

## DEMENTIA CARE CONFERENCE: THE WAY FORWARD

21-22 February 2008, Hobart.

### **All Roads Lead to the Consumer**

That was a wonderful presentation Robyn. I suspected that it would be a mistake to follow you. If there are rules about actors not appearing with children and animals, so perhaps there should be about ex-bureaucrats following family carers - particularly those who have very special communication skills.

My focus, fortunately is different - politics and policy - though, like Robyn I will be focusing on the consumer

The question I want to ask at this point in the life of a new federal Government is how do we persuade the new Government in Canberra that all roads lead to the consumer in the provision of dementia care services?

The Communique agreed at the 2005 Consumer Summit at Parliament House, the work of the Alzheimer's Australia National Consumer Committee and the Manifesto agreed by the Committee have positioned us well to identify priorities for the 2008 Budget and beyond that would improve the quality of life for people living with dementia.

Let me focus on two aspects of our strategy today.

- Firstly, to advocate for people with dementia and their family carers to at least have the option of making their own choices in respect of the care services they think they need to meet their own individual circumstances.
- Secondly, to identify - within the commitments given by the new Federal Government - the opportunities for improving the access of people with dementia to quality dementia care in the primary care, community care, residential care and acute care settings.

### **Making Choices**

Let's start out with what in our current environment may seem to be a very radical thought. Why not set the overarching objective of giving people with dementia and their family carers the option of greater independence and choice in the services they receive, thus giving them greater control over their lives? Equally, those who wish to let service agencies make choices for them should be free to exercise that option.

Why should a family carer who wants to attend church on Sunday be denied respite because the service doesn't operate at those hours, or cannot provide the hour and a half respite necessary?

If a person with dementia likes getting up early, why should the support the person needs not be available until agency staff are available later in the morning?

If a person with dementia and their family carer have set the objective of remaining in the community for as long as possible and possibly until death, why should a consumer be offered a residential care place rather than a community based high care package?

If a person from a culturally and linguistically diverse background or an Indigenous person knows of people in their family and community networks who could provide respite care, why should they not be able to ask the service agency to employ them or to broker out the service provision to a more suitable or acceptable agency?

If a person with dementia and their family carer want to plan ongoing respite on the basis of two months residential respite and two months in the community why should it not be possible?

Why should a younger person with dementia who does not want to go to a day care centre for older people not have the opportunity to access more appropriate forms of respite, for example to be accompanied to an activity of their choice?

The objective of Consumer Directed Care (CDC) is to give the person cared for and their family carers more choice and control over their care services by being able to choose which services they receive, who will deliver these services and when.

Arguably the best way of maintaining a person's independence is to allow them the option to decide what services would enable them to live as independently as possible for as long as possible in the setting of their choosing.

And with dementia there is no one size which fits all.

The principle of CDC is embodied in care approaches in many overseas countries – and it is a principle we are talking about, not a new program. The Japanese and German health financing systems are of this kind and give individuals the choice of receiving cash or service. A number of European countries, including the Netherlands and the United Kingdom have introduced the principle in their care systems. So too have a number of States in the USA.

I do not find it surprising that across these different countries with varying cultures and programs, CDC has been shown in evaluations to provide better outcomes than those which rely on mainstream agency delivered programs. And the evidence seems to be that the quality of the care provided is at least as good.

In some countries, consumers take the cash option when it is less in value than the equivalent service on offer from an agency.

Indeed, the principle of CDC is familiar in the Australian context. It is embodied in many programs for younger people with disabilities. It was the principle that inspired the development of community options in the late 1980's and still does. Let's finish the job and adopt CDC more widely in aged care programs.

Many people with dementia and their family carers may be happy with the mainstream agency services that are available. But many others are not and wish to exercise choice.

Last year Alzheimer's Australia was fortunate in being able to invite Dr Jane Tilley to Australia to promote discussion about overseas experience with consumer directed care and its possible relevance to Australia. A discussion paper that accompanied Dr Tilley's seminars and the report on the consultations are on the Alzheimer's Australia website.

The response at the consultations was overwhelmingly in support of trialling consumer directed care. The reservations expressed were primarily about whether consumers would want to accept all of the responsibility for managing the care, including the payment and employment of staff. The majority view was a preference for a stronger say in the determination in the services received, and to have an individual budget that a service agency would administer in line with the agreed plan.

There are of course, special issues that concern people with dementia and their family carers. For people with dementia who want to exercise the right of determining their future care, advance care planning is an option that will assist the family carer and others to make decisions when it is judged that the person concerned is no longer able to take decisions for themselves in respect of their care and living arrangements. Many of the programs that Dr Tilley talked about overseas provide for people with dementia to participate in CDC.

It is uncertain at this time how the new Federal Government will take forward the unfinished work commenced by the Howard Government in the reform of community care, including the Review of Subsidies and Services in Australian Government Funded Community Care Programs. But Alzheimer's Australia has made a point of arguing, that along with many other issues, consumer directed care should be considered in the reform process.

On the basis of the response from family carers, people with dementia and service providers at the seminars last year, Alzheimer's Australia has suggested that there are three options that should be trialled in Australia.

## **1. Applying CDC to Australian Government Aged Care Packages**

This is the easiest option to implement within existing programs in Australia. These programs – Community Aged Care Packages, Extended Aged Care at Home packages and Extended Aged Care at Home Dementia packages - are currently funded on the basis of a fixed subsidy paid to a service provider in respect of an approved person receiving a package of care.

CDC would allow the care recipient to inform the care package provider of the services they would like and who they would want them delivered by, all within the care recipient's "budget". The care package provider would have the responsibility to inform the care recipient of the range of services available and the cost of each service type, once the "shape" of the necessary care package has been decided on. .

The provider would then have the task of arranging these services and their payment.

This option is very close to what should constitute “good practice” in CACP and EACH provision, where the care recipient’s needs and wishes are paramount, and the task of the package provider is to facilitate the provision of the services that the client needs and wants.

Some benefits of this model include the following.

- It could work well in small rural communities and for ethnic groups, where local people or people of the same cultural background could be employed.
- It would more easily enable the employment of family members, which is currently permitted under CACPs and EACH where a formal employment agreement exists.
- It avoids the complications of the care recipient or family carer having to be an employer.
- It does not necessarily require all care recipients to have the same “budget”. Currently CACP and EACH providers “pool” the individual subsidies and allocate services according to assessed need. This arrangement could continue, with the service provider determining a client “budget” after discussion with the client and an assessment of needs. It is important that the care recipient knows in advance exactly what their “budget” is.

It would be the responsibility of the package provider to ensure that the client was informed of the whole range of available services, not just those available from the package provider.

## **2. Providing a cash option to users of respite care**

Despite increased Government funding of respite, access to flexible quality respite care continues to be a problem for family carers. Carers complain that appropriate quality respite care is rarely available where and when they need it. This is particularly the case for people from a cultural and linguistically diverse background, or people with special care needs such as dementia, and people in rural and remote areas.

Under the National Respite for Carers Program, brokerage funds could be allocated to carers to enable them to select for themselves the respite most appropriate for them. To avoid the carer having to be responsible for handling the payments, the funds could continue to be administered through Carer Respite Centres, that would also provide information on respite services available, and the funding available.

Care recipients who wished to access respite services subsidised under HACC, the National Respite for Carers Program or the Residential Aged Care Program would still be able to do so. The budget allocated to the carer/care recipient would be solely in regard to the brokerage funds.

This would not be an option that everyone would choose. However, for those who do, there would be considerable advantages in being able to obtain respite care consistent with their cultural and social background, or special care needs.

### **3. Choice between home based care and residential care**

The key decision for most frail aged people or people with dementia needing care is whether, and if so, when to receive that care in their own homes or in residential care.

Put simply the Aged Care Assessment Team would assess the individual for a level of care and the subsidy it would attract. The individual and their family carer would decide with the Team where the care would most appropriately be delivered – in a care package in the home or in residential care. For a range of reasons including the health of the carer, residential care may be the best option. But for others, remaining in the home or a retirement village may be the preferred choice.

And that is often not possible now because there are so few high care aged care packages compared to residential places.

Alzheimer's Australia would favour having a trial based on existing assessment methods, to give consumers a real choice in where they receive care. Such a trial could operate in conjunction with diversified service providers who currently offer all of these forms of care. A control group could be devised from a comparable region or regions.

### **Opportunities to Improve Dementia Services**

Let me turn to advocacy and the new Government more generally. One of the most welcome developments has been the commitment of both the major parties prior to the recent Election to extend beyond 2009 the Making Dementia a National Health Priority Initiative together with additional funding. The 2009 budget will be critical to giving effect to that promise and determining the priorities to be set for the use of any additional funding over the following five years.

Generally, the 2007 Federal Election was disappointing in that aged care issues received so little attention. While there are opportunities within the commitments given by Labor during the Election to improve access to services, it needs to be said at the outset that Alzheimer's Australia shares the serious concerns of the National Aged Care Alliance about the ongoing sustainability of the system.

Serious concerns exist, for example, in terms of the short supply of high care dementia care packages, the gap in subsidy levels between CACPs and EACH packages, the decreased purchasing power of the packages, the need for greater flexibility in the range of service types permitted, the need for greater capital funding for residential services, the inadequate arrangements for the indexation of residential aged care and community care recurrent funding and differentials between wages in the aged care sector and acute sector. The list of serious concerns is getting very long!

We have expressed the view in our recent Budget submission to the new Treasurer that, at some time during the next three years, these issues will need attention or there will be a serious deterioration in the quality of care provided to older people generally and people with dementia in particular because their prevalence in the aging population is rapidly increasing.

So looking to the other positives, what is there in the politics of the last Election and the new Government that provides some promise?

### **Primary Care**

Firstly, Labor has made a commitment to strengthen primary health services and to better care for those with chronic diseases.

Improved diagnosis and management of dementia by GPs is perhaps the most sensitive and longstanding issue for consumers. Last July, consultants reported to the Department of Health and Ageing on the Dementia Primary Care project which has the objective of improving the diagnosis, management and referral of dementia clients. The Better Outcomes in Mental Health Care Program provides a model in the incentives it provides to GPs to undertake training and to be better resourced to care for people with mental health issues.

After many years of advocacy we will be trying even harder to get dementia better supported in the primary care context so that through for example, training, increased Medicare incentives and budgets to employ practice nurses trained in dealing with people living with dementia, there is some hope of people with dementia and their families experiencing less trauma and delay in the diagnosis of the condition.

### **Community care**

Secondly, Alzheimer's Australia strongly supports the initiatives proposed by Labor in *New Directions for Older Australians* for improving the transition between hospitals and care in the community and residential care. Such programs are likely to benefit many older people with dementia assuming that the range of services necessary to cope with any changes in their condition after their hospitalisation, including rehabilitation, are available.

We have also argued strongly in our recent Budget submission for the Home and Community Care program to be indexed at ten percent real per annum over the next three years. This program is the cornerstone of the community care system and it is important for all people with disabilities - both young and old - to have better access to community care.

The new Government is committed to review recurrent aged care planning ratios which were originally introduced in the mid 1980s. Among the important considerations noted in *New Directions for Older Australians* was "the changing balance between high care and low care, including recognition of the expansion of community care". The review could provide an important opportunity to look at the balance of community and residential care. Community care's share of national aged care funding has not changed much since the early 1990s from its current level of

around 23%. It will be important for consumers to take an interest in this review, if in fact it takes place, as it will provide a real opportunity to provide input into the future shape of the Australian aged care system. It will also demonstrate to government the role and importance of community care.

## **Social Inclusion**

Thirdly and importantly, the commitment of Labor to social inclusion may provide an opportunity to reduce some of the disadvantage experienced by people with dementia and their families and carers. Specifically, we have included in our budget submission:

- a) A proposal that \$10 million should be provided over three years to develop services for people with younger onset dementia including appropriate day care and other respite care, and cluster accommodation in residential care facilities through existing dementia care networks and services. Alzheimer's Australia documented in a report funded by the Australian Government, *Exploring the Needs of Younger People with Dementia*, the barriers that younger people face in getting access to timely, quality and accessible services that meet their individual needs. This group faces issues that are unique and complex and a start needs to be made in shaping services that respond to their special needs.
- b) An initiative that would better position Alzheimer's Australia in partnering with people from Culturally and Linguistically Diverse backgrounds and Aboriginal and Torres Strait Islanders in promoting awareness of dementia and access to services.
- c) The establishment of a Government taskforce with resources to develop and implement in consultation with consumers the recommendations on substitute decision making in the report on *Older people and the law* of the House of Representatives Standing Committee on Legal and Constitutional Affairs. The priorities we have proposed are first to develop an education campaign to inform the Australian community of the benefits, issues and processes involved with advance planning for their health, their money and their lives; and secondly, to facilitate national consistency and mutual recognition in advance care planning, including enduring powers of attorney across the Australian jurisdictions so that the law and documentation are nationally consistent, user friendly and readily available.

## **Risk reduction**

Lastly, there has been a welcome recognition that “prevention of or delay in the onset of dementia is a valuable goal. Extending the age of onset by five years will lessen the effect of dementia on our community and on the individuals affected”.

Alzheimer's Australia has through its Mind Your Mind publications and program worked hard over the last few years to promote awareness of the lifestyle changes that may reduce the risk of dementia. We believe that the Program and the resources that are available to underpin it should be rolled out Nationally to increase public

awareness that individuals may be able to help themselves by nurturing a brain-healthy lifestyle.

### **Conclusion**

I was given my concluding line appropriately by the Chair of the Alzheimer's Australia National Consumer Committee, Ron Sinclair. Dementia care – for the people, of the people, by the people – a timely cliché given US election frenzy!