

**Presentation on consumer directed care and dementia**

**Delivering consumer directed aged care conference  
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**Glenn Rees  
CEO, Alzheimer's Australia**

I am grateful to Criterion Conferences for organising this event and inviting me to speak about consumer directed care and dementia.

We have heard a good deal already at this conference about the challenges of implementing consumer directed care. The challenge I think is even greater in the context of aged care reform than it is in respect of disability reform as our commitment is less well articulated.

The stark difference between DisabilityCare and ***Living Longer. Living Better.*** is all too obvious in concept, philosophy and funding.

We are not able to say in aged care as they are in the DisabilityCare that funding will revolutionise the system and be based on assessed need rather than rationing. Nor do we have in aged care the same recognition of the importance of social issues, capitalising on existing strengths and looking beyond immediate need to long term goals set by the person.

In the world of Disability Care it will be the care needs of the individual which is paramount. The philosophy is one of realising the full potential of the individual and their participation in society rather than one of care and institutionalisation.

This is so enlightened. By comparison the guidelines on consumer directed care released lately by the Department of Health and Ageing are more controlling.

They still insist for example that access to ACATS for younger people will only be allowed where there is no other alternative. For goodness sake, what other services are there for this group in most parts of Australia and what hope is there for sensible arrangement for people of all ages with dementia if bureaucracy is going to put roadblocks in the place of sensible access to services.

People with younger onset dementia already have to straddle the two reforms.

We have an assurance that people with younger onset dementia under 65 years will be eligible for assistance under disability care. People who seek assistance after the age of 65 will continue to receive care through the aged care system.

The differences between the two systems, and the opportunities provided in disability care will become even more obvious as we compare the trajectories of someone with dementia at age 64 under DisabilityCare with someone diagnosed at age 65 under aged care.

We will not know until the trials begin in Barwon and the Hunter exactly what DisabilityCare will provide or how it will work in respect of the services that

Alzheimer's Australia is now funded to provide through our Younger Onset Dementia Key Workers across Australia.

Coping with two sets of very different reforms is an enormous challenge for an organisation like Alzheimer's Australia that has previously had a focus on aged care services.

This is so even though we have been an advocate for consumer directed care over the last ten years.

If the challenges in implementing consumer directed care are daunting to the disability and aged care sectors then my suggestion is it is still more challenging for people with dementia of all ages.

I believe this is so for a number of reasons because of.

1. First the stigma and discrimination and lack of understanding that exists in respect of dementia.
2. The need for a better understanding of social engagement and participation in society for both the family carer and the person with dementia.
3. Recognising the additional costs of dementia care.
4. The enduring problems of achieving good quality care in residential services.

### **Stigma and discrimination**

People with disabilities have been proud advocates of independence and self-determination for decades.

Historically this has not been the case with dementia. Even in our own organisation people with dementia were not truly included in the life of the organisation until after 2000. At that time people with dementia were supported to self advocate for the first time at conferences, seminars and meetings with ministers.

A diagnosis of dementia still brings with it social isolation for the individual and their families and carers, and for many a sense of shame.

It also brings with it an assumption that the person is no longer able to make decisions or choices over their life. This is of course in many cases incorrect and completely at odds with notions of consumer directed care.

But issues of capacity have to be considered within the context of CDC and dementia. There will be cases where the person with dementia expresses a

preference about their care that others may disagree with, such as not wanting to shower or wishing to go for walks late at night. CDC will raise interesting questions. The carer needs to be supported to distinguish between choices that they don't agree with and choices that are unsafe or show a lack of capacity.

There is a need to document care wishes before a person loses the capacity to make their own decisions. We often discuss this with regards to end of life care. But with CDC it is not just about what they want in terms of the last days of life. Instead we need to have enough information about the person and their preferences to ensure that care is matching their preferences and goals, even after they are no longer able to communicate these things.

But perhaps a harder issue is an assumption of lack of capacity and the stigma associated with the diagnosis of dementia. A study released last year by the Centre for Health Initiative at the University of Wollongong found that many people have negative attitudes towards people with dementia.

Of the 616 people who responded to the survey:

- Over half said that people with dementia can't be expected to have a meaningful conversation.
- Over one third said that people with dementia could be irritating.
- One in ten said they would avoid spending time with people with dementia.

Study respondents also said that if they received a diagnosis of dementia they would feel a sense of shame and humiliation coupled with the fear their diagnosis they would be discriminated against both in the community and the health sector.

Stigma and fear can play a huge role in the delay in diagnosis because there can be reluctance on the part of consumers to seek a diagnosis and on the part of medical professionals to give one. Yet early diagnosis can be critical to ensuring a better quality of life for people with dementia.

While the needs of the individual should not be determined by their diagnosis it is important to ensuring that the person with dementia and their family carers are able to plan their care and support for the future free from discrimination and fear.

The good news is that as part of ***Living Longer. Living Better.*** there is a recognition of the need to take action to achieve timely diagnosis. However, achieving this will not only require a better understanding by medical professionals, but from our broader society as a whole.

A news poll survey conducted last year showed that there is a lack of understanding about dementia in the community. Nearly one in five said that if a family member had memory loss or confusion they would think it was a natural part of ageing.

And lets remember that it was only last August that dementia was finally recognised as a National Health Priority Area.

Choice is a difficult challenge to promote when individuals are facing such difficulty from the moment they receive a diagnosis and sometimes even earlier. But at the same time, empowering individuals to have control over their care is all that much more important in the context of social isolation and discrimination.

It maybe harder to address some of these issues in the aged care reforms than it will be in respect of younger onset dementia in disability care.

While there is no great understanding of dementia in the disability sector, there is the focus on respect for human rights, independence and social inclusion which is not yet paralleled in aged care and attitudes towards older people.

## **Social Engagement**

I think one of the greatest challenges in achieving CDC is in designing services and funding models that embrace social engagement for both the person with dementia and the family carer as a key component of care.

Alzheimer's Australia has made respite care a priority over many years. This is simply because family carers of people with dementia attach a higher priority to respite than family carers of people with other conditions.

Both planned and emergency respite care are crucial components of support for carers and can enable individuals with dementia, including those with BPSD, to continue to live at home.

Respite care provides both the person with dementia and the family carer with opportunities for social engagement and participation in appropriate and meaningful activities.

The sad reality is that people with dementia have difficulty accessing any respite services that meets their needs.

In the most recent Australian wide survey of disability and carers, 48% of primary carers of people with dementia reported that their main unmet need was respite care, where as only 15% of all primary carers said that this was their main unmet need. Only 27% of people with dementia approved for residential respite care use it within a year of the approval.

The reasons for the underuse of respite are complex. An important contributory factor is that respite care is often not flexible and not available at the right time or provide sufficient hours of care.

Consumers for their part may be reluctant to use the service because there is no perceived benefit for the person with dementia.

Service providers may feel unable to provide care and support for people with dementia, or lack resources and appropriately trained staff. Family carers report being turned away once dementia is mentioned or that once the person with dementia develops BPSD services refuse to continue to provide support.

With CDC we have the opportunity to be creative and think of new ways of providing respite that meet the needs of both the carer and the person with dementia.

It is difficult to imagine choice in respect of respite care within the current funding arrangements. Dementia specific respite services that can provide specialised care and support for people with BPSD need to be resourced and that requires a dementia supplement of some kind to help services to meet the extra costs of service provision and training staff.

The publication that Alzheimer's Australia released last week at our National Conference reviewing current respite provision made a number of important recommendations for improving the quality of dementia respite care. This was prepared as an input to the discussions within the group in the National Aged Care Alliance on Home Care Services.

In the context of this conference I believe a priority is support for a trial that enables carers to receive cash instead of respite services and to be able to employ family members or friends.

If we are to break through some of the complexities and uncertainties around direct payments in aged care, we need in my view to be bold enough to undertake a major trial now so that we will be better positioned in three or four years time to think laterally about where we want to take the funding of aged care funding services in the longer term.

From our perspective there is no more important area than respite in determining whether it will be possible to improve the quality of services to people with dementia if the family carer and the person had control over the resources available. There are many important issues to tease out in such a trial including:

- Information on services
- The quality of services that result.
- The adequacy of the information necessary to make decisions
- Whether abuse is a serious issue.
- Workforce issues.
- Continuity and availability of provider based services to purchase.

A trial of direct payments should begin with a scoping study of the benefits that such an approach may hold compared to budget holding by the service provider and drawing on evaluations from Australia and overseas. Consideration should be given to offering a range of choices in the trial, including personal budgets with case management as well as direct payments.

The findings of the scoping study could then be used to establish the basis for a trial with a robust design that would be of sufficient scale and duration to allow outcomes to be compared and assessed.

## **Residential Care**

There is also a commitment within the *Living Longer. Living Better.* aged care reforms to look at consumer directed care within residential care.

The challenge is fascinating. What sense can we make of choice for people with dementia in residential care when around one quarter residents are chemically restrained with anti-psychotic medications, mostly without the consent of the resident or their carers and in circumstances where as few as 20% benefit from them.

This is despite the fact that these medications are known to have significant side effects and increased risk of stroke, heart attack or death.

Clinical guidelines require them to be used as a last resort for those that will derive some benefit.

It is these issues that make me wonder whether stigma and discrimination is an even greater barrier to the achievement of choice and flexibility in services in respect of people with dementia.

I am not suggesting that the staff who work in residential care are uncaring. There is plenty of evidence to the contrary. But we have to wonder why there is such variability in the quality of dementia care. Why do some facilities manage to do it well while others struggle?

At our Alzheimer's Australia Conference last week in Hobart a wonderful paper was presented by Catherine Morley from Rural Northwest Health in the Wimmera Mallee region of Victoria about the application of Montessori methods and the results they have achieved including reducing anti-psychotics to the one resident who needs them. Her question as a manager is "Is that how I would want to live".

There is an important Senate Inquiry into the care of people with behavioural and psychological symptoms of dementia currently underway. I very much hope that putting a spotlight on the issues of the management of BPSD both in community and in residential care will contribute over time to the achievement of better outcomes.

When we think about choice in residential care it is not just about the every day decisions about when to have a shower, or eat dinner. But it is also about how the person with dementia is supported to maintain as much independence and control over their lives as is possible. For example, are staff focused on enablement and maximising strengths of the individual, or just on ensuring that the person's basic needs are being met. Choice for people with dementia will only be possible if the staff understand the needs of someone with dementia and how to support them to continue to make decisions about their lives.

The development of quality indicators for residential aged care may come to play an important role in promoting transparency in care and provide consumers with the information necessary to make informed choices about residential aged care.

There needs to be greater flexibility for consumers to leave a facility and find a new place if they or their family are unhappy with the care being provided. Right now, many residents and their families are afraid to even complain about care because they are so concerned about losing their 'spot' in the system or their loved one receiving worse care than they already are.

We also need to ensure that people can make their care wishes known and have them respected with regard to end of life care.

There is a need to accept that empowering consumers to make choices over their care means that they may not always make the decisions that health care professionals think are best. For example, an individual may decide that they no longer want food or hydration. Care staff may be inclined to do everything they can to preserve life. There has to be an acknowledgement that if we want to have truly

consumer directed care this has to include respecting difficult decisions and even unpopular ones.

We will be one step closer to ensuring an individual's care wishes are known with the recent announcement by the Gillard Government to include Advance Care Directives in Personally Controlled Electronic Health Record.

The next logical step would be an overhaul of the current state and territory laws that govern advance care planning. Nationally consistent legislation and common terminologies are needed to reduce the uncertainties and confusion that currently exist in relation to advance care plans and end of life care.

It has also been suggested that perhaps every individual entering the aged care system should be encouraged to complete an advance care plan, while providing an opt out system for those who do not wish to.

This would ensure that individuals have the choice to receive care they want even at the end of their lives, and avoid being sent to hospital if that is their wish.

## **Resources**

We have welcomed from the start the policy framework in ***Living Longer. Living Better.*** as one that has the potential to achieve expanded community care, more flexible services and more decision making by family carers and older people themselves.

But as the implementation process progresses so too will the limitations on funding become more apparent and a still greater constraint on achieving the policy objectives that have been set.

I have referred already to the difference between DisabilityCare and the aged care reforms. DisabilityCare has the promise (still to be realised of course) to transform a rationed system into a marketplace for which there will be long- term sustainable funding including through the proposed increase in the medicare levy. Funding is allocated to the person with a disability allowing real choice over the services they receive.

After years of uncertainty it is a relief that younger people with dementia will be eligible for assistance under DisabilityCare.

Within aged care, for decades there has been a fiction particularly in the funding of residential aged care that the services can be all things to all people without recognising the extra costs and complexity of care including for those with people with dementia.

There is of course some recognition of this in the Aged Care Funding Instrument. But the funding generated by the Instrument is pooled by a residential care provider with the consequence that those with the most severe behaviours or complex needs may not be met.

The introduction of the dementia supplement in the community and residential care context marks an important break in policy in recognising extra costs and the need to target precious resources on those who have the highest level of need.

We cannot be sure at this point how those arrangements will work but their introduction and the opportunity to evaluate them will provide a valuable source of information about how we can do better in providing good care and support for those with the highest needs.

Again, choice will still be a dream for many until basic care needs are met

## **Conclusion**

The vision for consumer directed care in DisabilityCare and in the aged care reforms has set an exciting challenge to consumers, service providers and bureaucrats.

We are as positive and passionate about achieving greater consumer choice and decision making and flexible services as we were back in 2000. But the reality is that achieving these goals are likely to still be more difficult in respect of those with dementia than older people more generally.

We have accepted from the outset that hastening slowly with the aged care reforms is the right course given the magnitude of the cultural shift to CDC and the administrative changes involved in moving away from the current system. The budget holding approach adopted in the aged care reforms is conservative but we have had no indication from consumers that at this stage they want to take on the responsibilities that would be involved in holding the cash except in the area of respite.