

Visions for Aged Care

Response to Consultation Paper 1

Royal Commission into Aged Care Quality
and Safety

AGED CARE PROGRAM REDESIGN: SERVICES FOR THE FUTURE

January 2020



Preamble

National Seniors has represented the interests of older Australians with research-based advocacy for over 43 years. Drawing on perspectives in a number of recently published and some yet unpublished research reports on aged care and new older Australian’s comments gathered in the last month, we are providing this response to the Royal Commission into Aged Care Quality and Safety Consultation Paper 1, *Aged Care Program Redesign: Services for the Future* (hereafter referred to as the Consultation Paper)

Contents

Introduction	4
Purpose.....	4
Overall - negativity dominated but so did ‘choice’	5
PART 1: Responses on the proposed Program Areas	7
Information, assessment and system navigation.....	7
Entry-level support	11
Respite	13
Restorative care.....	14
Care – personal care, nursing care and allied health	15
Specialist advice and services	17
Access for diverse groups	18
Access in rural and remote areas	19
Financing aged care	21
Quality regulation.....	24
PART 2: Building a new culture of ageing and planning	25
Re-imagining ageing in Australia.....	25

PART 3: Older Australians’ Ideal Aged Care Experience	28
National Seniors responses summarised	32
Substantially improve Information, assessment & system navigation	32
Entry level care	32
Respite	32
Restorative care	33
Care – personal care, nursing care and allied health	33
Specialist advice and services	33
Access for diverse groups	33
Access in rural and remote areas	34
Financing aged care	34
Quality regulation	34
Conclusion	35
References	36
Current Publications	37

Introduction

Purpose

The Royal Commission Consultation Paper invited submissions addressing how a new aged care system should be re-designed, focusing on creating “the best possible program” enabling older people to have “the best life possible.”

National Seniors embraces the Royal Commissioners’ recognition of the need for a fundamental overhaul of Australia’s current aged care system. We are concerned about risks of the proposed ‘complex and interdependent’ change without carefully planned communication before and throughout and a long-term change strategy and plans with clear identification of who will manage change. Many older Australians are just getting used to the system we have. As well as we report here, it is the view of older Australians that there are already plenty of good practices to grow and bad ones that should be stopped now.

Our response provides a counterbalance to the largely negative but factual depictions of aged care that have emerged from Royal Commission proceedings to date. We will emphasize in our response the positive aspects of Australia’s approach to aged care and older Australians visions for a better future. In particular we identify what people want to keep and grow as well as what to remove. As we contemplate major change it is crucial to ‘accentuate the positive’ and ‘eliminate the negatives’ to facilitate acceptance of changes.

We sought to ensure that National Seniors’ response to the Consultation Paper accurately reflected current views of Australia’s older population and ‘topped up’ the extensive research on relevant themes done by National Seniors over the last two years. The specific program areas do not provide suitable questions for a general audience so more general positively directed questions were used as prompts. We put the following questions to older Australians soon after the Consultation Paper was released. We included in this full participant information and their agreement to consent to have their responses reported publicly by those responding.

These were the questions asked:

- 1. In your experience, what aspects of Australia’s current aged care system work well?**
- 2. What would be your ideal aged care experience? You can respond however you like, but areas you might like to focus on are:**
 - accessing information
 - being assessed
 - making choices for yourself or loved ones

- **paying for care**
- **changing between types of care**
- **end of life care**

Responses to these questions were then organised according to their relevance to main program areas identified from the Consultation Paper and are presented here *verbatim*. These inputs were interpreted in the context of prior National Seniors research reports relevant to the Consultation Paper. As yet unpublished findings from the National Seniors Social Surveys have also been included as evidence where relevant.

We received 222 responses to the first question asking about the positive aspects of Australia's aged care system and 225 responses to the second regarding an ideal experience. While this work has been constrained by the short time period between the release of the Paper and the Christmas/New Year period, the responses were extensive and were also validated against the findings in previous research. The responses typify the conversations that older Australians are currently having about aged care. Please note that comments in this report reflect the exact text typed in by participants and have not been edited for typographical or grammatical errors. The comments included represent the views and sentiments of individual National Seniors that are not necessarily those of the organisation as a whole.

Overall - negativity dominated but so did 'choice'

Despite the fact that we asked respondents to reflect specifically on the positive aspects of aged care in Australia, many responses remained strongly negative, with over 1 in 5 respondents stating that there were no aspects of the current aged care system that worked well. Others commented negatively on specific aspects:

In my experience, I cannot see any aspects in the system truly and consistently working well

Don't think any of it works well, needs a good overhaul

None, waiting lists too long, assessments take forever, retirement homes a rip off, etc etc

It has not worked well for me at all. I have a terminal illness, live alone, but have been rejected for Aged Care package as 'Too well'

My parents often said aspects of nursing home care were appalling. No staff around, people wandering along, calling at night out for people, only 2/3 staff at night. I personally couldn't find a carer when my mum was dying to give her a hug. She had an alarm and I didn't know how to turn it off. She had sponges around her bed there was nobody around, it was awful!

Before improvements in care are made, these dominant sentiments indicate there will be a need for an extensive campaign to improve the positivity of Australians about aged care and their acceptance of communications about changes. Subsequently positive experiences in a reformed system can assist with this attitudinal change. Currently Australians of all ages are loath to make long term plans preparing for a longer life without good aged care to attract them. National Seniors proposals on what to do about this are discussed later in the text.

Considering the positive themes, people commented on good age care facilities:

Quality of building structure lighter and brighter more modern and lack of faecal smell entering the newer building lack of offensive smell incontinence

Many of the facilities are very good building wise, and depending on the region you live in waiting times are not too long as long as you have the funds to go in as a private resident

Some noted that we should be appreciative that we have a system in Australia that supports families:

...its existence. There are countries where there is no such system for caring for old people

Whilst there are many flaws at least we do have an aged care system

the fact family do not have to babysit their aged parents in their own home & they can have a life too & they do not have to worry they will turn up one day and find their parent dead on the floor

People were interested and excited in change and innovation in their local environment:

A trial and now permanent service of the "GRACE" team, standing for "geriatric response aged care " run out of a hospital. This response team was trialled and found to be very successful in keeping Aged care residents out of hospital whilst receiving excellent, experienced care from nurses working out of the hospital. My mother was cared for by the team on at least five different occasions, resulting in her being able to be assessed and treated without admission to hospital. I cannot speak too highly of their service, especially for those with dementia. This also helps the hospitals to keep beds free for acute health care

The availability of services to keep older people out of hospital were valued. There were also some generally positive comments about some service models that have worked well for Australians so far:

Some aged care facilities work very well. Some in home services meet some people's needs

In the experience of both my late wife and myself both home care and residential aged care have worked quite well

Small aged care facilities on country towns where its highly visible that care of the elderly works well

The availability of Residential Aged Care Facilities on site in Retirement Villages

Putting people at the centre of aged care is the key principle guiding the proposed system in the Consultation Paper and supported in previous National Seniors' submissions. A person-centred approach offers people autonomy, especially in decision-making capacity. The overarching theme that emerged from respondents' comments was the primacy of having and making choices about all aspects of care, from initial engagement with the system to the end-of life experience:

Not to be talked over me as if I was not there and ASK before any decision is made regarding me

Making choices is a primary concern. The assessment process seems daunting when you investigate it

Making choices for yourself with sufficient govt. funds for choices to be possible

Choosing where we would like to spend our later years

Making choices myself, deciding when to pass them by myself

These freely provided sentiments confirm support for the key guiding principles proposed in the Consultation Paper. The challenge is how to embed and action these in a system that is, in many parts, broken. The centrality of improved staff training to achieve this is being actioned through the Aged Care Workforce Industry Council. There is a need for a well planned and facilitated conversation to engage Australians of all ages in the realities and positive features of an ageing society. This is addressed later in this response.

PART 1: Responses on the proposed Program Areas

Below we provide the recent responses *verbatim* to the two-questions and, other National Seniors research in the last 2 years, relevant to the program design topics identified by the Consultation Paper.

Information, assessment and system navigation

Information, assessment and system navigation are essential services and are a high priority for improvement to allow people to meet their needs without paying navigators or overburdening carers. People are only empowered to make choices when they have adequate information. The difficulty previously expressed aptly by National Seniors members is that “you don’t know what you don’t know” when it comes to aged care (1). This surfaced again in recent responses to the questions:

If care is required unexpectedly we need to find out quickly what "we do not know", where to find what is needed, and who to contact. This is not everyday stuff for the average person

Currently, when people access the aged care system they are often driven to do so by a crisis and struggle to navigate its complexities and unexpected delays when help is needed immediately:

Most older people only ask for help when they know that they can't go on much longer. The jumps and hoops and mental "torture" that some go through to access help is really too much for people in pain and/or stress to cope with

I know how much paperwork there was to get my fee level to have a home care package. I just had an answer on that (I had to get my local member to intervene to get a figure) and then I had to fill out another set of figures to get the daily rate I'd need to pay for my wife to be admitted to a care facility. This was because I am a self-funded retiree. There needs to be a single form so that families in crisis don't have to jump thro' all the red tape twice over

Access to information before a crisis occurs should be promoted but this won’t be effective until people have more positive attitudes to aged care. This information exchange is most critical at the entry level first encounter on the care need journey:

My husband and I are in our 80s, are still self reliant and care for each other thankfully, but know that assessing information when we have no family to ask for help, may be a concern. We really know nothing other than hearsay from acquaintances what may lie ahead of us. It's quite frightening but we carry on just taking day by day

Please send pamphlets in the mail to potential customers i.e. over 70's so they know what to expect with home help or at nursing homes, so they don't need to fear going into a home after all the stuff that has been on the news

National Seniors has not yet had the opportunity to assess members’ experiences of the re-designed My Aged Care website, however previous research highlighted the level of dissatisfaction with the experience:

have never met anyone who didn't find the journey through My Aged Care and aged care itself very disjointed, extremely frustrating and time consuming

The need for face to face alternatives to online information was a common theme in our report (*The Centrelink Experience*) and the Consultation Paper emphasises the importance of face-to-face access to information. Nonetheless, people also acknowledged the utility of online services to provide information and the improved usability of the My Aged Care website:

It's good that so much information can be accessed on line regarding options open to the elderly but not all seniors are able to access this

Accessing information is very difficult... but the revamp of MyAgedCare website is a step in the right direction

Our recent study of digital literacy in older Australians (2) found a diversity of digital abilities from very high to none. Regardless of literacy levels, the undeniable reality is that digital innovation will continue in aged care and, more generally, in everyday life. Digital literacy is becoming as important as service literacy and our research found that peer support is one good way of encouraging it. It was preferred to young-old mentoring because the young moved to fast and didn't understand problems they had. As well literacy, the older Australian interfaces with digital technologies need to be codesigned with older Australians to minimise the need for external help and navigation. As well as alternative non-digital communication channels, there is a need to bring people along with digital changes and not leave them without options to keep up to date.

There were successes of the current system in delivering information and assessment that were acknowledged:

Australia has made provision for elder care and there is a website for users to find available care near them

MyAgedCare appears to be very good at keeping people at home, for as long as possible. Excellent Health policy! Thorough Assessments leads to appropriate care at home.... although these take too long to accomplish

My Aged Care and the DVA equivalent are under resourced but provide excellent service

Entry process into aged care is organised well

Help is actually available

While noting significant delays, people also praised the current ACAT assessment:

The assessments completed by ACAT. They are prompt in their assessment and have a professional approach in consideration to the Level of Care necessary.

The Assessment process by ACAT was brilliant & easy. But they have long delays till appointment time.

Others found the information they were looking for and advice on availability of services was noted as an aspect of the aged care system that worked well:

Information on entitlements is easy to access

Entry process into aged care is organised well

While others still felt the need to state that the obvious characteristic that was still missing. They pointed out that an ideal aged care system should provide clear and simple information:

I would like my options to be made clear to me in plain English, with respect for my wishes. I want the services to understand me - it's too difficult if it's the other way around

Full & clear information to provide a valid choice

Once I put my hand up for assistance, knowledgeable people materialise to assist me to navigate my way through the maze and devise a plan/strategy, right from first step to end of life care. Including legal documents/requirements

Such a system would include readily accessible overarching information and a wholistic assessment system that includes assistance that could be provided by DVA as well as Commonwealth and State aged care services. That is a one stop shop. Such a system would include fully funded support and extend to user pay options

Information availability and assessment processes are highly relevant to managing care. For respondents, the ideal system enables them to manage the complexity of co-ordinating care and easily transitioning from one level of care to another:

Ability to change between types of care easily as circumstances in mine and others occur

The process of moving from one level of care to another should be stress free so that the person doesn't feel a burden

Changing between levels of care should be very simple and easy and determined by the person's doctor and the individual's needs

The role of medical and allied health professionals in providing information was also appreciated:

In view of the complexity of the system I believe that steps should be taken to ensure that medical and allied health personnel have the knowledge and ability to provide guidance to their elderly patients about aged care options

This is a topic recently addressed in our report on service literacy (1). Medical and allied health professionals are often first points of contact and consequently they have a key role in providing accurate and detailed information to older Australians. This remains to be addressed in training and practice since it is known that many providers of medical and allied health care have little knowledge of aged care.

The proposed Consultation Paper strategies have a strong emphasis on person and family direct contact with care providers which is the ideal but the most costly care modality. Older Australians don't want change plans which are unlikely to be funded. Better information to older Australians and their families and digital literacy training are good investments to alleviate some costs. Savings made by both government and industry with digitisation must be allocated to digital and related literacy training to bring people along with the changes.

Entry-level support

Many participants mentioned Home Care as an aspect of the current aged care system that works well. As will be discussed further there is little distinction for older Australians between Home Care Packages and the Community Home Support Program:

The in-home care at this stage for me is domestic assistance which has been a godsend to me - I have a permanently disabled right shoulder and my wonderful GP arranged the care package as an alternative to pain medication

Adequate support to the elderly to stay in their homes as they age is needed but insufficient packages available and last time I checked there was a huge backlog in processing applications. This leaves applicants wondering if they should apply before the assistance is required so that they are not left waiting when they need assistance

The ability of offering our aged persons a chance to stay at home for as long as possible. Providing assistance for these people is of utmost importance, and with continued aid and improved steps put into place we hopefully can keep many, at home for longer and in an environment they feel secure in

Home care is great but there is a lot of companies just in it to make money and no quality control

My husband's Home Care Package was great as it allowed some time for me while I was caring for him

Once you're in care, it works reasonably well, but getting that care is another matter.

High levels of satisfaction with Home Care

A major finding of the National Seniors research on home care for the Workforce Strategy was the solid positive sentiments for home care. Recipients of Home Care Packages Program (HCPP) and Community Home Support Program (CHSP) were surveyed in the National Seniors Social Survey 2018, and further work on unpaid care is now in preparation for publication.

Care and support needs

760 people in our survey with over 4,000 respondents had accessed home care. Of these 74% of HCPP recipients agreed their needs had been met compared to 59% of CHSP recipients which may relate to components of HCPP which provide higher levels care than CHSP and clients waiting for HCPP can be provided with CHSP services.

However, a higher proportion of HCPP recipients (44%) compared to CHSP recipients (37%) thought things could be done better.

There was little difference in the key value of supporting client independence with 56% of HCPP recipients agreed that their independence was encouraged compared to 52% of CHSP recipients.

Also, a very high percentage of recipients of both programs believed workers treated their household with respect across both programs: 94% for HCPP and 91% for CHSP.

Finally, a higher proportion of recipients of **HCPP** compared to **CHSP** believed that

- workers explained things well (75% HCPP vs 69% CHSP),
- were well trained (80% HCPP vs 69% CHSP) and
- had a good relationship with the household (84% HCPP vs 77% CHSP)

Satisfaction with the organisation

HCPP recipients (50%) believed the organisation was *well co-ordinated* compared to CHSP recipients (47%); but 72% of CHSP recipients compared to 69% of HCPP recipients thought the organisation was *well run*. This indicates little difference between the programs.

The lowest level of satisfaction with either program was for whether consumer directed care helped meet needs. However, there was little difference with 37% of CHSP recipients and 39% HCPP believed CDC helped meet their needs.

CHSP has proved to be a flexible element of home care and highly valued by providers to diversity groups and in rural and remote areas. It has been under-valued in the shift to what has proved to be a poorly designed HCPP. It is one element of home care that older Australians want to remain and grow and not disappear. They do, however, remain concerned about administrative fee levels:

I think Home Care Packages are a good idea and when I was looking after my wife (died 14/06/2018) I was offered a Level 2 and then a Level 4, However, I found the Providers were taking a large share of the money in Administration and fees. Even with \$52,000 a yr. they didn't want to give me any more than 15/16 hrs a week. I dealt with a dementia patient with serious incontinence issues, unsettled sleep, etc, etc. I was grateful for the help I got and the carers who came were mostly excellent. I was old myself and found difficulty dealing with injuries such as stubbed toes (toenail kicked off), finger injured in slammed car door, gravel rash on hands and knees from falling when more care should have been taken, etc. All these needed me to be bending down and then I could hardly get up again. Getting my wife up the floor was also difficult, even though she was only a small woman. Sometimes I had to ring a friend to come and help me get her onto the bed as I have a problem with my back. All in all, I was glad I was able to keep my wife at home until near the end. I am concerned about the vulnerability of people in care facilities once they can't speak for themselves. They are seriously at the mercy of staff and other residents.

My husband's Home Care Package was great as it allowed some time for me while I was caring for him.

CHSP was intended to be taken over by the HCPP but it remains as a valued model without unspent funds. The purpose and interaction of the two programs needs to be clarified so that there isn't unnecessary complexity leading to, for example, possible double counting of people wait listed for care and the programs are harmonised. Despite the real concerns about the difficulty of accessing home care, it is universally preferred and needs to improve in quality and expand its availability. In the view of older Australians, it is clearly the 'best bet' for expansion and innovation.

Respite

Our previous response to the Royal Commission (3) provided evidence of lack of appropriate respite care to maintain the carers of people being cared for at home. A significant tension remains between supporting carers and preparing people for residential care. In response to

the Consultation Paper statement that respite care should not operate as an opportunity to “try before you buy”, a 93 year-old aged-care resident forwarded us his disagreement:

Persuading a loved one to spend a short period in an aged care facility may be an important way of encouraging them to becoming full time residents if such proves to be necessary

Clearly the priority must be to support carers working at home to provide for an older person. This is an area that should be another priority for growth to sustain stressed home carers. It is a natural component of growth in funding for home care over residential care. This is a balance that does not exist at the moment with extensive waiting lists in both home and residential care that need to be addressed.

Restorative care

Respondents had positive comments about existing arrangements:

The range of services available in some aged care facilities for maintaining an engaged life. Lifestyle Co-ordination support and Diversional Therapy. Activities, social interactions with the communities. Seniors and children/youth programs. Sharing knowledge. Schools and Church groups enjoy this. Animal Therapies, Farms visiting the facilities. Owning animals at the facilities that Residents care for Cats, Dogs, birds, Fish... Homelife Domestic activities are popular. Indoor and outdoor. Recognition of special events, including birthdays, sport, art, cooking small easy things to share. OH&S is easy to apply. Plans, back-ups, funding all are part of the assessments when considering activities. Monthly meeting with the residents and a Newsletter is crucial to them accessing appropriate Lifestyle support

the fact family do not have to babysit their aged parents in their own home & they can have a life too & they do not have to worry they will turn up one day and find their parent dead on the floor. Some centres get residents active in programmes such as dance, music, reading clubs, board games, outdoor games, centre walking groups etc

Health and Wellness programs for over 65's. They keep us active, engaged and make it easier to socialise with people of our own age

In some aged care facilities the entertainment is very good when ALL members are encouraged to participate

Preventative programs ie exercise, health, general home maintenance

As well as ideas for improving quality of life through restorative care:

I've witnessed the joy that my dog visiting brings to the residents of my aunt's aged care home when he visits. Animal presence in residential aged care and home care services would be a huge blessing, and an easy one to implement

Another factor is happy staff, to be given the training needed to carry out their tasks, and involve them in activities outside work to build their camaraderie. Works a treat when they attend trivia nights together and also when encouraged by a great Diversional Therapist, dress up one night a week during the evening in costumes, anything from Abba to Back to School outfits, raises the morale of both resident and worker

There are many sophisticated restorative programs of which older Australians are unable to name. These statements expressed their support for and interest in restorative care. However restorative care cannot be forced on people. It has to be a choice offered to them. National Seniors research in press also emphasises to importance of maintaining an active life at younger ages to enable good health and better acceptance of restorative care later in life (4) .

Care – personal care, nursing care and allied health

The strongest theme to come through in relation to care was positivity regarding carers of all types and the work that they do:

There are despite the media coverage some very dedicated workers in the aged care system

The dedication of the majority of the Aged Care workers is exceptional

Caring Staff drawn from ones Local Community, people who know us Oldies. No Foreign workers who have different values

There are many dedicated and very good staff and good providers we need to highlight these and look at what they are doing. We are hearing only negatives.

Kind and compassionate carers. Facilities that are well staffed, and have experienced and knowledgeable carers

The care shown to those in care (e.g. to my late husband) and to the family (certainly shown to me!)

Some staff are very caring and supportive of their clients

There are some aged care homes which really do look after their clients e.g. 'local facility mentioned'

In my limited experience, some places care

It is critical that positive messages such as these get back to currently embattled workers in aged care. The Royal Commission exposés have taken their toll on good care workers. There will be a campaign for recruitment of new workers into aged care which is a strategy of the Workforce Council. This could be supported by making existing workers know that they are valued by older Australians.

This praise was provided with accompanying acknowledgement of the challenges that carers face:

The majority of carer's are very caring but their time is restricted

The caregivers work extremely hard are dedicated but are not supported and are under paid

Many of the staff are very caring towards the residents but are overworked and underpaid

Caring staff who are overworked with lack of assistance still support residents well

Despite the adverse publicity many people who work in the aged care system are dedicated. Unfortunately, they are grossly underpaid hence the difficulty in tempting others to come into aged care. They need more positive encouragement

The majority of floor staff actually care for their charges and try to make their days a little better

Initially going into aged care seems quite good but drops away because of lack of enough staff

At core of these challenges are training and workforce improvements, now being addressed by the new Workforce Council.

Respondents typically had positive comments about nursing staff and the use of registered nurses:

ONLY in facilities that mandate Registered Nurses to provide both Administration & residents care plans, does everything function well, residents are happy & properly treated & properly medicated

Having registered nurses as team leaders instructing care staff attend general care

People noted staffing issues in residential aged care, addressing understaffing which is open to options like mandated ratios:

Where people are allowed to exercise choice in residential care, such as when to get up in the morning, choice of food, choice of activities and when to go to bed at night, this is a good thing that needs to be part of everyday practice. FOR THIS TO HAPPEN THERE NEEDS TO BE ENOUGH STAFF WORKING THERE TO BE ABLE TO MAKE THIS HAPPEN. Currently many residential facilities do not have adequate staffing to comply with the aged care standards that commenced 1 July 2019

When a facility has permanent staff both full, part time and casual who receive satisfaction on caring for people in residential care vs agency staff who are often newly qualified and many have poor command of English frequently not understanding what is being asked by relatives and with older residents being unable to understand them at all

The topic of tertiary care skills training was recently addressed in the Aged Care Workforce Strategy (5) and remains to be addressed in training and practice. The initial focus in the Aged Care Industry Reference Committee (IRC) has been on personal care workers. The quality of skills training is one area of concern among others being addressed. The comments in our survey, while not explicit, would be supportive of at least minimum staff ratios and ensuring that money from government goes directly into care.

Specialist advice and services

Respondents explained in detail the way in which the public health system fails older people with multiple chronic health conditions:

There is a glaring problem for the elderly that suffer from chronic health issues particularly when there are multiple chronic issues, any of which could be termed terminal. When a patient reaches this unenviable stage of life their GP will, because of the complexity of treatment and medication, refer the patient to a Specialist treating the particular issue. The best explanation is to relate to you my own experience. My diagnosed conditions are PTSD, Complicated grief, Major Depression, Osteopenia, Diabetes, Fibromyalgia, COPD and over the last year loss of Balance, Craniofacial hyperhidrosis. My Aged Care will not pay for any process/consultation that is covered by Medicare. As we know Medicare does not cover true costs of treatment. Here I am receiving Level 3 My Aged Care however I cannot utilize these funds to treat my chronic medical conditions. I have no answers and I am hopeful that you may see these anomalies as a seriously flawed method of caring for those patients left with No hope and unable to look after themselves

Another respondent noted flaws in the health system in terms of wait times and costs of specialist health care:

Most sections are OK but health is a major issue both in the public sector with waiting lists and delayed treatment and the private sector with increasing gap costs of specialists

The issues around specialist services were the familiar ones, availability and costs, particularly out-of-pocket expenses and the limitations of narrow focused specialties for people with multiple conditions. There is growing innovation and capability of providing specialist services in the home which should be prioritised. However proper geriatric care, when available, is the best modality to deal with the multiple conditions but it is currently a very limited resource. This requires workforce planning at the higher end of the skills range and liaison with tertiary education and medical colleges.

Access for diverse groups

National Seniors has focused its attention on new and emerging migrant communities as among the most vulnerable of diversity groups (6). Many issues occurring in their communities were captured in focus groups run with Horn of Africa communities, Karen (Thai-Burma Border), Central American (US swap) and others.

Language barriers affect people's ability to access the aged care sector and more if they have spent time in refugee camps without access to English language. This leads to issues in accessing My Aged Care using family members as a translator. Cultural beliefs and practices are also important such as ageing in place and dying at home putting extra burdens on informal carers particularly CALD women when the family member has dementia. Unfortunately, then the long wait times for aged care Home Care Packages which genuinely surprise and confuse them:

In African Australian community, letting your parent to go to residential care is the last thing, it is taboo. One of our members sent his 75-year-old father to residential care. The whole elder in the community came to me not to send his father, even the priest. I said there is no way we can intervene. Another man had cancer and they said he had to go to palliative care and the family said no. All African want to die at home rather than send their family to residential care

Being at home leads to loneliness of older CALD people when their family members are at work or school, and also isolation felt by CALD carers. Because of their outer city locations transport services to support aged people in their communities are important.

Whilst there are cultural and linguistic advantages of digital access, digital issues in accessing aged care information occur through the cost of digital technology and having to access websites. Clearly this is exacerbated for refugees, for whom language and digital literacy become even greater barriers to entry.

The remains a status but responsibility seniors feel to improve the unity of the whole community:

The unity has to be done by the senior. It is difficult for the young people, but if we as the senior citizen do that, then our country will be a good country. I appreciate the work of my brother bringing people together. I work with the Uniting Church, voluntary

Participants advocated for grassroots, bottom-up solutions to the issues experienced in their communities, and some were already actively involved in supporting their own people, as well as CALD people generally. It was notable that longer settled groups, such as Vietnamese participants, took the floor to offer advice. Established groups were once new and emerging and identify with the issues NEC groups are experiencing:

We are people from different homes from America – Chile, Salvadoran, Argentinian, Bolivia, doesn't matter. People learn from each other, taste the food, learn to say things in Italian to those people in this centre. I learn something from Vietnam. Many benefits for the community. For those who live alone they can do nothing. They forget to put off the gas

The facilitation of existing information supplies is best done at the community level and supported by local government. More established CALD groups have similar issues which may be less acute. Other diversity groups have specific issues which we are currently exploring within LGBTI communities.

Access in rural and remote areas

Respondents expressed the sentiment that aged care in rural areas can work well when it is focused on local needs:

Small aged care facilities on country towns where its highly visible that care of the elderly works well

Having some newer Aged Care facilities built close to where people in country regions live. Unfortunately, they are sometimes taken over by big companies who are more profit, than level of service and community based care, driven!

The staff in county areas seem to be far more dedicated to aged care.

Unfortunately, care delivered locally is not readily available for some. Unpublished data from the latest National Seniors' Social Survey found that rural and remote residents worry about being isolated from a partner family and home if they need residential care:

In our area, if the nursing home or hospital in town has no vacancy, then the elderly person is accommodated in another town/village which may be anything from 30 to 50 km away. There is no public transport connecting the towns which means no or limited visits from an elderly partner which is upsetting for both patient and partner.

As well, local ties are important:

I want to be able to access it (care) where you spent most of all of your life (in my case 75 years so far).

The potential cost of accessing aged care was also keenly felt by rural and remote participants who experience higher living costs and are on average less financially secure than people living in metropolitan areas:

Aged care homes are way too expensive for most people

High cost of admission to aged care facilities will preclude many from obtaining care

Rural and remote participants, in common with the broader survey sample, had a strong preference to remain in their own home as they aged. Ageing at home, however, requires access to appropriate health, medical and community services to optimise health, thereby preventing early entry into residential care. In the rural and remote subsample, only 13% rated their health as excellent compared to 18.5% of the main sample, with higher proportions in the 'Fair' and 'Poor' health categories. Inadequate access to health and medical facilities was the overarching theme of rural and remote residents' responses:

Most significant health facilities are located in major cities so to access adequate health care and specialist services often requires a 6-hour round trip. As we age, we'll all need these services but they just aren't available unless you live in or close to a capital city

Most options are none existing in rural community here. We have a hopeless medical/health option as we are down to 2 doctors, at all times, to aid the population here, so waiting time is 2 weeks

To access specialist health care, it is necessary to travel up to two hours, which is fine IF you can drive or have family to transport you. I have neither

Some rural and remote residents felt wrongly disadvantaged compared to city dwellers:

Anyone not in a city is unseen by the policy makers

Our area is known as Far North Qld. It would be better described as FORGOTTEN North Qld as everything is available if you live in a major centre. Not so in the country

A lot of the medical services available to our city folk are not available to us, even though we have to pay the same level for private health cover, & even if we are able to get access to needed health services, we have to be on an often unacceptable list of preference. It's not only health services we suffer loss of in rural regions, the cost of living & general services are often dearer as we have no other options available to us & the providers know it & charge accordingly

Accessing aged care services requires internet connectivity and difficulties were a problem reported by rural and remote residents:

Mobile connection, it's always dropping out. NBN, well that's a complete joke. Telstra seem to be constantly working on it and we are always checking the home phone to see if it actually works

As was access to information without the internet:

If you do not have internet there is next to no medical information available in the community. Communication is very slack

Better coordination across departments is required to deal with digital issues so that better solutions to isolation and distance can be created for rural and remote older Australians needing age care.

Our data indicate that for rural and remote residents', health and aged care are inseparable and that for this group in particular, strengthening the aged care and primary health care links are critical. Difficulties in accessing medical care, plus the desire to age in place suggests an even greater need for effective joint preventive health and home care initiatives in rural and remote locations to support ageing well outside metropolitan areas.

Financing aged care

While there needs to be more money spent on the growing older population it needs to be spent on the right things which will require change and innovation. As well the current waste and inefficiency must be rigorously addressed. These come from poor program design, such as the Home Care Packages, as well as inefficient implementation for example MyAgedCare. In our responses there was a general awareness of the large amount of money being allocated to aged care by the government:

Plenty of money is spent on the flow from the government. Funding for people to stay in their own homes although it needs to be easier to access

Moderate success with Govt funding but needs great improvement/expansion. Also insufficient funding is evident throughout the system

There were also mention that funding of the Pharmaceutical Benefits Scheme was an aspect of the current system that works well.

Respondents don't separate retirement income from care and pension payments were mentioned as a fairness element of the current system:

People on pensions are able to access Home care services as well as residential care

Availability of pension for some, although self-funded retirees are penalised for working/saving

Care is available for people who do not have lots of money

Our research found previously that a large majority of people were prepared to pay for services if the charges were fair (77% in 2016 and 80% in 2018) (1). In the recent work people questioned the fairness of the bonds and regretted the impacts of paying for care on their savings in phrases and comments:

the destruction of wealth of retirees and asset destruction

Nursing Homes are happy to take large bonds from residents and our family is not complaining about the current system, but in our five years of having a relative in care, we have never had any information of how those bonds are used. It must've been a huge windfall to the homes

If you have the money to pay for the care, if you have a property you can sell to pay to get into a retirement age care facility and hoping to get a decent treatment

The cost of entering and being in aged care is also out of control. People in their late eighties and nineties can cope with this and family's risk losing all when these institutions go under

However, I found the Providers were taking a large share of the money in Administration and fees. Even with \$52,000 a yr. they didn't want to give me any more than 15/16 hrs a week

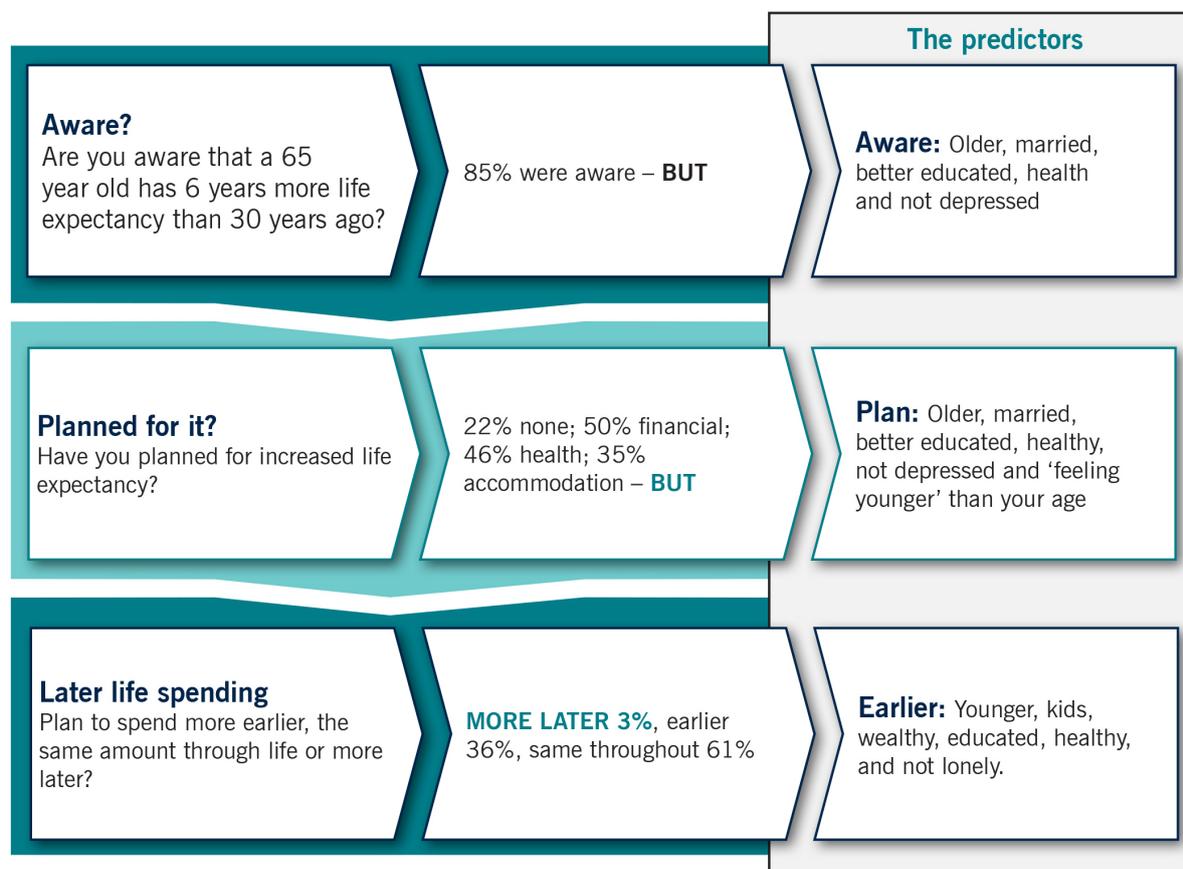
Those with disabilities seem to be catered for but those who can support themselves are drained dry before being helped by the government

The more money you have the better the care

The only thing was the cost needed to be cheaper

There isn't wide understanding or acceptance of personal responsibility for obtaining quality care in later life without government assistance or asking families to pay more for care. The National Seniors report 'Hope for the best, plan for the worst?' identified the lack of attention of older Australians to planning for care needs in later life (7). While most people were aware of long life expectation (85%), 22% had done no planning of any kind for it and only 3% had planned to spend more in later life when they could expect significant care needs. Those who had planned were typically older, married, better educated, healthy and not depressed. This lack of awareness or recognition of needs in later life as opposed to enjoying experiences that weren't accessible during working life. This is an issue that needs addressing at all ages. The Australia Talks surveys by the ABC report that 62% of people of all ages are worried about retirement income. The irony is that prior to retirement it is easier for something to be done about it rather than sitting and worrying about it (8). Incentives to have a larger conversation on ageing and making plans needs to be facilitated.

Figure 1: Awareness of longer lives and planning for needs



Australians of all ages need realism in the financing of aged care. We don't have it in the funding of Home Care with top ups as political announcements rather than realistic, adequate funding. Older Australians particularly value highly system stability and communication that assists their planning with remaining assets. Australia has three major cost drivers of aged care services: demography, better technology with more expensive care and systems, and higher salaries for higher quality staff. The industry needs to look first to innovation and problem solving when it's in trouble not to government bail outs which don't fix fundamental problems. Some simple costs reductions would come from better communications and information allowing older people and their families to do things themselves and without navigators. This requires less complexity than exists at the moment. With unacceptable waiting lists for both home and residential care this will require people to pay more for their age care into the future. The strong emphasis in the Consultation Paper on ideal service types and the lack of emphasis on digital modalities will not provide a sustainable future for aged care services.

A shift in attitudes is needed if there is to be effective planning for services in later life. At an early stage as early as practical before retirement, there has to be a focus on savings for later life in which superannuation funds and financial advisors need to play a central role. As early as practical there needs to be an informed conversation about care needs and risks in

later life. Unless this is talked about it will be neglected and avoided as a probable risk. Later in life, particularly when there are early signs of risk, planning needs to begin to avoid a crisis for which nothing is prepared and all options have to be discovered anew. The issues of ageing need to be lightened up and dealt with realistically. Serious cultural change can only come with realism and thoughtful discussions. This is discussed later in this submission in the ideal model proposed.

Quality regulation

Previous National Seniors research has shown that only 35% of over 5000 survey respondents feel that there are options for them to complain about the quality of the aged care they receive (1).

In our new data respondents supported the introduction of spot checks as a good idea:

Spot checks. I am under the opinion that audits should be done without notification to the aged care facility. This is the only way the facilities can be monitored and the results not rigged

And others, while appreciating the existence of a system, noted that financial and quality control were lacking:

Whilst there are many flaws at least we do have an aged care system. Home care is great but there is a lot of companies just in it to make money and no quality control

In our response to the Interim report (22/11/19), National Seniors referred to the regulation pyramid and put at the high end for criminal sanctions for management in aged care where serious incidents occur. It would be both unreasonable and unfair for care workers to have greater protection than residents and receivers of care.

PART 2: Building a new culture of ageing and planning

Re-imagining ageing in Australia

National Seniors members often comment that they would do anything to avoid entering aged care facilities in Australia. There is a general sense of resistance to the process of ageing and the planning and decision-making required to age and die well. Redesigning aged care in Australia will require a cultural shift in the way ageing is perceived: ageing milestones will need to be celebrated rather than denigrated; ageing-related functional decline will need to be normalised, with more adaptations made to private and public spaces to accommodate different levels of capacity; and the process of ageing will need to be accepted as something that begins at birth and continues throughout life, with intergenerational engagement allowing people of all ages to support and learn from each other.

In the figure below (Figure 2), we propose a model that:

1. encourages individuals to start thinking about their care needs earlier rather than later;
2. starts the conversation on ageing with clear and reliable information;
3. incorporates existing healthcare services as an integral part of assessment and care integration and co-ordination;
4. focuses on prevention and enablement;
5. ensures individuals are informed and offered appropriate choices at relevant stages.

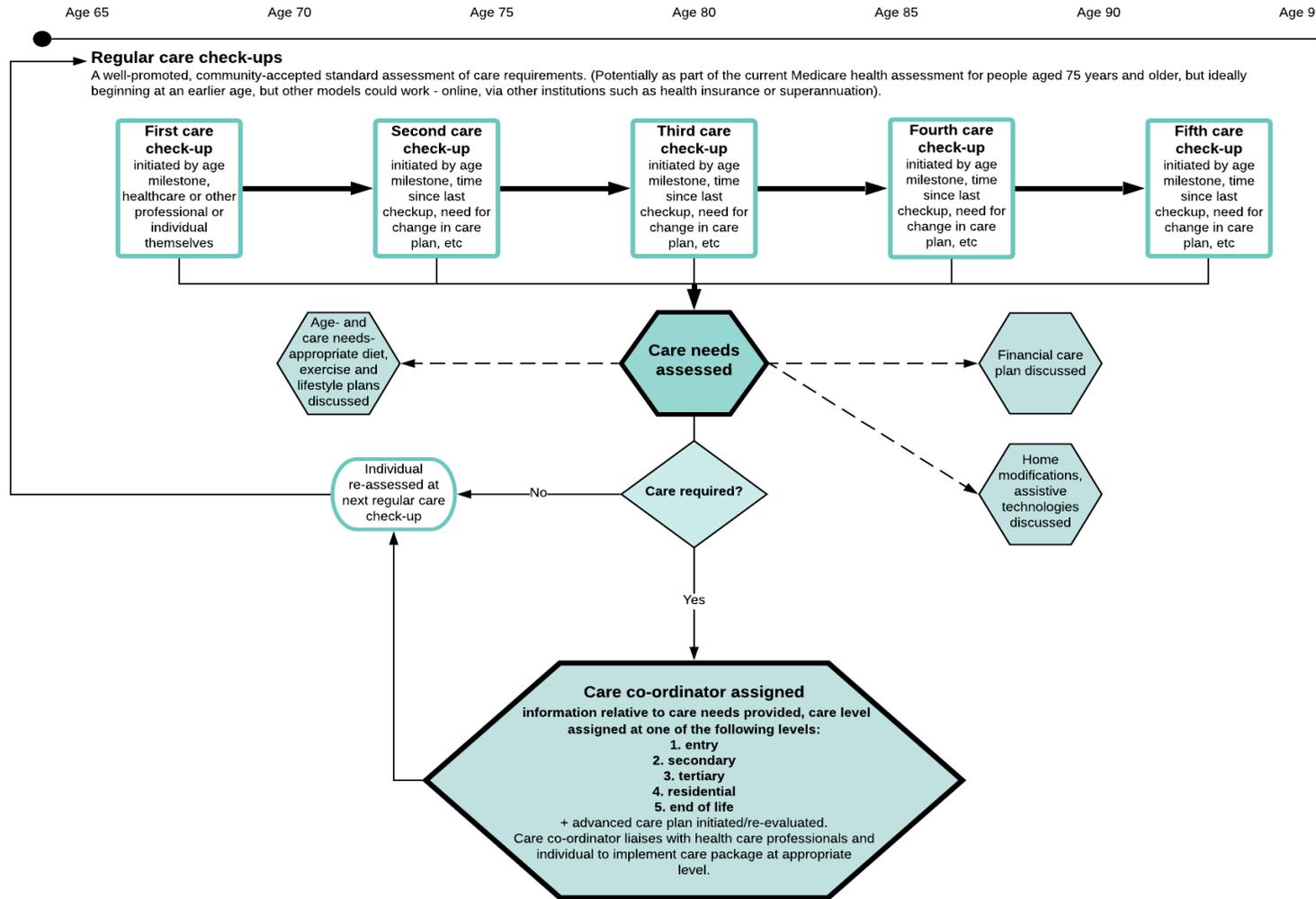
There are many aspects of the existing aged care arrangements that work well but the preparation and information exchange is poor. In our proposed model, advisory check-ups begin at a specified age or as recommended by a healthcare professional or requested by an individual themselves. At a care check-up, an individual's care needs are assessed. Based on this assessment, the individual is offered referrals to professionals to consult on a) diet, exercise and lifestyle suggestions to maximise independence; b) financial arrangements to fund care now and in the future and c) home modification and assistive technology options to improve quality of life. At this stage an individual is also provided information on the care options available relative to their specific needs. If care is required, a care arrangement appropriate to needs is agreed upon and put into place. This care check-up procedure is repeated at regular intervals, regardless of whether an individual is already receiving care or not. A care check-up can also be initiated at any time by an individual or by their healthcare professional.

We imagine that such a model could be incorporated into existing healthcare arrangements, e.g. care check-ups could be performed at a general practice by a GP. Alternatively, aged care specialists could operate at general practices or offer home visits if preferred, providing care check-ups and then follow-up information and support relating to care needs. With the rollout of the More Choices For A Longer Life program, the Government began in 2019 with the introduction of the Life Check website. It urged the target audience to take the quiz on older Australians' health, wealth, work and social wellbeing. There were separate resources for 45-64 and 65+ groups with a potential audience of over 10 million Australians over age 45. This is an online information source with email responses but wasn't fully developed and isn't well known even though it is relatively recent. It needs to be coordinated in a bigger mix of information and advice.

There is also an existing health structure in place that could accommodate such check-ups, namely the Medicare health assessment for people aged 75 years and older (9). Uptake of this assessment is reported to be low (10,11), despite the fact that a majority of recipients in one study reported it as beneficial (12). The success of such a system will depend on promotion and accessibility (financial and physical) (13), but we suggest that a conceptual and universal shift in approach is required to encourage older Australians to see discussions of their care arrangements as routine, regular and a fundamental human right. It would be expected that there would be a well designed digital platform for this with wide access.

A consistent finding in all National Seniors research is that "older Australians" are not homogeneous. This is a very diverse group of people with very diverse needs and wants when it comes to care, and any changes to Australia's aged care system will need to accommodate this diversity through more choice. Our recommendation, therefore is that any redesign of Australia's aged care system is conducted through a real user-centred design process, carefully consulting with, and actively involving, a wide representation of users at all levels and at each stage of design and development, in iterative processes.

Figure 2: Proposed model for discussion to re-imagine ageing in Australia



Given that older Australians don't live their lives in the categories represented by Government Departments, there is an opportunity to facilitate a wider conversation about ageing covering the categories in Life Checks but facilitated by experts with authority. The first port of call is the GP and the practice nurse. They are already doing health checks which have a low take up. Despite this older Australians are usually regular visitors to clinics without the health check purpose and the conversation could be done at any visit. The population is already covered with reminder of bowel and breast cancers and other reminders so the cost is relatively cheap. As well, superannuation trustees need to become more active in this bigger conversation about ageing. They are also trusted sources of information and usually have lifelong relationships with older Australians.

PART 3: Older Australians' Ideal Aged Care Experience

Our second question to respondents asked them what their ideal aged care experience would be. The previous text selections reflected respondents' views and experiences relevant to the Consultation Paper headings, however, the following more extensive responses encompass multiple themes. Some responses are focused on very specific areas needing improvement or redesign, such as the interaction between aged care facilities and the local community, and how information, education and shared decision making should flow across families, residents and staff. The issue of equity of access to care and a funding model that navigates people's divergent expectations according to wealth and contribution were also areas of concern, as was the need for better integration across aged care systems.

In considering the ideal aged care experience, others took an overarching view of the cultural and structural changes needed in society to enable good aged care. They tackled ageism, promoted self-efficacy, and advocated for information, systems and services that support and enable planning for the practical realities of later life.

The extensive responses below that were provided to National Seniors by our members offer the voices of older Australians as a source of inspiration for any redesign of Australia's aged care system in the future.

.....

“Have a facility which the local community has an pro active. and influential role in. Lots of music therapy, visits by (or resident based) cats and dogs, children of various ages from toddlers to school age, and easy access for residents to lots of modern means of communication. More real decision making by residents, and their families, not just big corporations promising wonderful things in glossy marketing brochures, and then running aged care facilities with minimum staff levels, and stressed workers

who are often under paid, trained, or emotionally supported to do their job! Aged Care facilities making use of the latest research/practices on dementia care from overseas, and providing high standards of end of life care, with as large degrees of involvement from the families of residents!”

.....

“A system that fully supports individuals to stay in their own homes if that is at all possible. Such a system would include readily accessible overarching information and a wholistic assessment system that includes assistance that could be provided by DVA as well as Commonwealth and State aged care services. That is a one stop shop. Such a system would include fully funded support and extend to user pay options.”

.....

“I think aged care is a personal thing and what suits one does not suit another. The system needs to be flexible and have more people managing and running it with a better understanding of older people’s needs aspirations and the life style they have had and wish to sort of retain. I realise cost is a major factor here but putting everyone in the same batch is not right. Those who have go without saved and worked hard all their lives are put into the same batch as those who have nothing. The hard workers pay top dollar while the nothing contributors get it all free. To make matters worse the nothing contributors make the most noise, complain the loudest usually because that believe they are entitled. The workers and savers just accept what they cannot change. The whole aged care system needs review. Every part of it from assessment of assets to going into it, changing venues needs to be as easy as possible and community perceptions need to change. It was the old people that built the country we have today. They built it with hard work and going without - at the tail end of their lives the country they built should be looking after them with minimal cost to them. Not one that takes away. Many old people I know like to look at their bank account and see it grow. Paying a bond in a home takes this pleasure away from them. When these pleasures are removed older people get depressed and give up. Active living in needs to be increased in aged care centres”

.....

“There needs to be more shared information amongst all parties, bodies providing Home Care Packages, hospitalised patients needing permanent/respite care, and current doctor. Being told a patient requires Aged Care opposed to providing the steps or the contacts to take this step would save a lot of time and possibly repetition of information at each contact rather than a central area actioning these steps. There does not seem to be any availability for people who have used their respite care and

time in hospital and are unable to find a place to go while waiting for the availability of a bed in an Aged Care home. The Accommodation Payment is excessive, especially for people who just fall into paying this. If they need to draw on this deposit to pay this as an ongoing fee, there is the added concern of being able to stay in the Home over time. The people with large sums of money seem to be protected with maximum limits. These fees need to be looked at in much more detail. More training needs to be given to the people who sign off on Advanced Health Directives, so people can discuss with them what they are signing. Much more training needs to be given to carers leading up to Aged Care, to ensure they are up to date on the changes for the better that have been made. There is still a bias in the community of stories of past shortfalls, opposed to the developments that have occurred. For peace of mind of all residents and their families, security cameras in all the common areas of the Aged Care homes should be welcomed. This would highlight the people who treat our families and friends with dignity and respect and have the time to listen and let people have something to smile about during their day. (J238)

.....

*“My ideal aged care experience? Hmm. Firstly, we need to change our cultural stance and cease to worship youth, and recognise that all people, no matter what age, religion etc etc are valuable and useful to a society. Barring those who seek to destroy it, obviously... Secondly, the government should encourage greater responsibility for self for people of all ages. It is well-documented that there are a number of ways in which lifestyle impacts health. People of all ages need to be reminded that they will grow old and they will die - but they can take many steps to improve their healthspans, if not lifespans. And this goes way beyond the usual rubbish that is fed to retirees regarding 'anti-aging' skin creams, cruises and the 'grey nomads'. Seriously. I would like to see the government implement things that are really meaningful and useful to people who are no longer working. Bus routes that don't only go to the local Westfield; use of transgenerational design (especially with the construction of new houses, and renovating and retrofitting old ones); and assistive technologies; 'real' senior discounts on important foodstuffs and services; Medicare-based dental work (why is dentistry separated from the rest of medicine anyway?); investment in self-driving cars; and a realisation of our untapped potential. Instead of *numerous* organisations dealing with the older people in Australian society - COTA, National Seniors, Aged and Community Services, NARI, Older Women's Network, Seniors' Rights and all the rest of them - it would really be helpful if government had one central website with links to all these various associations (and don't get me started on why they are different in different states...), as well as publishing all the latest information that is relevant to oldies, and perhaps even brief but authoritative guides to the current research on ageing. There*

*is no one site that does this (although I am in the process of starting such a website, through sheer desperation regarding the lack of information) and, in my professional and personal experience, I know that few people know how to search online effectively. I have not yet reached the stage of having to be assessed (I am a fit and healthy 68 year old) but I would like somebody to assess what domestic or other help I required, and whether my home was suitable for somebody of diminishing mobility, and I would wish to automatically be put in touch with the appropriate *reliable* and *trustworthy* people offering such services. I would hope that the government would go some way to pay for such services. Choices and opportunities should be widely publicised, so that we all know what is available, when and for how much. I would also hope that there would be a much closer examination of the design, provision and funding of retirement communities and retirement homes, as presently it would appear to be cowboy country, where individuals are pursuing profit above all else. Utterly sickening, really, when people are so vulnerable. As far as end of life care is concerned, I would hope that we all have access to the best that is available, according to research, and that cost to government is not a consideration. Dammitall, we senior citizens have contributed to society our whole lives, through work, children and taxes, and we deserve a bit of dignity at the end of our days.”*

National Seniors responses summarised

The existing negativity about ageing itself and the failures highlighted by the Royal Commission require a big, national conversation about ageing that is realistic and encourages planning. National Seniors have provided a model to facilitate and guide this big conversation. We also have addressed the main program areas in the Consultation Paper.

Substantially improve Information, assessment & system navigation

Priority issues for our respondents were: general frustration at the system's complexity, inherent delays and inefficiencies and, more often than not, accessing the aged care system at a time of crisis and considerable stress. Simplicity and efficiencies are urgently needed.

The positives included the online system, as were the recent improvements to the My Aged Care website and the current ACAT assessment process.

Digital literacy will be required now and into the future with increasing innovation and efficiencies. Peer training and programs need to continue as well as effective communications for the non-literate. Savings made in digitisation must be invested initially in bringing people along through training and organised digital mentoring. This imperative is imperative for government and industry.

Respondents highlighted the importance of managing the transitions between levels and types of care and the important role of medical and allied health professionals as early points of contact in an ideal aged care system.

Entry level care

Respondents highlighted that care delivered at home was for them a positive component of the current system regardless of whether the care was through a Community Home Support Package (CHSP) or a Home Care Package Program (HCPP).

Care at home is universally preferred but requires more integrated and streamlined administration. It is the universal preference for growth.

Administration costs still need to be minimised and money directed at quality care rather than into inefficiencies including poor management of travel costs.

Interfaces with unpaid care at home including assessment, help with care plans and respite need attention to maintain quality of care and motivation of 'volunteer' carers.

Respite

Respite care is an invaluable resource to:

- Support informal carers maintain care at home for their care recipient as long as possible
- Help ease the pathway into full time residential care if it becomes necessary.

This resource is very limited must be expanded to deal with these critical goals. It is naturally a component of the required growth of home care. With unacceptable waiting lists for home and residential care this requires urgent attention.

Restorative care

Members provided examples of the life engagement programs and activities provided in residential care facilities such as pet therapy, social engagement, family involvement.

Improving quality of life through this restorative care approach was enthusiastically supported both in residential and home care settings. The benefits for staff through restorative activities for clients were also highlighted.

Restorative care will depend on the willingness of clients to accept it which can be facilitated by promoting more active ageing through later years.

Care – personal care, nursing care and allied health

The high value of the commitment and dedication of carers was the strongest theme to emerge from members' comments in relation to care provision

The challenges of providing care were also widely acknowledged with emphasis placed on the problem of understaffing and poor remuneration in aged care facilities. The comments were consistent with the introduction of minimum staffing categories and ensuring government money is directed to care costs.

A campaign is needed to get the positive messages from older people back to care workers. This should be coordinated with the Aged Care Workforce Committee to run a campaign to attract new care workers and retain existing ones.

Specialist advice and services

It is common for older people to have multiple chronic conditions. Responses showed that the cost and management of medical care needs to be improved in both the private and public sectors.

Geriatric medicine recruitment and training needs continued promotion and support to meet the multiple conditions typical in an ageing population.

Better integration across the health, primary and acute, and the aged care, residential and home care is needed now to enable effective management of medical and care costs.

Access for diverse groups

The National Seniors response has focused on CALD but we are engaged in current research with other groups. As new and diverse waves of immigrants come into Australia there is need for continual recognition and action on: language barriers, cultural difference in particular taboos, special information channels, digital issues, and transport. Many of these are best dealt with at the local level where national programs are weakest.

Access in rural and remote areas

Respondents supported aged care that focused on local needs and provided in local areas.

Potential cost of residential aged care was a concern for rural and remote residents who on average are not as wealthy as seniors living in metropolitan areas.

There was a clear preference for ageing at home, but in rural and remote locations, access to health and medical facilities that support home care are lacking.

Rural and remote populations are also generally in poorer health than the majority of older Australians.

Accessing aged care services is more difficult for rural and remote residents due to poor connectivity. Commonwealth 'blackspots' programs need to be coordinated with aged care opportunities for digital information and services.

Rural and remote residents felt wrongly disadvantaged compared to city dwellers. Continuing support and actioning of recommendations of the Remote Accord is required and there is a need for a clear Action Plan for rural and remote aged care needs.

Financing aged care

Respondents were aware of the large proportion of government funds allocated to aged care services and the pension was recognised as providing equity in the current system.

The comments indicate support of accountability that public money goes to care and that at least minimum staffing ratios are mandated.

There were divergent views from members on if and how they should finance their own aged care. Fairness was a common theme with many unwilling to see their hard-earned savings eroded when others had access to care at little or no cost

Previous National Seniors research showed that people had mixed views of personal responsibility for obtaining quality care in later life and most had not planned for it financially.

Effective financial planning for aged care services will likely require a shift in attitudes about care needs and a more realistic appreciation of care risks in later life. The proposed model for facilitating cultural change must include this as a planning item.

Quality regulation

Older Australians are not well-informed about the options for making complaints about the aged care system. Providers have to play a stronger role in facilitating this particularly at early points of contact with the system.

Better financial and quality control are needed with the potential implementation of criminal sanctions against aged care management in cases where serious incidents occur.

Finally it is critical that the ‘fundamental overhaul’ proposed for aged care has realistic financing. This will involve politically difficult decisions such as increasing the aged care share of the budget and shifting more costs to older people and their families. It also requires lean and efficient design which needs elements of better information and digital literacy.

Conclusion

This submission has matched the *verbatim* words of older Australians with the themes of interest to the Royal Commission. It is central for the change process to be aware of seniors’ preferences and sentiments and to speak to people in their own ‘language’. Older Australians may not articulate ideas for highly technical changes but these must meet their needs and the best way to do that is to listen to them. At the moment attitudes to many aged care services and financial support are negative and many ‘don’t want to think about it’.

Given the serious failures of care in later life for older Australians documented and discussed in the Interim Report of the Royal Commission, people of all ages would do well to reflect on the thoughts of the Oxford philosopher Derek Parfit in his book *Reasons and Persons* (Oxford University Press 1984): “We ought not to do to our future selves what it would be wrong to do to other people.” The cases of abuse and neglect before the Royal Commission could happen to anyone of us in the future. The best way to deal with this is through considered planning and supporting reforms of aged care.

Parfit describes a journey of his own in the same book: “My life seemed like a glass tunnel, through which I was moving faster every year, and at the end of which there was darkness. When I changed my view, the walls of my glass tunnel disappeared. I now live in the open air.” This is the journey Australians have to take in to live well while ageing in the 2020s.

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