What we want in aged care – perspectives from older Victorians to the Royal Commission into Aged Care Quality & Safety

Date: 15 August 2019

Background:

"We're seeking to change the culture of ageing in Australia but sadly older people here are seen as a burden. We don't value their skills and what they can contribute. We use the word decline. This contributes to an aged care system that doesn't consider quality of life. Yes, we're encouraged to live a long time, as long as we don't get old," [i]Valerie, Melbourne workshop, 28 March

In 2019, COTA Victoria (COTA) conducted a round of interactive community information sessions to support older people and those people connected with them to make submissions to the Royal Commission into Aged Care Quality and Safety.

COTA hosted nine sessions from February-July, listening to about 269 participants, including carers of older people, family members and people working with older people in the aged care system. Most sessions were organised in partnership with organisations/councils and seniors groups. The cohort included older people living with disability, older people who are migrants representing 19 different language groups, and people living in regional Victoria. Participants were aged between 50 and 90 years, with most people between 60-80 years. People living in regional areas were less likely to be able to access the internet when compared to their metropolitan peers.

The goals of the sessions were to:

1. Educate older people so they feel more confident to make a submission.
2. Inform COTA on some of the major issues in aged care and some suggested solutions for our input to the Royal Commission into Aged Care Quality and Safety.
3. Collaborate with organisations/councils and older people so the information sessions are tailored for their needs. This included the intention to write organisational submissions, and to empower older people in their communities to participate as individuals or collectively to have a say about the future of aged care.

Getting people to speak up about their aged care experiences was not hard. Many people noted to the groups, that this was the first time they had been able to share their experiences, to be heard.

They were grateful for the opportunity, and hopeful this royal commission would lead to change for Australia's aged care system.

COTA has collated the information from table discussions hosted at each workshop into three sections. These are:

- Consumer issues about aged care quality and safety raised by older people (section 2),
- Solutions for aged care quality and safety suggested by older people (section 3) and a
- Summation of emerging community concerns as they translate into the way older people experience aged care in Australia (section 1).

There was some confusion between the role of this royal commission (hopefully addressed in COTA's information sessions), making an immediate aged care complaint or just needing someone to help them navigate a complex and confusing aged care system. In some instances, consumers wanted assistance with all three.

Section 1: Community concerns with aged care

Underlying the discussions at all the events were common causes of distress, which included disempowerment, denial of an individual's personal experience or identity, and culture and ageism.

Disempowerment:
"You feel powerless, why couldn't I help Mum?" Elizabeth, [ii]Point Lonsdale workshop, 10 July

Older people often felt disempowered by the current aged care system and "worthless". They say the system is confusing and set up to provide a basic level of care that reacts to people's health deteriorating rather than proactively considering their well-being. Providing a quality element to life so older people can experience joy is a last priority. This is often in stark contrast to older people's life experiences and choices prior to being 'taken over' by the institutionalised system. Carers and family members expressed feeling sad, angry and frustrated at having no control to support the older person receiving care, with some family members experiencing long lasting trauma years after their loved one has passed away.

Intersectionality:
*"Communities are lumped together but there are nuances and diversity **within** diversity, which is rarely acknowledged by the aged care system. For example people who are Indian nationals may not share the same culture or be able to communicate with those from a neighbouring state. It can cause tension, bring back memories and leaves people feeling isolated," Abdul, Dandenong workshop, 6 May*

Ageing and entering "the system," particularly aged care is literally feared by many older people – this was a common response at COTA's workshops. They feel they are forced to check their identity and dignity at the door, despite coming from diverse backgrounds. While there were many similar issues with aged care expressed by older people, there were also particular challenges for people depending on their intersectionality. People receiving aged care services all have a life story. Some of them have similar backgrounds, but all of them are different. Stories mentioned during COTA's workshops included:

- older people who have always lived with disability,

- migrants to Australia (note migrant was the term preferred by the community we spoke to rather than Culturally and Linguistically Diverse (CALD)),
- migrants from communist countries who fear complaining,
- people who never received an education, many non-English speakers,
- a carer with a lesbian partner with early on-set dementia,
- people touched by war, people who have survived a lifetime of abuse,
- a person without any family members, an older person who is also a carer,
- a person placed in aged care by family members 'because it's easier',
- workers who are the only contact for the remotely located older person they visit at home,
- the daughter of a mum who has no voice since her dementia progressed.

Ageism

"Most of us fear 'the system', that storm troopers will assess me, will take my house and put me in a home. There is disproportionate amount of funding between aged care and in home care when most people want to stay at home. Why are we building 120-bed institutions?" Amira, Dandenong workshop, 6 May

There was a perceived link between the experience of ageing and human deterioration when receiving aged care, rather than older people being provided with a system of care that embraces this life stage, and values individuals. Older people feel ageist attitudes pervade the system, both within institutions and broadly in the community. They expressed that as older people they feel invisible, infantalised and often portrayed or assumed as helpless. They say this is perpetuated in mainstream media. It is also evident in the way older people are excluded from the aged care system if they cannot access information online, do not have a certain level of digital competency or were never educated. The lack of respect and negative perception of ageing leads to people feeling they are a burden.

"Aged care is a failing system. There is too much red tape, it is hard to navigate the website, everything. It is designed to erode your confidence. All of it is so confusing that I can't get to first base. I lose confidence and just give up," Graham, Ballarat workshop, 20 June

Section 2 – Consumer issues raised about aged care:

Beyond the community concerns, consumers raised various issues in table discussions. COTA has grouped these below into subject areas, using the words from consumers. It should be noted these issues do not necessarily reflect the views of COTA:

Workforce and system failures – the quality and cost of care

"The volume on the TV in residential care is often turned up to drown out the moans of some residents," Graham, Melbourne workshop, 28 March

- The layers of fees undermine the total worth of packages, with administrative costs higher when you go on a package. It's confusing.
- Actual care time is often imposed, not consumer directed which leaves the quality of care patchy depending on who provides that care.
- The system is passive and doesn't consider proactive action which could focus on the well-being of the person. And when health care needs change rapidly it puts undue pressure on carers/family members, not the service provider who have the skills to deal with it.
- Recreation activities in aged care are limited, often delayed or cancelled. Often it's one activity per day, the same each week day, the same each week. And food menus are often the same. Bingo on a Monday and fish and chip Friday.

- The council implemented services are often well regarded because staff are considered to be consistent, better trained, the cost is affordable and can often meet more basic needs such as assistance with gardening and cleaning.
- Casualisation of the workforce has resulted in the reduction of staff quality, lack of continuity (and meaningful relationships), specific training gaps and workers not being supported.
- In residential aged care, particular issues include enough staff members with training, health and safety concerns (over-medication, injuries while in care, other residents violent and not supervised), language and cultural barriers (in Australia we don't hit non-compliant older people) social isolation and loneliness (no visitors, no walks).
- Hard to get clear, good information that is not "glossy bias" from a provider.
- Family members are sometimes not able to access service agreements or even know what package their loved one is receiving, even when they are the carer of that person.
- There is a lack of end-of-life planning.
- People's mental health needs are not considered. There is no support to transition into ageing or aged care. There should be grief counselling for the sense of loss and support for people who end up feeling depressed.
- Negative image of residential aged care creates a society stigma about aged care and a fear of this life stage, when there are some good providers/homes.

Self-advocacy and the rights of older people:
"If you don't have someone to advocate for you then look out," Betty, Portarlington workshop, 17 July

- Consumers are often unable to direct their care and are not aware of their rights.
- Older people are confused about the system and how to provide feedback. They fear speaking out and not being understood, particularly if from CALD background or living with mental health issues.
- Older people say they don't know how to speak up and say they don't want to sell their homes.
- There is an inequity of access to services due to the cost imposition, knowledge of what's available and the self-advocacy needed to access care. Some people have nobody advocating for them.

Transport:
"What happens when you have to stop driving – how do you get to medical appointments or hospital visits or to see a friend in aged care?" Wilma, Portarlington workshop, 17 July

- There are few options when people can no longer drive, particularly if your health condition restricts public transport access or you live regionally.
- Lack of transport means people can't visit partners in nursing homes or remain social themselves.
- In regional areas, transport services may lack enough volunteer drivers.
- Migrant communities say that sometimes there is a community bus but no suitable driver, because the volunteer drivers may not relate to culture differences and make inappropriate comments.

Cultural diversity challenges:
"There's no transport in the area where I live, no bus route to get to my doctor and a lack of transport to get to clubs even though there is five of us that want to go," Ra, Dandenong workshop, 6 May

- How do you meet the needs of a person when staff cannot speak the same language as an older person, or an older person can't speak English?

- Cultural communities are lumped together despite inter-racial diversity (eg. more than 22 languages in India).
- A staff member caring for an older person from a culture where that would be inappropriate, for example a younger "girl" washing older man.
- Concern about repercussions if a complaint is made, particularly if the person complaining is from a cultural background where people just accept care levels provided.
- Cultural differences in the way older people are cared for and respected "back home".
- As for all cultures, older people don't want to sell their homes to get care but for some migrants this is not even a choice because it is culturally unacceptable and seen as a failure.
- My Aged Care creates more barriers for people from CALD background. Information is in English and online – so often not accessible. Older people often rely on the next generation of family members to access services for them due to language barriers.
- Many CALD older people don't even know what services are available.
- Workers supporting CALD communities can find it challenging providing support to older people to fill out applications when personal information is requested as the older person doesn't understand why this information is needed, particularly if they weren't educated.
- Some older migrants have few/no family support or close social networks.
- Elder abuse is often not acknowledged. The understanding of it and the supports in place varies across CALD communities.
- Unknown gap of service provision for older migrants who enter Australia under a Contributory Parental Visa/Parent Visa and are required to have assurance of support (from family). They are not able to access benefits for determinable periods (usually 10 years), leaving them vulnerable to elder abuse or often experiencing isolation from anyone outside their family.

Older people with disability:

"Language used in the broader disability sector focuses on independence, participation and inclusion – it's about what you can do with supports in place. But the way disability is framed under aged care sector is very negative and based on principles of frailty and ageing. It's about decline," Simon, Melbourne workshop, 3 May

- Older people with disability think there is a lack of staff with appropriate assessment skills and understanding for older people with disability, and sometimes not enough staff members to meet the additional needs.
- Lack of clear funding stream and access for Assisted Technology and mobility aids for people over 65 years. Some older people are having their purpose-built equipment (eg wheelchairs) taken off them to be replaced with generic items that don't meet their needs.
- Waitlists can pose unique challenges for people with a disability who have a degenerative condition. Access to care needs to be timely so condition doesn't decline unnecessarily.
- There is a lack of simple information and education for people about their rights, choice and control as they move from the enabling disability sector to the aged care system, which focuses more on a person's health decline. So people have to be strong self-advocates.
- NDIS age limits are arbitrary. An individual who is under 65 years can have all their support needs fully funded, but someone with the exact same needs who is over 65 will be subject to high costs and may not have all of their needs met, even though they may have lived with disability for their entire lives.
- Accommodation access issues. Even just getting in the front door can be a problem.
- Some people are not receiving copies of critical documents, such as service agreements.
- People are having disability-specific funding, such as funding that is provided under the Commonwealth Continuity of Support Program removed when they enter residential care. This leaves them without the additional funding needed to provide disability-related support, such as attendant care support or a support worker to enable community access.

- One person was happy with the amount of funding they received (level 4 home care package) but stated that there were too many restrictions on how they spent it for it to be of any use.

Additional barriers:
"Adding to my wife's dementia, she has chronic arthritis in both knees which require specialist intervention. Sometimes she is confined to a wheelchair and the task of pushing her around the uneven surfaces of a country town and lifting her in and out of the car are becoming increasingly physically difficult for me. Then her respite service withdrew its availability until she is ambulant. It seems the only option is to sell our home of 21 years and move to the city," Phil, Point Lonsdale workshop, 10 July

- Older people who identify with different intersectionalities can experience greater isolation and loneliness because they don't feel they belong – anywhere, and they can feel no-one has time to listen to them, let alone understand or accommodate their needs.
- The sector needs innovative support options to keep people connected to the outside world e.g. telephone volunteers in their own language, local language-specific radio programs, LGBTI-friendly visitors for LGBTI people living in aged care.
- Cumulative life experiences can include leaving school early or not attending school, resulting in low literacy levels for older people across the community, including older migrants who just get lost in the system, particularly if they are alone.
- Carers can often experience burn-out, not just from the exhaustion of caring but of dealing with the system. One older carer told us he couldn't get information from My Aged Care about his wife's home care package to consider the next stage of care because they did not have his details in the system. They wanted to speak to his wife, who had become non-verbal with dementia. This was despite him being nominated as her carer for medical, Medicare, MyGov. He had to provide a statutory declaration from his GP and complete a My Aged Care form, which arrived with no return address, requiring yet another long phone call. Three weeks later he was still waiting for a response to his correspondence while caring for his wife 24/7.

Regional communities:
"There's a feeling you're just being locked away – and they just want you to die," Harry, Warrnambool workshop, 27 June

- Transport is a huge issue in regional communities – options and cost are restrictive, which increases isolation from services, supporting loved ones in care, shopping and socialising.
- Access to doctors and services both in care and at home is difficult with long wait lists, even just navigating the distance to find people with information to help you. For example, it takes 3-5 hours to go from Point Lonsdale to Portarlington by public transport for what is a 21 minute direct drive.
- Older people feel a disconnect from their community when they move into care, particularly if they move a great distance to access an available bed.
- Mental health challenges in regional communities are huge, especially for older men. We need more social options like Men's Sheds.
- Lack of providers and choice on the ground to meet the demand, with a lot of the funding going to the service provider costs (such as the cost of getting there) not the actual care. Some doctors have no experience treating people in aged care.
- Care is not person-centred, individualised. The quality of care varies, but there is a plus with smaller towns – bad news travels fast, so workers are more likely to take care.
- Lack of alternative housing for younger people with disability living in aged care.
- There is an assumption that people have families or other support systems, but more families have to keep working these days or they just live too far away. Older people often have little knowledge of services available to support them and no one to help them find out.

- Internet access and online services are often poor, which means people are even more isolated and unable to get information or support.
- There has been a change and decrease in the support provided for "unpaid" family carers due to Government changes in policy and funding which puts pressure on older people, both physically and financially.

Section 3: Solutions for aged care:

Participants often had suggestions on how they would like to see the system improved. These have been grouped into topics and again do not necessarily represent the views of COTA.

Topics	Participants' Suggestions
Home care packages	• Use the electoral roll to notify people of their entitlements (regarding aged care) at 65 years. • Provide the package that meets the needs of older people in a timely fashion or increase the package - lengthy wait lists means the needs have often increased to the next level of care. • Introduce more than four package levels to address the needs of older people. • Address price gouging by service providers who have multiple charges for administration and case management before any care is provided. Perhaps provide set fees or maximums and demand transparent, simple fee statements for consumers.
Workforce	• Better training, including specific training for challenges beyond ageing such as disability, people from migrant communities and people with dementia. • Increase staff ratios, including having better quality staff such as registered nurses on every shift. • Do random unscheduled inspections of age care facilities. Trial the effective Office of the Public Advocate (Vic) model of volunteer community visitors, who are legislated to do spot checks of supported accommodation services, disability group homes and mental health wards. • Increase the pay to attract better quality staff • Listen/consult every older person about what they need to provide person-centred care. • Staff need job security through permanent roles – reduce the reliance on casuals. • Employ staff committed to treat people as individuals, with respect and dignity and reward care provided with kindness, integrity, respect and compassion.
Increased quality and flexibility of services	• Look at the other aged care models that work, internationally and in Australia – where older people thrive and don't just survive.

	• Move aged care away from a deficiency framework that emphasises decline/disease/frailty. • More housing options needed for people with complex needs living in the community. For example, access for people with disability can be challenging. • Improve gaps/transition between NDIS and aged care. • Financial assistance/options to support older people to access low-cost services such as gardening services • Innovative approaches to provide better quality care seem to be dependent on the interest of a provider, not universal. Some community-based solutions would be great such as art therapy or music lessons. • Consider simple solutions to keep people more connected to diverse communities, such as language-specific radio programs and church services. • Provide aged care information options that meet an individual's needs, ask them! For example, in the older person's first language, in plain English not complicated, in written format for people without computers, recorded information for people with vision impairment. • More social interaction so people don't rely on busy families, particularly to meet cultural needs. • Provide transport options to support older people's independence or connection to community, especially for those in rural and regional areas and who may have moved long distances to obtain residential care.
Social inclusion / isolation	• Focus on people living alone – potentially lonely people. Don't let people die alone. It is important for people to have personal alarms. • Better transport options so people don't miss medical appointments due to lack/cost of transport. • Provide options for older people who cannot access the digital world. • Boost companionship programs. • Support culturally specific seniors clubs who often volunteer the provision of community connections, recreational events and ethnic specific food. • After a hospital stay provide patients with all the information on services and support they can access.
Residential aged care	• Better quality of food (not party pies, sausage rolls) in aged care facilities and more fresh food, plus a glass of wine each night. • Cater for dietary needs. For example provide People with coeliac disease need fresh food, not just pre-packed/frozen gluten-free food • Collaborate with community organisation with specific language/cultural connections to support an older

	person's transition into care either in home or at residence. • Relevant bilingual staff are critical to providing care. • We want to make choices, for everything, from when you can eat, what you eat, to living with similarly aged people or people from similar cultural backgrounds, and even choosing a doctor, so if you're Muslim you can have Muslim GP. • Provide interesting activities, not just TV, a walk around the block, bingo and colouring-in books. Some places do this well, such as attending art exhibitions, music lessons, movie days, and having entertainers. • Address specific training needs such as dementia care. • Residential care should be a home, so move away from a medical model, staff could not wear uniforms and have more engagement with local communities. • Mercy Place at Ballarat is a "game changer" with 8 people groups, modelled on a village. This includes a grocery store, a pub with a two-glass limit, residents being able to help with cooking and washing. Activities are organised, including exercise class choices. People with dementia are part of the community. Care is modelled on relationships not ratios.
Retention of Council services	• People who receive care via local government support often want this retained: "Governments at each level need to be more involved in councils retaining aged care services where desired and effective. It keeps it local and personalised."
Empowerment of older people	• Make it easier for people to take up grievances with the system without fear of repercussions. • More support/respite provision for carers/family who are often older people, and possibly emotional/challenged and physically exhausted by the changing circumstances. • More service provisions for people to stay at home longer or want to stay (supported) with family.

COTA Victoria hosted the following information sessions, with collaborators mentioned:

8 February: *Royal Commission into Aged Care Quality and Safety information session*, Victoria University, Melbourne CBD (Chinese translation provided, Interactive live-streamed via Facebook)

28 March: *How to write a submission- Royal Commission into Aged Care information session*, COTA Victoria (language services offered)

3 April: *How to get your story heard - RC into Aged Care information and how to write a submission*, with the City of Darebin at council chambers, Preston (language and relay services offered)

3 May: *Disability & Aged Care – Making aged care work for people with disability*, with the Disability Advocacy Resource Centre at Queen Victoria Women's Centre, Melbourne (interactive live event relay provided)

6 May: *The Royal Commission into Aged Care - How to tell your story from older people from culturally and linguistically diverse communities*, with Southern Migrant and Refugee Centre (SMRC), Dandenong (interpreters offered)

20 June: *Royal Commission into Aged Care community forum – how to get your story heard*, Ballarat Community Health, Sebastopol

27 June: *The Royal Commission into Quality Safety and Aged Care free information session to help you tell your story*, South West Carer and Respite Services Network, at Archie Graham Centre, Warrnambool

10 July: *Learn About the Royal Commission – How to get your story heard,* Bellarine Community Health, Point Lonsdale forum

17 July: *Learn About the Royal Commission – How to get your story heard*, Bellarine Community Health, Point Arlington forum

COTA Victoria would like to acknowledge and thank our partner organisations/collaborators:

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Southern Migrant Refugee Centre (SMRC)
Ballarat Community Health
Bellarine Community Health
Bellarine Older Person's Network
South West Carer and Respite Services Network
Community members, their carers, family members, and staff members of aged care providers who often attended the information sessions anonymously.

[i] Names have been changed to respect the privacy of information workshop participants.
[ii] Workshop partners are listed by date towards the end of this appendix.