

# **ALZHEIMER'S AUSTRALIA NATIONAL CONFERENCE PERTH 2007**

## **THE FUTURE – IMPOSSIBLE DREAMS**

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### **Introduction**

The one question that I am asked most frequently – apart from the difference between dementia and Alzheimer's disease – is how it came about that dementia was made a National Health Priority.

In response, I point to the three elements that gave the necessary impetus to drive an historic shift in government agendas and priorities:

- Firstly, the change of culture within Alzheimer's Australia. We have become a more unified, positive and assertive organisation.
- Secondly, the establishment of intellectual capital on which to base our arguments.
- Thirdly, the many different strategies employed to effectively communicate our advocacy.

A different answer is that the glue that welded passion and purpose was a dream. In 2000 our 'impossible dream' was to gain dementia the National prominence it merited alongside the other chronic diseases that had been identified and targeted as National Health Priorities. A dream we could all share while having our views about what it meant.

The theme of this conference is about passion and purpose and the journey of dementia, and with your indulgence what I want to do is to capture the 'impossible dreams' that I believe will be instrumental in carrying forward our passion and purpose over the next few years. In doing so, I will point to the building blocks that may be the beginnings of their foundations.

### **A Society that Values People with Dementia**

The starting point is to achieve the dream of a society that values people with dementia. Together, we have come a long way in recent years in getting the dementia skeleton out of the closet. But that does not make the person with dementia welcome at every table.

I was listening to a talkback program on ABC that discussed the recently released book by Tom Valenta, "Who am I Mrs V?" The core concern of many callers was that people with dementia had been devalued from the point of diagnosis. Consumers told stories that illustrated all too well how doctors had lost interest in the person, how it had become more difficult to access rehabilitation and services and how friends and relatives had become more distant.

In short, there was not only the trauma of the diagnosis of dementia to cope with; there was also often a denial of services and social isolation.

Life does not stop with the diagnosis of dementia for the person or for their families and friends, even if life can never be quite the same – as Andrew Watt’s powerfully related in his presentation. After a century of denial and stigma, there can be no quick way to change societal attitudes, although the interest and hope that springs from advances in research does and will help. Stigma is reduced when there is understanding and there is hope of remedies for what ails us. The first Alzheimer medications are of limited effectiveness but they have arguably created a more positive climate for the care and treatment of Alzheimer’s disease.

To accelerate community change in attitudes we need a much greater investment in awareness and education to promote greater understanding of dementia and awareness that there are people and services available to help us cope.

### **A World where all Doctors Understand Dementia**

Secondly, we should aspire to a world where all doctors understand dementia and its management – and as those in the consumer workshop yesterday argued refer their patients to Alzheimer’s Australia or other organisations. Fear and uncertainty inevitably surround the diagnosis of a terrible condition such as dementia. Nonetheless, it is clear from the stories that people with dementia and carers so bravely tell about their own experiences, that one issue that can contribute most positively or negatively to their journey is how diagnosis occurs.

Those consumers fortunate enough to have well-informed and empathetic GPs, with reasonable access to specialists or memory clinics, can tell about the relief of getting a diagnosis and the positives of starting the journey with good information about where to go for support and help, including medications where appropriate.

Those who started their journey with doctors who had little or no understanding of, or empathy with dementia, or those who lived in areas where access to specialists or memory clinics was difficult or non-existent had a totally different experience.

In recent months, the Department of Health and Ageing has responded to our requests for broad consultation with consumers on these issues. These consultations will complement another consultancy which is looking at the views of doctors and practice staff on these issues.

Greater medical education and training, the right Medicare incentives, access to budgets to support and educate allied health services and better access to specialists. These are some of the building blocks to achieve the ‘impossible dream’ of a medical profession with a better understanding of dementia.

## **A World with Consumer Choice**

Thirdly, let us imagine a world with consumer choice.

The reforms in aged care since the mid 1980s have been founded on the proposition that people want to live for as long as possible in their own homes. The policy response has been founded on consumers having choice primarily through available community services.

Governments have built on this policy response in important ways. The range of community services has been expanded, with more varied - and sometimes dementia-specific - services being available. Community care packages and community options approaches have provided greater choice to consumers. This has coincided with greater access to the Carer's Allowance and other carer support.

We have heard some consumers say at this conference how supportive and valuable the agency services are that they receive. However, the experiences of others suggest that all too often consumers are unable to access the services they need, when they need them and delivered in the way they need them. The experiences of people from CALD communities, Indigenous communities and people with younger onset dementia are frequently even more unsatisfactory.

Remember too that access to services is not an entitlement; rather access to services is rationed within available program budget limits.

The work being done on the Review of Commonwealth Funded Community Aged Care Programs provides opportunities to resolve important issues. These include, for example, the gap in resources between low and high care packages, the range of service types, a flexible funding model for community care, the level of resources available, the number of high care dementia packages and the need for flexible respite care.

One way of opening up this very difficult debate might be to give those consumers that want it the choice of cash, voucher or pre-set budget to determine for themselves what combination of services they need and will use. With that in mind, Alzheimer's Australia is holding seminars across Australia later this month and in July on overseas experience in this area and how it might relate to the Australian context. In many states and territories these seminars are being held jointly with peak service bodies. Details of the seminars are on our web site together with a discussion paper.

Not all people with dementia or their carers will want to take on this type of responsibility, but if even a small minority do, the experience will contribute to a better understanding of the services consumers would access given real choice. And consumers need to have a louder voice in the debate about service delivery.

## **A World without Dementia**

Lastly, a world without dementia. If changing community attitudes lies partly in sharing positive messages and stories, then clearly research into the causes, prevention, treatment and care of people with dementia holds out the ultimate promise of a world in which the human and economic cost of dementia can be diminished.

Alzheimer's Australia's *Mind your Mind* program and the evidence about the potential for populations to reduce their risk of dementia are good illustrations of how we can all respond to positive approaches and the opportunity to be able to do something for ourselves.

Australia has made a great contribution to dementia research through the work of people like Professor Colin Masters, Professor Tony Jorm and Professor Henry Brodaty. I can only speculate on what Australia could achieve as a country if past expenditure on research had represented more than some 0.3% of the direct and indirect cost of dementia. As a consequence of dementia becoming a National Health Priority, there has been recently a greater investment in dementia research. The recent Federal Budget saw resources going to much needed infrastructure for neurological research.

With current advances in dementia research and hope of breakthroughs in the coming years, investment in targeted quality research will produce real dividends in terms of better identification and management of dementia and its causes. This is the 'impossible dream' that is most reachable with greater investment now. As Samuel Johnson said: "The future is purchased by the present". For many years to come though we will need high quality dementia care services.

## **Conclusion**

In conclusion, I feel some optimism that the beginnings of foundations are there to build upon. The Dementia Manifesto that has been developed by the National Consumers Committee of Alzheimer's Australia and discussed at the Workshop yesterday, articulates what consumer priorities are in the next 3 years. Our capacity to build the foundations for our dreams will be increased if we provide the National Consumer's Committee of Alzheimer's Australia and the consumer groups at the state and territory level with the resources they need to do their work and self-advocate.

We do not know what other challenges will be in store for us in the next few years as the population affected by dementia grows. We do not know what will be the impact of diabetes among the baby boomers or, more positively, their interest in healthier lifestyles.

As I suggested at the outset, our passion and our purpose on the journey with dementia can be built upon if we are able to articulate our impossible dreams

in the form of seemingly simple ideas. And before we get too complacent that dementia has been made a National Health Priority, let's reflect on what we have to do to persuade the next Australian government to renew that commitment and provide additional resources when the current program terminates in 2009.

I will leave you with some quotes which capture I think the spirit of this Conference and what I have tried to convey

***We cannot work to create a future which we do not first imagine***  
**Dr Peter Ellyard**

**"The future belongs to those who believe in the beauty of their dreams."**  
**~ *Eleanor Roosevelt***

**"Dreams are the touchstones of our character."**  
**~ *Henry David Thoreau***

**"Dream your dreams with open eyes and make them come true."**  
**~ *T. E. Lawrence***

***It's kind of fun to do the impossible.***  
**Walt Disney**

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