

CONTEMPORARY COMMUNITY CARE WORKSHOP 18th June 2009, Brisbane

MAKING CHOICES

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Thank you for the invitation to speak at this workshop. I greatly value the partnership that Alzheimer's Australia has with Aged Care Services Australia at the National and State levels.

It was refreshing to see in the Interim Report ***A Healthier Future For All Australians*** from the National Health and Hospital Reform Commission earlier this year a chapter on aged care and a focus on increasing choice in aged care. Even more encouraging has been the largely positive response of national bodies interested in aged care to the directions proposed by the NHHRC.

The interest of my own organisation in increasing choice through consumer directed care started with the paper we commissioned from Anna Howe back in 2001. Subsequently, we invited Dr Jane Tilly to undertake a lecture tour in July 2007 and published ***Consumer Directed Care: A direction for Australia?***

In thinking about quality dementia care and aged care more generally the focus has been on person centred care. Alzheimer's Australia has taken the view that the quality of dementia care is likely to be high if:

- It is driven by a person centred care approach.
- A partnership between service providers, the person with dementia and the family carer.
- A service environment characterised by strong leadership.
- The adoption of best care practices.

Some of you may have heard Dr Dawn Booker speak at the Alzheimer's Australia National Conference in Adelaide a few weeks ago on ***Person Centred Care: Are You Serious?*** She made the point that it has been over twenty years since the late Professor Tom Kitwood first used the term person centred approaches in relation to long term care for people with dementia. She asked "Are we any closer now to achieving this vision than we were then?"

As usual, Dawn gave a wonderful and passionate presentation on the importance of person centred care, the values that underpin the approach and what the implications are for service delivery. She suggested that we are still struggling to achieve the vision that person centred care holds out.

Possibly many of us share Dawn's concerns. Some may attribute the struggle to lack of funding and staffing resources. Others might say that the need is still for a change in culture and more staff who have the commitment and passion for providing person centred care. Others might say the need is for stronger organisational leadership.

I think a fascinating question in this debate is whether person centred care is truly achievable without empowering the consumer. What we are lacking perhaps is the demand side of the equation if more flexible services are to be the norm in response to the goals of consumers.

It would be naïve to think about consumer sovereignty in terms of market forces in the commonly accepted sense. However, it is possible that person centred care will be more likely to eventuate if there is a more equal relationship between the service provider and the consumer in the form of the consumer having a greater say in the services to be provided. We need a more informed consumer driver.

The two reports I will talk about today – the report commissioned from Access Economics, ***Making Choices: Future Dementia Care*** and ***Respite Care for People Living With Dementia: “It is more than just a short break”*** – raise important issues about choice and how dementia services are delivered.

So let me turn to:

- Firstly, the ***Making Choices*** report and its major findings.
- Secondly, the ***Respite Care*** report and what it has to say in respect of carers being unable to access the kinds of respite care they need.
- Thirdly, to the policy implications of those two reports.

Making Choices: Future Dementia Care

In commissioning the report, we had two main objectives.

Firstly, we wanted to translate the dementia epidemic into the reality of 2030. Policy makers and politicians have become familiar with the fact that the number of Australians with dementia will double from 230,000 today to 460,000 by 2030 unless better medical interventions are found to delay the onset of dementia. But what does this mean in terms of services?

Secondly, to provide evidence on the choices family carers they would make when faced with different packages of community and residential care.

The total value of care provided to people with dementia is estimated in the report at between \$4.8 billion and \$10.9 billion in 2008. ().

The difference in the figures is largely accounted for by the way that the cost of family carers is calculated. Namely, whether the cost of replacing a family carer (the higher figure) or, the lost productivity borne by individuals, business and Government (the lower figure) is used.

The report concludes that as a consequence of growth of the number of people who have dementia there will be a rapid growth in the demand for care services and workforce care needs. The modelling in the report suggests that in the absence of any policy or other change, by 2029:

- There will be a shortage of nearly 59,000 full-time equivalent (FTE) paid dementia care staff (70% of the current workforce).
- Of these paid staff, 91% work in high care residential aged care facilities with the remainder providing various forms of dementia community care.
- There will be a shortage of over 94,000 FTE family carers (80% of the current unpaid dementia family carer workforce).

In summary, this is a shortage of over 150,000 FTE carers for people with dementia in 2029, relative to 2008.

From this, it is clear that on the current policy settings, the major supply constraints are in relation to unpaid carers and paid staff in high care residential aged care facilities. And scenarios that involve fewer family carers will place more demands on residential care.

The choice modelling survey undertaken by Access Economics differs from other types of surveys in that respondents are not asked directly what attributes they value. Instead, the value placed on each attribute is implicitly revealed by observing the choices that respondents make between different scenarios.

For community care the outcome of the choice survey was that:

- Home support services (such as shopping, transport and cleaning) were valued by family carers highest; the increase in demand for a care option with home support twice a week compared to one with no home support was around 55%.
- Respite services available daily and for extended periods of time were also valued highly; a care option including this attribute would have 48% higher demand than one that did not include regular respite.

This figure shows that home support and respite occupied the top five spaces in terms of ranking community care attributes.

In residential care, the outcome of the choice survey was that:

- A private room and bathroom were most highly valued with over 50% higher demand than an option without these facilities.
- Skilled residential aged care workers specialising in providing dementia care was next most highly valued with 46% higher demand compared to minimum legal standards of care.

There are a number of important recommendations in ***Making Choices*** but the main ones relate to:

- Expanding the availability of community and residential care services for people with dementia.
- Increasing access to information to enable people with dementia and their carers to make informed choices about their care.
- Improving work force training to increase the skilled paid and informed dementia care workforce.
- Assisting carers to balance their work and caring responsibilities including access to long day care respite care and greater workforce flexibility.
- Increase investment in dementia research - whether cause, cure or care – as assisting the key strategy for addressing the dementia epidemic.

Respite Care

The report, ***Respite Care for People Living With Dementia: “It is more than just a short break”*** compliments the information from the choice survey.

It demonstrates that carers of people with dementia are more likely than other carers to need and use respite. Compared with all carers, dementia carers are:

- About half as likely to say that they have no need and have not used respite.
- 50% more likely to need and have used respite; and,
- More than ten times more likely to say they need respite but have not used it.

The evidence in the paper suggests that the take up of existing forms of respite by people with dementia is markedly less than optimal. In other words, the report tells us that many carers are unable to access the kinds of respite they need, when they need it, or are reluctant to use the services that are available.

On the basis of the analysis in the report, more than a quarter of people who care for someone with dementia need respite care but don't receive it.

The report also highlights the need to change from the notion of respite care from being more than just a “short break” for the carer. There is a need too, for respite care that provides the opportunity for the person with dementia to continue with their lives and engage in society.

The respite paper, which reflects the views of the Alzheimer's Australia National Consumer Committee – a committee of people with dementia and carers - makes two main recommendations aimed at making services more flexible and more responsive to the needs of people living with dementia.

First, a redirection of funds that are available for, but not spent on, residential respite care to the National Respite for Carers Program to purchase other respite options.

Second, to fund a trial of consumer-directed respite care in which clients and carers have more say in the choice of respite care they want and how it is provided.

The report recommends a number of other ways of enhancing the access of people living with dementia to respite care:

- Expanded care education to ensure that carers understand the value of respite and access it early.
- Establish priority for dementia respite services in the funding of new respite services.
- Take steps to ensure the quality of dementia respite care by the development of standards through the Aged Care Standards and Accreditation Agency.
- Recognise the special needs of younger people with dementia for respite services.
- Undertake an audit of respite care to better establish what kinds of services are most often used by people with dementia and their family carers.

Policy Implications

The 2010 budget is a critical one for people living with dementia. It is the point at which the Federal Government will take stock of what has been achieved through the Dementia Initiative – Making Dementia a National Health Priority and its funding of \$320 million over five years.

Both major parties are committed to continuing the funding of the Dementia Initiative. We have not yet seen the evaluation of the Dementia Initiative commissioned by the Federal Government. However, there is no reason to doubt the effectiveness of the major elements including Extended Aged Care at Home (Dementia) packages, training initiatives, research grants and the National Dementia Support Program administered by Alzheimer's Australia.

The vision for 2010 and beyond should be to build a world class dementia care system that:

- Promotes access to quality dementia care for Australians of all ages and cultures regardless of where they live.
- Reduces the new cases of people with dementia in the future.

The major challenge is to achieve a public health policy that reflects dementia as a health priority and not just as an issue for aged care.

Building on the policy recommendations made in the ***Making Choices*** and ***Respite*** reports and the views of our National Consumer Committee we are identifying priorities for 2010 and beyond within the following framework for national action::

1. A major investment in health infrastructure, including prevention measures.
2. Measures to promote quality dementia care.
3. Measures to improve access to dementia services.

Health Infrastructure

The potential for reducing the incidence, prevalence and disability burden of dementia in the longer term is dependant on research. Investment in dementia research has increased in recent years, in part as a consequence of the Dementia Initiative.

The available evidence suggests dementia research is under resourced in comparison to other chronic diseases. Indeed, because dementia is not regarded as preventable in the same way as say cancer and diabetes it is not clear that dementia is regarded as a chronic disease by the Commonwealth Department of Health and Ageing. Yet there are huge potential savings from investment in research through delay in the onset and progression of dementia. An increase in dementia research to 1% of the direct health care cost, or about \$50 million per annum would be a more reasonable investment.

In 2009-10 the Minister for Ageing has agreed to provide some funding that will enable Alzheimer's Australia to continue the roll out of **Mind Your Mind**® and promote greater awareness of risk reduction. We must continue to insist that public health policy embrace dementia risk reduction as willingly it does preventative action in respect of the other chronic diseases.

We need an investment in the primary care system that results in quality diagnosis and early intervention. Of all the issues over the years that are raised by consumers, concerns about delays in accurate diagnosis, the way it is communicated and the failure to refer to support services continue to be among the key concerns.

We need incentives for doctors that encourage them to spend more time with people with dementia and their carers; incentives that result in better training and education and measures that build on the developments in respect of nurse practitioners and practice nurses to promote assessment in the home. Key workers are needed to provide ongoing points of contact for people with dementia and their family carers who need assistance in finding their way through the health system.

Quality Dementia Care

There are a number of strategies that available to improve the quality of dementia care.

At the beginning of my talk I suggested that the quality of dementia care is likely to be high if it is driven by a person centred care approach. I went on to suggest the introduction of consumer directed models of care would enable consumers - if they wish - to access the services that respond to their particular needs.

I hope that the day is not far away when such models will be trialled in care packages and respite care and that those consumers, who wish to do so, are able to determine for themselves the use of their individualised budget for the services they most need and how, when and where the services are delivered.

Other important strategies for improving the quality of dementia care are:

- Building on the workforce initiatives taken under the Dementia Initiative, for example by promoting dementia specific qualifications at the certificate 4 and diploma level and improving care pathways, creating dementia champions in the workplace, promoting dementia training in key areas such as pain management and end of life issues.
- Knowledge transfer that enables researchers, consumers and service providers to collaborate in working to improve care practice based on the best research evidence. This has become an important focus of the work of the three Dementia Collaborative Research Centres. Knowledge transfer is an important part of the work of Alzheimer's Australia and in partnership with the DCRCs we are exploring new ways of developing our role.
- Better supporting carers who provide so much of the dementia care that individuals need. We know that carer education can increase take up of respite care. We know that living with memory loss programs can reduce stress and depression for both the person with dementia and the family carer. So resources are needed to expand the reach of those activities through the National Dementia Support Program administered by Alzheimer's Australia are needed.
- Action to assist carers to balance their work and caring responsibilities through greater workforce flexibility and improved access to long day respite care.

Improved Access to Dementia Services

The carers who established Alzheimer's organisations in the early 1980's had a single minded determination to promote access to dementia care. The ***Making Choices*** report suggests that around 60% of people with dementia live in the community and that some 37% of people with dementia received no formal care in 2008.

For some groups such as those with younger onset dementia, the lack of access to appropriate services, or clear responsibility between levels of Government to provide them, remains a matter for great concern.

Much of what is needed in promoting improved access to services is dependent on long overdue reform in aged care, embracing for example, graduated community care packages, the adoption of consumer directed care models and greater choice for the consumer in the mix of community and residential care that best suits their needs.

Priorities that might be included in our plan for action for achieving world-class dementia care are:

- Funding for more dementia specific community care packages.
- The planning and allocation of dementia specific residential places for those with special needs, including, for example, those with both dementia and psychiatric needs and those with younger onset dementia.
- Priority for the funding of new flexible and responsive dementia respite services that meet the needs of both the family carer and the person with dementia.
- Measures to make the acute care sector a less dangerous place for people with dementia.
- A recognition in the Government funding of Alzheimer's Australia that partnerships with CALD and Indigenous organisations need to be properly resourced if we are to achieve the objective of greater awareness of and access to services for those groups as part of mainstream program activity.

Conclusion

In the last ten years we have travelled a long road to get dementia on the political agenda. A new vision is needed to build a world class dementia care system built on a recognition that dementia impacts on every part of the health and care system. The time is right for a bold initiative to face the dementia epidemic and the 2010 Budget is that time.