

**SPEECH NOTES**  
**2010 AUSTRALIAN LEADERSHIP CONFERENCE**  
**SYDNEY**

**Leadership for Consumer Centre Approaches: Objectives, Ethics, Communication**

Many thanks for the invitation to speak at this conference.

Talking about leadership might encourage a sense of false modesty.

So for the record, let me say that I think I have probably been a slow learner in putting into practice in the last ten years as CEO of Alzheimer's Australia some of what I have learnt through experience at senior level in the public services both in the UK and in Australia.

Consumer centred approaches in health services has a nice ring, the equivalent of the customer is always right.

Everybody stands to gain, so it would seem.

The individual, in gaining access to the health and care services they need to meet their individual and family circumstances.

The organisation, as its brand gains credibility in understanding and responding to the needs of its clients.

And staff, who in my experience, want to do the best job they can in seeing that the person they are caring for has the best possible quality of life.

Yet we all know that the barriers to achieving a consumer centred approach are great. Perhaps the greatest barrier is a lack of agreement in what is meant by consumer centred care. 'Person Centered care' and 'Consumer centred approaches' have become buzz words which have been embraced by the aged care industry, but at times are not as closely linked to the preferences and choices of the person with dementia as one would hope. For Alzheimer's Australia the key to having a 'consumer centred approach' involves listening to and responding to the concerns and wishes of those with dementia and their families.

But of course the barriers are far greater than terminology. Some of these include:

- financial and staffing resources
- physical environments; and
- compliance with regulations and reporting requirements ,which can swallow up staff time

'Consumer Centred Care' is not an area for the fainthearted manager and one that requires sustained effort and commitment over a long period.

Individual organisations, managers, and facilities all have their own cultures, values and strengths and weaknesses.

This is evident in the significant effect that a single individual – a manager or director of care - can have on the quality and consumer-focus of care within a facility or organisation. I have witnessed and heard of many cases of the quality of care and, in particular, the consumer focus of care, changing overnight as the result of a loss of a particular staff member.

However, staff operate within the culture of their organisation, and organisational culture is influenced most strongly by management and leadership.

Which brings me to my topic today: that effective leadership is essential for the promotion of a consumer centred approach within care organisations.

It is self evident there is no one size fits all approach to leadership that will achieve consumer centred approaches.

My own experience over the last ten years has been as CEO in the National Office of Alzheimer's Australia. Alzheimer's Australia is a Federated non-Government organisation made up of member organisation from each state and territory. These organisations are separately incorporated and glued together by a common commitment and a belief that unity will deliver more than the sum of the individual parts.

Alzheimer's Australia like other NGOs struggled in the late 1990s to achieve unity. It is no coincidence that the greatest achievements of the organisation in its advocacy for people with dementia and their family carers and in the delivery of services has been at a time of unparalleled commitment to work together at the National and State and Territory levels.

My own skills are policy based. I have retained a belief in the power of logic in part from training early on in my working life based on management by objectives. My work experience has told me that logic should be leavened with a great appreciation of the importance of values and communication.

My belief is that a consumer centred approach is both the driver of our organisation and the glue that holds it together. It is the common passion to a consumer centred approach that is dedicated to improving the quality of life of the individual with dementia and their family carers that is at the core of what we strive to do within our organisation and in our advocacy.

I would like to identify for you the strategies that I think have helped Alzheimer's Australia to have credibility as a consumer centred organisation. I hope that these thoughts have wider application to health services of different kinds.

But first let me do a brief environmental scan of the social context within which Alzheimer's Australia operates.

## **The Social Context**

The shaping of strategies for leadership in consumer centred approaches starts with a realistic assessment of the social context. In the case of dementia there is often a presumption that people with dementia are “aged, helpless and dependant”. Tom Kitwood talks of a “malignant social psychology” which results in consequences for the person with dementia such as disempowerment, labelling, infantilisation, stigma, invalidation, ignoring and objectification.

As a result of these pervasive, negative stereotypes, Alzheimer’s Australia and others in this area work in a social context defined by hopelessness and fatalism. Hopelessness as there is no cure, and avoidance due to discomfort of people who do not behave according to the norms of society. .

To achieve consumer centred approaches in such a negative context, it is essential that leadership is focused on the positive. In particular, all of those involved in dementia care, from managers to care workers, must work to recognise the remaining capabilities of the person with dementia.

There is no doubt that dementia is a terrible condition, but engaging within the organisation and with the community in promoting the rights of people with dementia is only possible if there is hope.

And where does this hope come from?

First, our best scientists and clinicians at the exciting forefront of research into dementia are making daily advances in research, and there is a strong possibility that within the next decade, new treatments will be available that modify the onset and progress of the disease. There will also be biomarkers that help to identify those at risk of dementia in time for medical treatment and lifestyle changes to have maximum effect.

Hope also comes from the evidence that the diagnosis of dementia is not the end of a previously productive, fulfilling life. Instead, with good, well coordinated carer support and dementia services, individuals with dementia can live for many years, maintain fulfilling relationships and activities, and enjoy a high quality of life.

Thanks to the media and the work of Alzheimer's Australia and others some of these positive messages are now talked about. Unfortunately it is still the case that an individual is defined by their diagnosis rather than as a person. And it is that simple realisation and commitment to the essence of the humanity of the person with dementia that I think drives us in Alzheimer's Australia.

## **The Role of Advocacy**

Enabling the voices of people with dementia to be heard is both the start and the end point of our organisational life. It is also the best, and in many ways, the only way for us to promote a true consumer centred approach.

In particular, we need the voices of people with dementia to be heard in order that they can:

- Advocate for their rights.
- Contribute to the development of policies that affect them, both directly and indirectly.
- Assist in service development and delivery.
- Influence the media and political processes by telling their own stories.

The personal stories of individuals with dementia are perhaps the most powerful way to increase community awareness and understanding of the condition. It is only in the last ten years that people with dementia have been heard at conferences and seminars and in the media in Australia and this has been an important shift for both our organisation and the wider community. In recent times a story that has become even more powerful has been the realisation that there are many in our community who develop symptoms of dementia in mid-life; some as early as their 20s and 30s.

Consumer empowerment and advocacy are centre stage in what Alzheimer's Australia does as an organisation. The stigma and social isolation that can result from the diagnosis of dementia will not be changed unless the wider community comes to better understand the journey of dementia.

Arguably, this focus and the involvement of consumers in our organisation makes my role as CEO that much easier in terms of providing leadership because there is a common point of departure.

Our organisation is not worth listening to just because we are dementia experts or have doctors on our Boards. Rather, we are worth listening to because we hear and represent the issues as they are understood by people with dementia and the family carers that support them.

There is no doubt in my mind that organisational power in many areas of social endeavour, including our own, rests on the organisation's credibility in representing the interests of their primary stakeholders.

Most importantly, our goal is not to advocate purely on behalf of people with dementia, but to provide them with the necessary co-ordination and support for self-advocacy; to be advocate *that much more effectively* on their own.

Let me now describe the internal and external strategies that our organisation has used to promote consumer centred approaches.

## **The Strategies**

### **Internal Strategies**

There have been four internal strategies that have worked well in Alzheimer's Australia in securing a consumer centred approach within the organisation.

First, when I first became CEO 10 years ago, we embarked on a project called consumer focus. This project:

- 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.
- Brought together information to guide future legal, governance and insurance provisions.
- Provided a basis for the further work required to allow people with dementia and their carers to become full partners 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 changed permanently for the better.

Since that time, regular reports have been made to the Board, and consumer focus is now one of our four key result areas against which we develop our Strategic Intent and conduct all of our planning.

Interestingly, we spent a lot of time talking about the legal issues and the capacity of people with dementia to be on Boards. The reality, at least in our organisation, seems to be that people with dementia tend to be rather less interested in being on Boards – which shows they have much sense – than in self advocating at Conferences, providing input on policy and telling their stories in the media and elsewhere. It is perhaps a more obvious way of making a real difference.

Secondly, the consumer focus exercise led to setting up and resourcing structures inside the organisation to empower the consumer voice. We have National, State and Territory level Consumer Advocacy Committees involving both people with dementia and their family carers.

We have a National Cross Cultural Dementia Network which brings together people from Culturally and Linguistically Diverse backgrounds from across Australia. The purpose of this Network is to identify both the specific inequities that individuals from CALD backgrounds face when they are diagnosed with dementia, and the actions that can be taken to address these. Often, these actions focus on increasing awareness and information as well as the provision of culturally specific dementia services.

There is a National Aboriginal and Torres Strait Islander Dementia Advisory Group that similarly seeks to come to terms with the lack of understanding among Indigenous people about dementia. This group works to promote the realisation that just because Indigenous people have a lower life expectancy does not mean they have a lower prevalence of dementia than mainstream

Australia. In fact to the contrary, there is now evidence of the rate being four to five times higher in rural and remote areas.

Thirdly, there is my own commitment as CEO. I make it my business to be at all the meetings of the National Cross Cultural Dementia Network, the National Aboriginal and Torres Strait Islander Dementia Advisory Group and a further National Consumer Advisory Committee. This is a significant commitment in terms of time and travel, but it seems to me that the CEO should be willing to make a commitment at least as great as those who are willing to provide their views and their time as volunteers.

It has been my experience since being involved in aged care and disability in the mid 1980's that the policy person who goes further than consultation, and actually listens will be far more effective in policy work. There is no road to Damascus in all of this. Rather the realisation that after talking with consumers on any issues, your views as a policy maker will never be quite the same.

Lastly, our approach to planning is through Strategic Intent. Recognising that the activities of the national and state and territory organisations both overlap and differ, we share four key result areas but provide for flexibility within those for the way business plans are shaped. We also identify within the National Business Plan each year those priorities that most require the joint commitment of the federation.

The first KRA in Strategic Intent is on *Improving Advocacy and Empowering Consumers*. Within that are set out the strategies and activities I am telling you about today.

## **External Strategies**

The goal of greater consumer involvement within our organisation is of great importance but it is not the end game in my leadership role.

Rather, the end game is to improve the quality of life of people with dementia through making consumer centred approaches the norm rather than the exception. There are many dimensions to working towards this goal in our awareness, advocacy and policy work. But let me touch on three.

First, is our commitment to embed Consumer Directed Care at the centre of the aged care reform agenda.

The objective of CDC is to enable the care recipient and their carers to have greater control over their own lives. This is achieved by empowering them to be able to make choices about the types of care they access and the delivery of those services, including who will deliver the services and when.

CDC is both a philosophy – the right of consumers to choice – and a spectrum of options that extends from consumer participation and delivery of agency services to budget holding by the service providers for the use by consumers to cash or vouchers.

What better way than CDC to make the point that life goes on with dementia and that people with dementia and their families and carers should have the right to make the choices that best meet their needs for support and care. What better way to focus passion in a leadership role?

The strategies that we adopted to this end were many but included:

- Commissioning a paper entitled ***Is Consumer Directed Care a Direction for Australia?*** This report was authored by Dr Anna Howe back in 2003 . It looked at the international evidence and asked the hard questions about how CDC might or might not translate into the Australian environment.
- Supporting a lecture tour by Dr Jane Tilley from the United States to talk about experience there and in European countries with CDC. These seminars were informed by a publication by Dr Jane Tilley and me entitled ***Consumer Directed Care: A Way to Empower Consumers?***
- Drawing together consumer views expressed at various seminars. These included the strong support for the concept of budget holdings by service providers rather than cash, and also the potential for CDC approaches in the area of respite.
- Participation in conferences and seminars to promote CDC.
- And perhaps more importantly, working with service provider organisations, not only to promote debate, but also to pilot and evaluate CDC approaches within existing service programs.
- And of course, to promote the concept and ideas in Ministerial and Departmental Advisory Groups and in our submission to the Productivity Commission's current Inquiry into Aged Care.

The end result of our efforts and those of others is the commitment of the current Government to 1400 CDC packages including 400 respite care packages.

For 25 years, the cornerstone of aged care policy has been to enable older people to stay at home longer.

And there has been a commitment to person centred care in the rhetoric and practice of many service providers.

But without doubt in my view we have been slow as a society to recognise that the choice of staying at home or of achieving person centred care is likely to be a distant reality unless consumers are empowered to make choices about both the services they need and when and where they would like them delivered.

Leadership has to be about learning and we have advocated strongly that the new CDC packages should be evaluated to see how they will work and how best they can be applied in the Australian context. There are a great many important issues that need to be addressed including:

- Ensuring the quality of services
- Determining the financial and administrative costs associated with CDC

- Establishing the best way to support individuals and their families to make informed choices
- Evaluating the effect of CDC on the service system and the capacity of providers to achieve cultural change

Our second major external strategy to promoting consumer-centred approaches to dementia care has been in the huge investment that Alzheimer's Australia has made in information and awareness related activities.

We have a formidable arsenal of information and intellectual capital to assist those who have concerns about their memories to access assistance. And we are making a significant investment in a new website to provide a still better service to consumers. We have also invested in special access liaison officers to try to reach individuals who may have less access to information because of cultural, language or geographic barriers.

Positive language and images are an important part of empowering the individual with dementia. Like the disability sector, we have focused on using language that respects the person. Avoiding terms like dementia sufferers and dementia victims in favour of terms such as person with dementia, care recipient and service user is a simple, but very important step.

In dementia, an important part of promoting positive images is to make people more aware that although life may never be the same after a diagnosis of dementia, it does, none-the-less go on.

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 supporting the person with dementia to continue their involvement with activities that have been important in their lives.

Consistent with these approaches, Alzheimer's Australia has produced over the years and with the wonderful support of photographer Lynton Crabb, a series of positive images of people with dementia engaging in life – young and older people from different cultural backgrounds and in different settings.

Our final external strategy is the promotion of a consumer centred approach in dementia research through the establishment of a Consumer Dementia Research Network. This network comprises 23 people with dementia and family carers from all walks of life and from across Australia. The broad goal of the network is to provide individuals living with dementia an opportunity to have input into research and knowledge translation activities.

The objectives are to

- Set priorities for knowledge translation projects by identifying those areas of dementia care that are of most concern to consumers
- Have consumer involvement in knowledge translation projects



- Assist the three Dementia Collaborative Research Centres in setting priorities for research, identifying opportunities for consumer involvement in research projects and disseminating the outcomes of research.
- Seeking opportunities to work with others in the dementia research community interested in a consumer perspective.

The Network is a critical part of the National Dementia Quality Care Initiative that Alzheimer's Australia is administering with funding from the ANZ Wicking Trust and BUPA care Services. The objective of the Initiative is to promote the quicker adoption of research evidence into practice.

We expect to learn much from this project about consumer centred approaches in knowledge translation and research from an evaluation commissioned from the Centre for Health Service Development at Wollongong University. Hopefully this will not only benefit Alzheimer's Australia but other organisations in implementing knowledge transfer through a consumer driven approach.

## Conclusion

Effective leadership is essential to achieving a genuine consumer-centred approach to care. Today I have described the internal and external strategies used by Alzheimer's Australia to increase our credibility as a consumer-centred organisation. I am not under the misapprehension that these strategies will work in every organisation. That being said- the *principles* that underpin these strategies are key to any consumer oriented approach.

The first of which- and perhaps the most obvious- is listening to the consumer. I have found that this is often not as easy as it may sound. To let go of your own paradigms and shift your view to that of the consumer requires a level of flexibility and humility that can be hard to achieve.

The second principle is responding to the preferences and choices of consumers. This again can require a paradigm shift. It means moving from a frame of mind of reducing risk to keep people safe, 'knowing best', and working under cost and resources pressures to one of choice – even if at times these choices seem to stray from our own notions of what would be the best for the person.

The third- and last principle underpinning our strategies is the need to create lasting structures within an organisation that will lead to cultural change which will outlast a single leader in an organisation. I anticipate- and am hopeful- that when I leave Alzheimer's Australia many of the structures I have put in place to support a consumer centred-approach – such as our consumer networks- will provide the needed support for further work on improving engagement with consumers and will ensure that the loss of a single leader will not mean a loss of consumer-centred approach.

There is an increasing awareness and understanding of consumer-centred care both within the sector, and amongst consumers which is evidenced by the growing number of organisations professing to provide consumer-centred care -

some with a genuine and deep commitment, and others superficial – as well as the growing attention and fledgling programs within government.

Moreover, there appears to be an increasing realisation amongst some in the industry that strong leadership directed at consumer-centred care does not need to be against the odds, or with disregard for the bottom line. Instead, a consumer-centred approach to care entails benefits not only for consumers, but for care workers and their employers as well.

I have outlined today several internal and external strategies that have allowed Alzheimer's Australia to demonstrate leadership in promoting consumer centred care. I hope that some of the broad principles which underpin this work will be of some use to you and your organisation.

I'll leave you with just a few thoughts about the importance of choice

*'One's philosophy is not best expressed in words; it is expressed in the choices one makes.. and the choices we make are ultimately our responsibility'*  
Eleanor Roosevelt

*'Life is a sum of all your choices'* Camus

*'Few things help an individual more than to place responsibility upon him, and to let him know you trust him'* Booker T. Washington