

## **SPEAKING NOTES FOR RESEARCH FORUM**

The vision statement of Alzheimer's Australia gives equal priority to services and research. Over the last four years we have sought to aspire to that vision but the reality remains somewhat different.

The larger part of our resources is for contracted service delivery. But the awareness, advocacy and policy work of the National Office is split about equally between services and research. Our National Office is small – 6 staff currently of whom one has a neuroscience background.

I will tell you briefly what we have done and what we plan to do.

I believe we have been entrepreneurial and energetic in the last four years in supporting Australian dementia research. Our roles fall into three main areas – knowledge, advocacy and partnerships with researchers.

### **Knowledge**

We have made information on dementia research more accessible by:

- Disseminating information on clinical trials and the latest developments in research through our web-site, publications and newsletters.
- We now have a more rapid response to media stories but regrettably seldom get stories in advance of the media. Maybe some of you can help with that.
- Promoting awareness of both dementia and dementia research through our biennial conference, Dementia Awareness Month, seminars by distinguished researchers and visits by eminent speakers such as Zaven Khachaturian. We plan to have another eminent overseas speaker next year.
- We have started to map Australian dementia research and expect to access funds shortly that will enable us to do this in a much more effective way over the next few years.
- Research will be included on the agenda of the National Consumer Summit at Parliament House in October.

### **Advocacy**

Perhaps our most important role is to advocate for increased investment in research on the basis of social and economic analysis.

- The report we commissioned from Access Economics in 2003 'The Dementia Epidemic Economic Impact and Positive Solutions for Australia' set the scene for advocacy for dementia to be a national health priority. An important part of our advocacy for National Health Priority status was to promote dementia research. I should acknowledge the part played by Tony Jorm in providing the intellectual framework within which to frame that report.
- Successive Reports from Access have been used to reinforce our advocacy.

### **Partnerships with researchers**

We have had more support from researchers than I can acknowledge today

- This has happened through speaker programs, conferences and advice on media stories.
- In the last two years we have been assisted by two virtual groups of scientists to produce valuable documents: Dementia Research: A Vision for Australia and shortly we will release Dementia: Can it be Prevented?
- For our part we can and are playing a greater role in raising money for research. The Heart Foundation and the Cancer Council have shown what is possible. In the last few years the size of our Research fund has doubled to

over \$1.5 million. And with our awareness activities planned over the next 12 months I can see that being a continuing trend.

- Through Alzheimer's Australia Research, annual research grants and scholarships are provided. These funds aim to fill gaps in other funding mechanisms and in particular by focussing on emerging researchers.

These activities are important and need to be done with more intensity. However, to achieve more, we need to reflect on how far we can and should influence the determination of research priorities and the funding models adopted for dementia research.

### **Priorities**

I believe consumers and their organisations can only be credible in assisting in setting priorities if they are partners in research - although we have to be realistic about the extent of that influence for a number of reasons.

Research is dynamic and moves quickly and so do priorities. Consumers are not positioned to debate the relative merits of beta-amyloid and tau hypothesis. Nor are we well positioned to have a perspective on the linkages between dementia and other areas of research including other chronic diseases, epidemiology and ageing research.

However, there are areas of research where consumers can make a valuable contribution, such as the area of dementia care. We have started helping some researchers access funds for the purpose of validating assessment instruments for CALD communities and also for Indigenous People in rural and remote communities. We are a junior partner in a recent initiative funded by NHMRC and conducted by Professor Dimity Pond to investigate patient outcomes from a randomised controlled trial of the systematic approach to diagnosis and management of dementia.

We are doing our first consultancy for the Department on models of dementia care and best practice in the context of developing the new EACH dementia specific packages.

All of this is consistent with our concern that dementia care is the poor cousin in the under funded area of dementia research. By being partners in research, we can both address research priority concerns and actually make a contribution to an important area of research activity.

### **Funding**

In the next 12 months I should like Alzheimer's Australia to have a much clearer view about models for funding research. We currently have our first joint partnership in place with NHMRC and are exploring the possibility of joint fellowship with a university. The funding available for Ageing Well ageing Productively also presents new opportunities for partnership. Through this kind of involvement we will better understand the byzantine world of research funding and how we should connect with it.

I should like consumers to have a framework within which to think about:

- A sustainable funding system. Evidently we need a commitment which goes beyond the five years of dementia as a National Health Priority. The need is self evident in terms of security for researchers and because of the increasing numbers of people who will develop dementia later this century, if we do not take the small window of opportunity we have now.
- The balance between new research and the application of research findings – a balance the National Institute of Ageing is changing in setting their priorities.
- Multi - disciplinary approaches that recognise the linkage between areas of research.

- Collaborative models in research promoting co-operation between researchers, data sharing and outcomes. In this we may be able to learn from the National Institute of Health in the USA.
- The merits or otherwise of centres of excellence as a mechanism of research funding and critical masses of researchers examining issues around basic research or care issues.
- Strengthening the translation from clinical research into clinical practice.

### **Conclusion**

I believe that what we have achieved to date will encourage us to be both more active in advocating for research and being a part of dementia research. There are new opportunities every day and it will be up to us to take advantage of them and build a much greater investment in dementia research.

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