

LEADING CARE FOR OLDER AUSTRALIANS

I am grateful to Catholic Health Australia for the opportunity to speak today about leading care for older Australians from a consumer perspective.

The Minister for Mental Health and Ageing, Mark Butler, has said on a number of occasions that the last major reform of aged care was in the mid 1980s.

I agree entirely in the sense that it was the last time that aged care was looked at from the perspective of older people. The hallmark of those reforms and indeed the important Parliamentary Reports that laid the basis for those reforms was choice.

Does that sound familiar?

It was the time when the Home and Community Care Program was born and hostel options laid the basis for what became community care packages.

The central goal of those reforms was that older people should have the choice of staying at home for as long as possible.

The Hawke Government implemented almost to the letter the report of my review group on nursing homes and hostels, had the political foresight to implement change over a period of 8 years.

We have come a long way since the mid 1980s but the lesson learnt is that consumer organisations need to be a lot more active in their advocacy if we are to deliver what we have promised by way of choice to older people and people with dementia by 2020.

I would like to leave you with the four critical factors that I believe require leadership in implementing the Government's **Living Longer. Living Better.** aged care reform package if the dream of choice and staying at home longer is to be the reality not the rhetoric.

My four priorities are:

- i. Expansion of community care and particularly respite.
- ii. Empowerment of consumers through consumer directed care.
- iii. A commitment to serious monitoring of care outcomes.
- iv. Maintaining a focus on dementia care.

Taking those priorities in turn.

Community Care

We have come a long way since the mid 1980s in developing community care. But arguably it is still the Cinderella of the health and care system accounting for less than 30% of available resources in aged care.

Huge administrative challenges exist in locking in a national program with the support of all States and Territories.

Complex questions remain around:

- The numbers of packages that are really needed.
- The profile of those packages at different levels of care.
- The design of those packages and the services included.
- The resourcing of packages at different levels.
- The adequacies of the supplement for dementia care.
- The relationship of the packages to other programs including the National respite for carers program and HACC

Arguably consumer organisations will need to be much more articulate and demanding in respect of community care if the promise of Living Longer, Living Better is to be delivered.

I applaud the Government for the decision to move from two levels of packages to enable a more seamless delivery of levels of care. But looking ahead at the balance of Home Care packages to be in existence by 2020, the distribution does not seem to be a good match with dependency and the pressures in the system.

Level C packages (packages which are effectively mid-level between existing CACPs and EACH) will be around 10% of the total whereas B level packages (equivalent to existing CACPs) will be over 50%.

And would the resources available for Level A be better used at Level C?

We need a careful assessment of how the numbers of each of these packages fits with the expected demand and dependency ratio. There is some concern that 10% is insufficient to address the existing bottle neck of people on a CACP waiting to move into a high care package.

Aiming for a more even balance by putting a much higher share of new places into the higher level packages would be more in line with dependency and also more cost effective.

There is also a need to ensure that the dementia supplement is administered in a way that leads to better quality care for people with dementia.

Consumer Directed Care

The risk for consumers in consumer directed care is that it will be tokenistic and not achieve genuine consumer empowerment and support consumers to make decisions in respect of what care they need and when, where and how care will be delivered.

The cultural change involved in achieving consumer directed care is enormous.

Consumers for their part need to be better informed and prepared to be more assertive in expressing their needs.

Service providers for their part need to understand the importance of flexibility and responding to the needs of the person in front of them.

I see little prospect of achieving person centred care unless consumers are genuinely empowered and a workforce trained to understand the importance of flexibility and tailoring services to the individual.

We need to understand the spectrum of possibilities that consumer directed care provides from planning to budget holding through to the consumer holding the cash.

Consumer leadership, I believe involves pressing as a top priority to Government the need for a cashing out trial of respite.

In promoting a trial, we can better determine how consumers would exercise choice in this critical area of service delivery, particularly for people with dementia and their family carers.

If Government and stakeholders are interested in laying the basis for the future we need to start establishing an evidence base that helps shape it now.

I can think of nothing more challenging to the conservative administration of aged care in Australia than opening up the possibility of genuine consumer empowerment.

Such a trial would be an opportunity to learn:

- What choices consumers would make in respect of respite.
- Ways of ensuring that workforce issues are properly addressed.
- About the information base consumers require to make choices.
- The attractiveness or otherwise of such approaches to diverse communities whose needs are so much more difficult to respond to in the mainstream system.
- The ways of addressing possible abuse.

Alzheimer's Australia have been advocating for consumer directed care since 2001.

We are not going to stop.

The focus now will be not just on ensuring that the roll out of CDC packages leads to real consumer choice, but also encouraging government to embrace the notion of a major trial in respite to see how cashing out might work.

Quality

Despite a high level of regulation in the Australian aged care sector there are real concerns about the quality of care provided. In addition, it is difficult for consumers to be able to differentiate between excellent services and those of more questionable quality.

The current Residential Aged Care Accreditation Standards and the Community Care Quality Standards offer a process of monitoring care; but the standards represent a minimum benchmark rather than promoting optimal quality of care.

The focus of providers in accreditation and quality assurance is towards good processes rather than good outcomes.

We believe that a national set of quality indicators should be developed for Australian community and residential aged care services.

This will be the first step towards providing consumers with transparency around outcomes and quality of care, and a necessary step towards developing a 'MyAgedCare' website which will enable consumers to make more informed decisions.

We hope that Living Longer Living Better will also provide the platform to drive evidence-based research into the effectiveness of specific health care practices and their relationship to quality of care.

Dementia

Living Longer, Living Better delivers the Minister's promise that serious aged care reform requires a focus on dementia. We unreservedly welcome the focus the package has achieved in respect of dementia, not only in aged care, but in the context of health.

Dementia has now been made a National Health Priority Area alongside other chronic diseases. This is a landmark decision for people living with dementia.

Importantly it sets the scene for dramatic change in public health policy in respect of dementia, allowing for the first time a focus on timely diagnosis, making hospitals safer, and dementia risk reduction.

Consumer leadership through Alzheimer's Australia has, I believe, been critical to getting the sea change in policy and the action promised in Living Longer, Living Better. We owe a great deal to the Minister for listening.

This is not to say we are done campaigning. The Fight Dementia Campaign will continue, and the focus for the 2013 budget will be dementia research.

It is the unfinished business of our advocacy and the critical part in facing the future. We all want to provide good quality care in health and aged care but the best possible longer term solution is to reduce the number of people with dementia.

By any standard dementia research is grossly underfunded in Australia, not only in terms of project funding but a lack of commitment of supporting new dementia researchers and building capacity in the future through the NHMRC funding.

While we will not take our eye off the ball in terms of aged care reform we will be relentlessly pursuing funding for dementia research, not only through Government, but through community support.

We will continue to advocate for the expansion of community care and respite, empowerment of consumers, a commitment to quality of care.

If the reforms can start to tackle these key areas then the next ten years will tell a very different story for consumers of aged care services and we look forward to being part of it.

Conclusion

Living Longer. Living Better offers a strategic framework at a high level to reform aged care. The downside of this is that there are many questions left unanswered. The positive is that the reforms can be shaped over a long period to the needs of older people. That opportunity is what strong leadership from consumer bodies will have to focus on.

Thank you.