

## **ATTACHMENT A**

### **DEMENTIA IN PRIMARY CARE**

#### **Proposal**

To complete the Dementia Primary Care Project as soon as possible.

#### **Background**

As part of the Dementia Initiative the Department of Health and Ageing commissioned the Dementia Primary Care Project. The objectives of this project are to:

- Improve screening, diagnosis and ongoing assessment for dementia clients and their carers;
- Improve care planning, treatment, management and referral for dementia clients and their carers;
- Increase awareness and best practice dementia care eg. communication, latest research, access, incentives, education and training, advance care planning;
- Support and encourage through integration good multidisciplinary care; and
- Identify and explore opportunities in the Primary Care setting for Dementia Care.

The first stage of the report was provided by the consultants for comment to Alzheimer's Australia and others in June last year. Importantly, the report endorses what Alzheimer's Australia as a consumer organisation and the Australian General Practice Network and others have been saying for many years about the problems that exist in the recognition of dementia by GPs, the inadequate access they have to support (including to specialists, memory clinics) and the failures of GPs to refer patients to available services, including those of Alzheimer's Australia. The report makes a series of recommendations in response to the barriers identified to early detection, the opportunities identified through the research and consultation, and draws on approaches tested in other parts of the health system, both here and overseas, which were identified through a literature review.

#### **Next steps**

Alzheimer's Australia proposes that action to implement the recommendations of the report should be taken as soon as possible as part of Labor's commitment to strengthen primary health services and to better care for those with chronic diseases. As with the Better Outcomes in Mental Health Program, evaluation should be built in to any action taken, so that there can be an opportunity to fine tune the system with experience.

The objective is to ensure that GPs should be able to recognise dementia and refer the patient on for diagnosis by a specialist. However, we would not rule out the possibility that those GPs who upgrade their skills should be able to diagnose dementia and prescribe appropriate medications, albeit with the supervision of a

specialist. Such an approach might make maximum use of those GPs with the skills in this area; particularly in regions where there is limited or no access to specialists.

The initial priority should be to provide the opportunity for those GPs with an interest in dementia and older people to upgrade their skills and be rewarded in some way for it. A strategy that builds initially on those GPs with a serious interest in dementia seems the best way forward.

We agree broadly with the three domains identified in the draft report as requiring immediate action, namely:

- **Addressing knowledge gaps.** The study concludes that GPs may not be using latest available good practice information and that this poses a barrier to early diagnosis and early intervention. There is evidence too, that GPs are uncertain about their role in relation to legal matters arising in dementia care eg. driving, enduring power of attorney, advanced care plans. This is a source of considerable frustration and confusion to both GPs and patients and carers.
- **Addressing the capacity of GPs to communicate** with older patients and their carers. There is evidence that the carer/GP relationship is highly contested ground in terms of the value placed on the carer as a key informant.
- **Systems issues** around GPs access to specialists and support through practice nurses. Alzheimer's Australia believes that GPs need either more incentive or better use of existing Medicare items if they are to spend the time required with patients and their carers.

## **Costing**

Alzheimer's Australia understands that the funding for the work to complete the Primary Care and Dementia Project is included within the Dementia Initiative.

## **ATTACHMENT B**

### **NATIONAL DEMENTIA RISK REDUCTION PROGRAM – MIND YOUR MIND®**

#### **Proposal**

To implement the first National Dementia Risk Reduction Promotion Program using **Mind your Mind®**.

#### **Background**

Preventative health is now an established strategy within health services planning.

In recent years, preventative and risk reduction strategies have gained credibility in the dementia field. A major international research effort is currently proceeding and promising findings are providing a base for greater optimism in addressing the progression of Alzheimer's disease and other dementias. At the same time, action is being taken through public education programs to change individual behaviours (particularly lifestyle changes) to reduce the risk of developing dementia.

There is now strong evidence to suggest that reducing the risk of dementia may be possible by adopting certain health and lifestyle choices. Some of these risk reducing factors include having a healthy diet, reducing hypertension, lowering cholesterol, and promoting physical and cognitive activity. While there is no certain way known to prevent dementia, it is critical to ensure that people are informed of the impact their health choices may have on their brains as well as on their bodies. Dementia prevalence projections are a major driver of the need for dementia risk reduction programs.

Alzheimer's Australia has taken a leading national position through the development of the first dementia risk reduction program in Australia. This ranks Australia highly against most other westernized countries.

In 2005, Alzheimer's Australia launched its **Mind your Mind®** program. Drawing on the support of the philanthropic sector, Alzheimer's Australia has developed a national dementia risk reduction program.

The Alzheimer's Australia **Mind your Mind®** program has laid the foundation for a truly national effort to reduce the risk of dementia.

In economic terms, reducing dementia risk has significant impact over time:

- If the average onset of Alzheimer's disease could be delayed by just five months from 2005 there would be a cumulative saving of \$1.3 billion by 2020 and \$6.6 billion by 2040.
- If the average onset of Alzheimer's disease was reduced by five years from 2005 then by 2020 cumulative savings of \$13.5 billion would be realized, and by 2040, \$67.5 billion.

In community terms, the reduced risk of developing dementia would have immeasurable benefits for individual health and quality of life.

For **Mind your Mind**<sup>®</sup> to move to its next level of impact, it is essential that the Australian Government now commit to rolling it out as a national program.

### **Mind your Mind**<sup>®</sup> and Government

The **Mind your Mind**<sup>®</sup> dementia risk reduction program has moved through two phases since 2005 and is now positioned to enter phase 3.

- Phase 1 provided the evidentiary research basis (i.e. credibility) for a dementia risk reduction program.
- Phase 2 developed a 'brand name', marketing program, collateral development and the commencement of program rollout.

The objectives of Phase 3 at a national level are to:

- Roll out across Australia a high profile dementia risk reduction community education program.
- Introduce **Mind your Mind**<sup>®</sup> as a nationally recognised preventative public health initiative, particularly through the application of media and education.

### **Next Steps**

Alzheimer's Australia is seeking Australian Government recurrent funding commitment for the roll out of the **Mind your Mind**<sup>®</sup> dementia risk reduction community education program across Australia.

The proposed components of the program are:

1. Appointment of a Dementia Risk Reduction Program Manager (recurrently funded)
2. Roll out of a 'train the trainer' **Mind your Mind**<sup>®</sup> community education risk reduction program
3. Roll out of a nationally based health promotion program
4. Media promotion of dementia risk reduction.
5. Roll out of a multicultural and Indigenous dementia risk reduction initiative

## Program Evaluation

Measures would be applied for reporting and evaluation purposes and could include:

- Impact evaluation through pre and post community surveys.
- Number of presentations.
- Number of people at presentations.
- Number of information publications/materials distributed.
- Lists of other health promotion agencies involved.
- Media exposure (print/radio/TV).
- Conference and seminar presentations.
- Number of train-the-trainer sessions.
- Presentations to CALD and Aboriginal and Torres Strait Islander groups.
- Analysis of feedback surveys from community education sessions.

## Funding

The estimated funding support from the Australian Government required to develop a National Dementia Risk reduction program;

		<b>2008/09</b>	<b>2009/10</b>	<b>2010/11</b>	<b>TOTAL</b>
Dementia Risk Reduction Manager	1.0 Full time equivalent (FTE) plus overheads	100,000	100,000	100,000	300,000
Mind your Mind train-the-trainer	1.0 FTE plus overheads	90,000	90,000	90,000	270,000
	Travel & accommodation	5,000	5,000	5,000	15,000
	Equipment/ teaching materials	30,000	30,000	30,000	90,000
Multicultural Mind your Mind	1.0 FTE plus overheads	90,000	90,000	90,000	270,000
	Travel	5,000	5,000	5,000	15,000
	Teaching materials	20,000	20,000	20,000	60,000
Aboriginal and Torres Strait Islander Mind your Mind®	1.0 FTE plus overheads	90,000	90,000	90,000	270,000
	Travel	5,000	5,000	5,000	15,000
	Teaching materials	20,000	20,000	20,000	60,000
Rollout of program by States and Territories	Seminars, partnerships, special groups	250,000	400,000	400,000	1,050,000
Evaluation	Pre and post impact surveys and other analysis	50,000	50,000	50,000	150,000
Media promotion	Radio and TV Community Service Adverts	200,000	550,000	550,000	1,450,000
Support	0.3 FTE support position	45,000	45,000	45,000	135,000
Total recurrent cost		1,000,000	1,500,000	1,500,000	4,000,000

## **ATTACHMENT C**

### **COMMUNITY CARE**

#### **Proposal**

This proposal is in two parts:

1. Increase the level of real indexation of HACC from 6% to 10% to strengthen the base of community services available to people of all ages with disabilities.
2. Implement an expanded transition from hospital to residential aged care program.

#### **Background**

Recognising that community care is the cornerstone of the care system the Australian Government has indexed the Home and Community Care Program (HACC) at a level of 6% in recent years (with some additional "one off" funding in 2007-08). This growth of funding has been welcome, but is inadequate to ensure access to services for those that need them because:

- Some 37% of people assessed by assessment teams in 2004-05 were receiving no services at all at the time of assessment. Of these 37%, 39% were recommended for residential care, and 43% were recommended to stay living in the community with community care services (Aged Care Assessment Program National Data Repository Minimum Data Set Annual Report 2004-05. p.176).
- The Australian Institute of Health and Welfare reports that people who had been using HACC services at the time of assessment were less likely to be recommended for residential care than clients who were not using any services ("Australia's Welfare 2007" AIHW, p116).

Many of those older people occupying beds for longer periods in hospitals have some cognitive impairment. Recent cost data suggests that a hospital bed costs on average nine times the cost of an aged care bed.

Both in terms of the cost to the health system and in terms of quality of life, Alzheimer's Australia strongly supports expanding programs that seek to enable people to move out of hospital to residential care or back into the community. This requires a multidisciplinary approach and a range of services including rehabilitation delivered by State and Territory health services.

#### **Next steps**

To enable State and Territory health services to plan ahead, a forward commitment should be given to indexing HACC at 10% for the next 3 years. In this way, it is more likely that State and Territory health services will secure the additional funds required to match increased Commonwealth funding. It is important to plan services over a

three year cycle. We estimate this would cost the Commonwealth some \$272 million over three years, and the States and Territories some \$181 million over three years.

The Labor Election commitment to spend \$158 million over the next 5 years to provide 2,000 additional transition care places for older Australians is strongly supported. The concept is important as it is likely to benefit many older people with dementia assuming that the range of services necessary including rehabilitation are available to make transition back to residential care or the community possible. But this is only a small beginning of the investment needed more generally in community care and especially in high care packages which are in very short supply. The level of funding promised works out at only some \$43 per place day which may not be sufficient for 2000 transition care places.

## ATTACHMENT D

### SOCIAL INCLUSION

#### Proposal

Within initiatives taken to promote social inclusion it is proposed that measures should be taken to:

1. Promote access to services for those with younger onset dementia.
2. Develop the capacity of Alzheimer's Australia to partner with organisations of people from culturally and linguistically diverse backgrounds and with Aboriginal and Torres Strait Islander organisations.
3. Promote awareness of, and information on, advance planning and consistency in legislative provision.

#### 1. Younger Onset Dementia

There are some 10,000 people with dementia in Australia under 65 years of age. In a report prepared by Alzheimer's Australia to the Australian Government "***Exploring the needs of younger people with dementia***", it was concluded that younger people, like older people, want timely quality and accessible services that meet their individual and holistic needs throughout all stages of the disease process. However, there are unique and complex issues faced by younger people with dementia and their family members. These are well reported in literature in Australia and overseas.

The issues younger people may face include:

- Difficulty and/or delays in getting an accurate diagnosis;
- Family responsibilities including still actively raising a family;
- Currently working or being only recently retired;
- Having significant financial commitments based on previous earnings;
- Needing to revise their expectations of everyday life, such as work, finances, living arrangements, social and sexual relationships, and independence and responsibilities for others;
- Future plans that are affected at an earlier stage in life;
- Being more likely to have a rare form of dementia than Alzheimer's disease or a genetically based cause; and
- Experiencing difficulties in accessing appropriate services, particularly as younger people with dementia are often otherwise physically strong and healthy.

Alzheimer's Australia has prepared a set of recommendations to address the issues of people with younger onset dementia and their families and carers. The initial priority is to improve access to ongoing support in a way that recognises the different physical, social and emotional needs of younger people. The development of cluster services run by agencies that understand dementia and are able to relate to the needs of younger people is proposed as the best way forward. There are some models overseas in countries like Denmark that could be reviewed.



## Costs

It is proposed that over 3 years \$10 million should be provided to develop and deliver services for people with younger onset dementia including appropriate day care and respite care and cluster accommodation in residential care facilities.

## 2. Special Groups

### Background

A report commissioned by Alzheimer's Australia from Access Economics, "***Dementia prevalence and incidence among Australians who do not speak English at home***", concluded that currently some 12.4% of Australians with dementia (around one in eight) do not speak English at home.

Through the funding provided under the National Dementia Support Program by the Australian Government, Alzheimer's Australia has taken a number of initiatives to provide information to people from Culturally and Linguistically Diverse (CALD) backgrounds. This has been achieved through:

- The establishment of a National Cross Cultural Dementia Network.
- The development of resource materials in up to 19 languages to ensure a greater awareness of dementia among people from CALD backgrounds and of the services that are available.
- Developing language specific support programs such as Living with Memory Loss and Carer Education.
- Collaborating on the validation of an assessment instrument for people from CALD backgrounds.

Importantly Alzheimer's Australia Vic and Alzheimer's Australia SA have been able to demonstrate partnership models that enable Alzheimer's Australia to work with organisations representing CALD groups to inform and provide services for people with dementia

With funding from the National Dementia Support Program a successful National Indigenous Dementia Forum was organised with Indigenous people from all over Australia in Adelaide in 2006. The Forum agreed that dementia was a priority in Indigenous communities and identified a substantial program of work in the report "***Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander Communities***". Since that time with funding from the Australian Government Alzheimer's Australia has appointed a National Indigenous Liaison Officer and published "***Dementia: A Major Health Problem for Indigenous People***" based on the research work of the University of WA and the Kimberley Aboriginal Community Health Organisation. This research suggests that the prevalence rate of dementia among rural Indigenous people may be 4-5 times higher than in the general Australian community.

## **Next Steps**

To build on the experience and resources of Alzheimer's Australia in promoting awareness and access to services among special groups, it is proposed that a network should be set up of Staff in all Alzheimer's Australia State and Territory organisations to assist in the development and support of partnerships with organisations representing people from CALD backgrounds and Indigenous people.

## **Costing**

On the basis of 7 EFT, Alzheimer's Australia would undertake to build partnerships with CALD and Indigenous organisations over the next 3 years. The cost of this initiative would be \$700,000 pa.

## **3. Advance Planning**

### **Background**

Advance care planning plays an important role in allowing people with dementia to plan for their future health care and financial capacities against the time when they lose their capacity to make those decisions. The law not only has the potential of offering people with dementia the ability to make decisions about the future, but of protecting their financial, and medical choices. Unfortunately current legal provisions relating to enduring powers of attorney and advance care directives are complex and vary across the jurisdictions; terminologies are confusing and inconsistent and all too often the wishes of the person with dementia are not appropriately followed. Currently the opportunity of advance decision making is underutilised.

Most people are unaware of their legal right to appoint a decision maker, particularly with enduring powers. Barriers that have been identified include a reluctance to think about death and disability, lack of confidence, and a perception that the law is disempowering. Structural factors such as lower income, cultural background, disability and gender can limit the capacity to make informed choices.

Community education on these legal matters appears to be limited and ad hoc. Currently there is little assistance for people to attend to the legal documents and to decide whom they can trust and appoint as their substitute decision maker. The subject is complex, involving the law, medicine and family values. It is about relationships, not just about completing legal documents. The law and practice varies across the state jurisdictions and the terminology is confusing and inconsistent. The legal documents completed in one state are not always recognised in another, which can create additional difficulties for families.

Research has demonstrated that not all health professionals, including general practitioners are well informed about the enduring powers and advance directives and may lack the time or skills to assist people with this process. Lawyers also vary in their knowledge of the issues confronting people with a recent diagnosis of dementia. There is no formal training in capacity assessment and no consistent method currently used in legal practice.

While informal arrangements can often work well in families, many individuals with dementia and their families encounter significant problems when wishes for future care and decision-making are unknown. End-of-life care can also become more difficult in the absence of advance directives. If powers are not in place the guardianship law may have to be utilised.

An increasing number of people with dementia who have not put enduring powers in place are referred to Guardianship Tribunals across Australia. Approximately 50% of all referrals relate to people with dementia. The House of Representatives Standing Committee on ***Older people and the law*** in its report agrees that advance planning would reduce the demand for publicly funded guardianship tribunals and that “enduring powers of attorney are valuable instruments and older people, in particular, should be encouraged to make them”<sup>1</sup> but that at this present time “the complexity of instruments within and between States can also confuse and deter people from making an enduring power.”<sup>2</sup> Advance planning could reduce not only this economic cost but also the social cost for people with dementia and their families.

## **Next Steps**

The 2006 National Framework for Action on Dementia agreed by Australian Health Ministers provides for them to refer the issues of legislative barriers regarding Guardianship, advance care planning and advance care directives, wills and powers of attorney to Australian Government, State and Territory Attorneys Generals Departments.

There is strong support for initiatives in this area including from the Australian Medical Association. Advance planning has been identified in National Prescribing Service stakeholder meetings as a prerequisite for Quality Use of Medications, particularly in residential and acute care. At the recent National Bioethics Conference, *Health Bioethics and the Law: Inclusions and Exclusions* in November in Melbourne, an *Advance Directive Special Interest Group* was established.

The National Consumer Committee of Alzheimer's Australia advocates for:

- Achieving national consistency in advanced care planning legislation and regulations across all jurisdictions including clear guidelines on the status of these documents and their impact on the provision of appropriate care.
- Implementing education and support programs for consumers, care providers and health professionals about how to develop and use an advanced care plan, including enduring power of attorney documents.
- Providing training for professionals who will be advising people on legal, medical and social implications of the relevant documents.
- Establishing a national registry to ensure that the status and content of an advanced care plan is known and accessible in all health care settings in each jurisdiction.

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<sup>1</sup> Standing Committee on Legal and Constitutional Affairs, House of Representatives, *Older People and the Law* (2007) 3.16

<sup>2</sup> *Ibid* 3.14

In September 2007, the House of Representatives Committee on Legal and Constitutional Affairs in its report “**Older people and the Law**” made wide ranging recommendations on substitute decision making that respond to widespread consumer, sector and professional concerns. The report is consistent with the views of the National Consumer Committee of Alzheimer’s Australia and should be acted upon without delay.

## **Costing**

One million dollars to set up a Governmental Task Force to develop and implement, in consultation with consumers, proposals to address the recommendations made by the House of Representatives Committee .

The priorities are to:

- Develop an education campaign to inform the Australian community of the benefits, issues and processes involved with advance planning for their health, their money and their lives.
- Facilitate national consistency and mutual recognition in advance care planning legislation, including enduring powers of attorney, across the Australian jurisdictions so that the law and documentation are nationally consistent, user friendly and readily available.