

ANNUAL REPORT 2011-12

MISSION STATEMENT

Our mission, as the National peak body for people living with dementia, is to provide leadership in advocacy, policy, services and research. As the National peak body for dementia, 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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Jessica Campbell – National Program Manager (from June 2012)
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Jenny Warren – Project Officer (from August 2011)
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Samantha Blake – Policy Officer (from June 2012)
Angela McKeegan – Manager, Alzheimer's Australia Dementia Research Foundation (from March 2012)
Tegan McGrath – National Marketing and Communications Officer (until June 2012)
Kayla Morgan – Campaign Manager (from August 2011)
Alex Nielsen – National Media and Communications Manager (from June 2012)
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Australian Government Attorney-General's Department
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CONTENTS

Mission Statement	3
Our National Philosophy	4
Acknowledgements	6
Report from the President	8
Report from the CEO	9
Fight Dementia Campaign	11
Consumer Engagement	12
Consumer Consultations	12
Consumer Focus	13
Policy	14
Outcomes of Aged Care Reform Advocacy	14
AIHW Hospitals Project	14
Submissions to Parliamentary Committees	15
Submission to McKeon Review	16
Better Services	18
National Dementia Support Program	18
National Cross Cultural Dementia Network	20
National Aboriginal and Torres Strait Islander Dementia Advisory Group	21
Research	23
National Quality Dementia Care Initiative (NQDCI)	23
Consumer Dementia Research Network (CDRN)	23
Dementia Collaborative Research Centres	24
NHMRC Partnership Centre on Dealing with Functional and Related Cognitive Decline	24
Alzheimer's Australia Research Partnerships	24
Dementia Awareness Week	27
Speaker Tours and Conferences	29
Professor John Bretnner	29
Professor Sube Banerjee	29
Baroness Susan Greenfield	29
ALP Conference	30
International Work	31
Publications	32
Alzheimer's Australia Publications	33
Financial Reports	34

REPORT FROM THE PRESIDENT



This year has been significant for people living with dementia and for Alzheimer's Australia.

It began in July 2011 when Alzheimer's Australia decided to take action to reverse the termination of the Dementia Initiative in the 2011 Federal Budget. The Productivity Commission's final report on *Caring for Older Australians* in August did nothing to reassure us that dementia was at the heart of aged care reforms. To the contrary there was not a single recommendation on dementia in the report.

Our response was to advocate for action in our Fight Dementia Campaign with the aim of getting \$200 million over five years allocated in the 2012/13 Federal Budget to tackle the dementia epidemic and to achieve an emphasis on dementia in the reform of aged care.

We launched the campaign and the new Alzheimer's Australia brand with a march on Parliament House, Canberra, on 13 October. People with dementia, their carers and health professionals were among the marchers. It was the first time in the history of Alzheimer's Australia that we have taken our advocacy to the streets in such a public way. Stakeholders at all levels applauded our decision to do this and told us that at last we were "doing something". Their stories became the "voice" of our campaign. Without the courage of so many people telling these stories and effectively getting the message across to our federal politicians, the campaign would not have been the success it has proved to be.

On 20 April 2012 the Prime Minister, Julia Gillard, and the Minister for Mental Health and Ageing, Mark Butler, announced the Government's commitment to the reform of aged care and tackling dementia in ***Living Longer. Living Better***. We have set out in this Annual Report the many ways in which this package is ground-breaking for people living with dementia. Not only do the aged care reforms address issues regarding the funding of dementia care but for the first time in the history of Australian health policy, a commitment has been made to addressing the timely diagnosis of dementia and making hospitals safer places for people with dementia. Funding has also been made available for a dementia risk reduction program – a world first initiative.

However, we did not get all we asked for – there was no additional funding for dementia research. This will be the focus of the second stage of our Fight Dementia Campaign which seeks consideration of this issue in the 2013/14 Federal Budget.

I would like to thank all our stakeholders, the hard-working staff at Alzheimer's Australia and the wider community for their support of the Fight Dementia Campaign. We can all be proud that dementia is now a National Health Priority Area alongside eight existing health priority areas including, cancer and cardiovascular disease. At last dementia is where it should be, centre stage on the health and aged care reform agenda.

A handwritten signature in black ink, reading 'Ita Buttrose'.

Ita Buttrose AO, OBE
President

REPORT FROM THE CEO



With funding from the Department of Health and Ageing, Alzheimer's Australia had the opportunity in October 2011 to consult with people with dementia and their family carers across Australia about their experiences in accessing services.

We listened to the experiences of more than one thousand consumers. The overwhelming feedback of those consulted was that the aged care system is not working well for people with dementia, and even less so for people from diverse communities.

Consumers were concerned that they have no clear pathway to access services and once consumers did find some support, it was often inflexible and unable to cope with the special needs of people with dementia and their carers.

I was shocked and surprised at many of the stories we heard during those consultations.

There was a dramatic contrast between experiences of people with dementia and family carers who benefited from timely diagnosis and referral to services, and the overwhelming majority of those who were traumatised by delays in diagnosis, lack of information, and care services that had next to no understanding of dementia.

It was important that the Minister for Mental Health and Ageing, Mark Butler, took part in these consultations and heard first hand the stories of consumers.

The ***Living Longer. Living Better.*** aged care reform package that was announced in April 2012 gives hope for the future. The package responds to many of the concerns raised at the consultations and to many of the priorities established by stakeholders of Alzheimer's Australia in the last 30 years. It provides a focus on dementia within the reforms and a commitment to tackling dementia in the wider context of health policy.

Nonetheless there is a long way to go in implementing these reforms before they deliver the quality of care and life that people living with dementia have a right to expect.

Difficult issues remain to be addressed. Although ***Living Longer. Living Better.*** contains some support for people with younger onset dementia, the poor access to services for the 16,000 people aged under 65 who have dementia is something that should be a high priority.

There remains a disturbing lack of transparency in the quality of residential care services. In the last two years Alzheimer's Australia has drawn attention to concerns about the use of anti-psychotics as a means of medically restraining people with dementia in residential care. Not only is this poor care practice but it presents a risk to life. There is hope that the reforms will lead to greater transparency and reporting on quality indicators but there is a great deal of work that needs to be done.

The report we released this year on Exploring Dementia and Stigma Beliefs highlighted yet again the stigma attached to dementia and the negative stereotypes that characterise attitudes in the community.

For the moment we should celebrate the promise of reform in aged care and health policy in respect of dementia and some funding to implement changes in ***Living Longer. Living Better.*** I am optimistic about what Alzheimer's Australia can achieve in partnership with government and others. It has been a year of achievement and promise for the future.

A handwritten signature in black ink that reads "Glenn Rees". The signature is written in a cursive, flowing style.

Glenn Rees
Chief Executive Officer

DEAR PRIME MINISTER,

What would you do if your loved one couldn't remember you?

This Valentine's Day there are almost 200,000 people living with dementia and 1.2 million people who care for them. Unless we invest now, hundreds of thousands more will be affected.

Please support the Fight Dementia Action Plan this budget.

The Hon Julia Gillard MP
Prime Minister
PO Box 9032
Parliament House
Canberra ACT 2600

DEAR PRIME MINISTER,

What would you do if your loved one couldn't remember you?

This Valentine's Day there are almost 200,000 people living with dementia and 1.2 million people who care for them.

FIGHT ALZHEIMER'S LOVE AUSTRALIA
FIGHTALZHEIMER'S.ORG.AU



APPEAL

PLEASE RESPOND TO THIS URGENT APPEAL

Sender

Address

FIGHT ALZHEIMER'S LOVE AUSTRALIA
FIGHTALZHEIMER'S.ORG.AU



PLEASE RESPOND TO

Sender

Address

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Address

Sender

TO THIS URGENT APPEAL

remember you?

FIGHT DEMENTIA CAMPAIGN

In the 2011-12 Federal Budget the Dementia Initiative – making dementia a national health priority was terminated. As a result Alzheimer's Australia brought together two separate but related strategies, with a view to promoting a social movement.

Firstly, with the guidance of Interbrand, a leading international branding consultancy, we developed a revolutionary new look for Alzheimer's Australia's brand and image. The advice we gave to Interbrand early in the process was that we wanted to let off "a great explosion" to combat the lack of understanding and support for dementia in the community.

Secondly, to ensure this "great explosion" had the desired effect we engaged Porter Novelli, a leading public relations agency. With their ongoing support the Fight Dementia Campaign was developed.

The campaign has focused on promoting awareness using the stories of people directly affected by dementia. The campaign has been supported by:

- 3,400 Dementia Champions
- 10,000 Fight Dementia Facebook fans
- 1,900 Alzheimer's Australia Facebook fans
- 1,800 Twitter followers
- our National President, Ita Buttrose who engaged her 19,000 Twitter followers.

This online army of over 36,000 people, put pressure on the Government to put in place a funded action plan in the 2012-13 Federal Budget to combat dementia.

On 13 October 2011, we launched the new brand and the campaign with a march on Parliament House in Canberra. 500 people took part in the march and the media coverage of the event reached an estimated 7,677,882 Australians. Bi-partisan support for the campaign was also demonstrated, with the Minister for Mental Health and Ageing, Mark Butler, and the Shadow Minister for Ageing, Senator Concetta Fierravanti-Wells, both speaking at the event. The day culminated with a consumer forum, hosted by Ita Buttrose, in which individuals with dementia and their families talked about their experiences and concerns about the care and support of people with dementia.

During summer we launched the Christmas and New Year's component of the campaign. To count down the 12 Days of Christmas, 12 people, both those living with dementia and family carers, shared their Christmas wishes in the form of an online Advent calendar. We then launched our New Year's resolution: "to wake our leaders up to the looming dementia

epidemic" in an online video. Again, this was supported by people living with dementia and their family carers, who told Australia what their New Year's resolutions were. Both the Christmas and New Year's videos were supported by an advertisement in The Australian newspaper.

In the lead up to Valentine's Day supporters sent thousands of cards asking our political leaders, "What would you do if your loved one couldn't remember you?". On Valentine's Day Alzheimer's Australia staff and supporters took to the streets around the country, encouraging the wider community to send cards. Approximately 7,500 cards were received at Parliament House in Canberra. The cards were acknowledged by the receiving politicians, including via a letter from the Prime Minister and a message on the Twitter website from the Leader of the Opposition. We achieved a radio reach of 1,019,700 people (including Community Service Announcements and paid spots on Nova FM) and a total print audience reach of 219,700 people. Thanks to all the organisations and people who showed their support on Valentine's Day.

Ensuring the Fight Dementia Campaign was front of mind for our politicians before Federal Budget day, we placed branded serviettes and posters in popular restaurants and bars close to Parliament House, Canberra. This coincided with a peak in daily visits to the campaign's website of 1,877 visitors, with over 55 per cent being new visitors.

Our biggest media reach to date occurred on 10 April 2012 after Minister Butler released the *Consumer Engagement in the Aged Care Reform Process* report. The report was based on the findings of a series of consumer consultations, conducted by Alzheimer's Australia, on behalf of the Department of Health and Ageing. A total of 237 pieces of media coverage across television, radio, print and online, resulted in a cumulative audience of 17,403,309.

On 20 April 2012, in response to the Fight Dementia Campaign, the Prime Minister and the Minister for Mental Health and Ageing announced an investment of \$268.4 million over 5 years to tackle dementia as part of the **Living Longer. Living Better.** aged care reform package. This package addresses dementia across the health and aged care system and responds to a number of the priorities from the Fight Dementia Campaign.

Thank you to all the supporters of the campaign and to Porter Novelli and Interbrand for your guidance and support. Together we achieved many of the campaign's goals.

However, there is still work to do. The Government did not make any commitment to increase investment in dementia research, so our Fight Dementia Campaign will continue with its ask of \$200 million over 5 years for dementia research.

CONSUMER ENGAGEMENT

Consumer Consultations

Alzheimer's Australia was commissioned by the Department of Health and Ageing (DoHA) to undertake consumer consultations based on the Productivity Commission's report *Caring for Older Australians*. These consultations aimed to:

- provide the community with information about the report and aged care reform
- gather feedback and information from consumers
- highlight any emerging concerns from consumers
- enable Alzheimer's Australia to provide this feedback to DoHA.

Sixteen consultations were held across Australia in capital cities and regional centres including consultations for people from culturally and linguistically diverse backgrounds, Indigenous Australians, and gay, lesbian, bisexual, transgender and intersex communities. The Minister for Mental Health and Ageing, Mark Butler, attended four of the consultations to listen to the stories and experiences of people who attended. Attendance ranged from 30-200 people at each event.

Across all 16 consultations, the view of consumers was that the aged care system is not working well for people with dementia, even less so for diverse communities. For those with younger onset dementia there are few age appropriate services. Consumers are frustrated that they are unable to get the services they so desperately need and that the services that are available are often inflexible and of poor quality.

The consultations suggested that the Productivity Commission seriously underestimated the issues that continue to beset aged care in the provision of care for people with dementia both in the community (particularly in the case of respite care), in residential care, and in the broader health system. The challenges to accessing appropriate services are even greater for individuals with severe behavioural and psychological symptoms of dementia and those with younger onset dementia.

Overall, the priority for people with dementia and their families is a focus on the basics of improving care services. For the person with dementia the journey needs to start with a timely diagnosis, referral to support services, properly resourced assessment services and a link worker - not an anonymous government call centre - to provide guidance when needed. For the family carer access to dementia education, support in managing behavioural and psychological symptoms, flexible community care services and respite are key. Feedback from the consultations was compiled into a report, *Consumer Engagement in the Aged Care Reform Process*, which was released publicly on 9 April 2012 by Minister Butler. This resulted in a total of 237 pieces of media coverage across television, radio, print and online, reaching a cumulative audience of 17,403,309 and achieving a total advertising equivalent of over \$2.040 million.

The consultation report played a critical role in the Government's **Living Longer. Living Better.** aged care reform package. As part of the package the Government announced *Tackling Dementia*, an initiative which will invest \$268.4 million over 5 years to address dementia across the health and aged care system. Funding will be used to:

- expand the Dementia Behaviour Management Advisory Service
- provide support for timely diagnosis of dementia
- provide better care of older Australians with severe behavioural problems
- provide improved acute care services
- provide support for those with younger onset dementia.



Right: Kate Swaffer at ADI London conference

Consumer Focus

During 2011-12, 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 (NCAC). Regular reports from the Committee and other aspects of consumer focus are discussed at the Alzheimer's Australia Board meetings and teleconferences.

Consumers played a major role in the Fight Dementia Campaign, by taking the campaign message to Federal politicians and by participating in the march on Parliament House on 13 October 2011. NCAC members Kate Swaffer (SA) and Judy Woolstencroft (ACT) told their stories at the gathering.

Around 200 people attended the consumer forum after the march, many of whom identified their priorities and told their stories.

National Consumer Advisory Committee

The National Consumer Advisory Committee has members from every state and territory. Alzheimer's Australia National Office provides Secretariat support for the Committee.

The membership at 30 June 2012 included three people with dementia and ten family carers, with four members who live in regional areas. Elizabeth Fenwick (Victoria), Shirley Hancock (Tasmania) and Bill Upton (New South Wales) left the Committee during 2011-12.

The members at 30 June 2012 were:

- Tony Ramshaw (Western Australia), Chair
- Lucille Bloch (New South Wales)
- Carol Cronk (New South Wales/Western Australia)
- Marianne Gevers (Queensland)
- Merv Gillies (New South Wales)
- Gene Griffiths (Western Australia)
- Carol Liavas (Victoria)
- Desley O'Brien (Queensland)
- Glenda Parkin (Western Australia)
- Kathleen Short (Northern Territory)
- Ron Sinclair (South Australia)
- Kate Swaffer (South Australia)
- Judy Woolstencroft (ACT).

The Committee met in Canberra in May 2012. Between meetings, members hold regular teleconferences and are regularly consulted on a wide range of issues.

Committee priorities have included:

- consumer consultations on the outcomes of the Productivity Commission's Caring for Older Australians Inquiry
- development of the Fight Dementia Campaign
- end of life issues for people affected by dementia
- legal rights and dementia.

In October 2011 Judy Woolstencroft (ACT) joined a number of Alzheimer's Australia's staff at a meeting with Senator Jan McLucas, Parliamentary Secretary for Disabilities and Carers. The focus of the meeting was younger onset dementia and the outcomes of the Productivity Commission's Disability Care and Support Inquiry.

Two members - Carol Cronk (NSW/WA) and Kate Swaffer (SA), attended the Alzheimer's Disease International Conference in London in March 2012 to present papers on person centred care, non pharmacological approaches, involvement in clinical drug trials, and diagnosis and early treatment.

At the NCAC meeting in May 2012, members met with Dr Jeff Harmer, Chair of the National Disability Insurance Scheme (NDIS) Advisory Group to discuss disability reform; the issues affecting younger people with dementia; and ways in which the NCAC and Alzheimer's Australia might support the development of the NDIS. Members emphasised the need to provide consumers with a clear consultation process/pathway which supported them in contributing to the design of the NDIS, resulting in better outcomes for those affected by a disability.

The Committee members reiterated their interest in being involved with the NDIS development and recommended engagement of other Alzheimer's Australia advisory committees – the National Cross Cultural Dementia Network and the National Aboriginal and Torres Strait Islander Dementia Advisory Group.

Members also met with representatives from the Department of Health and Ageing to discuss respite issues in the context of the Government's aged care reform agenda under the **Living Longer. Living Better.** package.

During 2011-12, members have considered a range of other issues including:

- renegotiation of the National Dementia Support Program subsequent to the **Living Longer. Living Better.** package
- potential roles for Key/Link Workers for younger onset dementia
- issues for people with dementia in primary and acute care
- the 2011 Consumer Survey
- consumer involvement in research including the Quality Dementia Care Initiative
- dementia risk reduction
- quality of care/life indicators
- stigma and dementia
- the 2011 Service Access Liaison Officers Evaluation.

Outcomes of Aged Care Reform Advocacy

On 20 April 2012, the Prime Minister, Julia Gillard and the Minister for Mental Health and Ageing, Mark Butler, announced the **Living Longer. Living Better.** aged care reform package. This was an exciting day for people with dementia and for Alzheimer's Australia as the package included funding of \$268.4 million specifically to tackle dementia. The package responded to a number of the issues which Alzheimer's Australia had long been advocating for as well as some of the priorities of the Fight Dementia Campaign.

The package represents a shift in health policy with dementia finally being addressed across the health system and not just within aged care. Additionally the package includes, for the first time, funding for action on timely diagnosis, improving quality of care in hospitals and providing better support for individuals with younger onset dementia. As part of the package, a commitment was made to make dementia the ninth National Health Priority Area.

In addition to the specific measures to address dementia, the reforms proposed for aged care also have a focus on dementia and on improving quality, choice and sustainability of aged care.

More specifically, the package includes:

- expansion of community care packages to enable more people to receive care in their homes
- a focus on improving consumer choice by expanding Consumer Directed Care to all new community care packages
- an acknowledgement of the additional cost of dementia care through a dementia supplement
- a focus on providing better care for individuals with severe behavioural symptoms of dementia through an expansion of Dementia Behaviour Management Advisory Service (DBMAS) and a new supplement in residential aged care to acknowledge the cost of providing care to this group
- a promise to improve respite care and explore more flexible options of respite.

Alzheimer's Australia is pleased that the Government has responded to many of the priorities in the Fight Dementia Campaign and the issues that were raised at the consumer consultations conducted by Alzheimer's Australia on behalf of the Department of Health and Ageing. Alzheimer's Australia will continue to work closely with the Government to ensure that the implementation of the reforms leads to better outcomes for consumers.

AIHW Hospitals Project

There is good evidence from both Australia and overseas that hospital services for people with cognitive impairment are generally poor and that hospitals are dangerous and confusing places for people with dementia. As a result individuals with dementia often have longer stays in hospital and may have worse outcomes. This results in part from failure to identify patients with cognitive impairment and lack of staff training in how to communicate with these patients.

In Australia there has been an assortment of small projects which have focused on improving the quality of dementia care in hospitals. These have included Dementia Education programs, a Cognitive Impairment Symbol, a dementia volunteer project, Dementia Champions project and education on delirium. Most of these projects have been implemented in only a few hospitals and some have shown benefits for people with dementia in hospital.

In 2011 Alzheimer's Australia successfully applied for a grant from the J.R. and J.O. Wicking Trust for a project to examine the impact of poor quality dementia care on the cost of care. This project, in which we partner with the Australian Institute for Health and Welfare (AIHW), will examine the evidence base for strategies to improve the quality of care in hospitals and ways to reduce unnecessary hospitalisations. It will also provide the economic argument to support such an initiative. Alzheimer's Australia expects to be able to release this comprehensive report in February 2013.

Submissions to Parliamentary Committees

Alzheimer's Australia made a number of representations to Senate, House and Joint Inquiries during the first half of the 2012 calendar year.

Senate Community Affairs Committee Inquiry into Palliative Care in Australia

Alzheimer's Australia consulted widely with consumers and other stakeholders on the broad terms of reference of this Inquiry, and made a submission in late March arguing that although elements of the palliative approach to care are appropriate for people with dementia, the sequence and emphasis with which they are applied and funded often are not. Alzheimer's Australia was invited to appear before the Committee as the first witness on the first day of hearings on 24 April 2012. National CEO Glenn Rees and National Research Manager Chris Hatherly were accompanied by three members of the Consumer Dementia Research Network - Joan Jackman, Tara Quirke and Ron Sinclair - each of whom talked about their own direct experience obtaining palliative care for their loved ones who had died with dementia. These very personal consumer stories were useful in bringing home to the Committee the complexity of dying well with an enormously variable and complex condition such as dementia. At the request of the Committee, a follow-up submission was made in May detailing strengths and weaknesses of the current guidelines around palliative care, as well as highlighting examples of best practice around the country. Alzheimer's Australia would particularly like to thank Professor Jenny Abbey for her assistance in developing the submissions. The Committee is due to report in September 2012.

The submission is available at: http://www.fightdementia.org.au/common/files/NAT/20120813_AA_Senate_Community_Affairs_Committee_Palliative_Care_Inquiry.pdf

House of Representatives Standing Committee on Health and Ageing Inquiry into Dementia: Early diagnosis and Intervention

This Inquiry was initiated by the Minister for Mental Health and Ageing, Mark Butler, following many years of research and advocacy by Alzheimer's Australia and others on the importance of timely diagnosis to ensuring appropriate levels of support and the best outcomes for people with dementia and their carers.

The submission from Alzheimer's Australia was supported by quotes and statements from consumers and made a number of detailed recommendations for:

- achieving earlier diagnosis of dementia - including more strategic use of Medicare Benefits Scheme (MBS) items, accredited training for 'dementia-specialist' GPs, and better use of Practice and Specialist nurses
- improving access to publicly funded specialists and memory clinics

- increasing community awareness and understanding of dementia
- improving services for people diagnosed with dementia, including better respite services, a key worker program, and through enhancements to the National Dementia Support Program
- prioritising research into primary dementia care.

The Committee is scheduled to undertake public hearings around Australia in mid 2012 and is due to report in March 2013.

The submission is available at: http://www.fightdementia.org.au/common/files/NAT/20120813_AA_Submission_to_the_Inquiry_into_Dementia_Early_Diagnosis_Intervention.pdf

Pharmaceutical Benefits Advisory Committee Post Market Review of Pharmaceutical Benefits Scheme anti-dementia drugs to treat Alzheimer's Disease

To the surprise of Alzheimer's Australia and many others in the sector, this review was announced in May 2012 to assess the cost effectiveness of PBS subsidised anti-dementia medications and the rules governing access to them. The four medications currently available to treat dementia symptoms amongst those with mild to moderately severe Alzheimer's disease (not other forms of dementia) were approved in the early 2000s. Access to these medications is dependent on a diagnosis of Alzheimer's disease by a specialist, and demonstration of a significant improvement in cognitive abilities within 6 months of treatment to be eligible for ongoing prescription. With support and feedback from a large number of consumers, Alzheimer's Australia's submission made the case that the medications can help with behaviour and functional abilities as well as cognition, and that use of the Mini Mental State Examination (MMSE) to assess improved functioning is not supported by the research. The main recommendation was that the rule governing improvement on the MMSE should be scrapped, and clinicians should be allowed to use their judgement in determining the appropriateness of treating their patients with anti-dementia medications. The submission was made in early July 2012, and a report is due by the end of 2012.

The submission is available at: http://www.fightdementia.org.au/common/files/NAT/20120820_AA_SUB_Review_of_the_Pharmaceutical_Benefits_Scheme.pdf

Submission to McKeon Review

In September 2011, the Minister for Mental Health and Ageing, Mark Butler, announced a strategic review of health and medical research in Australia. 2011 Australian of the Year Simon McKeon was appointed to head this review and was tasked with developing recommendations for a 10 year strategic plan for the \$4 billion per annum health and medical research sector.

Alzheimer's Australia worked with the National Health and Medical Research Council to secure the release of funding data which was analysed by Professor Kaarin Anstey and her team from the Australian National University to identify current gaps in dementia research funding. Alzheimer's Australia National Office staff then worked closely with members of the Consumer Dementia Research Network (CDRN) using this data to develop a position and the final submission was made under the auspices of the CDRN. Recommendations included increasing capacity in dementia research by funding emerging researchers to enter the field; earmarking research funding to address urgent health priorities in areas such as dementia; increasing the emphasis on translating research evidence into practice; and improving consumer engagement in health and medical research, learning from successful models such as the CDRN. Alzheimer's Australia was invited to appear before the review panel in late June 2012.

The submission is available at: http://www.fightdementia.org.au/common/files/NAT/20120403_Nat_Sub_McKeon_Review.pdf



BETTER SERVICES

National Dementia Support Program

For over 10 years the National Dementia Support Program has been delivered by Alzheimer's Australia providing services across Australia to improve the quality of life for people with dementia, their carers and family. Services include:

- National Dementia Helpline and Referral Service (phone 1800 100 500)
- national website (www.fightdementia.org.au)
- support groups
- up-to-date information and resources
- Dementia Memory and Community Centres
- face-to-face counselling
- carer education and workforce training programs
- Living with Memory Loss programs
- awareness, information and education sessions

Through delivery of these services, the National Dementia Support Program helps increase the capacity of people with dementia, their carers and families, to understand and manage their life with dementia. Through a wide range of awareness and education activities, the Program promotes awareness and understanding of dementia across the whole community.

The National Dementia Support Program has delivered these services through funding from the Australian Government, with a total of \$10,043,862 (GST exclusive) received during the 2011-12 financial year. The Government also funded an Enhancement Grant to support maintenance of vital national infrastructure and projects including The Care Manager, our client and contact management database, Alzheimer's Australia's website and the National Service Access Liaison Officer Project.

How does the National Dementia Support Program Help?

National Dementia Helpline and Referral Service

The Helpline provides counselling, information on prevention, risk reduction and early intervention (including timely diagnosis), and provides a referral service to support specific client needs. The Helpline assists clients to access local services and support. A total of 26,788 contacts were made to the National Dementia Helpline and Referral Service during the year.

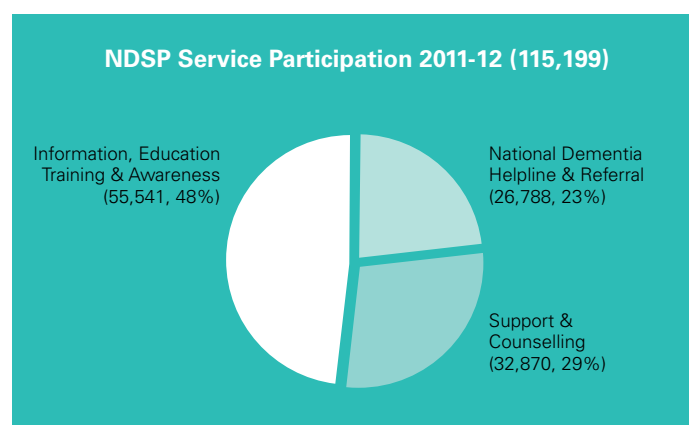
Counselling and Support

Service activities include a range of counselling, early intervention and support services such as the Living with Memory Loss Program, Dementia Memory Community Cafés, outreach activities, travelling Memory Vans and internet cafés.

Information, Awareness, Education and Training

A wide range of services are offered such as courses for family carers, community education and training for people working in health and aged care. Alzheimer's Australia also raises awareness and increases understanding about dementia in the community through Dementia Awareness Week (September each year), as well as public speaker programs, seminars and events.

This chart summarises the services and participation (number of contacts and percent of total) under the National Dementia Support Program for 2011-12.



National Website

The number of people accessing information and services via our “Fight Dementia” website continues to grow. This year the website received 497,484 visits. First-time visitors represented 57 per cent, or 284,710 of the total number of visits made to our website, indicating that this is an increasingly important avenue for people seeking information and support.

The most popular website pages are those that contain consumer and general public information sources and include pages such as, About Dementia, Caring for Someone with Dementia and the Dementia Help Sheets.

The majority of our visitors arrive via search engines. Google is the most common access point, followed by direct traffic to www.fightdementia.org.au and then by referral traffic via links from other websites. Referrals from social media websites such as Facebook and Twitter are increasing as these avenues become more popular as a form of communication within the broader community.

Mind Your Mind ®

Mind Your Mind is Alzheimer’s Australia’s National Dementia Risk Reduction Program launched in 2005. The long-running Program has been successful as a public education program and has allowed Alzheimer’s Australia to publicise the evidence base that shows that lifestyle choices may reduce the risk of dementia.

Special Needs Program

The Service Access Liaison Officer (SALO) projects that commenced in 2010-11 in all states and territories except Tasmania continued across Australia through 2011-12. The aim of these projects was to help increase access to services for a wide range of people with special needs.

Alzheimer’s Australia Tasmania continued their Restorative Therapies project, a Cognitive Rehabilitation Treatment Program for people with Mild Cognitive Impairment (MCI) or diagnosed early dementia.

Fourteen projects have been successfully undertaken addressing the needs of people with dementia and family carers in special needs communities including culturally and linguistically diverse communities, Indigenous communities, people with younger onset dementia, rural and remote communities and gay, lesbian, bisexual, transgender and intersex groups.

Projects have been developed to enable state and territory services to focus on the special needs in their region and all have engaged a Service Access Liaison Officer. Substantial ‘in-kind’ resource is being contributed by Alzheimer’s Australia’s State and Territory organisations and National Office to manage, support and provide the tools and resources needed for the project to be successful.

A formal independent evaluation of the SALO projects was carried out by Royal Melbourne Institute of Technology in late 2010-11 with positive results and the feedback was incorporated into the ongoing program.

These projects have been a significant step forward in the development of services for diverse communities and demonstrate a commitment by the Australian Government to provide equity and access to dementia services for all Australians.

Alzheimer’s Australia has been successful in securing further funding to continue this work.

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

The TCM database has been used to manage the operations of the National Dementia Support Program since July 2010 with funding from the Australian Government. TCM continues to be utilised by all States and Territories, with the exception of South Australia, to more effectively support clients, manage services and make referrals.

Alzheimer’s Australia State and Territory offices have been supported in maintaining the system, training staff, and increasing capacity within the organisation to use the system effectively for management of service delivery. TCM enables valuable data to be collected and analysed allowing Alzheimer’s Australia to deepen our understanding of the needs of our clients and the community in general, and enable better future planning of services.

National Cross Cultural Dementia Network

The National Cross Cultural Dementia Network (NCCDN) supports 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. For more information on the NCCDN and for a comprehensive membership list please refer to the national website under Cultural Diversity, <http://www.fightdementia.org.au/understanding-dementia/cultural-diversity.aspx>

Membership

The NCCDN membership is drawn from across Australia. It is multidisciplinary and represents a diverse mix of cultures and ethnicities. Members come from a range of professions such as geriatrics, residential aged care, research and knowledge, education, community work, acute care, peak ethnic agencies and management, as well as Alzheimer's Australia staff. It is important to note that a new member of the NCCDN, Ron Sinclair, is also a member of the National Consumer Advisory Committee (NCAC). His membership will ensure that there is a sharing of information across both these groups.

Meetings

The NCCDN holds regular meetings by teleconference and met twice in person during 2011-12 in:

- Melbourne, November 2011 - the meeting focused on the Productivity Commission CALD Consultations, Dementia Awareness Week 2012 CALD activities, the work of the Service Access Liaison Officer positions and translation standards for Alzheimer's Australia's consumer resources.
- Canberra, May 2012 - the meeting focused on addressing the need to increase CALD dementia research. Currently, only a very small proportion of research grants/projects go to CALD community groups or have a CALD focus. This has been the focus of preliminary discussions with the National Health and Medical Research Council. It is important to note that the two research networks of Alzheimer's Australia (National Quality Dementia Care Network and Consumer Dementia Research Network) both encourage projects to be inclusive of diversity. The NCCDN as a priority is keen to ensure that Alzheimer's Australia develops a national Access and Equity/Diversity Statement. This will be addressed during the 2012-13 financial year.

In December 2011 the Chair of NCAC, along with the Chairpersons of Alzheimer's Australia's other two national consumer groups, NCAC (see page 13) and NATSIDAG (see page 21) met during the CEO meeting in Melbourne. The meeting identified common issues across the three groups and fostered a stronger working relationship between the groups and with the eight Alzheimer's Australia State and Territory CEOs.

Projects

During 2011-12 members of the NCCDN have provided input into a number of projects and papers, namely:

- development of five national briefing papers: Palliative Care, Issues for CALD People with Dementia and their Carers Living in Regional and Remote Australia, Primary Care, Timely Diagnosis and Respite Care
- NSW Dementia Collaborative Research Centre (DCRC) Advisory Group
- review of CALD guidelines for the Dementia Behaviour Management Advisory Service
- Federal Health Minister's Dementia Advisory Group
- Federal Health Minister's Dementia Advisory Group Forum on Early Diagnosis and Primary Care
- DCRC research project, Improving support for caregivers of people with dementia from culturally and linguistically diverse background by strengthening community care services: a randomised control trial
- Service Access Liaison Officer workshop and review
- NSW DCRC funded research grant for translating an American cognitive behaviour program for CALD carers into the Australian context, focusing on two CALD communities, the Chinese community in South Australia and the Spanish community in New South Wales
- development of the 2012 Dementia Awareness Week CALD strategy, in conjunction with the Alzheimer's Australia Communications team.

Partnerships

The NCCDN has fostered working links and partnerships with a range of agencies, educational institutions and peak bodies, ensuring that CALD dementia issues are kept on their agenda. Some of these agencies include:

- Federation of Ethnic Communities Council, new CALD Ageing Strategy
- National Consumer Dementia Research Network
- NSW Dementia Collaborative Research Centre
- South West Sydney Area Health Service
- Queen Elizabeth Hospital SA - Cognition and Delirium Memory Group
- Spanish and Latin American Society for Social Assistance
- Chinese Welfare Services of South Australia
- Flinders University of South Australia
- The Migrant Resource Centre of Tasmania
- Multicultural Communities Council of South Australia
- Ethnic Communities Council of Victoria.

The NCCDN produced three issues of the Cultural News newsletter during 2011-12. It is encouraging to see that government departments are seeking to promote their diversity programs through Cultural News. Copies of Cultural News can be viewed on Alzheimer's Australia's website, <http://www.fightdementia.org.au/research-publications/cultural-news.aspx>

National Aboriginal and Torres Strait Islander Dementia Advisory Group

The National Aboriginal and Torres Strait Islander Advisory Group (NATSIDAG) is funded by the Department of Health and Ageing under the National Dementia Support Program.

Significant achievements for 2011-12 include:

- assisting Alzheimer's Australia National Office to secure funding for continuation of the Service Access Liaison Officer (SALO) Project.
- providing input into the external evaluation of the SALO Project with an emphasis on ongoing investment, community ownership and local capacity building.
- contributing to a report jointly developed by the World Health Organisation and Alzheimer's Disease International called "Dementia: A Public Health Priority" which raises awareness of dementia as a public health priority and advocates for action at international and national level. The Advisory Group provided information on barriers preventing Aboriginal and Torres Strait Islander people accessing health and social services and the importance of flexibility in care pathways and policies.
- providing ongoing input to the "Koori Growing Old Well Study" which explores healthy ageing and memory in urban Aboriginal

and Torres Strait Islander populations in New South Wales. The study will also investigate the incidence of diseases including dementia through the use of culturally safe cognitive screening tools. Data collection for this study will continue until September 2012, followed by data analysis and reporting of results.

- assisting in the development of a training collaboration workshop pilot and subsequent evaluation - "Collaborative Training Workshop". The objective of the workshop was to promote systematic and collaborative delivery of training utilising the Dementia Learning Resource for Aboriginal and Torres Strait Islander Communities 2nd Edition. The workshops were delivered by trainers from Alzheimer's Australia State and Territory organisations and Aboriginal and Torres Strait Islander Health Registered Training National Network. Two of the collaborative training pilots are to be evaluated externally with a final report to be prepared detailing outcomes and recommendations in late 2012.
- providing a submission to the Aged Care Service Improvement and Healthy Ageing Fund highlighting the necessity for local capacity building and themes for engagement in Aboriginal and Torres Strait Islander communities.

Members of NATSIDAG come from diverse professions including social work, nursing, aged care, and geriatrics from around Australia. In the upcoming year the Advisory Group will be formalising its membership processes as well as reviewing its membership's broad base of knowledge and experience to ensure optimal representation at an organisational and community level.

History

In 2006, Alzheimer's Australia consulted with 30 people involved in caring for Aboriginal and Torres Strait Islander people with dementia. It was agreed that dementia needed to be addressed to enhance community Elders' capacity to age successfully into the future. A wellness approach was seen to be necessary to address the issue of dementia along with other health conditions. The results of the consultation are in the publication *Beginning the Conversation Report: Addressing Dementia in Aboriginal and Torres Strait Islander Communities* (2006) available on Alzheimer's Australia website, www.fightdementia.org.au

MEMORY WINDOW



RESEARCH

National Quality Dementia Care Initiative

The Alzheimer's Australia National Quality Dementia Care Initiative is a \$3.3 million, 4 year program that aims to fast-track the implementation of existing dementia care research into widespread improvements in practice. The Initiative was established with the support of the J.O. and J.R. Wicking Trust, managed by the ANZ Trustees, and Bupa Care Services Australia. It is directed by members of the Consumer Dementia Research Network (CDRN).

The highlight of 2011-12 for the Initiative was a second round of knowledge translation projects addressing priorities set by members of the CDRN in May 2011. Six new projects were established through direct commission or request for applications. Members of the CDRN met to make a final decision on applications in February 2012, and projects were announced on 1 June 2012.

The six projects are:

1. Person-centred dementia support in the community (led by Alzheimer's Australia Victoria in partnership with Alzheimer's Australia)
2. Integrated care framework for advanced dementia (led by HammondCare in collaboration with Alzheimer's Australia New South Wales)
3. Advance care planning for people with dementia (led by Liverpool Hospital in collaboration with Alzheimer's Australia New South Wales)
4. Heart Foundation Walking for the Mind (led by the Heart Foundation in collaboration with ACH Group and Alzheimer's Australia South Australia)
5. Improving staff-family relationships for people with dementia living in residential aged care (led by the Australian Centre for Evidence-Based Aged Care in collaboration with Alzheimer's Australia Victoria, Alzheimer's Australia Queensland and Alzheimer's Australia Tasmania)
6. Improving timely diagnosis and management of dementia in general practice (led by the Dementia Collaborative Research Centre – Assessment and Better Care in collaboration with Alzheimer's Australia New South Wales)

More information about these projects is available at www.qualitydementiacare.org.au

Consumer Dementia Research Network

The Consumer Dementia Research Network (CDRN) is a group of 25 people from across Australia with an active interest in dementia research and improving the quality of dementia care. Five members of the network have dementia themselves, and the others care for or have cared for a close family member with dementia.

The CDRN was established in September 2010, and as well as setting priorities and deciding on funding for the research implementation projects, they have become actively involved in many aspects of dementia research as advisors, advocates, and active participants.

The CDRN is supported in part by a grant from the Dementia Collaborative Research Centre and maintains an active role in many of the research activities of their three Centres.

The Network also has an active involvement with the Alzheimer's Australia Dementia Research Foundation, and with the National Health and Medical Research Council (NHMRC), in particular, the new NHMRC Partnership Centre on Dealing with Cognitive and Related Functional Decline in Older Adults.

Dementia Collaborative Research Centres

Alzheimer's Australia has continued an active involvement with the three Dementia Collaborative Research Centres, based at University of NSW, Queensland University of Technology, and the Australian National University.

Along with Alzheimer's Australia's membership of the management and advisory committees of two of the three Centres, members of the Consumer Dementia Research Network have developed an active involvement with the Centres, including:

- 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.

NHMRC Partnership Centre on Dealing with Functional and Related Cognitive Decline

In late December 2011, the Minister for Mental Health and Ageing, Mark Butler, announced the National Health and Medical Research Council's (NHMRC) Partnerships Centres for Better Health program. The Program endeavours to bring researchers and industry representatives together to work collaboratively on addressing health priorities by collaborating in research, dissemination, capacity building and knowledge translation. The first of the 5 year, \$25 million Centres is being established in the priority area of cognitive decline. Following discussions with the NHMRC throughout late 2011, Alzheimer's Australia is involved as one of six key industry partners in the Centre.

A competitive application process throughout the first half of 2012 resulted in the selection of a strong multidisciplinary team led by Associate Professor Sue Kurrle, director of Rehabilitation and Aged Care, Hornsby Ku-ring-gai Health Service and Curran Chair in Healthcare of Older People at the University of Sydney. Working closely with Sue and with the Alzheimer's Australia Dementia Research Foundation, Alzheimer's Australia has been able to appoint a member of the Consumer Dementia Research Network to a part-time position working with Sue on the management team of the new Centre to ensure representation of consumer issues. The Centre is scheduled to commence its 5 year work program towards the end of 2012.

Alzheimer's Australia Research Partnerships

- Dementia Collaborative Research Centre – Early Diagnosis and Prevention: working with Professor Kaarin Anstey and her team on the development of the publication: Evaluation of NHMRC Data on the Funding of Dementia Research in Australia.
- Dementia Collaborative Research Centre – Early Diagnosis and Prevention and Alzheimer's Australia Victoria: collaborative project evaluating dementia risk reduction eHealth tools.
- Australian National University – Partnership on a successful ARC Linkage Grant Application: Improving methods of grading, transferring and facilitating translation of knowledge in population health.



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DEMENTIA AWARENESS WEEK

Dementia Awareness Week (DAW) was held from 16 to 26 September 2011, incorporating World Alzheimer's Day on 21 September. The theme *Worried About Your Memory?* was repeated from 2010 due to: the importance of understanding that an early diagnosis leads to appropriate treatment, information and support; the chosen message from Alzheimer's Disease International (ADI) *World Alzheimer's Report 2011 – The benefits of early diagnosis and intervention* covering the world wide statistics on diagnosis rates and times; and, the release of the Alzheimer's Australia report *Timely Diagnosis of Dementia: Can we do better?* that found the average time between first symptoms and receiving a diagnosis is 3.1 years.

The messages this theme promotes centre around the benefits a timely diagnosis brings, including involving the person with dementia in planning, preparation and getting the help and information that is needed to support families throughout the entire dementia journey. This was reinforced with the reprint of the consumer booklet *Worried About Your Memory?* originally published for DAW 2010.

Both the ADI and Alzheimer's Australia reports were released on 13 September 2011, 3 days before DAW. This was a great opportunity to present a unified international message to policy makers, service providers and the general community, and to attract media attention to DAW. The release of the reports was covered on ABC TV's Midday Report and syndicated across all ABC television channels across Australia and ABC radio's AM program.

This year DAW activities received \$165,000.00 in funding from the Australian Government. Alzheimer's Australia was able to leverage almost \$1.7 million advertising equivalent worth of media coverage.

DAW events involved a broad cross section of the community and ranged from the popular annual morning teas, Memory Walks, information stands and seminars to national speaker tours.

- On 21 September, World Alzheimer's Day, a national Parliamentary Friends of Dementia meeting took place at Parliament House in Canberra involving federal parliamentarians and key health and aged care organisations. Minister for Mental Health and Ageing, Mark Butler, Alzheimer's Australia President Ita Buttrose and Dr John Breitner were the speakers. The reports from ADI and Alzheimer's Australia were the focus of media activity.
- Alzheimer's Australia ACT and 120 guests welcomed guest speaker Dr John Breitner at the Annual Members' Luncheon on World Alzheimer's Day. Art Group members, all people with dementia, showed off their works at an exhibition at the ACT Legislative Assembly from 19-23 September.
- Alzheimer's Australia New South Wales held five Memory Walks around the state in addition to their main Sydney event in May. Over 1,000 walkers participated in the regional events. New South Wales also despatched their two Memory Vans to various locations, held information sessions with many different stakeholders and ran a press campaign in ATSI and CALD media.
- Alzheimer's Australia Northern Territory organised numerous activities including their annual Tea Dance in Darwin, and a joint presentation by Dr Michael Lowe in Darwin and Alice Springs entitled Understanding Dementia. They also continued their tradition of displaying DAW banners over major roads capturing the attention of all passing road users.
- Alzheimer's Australia Queensland saw 200 people attend Dr Breitner's lecture and held various events throughout the state including a Memory Walk on the Sunshine Coast involving almost 500 people and public forums on dementia in Mackay and Caloundra.
- Alzheimer's Australia South Australia held a Carers Conference and participated in the International Day of Older Persons. Their Memory Van also visited Queen Elizabeth Hospital, Riverland Field Days, Southern Services Reform Group and Yorke Field Days.
- Alzheimer's Australia Tasmania held a Mind Your Mind and Brains Games event over 2 days attracting nearly 200 people. They also had an art exhibition and a dementia forum in Hobart and a community display in Devonport.
- Alzheimer's Australia Victoria held 22 DAW events. These included film screenings, Memory Lane Cafés and many information sessions, such as the free public lecture by Dr John Breitner. They held regional events in Wangaratta, Ballarat, Wodonga, Warrnambool and Geelong which ranged from information sessions to a full Dementia Expo.
- Alzheimer's Australia Western Australia held a Dementia Master Class with Curtin University and the annual Memory Walk attracted 1,500 participants. They also held Mind Your Mind workshops and DAW information displays.

Below: Glenn Rees at Pfizer presentation



SPEAKER TOURS AND CONFERENCES

Professor John Breitner

This year Alzheimer's Australia also hosted a national speaking tour by Dr John Breitner, Director of the Centre for Studies on Prevention of Alzheimer's Disease at McGill University and the Douglas Mental Health Research Institute in Canada.

Dr Breitner commenced his tour on 19 September 2011 in Melbourne and then visited Hobart, Canberra, Brisbane and Sydney.

His tour and presentations attracted significant crowds and wide media coverage including a pre-tour interview with ABC's The World Today program on Radio National. His presentation Early Diagnosis of Dementia: Can We and Should We? supported the theme for DAW.

Professor Sube Banerjee

In May 2012 Professor Sube Banerjee, Professor of Mental Health and Ageing, King's College London, toured Australia. Professor Banerjee led the development of England's Department of Health's National Dementia Strategy for 2007-10 and the independent Ministerial review on the use of antipsychotic medication for people with dementia in the National Health Service in England. He also authored the report *The use of antipsychotic medication for people with dementia: Time for action* commissioned by the UK Government.

In his Australian engagements, Professor Banerjee discussed perspectives in depression, dementia and medication management. He highlighted current evidence-based developments in international and national research relating to the inappropriate use of antipsychotics in managing behavioural and psychological symptoms of dementia. He warned that antipsychotic medications are being used as a form of chemical restraint and are dangerously overused. He said that this should be a major concern for health services and policy makers and advised that governments, including Australia's, must tighten up practise in the use of antipsychotic medications in people with dementia as overuse can lead to unnecessary deaths.

Baroness Susan Greenfield

From the 4-15 July 2011 Alzheimer's Australia invited Baroness Susan Greenfield to present a series of seminars and lectures with the theme A Dementia Free Future: Fantasy or Reality. Her presentations focused upon current approaches for treating dementia, the future of dementia treatments and research strategies that may lead to a dementia-free life. The Baroness also discussed the social stigma and community concern and fear surrounding dementia. These topics proved to be of significant interest to the media and community which ensured large audiences and extensive media coverage throughout the tour.

Baroness Susan Greenfield is a Professor of Synaptic Pharmacology at Oxford University and is one of the UK's most eminent neuroscientists. She was named Honorary Australian of the Year back in 2006 and currently heads a multi-disciplinary research group that investigates neurodegenerative disorders. In addition, she is the Director of the Oxford Centre for the Science of the Mind and was the Director of the Royal Institution of Great Britain 1998-2010, being the first woman to hold the position.

During her seminars, Baroness Greenfield discussed complex issues surrounding the relationship between government funding, research development and the future of dementia.

- Baroness Greenfield presented in every state and territory capital city starting in Sydney on 4 July. Baroness Greenfield's topic proved to be of great interest to the community with many events selling out or attracting significant numbers, particularly in Northern Territory.
- Baroness Greenfield addressed the National Press Club of Australia on 13 July which was broadcast live on ABC1. Her speech, A Dementia Free Future: Fantasy or Reality also marked the announcement of Alzheimer's Australia's new campaign, Fight Dementia.
- Baroness Greenfield received national media exposure from the very first day of her tour with articles appearing in The Age, Northern Territory News and The Sydney Morning Herald. She was a feature guest on ABC's Drive and 2UE's Legal Matters as well as many other broadcast programs during her two week tour.

ALP Conference

Alzheimer's Australia held a Fringe Event at the Australian Labour Party's 46th Annual Conference on 2 December 2011. The theme Dementia: The Chronic Disease of the 21st Century was chosen to encourage politicians to support the Fight Dementia Campaign when considering aged care reform.

The Fringe Event luncheon was held at the Sydney Convention and Exhibition Centre, Darling Harbour. The 60 guests including Labour Party members and Alzheimer's Australia consumers, were hosted by Alzheimer's Australia National President Ita Buttrose, National Ambassador for Alzheimer's Australia Sue Pieters-Hawke and Professor Henry Brodaty, Director, Dementia Collaborative Research Centre - Assessment and Better Care.

Glenn Rees, CEO of Alzheimer's Australia, opened the function by encouraging people with dementia to self advocate. He then introduced the guest speaker the Minister for Mental Health and Ageing, Mark Butler, who told the audience that the upcoming aged care reform would be ineffective without putting dementia front and centre.

Ms Buttrose spoke about how Australia can beat dementia. Ms Pieters-Hawke shared her experiences of caring for a person with dementia and Professor Brodaty educated the audience on dementia, its impact on individuals and society and risk reduction.

Above, from left: Ita Buttrose AO, OBE, Baroness Susan Greenfield, Glenn Rees, CEO, Alzheimer's Australia, Jane Halton, Secretary, Department of Health and Ageing at the National Press Club, July 2011.



INTERNATIONAL WORK

Alzheimer's Australia has taken an active part in work on dementia at an international level.

Most importantly, the strong commitment of Alzheimer's Australia to Alzheimer's Disease International (ADI) has continued. Alzheimer's Australia CEO, Glenn Rees, attended the 14th Asia/Pacific Regional Conference in Bangkok in January 2012 and delivered a key note speech at the 27th International Conference of ADI in London in March 2012.

The theme of the speech was *Alzheimer's Organisations as Agents of Change*. This presentation focused on the challenges that Alzheimer's organisations face over the next 10 years and how they represent an opportunity for revolution rather than evolution in the role of Alzheimer's organisations.

Some of the challenges identified in developing the roles of Alzheimer's organisations included:

- Changing the balance of organisational activity from service provision to advocacy and system change.
- Addressing the pervasive negative social attitudes towards people with dementia that lead to social rejection, internalised shame and socialised isolation.
- Insisting that dementia is recognised as a chronic disease that has to be addressed within a public health framework. Dementia is not an aged care issue alone, but impacts on all aspects of health policy including primary care, acute care, risk reduction and investment in research.
- Adopting communication strategies that embrace marketing and branding and social media. The speech was an opportunity to showcase the new marketing and branding of Alzheimer's Australia and the Fight Dementia Campaign.

The CEO had other opportunities at the 21st Alzheimer's Europe Conference "European Solidarity without Borders" in Poland in October 2011 and at a major international conference in Dublin on "Dementia Strategy" in January 2012 on a similar theme. These opportunities were useful to convey at the international level, the need for a much more proactive approach to the advocacy of dementia as an issue.

The CEO, among a number of others, was invited by ADI and the World Health Organisation (WHO) to contribute to the development of the WHO report "Dementia – A Public Health Priority Publication," released in April 2012. This publication is well produced and written and will be a useful resource world wide for Alzheimer's organisations in arguing for dementia as a national health priority.

The CEO prepared for the Council meeting of ADI in March 2012 a paper on the regionalisation of the structure of ADI to allow country groups with similar cultural and other interests to come together to work more closely. The driving force for this initiative came from the Asia/Pacific region. Part of this work has been the development by ADI, the Alzheimer's Disease Association of Singapore and Alzheimer's Australia of a blueprint for an ADI Asia/Pacific Dementia Resource Centre.

A detailed proposal for this Centre will go to the ADI Asia/Pacific Dementia Resource Centre in December 2012.

PUBLICATIONS

During 2011-12, Alzheimer's Australia has produced or commissioned a number of publications and policy documents – including submissions, papers, articles and speeches, all of which can be found on our website www.fightdementia.org.au

Significant papers include:

- Deloitte Access Economics' Dementia Across Australia: 2011-2050
- Timely Diagnosis of Dementia: Can we do better?
- National Strategies to Address Dementia
- Evaluation of NHMRC data on the Funding of Dementia Research in Australia
- Alzheimer's Organisations as Agents of Change
- Exploring Dementia and Stigma Beliefs.

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
6. Understanding Dementia Care and Sexuality in Residential Facilities
7. No time like the present: the importance of a timely dementia diagnosis

Papers

1. 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
6. Dementia: Can It Be Prevented? August 2005 (superceded by paper 13)
7. Palliative Care and Dementia. February 2006
8. Decision Making in Advance: Reducing Barriers and Improving Access to Advanced Directives for People with Dementia. May 2006
9. 100 Years of Alzheimer's: Towards a World without Dementia. August 2006
10. Early Diagnosis of Dementia. March 2007
11. Consumer-Directed Care – A Way to Empower Consumers? May 2007
12. Dementia: A Major Health Problem for Indigenous People. August 2007.
13. Dementia Risk Reduction: The Evidence. September 2007
14. Dementia Risk Reduction: What do Australians know? September 2008
15. Dementia, Lesbians and Gay Men. November 2009
16. Australian Dementia Research: current status, future directions? June 2008
17. Respite Care for People Living with Dementia. May 2009
18. Dementia: Facing the Epidemic. Presentation by Professor Constantine Lyketsos. September 2009
19. 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
21. 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
26. Evaluation of NHMRC data on the funding of Dementia Research in Australia March 2012
27. Alzheimer's Organisations as agents of change April 2012
28. Exploring Dementia and Stigma Beliefs June 2012
29. Targeting Brain, Body and Heart for Cognitive Health and Dementia Prevention September 2012

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 2012

Key financial results have been included in this report.

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

ALZHEIMER'S AUSTRALIA INCORPORATED

BOARD REPORT

Your Board Members submit the financial report of Alzheimer's Australia Incorporated (the Association) for the financial year ended 30 June 2012.

Board Members

The names of Board Members throughout the year and at the date of this report are:

Ita Buttrose
Glenn Rees
Michael Pedler
Craig Masarel
Neil Samuel
Peter Baume
Marianne Gevers
Richard Cooper
John Giles
Vicki Krause

President
Chief Executive Officer
Secretary / ACT Representative
Treasurer / WA Representative
VIC Representative
NSW Representative
QLD Representative
TAS Representative
SA Representative
NT Representative

Principal Activities

The principal activities of the Association during the financial year were:

- to represent the state and territory Associations at a national level in all facets of advocacy to the Commonwealth Government and kindred peak organisations;
- co-ordination of national projects, lobbying, promotion and advice to Government; and
- keeping alert of and providing information on research relating to Alzheimer's disease and other dementias.

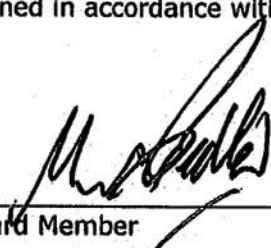
Significant Changes


No significant change in the nature of these activities occurred during the year.

Operating Result

The loss for the financial year ended 30 June 2012 is \$93,638 (2011 profit: \$100,188).

Signed in accordance with a resolution of the Board Members.



Board Member

Board Member

Dated this 17th day of SEPTEMBER 2012.

ALZHEIMER'S AUSTRALIA INCORPORATED

**STATEMENT OF COMPREHENSIVE INCOME
FOR THE YEAR ENDED 30 JUNE 2012**

	Note	2012 \$	2011 \$
Revenue	2	12,900,770	12,508,665
Depreciation expense	3 (a)	(84,071)	(68,563)
Employee benefits expense		(1,642,187)	(1,503,286)
Program costs	3 (b)	(1,616,787)	(1,414,521)
Program distributions	3 (b)	(9,101,588)	(9,002,081)
Operating lease expense	3 (a)	(38,160)	(37,049)
Other expenses		<u>(511,615)</u>	<u>(382,977)</u>
(Loss)/Profit from operations		<u>(93,638)</u>	<u>100,188</u>
Other comprehensive income:			
Net gain on revaluation of non-current assets		<u>-</u>	<u>8,672</u>
Other comprehensive income for the year		<u>-</u>	<u>8,672</u>
Total comprehensive income for the year		<u>(93,638)</u>	<u>108,860</u>
Total comprehensive income attributable to members of the entity		<u>(93,638)</u>	<u>108,860</u>

The accompanying notes form part of this financial report.

ALZHEIMER'S AUSTRALIA INCORPORATED

**STATEMENT OF FINANCIAL POSITION
AS AT 30 JUNE 2012**

	Note	2012 \$	2011 \$
ASSETS			
CURRENT ASSETS			
Cash and cash equivalents	5	3,371,364	1,959,945
Trade and other receivables	6	346,227	1,022,635
Other current assets	7	<u>129,228</u>	<u>36,304</u>
TOTAL CURRENT ASSETS		<u>3,846,819</u>	<u>3,018,884</u>
NON-CURRENT ASSETS			
Plant and equipment	8	<u>225,494</u>	<u>298,335</u>
TOTAL NON-CURRENT ASSETS		<u>225,494</u>	<u>298,335</u>
TOTAL ASSETS		<u>4,072,313</u>	<u>3,317,219</u>
LIABILITIES			
CURRENT LIABILITIES			
Trade and other payables	9	601,174	298,708
Other liabilities		<u>2,827,648</u>	<u>2,288,998</u>
TOTAL CURRENT LIABILITIES		<u>3,428,822</u>	<u>2,587,706</u>
NON-CURRENT LIABILITIES			
Long-term provisions		<u>12,557</u>	<u>4,941</u>
TOTAL NON-CURRENT LIABILITIES		<u>12,557</u>	<u>4,941</u>
TOTAL LIABILITIES		<u>3,441,379</u>	<u>2,592,647</u>
NET ASSETS		<u>630,934</u>	<u>724,572</u>
EQUITY			
Asset revaluation reserve		8,672	8,672
Retained earnings		<u>622,263</u>	<u>715,900</u>
TOTAL EQUITY		<u>630,934</u>	<u>724,572</u>

The accompanying notes form part of this financial report.

