

HOW INDUSTRY ASSOCIATIONS CAN INFLUENCE GOVERNMENT AND COMMUNITY OPINIONS

Glenn Rees, National Executive Director Alzheimer's Australia.

Many thanks for inviting me to speak to you about the experience of Alzheimer's Australia in seeking to influence government and the community. Much of what I will say has been influenced by our experience in recent years in securing bipartisan support for dementia to be made a National Health Priority.

As those of you who have worked in peak bodies will know, there is no magic bullet to gaining influence or good outcomes. I suspect there is a good deal that we can learn from one another. However, it cannot be assumed that the strategies that have worked for Alzheimer's Australia will necessarily work for other stakeholders in the aged care sector or indeed other chronic diseases.

The commitment by the Howard Government to make dementia a National Health Commitment in the 2004 election and its implementation in the 2005 Budget represented for Alzheimer's Australia what seemed "the impossible dream" in 2000.

None of that makes us complacent in the sense that welcome though the additional funding is, it represents a small part of total health care expenditure on dementia and there remains much to do. Moreover, there is the political reality that the task is still in front of us to get the commitment to dementia as a National Health Priority renewed at the end of five years in 2009.

The decision to make dementia a National Health Priority was political. There are three main elements in achieving that outcome that I would like to talk about today:

- Firstly, the change in the culture of Alzheimer's Australia
- Secondly, building intellectual capital to make our case - the bullets of advocacy.
- Thirdly, communicating our advocacy more effectively – firing the bullets effectively at the right targets.

Culture

Let me begin with the change in the culture of Alzheimer's Australia.

At the end of the 1990s our National organisation had fallen on hard times as the result of poor governance and conflicting personalities. Member organisations recommitted in 1999 to the National body in the belief that the whole would be greater than the sum of the parts. National unity has been a prerequisite for more effective advocacy but the change in culture has been dramatic in other ways.

As an advocacy organisation we are now much more assertive, positive and focussed than at any time in the twenty five year history of the Alzheimer's family in Australia. The slogan "make dementia a National Health Priority" in itself represented a new way of thinking.

Intellectual capital

In making our case it is building intellectual capital which I believe has been the cornerstone of our achievement. Flawed as they may be the political processes can be used to win arguments and like water dripping on a stone, sound advocacy will have its day.

The publication of *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia* in May 2003 was the starting point of our advocacy to make dementia a National Health Priority. The report was commissioned from Access Economics. The independent report not only articulated the problem in terms of demography and economic impact, it also recommended dementia should be a National Health Priority.

We have since commissioned four other reports from Access Economics on a range of issues.

In addition to these reports we have published many other papers. They include *Dementia and the Built Environment*, *Legal Planning and Dementia*, *Palliative Care and Dementia*, *Dementia: Can it be Prevented?* and *Decision Making in Advance*. More recently we have started a new *Quality Dementia Care* series with the objective of promoting a wider understanding among stakeholders about what constitutes quality dementia care including for those with special needs such as people with younger onset dementia.

The brand of Alzheimer's Australia is "the dementia experts with compassion". The development of intellectual capital has been critical to our credibility and our brand. So too have the well regarded services provided through the eight member organisations of Alzheimer's Australia.

Communication

Having intellectual capital is of little use if it is not communicated effectively to decision makers and the wider community. There have been many key elements in our effort to communicate more effectively.

First, is the unity of our organisation. It is critical in the Australian context to be able to speak nationally on behalf of all people with dementia and their families and carers.

Second, is the recognition we have at the political and bureaucratic level that the views we advocate represent those of people with dementia and their carers. Self advocacy by consumers has been a critical part of our success.

It was a significant advance in 2001 when for the first time people with dementia spoke at our National Conference and since Christine Bryden and many others have powerfully advocated from the perspective of people with dementia.

Third, is the adoption of what we call an intelligent approach to lobbying. Essentially this means that we do not spring surprises on Ministers. With major reports and publications we normally give Ministers at least four weeks notice so that they can consider what we are about to say and hopefully be positive in their responses.

Fourth, is an active approach to partnering with other organisations. In particular, the support of the Australian Medical Association and the Australian Nursing Federation was I believe critical to our political advocacy since those organisations were strongly supportive of our case and have stronger relationships with Ministers. And the National Aged Care Alliance played an important and very supportive role too.

Fifth, is the establishment of a bipartisan group; the Parliamentary Friends of Dementia in the National Parliament. This group has contributed significantly to enhancing our political profile and providing Alzheimer's Australia with political advice. It was with the support of Parliamentary Friends that we held the first National Consumer Summit of people with dementia and carers at Parliament House for two days. This was a landmark occasion in promoting awareness of dementia and in the articulation by consumers of the action needed by government in implementing dementia as a National Health Priority.

Sixth, is having a champion. The disclosure by Hazel Hawke, the former wife of Prime Minister Bob Hawke was critically important in promoting awareness of dementia. Sadly in Australia disclosure by eminent people in public life of their diagnosis is rare.

Seven, is having the confidence to handle the media and to do our own media work and a good national web site to back that effort up. We do not use public relations agencies now although we did with some success (and considerable expense) in launching the May 2003 Report I have told you about. A great deal of care is taken to ensure that the Executive summaries of key reports and papers are well written and easily translated into media releases.

It is important too to recognise that it is not just the National Executive Director who is out in the market place but the Executive Directors of our state and territory organisations and the eminent clinicians who support us. This is possible because we have agreed national positions and media releases.

The last element is the priority Alzheimer's Australia has given to research in recent years. This has been important in maintaining our profile and building intellectual capital. We get asked frequently by the media for responses to the latest stories on dementia research. Research has provided the basis for our

Mind Your Mind public education program which addresses the ways in which people may potentially be able to reduce their risk of dementia.

Lessons Learnt

Many of you have at least as much experience as I in advocacy and national lobbying. But if I may, there are a few observations that I would like to leave you with.

Firstly, it is important to present a unified position on the issues that you wish to pursue as an industry. From my perspective, it is certainly true that aged care service providers work together more closely than they did in the 1980s and early 90s when I worked within the Department of Health. But from the perspective of a consumer organisation, it seems to me that the industry voice can appear to be too fragmented and mitigate against achieving the optimal result.

In saying that I recognise the range of different interests in the aged care sector, for example, between for the private and charitable sectors, residential and community interests, rural and urban. I should add too that ACSA, CHA and ANHECA were of course founding members of the National Aged Care Alliance

Secondly, service providers have many important arguments to make in terms of quality of care and the funding necessary to achieve it. As a consumer organisation, Alzheimer's Australia is generally supportive of both aged care staff and service providers in their important work. But to return to my theme of intellectual capital, it is not easy for those of us outside the industry to understand what the concerns of the industry are in any depth or comprehensive way.

In part that may be due to the complexity of the aged care system. However, if we are to support the resource needs of the industry we need to have the clearly-presented facts about, for example, funding whether in relation to capital or recurrent needs.

Thirdly, the industry is probably perceived as economically focused. It does seem to me that the industry might well talk more about its consumer focus and more often lead with concerns about care and the problems it faces in achieving balanced outcomes for consumers, staff and management. There is no reason why the spokespeople on any particular issue should always be the management or Presidents of organisations. I understand that ACSA in the national and state launches of its federal Election Campaign is involving residents and family members and it is clearly a positive strategy to ask those who benefit from your services to help you to present your case if the issue warrants.

We know that the media is interested mainly in bad news when it comes to residential aged care services. This can be difficult for staff as well as for

consumers. Building your intellectual capital and strengthening your partnerships with consumers will help to put these difficulties into perspective.

Fourthly, nothing combines passion with purpose better than demonstrating new ways to provide better care. The work done by Mike Rungie in the 1980s on community options, the advances made by the industry in domestic residential design and the work done by Helping Hand in demonstrating ageing in place are testimony to that. It is a wonderful way to influence visiting Ministers and bureaucrats that the industry is dynamic and focused on care and the consumer.

Lastly, we have good relationships with the industry. I value greatly the support I get from Greg Mundy, Rod Young, Richard Gray and Pat Sparrow and many others. Sometimes I feel the assistance is all one way. The industry could seek more support from consumer organisations, like Alzheimer's Australia, in the arguments it is developing and running.

Conclusion

As I observed at the outset, the decision to make dementia a National Health Priority was political. Nonetheless, in all that we do we try to take along with us both the political and the bureaucratic level as well as our partners in the aged care sector. I suppose the question for the industry is whether they are satisfied that there is sufficient awareness and real understanding at the political, bureaucratic and community levels of the work of the sector and the issues it faces. As a more interested outsider I suspect there is a fair way to go in terms of making your bullets and delivering them.