

**Caring for the future consumer conference
Opening address**

**Northside Community Forum
The Epping Club, Epping**

June 6, 2012

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I am pleased to have been asked to deliver this keynote address this morning and I want to begin by congratulating the Northside Community Forum for organising this “Caring For The Future” consumer conference. I am delighted to be a part of this important forum.

It is an excellent initiative on the part of the forum’s executive officer, Irena Liddell and her team and recognises the need for people who live in the northern Sydney region to be informed and educated about the many community care services available to them.

I want to acknowledge the valued support of the Northside community forum board, chaired by Janet Grant and the generous sponsorships of the catholic community services and independent living specialists.

There are a number of other health care organisations here today that I’d like to thank for either being involved as exhibitors, presenting workshops, panel discussions or just coming along to support the forum.

The theme for this conference ‘caring for the future’ is not only topical but one that I am passionate about. It’s one the many reasons why I decided to become National President of Alzheimer’s Australia.

I’ve been president of Alzheimer’s Australia for 16 months, having previously been a member of the advisory board of Alzheimer’s NSW for three years.

It has been a challenging – and also rewarding – 16 months.

It has included the launch of our Fight Dementia Campaign which we created to inform the Australian community about dementia and the need for action – in particular for government support and funding to help people with dementia and their carers.

At the same time we successfully rebranded our organisation; and met with politicians of all political persuasions in Canberra as well as Prime Minister Gillard – she incidentally gave me and Alzheimer’s Australia’s hard-working CEO, Glenn Rees, a most sympathetic hearing and we were able to tell her a few things about dementia that she didn’t know and was most interested to learn about. This was all part of our fight dementia campaign strategy.

I’ve also had the privilege of listening to people’s stories, some positive; some heart-breaking...many of them similar to my own story of looking after my father who lived with vascular dementia.

As dad’s principal carer I understand the effect dementia has on the individual and their families and friends. I know the tears, the laughter and the mixed emotions that are part of the dementia journey. This experience has helped me to understand and appreciate what many families go through and the stress and strain that this disease brings to family life.

My story, and the stories I’ve heard since becoming president, highlight the extent that the Australian health and aged care system is letting down people with dementia and their family carers.

I suspect many of you here today have taken the time to look at the reforms the Federal Government announced in *Living longer. Living better* in April this year.

The driving force of the reforms is one which I think we all, as consumers, support especially as the main emphasis of the reforms is greater choice, easier access to care and better quality care for all older Australians.

There is an emphasis too on wellness and ensuring that services are designed to build on the independence and strengths of the older person.

The government has made a commitment to spend \$3.7 billion over five years to reshape the aged care system.

This investment will include:

- \$1.9 billion to deliver better access to aged care services;
- \$1.2 billion over five years to tackle critical shortages in the aged care workforce;
- \$80.2 million to improve aged care linkages with the health system;
- \$54.8 million to support carers;
- \$268.4 million to tackle Australia's dementia epidemic; and
- \$192 million to support the diverse care needs of Australia's population.

At this point I sense that your eyes are glazing over; it's not easy getting your head around such vast sums of money is it?

Governments talk in terms of billions of dollars and it's difficult for any of us to fully appreciate what a major package, such as this, will mean for consumers.

Stakeholders in aged care including consumers, service providers, unions and professional organisations generally welcomed the package when it was announced.

In part I think that the reaction of the sector is a reflection of the urgency of the need for reform, and the desire of the aged care sector as a whole to get some action after many years of waiting.

But since the package was announced there has been some reassessment.

Some have suggested that the amount of "new" money is limited; that over five years the net cost of the package to the government is some \$580 million; that there will be very little new spending in the next two years.

Reflecting that concern, some service providers, particularly those in the residential care sector do not believe the package will deliver the sustainable funding they need to invest with confidence over the next ten years.

Others express some concern that although there is significant expansion in the provision of community care, it will not be enough to enable older people to have the choice to stay at home.

Now generally I do not have much sympathy for governments of any persuasion.

But it seems to me that governments get criticised when they do not put forward enough detail in a reform package. People want to know the answers.

But then, if governments provide the detail, they get roundly criticised for lack of consultation.

My general view is that it is positive to have the government committed to aged care reform and to set out, albeit at a high level, the objectives of reform and the major elements to which they are committed

But there is also a need to be realistic that this is a reform process which could take ten years in terms of changing not only the financial fundamentals of the system but also the way services are delivered.

It is frustrating that the major reforms will not be implemented until the middle of 2014, but we need to remember that pulling together a national aged care program that gives some hope for the first time of a national approach, rather than the fragmented system we have of commonwealth and state involvement, will involve a good deal of complex administration and change.

The thing that excites me is that the government has committed to a major reform process and has mapped out the key elements of the reform, and these elements match what consumers have asked for.

The next step will be for all of the stakeholders, including consumers, to engage with government in an implementation process that is transparent and leads to real changes in outcomes.

So while I think it is legitimate to have concerns about the package, I do not want to lose this opportunity for reform of a system that has been continuously patched up over the last decade or so, rather than fundamentally changed to better respond to the needs of older people.

So let me set the scene for you today by tackling three questions.

- Firstly, what have older people said about the aged care system we currently have?
- Secondly, what are the elements of the proposed reforms that we can be positive about?
- And thirdly, why does dementia have to be centre-stage in our thinking about health and aged care issues?

Older people have been unequivocal in expressing the view that the current system is not working well for older people generally or for people with dementia.

It is working even less well for people from culturally and linguistically diverse communities, indigenous people, people from rural and remote communities and for the gay and lesbian communities.

The Minister for Mental Health and Ageing, Mark Butler, gave Alzheimer's Australia the opportunity to conduct consultations with older people and people living with dementia on aged care.

We produced a report *Consumer Engagement in the Aged Care Reform Process* that showed consumers have no clear pathway on how to access services...and once consumers do find support, it is often inflexible and unable to cope with the special needs that older people and people with dementia and their carers require.

I attended the first of these consultations at Parliament House, Canberra, after the historic march on Parliament House by 500 people with dementia and their family carers last October.

It was an emotional experience for all of us. There were so many heart-rending stories of trauma and upset mainly caused as a result of people having difficulty getting support and finding their way to the support they desperately need.

It was impossible not to be moved by the stories we heard; not to marvel at the courage it must have taken for people to get up and share them with us...

For those with dementia there was a dramatic contrast between the experiences of those people who have benefited from timely diagnosis and care services and the overwhelming majority of those who were traumatised by poor diagnosis, lack of information and care services that had next to no understanding of dementia.

The message from our meetings with consumers across Australia was quite clear. People with dementia and their carers don't know where to turn to receive services and support that will actually help them.

The consultations conducted by the Council On The Ageing suggested much the same degree of failure of the aged care system to meet the needs of older people.

Minister Butler took the time to attend many of the consultations arranged by the Council On The Ageing and Alzheimer's Australia. There is no doubt he listened closely to what people said because he concluded:

“The Alzheimer's Australia report makes sober reading. It is clear from the feedback received through the conversations the issues that continue to beset the provision of care for people with dementia have not been given the prominence they deserve in the debate about the quality of aged care.

“The overwhelming view of older Australians is that the aged care system is simply not meeting the needs of dementia sufferers and their families.”

So even though we may not have accomplished all that many of us would have liked in the aged care reform package we mustn't for one moment take our foot off the accelerator and lose the opportunity we have to force change in the system.

And as we go, we can seek to press harder for those elements of the reform process that we believe need to be more ambitious.

What can we be positive about in the reform package?

The government asked the productivity commission when undertaking its inquiry into the care needs of older Australians to do so from the perspective of older people.

That in itself is a positive....over the years, too many reviews have simply concerned themselves with issues around financial sustainability rather than what it is we are trying to achieve through the provision of aged care services.

To a large degree the government's reform package has concentrated on the system changes needed to enable services to better respond to the needs of the older person.

Let's look at some of the specifics.

The reforms hold out the promise of strengthening the community care system to make it possible for older people to stay at home longer.

There will be more community packages and more funding for respite care. This is central to any strategy for consumer choice and supporting people to live at home for longer.

However, as I have said, I have some doubts about whether the growth in community services will be fast enough to meet the demands of people wanting to receive care at home.

Alzheimer's Australia has expressed very strong views about the need for respite care, in particular, to be more flexible including a trial of cashing out of respite care funding.

This would mean giving the consumer cash to spend instead of receiving a service from a provider

Cashing out would enable the older person and their carer to have greater choice in purchasing the care that would best suit their requirements as well as when and where they have the service delivered.

There are some challenging issues to work through including accountability for the funding and possible abuse which is why we need a careful study of what the benefits might be of cashing out in respect of respite.

The reforms empower consumers through adopting consumer- directed care in all care packages, an approach that will enable consumers to have more say over the services they receive, when they are provided and who delivers them.

We should not underestimate the change in attitudes required on the part of both consumers and service providers if consumer- directed care is to achieve the goal of more responsive services. If this is to be successful an active information and training program will be required for consumers and service staff.

Older people and their family carers will need to be more confident and better informed about what the options are in order to make their choices.

For their part, service providers will have to enter a new world of responding to the needs of the individual rather than pressing their particular programs of care.

The approach to the funding of aged care services will embrace the principle of supplementary funding to meet the extra costs of dementia care in both residential and community settings.

In other words, there is a long-overdue focus on dementia in the aged care reforms and recognition of the extra costs of providing dementia care.

There are measures that should help reassure consumers there will be greater transparency of the quality of care through the independent Aged Care Financing

Authority, the new Australian Aged Care Quality Agency and the My Aged website combined with the greater independence of the Aged Care Complaints Scheme.

Critical to increasing transparency in the quality of care for older people and their family carers will be work on the quality outcomes.

This is a complex and difficult area but, unless work is more highly developed on indicators of care outcomes, it will be hard if not impossible for people in the wider community to make judgements about where to access care services.

Finally, there is a plan to tackle dementia and I want to talk about this now.

In the context of aged care reforms Alzheimer's Australia has two objectives. Firstly, to ensure that dementia is centre stage in the design of the reforms and secondly, to get a government commitment to tackle dementia across both the health and aged care system and to plan for the future.

The April 20 reform package went a long way to reassuring me that our messages and those of the people that Alzheimer's Australia represents have been heard.

Importantly, the government will take a proposal to the next meeting of Commonwealth and State Health Ministers in August to make dementia a National Health Priority which, if successful – and surely it will be – means that dementia will be added to the other eight major chronic diseases including cancer and heart disease.

This is significant symbolically as well as in substance.

The symbolism is important because at long last dementia will be recognised within health policy not as an inevitable part of ageing. There is the recognition that dementia is not the sole responsibility of aged care but rather a chronic disease.

As a chronic disease dementia needs to be tackled within a public health framework that addresses the need for awareness, early diagnosis, quality services and support, preventive health and investment in research.

Health ministers will have the opportunity of putting this new framework into place as they design a replacement for the national framework for action on dementia that terminated in 2010.

The *Living Longer. Living Better* package starts this approach and includes initiatives that set the scene for health policy to respond to the needs of people with dementia.

The package includes funding for action on achieving timely diagnosis of dementia. We know that from the time of first noticing symptoms it can take three years to get a diagnosis of dementia.

These are lost years for the person with dementia and their families in planning the future particularly as most of them know, only too well, that something is wrong.

Alzheimer's Australia, together with other stakeholders, is meeting next week to discuss the barriers to timely diagnosis and the strategies necessary to overcome them.

I hope the scene is set for change and that action can be taken to achieve timely diagnosis and prompt referral to services, two things consumers have long been asking for.

The package also includes funding to improve acute care services for people with dementia.

This is imperative because both in Australia and overseas the evidence suggests that hospitals are dangerous places for people with dementia.

In part this is because people are often not recognised as having a cognitive impairment; consequently they are more liable to falls, malnutrition and delusion.

Even if someone is recognised as having dementia often hospital staff do not have the training or the time to provide the care that is required.

I know this from personal experience... It didn't take me long to find out that our health system is not designed to care for people with the dementia.

Dad was in and out of hospital in the last 12 months of his life –each time I had to explain to nursing staff the needs of someone with dementia and to ask them to make a special effort in communicating with him.

“Your father has been very difficult, quite unruly,” a nurse told me crossly. It was as if the staff assumed he was being deliberately difficult. This happened every time he was in hospital.

I had to explain that when the routine of someone with dementia is interrupted they can become confused, agitated and sometimes aggressive.

He was often cold too and again I had to explain to the nursing staff that elderly people often do feel cold and need extra blankets.

In the last week of his life, when he was admitted to a private hospital in Sydney, and required help to eat, the hospital told me they didn't have anyone available to feed him his meals. Couldn't I arrange for his carers and family to come in and do that?

I was appalled. What kind of health system is it that can't properly feed our elderly citizens who are hospital patients? What happens to people whose families can't afford to pay for carers? Or who haven't got family members who can do the feeding.

Action is needed through the additional funding to train hospital staff and to put in place protocols at the point of admission to recognise people with cognitive impairment and to provide better co-ordination of their care.

There is some additional funding to expand the dementia behaviour management advisory services into acute and primary care settings.

This is intended to help workers and health professionals to better care for people with behavioural and psychological symptoms of dementia in acute and primary care settings. It may also enable people with dementia to be cared for at home for a longer period of time.

There is not only a provision for dementia supplements in community and residential care funding, but also additional funding to care for those with severe behavioural and psychological symptoms of dementia in residential care.

This funding is targeted to address the long-standing problem of people with dementia who also have difficult psychiatric issues and the risk they face of falling between the mental health system on the one hand and the aged care system on the other.

I welcome the support in the package for people with younger onset dementia.

I know the focal point of today's event is on older people but it is important to remember that for the 16,000 people under 65 who have dementia, there are few, if any, services to respond to their needs in an age appropriate way.

The recognition of the need to better support younger people with dementia is a crucial step forward at the national level.

And I'm pleased to see that the NSW Government has taken some welcome action in this area as well.

The scene has been set for change in a positive way by the aged care reform announcements made by the prime minister and minister butler earlier this year.

We are at the beginning of a long and difficult process for change and during that process we will have to work as diligently as ever to keep the government of the day honest in ensuring that aged care reforms put the consumer first...and that the implementation of reform leads to services that are flexible enough to respond to the individual needs of people.

If we needed to remind ourselves of the necessity to be vigilant we might simply recall that the cornerstone of aged care policy since the mid-1980s has been to enable older people to stay at home for as long as possible.

Yet notwithstanding that policy objective, residential care has continued to dominate in aged care policy with the consequence that by comparison the community care has been relatively underdeveloped.

The April 20 package certainly represents a genuine commitment to tackle dementia both within the aged care reforms and in the health system more generally.

And we can take some pride that the reform package responds to all of the priorities in Alzheimer's Australia's fight dementia campaign with one major exception...and that is increased investment in dementia research.

Not only must we care better for people with dementia, but we must do a lot more to ensure that we are able to identify those at risk of dementia and to find better ways to treat the condition.

In this way we might succeed in reducing the future numbers of people with dementia.

The fight dementia campaign will go on as will our determination to make sure that the aged care reforms are about older people and that the implementation of the reforms leads to better outcomes for all older Australians, providing the flexibility and choice they desire.

Alzheimer's Australia will continue to advocate for a national awareness program that promotes a better understanding of dementia and we will continue to campaign vigorously to secure an additional \$200 million for dementia research over five years.

Research is crucial if we are ultimately to defeat dementia.

Thank you.