
**SUBMISSION
BY
ALZHEIMER'S AUSTRALIA**

**INQUIRY INTO LONG-TERM STRATEGIES
TO ADDRESS THE AGEING
OF THE AUSTRALIAN POPULATION
OVER THE NEXT 40 YEARS**

December 2002

Dr Andrew Southcott MP
Chairman
Standing Committee on Ageing
Parliament House
Canberra ACT 2600

Dear Dr Southcott

Thank you for the opportunity to make a submission to your inquiry into long-term strategies to address the ageing of the Australian population over the next 40 years.

I believe the attached submission will be helpful to your committee in appreciating and supporting the urgent need for a planned and strategic approach to meet the dementia epidemic. A long-term strategy to address the ageing of the Australian population cannot be undertaken without full account being taken of the impact that dementia will have not only on people with the disease but their families and carers.

There is of course an urgent need for improved quality dementia care services now. However, the point we want to emphasise in the context of your important work is a commitment to the prevention of dementia through research and an active approach to the management of dementia through early diagnosis and medications as they become available.

Also attached as exhibits are some recent publications of the Association including Dementia : a major health priority, Consumer Focus, Research Priorities and Future Directions which support the arguments we put forward in our submission.

I wish you every success in this important inquiry.

Yours sincerely

Robert Yeoh
National President
Alzheimer's Australia
6th December 2002

Executive summary

Long-term strategies to address the ageing of the population over the next 40 years need to address the social, economic and health impacts of the dementia epidemic.

Dementia is already the fourth biggest killer disease of older people in Australia. By the middle of this century over 500,000 people will have a dementia.

Dementia is already the third largest cause of disability burden among women and will be the largest by 2016. It is the fifth largest cause of disability burden among men currently.

In 2000 less than 1 percent of total National Health and Medical Research funding was spent on dementia related research. In total expenditure on dementia related research in Australia represents less than 1 per cent of health care expenditure on dementia. This does not represent an adequate investment in prevention.

The need is for a planned program of action to address the dementia epidemic. This should comprise the following elements:

- Additional funding to be allocated for research on dementia with a continuing priority for biological research directed at cause and prevention and increased priority for research directed at care.
- Evidence based policy work that will form the basis for planning over the next 40 years.
- The provision of information to consumers on what realistic steps can be taken to delay dementia until later in life.
- The need for a more active approach to the management of dementia involving early diagnosis and access to new medications as they become available.
- Additional funding for the services of Alzheimer's Australia to keep pace with the dementia epidemic.
- An expansion of access to quality dementia care and in particular to dementia specific residential care. The residential care planning guidelines should be changed to ensure

that all facilities have the capacity to care for people with dementia and that at least 10% of places be made available for people with dementia with special support needs.

Alzheimer's Australia

December 2002

Background

Alzheimer's Australia is the peak national 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 disease and other dementia. The national body was formed in 1990.

The main activities of Alzheimer's Australia as the peak national body is to

- Advocate on behalf of people with dementia, their families and carers.
- Develop policies on key issues.
- Provide a range of services including a National Dementia Helpline, face to face counselling, memory loss programs for people with early stage dementia, support groups and education and training for carers and aged care workers.
- Promote and participate in research through Alzheimer's Australia Research.

We are committed to a strong consumer focus. As part of our approach to advocacy and awareness, and reducing the stigma of the disease, the Association has completed a report on consumer focus directed at strengthening the involvement of carers and people with early stage dementia in the life of the Association. The report is available on our website www.alzheimers.org.au.

It is critical for the wider community to understand that life does not stop with a diagnosis of dementia. As diagnosis gets earlier, we need to be clearer as a society about the value that we put on people with dementia and the contribution that they can make. In the context of the current inquiry the Association urges the Committee to take a positive approach to dementia and to recognise that the quality of life of hundreds of thousands of Australians who will be diagnosed with dementia over the next 40 years will depend on a well planned and coordinated approach by government to the issues that the dementia epidemic presents.

The Dementia Epidemic

Currently the number of people in Australia with a diagnosis of moderate to severe dementia is estimated at over 160,000 and as many people again may be in the early stages of dementia. It is estimated that of those people with a diagnosis of dementia some 2000 are less than 60 years of age.

By 2041 it is estimated that our population will be 25 million and that 460,000 will have dementia – during that time our population will grow by 40% while our population with dementia will increase by three and a half times.¹ For each of those people the disease will personally affect at least 2-3 family members/carers. Dementia is the fourth biggest killer disease in Australia of older people. There is evidence to suggest dementia is under recorded on death certificates as either a cause of primary death or contributing condition.

Diseases causing dementia are among the most important causes of disability among older people but are frequently not recorded as causes of death. To solve this researchers have developed methods of combining together both mortality and disability data to get a picture of what we call disability burden. As the prevalence of dementia increases so too does the importance of dementia as a cause of disability burden.

Dementia is already the third largest cause of disability burden among women and will be the largest by 2016². It is the fifth largest cause of disability burden among men currently.

Dementia is an insidious disease and Alzheimer's accounts for up to 70% of all dementia cases. The disease by its very nature changes the lives of those with dementia and their relationship with family member and friends, often to a critical degree.

Dementia as a national health priority

¹ Dementia: a major health problem for Australia, Professor Tony Jorm, Alzheimer's Australia Policy paper No 1

Dementia will be, without question, the major health issue of the new millenium. Experience with cancer and HIV/AIDS, for example, in the last century has shown that if action is planned and taken, the quality of life for many can be greatly enhanced and health issues more effectively managed.

The Association believes that to achieve this it is necessary to identify and promote dementia as a national health priority within a framework that covers prevention, research, early diagnosis and best practice management to maintain and improve quality of life. Dementia should be recognised as a major health issue that goes beyond aged care programs. It impact on all parts of the health and community care system and requires a coordinated approach by the Commonwealth and state and territory governments. Development of a framework requires political support from all levels of government and consultation with consumers. From a consumer perspective the main elements of that which needs to be done is already identified. Indeed, it is one of the positives of the last 20 years that issues in the management of dementia have progressed from focussing on carers'support, to focussing on the needs of the person with dementia and to fledgling debates about prevention and treatment.

Research

As research is fundamental to the vision of the Association for a society committed to the prevention of dementia, Alzheimer's Association has made a submission to the National Health Research Priorities Taskforce³.

Current dementia related funding for research in Australia is inadequate.

- Small grants totaling some \$30,000 are available through Alzheimer's Australia Research. In 2000 dementia related research grants in Australia totalled around \$2 million.
- Expenditure on dementia related research in Australia is less than 1 percent of health care expenditure on dementia.

² <http://www.dhs.vic.gov.au/phd/9903009>

³ Research Priorities: Dementia, A Submission to the National Health Priorities Taskforce, Alzheimer's Australia, August 2002

- Within National Health and Medical Research Council funding less than 1 percent is spent on dementia related research.

The Association believes that by any benchmark dementia should be a high health research priority.

This is so because:

- Dementia already represents a significant cost to the health care system
- These costs are likely to grow dramatically as the numbers of people with dementia increase rapidly by the middle of this century
- There are significant costs to families and carers of people with dementia
- Dementia is a major cause of disability burden.
- Overseas work has started to identify significant costs for employers as a result of dementia care.

Equally, the criteria should take into account the evidence that while morbidity related to chronic systemic diseases (particularly cardiovascular diseases, lung diseases, and cancer) appears to be declining, or being compressed to the end of life, the morbidity related to neurodegenerative disease, particularly dementias, is increasing with advanced old age.

Even within the mental health area, recent work done by the Centre for Mental Health Research at the ANU suggests that dementia has not been given a high priority. Of published articles on mental health disorders, a relatively low percentage dealt with dementia at the time of the ANU study and only a small percentage of those dealt with dementia treatment, service research, epidemiology, prevention and promotion. By contrast rather more was directed towards biological research.

Investing in dementia research is investing in what is important in ageing, and therefore, it is investing in the future and the quality of life of people with dementia, their families and carers. However, dementia is not a disease in isolation and a multi-disciplinary and

collaborative approach is required to address the complex inter-relationships of issues in this area.

Alzheimer's Australia recommends that additional funding be allocated for research on dementia with a continuing priority of biological research directed at causes and prevention and an increased priority of research directed at care.

Policy Work

Evidence based policy work is needed to lay the basis for soundly based planning over the next forty years. Alzheimer's Australia is working on an approach that will contribute to national policy. This project will:

1. Reinforce the evidence already available about the scale of the Dementia epidemic.
2. Estimate the economic and financial impacts of dementia on people with dementia, their families and carers, including impacts on employment/absenteeism.
3. Analyse the current and projected costs of Dementia care on the health and community care system.
4. Make comparisons between dementia and other diseases in terms of the numbers of people affected, the health and community care costs and the burden of disease
5. On different scenarios analyse the potential benefits that would accrue by effective interventions in Dementia care and prevention (e.g. what the impacts might be of delaying by one or two or three years, entry to residential care).
6. Identify the work which government might promote in working with academia and the private sector to delay, prevent and or cure Dementia.
7. Identify constraints on extending service provision to meet need and the positive agenda that could sustain an effective response to dementia care in the longer term.

The Association expects to be in a position to present the outcomes of this work in March 2003.

Prevention

It is now realistic to promote prevention in terms of postponing dementia until later in life even if the prospect of a cure or the elimination of dementia is some way off. If people develop dementia later than they normally would, they will have more healthy years of life. The delay in the onset of dementia by even one or two years across the whole Australian population could reduce the prevalence of dementia by tens of thousands of cases.

Professor Tony Jorm reviewed the prospects for the prevention of dementia recently in the March volume of the Australasian Journal of the Ageing and concluded that “There are a lot of promising areas for preventive action and large randomised controlled trials are needed to evaluate their effectiveness. The prevention of dementia is certainly one of the big frontiers for gerontological research....”

For Alzheimer’s disease possible medications that may have preventative potential include anti-inflammatory drugs, oestrogen and antioxidants. For vascular dementia, there are possibilities for prevention through lifestyle changes and medications like antihypertensives, anti-platelet drugs, folate and cholesterol lowering drugs. There is little hard evidence and consumers want guidance about how to help themselves.

Alzheimer Medication

There is a need to adopt a more positive approach to the management of dementia. It remains true for many that the process of diagnosis is, in itself, traumatic, because the implications of the diagnosis are not properly communicated or because the signs and symptoms are dismissed as a natural part of ageing. Often little or no advice is given about the supports available in the community through Alzheimer’s Associations and other organisations at the time of diagnosis.

Nothing can disguise the terrible nature of the disease but the advent of new Alzheimer medications to slow the progression of the disease and the recognition of the benefits of early intervention provide a basis for a more positive approach to the treatment of dementia. Life does not stop with a diagnosis of dementia and with medication, education and support in the community the quality of life for many can be improved.

In that context the approval of Alzheimer medications under the Pharmaceutical Benefits Scheme was a significant step by the Commonwealth Government. But access under the current guidelines is problematic because:

- defining medication benefit in purely cognitive terms is too restrictive as many people with Alzheimer 's disease improve in other ways (function, behaviour and reduction in stress/burden of family and carers);
- in a condition associated with progressive and continuing decline, maintenance of existing cognition or other function demonstrates considerable benefit – existing Australian guidelines (unlike those in the UK) require people on Alzheimer medications to show a pre-determined minimum improvement in cognitive function;
- access to specialists may be difficult and often much delayed, especially for people in some rural areas, denying prompt access to these medications early in their disease when they would be most beneficial – broadening the range of approved prescribers would assist.

In the absence of any evidence to the contrary, the current guideline arrangements should be replaced by a simpler access regime comprising:

- diagnosis by specialists;
- ongoing access predicated on best clinical practice; and
- access to telephone approval of authority scripts.

Affordable access to medications appropriate to their diagnosis should be expedited for all people with dementia. Currently disadvantaged groups include:

- people with non-Alzheimer dementia; and
- all people with dementia who need anti-psychotic treatments.

Services

There is a need for services that offer quality dementia care. Work being done in Australia and overseas is defining best practice in dementia care through person centred approaches which focus on the need to appreciate and understand the uniqueness of each person with dementia.

Even at this stage of the growing epidemic difficulties are experienced in getting access to quality dementia care – both in the community and in residential care.

An urgent need is for the expansion of services through Alzheimer Associations that promote awareness and provide information, counselling, support groups and education and training for carers and aged care workers. The Association provides specialist services in the management of behaviours of concern and the new Living with Memory Loss Program for those newly diagnosed are recognised internationally as breaking new ground. The Australian National University Report⁴ has estimated that given the current limited funding available the services of Alzheimer's Australia are only able to reach 5-10% of the target group notwithstanding increased Commonwealth and State and Territory funding in recent years.

And the reach is even lower in ethnic groups, indigenous communities and rural and remote communities.

Nearly half of the people with moderate to severe dementia in Australia currently live in residential care, with 60% of our high care residents and 30% of low care residents having dementia. Yet only 5% live in dementia specific settings.

This problem can only be addressed in mainstream community and residential care by ensuring that staff have the specialist training to provide quality dementia care and to

⁴ Future Directions, Consultancy Report to Alzheimer's Australia, Michael Bird and Ruth Parslow, ANU, July 2001

understand memory loss, disorientation and the many other health problems that arise from this illness.

There has been a welcome expansion of respite services in recent years including for people with challenging behaviour through the Commonwealth's National Respite for Carers Program and the Home and Community Care Program. Nonetheless, consumers continue to report problems in accessing community services suitable for people with challenging behaviours. This is particularly true of access to flexible respite services that respond to the needs of both the person with dementia and their families and carers-in terms of their availability when needed, where they are located and how they are delivered - and in particular for overnight respite whether planned or for emergencies.

Evidence provided to the Commonwealth Government's Two Year Review of Aged Care Reforms suggests that it is still problematic for families to find residential care for those with challenging behaviours. This only serves to heighten the trauma experienced by people with dementia, their families and carers at a most difficult time.

The policy and program settings of the early 1990s resulted in innovation in design and care in dementia specific care-especially in hostels. Many people with dementia will be appropriately cared for in mainstream residential care. But some will need dementia specific care and there is a shortage of properly designed and staffed residential facilities that can provide appropriate care for this group

It is recommended that the residential care planning guidelines be changed to ensure that all facilities have the capacity to care for people with dementia and that at least 10% of places be made available for people with dementia with special support needs. Financial incentives, both capital and recurrent, are needed to assist providers to care for this most disadvantaged group.

Conclusion

Thanks to the efforts of thousands of carers, the last 20 years have seen the stigma of dementia at best reduced but not removed. More recently people with early stage dementia have become important advocates. A positive approach to planning dementia care now will ensure that in twenty years time the quality of life of people with dementia, their families and carers will be much improved - a society truly committed to the prevention of dementia. That is the vision of the Alzheimer's Association Australia.

Alzheimer's Australia

December 2002