

**GETTING DEMENTIA OUT OF THE CLOSET
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My thanks to the Singapore Association and ADI for giving me the opportunity to talk about getting dementia out of the closet in the context of younger onset dementia.

When I became CEO of Alzheimer's Australia back in 2000, little attention was given to younger onset dementia and we were only at the beginning of being inclusive of people with dementia in the life of our organisation.

At that time the objective of Alzheimer's Australia was to get awareness of the dimensions of the dementia epidemic in terms of the numbers of people with dementia, the economic costs and disability burden caused by the condition.

SLIDE 2

The difference now is that we have broadened the interests of our organisation beyond those of an organisation with a narrow focus on dementia to a broader policy interest in health and aged care, the linkages between dementia and other chronic conditions and consumer empowerment.

Some of the means we use today are the same as previous years. We continue to give priority to the development of intellectual capital as the basis for informed advocacy. This takes the form not only of social and economic analysis and publications on quality dementia care, but also the stories of people with dementia and their carers.

Alzheimer's Australia continues to be positive in emphasising that quality of life for people with dementia and their carers can be maintained or improved through good services, that dementia risk reduction is possible and that research holds out a promise of better medical treatments in the future.

Risk reduction is important because it makes the point that dementia is a concern not only for older people but everybody as the condition develops many years before diagnosis. A major element of our advocacy is to get recognition of dementia risk reduction in government public health programs. This is especially so given the links between dementia and vascular disease, diabetes and obesity all of which figure prominently in Australian Government health prevention programs.

Today, I want to focus on three elements of the work of Alzheimer's Australia in promoting a wider understanding of dementia that relate to younger onset dementia.

SLIDE 3

- Promoting awareness that dementia can strike at any age.
- Advocating for consumer choice in services through consumer directed care.
- Building new partnerships

Awareness of Younger Onset Dementia

There are about 10000 Australians with younger onset dementia. Younger onset dementia is a serious issue. It provides a good means to attract the attention of both politicians and the media. **SLIDE 4** Most people are simply not aware that dementia can strike at any age. It follows that there is little understanding of the special issues - both social and economic - that impact on younger people with dementia and their carers in terms of loss of income, family responsibilities and access to services.

Alzheimer's Australia co-hosted with the Parliamentary Friends of Dementia a Summit on younger onset dementia on 23-24 February. The Summit theme we adopted for the media and awareness was "Not too young for dementia". Nearly one hundred participants took part including 21 people with younger onset dementia and 49 carers. The Minister for Ageing opened the Summit. Members of her Department were present, as were experts to support the work of participants.

For a day and a half, the Summit participants worked very hard in working groups on key issues. The result by lunchtime on the second day was an agreed Summit Communiqué **SLIDE 5** that set out the actions needed if the quality of life of people with dementia and their carers was to be maintained and improved.

The scene was set for the Summit at the outset by eight people telling their stories - seven younger people with dementia telling their stories and one carer. The stories will be published on our website soon with the Summit papers but here is just a small extract from one of the stories by a family carer:

"Some 14 weeks after diagnosis Ged was placed in an aged care nursing home. At 36 years of age this was an enormously challenging time for Ged and his extended family. With the youngest person at the facility being 74 years of age, my husband and I together with the support of our eldest son defied the 'professional advice' believing this step was both premature and inappropriate given Ged's capacities, abilities and age, the lack of age appropriate facilities offered and the limitations in trained staff catering to the needs of a younger resident.

Following exigent and difficult decisions with Ged's wife who believed she had acted upon expert advice, Ged quickly left the nursing home.

Our greatest challenge at this point was that the professional advice that had determined Ged's institutional placement had been based on the "*usual pattern of people living with dementia*". I asked the question – How many 36 year olds were included in the evidence base and what consideration had been given to individual and family strengths and the capacities in making the determination? The outcome was obvious- nil!!"

If access to services was a major issue high-lighted by the stories the other main theme from the stories were of protracted and heartbreaking accounts of delays in diagnosis resulting from the refusal of some professionals to accept that dementia was possible "at your age" and from confusion with depression and stress. One

person with dementia told the Summit in his story that he was finally diagnosed with dementia after 10 years of tests and uncertainties at the age of 63. He said

“A recurring theme was that most of the doctors involved thought I could not have dementia because I was too young. At that time we saw this as a re-assurance rather than a criticism”

He concluded

“I believe that early diagnosis is important, patients and partners should be encouraged to keep records and most important carers and partners should be consulted and included well before diagnosis. All these we think will lead to the process running smoother”

Participants at the Summit identified six priority areas that require action and made many recommendations. In the time available the best I can do is to list the areas and give some examples of the action recommended against each one: **SLIDE 6**

1. Increased awareness to reduce stigma and social isolation. Proposed action included the development of a national awareness and social marketing program focusing specifically on younger onset dementia, involving younger people with dementia telling their stories. Participants called on the Government to recognise younger people with dementia within the Government's social inclusion policies.
2. Timely and accurate diagnosis. This as I have said was a main area of concern. A recommendation was made to develop a nationwide network of accessible specialist diagnostic clinics to assist people experiencing memory loss or cognitive changes. Recommendations were also made for a national framework for genetic testing supported by adequately resourced and skilled counsellors.
3. Access to appropriate services. The need was identified for a targeted strategy to improve the range and quality of in home and out of home services available for people with younger onset dementia, their carers and families including those living in rural, regional and remote areas. There was strong endorsement of the model of consumer directed care and services that respond to the social and leisure interests of younger people and the needs of their carers. I will say more about consumer directed care in a moment. There was a recognition too of the need for support to be given to children during the dementia journey of their parent.
4. Employment and financial needs. Among the many recommendations made was one to develop and fund a program to support younger people with dementia in maintaining a sense of purpose and achievement through participation in full time or part time work, volunteer or recreational activities. The need was recognised for employers to be encouraged to retain people with younger onset dementia in employment if they wish to continue work.
5. Legal and bureaucratic issues. Participants recommended that the Australian Government establish an independent Dementia Advocate to provide legal

assistance and advice to people with younger onset dementia and their carers. The multiplicity of legal issues identified included reducing the complexity of making advance care directives, superannuation and insurance issues and rights of younger people with dementia under the Commonwealth Disability Discrimination Act.

6. Increased investment in research. The need was identified for research to identify more accurately the numbers of those with younger onset dementia and models of care that are responsive to the needs of people with younger onset dementia and related conditions. At a practical level a recommendation was made to encourage enrolment into brain donor programs.

The Summit Communiqué was presented to the Minister for Ageing, the Shadow Minister for Health and the Shadow Minister for Ageing as well as a number of Parliamentary Friends of Dementia, at a lunch at Parliament House by a carer and three younger people with dementia.

The document will provide our template for advocating on behalf of younger people with dementia. Many of the Summit participants are now energised to go back and promote the outcome of the Summit to their local media and local members of Parliament.

Our advocacy is supported by three new publications. **SLIDE 7** – two Quality Dementia Care publications on younger onset dementia, one for clinicians and the other providing practical guidance for people with dementia and their carers.

SLIDE 8 We have also published *In their own Words...* which contains the moving stories of people with younger onset dementia.

In strategic terms, the Summit was well timed in establishing positions on younger onset dementia that need to be argued before decisions are taken in the 2010 budget on the future of the Dementia Initiative - Making Dementia a National Health Priority. Almost everything we do in the next twelve months will be geared to ensuring that we secure some additional funding for the Dementia Initiative for the five years from 2010. There is bipartisan support for continuing the Initiative after 2010 with funding – the question is how much funding.

It is too soon to assess outcomes in terms of policy change or services but the Summit was successful in a number of ways:

1. At the political level in promoting awareness of younger onset dementia.
2. In attracting the strong support of our Patron the Governor General including a reception at Government House
3. In mobilising a lot of good will among service providers and professionals
4. In focussing our organisation at the state and territory level on the issue including the development of resources to promote awareness in the longer term. An important part of this were the pre Summit consultations to identify the key issues for discussion in working parties at the Summit.
5. Attracting some media coverage
6. The agreement on next steps to promote the issue

What could we have done better? The main negative was that the environment was not ideal for younger people with dementia. The day and half was hectic, the noise levels difficult to cope with and there were the logistics of moving people between the hotel, meeting venue and Parliament House

Consumer Directed Care SLIDE 9

For over four years we have been advocating for the adoption of consumer directed care models in Australia. Essentially, consumer directed care is a term used to refer to an approach to obtaining care for older and younger people under which the person who needs care, with their family carer, is given direct control if they wish over the resources provided for their care. It is the consumer who chooses the services they need.

SLIDE 10 Consumer choice can take several forms including cash or an individual budget held by an agency for use by the consumer. In the Australian environment it seems probable that older people will be more likely to prefer individual budgets held by agencies rather than hold the cash and be employers. Experience with such programs for younger people with disabilities suggests that cash may be the preferred option.

In June 2007 we invited Dr Jane Tilly from the USA to do a lecture tour of Australia on consumer directed care. Jane is a wonderful advocate given her experience of evaluating programs in the USA and of other programs in European countries. Jane and I published a paper **SLIDE 11 *Consumer Directed Care: A way to empower consumers?*** drawing together evidence on the better outcomes achieved for older people and people with dementia. In de-mystifying consumer directed care and presenting the evidence the publication was successful in promoting an informed debate and in being widely quoted.

For those who want to know more about CDC, this publication is on our website.

While CDC will benefit younger and older people with dementia, the model of consumer directed care may be particularly helpful in tailoring responsive services to individual needs of younger people. **SLIDE 12** This is because there are unlikely to be mainstream agency services available for the relatively small number of people involved. Most dementia services in Australia are more suitable for older people.

Research evidence from the USA and a number of European countries suggests that people of all ages and their carers who receive CDC programs experience better outcomes in relation to quality of life, independence and satisfaction with the care received than those who rely on standard agency services.

SLIDE 13 Our engagement in this debate is strategic in a number of ways, including **SLIDE 14:**

- Broadening our role beyond that of a chronic disease organisation to consumer advocacy concerned with reform and change in the health care and aged care systems.

- Making the point that life does not stop with a diagnosis of dementia and that people with dementia want to continue for as long as possible in social engagement and lifetime activities supported by responsive and flexible services.
- Reinforcing the view that people with dementia and their carers are able to express their wishes and should have the choice, if they choose to exercise it, to take greater responsibility for the care they receive.
- Achieving more flexible services that respond to the needs of people with dementia of any age

Partly as a result of our advocacy and that of younger disability groups, consumer directed care is now on the political agenda in Australia and AA is a Member of a Working Party established to advise the Department and the Minister on a staged implementation of consumer directed care.

Partnerships

Let me turn to partnerships. **SLIDE 15**

Dementia in younger people can be the consequence of other chronic conditions, including Multiple Sclerosis, HIV/AIDS, Alcohol and Drugs, Motor Neuron disease, Huntington's disease, Stroke, Parkinson's and Down Syndrome. Alzheimer's Australia invited the relevant national organisations for these groups to the Summit to discuss common issues and develop strategies for collaboration.

The development of these partnerships is at an early stage. There is potential for working together on many of the priorities for action in the Summit Communique. **SLIDE 16** For example, on promoting awareness, establishing a national approach to genetic testing and counselling, improved access to care services, increased funding for dementia research and advance care planning.

If some of these relationships can be fostered and developed, they will complement the many partnerships we have as an organisation with those interested in aged care and more generally.

Conclusion **SLIDE 17**

The Summit Communique represents a huge agenda. In part of course it is an agenda for people with dementia of all ages but in other respects has aspects that are special to the younger group.

We are at the stage of ensuring the Communique is widely circulated at the political level and with staff and professional bodies. We have established our credibility with governments and other peak bodies as a consumer organisation that has a public policy contribution to service development through consumer directed care beyond that of being the dementia experts.

We have the elements of a strategy in place now, which hopefully within a few years, will get the issue of younger onset dementia out of the closet and acted upon at the political level. The immediate priority is to seek \$25 million over 3 years to provide

improved access to services for this group but there are many other recommendations from the Summit to progress. And hopefully there will be more more partners to join us in the common cause.

If you would like to read more, all the publications I have referred to today can found on www.alzheimers.org.au/youngeronssetdementia And I have some copies here which people are welcome to take.