

## SUMMARY REPORT ON THE CONVERSATIONS ON AGEING

### 1. Background

COTA Australia was contracted by the Department of Health and Ageing to undertake engagement with older people on the proposed aged care reforms. A key element of the project was to support the *Conversations on Ageing* conducted by the Federal Minister for Mental Health and Ageing, the Hon. Mark Butler.

The Conversations commenced on 19 August 2011 in Adelaide and concluded in Alice Springs on 1<sup>st</sup> February 2012. The following conversations were held:

<i>South Australia</i>	Adelaide CBD, Port Adelaide, Camden Park and Modbury
<i>Victoria</i>	Tottenham, Grovedale (Geelong), Ballarat and Berwick
<i>New South Wales</i>	Sydney CBD, Blacktown, Gosford, Port Macquarie, Newcastle, Ballina, Tamworth, Penrith and Wollongong
<i>Northern Territory</i>	Darwin and Alice Springs
<i>ACT</i>	Canberra
<i>Western Australia</i>	Victoria Park, Cockburn, Rockingham and Warwick
<i>Queensland</i>	Rockhampton, Mackay, Deception Bay and Acacia Ridge
<i>Tasmania</i>	Hobart, Launceston and Devonport

In addition to these Conversations the Minister attended a COTA Victoria Conference in the Melbourne CBD where he discussed reforms and received feedback from 100 participants.

People were invited to attend the Conversations and were asked to RSVP to ensure venue safety and to manage catering requirements. Invitations were sent out to COTA individual and organisational members and to Alzheimer's Australia, Combined Pensioners and Superannuants Association (CPSA) and affiliates, National Seniors Australia (NSA), Federation of Ethnic Communities' Councils of Australia (FECCA), Carers Australia, Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Alliance, Legacy, Returned Services League (RSL), One Generation, Security for Women, Young Women's Council Australia (YWCA), National Rural Women's Network and Palliative Care Australia for them to invite their members and networks to attend.

In addition COTA liaised with local councils and other community groups as required to make sure the invitations were widely distributed. Invitations were also sent to key provider groups requesting that they be promoted to their clients and residents and that they support these people to attend.

Over 3,400 people attended these Conversations, which ranged from about 40 to around 250 people. The majority of attendees were older people and their carers. In addition there were sometimes aged care workers and service providers in attendance.

This report provides a summary of the Conversations and identifies the common themes and issues that were discussed.

## Conversation Format

The Conversations ran for 2 hours. Typically Minister Butler spoke for 20 – 30 minutes on the Productivity Commission's final report *Caring for Older Australians* outlining the key reforms proposed. This was followed by an hour and a half of questions and answers and discussion.

People who attended the Conversations were provided with two summary documents (attached), prepared by COTA:

- What could aged care reform mean for me?
- Paying for aged care.

Attendees were also provided with a feedback sheet where they were able to make comments and or raise issues for consideration.

## Conversations

The Conversations were broad ranging but a number of recurring themes emerged at most, if not all of the Conversations.

### **Older Australians want to be seen as valuable and active citizens.**

The contributions older people make throughout their lives and continue to make was an underlying theme to many of the questions raised.

The Conversations highlighted that older people continue as volunteers across a range of areas, including in aged care, for many years. For example, in NSW the issue of grandparents acting as primary carers for their grand children was raised. They are often caring for their grandchildren as a result of their adult child's mental health and/or alcohol and substance abuse issues. Little support is provided to them in this role and there was particular interest in how paying for aged care could affect their ability to continue in their caring role.

Overall older people said that they wanted to be respected for who they are and what they continue to contribute to society. Many expressed the view that they were not valued by society and were seen as a burden.

### **Older Australians want to stay at home in their local community for as long as possible and preferably until their death.**

This was one of the strongest messages coming from the conversations. While many of the questions at the Conversations related to issues and concerns with residential care, when people asserted what they wanted as they age it was invariably support to stay at home.

Different aspects of community care were identified including help with little things such as changing a light bulb or some gardening. While some people indicated needing more support in most instances they were not talking about huge increases in hours of care. There seemed to be no illusions that there would be 24 hour/ 7 days a week high intensity care at home.

The availability of community transport, with the ability to go to destinations other than the local shops, was raised generally but it was a particular issue of concern in the Conversations held at Penrith and Blacktown in NSW.

### **Older Australians want to remain living independently for as long as possible.**

This strong desire came out in the Conversations in a number of ways including discussion of the provision of care at home or in retirement villages, but also in relation to staying mentally and physically fit. University of the Third Age and the value of ongoing education were discussed, particularly in NSW and Tasmania. The value and importance of art programs for people with dementia was highlighted in Port Macquarie with one woman talking about how proud she was of her husband who had only ever painted a fence before.

At some of the Conversations people expressed the view that there was more focus from services on physical wellbeing and not enough focus on mental wellbeing. Links were drawn between keeping mentally stimulated and connected and mental health issues in later life. Men's Sheds were cited as examples of a service that provides both physical and mental stimulation with a subsequent positive impact on mental health. The issue of funding for such services was also identified.

Preventative health measures were also identified as important for long term independence. The Conversations highlighted that people felt more needed to be spent on prevention and research than is currently.

The Conversations highlighted general knowledge and concern about how older people with mental health issues were supported in aged care services, particularly in residential care. A view often expressed was that more needed to be done for people in these circumstances.

### **Older Australians want easy access to services as needed.**

The Gateway concept was discussed at the Conversations and there was a strong consensus that it would be a valuable and welcome addition to the service system. Older people were clearly attracted to having one easily identifiable spot in their local community that they could go to and be linked in to the services they need. The provision of support to navigate the system and information (both on positive/healthy ageing and services) was also talked about as being highly valuable. Most people seemed to conceive of the Gateway as a physical location with people to talk to, in addition to online and phone access.

There were questions about the operation of the Gateway, including how locally based it would be. Some participants expressed concern as to whether the Gateway could really be as good as what the Productivity Commission's final report described. There was very clear and strong support for its creation.

### **Older Australians don't want rationed services.**

Many people spoke about the service rationing now and the issues people face to get into a residential care service or receive a Home and Community Care (HACC) package. Service providers in the audience were more likely to talk about this in relation to residential care. Consumers and carers were more likely to talk about waiting lists for community care services or not being able to access Extended Aged Care at Home (EACH)/Extended Aged Care at Home Dementia (EACHD) packages at all.

### **Older Australians want access to good information.**

Information provision was raised all the time at the Conversations. Information required ranged from general information about services that are available to more complex information that would help people make sense of personal circumstances, including financial.

People were particularly keen to have access to information on the quality of the services available. This most often focused on residential care and being able to tell a good, quality service from a less desirable one.

### **Older Australians want an aged care system they can understand and use.**

It was clear from the Conversations that older people are very keen to have a simplified system they can easily find their way around. This is linked to the desire for good information and the Gateway as an access point.

### **Older Australians want access to quality residential aged care when needed, but they hope it won't be!**

Older people generally acknowledge that there is a need for quality residential care. However, there were fairly wide spread concerns about its quality overall and whether or not there is enough activity and support for the older people who live there. It is seen as a last resort for older people and is not a service option people will actively seek out.

People often related stories of poor care for relatives and loved ones and there were particularly sad stories related in the Conversations held in suburban Perth and Sydney. These experiences also highlighted a lack of trust in the current residential care accreditation and complaints schemes. In Sydney in particular the audience did not accept that there were adequate resident protections and felt that residential care services were able to plan and prepare for accreditation visits. There is also a view that the penalties for providers that provide poor quality care are not strong enough, or effective.

In a number of Conversations participants said they did not know who to go to for assistance when things went wrong or they needed advice or support.

While it was strongest at the Sydney Conversation the concern about the adequacy of current accreditation and complaints arrangements, and penalties applied, was echoed at many of the other Conversations.

### **Older Australians want the payment arrangements for aged care services to be understandable and fair.**

Much of the discussion about paying for aged care (accommodation and care) related to how much an individual would have to pay in the new system. These questions were of course not able to be answered since one of the basic proposals is a cost of care study to determine what prices should be. Therefore the discussion focussed on payment principles. There was general support for the equity and fairness aspects of the Productivity Commission recommendations. However, a number of people indicated they wouldn't be able to endorse these recommendations one way or another until they knew what they would have to pay as an individual.

#### *Paying for accommodation.*

This was discussed at nearly all of the Conversations. The Conversations highlighted a significant lack of knowledge about the current payment arrangements as well as what was proposed for a reformed system. There were usually one or two people at each Conversation who expressed concern about having to sell their principal residence but this concern was not generally picked up and supported by the majority of the audience. There was recognition by many that this is the norm now. People who

raised this as an issue seemed to think that Government should pay fully for aged care for everyone. Many people accepted that using this asset was probably a reasonable way to pay for accommodation.

People were interested in the Pensioners Savings Scheme and the Credit Scheme. Concerns were expressed about the perceived similarity of the proposed Credit Scheme to reverse equity mortgages and the problems they can create for people who go into negative equity. There is mistrust about how such a product would work and the protections for people. However some people recognised that the Productivity Commission's proposal would be a much better deal than a commercial reverse mortgage.

Issues were raised about the protected persons' provisions. Some of the questions, for example what happened to a spouse, seemed to be due to poor knowledge of the existing protections. But there are other people where the answer is less clear and are of concern – for example gay partners where the relationship has not been declared for fear of coming out.

#### *Paying for Care.*

People were interested in, and generally very supportive of, the Stop Loss limit.

#### *Safety Net when people can't afford to pay.*

The fact that the Government would continue to pay for the majority of aged care services, and completely for those who can't afford to pay at all, was strongly supported by the people at the Conversations.

A very small number of people expressed the view that this, along with the proposed payment arrangements for those who can afford to pay, discriminate against people "who have done the right thing throughout their lives where others hadn't.

#### **Older Australians want to have choice about their services and support and far greater control of their lives.**

The concept of choice - of provider, of support at home or residential care – was strongly supported at the Conversations. This is coupled with recognition of the need for good information about options and service quality along with support to make the best choices (if such support was wanted/required) to be available. Having a choice of services and how they are delivered was seen to provide people with greater control over their lives.

There was also support for older people having dignity of risk. The Minister's introductory remarks, the example of the egg cooking regulation in NSW, drew audience support that people in residential care should not be treated as children.

#### **Older Australians want a skilled, respectful workforce able to spend time with them.**

The Conversations highlighted significant knowledge about the pay and conditions for workers in aged care. Generally Conversation participants expressed the view that the workers in aged care are underpaid and should be better paid.

The issue of understaffing was raised often, with people talking about the need for staff to be able to spend more time talking with and supporting residents. The lack of physical and mental stimulation, due to staff not being able to spend time with residents, was raised at many Conversations. People related stories of residents needing assistance to eat but not receiving that support with subsequent health impacts of malnutrition and in one extreme case death from starvation. At most Conversations the question of whether there should be a ratio for aged care was raised but generally by workers who attended the Conversations as well as by family carers rather than the older people in attendance.

The issue of training, in particular, ensuring that aged care staff are of high quality and have the skills and knowledge required to provide quality care, was raised by many older people. There was general audience support for the need to pay better wages including that Government should ensure that any additional funding provided to services for this purpose is spent on wages.

The number of staff, particularly in residential care, who come from different cultural backgrounds and in some cases are seen to have limited English language skills was raised at a number of the Conversations. Some people expressed concern about the impact of this on communication while others commented favourably on the care provided and acknowledged that they were prepared to do the job for the poor wages provided.

### **Older Australians want services that can cater for diversity and don't discriminate against individuals.**

The need for services to be able to cater for the needs of Culturally and Linguistically Diverse (CALD) people and others with different needs was discussed at most of the Conversations.

Whether people are best supported through ethno specific services or mainstream aged care was a major discussion point. Mixed views were expressed on this point. The Conversations highlighted that language is only one aspect of quality care and that there are many cultural aspects that need to be better delivered in aged care services.

Many people with different sexual preferences and orientation attended the Conversations. They raised issues they face accessing aged care services. While some issues about home care were raised, the majority of issues related to residential care provision. Some attendees talked about their reluctance to come out to service providers for fear of discrimination. Concerns were expressed too about whether gay partners of people in care are treated in the same way as other carers. Some of this seemed to be in relation to whether the protected person's provisions can be applied where a relationship is not declared. The issue of exemptions for faith based providers was a common theme and is an area most people wanted to see changed. The Conversations acknowledged, and supported, the Productivity Commission's recommendation for the development of a specific Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) aged care strategy.

### **Older Australians want to have control over their death.**

Having control over your own death was raised at every Conversation. Sometimes people use this as an opportunity to support voluntary euthanasia (and the written feedback forms also include a number of comments to this effect), many were clear about not wanting to be resuscitated and others raised the issue of access to quality palliative care.

A suggestion at a number of the Conversations was that there should be a national Do Not Resuscitate (DNR) register which would operate similarly to the organ donation registry.

It was clear from the questions and discussions that the majority of people want to die at home.

### **Older Australians want reform to happen now and with bi-partisan support.**

At most Conversations the Minister was questioned about the time frame for implementation of reform and Governments support for the proposals. There were also questions about what would happen if there was a change of Government and whether there is bi-partisan support for reforming aged care. These questions highlighted broad support for reform to occur, despite some concerns that the full details of the payment arrangements for individuals are not known.

### **Older Australians want to live in appropriate housing.**

The importance of affordable and appropriate housing for older people was a common point of discussion at the Conversations.

The financial issues and disincentives related to downsizing to more suitable and manageable accommodation was raised at most Conversations. Participants told the Conversations that the impact of income from the sale of a home on the pension and stamp duty stopped them from moving into more suitable accommodation.

The need for good access to home maintenance and modification services so that homes remain liveable and appropriate as people become frailer was also raised in this context.

**Older Australians are concerned about the financial arrangements for retirement villages and services and support provided there.**

At most Conversations the issue of whether retirement villages are part of the aged care system was raised. A number of concerns are expressed about retirement villages but the focus was most often on financial matters – particularly entry, exit and ongoing maintenance fees. Sometimes the issue of the level of support available to people is raised with a number talking about a mismatch between expectations and what is actually available.

The role retirement villages play in providing more suitable accommodation was also raised at a number of the Conversations.

**Older Australians want better support for people with dementia including younger onset dementia.**

A common question and topic of the Conversations was ensuring adequate support for people living with dementia. The lack of Extended Aged Care at Home Dementia (EACHD) packages and not being able to get enough care and support at home was routinely raised.

The importance of research in finding a cure and providing better treatments to people with dementia was also discussed.

The Conversations highlighted a growing awareness of the issue of younger onset dementia and its impact on families. This was a particularly strong feature of the Conversation in Ballarat where a number of families with a younger onset dementia diagnosis attended. Whether people with younger onset dementia are best supported in the aged care system or in some other way was discussed. Generally people indicated that they understood there was dementia expertise in aged care but there was a strongly expressed view that residential aged care services were inappropriate for younger people and that different accommodation options are required.

**Older Australians want access to dental health services.**

The current system doesn't make sense to people. There were many queries about why health issues with all body parts, except for your teeth, are covered by Medicare. There was awareness of the impacts of poor oral health on overall health. There was a very clearly expressed view that Government needs to address this issue.

**Older Australians want services to support and work in partnership with carers.**

Many family carers also attended the conversations and expressed the view that services should work in partnership with them. In addition, carers outlined the types of support they needed to be able to continue to provide care for their loved one. There was general support for the recommendations for a separate carer assessment and access to carer support services as outlined in the Productivity Commission's final report.

## **Non Aged Care matters raised at the Conversations.**

People also raised issues that were not about aged care or its reform but are worth capturing as an indication of the breadth of the Conversations and the broader concerns of older Australians:

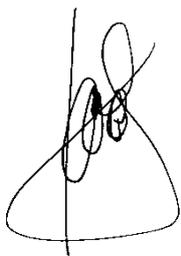
- Pension arrangements with other countries;
- Discrimination against older people including workers compensation, superannuation and travel insurance;
- Climate change, carbon tax and environmental issues and impact on future generations; and
- Inadequacy of the pension and rising cost of living (including utilities and fuel). This was particularly an issue and focus for people in Alice Springs.

## **Conclusion**

The top line messages from the conversations are that older Australians:

1. want quality services available when and where they need them;
2. have a clear preference for support to be provided at home, with people only wanting to contemplate residential care when there is no alternative;
3. desire a simplified and streamlined way to access information on healthy ageing, aged care services available and the quality of these services;
4. want to obtain their selected services in an equally seamless way; and
5. have strong views about the need to have as much control as possible over their own death, as well as access to palliative care at home (where it is required) rather than having to go to hospital.

These key messages, along with the range of views expressed during the conversations on a wide range of reform elements, need to be taken into account by Government in determining a program of reform for aged care.



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