

**Alzheimer's Australia Conference, Sydney May 2005**  
**Glenn Rees, National Executive Director, Alzheimer's Australia**  
**THE FUTURE**

At a Summit in 2000, Board members, staff and carers involved in Alzheimer's Australia from across Australia agreed to a new two-part vision for the future:

*To work for a society committed to the prevention of dementia while valuing and supporting people living with dementia.*

Prior to 2000, our work was largely directed to improving access to dementia services. In more recent times, we have been working to give some priority to increasing funding for dementia research whether directed to cause, cure, prevention or care. Other priorities have been to build on our consumer focus and intellectual capital.

So how far have we come in achieving our vision?

I believe consumers, both people with dementia and family carers, can derive confidence from the past in two ways.

First, consumers have known what they wanted in advocating for reforms in aged care and dementia care. The reforms have been a response to the desire of older people to stay at home for as long as possible and for appropriate models of community and residential care that respond to individual needs.

The papers prepared for the Dementia Forum in 1999 in Sydney captured what consumers had been seeking in the 1990s and before and they still make good reading. We learn that participants wanted:

- Upskilling of GPs in assessment, diagnosis and management
- A public health framework with dementia plans in every state

- Training to secure quality dementia care
- A review of bed ratios, particularly with reference to dementia care
- Access to appropriate residential care
- Dementia specific community care packages like EACH
- Funding for Alzheimer's Australia to fulfill its role as peak body
- Funding for a 5 year community awareness campaign
- A dementia coordination unit in the Department of Health and Ageing.

The list is much longer and importantly all items are still relevant today although there are some additions too. For example, there is now a greater emphasis on the needs of the person with dementia, on early diagnosis, on the availability of medications and on risk reduction.

Secondly, consumers should derive confidence from the progress that is being made on many fronts as is most dramatically illustrated in this week's Federal Budget.

Apart from its political significance the Government's recent decision to *Make Dementia an Australian Government National Health Priority* has great importance in the way that governments and the wider community will be encouraged to think about dementia. And it is significant that making dementia a national health priority has the support of the Opposition.

It is recognition that the dementia epidemic will be most effectively managed within a public health framework that addresses dementia research, early diagnosis and best practice management.

There is much to applaud in the current policy of the Australian Government:

- The priority being given to training.
- The funding of national programs through Alzheimer's Australia.
- The support given by the Government to awareness.

- The increasing emphasis in policy on strengthening community care.

And it is significant that the Federal, State and Territory Governments are joining together to develop a *National Dementia Action Plan* for consideration by Health Ministers later this year.

What do we need to maintain this progress towards the vision of Alzheimer's Australia in the next few years? I believe we need to:

1. Achieve and maintain a strong consumer focus in all we do
2. Further build the intellectual capital that underpins our advocacy
3. Secure increased funding for awareness activities
4. Promote access to quality dementia care
5. Advocate for increased funding for dementia research

### **Consumer Focus**

First, we need to work even harder to achieve a consumer focus in the advocacy role of Alzheimer's Australia. It is consumer advocacy - the courage of consumers telling their stories and the power of individual experience - that in the final analysis reinforces the statistics and sways a political argument.

The Australian Government's decision to *Make Dementia a National Health Priority* and the work of Australian Government and State and Territory officials on a *National Dementia Action Plan* provide the opportunity for consumers through Alzheimer's Australia to partner with governments in setting priorities.

The National Consumer Summit at Parliament House on 4-6 October will provide an opportunity to ensure that the concerns and priorities of consumers infiltrate every level of political and administrative thinking. The consumer policy workshops at this conference are a part of this process.

We expect the Summit to be a significant event both in terms of promoting awareness of dementia and in terms of setting priorities for the future. But it is the commitment to the ongoing involvement of both people with early stage dementia and family carers that will make a difference to the credibility of Alzheimer's Australia and build the national voice of consumers.

### **Intellectual capital**

Secondly, our advocacy and policy must continue to be built on a commitment to having the intellectual capital necessary to contribute to the work of policy makers and program managers in addressing the dementia epidemic. Impressing on governments and the community the economic and social impacts has been the cornerstone of our advocacy.

If we are to sustain the success of our advocacy we need to commit to deeper social and economic analysis for example, around the cost of dementia care. This could include investigating the cost effectiveness of various interventions in dementia, prevention and care. Or again, the comparative analysis of costs and benefits of community care compared to residential care and linking this to future social change when there may not be so many willing and able informal carers.

All areas of our activities will continue to benefit from building on our intellectual capital. In particular, will continue to

- Develop and deliver innovative services to help people living with dementia.
- Produce and deliver world class and well- targeted dementia resources.
- Build new expertise in acute care, palliative care and primary care.

Lastly, if we are to empower the consumers of the future, we need to think more deeply about models of consumer directed care where the consumer is able to determine and pay for the services needed to stay at home. In short, how can

service delivery be made more responsive to the needs of individuals? What are the alternatives to service driven models of delivery? What options can be developed for consumers as budget holders?

### **Awareness**

Thirdly, if our awareness activity has been effective over recent years in promoting a better understanding of dementia it has been done with limited resources. Given the dimensions of the health issues around dementia, we need a sustained and comprehensive awareness campaign over a number of years that is much better resourced.

Our focus this year will be prevention and risk reduction. Not because conclusive evidence exists but because the evidence is sufficiently good to encourage people to adopt healthy lifestyles in the knowledge that they can only do good in reducing their probable risk of dementia.

### **Quality Dementia Care**

Fourthly, the promotion of quality dementia care services needs to be addressed at a number of levels.

We have advocated for over two years for a project that will assess the training and support needs of doctors in better diagnosing and managing dementia care. Over 90% of Australians say that they would consult their GP if they had concerns about their memories.

The increase in the number and range of community care services over recent years is to be strongly supported. Yet there remain real difficulties in accessing appropriate respite when and where it is needed.

The introduction of dementia-specific Extended Aged Care at Home packages on 1 July 2006 provides an opportunity to further test and develop quality community

care services for those who can live at home. But there are many questions to be answered. Will the available hours be sufficient? Will the care workers have the necessary skills?

The introduction of a dementia care supplement as part of residential aged care funding from 1 July 2006 presents an opportunity to argue for new models of residential care and, in particular access to dementia specific care. But again there are many unknowns in this equation in terms of how the dementia care supplement will be resourced, the capacity of residential care providers to provide such care, the planning of dementia specific care places and the monitoring of outcomes.

The new and promising initiatives of the current Australian Government in community and residential care will not happen if there are not enough and available staff with the right skills mix. The issues are complex and largely unresolved.

One element of an approach would be to establish a centre of excellence that focuses on best practice and leadership in dementia care involving Alzheimer's Australia and other partners to:

- Promote best practice in dementia care.
- Provide advice on priorities in respect of research funding for the management of those with dementia.

### **Dementia Research**

Lastly, better funding for dementia research. The glittering prize is a reduction of 50% in the number of new cases of dementia by the middle of this century if we can delay the onset of dementia by five years. Australian researchers are world class. The investment in dementia research in Australia needs to be increased. This is a matter not only of governments giving it a higher priority but also of the

wider community including business being prepared to fund research that will have great social and economic benefits.

Research is needed into what may reduce the risk or delay the onset of dementia. And there are promising strategies that require further investigation in tackling dementia including;

- Modulation of known risk factors to delay or prevent progression of dementia.
- Prevention or removal of amyloid plaque formation using new medications or vaccination.
- Increasing the growth of connections between brain cells or growing new brain cells.

And finally, if that is not enough, achieving a higher priority for research into dementia care – not just the test tube variety.

## **Conclusions**

Those who started the State Alzheimer's organisations in the early 80's would, I think, be pleased with the progress that has been made in 25 years in respect of community attitudes, services and research. If Alzheimer's Australia can successfully address the five elements I have described, then I am sure we will achieve at least as much in the coming years.