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DEMENTIA – FACING THE HARD ISSUES

QUALITY IN DEMENTIA CARE: AN ALZHEIMER'S AUSTRALIA PERSPECTIVE

GLENN REES, NATIONAL EXECUTIVE DIRECTOR,
ALZHEIMER'S AUSTRALIA

We have been asked to focus on what is quality dementia care, evaluation of dementia care and policy.

Dementia Quality Care

Last year Alzheimer's Australia produced a position paper "Quality Dementia Care" which is based on the experience of our 400 staff across Australia. Copies are available at this Conference.

Our position on Quality Dementia Care is that there is no one size fits all approach and that a person centred approach is needed. Every individual is different and the causes of dementia are multiple.

A person centred approach requires three main elements.

Firstly that the provision of quality care should be based on a number of core principles including:

- Valuing the worth of every person
- Relating to the person rather than the illness
- Maximising autonomy, independence and participation
- Responding to the needs of the whole person

- Providing an environment and experiences that are enriching and meaningful
- Recognising the importance of working in partnership with family and friends of the person with dementia

Secondly, that the care environment has the following characteristics:

- A commitment to personalised care at all levels of the care organisation
- Leadership by senior care managers that promotes ownership of the core principles
- Knowledgeable staff who are encouraged to be positive, creative and flexible
- A well designed built environment

Thirdly, the adoption of best practice in key areas including:

- An accurate and detailed assessment of each person with dementia
- Careful staff selection, training and education
- Individualised care based on a knowledge of the cultural, historical, social and family background of the person in care
- Access to specialised services such as dental, speech pathology, etc
- Activities similar to those the person would experience in the community
- An emphasis on good communication both verbal and non verbal between staff and people with dementia

I encourage you to read our position paper.

Evaluation

I have two suggestions in respect of the evaluation of quality dementia care.

First, Alzheimer's Australia believes that Dementia Care Mapping, which is grounded in a person centred approach, should be adopted as the preferred

means of evaluation in Australia. In doing so we would be joining other countries including the United Kingdom, USA, Denmark, Germany, Switzerland, Spain and Japan. In the UK and Denmark, DCM is used at a policy and regulatory level to monitor care practice and life quality for people with dementia.

By evaluation I include both evaluation in terms of the purpose for which DCM was originally intended – to improve the standards of person centred care by a repeated cycle of developmental evaluations –and the development of DCM as a research tool. There are of course challenges not least in ensuring that DCM develops a coherent structure and usage as a research tool. These are issues that those responsible within the DCM family and Bradford in particular are conscious of and working on. The Bradford site has an intriguing menu of research projects using DCM.

Second, we should also seek to use approaches using clinical tools to do systematic investigations of dementia care in community and residential settings. There are few such studies but the evaluation of Alzheimer's Australia Living with Memory Loss Program by Dr Michael Bird and Dr Tanya Caldwell is an example I hope of the future. In the interim report Dr Bird has reported that there was positive movement on all validated outcome measures. For the person with dementia there was a significant decline in symptoms of depression. For carers/supporters, there was a significant decline in stress caused by behaviour they found difficult before the group started, and a significant increase in the proportion of participants who had made plans for the future.

Again, the ACT nursing home study (Bird, Walker, McNess and Burt) is looking at the extent to which care outcomes are improved as a result of improvements in staff knowledge, emotional state and social attitudes along the lines of the work done by the Swedish group in Lund in the 1990s. Despite the fact that Australia has a number of world class dementia specific units there is little evidence as to

why stress levels and clinical outcomes are superior in some homes as compared with others. The concept of ‘nursing home culture’ remains elusive

Policy

Lastly, what could be done in policy terms to promote quality dementia care? Some priorities are I am glad to say in the Hogan Pricing Review and in the Government’s responses to it. Important catalysts for ensuring quality dementia care include:

- First, financial incentives that ensure services providers are resourced to provide care for those who may need special care. The dementia supplement to be introduced from 2006 may achieve that goal. For too long policy makers have been allowed to claim that such care can be provided within mainstream funding. The end result has been that many services providers in the words of Professor Hogan ‘have cherry picked’.
- Second, a commitment to the adoption of a minimum qualification for all aged care staff and an investment in staff through education and training. Trainers in Alzheimer’s Australia developed the Dementia Competency CHCAC15A and subsequently succeeded in having it adopted as a core competency in Certificate III Aged Care Work. There is a need too for specialist skills in dementia specific units. The emphasis on training pre and post Hogan is welcome from the point of view of Alzheimer’s Australia.
- Third, review the current planning and allocation processes for residential care. It is important that those facilities making applications for new mainstream places demonstrate a capacity to provide quality dementia care in their planning. There was a welcome move in that general direction in the planning and allocation processes last year. The planning allocations should also provide for identified dementia specific places.
- Fourth, Professor Hogan somewhat nervously embraced some thoughts about consumer directed care as part of his long-term post 2008 policy

challenges. A look at overseas experience and a few pilots in Australia would help inform a debate post Hogan.

- Lastly, the Accreditation Agency has been pre-occupied by having to accredit large numbers of services in a short time span. The end consequence as Hogan has pointed out is that the Agency is not particularly sensitive to consumer interests. Maybe the Agency should be encouraged to do some evaluations of care outcomes that go beyond the two and a half day systems kind of visit. We would warmly embrace such a partnership perhaps based on DCM.