

Setting the Scene: What do the government's aged care and disability policies mean for people with dementia and their families?

Thank you for the opportunity to speak at this important forum. I would like to begin by acknowledging the people with dementia and the family carers who are here today and have volunteered their time to take part in this Summit. The focus of today, and especially the workshop this afternoon, is to hear from you about your experiences and your hopes.

My role in this presentation is to provide you with some context about the aged care and disability reforms and what they mean in terms of changes to services and supports.

The 2012 aged care reforms brought a sense of hope to consumers and advocates alike. The reforms had three important areas of focus:

- increasing consumer choice including in access to community care
- improving the quality of aged care services
- creating a sustainable system that would be affordable into the future.

For people with dementia, the reforms were a remarkable shift. The Government committed to significant investment in dementia including initiatives to improve hospitals, provide timely diagnosis and to raise awareness about risk reduction.

There was an understanding that the aged care reforms would lead to an increase in charges for consumers who had the capacity to pay, but that this would be balanced by an increase in choice and quality.

Importantly there was also the decision to make Dementia a National Health Priority Area.

When the Government was considering the reforms, Alzheimer's Australia undertook a series of consultations across the country. We held forums in every capital city and in some regional areas as well.

The overwhelming message from consumers was that the health and aged care system was not working for them. From consumers, there were four main areas of concern - and these areas are the same ones we will be talking about today:

1. community response to dementia (including stigma)
2. access to appropriate community care and respite
3. care within the health system (diagnosis and hospital care)
4. quality of residential aged care services.

We are now almost three years on from these forums and the announcement of the reforms and it is timely that we revisit each of these four issues and consider what has been achieved and the challenges still facing people with dementia and their families.

1. Community response to dementia (including stigma)

One of the biggest misconceptions about dementia is that people with dementia live in residential aged care.

The reality is that 70% of people with dementia are living in the community- and many of these without formal care services.

Unfortunately the stigma and social isolation which so often accompanies a diagnosis of dementia means that people with dementia in the community often give up their hobbies and activities long before their cognitive impairment means they need to.

Often people struggle to find services and supports as formal services are geared towards people in the later stages of the disease.

Mainstream activities are often hard to be involved in because of issues around stigma or the response people have to the issues facing a person with cognitive impairment.

Surveys of people living with dementia last year revealed that:

- 59% of people thought that people were avoiding them because of their diagnosis
- 41% wished they had more social contact in their communities.

One of the respondents to this survey told us; *“Sometimes my social death makes me more sad than the changes to my brain and the loss of my memories. It makes me so angry. I just want to be counted as a person again”*.

Alzheimer’s Australia has begun to tackle this issue through working with communities to develop ‘dementia-friendly communities’. People with dementia have been at the centre of this work, and have assisted us to identify strategies including looking at the physical design of spaces, developing opportunities for social engagement, and raising awareness among the community about dementia.

Challenges remain. The reforms have focused on formal care and support services. But there are few resources to tackle these important issues around social isolation and engagement.

This is a particular concern as we know that isolation can lead to an exacerbation of the symptoms of dementia and mean a reduced quality of life.

2. Access to appropriate community care and respite

In our consultations back in 2012, we heard from consumers how important access to good care in the community was. Many shared their frustration about waiting periods for services and lack of flexibility.

Others told us of being turned away from respite services because the symptoms of dementia were too severe.

There are a number of steps that were taken as part of the reforms to address these issues.

The reforms included a rapid expansion in the number of home care packages available in the aged care sector with packages continuing to increase over the next five years. The hope is that this will reduce waiting periods for important services in the community and hopefully mean that more people are able to make the choice to stay at home.

The Government also introduced new levels of packages. This was done in part because of consumer feedback that there was a gap between the level of services provided in the two tiered system of the past.

A dementia supplement was introduced as well which meant that people with dementia would have access to the additional support required, regardless of the level of care package they were accessing.

Consumer choice has now become part of home care packages - with all packages rolled out on a consumer directed care basis. This means people can choose the services and supports that best meet their needs with a more flexible provision of services.

These changes have generally been positive, but there are still questions about whether they go far enough.

Alzheimer's Australia has recently received funding for a respite project to look at options for more flexible approaches to respite and care. Clearly more needs to be done. Some of the issues that consumers have raised with us include:

- Is the increased supply enough? Shouldn't the number of packages available be based on need?
- Can a higher level of package be provided? For people with dementia 15 hours of care (which is the average provided in a high level care package) is simply not enough.
- Why are administrative charges so high? Some consumers believe that CDC has led to less service being provided as a result of excessive administrative charges
- What are the limits around choice? Many consumers indicated that providers are restricting their choice even in the CDC model of care because they are concerned about risk and there are issues about how people with dementia are supported to be involved in choice.

3. Care within the health system (diagnosis and hospital care)

Another theme that came out of the 2012 reforms was concern around access to timely diagnosis and care within the hospital system.

We know that on average it takes 3.1 years between first noticing symptoms and getting a diagnosis of dementia.

Recent research has revealed that up to half of all people with dementia in hospital do not have their diagnosis formally documented.

These are real areas of concern.

As part of the reforms the Government has funded a number of initiatives to drive better care and support in primary care and hospitals. This includes:

- training and information for GP's and practice nurses about dementia and diagnosis.
- an expansion of DBMAS into primary care and hospitals.
- programs to improve quality of care in hospitals and to assist in the identification of people with dementia in hospital.

These initiatives provide important first steps to improving the system - but change will take time.

I am sure many of you could tell us stories about your experiences in primary care and hospitals and what went wrong and what could have done better. I look forward to hearing your views on these issues- as we need to continue to work with Government on how best to improve the health system for people with dementia.

Dementia is a National Health Priority Area. We must ensure that we have a health system that can respond to it.

4. Quality of residential aged care services

For many consumers back in 2012, quality of care was the focus of their concern. We heard painful stories of the poor care received in residential aged care and the lack of access to physical and social activities within residential care. We heard of staff that were underpaid and under resourced, and who often did not have the training to respond to the needs of people with dementia. We also were told of the inappropriate use of antipsychotic medications to control behavioural symptoms of dementia which were often the result of unmet need within the care facility.

Of course this has to be balanced with some exceptional stories about staff and facilities that provided an excellent standard of care and often went above and beyond the basic requirements.

The Government listened to concerns expressed by consumers and committed to improving quality of care as part of the reforms.

Unfortunately, I think this is an area where most consumers feel that progress has been too slow.

A supplement was introduced in residential aged care to assist with the costs of providing good care to people with the most severe behavioural symptoms. This supplement was then removed as the costs of the supplement far exceeded what had been planned. A replacement scheme was recently announced which involves a multidisciplinary Severe Behaviour Response Team who will provide support to residential aged care facilities in responding to the needs of people with severe behavioural symptoms.

I am optimistic about this approach, but we will have to wait and see what the implementation looks like.

The Government also committed to developing quality indicators for residential aged care. The goal was to develop a way for consumers to be able to assess differences between aged care providers on the quality of care they provided. The development of these indicators has proven to be more difficult than originally expected. The process is still underway and consideration is being given to how to capture the consumer experience of the aged care facility as well. This is complex and important work, but again it has been a slow process.

Workforce issues within aged care continue to be complex and unresolved. The Government is doing some excellent work in reviewing aged care training and education - but much more needs to be done to continue to develop the aged care workforce. Challenges remain around wage issues and parity with other areas of the health sector.

Again the questions that I hear from consumers about quality of care include:

- Why do people with dementia continue to be given psychotropic medications to respond to behaviours when there is limited clinical evidence of their effectiveness?
- Residential aged care staff still struggle to meet the needs of people with dementia. How can this be improved?
- How can aged care facilities pass the standards and accreditation process when clients are so obviously receiving poor care in some cases?
- Is there a way to move from a system of institutionalisation to one with more person-centred care? Or small group home like environments?

These are all very important issues which I am sure you will have more to say about later today.

Finally I want to talk about the need for dementia-specific services and mainstreaming

The direction of reform that concerns me most is the focus on using mainstream services to respond to the needs of people with dementia.

The best example of this is the implementation of the National Disability Insurance Scheme.

We have been told that our Younger Onset Dementia Key Worker Program will be transitioned into the NDIS.

The Younger Onset Dementia Key Worker program which was established in 2013 provides one-on-one support to people with dementia and their families. This critical service provides the early support that helps people with younger onset dementia to maintain a high quality of life for as long as possible. The key workers not only provide direct support but they also work with disability and aged care services to develop appropriate care and support for this group of clients.

There is an unrealistic view that NDIS will be all things to all people and that specialised services such as the key worker program are simply not required.

Instead the view is that mainstream services can provide service coordination or integration with the hope it will achieve the same result.

The reality is that the specialist holistic approach of the key worker cannot be replaced by mainstream services. Instead younger people will again find themselves in the difficult situation of being bounced back and forth between aged care and disability services with neither having the knowledge or expertise to provide adequate support.

The NDIS trial sites are already illustrating the challenges we will face. People with dementia struggle to get access to the NDIS because of the paperwork involved. Once assessed, planners find it difficult to identify the needs of people with dementia as they do not have an understanding of the condition.

This is an example of reform that has been undertaken with the best intention - but if it is not carefully implemented will result in the loss of an important service for people with dementia.

This is just one example of this move towards mainstream services. Similar approaches are happening with changes to the Commonwealth Home Support Program.

We must be very careful that the move to reduce red-tape and costs does not lead to the loss of important infrastructure and services which are designed to provide the very specialist supports that people with dementia need.

If we have learned anything about dementia over the last decade, it should be that when we expect mainstream services, whether it be hospitals, aged care facilities or respite services, to provide high quality care to people with dementia, we are disappointed.

It is not surprising when you think of how complex the disease is, the very specific issues around behavioural symptoms and capacity, the individual experience of dementia and the different levels of support.

It is my hope that we can highlight the importance of these existing specialist services such as the key worker program, as well as the need for further specialist services for people with dementia.

Conclusion

The story of the aged care reforms is still unfolding. To date we can say that there have been some positive changes including greater community care, more choice and consumer direction, and an acknowledgment of the need to address issues across the health system.

With change comes both opportunities and challenges.

I am looking forward to hearing your perspective this afternoon. We need you to help us identify our priorities for our advocacy in these areas going forward. We want to draw on your knowledge and experience to inform our work with Government and the bureaucracy.

Ultimately, Alzheimer's Australia is about making it better for people who experience dementia, and although we have had some success, we are very aware that there is still a long way to go.

Thank you.