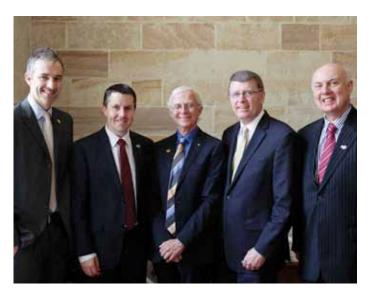
The National CEO has been invited to chair the new group set up to consider the regionalisation of the ADI structure. A report will be presented to the Council of ADI in London at the March 2012 ADI Conference.

There were also discussions in Toronto between the members of the ADI Asia Pacific region to map a way to work together more closely at the regional level. These issues will be discussed further at the regional meeting in Thailand later in 2011.

Alzheimer's Australia has supported ADI in its policy work. The CEO was a member of the ADI strategy group which oversaw the development of the ADI report released in September 2010.

DEMENTIA AWARENESS WEEK 2010

Dementia Awareness Week (DAW) was held nationwide from 16 - 26 September, the week including World Alzheimer's Day on 21 September. The theme *Worried About Your Memory?* was chosen to encourage people who are concerned about their memory to see their doctor or contact Alzheimer's Australia.



Dr Andrew Rochford, The Hon Mark Butler, Minister for Mental Health and Ageing, Professor Henry Brodaty, Mr John Watkins, CEO, Alzheimer's Australia NSW and Mr Glenn Rees, CEO, Alzheimer's Australia, at the launch of World Alzheimer's Day and Dementia Awareness Week, Sydney, September 2010

The message for the community was that an early diagnosis facilitates access to medical treatment and raises awareness of the need for planning finances and future care needs. This theme was supported with the development of an information booklet for consumers on what dementia is, the signs and symptoms, when a person should be concerned about their memory and how they may reduce their risk of developing dementia. For GPs, *No time like the present: the importance of timely diagnosis* was developed with information on dementia, the diagnosis process, medications, and how to support a family after the diagnosis is made.

Both these publications were released at a DAW Launch in Sydney by The Hon Mark Butler MP, Minister for Mental Health and Ageing; Dr Andrew Rochford, the first National DAW Ambassador; Professor Henry Brodaty, Director of the Primary Dementia Collaborative Research Centre and Glenn Rees, CEO Alzheimer's Australia. The Alzheimer's Disease International Report was released at the launch, and worldwide on World Alzheimer's Day, 21 September 2010.

The launch attracted significant media attention with coverage across every ABC channel, Channel 10, Channel 7 as well as multiple radio stations in almost every State and Territory. A segment on the *7pm Project*, an audience that Alzheimer's Australia could not normally reach, was made possible by DAW Ambassador, Dr Andrew Rochford.

Other DAW events included dinner dances, morning teas, memory walks and information stands and seminars. A comprehensive list of activities for people from culturally and linguistically diverse (CALD) backgrounds, saw over 300 people from different cultures participate in food activities and Dementia and Memory Community Centre (DMCC) activities in Victoria.

The launch of the new Alzheimer's Australia NSW Ambassador Program also provided Alzheimer's Australia a unique opportunity when Ita Buttrose spoke about World Alzheimer's Day and Alzheimer's Australia NSW Badge Day on Channel 7's *Sunrise* the morning of the DAW publications launch.

This year's DAW webpage saw a 128% increase in activity over last year's DAW page. All areas of the Alzheimer's Australia website recorded an increase this year with a 56% rise in user sessions compared to last year.

In 2010, DAW used television advertisements for the first time, with a campaign titled *There's a difference*. This advertisement was created to inform people about the difference between normal memory loss and memory loss related to dementia. The campaign reached over 1.3 million women aged 40+, the target demographic for the advertisement.

Many States and Territories' member organisations were also able to leverage free or reduced-cost radio advertisements. Alzheimer's Australia Victorie was able to secure a Toyota sponsorship with thirteen 15-second radio advertisements during the AFL Grand Final on 3AW.

This year DAW activities received \$206,167.00 in funding (\$154,167.00 from the Australian Government, \$50,000 from Pfizer and \$2,000 from Alzheimer's Disease International). Alzheimer's Australia was able to leverage more than \$1.5 million advertising equivalent worth of media coverage with 1,284 media reports mentioning Alzheimer's Australia during the period 6 September to 1 October 2010.

NATIONAL EVENTS AND ACTIVITIES

The Alzheimer's Australia State and Territory organisations arranged an impressive and comprehensive number of events to mark DAW in 2010. These include

- A National DAW Publications Launch held at the Prince of Wales Hospital in Sydney. The Hon. Mark Butler MP, Minister for Mental Health and Ageing was joined by Dr Andrew Rochford and Professor Henry Brodaty to launch Worried About Your Memory, No time like the present: the importance of early diagnosis and The World Alzheimer's Report 2010. Guests included medical and health professionals and carers of people with dementia. Radio and television reporters were present at the event.
- ACT welcomed Professor Henry Brodaty to present a seminar on Worried About Your Memory? ACT also held their annual members' morning tea and collaborated with the Canberra Institute of Technology (CIT) to run a month-long Fitness for Carers program. Information stands at ACT libraries and hospitals were also part of the week.
- NSW held a Memory Walk at Parramatta Park in Sydney with 500 people and another in Illawarra where 600 people attended. NSW also continued their street banners campaign and held their second annual Badge Day. NSW launched two policy documents to mark DAW, the NSW Dementia Services Framework at Parliamentary Friends of Dementia and the Stigma Discussion Paper which received wide coverage in NSW and nationally.
- NT had many activities in Darwin and Alice Springs, including a dinner dance, a lunch for carers and an art day. The NT saw 338,010 cars drive under their DAW banner on Bagot Road. A successful awareness campaign was run throughout the Territory.
- This year Queensland was host to the Dementia Collaborative Research Centres Forum, and raised awareness of dementia with a Sunshine Coast memory walk with over 250 participants. Mackay held a Dementia Public Forum with 82 attendees and Townsville had six static displays in libraries and hospitals as well as a community awareness session.

- Alzheimer's Australia South Australia opened a new office in Dulwich, held a health professional training event called Smile Therapy for Dementia, a Celebrities Memories and Lunch, and a members' morning tea as well as other events.
- Alzheimer's Australia Victoria held 18 events during and after DAW. There were many information sessions for CALD communities, a free public lecture by Professor Henry Brodaty attended by over 300 people, an information stand at Flinders St Station and a Memory Matters seminar.
- WA saw 180 people at the Many Voices Symposium which is aimed at minority groups and people from diverse backgrounds. There were also 500 visitors to their Memory Van and 950 participants at their annual Memory Walk in Perth.

MIND YOUR MIND®

Mind your Mind is Alzheimer's Australia's dementia risk reduction program. It is based on research evidence demonstrating that what we do, what we eat and how well we look after our health has a significant impact on our risk of developing dementia. Mind your Mind promotes a brain-healthy lifestyle through seven signposts including:

Mind your Brain - Keep your brain active

Mind your Diet - Eat healthily

Mind your Body - Be physically active

Mind your Health Checks - Manage blood pressure, blood cholesterol, blood sugar and weight

Mind your Social Life - Participate in social activities

Mind your Habits - Avoid tobacco smoke, only drink alcohol in moderation

Mind your Head - Protect your head from serious injury

This year has seen almost 9,000 people attending Mind your Mind community presentations across Australia, including presentations delivered to regional, rural and remote communities. In addition, approximately 5,000 people attended Mind your Mind exhibition displays, and over 9,500 people visited Memory Vans in New South Wales, Queensland, South Australia and Western Australia.

The new Mind your Mind website (mindyourmind.org.au) was launched at the National Dementia Research Forum in September 2010. The website was developed through the generous support of the Dementia Collaborative Research Centres and the auDA Foundation.

With many Australians not being aware of the vascular risk factors for dementia, including high blood pressure, obesity, smoking, poor diet and lack of exercise, new resources were developed to increase community awareness of the links between brain health and heart health.

Endorsed by the National Heart Foundation, the new flyer and tip sheet present the facts on brain health and heart health risk factors, providing practical strategies on how to look after your brain as well as your heart.

Another initiative was the development of bilingual dementia risk reduction tip sheets in 15 languages, which were developed through extensive consultation with relevant community groups. The tip sheets were launched in May 2011.

Other highlights for 2010/2011 included:

- Launch of Alzheimer's Australia Paper 21, Towards a National Dementia Preventative Health Strategy
- 'Filler' advertisements in newspapers and magazines
- Distribution of In the Mind, the Mind your Mind e-newsletter
- Conference presentations
- National media activity







Top: Brain health and heart health resources, endorsed by National Heart Foundation

Above: Bilingual dementia risk reduction tip sheets

Left: Alzheimer's Australia Paper 21 -Towards a National Dementia Preventative Health Strategy

AMBASSADORS

On 7 May 2010, Alzheimer's Australia announced their first Young Ambassadors, The Forget Me Not Girls: Sophie Pieters-Hawke, granddaughter of Hazel Hawke, Andrea Britz, Annabelle Boyd-Jones and Tess Paul.

During Dementia Awareness Week 2010, The Forget Me Not Girls showed extraordinary leadership by holding the first Forget Me Not fundraiser, raising \$26,000 for the Hazel Hawke Alzheimer's Research and Care Fund. Over 250 people attended the cocktail party at the Museum of Contemporary Art in Sydney where Denise Scott played host for the evening, Jen Cloher entertained the crowd with songs from her new album and Claire Lutton delivered the key address about her mother who is living with younger onset dementia.

The goal of Forget Me Not was, and still remains, remembering shared: opening a space for younger people who have been affected by dementia to share their stories and to raise awareness about the issues that affect younger carers.

The Forget Me Not Girls were chosen as Young Ambassadors by Alzheimer's Australia to represent and promote the issues that are faced by younger carers of people with dementia.

Ms Sophie Pieters-Hawke, Ms Andrea Britz, Ms Annabelle Boyd-Jones and Ms Tess Paul at the Forget Me Not fundraiser. September 2010





BETTER SERVICES NATIONAL DEMENTIA SUPPORT

PROGRAM

Alzheimer's Australia provides the National Dementia Support Program (NDSP) with funding from the Australian Government. The NDSP has evolved over ten years in partnership with the Australian Government and delivers services throughout Australia including in regional, rural and remote areas. The current NDSP Agreement commenced on 1st July 2010 for a period of three years. An additional NDSP Supplementary Grant for 2010/11 was funded by the Australian Government to support some core activities and innovative projects. The overall Program in 2010-2011 cost \$11,367,000 (GST inclusive).

Aim of the National Dementia Support Program (NDSP)

Through the NDSP, the Australian Government and Alzheimer's Australia work together to improve the quality of life for people with dementia, their carers and families, and support people with dementia to remain in their homes where appropriate.

The NDSP provides free support services to people living with dementia, their families, carers and health professionals. Support services are provided Australia wide, through Alzheimer's Australia's member organisations. These services include:

> National Dementia Helpline & Referral Service 1800 100 500

National website www.fightdementia.org.au

Up-to-date information in many diverse languages

Support groups

Referral services

Dementia Memory and Community Centres

Face-to-face counselling

Carer education and workforce training programs

Living with Memory Loss programs

Activity and information sessions

Through information and education, NDSP helps increase the capacity of people with dementia, their carers and families, to understand and manage their life with dementia and to ensure they have timely, reliable and affordable access to the services they require when needed. Some of the key activities include:

National Dementia Helpline & Referral Service:

The Helpline provides immediate counselling, help to clients to link into local services and support, information on prevention, risk reduction and early intervention (including timely diagnosis), and provides a referral service to support specific client needs. A total of 28,296 contacts were made to the National Dementia Helpline & Referral Services during the year.

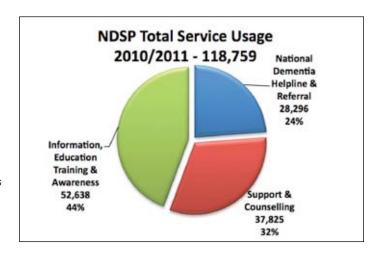
Counselling and Support: Service activities include a range of counselling services, Living with Memory Loss Program, Dementia Memory Community Cafes, community education, outreach activities, travelling memory vans and internet cafés in a number of locations.

Information, Awareness, Education and Training:

Alzheimer's Australia continues to provide services with a high demand for courses for family carers and community education as well as training for workers. Alzheimer's Australia also raises awareness and increases understanding about dementia in the community through the activities related to Dementia Awareness Week (September each year), as well as public speaker programs, seminars and events

National Website: The redesigned website went live in December 2010 and provides easily accessible and relevant information with more than 191,747 visits in the first six months of 2011, and the number of visits is increasing every month. Information on services including the National Dementia Helpline and Referral Service is available on the website 365 days a year.

The chart below shows the usage of services by type of service. The overall target was 76,210 contacts, the actual demand was 118,759 contacts, which was 55% in excess of target.



NATIONAL PROGRAMS

National Programs

Launched in 2005, Alzheimer's Australia received initial support for its National Dementia Risk Reduction Program, Mind your Mind. With supplementary NDSP funding in 2010-11, it has been possible to continue to provide access to this essential program nationally.

The **Mind Your Mind** Program has been successfully developed and tested as a public education program on dementia risk reduction.

Dementia cannot yet be prevented or cured but there is now sufficient scientific evidence to educate Australians about what they can do to reduce their risk of dementia.

Innovative Programs – Service Access Liaison Officers and Restorative Therapies

In the 2010-2011 NDSP Supplementary Grant funding supported the establishment of a number of projects.

Service Access Liaison Officers Project

Pilot projects in seven States and Territories were started to increase access to services for people from special groups. The projects have focused on developing networks and increasing awareness and access to services and cover a range of special needs groups such as Culturally and Linguistically Diverse and Indigenous communities, people with Younger Onset Dementia, rural and remote communities and Gay, Lesbian, Bisexual, Transgender, Intersex (GLBTI) groups.

Each State and Territory has developed individual projects that enable them to focus on the special needs groups in their region and all have engaged a Service Access Liaison Officer. There is substantial 'in-kind' resources being contributed by States and Territories and National Office to manage, support and provide the tools and resources needed for the project to be successful. A national and independent evaluation of the project is underway by Royal Melbourne Institute of Technology.

Consumers have been asking for the appointment of Service Access Liaison Officers in each State and Territory for over five years. The start of this project is a significant step forward in the development of services for special needs groups and demonstrates a commitment by the Australian Government to provide equity and access to NDSP services for all Australians.

Continued funding has been provided for 2011/12.

Restorative Therapies – Tasmania

This project will establish a pilot Cognitive Rehabilitation Treatment Program in Tasmania for people diagnosed with mild cognitive impairment (MCI) or early dementia.

The program is primarily aimed at enhancing attentional abilities and parameters of executive function with enhancement of other cognitive areas such as: memory, language and visuospatial abilities. This enhancement is achieved through different means using: music, motion, paper and pencil, discussion, relaxation, mental imagery, computer cognitive exercises, physical exercise, dance and drama. This approach is a holistic one, and therefore also has a psychotherapeutic outcome secondary to the cognitive one.

This project is in early stages of development and being piloted in Tasmania. It will be part of a national evaluation in 2011.

In 2011/12, Alzheimer's Australia Tasmania will continue the program and increase the sample size, implementing improvements from the pilot phase. The project aims to test whether the methods provide evidence of an improvement in quality of life, for both the person with dementia and their carer, improvement in levels of depression, and their client's own view about their memory impairment and difficulties. This project was developed based on research which is being conducted in a number of countries, which has demonstrated success in improving clients' quality of life and cognitive abilities.

A National Client Management System – The Care Manager (TCM)

On 1 July 2010, TCM was successfully implemented and replaced CMO, a system that had been in place and funded by the Australian Government since the inception of the National Dementia Support Program (NDSP).

This has been a complex project involving a large number of stakeholders. TCM is still in the early stage of implementation and usage and ongoing work will continue to support the States and Territories in establishing the new system, upskilling staff, and increasing capacity within the organisation to use the system effectively for management of service delivery. This system will enable nationally consistent services and delivery of high quality care that better meets client needs, and will allow clients to be more effectively supported through their journey. The valuable data being collected will deepen understanding of dementia and enable better future planning of services.

NATIONAL CROSS CULTURAL DEMENTIA NETWORK

The National Cross Cultural Dementia Network (NCCDN) continues to provide advice and support on culturally and linguistically diverse (CALD) issues to Alzheimer's Australia and its programs nationally. The Network has been an integral part of Alzheimer's Australia since 2003.

Dr Tony Cocchiaro, the inaugural Chair, resigned in June 2010, and Pino Migliorino has taken on the position. Mr Migliorino is currently the Chair of the Federation of Ethnic Communities Council of Australia (FECCA) and is well respected in the multicultural, non government and ageing sectors.

Membership

The Network membership, drawn from across Australia, is multidisciplinary and represents a diverse mix of cultures and ethnicities. Members come from a range of professions such as geriatrics, clinical psychology, nursing, residential aged care, education, social work, community work, and knowledge and information management. Members represent organisations across the health sector, as well as Alzheimer's Australia.

Meetings

The NCCDN undertakes teleconferences throughout the year to further its work and has twice met face to face during the financial period 2010-2011:

- Canberra, November 2010, the meeting focused primarily on reviewing the Terms of Reference and aligning the Work Plan of the NCCDN to that of Alzheimer's Australia. 2011-2013.
- Brisbane, May 2011, prior to the National Conference, members participated in the joint meeting of the three consumer interest groups, NCAC, NATSIDAG and NCCDN.

Alzheimer's Australia SA is contracted by the National Office to provide the Secretariat for the Committee. Two members of the NCCDN are also on the Minister's Dementia Advisory Committee.

Proiects

For the period July 2010 until June 2011, members of the NCCDN have provided input into a number of papers and projects, namely:

- The CALD Ageing Paper developed by the Federation of Ethnic Communities Council of Australia
- The Pathways Project of KPMG
- Alzheimer's Australia's response to the Productivity Commission Report
- NSW DCRC research priorities
- The use of Royal District Nursing Service translation standards in the development of National Alzheimer's Australia translated material
- Evaluation of the Special Access Liaison Officer projects.

In February 2011, the Chair of the NCCDN was invited to attend the NCAC meeting in Canberra with members of the Productivity Commission.

Partnerships

The NCCDN has developed working links and projects with a number of peak groups/agencies, ensuring that CALD dementia issues are kept on the agenda:

- National Consumer Dementia Research Network
- NSW Dementia Collaborative Research Centre
- Federation of Ethnic Communities Council
- South West Sydney Area Health Service
- SA Mental Health Services for the Elderly
- WA Dementia Behaviour Management Advisory Service
- University of Queensland
- Queen Elizabeth Hospital SA.

The NCCDN produced three issues of Cultural News newsletter during this period. The last issue was in collaboration with the Department of Health and Ageing on CALD Dementia Community Grant initiatives. Copies of Cultural News can be viewed on the National website. http://www.alzheimers.org.au/research-publications/cultural-news.aspx

During 2010-2011, NCCDN members have considered a range of issues:

- Dementia Awareness Week 2011 and 2012
- Respite issues pertinent to the CALD community
- Research, raising the need for more specific CALD research to take place
- Elder abuse.

NATIONAL CROSS CULTURAL DEMENTIA NETWORK TERMS OF REFERENCE NOVEMBER 2010

AIM

Through the National Dementia Support Program (NDSP) the NCCDN will provide advice to Alzheimer's Australia, its member organisations, government and peak bodies on quality dementia care and equitable access to programs and services for people from culturally and linguistically diverse (CALD) backgrounds.

TERMS OF REFERENCE

- To advise on how well existing NDSP programs meet the needs of CALD communities. Where gaps are identified, recommend remedial approaches or programs. To inform government, industry and service providers on issues for CALD people living with dementia.
- To identify and articulate CALD dementia issues that require a unique response. These may include, for example :
 - Stigma
 - · Access to services
 - Right to advocacy and;
 - Nature and availability of research on CALD dementia issues.
- To identify, articulate and promote CALD approaches, particularly in regard to:
 - Awareness of and information about dementia
 - Promotion of access to quality dementia services
 - Service advocacy
 - Dementia and carer research
 - Data collection appropriate to CALD utilisation of dementia services.
- To advocate for systemic responses which embed considerations for CALD communities within dementia planning, service development and service delivery.

NATIONAL ABORIGINAL AND TORRES STRAIT ISLANDER DEMENTIA ADVISORY GROUP

Alzheimer's Australia steadily progressed our overall aim to improve access to services and support for Aboriginal and Torres Strait Islander people with dementia, and for their carers.



The National Aboriginal and Torres Strait Islander Dementia Advisory Group (NATSIDAG) and the National Aboriginal and Torres Strait Islander Liaison Officer (NATSILO) worked together with Alzheimer's Australia and external service providers to continue consultation and progress projects as per The Indigenous Dementia Strategy.

The Indigenous Dementia Strategy is a difficult plan to implement due to the complex and diverse nature of social disadvantage of Aboriginal and Torres Strait Islander communities.

At its meeting in August 2010, which coincided with a National Aboriginal and Torres Strait Islander aged care forum, NATSIDAG reviewed and updated The Indigenous Dementia Strategy. The strategy is written as a two year operational plan, from 2010 – 2012.

NATISDAG reaffirmed the priority areas (listed below) within The Indigenous Dementia Strategy, taking into account capacity, resource availability and efficiency:

- Community awareness and prevention
- Workforce training
- Resource development to support community education and training
- Development of partnerships and collaborations.

Major achievements over the past year include:

- Formal agreement with the Australian Indigenous Health Infonet. Key outcomes of this partnership include a specific dementia section, and showcasing this work through an internet kiosk at Alzheimer's Australia National Conference in May 2011. Australian Indigenous Health Infonet disseminates information about contemporary research, better practice, service providers, policy, and provides forums for personnel to network.
- Improved the cultural safety and access on Alzheimer's Australia website, through the development of Aboriginal and Torres Strait Islander specific web pages. The website now has specific content, relevant photos, and a cultural warning.

- Emphasised and shared information about Aboriginal and Torres Strait Islander Complementary Medicine within two editions of the Aboriginal and Torres Strait Islander Dementia News. All past editions of the newsletter are available on Alzheimer's Australia website www.fightdementia.org.au.
- Dementia awareness radio segments aired throughout Australia on the National Indigenous Radio Service to increase awareness of dementia, and to promote the National Dementia Helpline within Aboriginal and Torres Strait Islander Communities.
- Additional resources through Service Access Liaison Officers (SALO) and service access programs in various States and Territories to improve access to existing or specific programs for Aboriginal and Torres Strait Islander peoples.
- Leading edge research findings to improve the evidence base for practice: comprehensive literature review from Koori Growing Old Well Study; evaluation reports of service provision model at Lungurra Ngoora from Indigenous Service Study; and Understanding Dementia Amongst Indigenous Australians from Queensland Institute of Medical Research and Dementia Collaborative Research Centre.

Upcoming activities:

- Collaborative workshop with participants from Aboriginal and Torres Strait Islander Registered Training Organisations, Alzheimer's Australia trainers and other key stakeholders to develop strategies for delivering a revised version of the Dementia Learning Resource for Aboriginal and Torres Strait Islander Communities.
- Presentation for Congress of Aboriginal and Torres Strait Islander Nurses (CATSIN) to disseminate better practice such as, use of the Kimberley Indigenous Cognitive Assessment (KICA) Tool.
- Strengthen collaboration between NATSIDAG and the Aboriginal and Torres Strait Islander Ageing Committee auspiced by the Australian Association of Gerontology.

NATIONAL CONSUMER ADVISORY COMMITTEE

The National Consumer Advisory Committee (NCAC) has members from every State and Territory. Alzheimer's Australia provides the Secretariat for the Committee.

The membership at 30 June 2011 included 1 person with dementia and 10 family carers; three members came from regional areas outside the capital cities. Phillip Alderton (South Australia) and Annette Altree-Williams (ACT) left the Committee during 2010-11.



Right: Annette Altree-Williams (ACT)

Below: Phillip Alderton (South Australia) meeting the Governor General at the Younger Onset Dementia Summit February 2009



The members at the end of 2010-11 were:

- Tony Ramshaw (Western Australia). Chair of the Committee:
- Lucille Bloch (New South Wales):
- Elizabeth Fenwick (Victoria);
- Marianne Gevers (Queensland);
- Merv Gillies (New South Wales);
- Gene Griffiths (Western Australia);
- Shirley Hancock (Tasmania);
- Desley O'Brien (Queensland);
- Kathleen Short (Northern Territory);
- Ron Sinclair (South Australia);
- Judy Woolstencroft (ACT).

The Committee met face to face in Canberra in February 2011 and before the National Conference in Brisbane in May 2011. A joint meeting was held in May with members of the National Cross Cultural Dementia Network and the National Aboriginal and Torres Strait Islander Dementia Advisory Group.

Between meetings, members hold regular teleconferences. Committee members provide a sounding board on a wide range of issues between more formal meetings and teleconferences.

A number of NCAC members participated in a round of visits to key politicians in Canberra in March 2011 to advocate in relation to the Alzheimer's Australia 2011 Budget submission and the Productivity Commission Inquiry into Caring for Older Australians.

Members have played a significant role in

- the preparation of submission to the Productivity Commission Inquiry into Caring for Older Australians and Disability Care and Support.
- the development of the 2011 Budget submission; and
- policy and resource development in the areas of ethics/end of life and Centrelink/income support/subsidy through Committee Working Groups.

At their meeting on 28 February – 1 March 2011, members met with the Minister for Mental Health and Ageing and representatives from the Productivity Commission to discuss current policy and program issues. The discussions, which were positive, focused primarily on key questions developed by members reflecting their concerns with the Caring for Older Australians Report's content and recommendations.

SERVICE ACCESS LIAISON OFFICER PROJECTS

In 2010-11, Alzheimer's Australia received funding from the Australian Government to employ Service Access Liaison Officers to promote partnerships between Alzheimer's Australia and specific groups at a disadvantage in accessing mainstream dementia care and support services. Projects were established in all jurisdictions except Tasmania¹.

Eleven projects were undertaken addressing the needs of people with dementia and family carers from the following target groups:

- people with dementia and family carers from culturally and linguistically diverse communities (NSW, Victoria and WA);
- people with dementia and family carers from Aboriginal and Torres Strait Islander communities (Victoria and NT);
- people with dementia and family carers living in rural/remote communities (NSW and Queensland);
- people with dementia and family carers from the Gay, Lesbian, Bi-sexual, Transgender and Intersex communities (SA);
- people with younger onset dementia and their family carers (Victoria and ACT).

RMIT was contracted to evaluate the use and effectiveness of the funding and report on strategies for further developing the commitment of Alzheimer's Australia to inclusion. The March 2011 Interim Evaluation Report concluded that there was evidence of progress towards achieving objectives, projects had been designed to suit their particular demographic, geographic and service system context, and Alzheimer's Australia had begun to implement clear and credible strategies for achieving the objective of increased access. Project achievements had been supported by working in partnerships with the specific target group and with relevant service providers, building on previous relationships, resources and skills, and integrating with other Alzheimer's Australia services.

In order to increase the likely impact of projects, the Report recommended that coordination and information sharing between projects be increased, monitoring and evaluation be continued, certainty about future funding be provided, and the inclusive and individually responsive approaches developed by the projects be integrated into the core work of providing dementia services.

The final report is expected by August 2011.

CONSUMERS AND RESEARCH CONSUMER FOCUS

During 2010-11, people with dementia and family carers continued to make an invaluable contribution to the work of Alzheimer's Australia nationally and through a range of activities with state and territory member organisations.

National consumer activity is focused through the National Consumer Advisory Committee. Regular reports from the committee and other aspects of consumer focus are discussed at the six-monthly Alzheimer's Australia Board meetings.

In May 2011, many consumers participated in the Alzheimer's Australia National Conference in Brisbane. With the assistance of government and corporate sponsors, people with dementia and family carers were able to attend from all regions across Queensland as well as from every other state and territory.

They contributed their experience and expertise in both plenary sessions and through individual papers. There was an opportunity to meet and share their stories with the Governor General, Her Excellency Ms Quentin Bryce AC, the Minister for Mental Health and Ageing, the Hon Mark Butler MP, and the new Alzheimer's Australia President, Ita Buttrose AO OBE.

Top right: The Hon Michael Kirby AC CMG and Ms Robyn Moore, MC at the Alzheimer's Australia 14th National Conference, Brisbane May 2011

Right: Ms Ita Buttrose AO OBE, President, Alzheimer's Australia, at the Alzheimer's Australia 14th National Conference, Brisbane May 2011

Far right: Her Excellency Ms Quentin Bryce AC, Patron of Alzheimer's Australia, at the Alzheimer's Australia 14th National Conference, Brisbane May 2011

Below: Ms Patricia Henwood, Ms Victoria Beedle, CEO, Alzheimer's Australia QLD, Mr Glenn Rees, CEO Alzheimer's Australia, Ms Ita Buttrose AO OBE, President, Alzheimer's Australia, Her Excellency Ms Quentin Bryce AC, Patron of Alzheimer's Australia, Ms Marianne Gevers, President, Alzheimer's Australia QLD and The Hon Mark Butler, Minister for Mental Health and Ageing at the Alzheimer's Australia 14th National Conference, Brisbane May 2011









QUESTIONS IDENTIFIED BY NCAC MEMBERS FOR THE MINISTER FOR MENTAL HEALTH AND AGEING OR THE PRODUCTIVITY COMMISSION ON THE DRAFT INQUIRY REPORT ON CARING FOR OLDER AUSTRALIANS

- Why is there no recognition of the need for a comprehensive plan to combat dementia in the Draft Report?
- Consumers want action in aged care reform. The Commission has recommended no changes to the availability of aged care places or packages until years 2-5 in the report. Shouldn't increasing the availability of community care be an immediate priority?
- Respite was included in the section on informal carers but there were no specific recommendations. Is the Commission aware of the importance of respite to both the family carer and the care recipient as well as the problems in accessing respite which are evident from the difference between uptake and need?
- Would the Commission consider a trial of cash options where there is difficulty getting access to appropriate services? Such as for respite or access to culturally appropriate care for individuals from non-English speaking backgrounds?
- In the new system consumers will be asked to contribute more to the cost of their care. Consumers may be willing to pay more for better services, but how can they be assured that the quality of care will be better?
- Consumers care not only about choice and access but also about the quality of care. The quality of care is dependent on the quality of the aged care workforce and their training. There are no recommendations to ensure better wages and dementia training for aged care workers. How will the new system ensure higher quality care without addressing workforce issues and how will quality be assessed?
- Consumers are excited about the prospect of increased community care. But one of the challenges that individuals face in the current system is that in some cases more than 50% of the package is spent on

- administration charges. How can the government make this process more transparent and ensure that the majority of funding is spent on care?
- Given that 60% of individuals in residential aged care have cognitive impairment, and the number of people with dementia is expected to reach nearly a million by 2050, why was dementia care not a central consideration in the Productivity Commission report?
- One of the tests of reform of aged care will be how those who are most vulnerable and have the most difficulty accessing appropriate care now will fare under the new system. Why has the Commission not made recommendations about the most vulnerable groups such as those who have severe psycho-geriatric needs?
- Individuals with younger onset dementia face challenges in getting access to appropriate services as responsibility for caring for this group falls between the aged care and disability sectors. Now that both draft reports on aged care and disability have been released, where do people with younger onset dementia fit in the reform agenda?
- What will the new gateway system mean for individuals who are trying to access low-level care and services? Does it make sense to require assessment for access to support and counselling?
- The Commission has recommended that data collection be done by the new 'Australian Aged Care Regulation Commission'. Instead of giving this responsibility to this new agency, why not use the expertise of AIHW who already analyse much of the aged care data that is available?
- Consumers are pleased with the emphasis on research and evaluation of outcomes in the draft report. But how will the data and information on aged care be translated into improvements in services?

During 2010-11, members have considered a range of other issues including:

- The Federal Election Kit, Let's Get Serious about Dementia;
- The Quality Dementia Care Initiative;
- Responses to Aged Care Reform Discussion Papers on Enhanced Prudential Regulation of Accommodation Bonds and Complaints Management Framework;
- Service Access Liaison Officers Evaluation;
- The Access Economics report, Caring Places;
- Research on stigma and attitudes; and
- Extra services.

RESEARCH PARTNERSHIPS AND ACTIVITIES

The past year has seen Alzheimer's Australia continue to build on a strong base of research partnerships and activities aimed at increasing our understanding of dementia, and promoting the involvement of consumers in all aspects of dementia research and research-related activities.

Research partnerships have included:

- Close involvement with the Dementia Collaborative Research Centres (DCRCs), including involvement as a key partner in the DCRC – Consumers and Carers, and as a member of the Advisory Committee of the DCRC – Assessment and Better Care.
- Representation at the DCRC Dementia Research Forum on the Gold Coast in September, 2010. National Office staff gave one presentation and also led a workshop on knowledge translation in dementia care.
- Collaboration with the Australian Consortium of Centres for Clinical Cognitive Research (AC4R) promoting clinical research trials.
- Involvement on the advisory committees of six research projects covering topics ranging from palliative dementia care nurses, to developing quality frameworks for middle-managers in aged care, to new brain imaging techniques.
- National CEO, Glenn Rees also gave invited addresses at a number of dementia research conferences in Australia and abroad.
- Alzheimer's Australia Research Ltd, managed from the National Office, has continued to grow and provide research funding to support students and emerging researchers establish their academic careers in dementia. During 2010-11, a milestone \$1 million in grants, scholarships and fellowships which had been advertised for the 2011 program were awarded, including the 100th dementia research grant. This funding has been made possible by increased donations from members of the public, new funding relationships with aged care providers and charitable trusts, and most importantly, increased funding for dementia research raised by Alzheimer's Australia State and Territory organisations.

Other research activities of the National Office have included:

- Partnering with Pfizer to include dementia-related questions in the Pfizer Health Report.
- Jointly hosting a full-day workshop with the National Health and Medical Research Council (NHMRC) on consumer involvement in dementia research, and translating dementia research into better practice. The successful workshop involved over 80 consumers, researchers, service providers, community organisations and policy makers.
- Commissioning policy and practice related research from:
 - Access Economics (projecting future demand for aged care services);
 - Professor Colleen Cartwright (two publications on end-of-life care options for people with dementia);
 - Professor Dimity Pond (a publication on best-practice assessment and diagnosis of dementia).

A core component of Alzheimer's Australia's advocacy is a focus on promoting the importance of dementia research. In this regard, Alzheimer's Australia engaged on numerous occasions with a variety of politicians, with the National Health and Medical Research Council, with Research Australia, and with other relevant research bodies. The National Office also offered vocal support to the successful 'Discoveries Need Dollars' campaign against the rumoured funding cuts to Australian health and medical research in the 2011-12 Federal budget.

Finally, during the year Alzheimer's Australia sponsored national speaking tours from two high-profile international researchers.

- 1 Professor Julian Hughes, an old age psychiatrist and philosopher from the University of Newcastle, UK, who spoke at a number of events, including at the National Press Club, and the Parliamentary Friends of Dementia, about the many ethical issued raised by dementia.
- 2 Baroness Professor Susan Greenfield, an Oxford University neuroscientist and world-renowned science communicator who spoke about the possibilities of a dementia-free future.

CONSUMER DEMENTIA RESEARCH NETWORK (CDRN)

The CDRN was developed with the goal of supporting individuals with dementia and their family carers to achieve an active role in research and knowledge translation, and is broadly based on the UK Quality in Dementia Research Network. The CDRN is funded mainly through support provided by the Dementia Collaborative Research Centres as part of the Australian Government's Dementia Initiative.

The network commenced in September 2010 and there are currently twenty-five members. The group is made up of individuals from every state and territory with individuals from various backgrounds including CALD, Indigenous, regional/remote, gay and lesbian, and people with younger onset dementia. There is a mix of current family carers, former carers and individuals with dementia.

There are three main areas of involvement:

Alzheimer's Australia's National Quality Dementia Care Initiative (NQDCI)

The members of the CDRN met for the first time in September 2010 to determine the top six priorities for translation of dementia care research into better care practice. These priorities formed the basis for a call for project proposals in late 2010. The CDRN invited more detailed proposals from 8 of the 44 original submissions received, and with advice from industry and research experts, subsequently selected two projects for funding. The members met again in Brisbane in May 2011 to consider the funding priorities for the second round of knowledge translation funding. Members will again be involved in the assessment of applications and in the projects when these commence.

Dementia Collaborative Research Centres

Involvement of CDRN members in the Centres has included:

- Providing feedback on project proposals
- Representation on reference groups and the Coordinating Committee
- Providing consumer advice on methodology
- Assistance with recruitment for research projects
- Representation on a postdoctoral scholarship committee.

Alzheimer's Australia Research

Alzheimer's Australia Research (AAR), the research arm of Alzheimer's Australia, administers an annual Dementia Grants program which provides research grants, scholarships and fellowships. The CDRN has identified priority areas for one of the grants funded through this program, and has included additional questions in the grant applications on consumer involvement and dissemination of findings. Members have also been involved in the assessment process for this grant. Researchers funded through AAR have also asked for member input on projects and survey design.

WHAT IS ALZHEIMER'S AUSTRALIA?

Alzheimer's Australia is the National peak body for people living with dementia, their families and carers. Its vision is for a society committed to the prevention of dementia, while valuing and supporting people living with dementia.

In the early 1980's, State and Territory Alzheimer's Associations were established as self help organisations by and for family carers of people with Alzheimer's disease and other dementias. The National Federation was formed in 1989 with membership from all States and Territories. Alzheimer's Australia works in partnership with other peak consumer bodies and stakeholders, as well as Government.

Alzheimer's Australia administers leading edge National dementia programs and services funded by the Commonwealth. These services are provided by members of Alzheimer's Australia and other organizations and include

- A National Dementia Helpline that provides information, advice and local referrals to callers.
- Face to face counselling including emotional support and problem solving for individuals and families.
- A comprehensive 6-8 week program for people living with early stage dementia and their carers.
- Help sheets that provide information about dementia and living and caring for someone with dementia. Some are available in community languages.
- Metropolitan and regional support groups for carers.
- Accredited dementia care training for aged care workers.
- A National Dementia Behaviour Advisory Service that provides advice on the managing of challenging behaviours to carers and respite care workers.

Alzheimer's Australia is an active advocate for people with dementia, their families and carers. Alzheimer's Australia is committed to a strong consumer focus and encourages people with early stage dementia, their families and carers to

- Serve on National, State and Territory Association boards and committees.
- Participate in advocacy campaigns for better dementia services and policies.
- · Represent consumer views to Government and Industry.
- Volunteer, for example on speakers' panels or operating the National Dementia Helpline.
- Review and comment on information materials and policy documents.

Importantly Alzheimer's Australia has encouraged people with early stage dementia to self advocate and to be involved for example in the development of the web site and to be active participants in the biennial National conference.

If you would like to know more about Alzheimer's Australia or to make a donation please visit us at www.fightdementia.org.au or contact us at

Alzheimer's Australia

Tel: (02) 6254 4233 Fax: (02) 6278 7225

Email: nat.admin@alzheimers.org.au 1 Frewin Place Scullin ACT 214

PUBLICATIONS

During 2010-2011, Alzheimer's Australia has produced or commissioned a number of publications and policy documents – including submissions, articles and speeches – which may be downloaded from: www.fightdementia.org.au

Significant papers include:

- Towards a National Dementia Preventative Health Strategy
- Consumer Involvement in Dementia Research
- Planning for the End of Life for People with Dementia Part 1 and 2
- Access Economics Caring Places: Planning for aged care and dementia 2010-2050

ALZHEIMER'S AUSTRALIA PUBLICATIONS

Quality Dementia Care Series

- 1. Practice in Residential Aged Care Facilities, for all Staff
- 2. Practice for Managers in Residential Aged Care Facilities
- 3. Nurturing the Heart: creativity, art therapy and dementia
- 4. Understanding Younger Onset Dementia
- 5. Younger Onset Dementia, a practical guide
- Understanding Dementia Care and Sexuality in Residential Facilities
- No time like the present: the importance of a timely dementia diagnosis

Papers

- Dementia: A Major Health Problem for Australia. September 2001
- 2. Quality Dementia Care. February 2003
- 3. Dementia Care and the Built Environment. June 2004
- 4. Dementia Terminology Framework. December 2004
- 5. Legal Planning and Dementia. April 2005
- Dementia: Can It Be Prevented? August 2005 (superceded by paper 13)
- 7. Palliative Care and Dementia. February 2006
- Decision Making in Advance: Reducing Barriers and Improving Access to Advanced Directives for People with Dementia. May 2006
- 100 Years of Alzheimer's: Towards a World without Dementia. August 2006
- 10. Early Diagnosis of Dementia. March 2007
- Consumer-Directed Care A Way to Empower Consumers? May 2007
- Dementia: A Major Health Problem for Indigenous People. August 2007.
- 13. Dementia Risk Reduction: The Evidence. September 2007
- Dementia Risk Reduction: What do Australians know? September 2008
- 15. Dementia, Lesbians and Gay Men. November 2009
- Australian Dementia Research: current status, future directions? June 2008
- 17. Respite Care for People Living with Dementia. May 2009
- Dementia: Facing the Epidemic. Presentation by Professor Constantine Lyketsos. September 2009
- Dementia: Evolution or Revolution? Presentation by Glenn Rees. June 2010
- 20. Ethical Issues and Decision-Making in Dementia Care. Presentation by Dr Julian Hughes. June 2010
- Towards a National Dementia Preventative Health Strategy. August 2010

- 22. Consumer Involvement in Dementia Research. September 2010
- 23. Planning for the End of Life for People with Dementia. Part 1, March 2011. Part 2, May 2011
- 24. Timely Diagnosis of Dementia: can we do better? September 2011
- 25. National Strategies to Address Dementia. October 2011

Reports commissioned from Access Economics

The Dementia Epidemic: Economic Impact and Positive Solutions for Australia. March 2003

Delaying the Onset of Alzheimer's Disease: Projections and Issues. August 2004

Dementia Estimates and Projections: Australian States and Territories. February 2005

Dementia in the Asia Pacific Region: The Epidemic is Here. September 2006

Dementia Prevalence and Incidence Among Australian's Who Do Not Speak English at Home. November 2006

Making choices: Future dementia care: projections, problems and preferences. April 2009

Keeping dementia front of mind: incidence and prevalence 2009-2050. August 2009

Caring places: planning for aged care and dementia 2010-2050. July 2010

Dementia Across Australia 2011-2050. September 2011

Other Papers

Dementia Research: A Vision for Australia. September 2004

National Consumer Summit on Dementia Communique. October 2005

Mind Your Mind: A Users Guide to Dementia Risk Reduction. 2006

Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander Communities. November 2006

National Dementia Manifesto 2007-2010

In Our Own Words, Younger Onset Dementia. February 2009

National Consumer Summit Younger Onset Dementia Communique. February 2009

Dementia: Facing the Epidemic. A vision for a world class dementia care system. September 2009

These documents and others available on our website www.fightdementia.org.au

FINANCIAL REPORTS

Alzheimer's Australia Inc ABN 79 625 582 771 Financial Report

For the year ended 30 June 2011

Key financial results have been included in this report.

A copy of the full audited accounts is available on request.

ALZHEIMER'S AUSTRALIA INCORPORATED

STATEMENT OF COMPREHENSIVE INCOME FOR THE YEAR ENDED 30 JUNE 2011

	Note	2011 \$	2010 \$
Revenue	2	12,508,665	11,470,731
Depreciation expense Employee benefits expense Program costs Program distributions Operating lease expense Other expenses Profit/(Loss) from operations	3 (a) 3 (b) 3 (b) 3 (a)	(68,563) (1,503,286) (1,414,521) (9,002,081) (37,049) (382,977)	(9,818) (1,068,189) (2,178,695) (7,936,198) (38,881) (231,200)
Other comprehensive income: Net gain on revaluation of non-current assets Other comprehensive income for the year Total comprehensive income for the year	8	8,672 8,672 108,860	
Total comprehensive income attributable to members of the entity		108,860	7,750

ALZHEIMER'S AUSTRALIA INCORPORATED

STATEMENT OF FINANCIAL POSITION AS AT 30 JUNE 2011

	Note	2011 \$	2010 \$
ASSETS CURRENT ASSETS Cash and cash equivalents Trade and other receivables Other current assets	5 6 7	1,959,945 1,022,635 36,304	2,410,624 218,573 41,681
TOTAL CURRENT ASSETS		3,018,884	2,670,878
NON-CURRENT ASSETS Plant and equipment	8	298,335	263,363
TOTAL NON-CURRENT ASSETS		298,335	<u>263,363</u>
TOTAL ASSETS		3,317,219	2,934,241
LIABILITIES CURRENT LIABILITIES Trade and other payables Other liabilities	9	298,708 2,288,998	408,421 1,907,997
TOTAL CURRENT LIABILITIES		2,587,706	2,316,418
NON-CURRENT LIABILITIES Long-term provisions		4,941	2,111
TOTAL NON-CURRENT LIABILITIES		4,941	2,111
TOTAL LIABILITIES		2,592,647	2,318,529
NET ASSETS		724,572	615,712
EQUITY Asset revaluation reserve Retained earnings	8	8,672 715,900	- 615,712
TOTAL EQUITY		724,572	615,712

ALZHEIMER'S AUSTRALIA INCORPORATED

STATEMENT BY MEMBERS OF THE BOARD

In the opinion of the Board the financial report as set out on pages 2 to 17:

- 1. Presents a true and fair view of the financial position of Alzheimer's Australia Incorporated as at 30 June 2011 and its performance for the year ended on that date in accordance with Australian Accounting Standards (including Australian Accounting Interpretations) of the Australian Accounting Standards Board.
- 2. At the date of this statement, there are reasonable grounds to believe that Alzheimer's Australia Incorporated will be able to pay its debts as and when they fall due.

This statement is made in accordance with a resolution of the Board and is signed for and on behalf of the Board by:

Board Member

Dated this 41H day of NOVEMBER2011.



Independent auditor's report to the members of Alzheimer's Australia Incorporated

Report on the financial report

We have audited the accompanying financial report of Alzheimer's Australia Incorporated (the Association), which comprises the statement of financial position as at 30 June 2011, and the statement of comprehensive income, statement of changes in equity and statement of cash flows for the year ended on that date, a summary of significant accounting policies, other explanatory notes and the statement by members of the Board.

Board of Director's responsibility for the financial report

The directors of the Board of the Association are responsible for the preparation of the financial report that gives a true and fair view in accordance with Australian Accounting Standards - Reduced Disclosure Requirements and the Associations Incorporation Act 2009 (NSW) and for such internal control as they determine is necessary to enable the preparation of the financial report that is free from material misstatement, whether due to fraud or error.

Auditor's responsibility

Our responsibility is to express an opinion on the financial report based on our audit. We conducted our audit in accordance with Australian Auditing Standards. These Auditing Standards require that we comply with relevant ethical requirements relating to audit engagements and plan and perform the audit to obtain reasonable assurance whether the financial report is free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial report. The procedures selected depend on the auditor's judgement, including the assessment of the risks of material misstatement of the financial report, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial report in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by the members, as well as evaluating the overall presentation of the financial report.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

PricewaterhouseCoopers, ABN 52 780 433 757

Ground Floor, 44 Sydney Avenue, FORREST ACT 2603, GPO Box 447, CANBERRA CITY ACT 2601
T: + 61 2 6271 3000, F: + 61 2 6271 3999, www.pwc.com.au

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The accompanying notes form part of this financial report.



Independent auditor's report to the members of Alzheimer's Australia Incorporated (continued)

Independence

In conducting our audit, we have complied with the independence requirements of the Associations Incorporation Act 2009 (NSW).

Auditor's opinion

In our opinion the financial report of the Alzheimer's Australia Incorporated is in accordance with the Associations Incorporation Act 2009 (NSW), including:

- giving a true and fair view of the Association's financial position as at 30 June 2011 and of its performance for the year ended on that date; and
- (b) complying with Australian Accounting Standards Reduced Disclosure Requirements.

PricewaterhouseCoopers

Shane Bellchambers Partner

Dated this 4 day of November 2011

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