

FOCUSING ON THE PERSON WITH DEMENTIA PROVIDES NEW CHALLENGES FOR ALZHEIMER'S ASSOCIATION AUSTRALIA

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Background

I should like to thank Hammond for giving me this opportunity to speak to you this morning about the work we have been doing on consumer focus – and in particular, people with dementia.

As part of our approach to advocacy and awareness, and reducing the stigma of the disease, the Association has reviewed the effectiveness of its existing mechanisms for involving consumers in the life of the Association. We have completed the initial research and consultation phases of the Consumer Focus Project. The report is available on our web site (www.alzheimers.org.au).

It is critical for us to show 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.

Currently, dementia directly impacts on the lives of around 500 000 people including more than 160 000 people who have been diagnosed. We expect that by 2041, these numbers will triple - including a staggering 460 000 people with a diagnosis of dementia.

There are three areas that I want to address:

- First, the Consumer Focus Project and its outcomes;
- Second, current consumer focus initiatives within and outside the Association; and
- Lastly, two major issues that remain unresolved.

The Project

Turning first to the project.

In the early 1980s, family carers formed the first State Alzheimer's Associations and were successful in advocating for new services. Back then, there were no Alzheimer medications and diagnosis was often made at a late stage in the disease.

In more recent times, earlier diagnosis has enabled people with early stage dementia to find their voice. They have been important advocates for the Association and for their own needs - in specific areas such as access to Alzheimer's Disease medications, and more generally, through conference participation.

People with early stage dementia have started to access their own information and services. A few statistics to illustrate:

- there were more than 4.1 million hits on our web sites in 2000/01
 - many would have been made by people with dementia;
- the number of people with dementia receiving counselling and support from Alzheimer's Victoria trebled in 2000/01 compared with the previous year.

After our March 2001 National Conference, a group of people with early stage dementia made recommendations about how they could be more effectively involved in the work of the Association, including policy, program and information technology development, and work such as lobbying, education and media.

The Association's National Committee accepted these recommendations in principle, commissioning an internal research project to report on:

- 'The legal and medical issues that need to be addressed if people living with dementia are to be on decision-making committees, whether the Boards of State and Territory Associations or the National Committee.

- The structures that could be developed at National, State and Territory level to provide opportunities for input by carers and people living with dementia across the areas identified by the National Committee.
- The resources necessary to support carers and people with early stage dementia in their advocacy work.'

The research project:

- Investigated the current ways in which consumers – family carers and people with dementia – are involved in the Association; and how their participation might be supported and strengthened.
- Involved consultations with State Association Board members, staff and people living with dementia; and contact with international Alzheimer's associations, non-profit organisations in other sectors, government agencies and legal and insurance experts.

The main findings of the project were:

- 'consumers – and in particular, people with dementia – should be encouraged to play a greater role in the National and State Associations;
- mechanisms for engaging carers are more developed but need to be strengthened;
- people with dementia were keen to contribute in ways that reflected their skills and previous experience;
- the pool of people with dementia willing and able to serve on Boards or in policy roles was small and likely to remain so in the foreseeable future;
- consumer input was valued by Alzheimer's Associations, however consultation processes needed to be strengthened;
- resourcing and limited infrastructure were seen as restricting consumer involvement;
- legal and other advice suggested that ability to perform a director's duties was the crucial issue and that a person with dementia should not be precluded from serving on a Board, based only on their diagnosis;
- 'good governance' practices and risk management could be used to support consumer participation on Boards and in other roles;

- there were no clear lessons to be learned from overseas experience as most Alzheimer's Associations were still working through similar issues;
- experiences in the disability sector provided some guidance about how people could be supported to undertake a range of roles within the Associations;
- there was an opportunity for Associations to develop specific programs which directly assisted people with dementia to remain connected within their own communities and to take up new roles within Associations;
- while there were many initiatives, which could be developed to increase the participation of consumers, the preference was for an evolutionary rather than a revolutionary approach.'

The detailed findings can be found in the attachment to this paper or in the report itself. They are supported by proposals within the body of the report.

Improving consumer focus

Both within the Association and outside, much is already happening that parallels the findings of the Consumer Focus Report.

Carers are already represented on Association Boards - in some State constitutions, there is a requirement for a set number of Board members to be carers. At all levels of Alzheimer's Associations, carers play vital roles in advocacy, policy work and other volunteer capacities.

In a number of State and Territory Associations, structures have been set up to promote the involvement of carers and people with early stage dementia in policy work and identify the issues of greatest concern to consumers.

The National Conference of the Association in March 2001 in Canberra was the first occasion on which people with early stage played an important role - both in addressing the Conference and in having their own stream of activity.

The approach developed in Canberra was, indeed, something of a model for the Alzheimer's Disease International (ADI) Conference in Christchurch later that year. Again a number of people with early stage dementia addressed the Conference. They were instrumental in getting an important resolution passed which commits ADI to work on ways to be more inclusive of people with dementia.

Importantly, people with early stage dementia have taken a grip of their own destinies through self-advocacy and peer advocacy. They have formed the Dementia Advocacy and Support Network International (DASN) - an Internet based advocacy group run by people with a diagnosis of dementia and their care partners.

DASN has more than 160 members in 11 countries and is working - as I have said - with ADI to develop a more inclusive relationship with people with dementia. The ADI working group - of which DASN is a member - will make recommendations by the Barcelona conference in October 2002

The presence of people with early stage dementia at conferences, participating in workshops and manning their own display stands, illustrates better than any words the need for change in social attitudes towards people who have this terrible disease. Many people with dementia still face stigma and lose the right to contribute after diagnosis.

Let me give you a few recent examples from the DASN web site (http://www.dasninternational.org/regular/reg_presentations.htm) of what people with early stage dementia are saying:

- Speaking at the Callier Centre for Brain Research at the University of Texas Dallas, Ben Stevens stressed the need to 'advocate (for) continued emphasis on self-reliance for as long as possible' and called for more opportunities for mutual support and exchange of ideas;

- Jan Phillips spoke of her journey from 'apathy to advocacy' at the US Alzheimer's Association 14th Annual Public Policy Forum in Washington in April 2002. She said that the 'best hope for early-stage people is early detection, immediate and aggressive drug intervention, early stage services and an empowerment approach. Rehabilitation, self-monitoring and management, and vocational or recreational therapy must be elements of the patient's tool-box for coping';
- Morris Friedell at the same forum said that 'We are part of the disability rights movement, advocating for respect and inclusion, whose slogan is "Nothing about us without us"';
- At the 2001 ADI conference in New Zealand, Christine Bryden, an Australian with early onset dementia, spoke in a plenary presentation about 'the journey from diagnosis to death' and the 'challenge ... to reclaim (my) life with realism and humour'. She said
 - 'Our lives become limited by the stigma we face in the world around us People become awkward in our presence, are unsure of our behaviour, and our world becomes circumscribed by the stigma of our illness.'
 - 'Many of us have learned how to communicate over the Net, finding great joy in encouraging each other, and deep support in sharing with others.'
 - 'We have been where you are, in the world of normals, and know what that feels like intimately. But you have no idea what it feels like for us. We are bi-cultural, bi-lingual, speaking and knowing the language and mores of normality as well as dementia. So we can bridge the gap between the world of normality and the world of dementia, and help you to understand us and our needs.'

Christine Bryden, who has been such an important advocate for the Association, has identified a three-stage process that she thought would encourage consumers to become more involved while making a contribution to Alzheimer's Associations. Specifically she has suggested that:

- Initially, consumers would be offered support through the Dementia Helpline, support groups and counselling. This would allow consumers to begin to deal with their own issues, make new networks, and become more aware of Association activities;
- At a later point, consumers could be encouraged to become volunteers in Association activities such as speaking, co-facilitating groups, assisting with newsletters. This would be a time in which consumers discovered they had expertise to offer, and felt valued;
- Lastly, the Association could identify those consumers who were interested and able to become active in policy and program management, for example, through membership of State/Territory Boards, program steering committees or advocacy/advisory groups. This might mean providing mentoring or other assistance as necessary.

The next phase of work for the Alzheimer's Australia will build on the solid foundations provided by the Consumer Focus Report. Our State and Territory-based Associations will work with carers and people with early stage dementia to develop locally those approaches that best suit them.

There are a number of windows of opportunity for the National Association to push ahead with our evolutionary approach over the coming 12 months.

- Macquarie Bank has provided sponsorship for the redevelopment of our National website. This funding, together with funding from the Commonwealth, will enable us to develop a site that responds better to the needs of carers and people with early stage dementia. Consumers will be represented on the IT Development Committee.
- The National Conference in March 2003 will be another opportunity to embrace people with early stage in the life of the Association. We plan to use that conference more actively to enable both carers and people with early stage to input to the policy work of the Association.
- As a member of Alzheimer's Disease International, Alzheimer's Australia will - from our perspective - do everything we can to advance the work being done to include people with dementia.
- The Association's Living with Memory Loss program enables consumers to better come to terms with the trauma of diagnosis and to get on with their lives. This program provides one mechanism to find out what people with early stage dementia want and to support their involvement with the Association and more widely.
- The work being done on dementia care mapping and person centred care offers a window of opportunity to better understand the care needs of a person with dementia from their point of view.
- We will support consumer participation by developing a National Consumer Policy Statement for consideration by our National Committee in October.

Addressing the unresolved issues

There are two particular areas of difficulty that I would like to flag.

First, there is an issue of the representation of people with early stage dementia on our boards of governance. I believe that it is unwise – and indeed unnecessary - to change our constitutions to include a requirement for their direct representation - not least because there is probably not the critical mass of individuals that we could draw on to sustain such an approach.

While there is general support across the Associations for having people with dementia on Boards where the individuals themselves want to contribute, there is nervousness about the legal consequences - both for the individual and for the Associations.

It is, of course, the case that all potential directors - whether with early stage dementia or without - should be fully aware of the responsibilities and risks imposed by association legislation and the common law. Individuals and their families must be given the information that they need to make informed decisions about getting involved in Association activity at all levels.

If a person with early stage dementia has the enthusiasm and skills necessary to succeed in election to the Board of a State or Territory Association, then it seems to me that it would be quite wrong to place obstacles in their way. But, there will come a time as the disease progresses, when the person's capacity to participate may be called into question - and possibly before the person is aware of all the issues.

To address those circumstances, we need to develop Association guidelines to provide a clearly defined process that can be followed. Whether those circumstances are likely is perhaps a good question. Christine Bryden served on the Board of the ACT Alzheimer's Association for several years and moved on when she felt she had done all she could.

In a broader societal context, there is a need to ensure too that the rights of individuals with dementia are protected. In a thoughtful article in last month's National Health Care Journal, Ken Hancock commended the use of the six-step assessment process put forward by Dr Peteris Darzins and others in their recent book "Who can Decide?" The article pointed to the need for urgent public attention and debate about the way in which the courts approach capacity determination. I must agree that there are unresolved issues in law to address.

The other difficult area for the Associations is resources. The successful participation of people with early stage dementia and carers from all parts of Australia at our last National Conference could not have taken place without generous private corporate sponsorship and Commonwealth funding.

While individuals often contribute willingly to their costs, there will, over time, be many people with early stage dementia who simply will not have the resources to attend conferences or to easily participate in the work of the Association without considerable support. Yet it is vital to our work and the policy work of health authorities and government that they have the perspective of people with dementia themselves on their needs.

Resourcing remains an issue within our smaller Associations in terms of building the policy, training and management infrastructure needed to support volunteer activity. More generally, additional resources will be necessary as broader programs for people with dementia are developed.

Conclusion

I can think of no more effective long-term way of reducing the stigma of the disease and increasing awareness than by involving people with early stage dementia in every day life. We in the Alzheimer's Association have a particular responsibility to ensure that that happens in the life of our own State and Territory Associations. We can achieve that goal while recognising the carer origins of our Associations and the vital contribution that carers have made and will continue to make to our work.

The Association has a vision for a society committed to the prevention of dementia, while valuing and supporting people living with dementia. I invite you to join in that vision and to take an interest in the work that we are doing on consumer focus.

Consumer Focus Report findings

Legal and Insurance Issues

The available information suggests that there are no legal or insurance considerations that preclude people with dementia as a group from accepting election to the Board of State/Territory Associations.

Individuals may serve as Board members provided that they have the necessary mental capacity and expertise to understand their legal responsibilities and continue to fulfil their duties.

Associations should:

- obtain advice about State case law and statute in their jurisdiction;
- put policies in place to support the involvement of people with dementia; and
- advise their insurer about the policies in place to support Board members.

Governance

Risk to Associations can be managed provided that Boards practise 'good governance'. Existing governance arrangements can be used to support the involvement of people with dementia across Associations provided that constitutions and governance policies are reviewed to:

- add clarity where existing case law is deficient;
- update object(ive)s, language and membership to be inclusive of people with dementia; and
- address practical considerations such as terms of office.

Capacity

Members of Association Boards need more than 'legal capacity' to meet the requirements of governance legislation.

Capacity assessments should never be taken lightly, as they lead to substitute decision-making.

Practising 'good governance' will minimise the need to consider capacity assessment.

Consumer Engagement

Isolation for people living with dementia can be minimised provided that Associations:

- support consumers to remain connected within their own communities; and
- offer opportunities for consumers to be involved in the activities of the Association.

Consumer Empowerment

Associations can support the empowerment of people living with dementia by providing:

- opportunities to build new skills or practise existing skills;
- new roles within the Association;
- education about their rights;
- information to doctors and the general community which aims to reduce stigma and stereotypes.

Barriers to consumer participation

The real and perceived barriers to the participation of people living with dementia in existing Association policies and practices can be identified and overcome provided that Associations:

- plan to increase consumer participation in a systematic way;
- develop policies and guidelines around volunteer activity, committee membership etc;
- review programs to identify opportunities for participation;
- identify resources to support participation;
- inform and educate consumers, staff and other stakeholders about rights and opportunities to participate;
- monitor and evaluate progress.

Consulting with Consumers

Consultation processes can be strengthened by:

- including consultation as a core activity in strategic plans;
- providing formal mechanisms for input if these do not already exist;
- identifying a co-ordinating position within each Association;
- putting together a consultation program which identifies opportunities and mechanisms;
- identifying the additional resources needed to analyse and disseminate consultation outcomes;
- sharing consultation products, processes and outcomes with National/State Alzheimer's Associations.

Improving Consumer Participation Nationally

An effective national approach to consumer participation will require action and resourcing at many levels.

Consumer participation nationally is predicated on support at State level.

The National Committee can support improved consumer participation by undertaking a plan of action that builds on existing organisational capacity, encourages sharing of ideas and resources, and monitors progress.

The National Association should identify and build on existing initiatives that provide opportunities for direct consumer involvement. Some examples are the redevelopment of the National web site, current National Conference planning and the development of consumer policy panels.

Improving Consumer Participation in State/Territory Associations

Consumers are interested in becoming more involved in Association activities.

Associations can offer a range of opportunities for consumer involvement including volunteering, training and other activities, provided that the necessary resources are found. Resourcing options include government funding, private sponsorship, partnership arrangements and realignment of Association funding priorities.

The resources necessary to provide ongoing support to people with early stage dementia following the Early Stage Program should be secured by the National Association through submissions to the Federal Government.

Developing Guidelines on Board Participation

People with dementia may be supported on Boards by suitable education and training and a range of practical arrangements including careful chairing, time and paper management.

The development of Association-specific guidelines on Board participation - based on National core values and principles - will provide the policies needed to manage risk and for good governance, as well as to support consumers and other Board members in their role.

Developing Guidelines on Supporting Participation of People with Dementia in Other Roles

There are many opportunities for consumers – including people with dementia – to work with Associations.

Increased involvement will follow specific invitation and can be supported by the development of comprehensive Association-specific guidelines and policies, based on National standards.