FIGHT ALZHEIMER'S
SAVE AUSTRALIA
FIGHTDEMENTIA.ORG.AU

Submission No.044.1
(Dementia)
Date: 08/03/2013

Dr Alison Clegg
Committee Secretary
House of Representatives Standing Committee on Health and Ageing
PO Box 6021
Parliament House
Canberra ACT 2600

Follow-up submission from Alzheimer's Australia's to the Inquiry into Dementia: Early Diagnosis and Intervention

Dear Dr Clegg,

Alzheimer's Australia is grateful to have had the opportunity to meet with members of the Committee on 11 September, 2012, and is pleased to provide additional information that was requested during the hearing and which has become relevant since that time.

The enclosed submission covers the following issues in response to questions from the Committee during the hearing:

1. A strategy to establishing conclusive data on current and future dementia prevalence in Australia;
2. Average times to dementia diagnosis, and what more needs to be done.

I am also pleased to provide additional information about recent developments in the following policy areas that I believe are of central interest to this Inquiry:

3. Dementia and primary care;
4. Dementia and acute care;
5. Dementia-specific respite care.

Finally, I have included additional information on:

6. A new report on the potential impact of interventions to delay the onset of dementia;
7. The need for dementia research, including a copy of Alzheimer's Australia's Federal Budget submission;
8. The need for funding for additional research to improve understanding of the causes and progression of dementia.

Australia National Office
1 Frewin Place. Scullin ACT
T 02 6254 4233 F 02 6278 7225
Alzheimer's Australia ABN 79 625 582 771

Recommendations

I understand the Committee is developing its final report on the Inquiry. It would be very helpful to have a report that prioritised key action areas. From our viewpoint we should be grateful if the Committee would consider the following recommendations:

1. **Dementia prevalence**: funding for a national prevalence study.
2. **Time to diagnosis**: a comprehensive study to determine diagnosis rates and timings in Australia
3. **Primary care**: some urgency in identifying and modifying as necessary those Medical Benefit Items most relevant to the assessment and diagnosis of dementia.
4. **Acute care**: a suite of measures that will help to improve the quality of care for people with dementia in hospital as suggested in this submission.
5. **Dementia research funding**: it would be helpful if the Committee could include in its final reports a case and strategies for dementia research, as outlined in this submission.
6. **Respite care**: the development of dementia specific respite services, along with a trial to evaluate the costs and benefits of allowing consumers to cash out the value of respite services to enable them to choose the services they receive.

Finally, Alzheimer's Australia would like to let Committee members and the secretariat know about two upcoming events that might be of interest.

The first of these is a Parliamentary Friends of Dementia event at Parliament House on 14 March at which the Minister for Mental Health and Ageing will release a report from the Australian Institute of Health and Welfare on the cost of dementia in acute care. The second is an address by Alzheimer's Australia's National President, Ms Ita Buttrose to the National Press Club on 24 April. The theme of her address will be reflections on the society she hopes Australia can be.

Thank you once again for the opportunity to provide further information.

Glenn Rees,
CEO, Alzheimer's Australia
7th March, 2013

Australia National Office
1 Frewin Place, Scullin ACT
T 02 6254 4233 F 02 6278 7225
Alzheimer's Australia ABN 79 625 582 771

FIGHT ALZHEIMER'S
SAVE AUSTRALIA
FIGHTDEMENTIA.ORG.AU

Follow-up submission from Alzheimer's Australia's to the Inquiry into Dementia: Early Diagnosis and Intervention

1. Response to Questions on Notice

1.1 Establishing conclusive data on dementia prevalence

The Committee was particularly interested in what could be done through research to better understand the nature of the dementia epidemic facing Australia.

In response, Alzheimer's Australia has worked with Professor Kaarin Anstey from the ANU and in consultation with leading researchers from around Australia to develop the enclosed overview of a dementia prevalence research program. This program would, for the first time, establish conclusive data on the number of people with dementia in Australia currently and provide a reliable basis for projections into the future, including among at risk and marginalised groups. This program would link to existing population-based health surveys, and would cost an estimated $10 million over 3-4 years.

1.2 Average time to a diagnosis of dementia

The Committee expressed an interest in the amount of time it takes people to receive a diagnosis of dementia in Australia, and whether there are regional variations. Only one Australian study has addressed time to diagnosis, with findings based on a survey of 209 consumers in NSW in 2007. This study did not examine regional variations.

This study found that consumers noticed the first symptoms of dementia an average of 1.9 years before seeking medical assessment (usually from a GP), and from that point it took an average of 10 months for a provisional diagnosis, and a further 5 months for a specialist diagnosis to be made. Clearly a significant part of the issue is the reluctance of some consumers to seek medical advice. However, there are still things that must be done to reduce the 13 month delay between first consultation and diagnosis.

This study also found that on average carers were satisfied with their first interaction with their doctor, and reported that most doctors had performed a memory test and referred on to a specialist. While the study did survey some individuals living in regional NSW, no analysis was undertaken to examine potential differences between urban and regional areas. The study is also limited by its sampling method; only those with a diagnosis responded meaning there is no information about those who aren't diagnosed.**The Committee might consider recommending a much more comprehensive study on rates of dementia diagnosis in Australia.**

2. Information about Relevant Recent Policy Developments

2.1 Dementia and Primary Care

Since the Minister's Dementia Advisory Group held a Forum on Dementia in Primary Care in June 2012, there have been further discussions between the Group and the Medical Benefits Division of the Department of Health. In line with the Advisory Group's recommendations to the Minister, it is proposed that the funds available through ***Living Longer. Living Better***. to achieve timely diagnosis will be implemented through the development, piloting and national dissemination of a training resource package for health professionals including general practitioners, nurse practitioners and practice nurses. It is proposed the training programs will be implemented through Medicare Locals and include:

- Tailored innovative approaches to training;
- Development of local pathways for diagnosis and management in the primary care setting; and
- Education on the use of Medicare Benefits Scheme Items for cognitive assessment and management of dementia.

This is good progress but it has been much more difficult to identify Medicare Benefit Items that could be used by doctors to ensure that they are compensated for time required for diagnosis, assessment and referral of patients to services. Further work is to be done but it is clear that a "Business Plan" is needed for GPs to ensure they are able to the extent possible to use the MBS items to achieve timely diagnosis. Among the important issues to be addressed is how to make more active use of the 75 plus health check in cognitive assessment.

A recommendation from the Committee that there should be urgency in identifying and modifying as necessary, those medical benefit items most relevant to the assessment and diagnosis of dementia would be helpful.

2.2 Dementia and Acute care

The Minister's Dementia Advisory Group held a stakeholder meeting on acute care and dementia in November last year. On the basis of the stakeholder meeting and further discussions with the Department of Health and Ageing, a number of possible directions for action using the resources in ***Living Longer. Living Better***. have been identified. These include:

- A study investigating the costs and benefits of appropriate care for people with cognitive impairment with the objective of alerting the acute care sector to the potential for long term savings and efficiencies.

- A "Programs for Change approach" to support projects that build on existing systems within hospitals to improve care and health outcomes for people with dementia.
- An audit of dementia training in the acute care sector to determine the available resources and identify gaps.
- An approach to the National Safety and Quality Health Standards Commission to promote quality dementia care.
- Undertake activity in respect of environmental design and acute care for people with dementia.

If the Committee supports an approach of this kind to improving the quality of dementia care in the acute care sector, it would be very helpful.

2.3 Dementia Specific Respite Care

Alzheimer's Australia had a valuable exchange of views on respite when we appeared before the Committee. Since that time we have prepared a report for the Department which should be published by the end of March on "Dementia and Respite Care".

The ***Living Longer. Living Better***. reforms will expand access to respite but they do not address the need for services which can better meet the specialised needs of individuals with dementia.

We know that:

- For every three dementia carers who have used respite, there are two dementia carers who need respite but have not used it.
- Dementia carers are ten times more likely than other carers to say they need respite but have not used it.
- One of the main barriers to accessing out of home respite care is the concern that the service use experience will be negative for the person they are caring for.
- Family carers also report that once the person with dementia develops behavioural symptoms or becomes incontinent, respite service providers often refuse to continue services.

On the basis of the work we have done, we are seeking your support for an approach that ensures that all people living with dementia in the community have access to appropriate flexible respite services. We believe this could be achieved by:

1. Developing dementia specific respite services. These services will receive a dementia supplement in line with the dementia supplement for eligible home care package recipients; a measure that would increase the funding payable in respect to the eligible respite care recipient by ten percent and would be linked to a requirement for dementia training for staff.

2. The funding of a pilot project to demonstrate the costs and benefits of a model in which the value of respite services could be cashed out by an individual so that they can choose – in line with their goals – how, when, where and by whom their respite services are delivered.

It would be of great assistance if the Committee were to consider supporting measures such as these in its final report.

3. Additional Relevant Information

3.1 New report on impact of future treatments to delay dementia

In late 2012, Alzheimer's Australia worked with Professor Henry Brodaty and his team from the University of NSW to produce a report, enclosed for your information, showing the cumulative number of people who would be expected to develop dementia over the coming decades, and the potential impact of future interventions to delay the onset of the disease.

The findings of this report are disquieting: without new treatments or interventions, over three million Australians will develop and mostly die from dementia in the 37 years between 2013 and 2050. However, the findings also have a bright side. If a new intervention capable of delaying the onset of dementia by just 5 years could be introduced in 2020, over 1 million Australians would be spared from the disease.

Alzheimer's Australia firmly believes that such interventions are possible. Despite disappointing results from several major international drug trials over the past 24 months, advances in screening technology – some being pioneered by the CSIRO-led Australian Imaging, Biomarkers and Lifestyle (AIBL) Flagship Study – will soon enable detection of Alzheimer's disease and some other causes of dementia years or even decades before the first symptoms appear. In the same way that pre-clinical screening for some cancers has revolutionised treatment and cure rates, screening for preclinical dementia will provide much better prospects for the development and eventual implementation of new treatments and interventions for dementia.

3.2 Need for additional dementia research funding

The development of such interventions must clearly be prioritised, and Alzheimer's Australia has made a representation to the Federal Treasurer for an urgent increase in dementia research funding in the 2013-14 Budget. This submission, enclosed for your information, makes the case for an additional commitment of $200 million over 5 years. This is equivalent to less than 1% of the direct costs of dementia care over the same period, and requires an initial investment of just $16.5 million in 2013-14. This funding is needed to support priority-driven research, such as the program of work to establish

dementia prevalence discussed previously, and to address the critical lack of dementia research capacity by supporting 150 new students and early career researchers to devote their careers to understanding and eventually beating the many causes of dementia.

I realise that the 2013-2014 Federal Budget announcement will precede this Committee's final report. However, if the Budget is not favourable for dementia research, Alzheimer's Australia would welcome the support of the Committee in maintaining the political impetus for an urgently needed boost for dementia research funding.

3.3 Additional research priorities

As the Committee will be well aware from the evidence provided by many of the witnesses at its hearings, Australia is leading the world in research to understand Alzheimer's disease through programs such as the AIBL study and many others. However, there remains a need for additional funding to support this important work. We have consulted with Associate Professor Cassandra Szoeke – a consultant neurologist and leader of the Women's Healthy Ageing project from the National Ageing Research Institute at the University of Melbourne – and have enclosed an proposal developed by her for a research program that would extend these studies in ways that would continue to expand our understanding of Alzheimer's disease and other dementias.