

## **VOICES OF PEOPLE WITH DEMENTIA**

### **ADI Regional Conference Taiwan**

#### **Glenn Rees National Executive Director**

Most, if not all, of us at this Conference will have their own personal experience of Dementia. It is the personal contact that makes all the difference to understanding.

For my generation growing up in English speaking countries there was generally ignorance about dementia. The experience was one of denial. Dementia was not something the family talked about. And of course that is the situation still in many countries today. I learnt of my grandmother's death from dementia 50 years after she died.

In my own experience as National Executive Director of Alzheimer's Australia, it is the voices of people with dementia that live most strongly in my memory. A moving moment was the first time people with dementia spoke at our National Conference in Canberra in 2001.

Another, when I went to a support group for the first time, to talk with a group of people with dementia to be asked by Max almost before I had sat down, "How did I think about death?"

And again on a boat trip with people with dementia on Lake Burley Griffin, to have Chris whisper across the table, his hand half in front of his mouth "Whether I was one of them?"

Individually, their voices are memorable, together they change systems and influence governments.

In our different countries and cultures, we will have different views about what it means to hear the voices of people with dementia and the strategies to achieve it. With that in mind, I will address two main questions:

- First, why is it important to hear the voices of people with dementia? And what do we mean by consumer empowerment and advocacy?
- Second, to identify the elements of a consumer empowerment and advocacy strategy that will have the end result of empowering people with dementia and family carers to speak for themselves?

#### **Consumer Empowerment and Advocacy – What does it mean?**

When we think about consumers and advocacy in Australia, we are seeking to enable the voices of people with dementia to be heard in order that they can:

- Advocate for their rights.
- Contribute to policy positions.

- Assist in service development and delivery.
- Influence better media and political processes by telling their stories.

We take the view that consumer empowerment and advocacy are centre stage in what we do as an organisation in Alzheimer's Australia. The stigma and social isolation that result from a diagnosis of dementia will not be changed unless the wider community come to understand better the journey of dementia.

And those attitudes will not change unless we lose the negative perceptions of ageing overall. We need to move to a view that ageing should be and can be a positive experience of engaging with life - not passive dependence.

Many people in Australia will still not know that over half those with a diagnosis of dementia are living in the community. They do not understand that although a person with a diagnosis of dementia will never feel quite the same, life has to go on. Specifically, the outcomes we are seeking in promoting the voice of people with dementia are to assist people with dementia to:

- Gain access to resources, funding and information.
- Give people greater control over their own lives.
- Secure recognition of the rights of people with dementia.
- Achieve changes in the legal system, for example in respect of advanced planning directives.

In summary we are trying through consumer empowerment and advocacy to assist the person with dementia to have their voice heard and to protect their rights. While the driving force of our commitment to consumer empowerment and advocacy is to assist the individual, it also empowers Alzheimer's Australia.

This is because it makes our organisation more credible, and our messages more powerful. Our organisation is not worth listening to just because we are dementia experts or have doctors on our Boards, but because we hear and represent the issues as they are understood by people with dementia and the families and carers that support them.

There is no doubt in my mind that in Australia that power of our organisation rests on having credibility in representing the interests of people with dementia and their family carers.

## **The Strategies**

The shaping of strategies starts with a realistic assessment of the social context in which we are working. There is often a presumption that people with dementia are "aged, helpless and dependent" (Bender & Cheston, 1997). Kitwood (1990) talks of a "malignant social psychology" which results in consequences for the person with dementia such as disempowerment, labelling, infantilisation, stigmatisation, invalidation, ignoring, and objectification.

This underscores the importance of working for a social context for recognition of the capacity of the person with dementia and their human desire to still be seen as a productive individual with a valid contribution to make to the world.

In Australia there are many different strategies that relate to hearing the voice of people with dementia. I recognise that in the cultures of many ADI members, there may be constraints on the extent to which it is possible to pursue these strategies and to enable people with dementia or indeed, their families, to speak out. After a century of denial and stigma, there can be no quick way to change societal attitudes and multiple strategies are needed to promote the voice of people with dementia.

The central requirement is to be positive. Dementia is a terrible condition but engaging with the community in promoting an understanding of dementia is only possible if there is hope. This comes from the advances made in research, the possibility of new treatments that will modify disease processes and biomarkers that will help identify those most at risk, the evidence that the risk of dementia may be reduced through lifestyle and the benefits that result from good dementia care.

The strategies, based on the Australian experience, that you might be interested in, include:

1. Positive images and awareness
2. Developing a consumer focus within the Alzheimer's organisation.
3. Promoting advocacy by involving people with dementia in the life of Alzheimer's organisations.
4. Adopting structures within Alzheimer's Australia that promote the involvement of the person with dementia.
5. Advocating on issues that promote empowerment of the person with dementia and their family carer.
6. Promoting consumer events to get political and media attention.
7. Selecting and training consumer advocates.
8. Identifying champions.
9. Research into how people with dementia experience their lives.

## **1. Positive images and awareness**

Alzheimer's Australia has produced, over recent years and with the wonderful support of photographer Lynton Crabb a series of positive images of people with dementia engaging with life – young and older, from different cultural backgrounds, overseas and more recently from Indigenous communities. One of the themes has been that life does not stop when dementia starts. Here are just a few of those images.

Re couple dancing: It is Patti and Robin Hodder. Robin won bronze in hockey in an Olympic Games. He was younger onset. Patti is a nurse and she did a lot pioneering work in Palliative care. The photo was awarded second prize at the ADI conf. in Berlin that Glenn attended. Photography by Lynton Crabb. We call the photo: Dancing in the Kitchen

People on bikes: two of our most involved consumers. Wife has dementia.

A picture may be worth a thousand words but language gives us so many clues to the social context in which we operate. Murna Downs said in a paper in 1997 that “a considerable amount of much published work has described dementia sufferers and dementia victims, and both the burden of caring and the view of family carers as victims have been common usage. The coming years may see more use of terms such as care recipient and service user when referring to individuals with dementia.

So we have developed and published a Dementia Terminology Framework that seeks to influence the way language is used in respect of dementia. Those interested will find it on our website. We encourage the media and others not to use the word sufferer or demented person as those words imply that the victim is helpless. This not only strips people of their dignity and self esteem, it reinforces inaccurate stereotypes and heightens the fear and stigma surrounding dementia. So we always refer to a person with dementia. Rather than challenging behaviours we refer to changed behaviours, at risk behaviours or the Behavioural and Psychological Symptoms of Dementia. In this way we seek to avoid implying that the person with dementia is being difficult but rather that there are causes for the behaviours. Do not judge by the symptoms is the message.

People with expressive language deficits, such as we see in dementia, are at risk of “having a limited voice and are therefore vulnerable to being disempowered and marginalised within society” (Lloyd, Gatherer & Kalsy, 2006). So an important focus of work within Alzheimer’s Australia is hearing the voices of people with dementia through self expression in music and art and in promoting the concept of social engagement in support activities that enable the person with dementia to continue their involvement with activities that have been important in their lives. Again the thought that although life may never be the same after a diagnosis of dementia life does not stop.

## **2. Consumer Focus**

In Australia it is only recently, since 2000, that people with dementia have been fully included in our advocacy. Before that, for 20 years or so, the advocacy was largely left to families and carers. So we initiated a debate in 2001 in Alzheimer’s Australia about what being an inclusive organisation means in terms of engaging people with dementia and family carers in the life of our organisation.

This project was called Consumer Focus and it:

- Identified the ways in which people with dementia and carers were involved in our member organisations.
- Distilled the views of many stakeholders about how the Consumer Focus of Alzheimer’s Australia might be strengthened.
- Pulled together information to guide future legal, governance and insurance decisions.
- Provided a basis for further work necessary to support people with dementia in becoming full partners with carers in the work of Alzheimer’s Australia.

The report was perhaps less important than the process in raising the profile of consumers – and in particular people with dementia – within the organisation. A National Consumer Involvement policy statement resulted, but more importantly, staff approaches and the involvement of consumers within Alzheimer's Australia were permanently changed for the better. Regular reports are made to the Board and Consumer Focus is now one of our four key result areas in our strategic planning.

Interestingly, we spent a lot of time talking about legal issues and the capacity of people with dementia to be on Boards. The reality, at least in Australia seems to be that people with dementia want to get on with their lives and that they tend to be rather less interested in being on Boards than in self advocating at Conferences and telling their stories. It is perhaps, a more obvious way of making a real difference.

### **3. Promoting advocacy by the person with dementia or their family carer.**

This can take many forms, but the opportunities for empowerment and advocacy are:

- In the governance of our Alzheimer's organisations.
- In the policy making processes within our organisations through advisory committees and commenting on draft documents.
- Contributing to external discussions with Ministers, Departments, in public meetings and in the media.
- Presenting at the openings of seminars and conferences.
- Developing and owning key documents that set out the priorities for improving the quality of life of people with dementia at the time of Federal Elections. The Dementia Manifesto developed by people with dementia and family carers is for us the blueprint for policy action and advocacy.
- The publishing of books by the person with dementia and their family carers of their experience with dementia.
  - ~ We have a number of accounts from books written by people with dementia, for instance Christine Bryden.
  - ~ There is a lovely quote from Hazel Hawke, former wife of Prime Minister Bob Hawke on her 75<sup>th</sup> birthday in the book Hazel's Journey. "I've got no embarrassment about it (Alzheimer's) being a shameful thing, because it's got nothing to do with shame. It's an illness, which is unpredictable and when it comes you've just got to cope with it. And the more research that's done – and money that's raised in order to research – the more it might be, well, not eradicated, but dealt with in better ways to assist people with Alzheimer's. Because it is very difficult, it's like losing your skin or something. But in fact you lose some of your head – your works'.

### **4. Adopting structures that promote the involvement of people with dementia in advocacy.**

In Australia we have tried to develop a structure that is inclusive. The most important part of this development is at the State and Territory level, and the various consumer groups at that level. Sometimes these groups are set up separately to represent the interests of family carers and people with dementia. In other cases, people with dementia and family carers work together in the same group.

We have had, in Australia, for almost 2 years, a National Consumer Committee with a membership of people with dementia and family carers. The Committee meets face to face twice a year and holds teleconferences in between those meetings. It has set three priorities which are respite care, younger onset dementia and advance care planning. There are many issues that could be embraced, but the Committee has been disciplined in how much work it can take on at any time.

We draw on the expertise of the group a lot in developing policy and a small subgroup met, for example, to develop a paper on respite care. Other members have been involved on the other priorities and have appeared before Parliamentary Committees and met with Ministers.

Slowly the National Consumer Committee is developing a public face. I believe that it will evolve to be the major policy driver in our organisation.

## **5. Advocating on issues that promote empowerment of the person with dementia and their family carer**

There are two areas of policy that we are putting a lot of effort into with a view to empowering people with dementia and their family carers.

Firstly, the issue of Consumer Directed Care. Essentially, this has the aim of making the person with dementia or their family carer an equal partner in determining what services will be provided, by whom they will be provided and when they will be provided. The objective is to enable people with dementia and their family carers to have more control over their lives and not simply to take whatever services may be available.

The idea is not new or Australian. Indeed, the principle of Consumer Directed Care is embodied in the services for younger people with disabilities and older people in many States of the USA and in many European countries including the United Kingdom, the Netherlands, Austria and Germany. Sometimes it takes the form of providing cash instead of services, so that people can purchase the services they want themselves. The idea is that people with dementia and their family carers are not passive recipients of services but should have the option of controlling their own lives. If you would like to read more about the issues in Consumer Directed Care, there are papers on the Alzheimer's Australia website.

Secondly, to promote advance care planning of finances and care. Over half the cases that come before Guardianship Boards in Australia relate to people with dementia. We are seeking better education and a more friendly legal system to assist people with dementia and their family carers to protect the wishes of people with dementia. There is a lack of understanding of the consequences of not having an advance plan, and few opportunities for people with dementia to get assistance to make an advance plan. People with dementia are vulnerable to financial abuse. They should have the right to choose the care they want at the end of their lives. People with dementia have a right to a good death.

## **6 Promoting consumer events to get political and media attention**

In Australia we held a National Summit at the National Parliament building in October 2005 at which were 50 people with dementia and family carers from all parts of Australia. It was organised through Parliamentary Friends of Dementia. The event itself and the resulting communiqué expressing the views of the participants about what they wanted had a significant impact at the political level within Australia in setting policy directions. It was those policy directions that formed the basis of the Dementia Manifesto developed for the recent Federal Election in Australia.

With the help of Parliamentary Friends of Dementia we are planning a Summit for people with younger onset dementia and family carers next February. Again we anticipate it will result in garnering the views of the participants on what would improve their quality of life. There will be seminars and forums across the country in advance to ensure we get the views of a variety of people on the ground.

## **7. Selecting and training for consumer advocates**

This could be the subject of a seminar in itself. The issues to be addressed include:

- How to select consumer advocates. There are people who are naturally more likely to be advocates than others in having the confidence to speak publicly, but it is never easy to find the right people, because people with dementia want to get on with the rest of their life and family carers often don't have the time or the energy to be involved.
- The training that should be provided. Generally media training is not available, but people are advised prior to an interview about what to expect, not to have too high an expectation and for the interview to be a positive experience. Most media requests relate to the personal experience of a person with dementia – how it affects the family and quality of life. We encourage people to talk about their experience so that they can speak from the heart, and not to impose the stress of having to argue particular policy positions.
- What support should be provided? A person with dementia is always accompanied to media interviews by someone from the relevant Alzheimer's organisation. Media contact with individuals is always made through a staff person. The person with dementia is asked what their preferred interview location would be. It is important afterwards to provide the person with dementia with feedback on the outcome of the interview and to learn what they felt about the experience. Rehearsing what is to be said is vital.
- The issues covered can vary greatly, from driving to assistive technology to elder abuse.

## **8. Champions**

In Australia only one person prominent in public life has disclosed their diagnosis of dementia – Hazel Hawke, former wife of former Prime Minister Bob Hawke. This in itself is significant in terms of the stigma which is perceived to still attach to dementia. The United States, of course, have been rather more successful in disclosures by people with a high profile.

- Champions help to break the stigma of what a person with dementia should “look” like.

- The author Terry Pratchett recently went public with his diagnosis of younger onset dementia in the UK and he is using his profile and his money to bring public attention to the dramatic underfunding of dementia research.

## **10. Research**

In March of this year a review of literature on dementia was published in the International Journal of Older People Nursing. It showed that biomedical research continues to dominate the literature and that our current knowledge base of how people with dementia experience their lives with this disease remains small. But, there is increased interest in studies that seek the views of people with dementia. This type of research has been impeded by the difficulties of conducting such research ethically and meaningfully. In particular, involving people with advanced dementia has been considered so fraught with difficulty that most studies have involved people in the early stages of the disease. Nevertheless, researchers have developed, and are continuing to refine, ways to actively engage people with dementia -- including those ones with advanced disease -- that are ethical, sensitive, and flexible, and the body of literature that advises on how such studies may be conducted is growing.

## **Conclusion**

When we listen, it is easy to rush to conclusions and to taint the message with our own personal experiences and biases. To listen to this voice we may need to be more patient, to keep an open mind and to listen to the non-verbal cues of the person.

The hardest thing for a National Executive Director to do, or perhaps any staff member of an Alzheimer's organisation, is to stand back and let the person with dementia or the family carer do the talking. It is all too easy to talk on behalf of the consumer and to forget that they might do the job rather better. One of the best moments in my time at Alzheimer's Australia was during the National Summit when a small group of people with dementia and family carers together with the Summit Facilitator met into the small hours of the morning to redraft the communiqué I had so carefully prepared for them. There is a lesson in everything in life and the important lesson for those who work in Alzheimer's organisations is to let go and let the person with dementia do the talking.

[www.alzheimers.org.au](http://www.alzheimers.org.au)