



NCOSS Conference Paper

Advocacy! 12 March 2003

**Preserving your independence
(while maintaining your income)**
Lew is Kaplan, Alzheimers Australia NSW



© L. Kaplan 2003

Council of Social Service of NSW (NCOSS)
ph: 02 9211 2599 f: 02 9281 1968 e: info@ncoss.org.au
w: www.ncoss.org.au m: 66 Albi on St, Surry Hills NSW 2010, Australia

Alzheimer's Australia is a very rapidly growing community-based charitable organisation. Its funding in New South Wales comes from Federal government, State government, a medium size membership and from fundraising efforts. Last year around 50% of our income was generated from our own fundraising efforts.

I will address our corporate support from the pharmaceutical industry in the first part of my presentation. I will follow this with a brief analysis of our position within the aged care sector as a consumer advocate.

We have important corporate allies in the pharmaceutical industry. There are three companies which have medications for Alzheimer's disease registered with the Therapeutic Goods Administration and also listed on the Pharmaceutical Benefits Schedule (PBS).

These three companies: Pfizer, Novartis, and Janssen-Cilag play an active role in promoting both their medications and our organisation.

We have a strong relationship with them, regular meetings and an annual round of sponsorship negotiations with two of the three companies. Typically we are able to promote our own priorities for financial support. It is clear that, on occasions, joint activities are in the interests of both our organisations. A solid example of this was the lobbying we engaged in to have these medications listed on the PBS. We only received direct financial support from one company for this initiative on one occasion when half page advertisements were placed in our name in all major daily newspapers around Australia on 21 September 1999. We were also offered media training by one of the companies as a way of improving our effectiveness as advocates for our constituency.

Subsequently we have realised that it is in both our interests to have a slightly more *arms' length* relationship around specific lobbying questions, so we are now, for example, in receipt of financial support for a detailed submission on dementia as a national research priority. This issue works both ways as there is no particular interest for the industry to diminish our independence and therefore credibility.

It seems to be clear to the pharmaceutical companies that a strong Alzheimer's organisation structure in any respect will assist the companies efforts to market their products albeit indirectly. There are, however, a number of direct connections. Recently Alzheimer's Australia was invited to participate in GP training programs conducted by Pfizer around Australia's capital cities. This gave us the opportunity to increase the level of consumer participation, to promote our products, services and information to a difficult to reach target audience (GPs) (and to have a very nice dinner in the process).

We also work closely with Medicines Australia, the former Australian Pharmaceutical Manufacturers Association, the peak body for the pharmaceutical industry. In many respects this is an easier relationship for us as there is no overt interference or appearance of interference when working via a peak body.

I would like to stress that pharmaceutical sponsorship represents a small part of total funding (\$300,000 out of \$15m) - the amounts although small are important as it is difficult to get money for policy and advocacy work from government.

Some years ago we were approached by a complementary therapy company which wanted to use our name and logo as a *de facto* endorsement of a particular product which may have helped people with Alzheimer's disease.

Our position was that we were happy to accept sponsorship from the company, but not from the particular produce/brand, as the implication of an endorsement was too strong. The question of what we would do if a particular product or medication was fully proven to be a very effective treatment for dementia has not yet arisen. It would, however, be unlikely that we would not promote such a product heavily as our vision statement includes the desire for a dementia free society.

The understanding on both sides of the need to maintain independence has been clarified on a number of occasions. We have developed a policy in this regard which is attached and pharmaceutical companies are very aware that part of our strength lies in our credibility as an independent body not as a *lackey* of the industry.

We insist on unrestricted grants with an indication there has been no direction of the project by the particular company.

We are always transparent in our accounts and publicly about sponsorships.

Interestingly most State Alzheimer's organisations are more heavily government supported than is New South Wales. As a result there is a tendency to be less vociferous in our advocacy than may be the case in a less heavily government funded organisation. It may be considered that our effective advocacy has resulted in additional government funding to our organisation to provide a broader range of services to our constituency. These services now take up a substantial amount of our time and effort.

Does this create less space for advocacy? Government does not seek to influence our priorities but we are required to let them know (i.e. in our National CSSS grant) when there will be media interest – which we do anyway as it is good politics.

While Alzheimer's Australia NSW has around 3,000 members, in fact we speak for a NSW constituency of around 55,000 people with dementia and as many carers. There is an even greater number of people with mild cognitive impairment, many of whom will go on to develop dementia over the next few years.

Our advocacy role has waxed and waned, depending upon the perceived significance of the issue. We certainly have a number of very vocal supporters among our membership who are very ready and willing to write to their local Members of Parliament to support policy positions we adopt on their behalf.

Where our advocacy has been relatively less successful is in the residential care arena. Given the \$4billion aged care budget and the fact that 60-80% of people in nursing homes have dementia, aged care is a core issue for our constituency and we play a very active role in advocating on government committees and through the National and NSW Aged Care Alliance.

I would like to describe an advocacy triangle with the government in one corner, the industry in the second and consumers in the third corner. There are occasions when government and consumers side against the industry. There are other occasions when industry and consumers side against the government. Sometimes it seems as though the status quo from the consumers' perspective is that government and industry are permanently sided against the consumer. Of course all parties would deny this, but being a person with advanced dementia, living in a nursing home, with a frail elderly carer (or no carer at all) is a very poor position from which to bargain or advocate.

However, we are not in a position to call our constituents out on strike. Nor are most of our constituents in a position to provide strong local advocacy. Fear of victimisation is still very prevalent. Many people are also grateful for the little they do receive rather than being angry for what they do not receive. While our constituents will always be among society's most vulnerable people, we are never going to generate adequate to ensure their rights are met with quality services and support on every occasion. We must use what resources we can muster to maximise our voice on their behalf.

It is clear that the Aged Care Industry is having a hard time under the constraints of the Commonwealth government's funding and accreditation regime, world-wide nursing shortages are having a negative impact on quality and quantity of care. There is nonetheless cause for some optimism if over-subscription to new aged care places released annually by the Commonwealth are to be accepted as long-term indicators of the industry's buoyancy. This optimism needs to be balanced by our view that much remains to be achieved to ensure quality dementia care for our constituents regardless of their residential arrangements. Nursing homes and hostels (now all "aged care homes") cater for about half our constituency. 60 – 80% of nursing home residents and 30 – 50% of hostel residents have dementia. Dementia is thus mainstream business for the aged care industry. Our position that all aged care home staff should have training and skills in dementia care has not yet resulted in a legislated position or an industry standard, but our continued advocacy will aim to raise the standard of care through empowering carers, through establishing quality criteria and through on-going lobbying of government and industry.

Lewis Kaplan
6/3/3