# “As close to home as possible”

# Older Australians’ hopes and fears for aged care

February 2022

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## Executive Summary

In a recent survey, National Seniors Australia asked older Australians to answer three questions about residential aged care:

> *Have the reports of neglect and abuse in the aged care system affected your aged care planning or decisions? (Q1)*
>
> *In your view, how could residential age care change to make it a better and more desirable option for those who need it? (Q2)*
>
> *What type of guidance, assistance and information do you think should be easily available for people when they need residential age care? (Q3)*

Just under half (49%) of the 5166 people surveyed for Q1 said the reports of neglect and abuse had affected their aged care planning or decisions.

The reports had prompted some people to decide never to enter residential aged care, for others to be more cautious about it, and for still others to take pragmatic steps to ensure they would enter a good quality residential facility when the time came. Over 70 people commented that they would prefer death rather than enter residential aged care.

Of those who said the reports of neglect and abuse had not affected their plans, some said they had no effect because their personal or professional experiences with the aged care system had already coloured their views. In some cases, those prior experiences had instilled negative views of the system. But in other cases, their prior experiences had been very positive, and they believed the reports of neglect and abuse unfairly emphasised the negative. Some respondents also had faith that current improvement processes would fix the problems by the time they needed aged care.

Survey questions Q2 and Q3 were asked to a subset of those surveyed for Q1, and each was answered by between 550 and 600 people.

Those who answered Q2 offered a huge range of suggestions for how residential aged care could best meet their ideals, including improvements to fees and profit arrangements, geographic placement of facilities, accommodation structures and models, care delivery models, living quarters, food, activities, staff pay and conditions, facility culture, and management accountability.

A common sentiment woven throughout responses to Q2 was that people want to live in a residential facility that is as close to home as possible. In other words, they want life in aged care to resemble life before aged care in every aspect, to the extent that that can be achieved.

Those who answered Q3 offered a rich variety of suggestions for how people seeking aged care can best be served in terms of information, guidance and assistance.

A common suggestion was that there be a single one-stop shop for aged care information, guidance and assistance at all stages of the process of accessing aged care. Within that one-stop shop model, many older Australians would like a case worker model whereby one professional supports a care seeker from start to finish, getting to know their needs and tailoring their service to suit.

Respondents also made suggestions for public communication strategies that will prompt older Australians to plan for aged care. They offered their insights into improving all communication about aged care in terms of language, formats and mediums, to make it as accessible and relevant as possible for older Australians.

Collectively, respondents to Q3 listed over 100 traits of residential aged care facilities that they would like information about when considering a facility. We have grouped those traits into a 15-point checklist that aged care providers and governments can use as a template when preparing information about specific facilities, and that care seekers can use to help ensure a facility will meet their needs.

# Introduction

In the mid-2010s the Australian public was shocked and shaken by media reports of residents in Australian aged care facilities being neglected and abused by staff or mistreated under poor management regimes. These reports included hidden camera footage of abuse that put the topic into Australians’ everyday conversations on a scale never seen before.[1]

In September 2018, the investigative current affairs program *Four Corners* aired a special investigation into the failings in aged care, including neglect and abuse in residential aged care facilities.[2] It had put a call out for members of the public to share their experiences, to which over 4,000 people responded.[3] The day before the investigation aired, the then new Prime Minister Scott Morrison announced the establishment of a Royal Commission into Aged Care Quality and Safety.

In February 2021, the Royal Commission handed down its final report.[4] The multi-volume publication made 148 recommendations for reforming the aged care system and reported extensively on problems with the current system including neglect and abuse in residential aged care facilities across Australia.[5] It incorporated more than 10,000 public submissions and evidence presented by over 600 witnesses at public hearings and workshops, many of whom wrote or spoke about neglect and abuse.

The launch of National Seniors Australia’s ninth annual social survey of Australians aged 50 and over, or the NSSS-9, coincided with the release of the Royal Commission’s Final Report. Because the stories of neglect and abuse in aged care were so prominent in public discourse, we felt it was timely to include a question about whether it had affected older Australians’ plans regarding aged care. We asked senior Australians:

> *Have the reports of neglect and abuse in the aged care system affected your aged care planning or decisions? (Q1)*

In total 5166 people, or just over 95% of the 5430 survey participants, answered this question, which had fixed response options of ‘yes’, ‘no’ and ‘prefer not to say’.

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[1] For example, ABC 7.30 (2016, July 25) ‘Secret camera captures nursing home ‘suffocation’.’ *7.30.* Available at https://www.abc.net.au/7.30/secret-camera-captures-nursing-home-suffocation/7659690
[2] ABC Four Corners (2018, September 20) ‘Who cares?’ *Four Corners*. Available at https://www.abc.net.au/4corners/who-cares/10258290
[3] Scopelianos S (2019, February 11) ‘The Royal Commission into Aged Care Quality and Safety explained’. *ABC News*. Available at https://www.abc.net.au/news/2019-02-11/aged-care-royal-commission-explained/10759398
[4] Royal Commission into Aged Care Quality and Safety (2021) *Final Report: Care, Dignity and Respect, Volume 1: Summary and Recommendations*, Commonwealth of Australia.
[5] See volumes 2, 3A and 3B. Royal Commission into Aged Care Quality and Safety (2021) *Final Report* [website]. Available at: https://agedcare.royalcommission.gov.au/publications/final-report

Just under half of those surveyed said the reports had affected their aged care planning or decisions. This would seem to indicate an active interest in this topic among older Australians.

Respondents were also given the opportunity to write comments in an open text box after this main question to elaborate on their answer, and 1305 people did so (24% of NSSS-9 survey participants). While there were some positive remarks about residential aged care, it was overwhelmingly the case that most commenters felt extremely negatively about it.

In August 2021, the Commonwealth Department of Health announced it was seeking feedback on proposed changes to the funding model used in the residential aged care system. Our previous research had shown that older Australians want to play a meaningful role in co-designing changes to the aged care system rather than merely reacting to proposals that others come up with.[6] Accordingly, we took a big picture consumer approach and went back to our survey cohort to gauge their ideas on what needed to change and how things could be done differently in residential aged care. We crafted a follow-up survey asking two open-ended questions:

> *Most people would prefer to avoid entering residential age care, but sometimes it is necessary if carers are not available or unable to provide care at home. In your view, how could residential age care change to make it a better and more desirable option for those who need it? Your answer can focus on specific issues or address more general concerns about the system. We are interested in whatever is important to you! (Q2)*
>
> *What type of guidance, assistance and information do you think should be easily available for people when they need residential age care? Feel free to answer in as much or as little detail as you like. (Q3)*

The follow-up survey was open to the subset of NSSS-9 participants who had agreed to be contacted for further research (see Appendix I for full methods of both surveys).

Over 550 people answered each question, painting a vibrant portrait of how the system might change for the better from a consumer point of view.

This report presents the results of all three National Seniors’ recent survey questions about aged care, from NSSS-9 and the follow-up survey. The Royal Commission made it clear that there are serious problems to be addressed in the Australian aged care system, and similarly, many of our survey respondents shared stories of neglect and abuse in residential

[6] Orthia L., McCallum J., Hosking D., Maccora J. and Krasovitsky M. (2021) *Co-Designing Aged Care: Views of 4,562 Older Australians*. Australia: National Seniors Australia and EveryAGE Counts.

aged care that they had witnessed as care recipients, staff, or family and friends of people in care. We acknowledge the grief, anger, and pain these experiences must have entailed and we join those who have suffered in calling for urgent change. However, to avoid merely treading the same ground as the Royal Commission and media reports, we here also highlight less explored topics that equally need urgent attention.

The results of the NSSS-9 question (Q1) are reported in Part A of this report and the results of the two follow-up questions (Q2 and Q3) are reported in Part B. We first discuss the varied ways older Australians have responded to aged care neglect and abuse, some of which are highly concerning (yellow section, Part A and Appendix II). We also highlight some positive experiences people have had with the aged care system, recognising the good work performed by many aged care staff under difficult circumstances (yellow section, Part A and Appendix III). We then discuss what older Australians need and want changed if they are to feel more positively about using the system for themselves or for loved ones. This includes material and cultural change to residential facilities themselves (teal section, Part B Section Q2) and people’s information and guidance needs when accessing aged care (orange section, Part B Section Q3 and Appendix IV). To help readers navigate this lengthy report we have placed a visual section map prior to each of the three sections reporting on the survey questions. Topics of interest can be found by clicking on that section of the visual map. You can return to the map for each section or the Table of Contents at any time by clicking on the map icon at the bottom right of each page.

It is our hope that the findings of this report will feed into solutions to the residential aged care crisis and a new vision of what Australian aged care can look like in the future.

# PART A

# NSSS-9 Survey, February 2021

# Q1. Effects of reports of neglect and abuse on aged care planning and decisions

## Q1. Section map

To return to this map at any point, click the Q1 map icon at the bottom of any page.

# 4 RESPONSES

**to reports of neglect and abuse in aged care**

Negative or fearful views formed or reinforced, alternative plans made

Positive experiences despite reports, trust that things will improve

Pragmatic steps taken to choose or monitor quality of care

No plans made, no knowledge of abuse, no new information

## Q1. Results

The quality of aged care in Australia is an issue that, understandably, many older Australians deeply care about, especially in the wake of the Royal Commission’s report. Public interest in the issue was reflected in the high percentage of NSSS-9 participants who responded to our question asking if the reports of neglect and abuse had affected their aged care planning and decisions, and the large number of respondents who took the time to write comments.

### 1.1. Quantitative overview: Have the reports affected people’s planning?

Over 95% of NSSS-9 respondents, or 5166 people, answered the main question which had fixed response options of ‘yes’, ‘no’ and ‘prefer not to say’ (Figure 1).

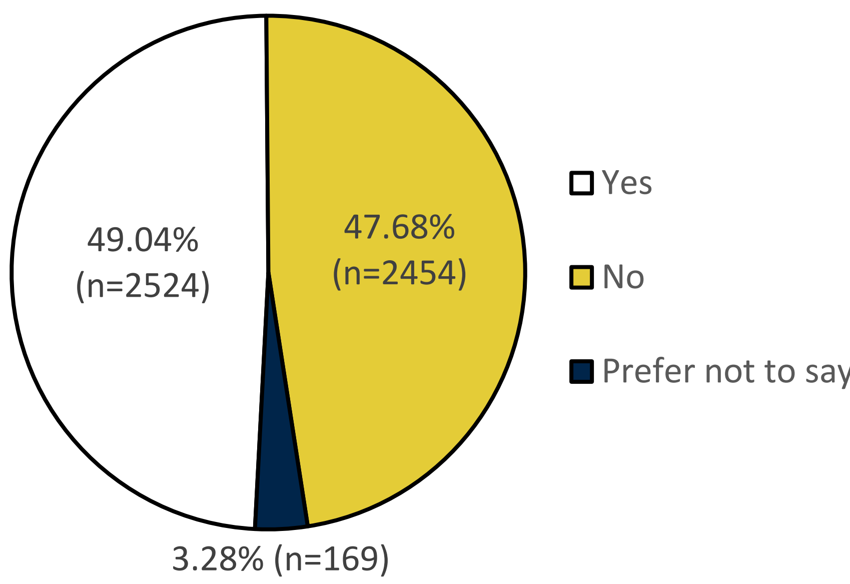



*Figure 1 Distribution of responses to the main question, asking if the reports of neglect and abuse affected the respondent's aged care planning and decisions.*

The fact that almost half the respondents answered ‘yes’ is some indication of how strong and pervasive the impacts of the reports have been. However, the ‘no’ responses should not be read as disinterest in aged care neglect and abuse. As we discuss below, people’s answers to the main question were shaped by a range of contextual factors, so we cannot interpret in a simplistic manner the reasons why around half the respondents said ‘no’.

## 1.2. Broad patterns in open-ended comments

To fully understand why people answered 'yes' or 'no' to the main question, we must turn to the comments some respondents wrote in response to it.

Out of the 5430 NSSS-9 participants, just under a quarter (1305 respondents) took the time to write a comment for this question. Around 79% of those commenting had answered 'yes' to the main question (1028 responses) and 19% had answered 'no' (250 responses). This distribution of 'yes' and 'no' responses among commenters was disproportionate to the overall distribution of 'yes' and 'no' answers, with people who said their planning or decisions were affected by the reports being far more likely to leave a comment. The remaining 27 commenters (2%) either did not answer the main question or answered, 'prefer not to say'.

Our analysis of the comments' themes showed there was considerable overlapping sentiment between those answering 'yes' and those answering 'no' to the main question.

Most obviously, within both groups many people expressed concern about neglect and abuse in the aged care system and articulated an array of other negative emotions about that. In both groups many people expressed hesitance about entering residential aged care and a preference for other options. Many commenters also shared their own stories of neglect and abuse in aged care, or alternatively their positive experiences of the aged care system. About 60 commenters mentioned professional experience working or volunteering in aged care or similar, and some of these people had also experienced the aged care system via loved ones in aged care. In addition to them, another 160 commenters said they had experienced aged care services via family members or friends in care. A few people wrote about their own experiences as care recipients in residential aged care, respite care or a retirement village.

This convergence of themes among 'yes' and 'no' groups suggests that people's answers to the main question were not strongly correlated with their feelings about the reports of neglect and abuse, or about aged care. Instead, their answers to the main question seemed to be determined by how they were situated within a decision-making process at the time of completing the survey, as we show below.

Nonetheless, despite this high degree of overlap, there were some distinct response types within the 'no' group that were not present (or were very uncommon) in the 'yes' group. Some of those who answered 'no' reported positive experiences with residential aged care; held hopes that problems would be fixed by the time they needed care; felt powerless to make care plans that aligned with their wishes; or already knew about the aged care system so were not overly influenced by recent reports. Some who selected 'no' had simply not made plans yet and a few were unaware of the media reports about neglect and abuse.

In the following sections we review the major themes we found in the NSSS-9 comments and illustrate them with quotes. Where relevant we relate themes back to commenters' 'yes' or 'no' answers to the main question.

## 1.3. Negative views of residential aged care prompted or reinforced by reports

The main message to be gleaned from the comments was the negative views of residential aged care that commenters expressed in various ways. Those who answered 'yes' to the main question sometimes said the reports were responsible for their negative views, but also often said the reports merely reinforced them. Those who answered 'no' to the main question often said they already held these views, so recent reports did not change their plans to avoid residential aged care, or the reports simply reinforced their pre-existing negative views too. In many cases, irrespective of their answer to the main question, commenters simply shared their negative views of residential aged care without discussing the reports' impacts explicitly.

### 1.3.1. Plan to never enter residential aged care or strong opposition

Approximately 325 commenters (24.9% of the 1309 commenters) explicitly stated that they (or, occasionally, their loved ones) will never enter aged care or they expressed a strong preference against it. While many of these answered 'yes' to the main question, suggesting the reports of neglect and abuse were responsible for their feelings, some made it clear that their view was influenced by other factors such as personal or professional experience with residential aged care:

*"The thought of nursing home for me now is a no,no"*

*"Decided not to go there!"*

*"The reports of neglect, and bullying, in these places makes me to plan to avoid these places for as long as possible, preferably for ever."*

*"Although I am not planning my future aged care needs right now as I am only 53, the reports of abuse and neglect have made me think that I never want to enter a [residential aged care facility]"*

*"The reports are so negative that we have decided never to become dependent on aged care, never to go to an aged care home. I worked as a volunteer in an aged care home. We have been dismissed. The whole set up in aged care is so far removed from what it should be, I can't see an improvement in this political climate. In short, total despair."*

*"I have no intention of going into an aged care home. My Mother was in one and three years later I still feel pain at her circumstance and the staffing, especially at night, one doctor for about 50 patients. Untrained and unsympathetic staff and my feeling of helplessness as she gave up."*

*"I would consider aged care a last resort after the current reports of abuse and neglect."*

*"Just confirmed my reasons for not going there"*

*"Not directly - but it scares me so that I'll avoid the aged care system as much as possible."*

*"It's a huge motivator to take every opportunity I can to maintain/improve my health and avoid the need of every placing myself in such a vulnerable position."*

*"Makes me never want to go into residential care - also having previously worked in residential care - no way!"*

*"Having witnessed the terrible situations whilst my mother was in care, they will drag me into a facility kicking & screaming"*

*"Trying to avoid ever needing to use the aged care system after seeing the poor service given to relatives."*

*"I am a former nurse and my experiences make me determined not to be part of the Aged Care system."*

### 1.3.2. Enhanced worries or fears about residential aged care

About 250 people (19.2%) across both 'yes' and 'no' groups said the reports of neglect and abuse had enhanced their worries or fears about aged care or their trust in providers. These 250 comments were over and above the 325 discussed in the previous section, not overlapping with them. Together these two comment types comprise 44.1% of comments, indicating a high degree of reservation about residential aged care among commenters:

*"I am more worried"*

*"It does increase concerns."*

*"Really nervous about aged care now."*

*"made it harder to be realistic about the future."*

*"very frightening to think of going into one of these horrid homes."*

*“I am very concerned about reports of neglect and abuse in the aged care system and the homophobia that exists in some facilities”*

*“Even though I am at present working part time and healthy my partner […] has Parkinson’s disease and is currently able to look after himself in his own home though we know the time will come when he has to make a choice. The point I wish to make is that both of us are concerned about these reports and have little trust going forward.”*

*“What I have seen and heard during the lockdowns the way elderly are treated in age care is very alarming this scares me to bits. After all we are still a person with a mind and respect for ourselves. It really gets to me how [a] human being can be so cruel to another. Age Care scares the life out of me”*

Worry and fear were not the only emotional responses people reported experiencing because of the reports of neglect and abuse, though they were among the most prominent emotions mentioned. Other prominent emotional responses included an urge to be careful in decision-making, feeling appalled at the situation, and being hopeful about reform. Figure 2 (on the next page) visualises the relative prevalence of each emotion word used in the >300 comments that explicitly referenced an emotional response, most of which were negative.

### 1.3.3. Plans to pursue other care options while ageing

Around 230 people (17.6%), including some of the 575 whose comments were counted in the previous two sections, said they planned or hoped to pursue accommodation options such as living at home or with family for the duration of their old age. Most stated or implied this was to avoid residential aged care:

*“The neglect and abuse in the aged care system has made me determined to stay at home with help as long as possible, My family agrees.”*

*“Following various media reports, we would prefer to financially support assistance & care in our own home.”*

*“We were quite prepared to go in to a facility to make it easier on the family but now it is quite horrifying to see the systemic neglect, abuse and under resourcing of the system. It seems like everything it is more about money making for the few than the care of the vulnerable/needy.”*

*“These stories have reaffirmed my strong preference to stay at home, ie receive home-based care.”*

*Figure 2 Word cloud of emotions that over 300 commenters felt in response to the reports of neglect and abuse in aged care. Only single word emotions are captured, with multiple word articulations of emotion excluded. Different grammatical variations were changed to one consistent form, e.g., 'I'm terrified', 'it terrifies me' and 'it is terrifying' are all captured as 'terrified', and so on for other emotions. Word size is proportionate to frequency of commenters who expressed the emotion, with some commenters expressing more than one emotion.*

*"Will be staying in our own home for as long as possible. Even though this may be very difficult for us. We would feel much safer."*

*"The amount of reported abuse has some bearing on my preference to make my home compatible to aged care living."*

*"Strengthened resolve to stay as healthy as possible and to organise my/our own supports - hopefully in co-ordination with local friends and neighbours who we understand are also resolved to live in their current nearby locations. I believe we have the knowledge and resources to avoid contact with any large aged care providers and organise among ourselves. We are more consciously investing time in reciprocal arrangements with our neighbours."*

*"I, like everyone else, was appalled at the reports and it has galvanised my determination that I will never go into the aged care system. That is why I am downsizing and making sure I give myself every chance to age at home."*

Some commenters in this group wrote about their decisions to care for elderly loved ones themselves rather than access residential aged care for them:

*"We have taken on extra burdens with current caring for a very elderly relative because the aged care industry is quite frankly appalling."*

*"In my early days I worked in aged care and the care was wonderful - in more than one facility. In those days I would have put either my mother or myself into such a place. Today, however, it is all down to money which leads to not enough food, training, staff etc. I now care for my 90 year old mother, who has dementia and her sister, aged 87, who has heart and lung problems, 24/7 oxygen. I am not paid to do this. I hope never to have to put these ladies into care, due to the horror stories."*

*"I will care for my husband at home for as long as I possibly can."*

### 1.3.4. Preference for death over residential aged care

Seventy-one respondents (5.4%) from both the 'yes' and 'no' groups expressed a desire to die rather than enter residential aged care. For some people this was based on a general desire to avoid deteriorating health or situations of dependence on others, but some respondents explicitly linked their preference for death to the reports of neglect and abuse in care. Forty-seven of the 71 stated their intention to end their life by suicide or voluntary assisted dying, or to investigate these options, if residential aged care is the alternative:

*"I always preferred to age and end my life at home, but now I am determined to do so if it is possible."*

*"The demonstrated problems in aged care homes convinced me to never trust them with my care - I would rather die at home by myself."*

*"Yes, After hearing the stories of the abuse and poor care, together with shocking food choices, I would prefer to die than enter a Nursing Home."*

*"I would prefer to die, than have to go to age care, especially after all the things I have read and seen on TV about it. I think it is a disgrace to our nation, it is hard to believe that we treat our seniors with such disrespect. I hope and pray I NEVER end up there."*

*"it is daunting, if I start to get dementia I would like to be euthanised go with dignity"*

*"In my Advance Care Directive I have stated that under no circumstances I am to be placed in aged care. I would rather shorten my life span than be placed in such a system to be tortured and treated with such a lack of respect and care."*

*"I will attempt suicide before I go anywhere near aged care accommodation."*

*"Having worked in Aged Care as an RN [registered nurse] I will kill myself rather than go into that type of care."*

In addition to these eight example comments, we have reproduced the other 63 comments about preferring death to residential aged care in Appendix II. We recognise this topic may cause some readers distress, so we have put most comments into an Appendix rather than here in the main text. We have also included the contact details of support services on the last page of this report for any readers feeling distressed and we urge readers to use them. However, we have made the decision to include all these comments in the Appendix, rather than passing over them, because their number suggests serious negative sentiments persist about the current residential aged care system. It should never be the case that death is preferable to entering a care facility.

## 1.4. Positive views of residential aged care despite reports

Not all commenters held negative views of aged care though. A substantial minority of commenters shared their positive experiences with residential aged care in their capacity as care recipients, as family members or friends of care recipients, and/or as professionals working in aged care. Others were optimistic about their future aged care choices because

of faith in government reforms of the sector. In most cases such people had answered 'no' to the main question and offered these reasons to explain why the reports had not impacted their planning.

### 1.4.1. Positive experiences counter negative reports

Some commenters said they believed media reports exaggerated the problems of neglect and abuse or inadequately contextualised them. Most of these commenters answered 'no' to the main question, suggesting the reports did not affect their decisions because the reports contradicted the respondents' own experience or opinions about aged care. Encouragingly, around 40 people shared their positive experiences with aged care:

*"Ridiculous question... You insinuate it is widespread.... Definitely not the case ... have friends and family in aged care and have not ONCE seen this type of situation!! Shocking assertion!!!"*

*"Unfortunately the professional outraged journalists always report the negative! I know from personal experience that many (maybe most) facilities are of a high standard and are well run - the one i know has excellent food prepared on [site]. I note the question does not [ask] whether my decisions are based on positive aspects of the aged care industry!"*

*"The question of abuse needs to be looked at from all angles. Have a member of my extended family in care who was bashed by another patient. Facility was marvellous and put plans in place. Sadly because of Dementia, my family member has now thumped another resident. The matter of aggression by residents to other residents / staff needs to be far more widely discussed."*

*"I'm concerned that the media portrayal suggests that all aged care providers and residences have problems rather than a very small percentage. This is misleading and very frightening for older people and their families. It is inaccurate and might 'sell' but is not helpful to the community."*

*"Having had my husband in care for two years I was very happy with the care both he and I were given."*

*"My parents lived for 5 years in an excellent aged care home. They were happy & respected there."*

*"The aged care attached to my retirement village has an excellent reputation"*

*"whilst the results and outcomes of the review are unacceptable and disturbing, from discussions with friends and family they do not reflect the actions of the majority of aged care facilities. There are bad apples in every industry."*

*"I have said before and will say again that there are some excellent aged care services around. Fix the bad aspects and bad services but give acknowledgement to the good."*

These experiences provide a refreshing contrast to the predominant public discourse on aged care, so we have reproduced the other positive comments in Appendix III. While it is critical to grapple with aged care problems, it is also important to acknowledge the good work done by aged care workers across Australia under difficult circumstances, as some of our commenters suggested.

### 1.4.2. The public response to the reports gives hope for systemic change

In addition to these positive experiences, around 30 people (2.3%) expressed the optimistic hope that the reported problems will have been resolved when they need to access aged care:

*"they will fix it by the time i need aged care"*

*"We are hoping by the time we have to access aged care - more stringent rules and regulations have been put in place."*

*"Now out in the open, this will be policed more"*

*"I know we will need aged care services sometime in the future as we don't have family to support us. While the reports are concerning, hopefully we can navigate the system carefully. We also hope the system can improve in some way in the near future."*

Most people who offered this kind of comment had answered 'no' to the main question. A few people who answered 'yes' also articulated this hope, though perhaps more as a desire for urgent change rather than a reliable basis for continuing with existing plans, for example:

*"I am hoping for the Royal Commission into aged care to be finalised soon, after several years, and that recommendations to improve the aged care*

*system be implemented, not glossed over and left undone. Then I may re-visit my aged care options for the future.”*

*“I am hoping the government fixes legislation to correct these issues but I am worried about going into [an] aged care unit”*

*“It's definitely something to think about Hopefully things will be better by the time we need it”*

## 1.5. Pragmatic approaches to navigating aged care planning

The reports of neglect and abuse prompted some respondents to take a more pragmatic approach to their aged care planning and decisions, rather than simply asserting they would not access residential aged care. Acknowledging the possibility that they would need residential aged care, they commented on how they would navigate the potential pitfalls.

### 1.5.1. Individual capacity to choose quality care

Several commenters said the reports had not affected their decision-making because they felt able to take things into their own hands. Others said that the reports of neglect and abuse had affected their decision-making by pushing them to take a more conscientious approach to planning for aged care. Across both groups, about 110 commenters (8.4%) said they were committed to doing personal research before selecting an aged care provider or were resolved to being more vigilant and careful in their decision-making:

*“Yes it has, as I’ve instructed my family to carefully look into any institution for ill treatment of older residents before planning my future care, after seeing several horrid stories about this on tv.”*

*“Would not go to a facility that did not have an excellent reputation. Would also talk to people already in that facility.”*

*“I would be very careful about selecting any aged care facility, whether it's a retirement village (independent living) or supported care - and I would be extremely concerned about going into a nursing home”*

*“Some age care facilities need to be further investigated by us, so that we can make an informed decision on what we want, as, we do not have family members who can help make these decisions. We also believe that no matter where we decide to go any of these places may change due to their outlook, profit margins and government decisions of which we have no control over.”*

*“Research is the key. Reputation and ask lots of questions of informed sources - not friends’ opinions.”*

*“Yes meaning, I am becoming really engaged in getting background information about some of the Care facilities that have been charged for neglect or mismanagement. I changed my Health Fund provider BUPA a couple of years ago due to their issues in Aged Care facilities care and investment.”*

Some commenters mentioned recruiting external support services when making a decision, and also formalising plans in writing to ensure they are fulfilled, even if the plans themselves have not been affected by reports of neglect and abuse:

*“Will make provision for protection and legal come back as a security”*

*“I have read a lot about the neglect as well as mismanagement and scandalous financial profiteering associated with aged care. We would need a good lawyer if we had to enter a contract with an aged care service. Our children would be well aware of these things. There [are] certain providers I know we have to avoid at all costs.”*

*“It's made me think more about who i want to act as my enduring guardian and power of attorney, who can go into bat for me if things go wrong. (i do not have children). Also about how I would choose aged care services (assuming i am up to making that choice for myself).”*

*“[The reports did not affect my planning] However I have organised for my partner and I to do our Advanced Care Directives and that has been the catalyst for discussions with our adult children. These discussions have therefore included our views on residential aged care and how we would like our needs to be accommodated should it be absolutely necessary to end our lives in that environment and requests on monitoring our physical and mental health after admission.”*

Another 30 or so commenters had already selected a provider through research or positive recommendations from care recipients, in some cases doing so directly because of the reports of neglect and abuse:

*“That is why I took extra care in finding the best care home for my mother in law.”*

*“It is important to select the right aged care provider. I have personal experience with assisting my Father into Aged Care in 2018. He is in a good*

*facility and is thriving, compared to how he was deteriorating prior to that."*

*"At the time of accessing this type of service you need to be very selective and research all your options - I did this for my mother and will be encouraging my family to do the same for me. Don't pick a facility just because it's just around the corner. Visit the facility and don't be overcome by a glitzy environment. Observe residents and staff - try to feel the vibe."*

*"Have investigated Aged Care facilities nearby with a high reputation of care and where there have been strong testimonial from residents in our Independent living facility"*

*"I live in a rural area when I know it is safe and well respected"*

### 1.5.2. The role of money in providing quality care

Some commenters believed their financial situation would facilitate them choosing quality care. Others were concerned quality care would be too expensive for them, though still others reported that money made no difference to quality:

*"We can afford and have facilities to have private care if and when needed"*

*"I would have 3 children to check on me as necessary and can afford good care. In the 1970s I had job looking into poor care of the aged - it was directly related to low income and rapacious private aged homes."*

*"One of the reasons I will NEVER go into an aged care system. Not all aged care homes are bad - just the ones with lower income residents."*

*"Very concerned - we do not want to end up in aged care but it is likely. Afraid that we will be abused or neglected and we do not have sufficient funds to get top notch care."*

*"I had to bring in ACAT for my Aunt and her neglect for high priced care."*

*"We have seen neglect first hand with an in law whilst still in a supposed premium facility."*

### 1.5.3. The role of loved ones in monitoring care quality

Another pragmatic enabler in navigating neglect and abuse in aged care is having family or friends to monitor care quality. Some commenters mentioned their plan to rely upon this

when receiving care themselves, or the role they currently played monitoring care quality for their loved ones:

*"my husband is in a care facility and although the care is fine I keep a close eye on things"*

*"Having had experience with a relative in an aged care facility, i am concerned with what can happen. I trust my daughters to keep a good eye on myself or my wife if and when we enter one of these facilities."*

*"My wife is in a respected aged care home and there are many things not getting done. I shower and feed her every day and I feel sorry for people who don't have family help. This is an area that should be investigated."*

*"Do not wish to have to go into residential care under any circumstances. My mother was in a highly recommended nursing home but got good care because the staff and management were well aware of my vigilance in relation to my mother's care and wellbeing. Others in the facility did not."*

Twenty-five people (1.9%) expressed the specific concern that they would have no loved ones to check on their welfare if they were to enter a residential aged care facility. For some this was the deciding factor against going into residential aged care if they had a choice:

*"As someone without any family to advocate for them it terrifies me and so I avoid thinking about the possibility."*

*"I would not want to go into an aged care facility at the best of times. However, because I am alone, totally, I would have no family member to make sure that I am being properly cared for, and checking that I have not been neglected or abused."*

*"I don't have any children so I don't really ever want to be placed in an aged care facility where I would be vulnerable. Luckily I have enough money to pay for someone to care for me in my home 'hopefully'"*

*"I witnessed ongoing neglect and when dementia crept in, abuse of my mother in her aged care facility. There is an outstanding abuse claim with the Aged Care Quality and Safety Commission, which is a slow, very upsetting process that is ineffective against those who control the facility. As her advocate, I was unable to keep her safe and that is a never-ending trauma to me. Therefore, I will avoid placing myself in a similar situation, as I doubt that I will have a suitable advocate for myself, as I have no children of my own."*

## 1.5.4. The need for more options and guidance

In contrast to those who felt empowered to make good choices, several commenters noted their relative lack of choice. Some said the reports of neglect and abuse had not affected their planning because their ability to decide between options was limited, irrespective of their wishes. In other words, they felt there was little point to planning for aged care. There were several reasons given for limited options: because the commenter had no family so felt they had few options to rely upon if they should become infirm with age; because they would not have any choice about entering residential aged care if they developed dementia; because they lived in an area with limited aged care facilities or services; or because another person (e.g., a spouse in need of care) was making the decisions about aged care so the reports had little impact on the respondent’s planning and decisions:

*“it's never something I will choose, but it may be the only option available”*

*“If dementia hits, I expect to be placed in care.”*

*“In the Rural town where I live there is only one Aged Care facility so there is no choice.”*

*“I've always seen residential aged care as the option of last resort but it's one that can become the only option as I have seen in my own family. So, while I am naturally concerned about the neglect and abuse revealed and would support moves to improve the system, residential aged care still remains the option of last resort and there's nothing I can do to change that fact. As we have no children, inevitably my husband or I (whoever lives the longer) will probably end up in residential care as we will have nobody else to care for us. It may be that we both end up in residential care as both of us are too frail to care for ourselves.”*

*“I am currently full-time carer for my husband who is 81 years. He has been ACAT assessed and has a HCP which assists us both. He refuses to go into an aged care facility or nursing home. The situation is extremely stressful.”*

Finally, several commenters expressed a desire for better guidance in evaluating aged care facilities, a theme explored in more depth in our follow-up survey:

*“How do I find a suitable place to live where I will be comfortable and well looked after? Won't know until I arrive.”*

*"I will be wary of prestige claims and shiny appearances. BUT how to find solid information is a puzzle. Most annual reports are sales fluff these days."*

*"Concerned about how to find provider that doesn't abuse. Need star rating from community."*

## 1.6. Additional reasons the reports did not affect planning

There were two additional reasons some commenters said the reports of neglect and abuse did not affect their planning. Some people had not made plans yet or had not heard any reports of neglect and abuse. Others said the reports were not news to them either because of their substantial prior experience with the aged care sector or because they felt neglect and abuse were inevitable.

### 1.6.1. No plans, no knowledge of neglect and abuse

Some commenters had not made any plans or decisions to access aged care services, so the reports had not affected their planning. Some of them said the reports did affect their feelings about aged care, even though they had no current plans.

The reasons for having no plans varied. Some people had not yet thought about aged care, some did not need aged care yet so had not planned anything, and a few others did not want to think about it:

*"Aged care is not on my radar at this point time"*

*"I've not made any decisions about aged care so the reports haven't influenced me at this point in time and I don't expect to consider aged care for many more years yet. A lot can change in a short time and with the report recently being released recently, many changes may be imminent so no point in planning with such a dynamic landscape."*

*"I prefer not to think about [it] try to stay healthy"*

*"The reports have helped me continue to procrastinate!"*

In addition, a few commenters were unaware of the reports, hence they had had no impact:

*"Nothing heard"*

*"Not aware of abuse"*

*"I don't have a television and do not buy newspapers, and rarely listen to radio except the news, occasionally, so although aware of problems have not been affected"*

### 1.6.2. The reports did not provide new information

Many commenters said the reports had not changed their views because they were already well informed of the issues via some other route. Some had insider industry knowledge from working or volunteering in aged care, nursing, disability support or advocacy for older people. Others received their knowledge from a consumer perspective, having accessed aged care for a loved one or themselves, witnessed the nature of care through the experiences of relatives and friends, or simply stayed abreast of the issues:

*"The reports have not really affected my decision. My decision is to stay in my own home as long as I am able. I saw my mother and aunt decide to enter a care facility and although it was well run and the care seemed excellent, I decided that this was not what I would want."*

*"I was already aware of the many shortcomings of the aged care system in Australia through observing the care received by my mother and other residents and friends in aged care residential settings and being aware of the problems faced by people seeking at home aged care."*

*"Having worked in Aged care for over 30 years I dread the thought of needing it. No matter how I tried I was unable to improve people's rights. Meals in almost all facilities are at the same time, and of the same poor quality; people must shower at certain times and are forced/ coerced to do so and so on. A nice building is not an indicator of care quality"*

*"My mother was in aged care for 10 years until her death in June 2020. I also worked briefly in the sector. The reports of neglect and abuse were no surprise. I will do everything I can to avoid residential care for myself but recognise it may become inevitable. I can only hope that we can maintain a focus on aged care and that the quality of aged care improves markedly!"*

Finally, a few commenters seemed to have resigned themselves to an industry plagued with neglect and abuse. There were two kinds of response along these lines. For some it was simply inevitable because of human nature so recent reports changed nothing. Others asserted their plan to fight off any bullies and abusers who threatened them:

*"This has always been the case in such residences, only more 'in your face' nowadays"*

*"problems with aged cared are endemic and have been since time began-- there will always be aged abuse no matter where in the home or in care places"*

*"I hope I can look after myself and my wife from predators of all types"*

*"I'm almost 70, and the lungs aren't the best, but an abuser would have problems with me at this stage of my life."*

## 1.7. Views on the causes of residential aged care problems

While the question we asked in NSSS-9 was about the impact of neglect and abuse reports on respondents' aged care plans, many commenters took the opportunity to discuss the nature of the problems as well. The comments expressed a great deal of anger and concern for the welfare of residents. Reporting some of these sentiments grants us further insight into why people hold their views on residential aged care. It can also help us determine what issues must be addressed before wary Australians will feel able to place trust in the aged care system – a topic we explored in depth in our follow-up survey.

The most common view, expressed by well over 100 commenters (>7.7%), was that a privatised system driven by money and profits has been responsible for many of the abuses:

*"Age care homes only care about profit not about people The workers care but not the homes."*

*"Age care should be run by government not private enterprise"*

*"Definitely. At this stage these facilities are medieval & while everyone knows what's happening Govts turn a blind eye. Gouging by the organisations that run these facilities has to stop. Needs regulating & proper auditing with aged care workers paid an appropriate wage. But this won't happen."*

*"It's called aged care for a reason, it is not a commodity but a care system should have NEVER been privatized for profit, PEOPLE need a caring organization, that they can trust."*

*"My career was in aged care 1992 - 2016 at senior level. I have made representation to all the enquiries, read all the reports, and things are becoming worse not better. Corporate ownership and financial accountability to shareholders has only made things worse. Covid in aged care was not only inevitable, it was a systems failure at all levels. I am ashamed for the care provided to the elderly in this country."*

A few commenters expressed negative views of aged care staff, though these were often tempered by comments about the poor contexts in which staff are working, including rostering conditions, pay, training, changing client needs, and even corruption. Current or former staff were foremost among those commenting on aged care staff and their situation:

> *“I once worked as a casual in aged care and was disgusted with the care. Not enough care given because of lack of staff and staff that were there only for the money. Staff were too young to understand that older people were incontinent etc due to illness not bad behavior. The worst of it was that the hierarchy had the attitude "toughen up".”*

> *“I saw how my mother was treated in the nursing home section of a country public hospital and with that experience and the reports I have seen I am very concerned about the possibility of having to rely on aged care. I also spent a short time in my 50's training to work in a low care facility. The low pay and hard work as well as being expected to give medication (not my responsibility or qualification) was the reason I stopped and it has also affected my opinion of aged care.”*

> *“I have worked in aged care in the past. Some have been excellent, but others not. The problem is, if we don't value and care for the workers we communicate that they and their roles are unimportant and so too those for whom they care. Training programs in the VET [vocational education and training] sector vary from being excellent to finding shortcuts with the aim to make profits for the RTO [registered training organisation] owners.”*

> *“As a retired RN I would prefer not to go into Nursing home or Aged Care. [One] trained person RN per shift is not enough to have in 8 hour time span and no trained person at night time. Owners of care homes not medical people and not in business to look after elderly..........only to make money!!!”*

> *“I worked in an aged care facility for 18 years as a clinical nurse and in management. Due to the age residents enter care now the residents care needs are complex and require more staff to be able to complete the standard of care required. Sadly there are not enough staff in all departments to complete the care. Due to the work involved and the poor wage in aged care it is difficult to attract staff to work in aged care. Also the amount of documentation required for funding and to meet accreditation standards is demanding and takes time away from clinical care.”*

*"Nothing has changed since 1995 when I was [a senior public servant – details redacted]. I was monitoring nursing homes and dealing with complains of abuse, lack of care, starving residents because the owner would provide little money for food and take most of the government grant for themself. Ghost rostering was rife. Money was taken from the government to provide staff but pocketed by the owners with minimal staff on duty who could not possibly look after all the residents. Disappointing that all my hard work fell in a heap when the nursing home owners and nursing staff convinced the government to take the monitoring out of our hands and create a separate agency [staffed] by former nursing staff who were there to look after their mates."*

In short, most commenters who talked about such matters blamed the system for the problems. They sought reform at a systemic level – be it facility management, government oversight or funding arrangements – usually not solely at the individual level of staff behaviour.

A small number of commenters wrote directly of the need for people to act and for governments to listen, if change is to be made:

*"we need to watch it carefully and advocate strongly for better standards monitoring and education of the public on the standards required. Congratulations to the student nurse 'whistle blowers in WA'"*

*"I am worried about the abuse highlighted in the recent Royal Commission, but feel powerless to get a better outcome - governments just don't listen, or worse, act."*

In line with the desire for change, we conducted a small follow-up survey in late 2021 to find out what older Australians want from an improved residential aged care system. We discuss those results in the next sections.

# PART B

# Follow-up survey, October 2021

# Q2. Making residential aged care a better and more desirable option

## Q2. Section map

To return to this map at any point, click the Q2 map icon at the bottom of any page.

**12 IDEALS**
**for improving aged care**

Reduced fees and support for non-profit models

Flexible, home-like living quarters with freedom and control

Increased staff numbers, improved pay and conditions

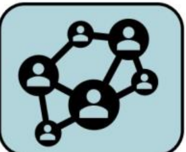
More residential care for all regions of Australia

More home-like meals and tailored food choices

Specialised health staff and flexible healthcare options

Diverse housing models, small homes and partner facilities

More socialising opportunities and better activities



Catering to diversity in care teams and facility culture

Facilities that enable ageing in place

Facilities for visitors, travel and online communication

Management accountability and abuse prevention

## Q2. Results

One question our follow-up survey asked in October 2021 was how respondents thought residential aged care could change to make it a better and more desirable option for people who need it. This question yielded 553 responses for analysis after blank, irrelevant and ‘I don’t know’ type answers were eliminated. The dataset of answers was complex, with people sharing a wide array of ideas for change. We grouped them into 12 themes and present each below together with some remarks reflecting people’s philosophical ideals.

It is worth noting that most respondents did not frame their answers in terms of changes to residential aged care as it currently exists, instead describing what their ideal aged care scenario would be like. As it happens, some features they described in their ideal scenarios are already offered by some Australian aged care facilities, so change is not required across the board. In addition, some elements of the ideal scenarios are things that have been widely discussed in the public domain in response to the Royal Commission – for example, good quality food and high staff numbers – so are not surprising to read about. Indeed, some respondents specifically mentioned the Royal Commission’s recommendations in their response. In addition to these more familiar ideas, respondents mentioned some desirable traits for residential aged care that have been less widely discussed and are therefore worthy of concerted attention. Some are suggestions current facilities could incorporate while others require government support or creative restructuring to implement.

### 2.1. Reduced fees and support for non-profit models

One of the most prevalent ideals for residential aged care among the responses concerns changes to the current fees and profits framework. Many respondents want to see fees go down and want aged care to transition to a non-profit model across Australia:

*“I think the way fees are structured and discussed is abominable. It is very complex, probably on purpose, and it seems like charges of whatever kind are meant to make fortunes for the residential owners.”*

*“Exorbitant up front costs and deposits need to be addressed so potential client aren’t kept out, and can afford to use to services without selling everything they own. There seems to be much gouging by the aged care system.”*

*“Take age care into public ownership as the industry seems more interested in profits for the investors and paying big salaries to excessive board members than the people they are supposed to care for.”*

*"In my view aged care should not be provided by private for profit companies. Or if it is, much closer Government oversight is needed."*

*"The aged care system should return to being non-profit. The mix of Federal Government, State and corporate responsibilities for the care of the aged is not working for anyone except the private sector and its bottom line."*

*"My mother had a very good experience of residential care in a not-for-profit facility in a country town. I think that the important phrase is 'not-for-profit'. I believe that that caring for profit is a complete contradiction in terms. One of my friends works in a small privately-owned care facility, and I am horrified at her stories of cost-cutting and staff exploitation."*

*"We know of an owner of an Aged Care facility. The bottom line is where they can make money!! Not the residents. E.g. no carpets, they have to be cleaned, that costs money! Homebrand food, it's cheaper. Maybe, there should be a look at profits before care of some of the facilities."*

One person argued the move to a completely non-profit-based system is a necessary as *"the only way I see operators within the industry improving their public perception, and thus (maybe) the public perception of the industry as a whole."* Another articulated their position this way:

*"I am not anti-business or the private sector but I find it difficult to reconcile the profit motive with very vulnerable, powerless people who very often cannot speak up for themselves – either because they lack cognitive ability or because they fear repercussions."*

Irrespective of whether that changes, older Australians generally want more transparency about how all facilities are run with respect to financial models and profits. As one person put it, rather pragmatically:

*"Some financial details of the operation should be provided to potential clients in an easy-to-understand manner, so they are aware they are paying for a service that is designed to make a profit and support corporate management."*

With respect to fees, some respondents specifically mentioned wanting to eliminate the large upfront refundable accommodation deposit (RAD) that aged care residents may pay, and for the only required payment to be the daily fees. On the other hand, there is ongoing concern for many that daily fees take most of the Age Pension, leaving residents without funds to pay for clothing, toiletries and so on:

*"There should be no massive up front accommodation fees. Just the daily/weekly rates. The way the system is structured it can practically leave the Husband/wife of a person who goes into aged care destitute. Virtually highway robbery."*

*"Firstly it needs to be affordable and doesn't leave our human beings left in a poverty situation with not enough dollars to live on after all the fees have been taken out of pension payments."*

*"For Aged Care facilities it should be affordable to the Family. The measly amount a person is left with, after fees are taken out of a pension, is inhumane! Old people still need to have shoes, clothes and entertainment."*

More generally, suggestions were made to make more places available to those on the Age Pension, to stop providing government subsidies to profit-based providers, and to triple government aged care funding to bring it into line with other countries. Cooling off periods are desirable for all facilities so that people can leave a facility without great financial loss.

An aged care system that is more financially fair is a prominent concern, though there are differences of opinion among respondents about what 'fair' means. Some respondents feel that user-pays elements of fees should be charged proportionately to each person's wealth or means. Others expressed frustration with situations in which wealthier people must more pay for their care while the government subsidises poorer people's care more. Those with more assets also identified the issue that if a couple's assets are drawn down to pay for one partner's care, it may leave the other partner nothing to draw on for their own care. Questions were raised about the appropriate levels of means tests and which assets were appropriate to include or exclude from them.

A few respondents were in favour of user pays add-ons being available in addition to a basic not-for-profit aged care service, so that those with enough money can buy *"extras and enhancements"*. For others this inequity was not desirable, with one person saying *"Extras for more money is offensive and demeaning. Each patient should be entitled to the same menus, entertainment and facilities."*

## 2.2. More residential aged care for all regions of Australia

Respondents expressed the desire for governments to continue supporting residential aged care facilities across the nation. While many older Australians would prefer to never enter residential aged care, they support continued investment into residential aged care for when it is needed or wanted. Concern was expressed about the current push for people to

age at home rather than relying upon residential aged care. Older people want to ensure residential aged care remains a good option.

The concern is in part that the current system of home care support is hard to access and, in one person's words, *"woefully inadequate"*, with many homecare recipients still relying on family to provide most of the assistance they need.

On the more positive side, one person expressed the view that co-housing people with widely differing abilities would foster a greater sense of community within residential facilities, and for this reason they supported making more places available, including for people without a pressing medical need for residential care. More age-in-place independent living vacancies would allow more people to transition between living in their homes and living in care through a *"downsizing stepping stone"*, as one person observed, before they needed to access high levels of care.

Some respondents expressed concern that those seeking aged care lack the ability to choose a facility in their region. The result, that aged care residents are located far away from their families and communities, is undesirable. Respondents called for government to back local and regional facilities financially to avoid such outcomes:

> *"One thing that has occurred in the districts surrounding the area where we are currently living is a number of residential aged care units have been closed down resulting that families have been separated sometimes by considerable distance. Families are important and that relationship needs to be retained. I understand that these units need to operate at a profit or close to it however I believe the first response should not be to close down the unit when they see financial difficulties arising. Perhaps the appropriate government department need to legislate to ensure our elderly citizens are looked after appropriately as in a lot of cases they are the ones who have developed and built this great country."*

Further, people want facilities to be centrally located in diverse populated areas or other desirable locations, close to public transport, shops and medical facilities, not *"banished"* to town or city outskirts as one person phrased it.

## 2.3. Diverse accommodation models including small homes and partner facilities

One of the clearest conclusions to be drawn from the survey responses is that older people want care accommodation to be less like an institution and more like home. Accordingly, respondents offered a variety of alternatives to an institutional accommodation model. A key point is that people are different, so need a diverse range of accommodation offerings.

For example, some people like living alone while others want to live surrounded by members of the community.

Smaller, friendly, co-housing arrangements were supported by survey respondents, including for groups of people with similar interests, backgrounds, cultures and so on, or groups of people with a variety of skills who can help each other. Some desire a share-house type model with the house based in the community. On the other hand, people often want a self-contained apartment, yet to be able to access help when needed. Single-story facilities are important to some people:

*"There is a need for smaller facilities which can cater to specific interests or ethnic/cultural groups, or for larger facilities to be broken up into smaller care units to enable more one-on-one care."*

*"I personally think it is time to move away from huge Residential Care Homes. I would suggest the option of having Aged Care Residential homes within the Community. Homes that have a main kitchen, dining room, lounge room and separate bedrooms with own bathroom. These homes would have a limited number of people in the home. For example 6 people. The home to also have large verandahs surrounding the home for residents to be able to sit outside to feel part of a community. This would also help create future employment within the community, involve the community as the residents would feel part of the area. There could be social Inclusion for young and old. I personally feel this would take the fear out of having to move from my home, knowing I was moving to another home with company, interaction, socialising and a sense of an extended family. I would like the home to be open for family and friends to be able to visit, once again this could help other residents of the home to feel part of the extended family."*

Older Australians desire freedom and autonomy in determining facility routines including for personal care, laundry and cleaning. These are further reasons to support smaller homes, so that aged care staff are not trying to schedule routines for large numbers of people, and they can know, remember and respect residents' personal preferences.

The notion of a *"mock village"* was raised too, with small versions of most of the services a person would want in ordinary life located within walking distance of the aged care facility (such as a beautician, hairdresser, massage therapist, etc). Including cafes and shops open to the public within facility grounds was suggested to minimise residents' isolation.

One person suggested a model for managing a larger facility as a group of smaller facilities, creating a more home-like environment in each by focusing on staff needs:

> *“Create living hubs for small groups of residents living in the complex. Provide the same core of aged care workers for that hub. Create teams of workers that are rostered to care for the same residents on each of their shifts. Structure this team so the registered nurses, carers, meal providers, cleaners, support staff etc. are the same teams and each are carrying out the tasks they are trained to do: this then creates a living, vibrant hub where the residents and providers know each other and communicate well […]. This then means family members also connect with the same core of persons caring for their loved ones which surely then creates a strong means of communication for all concerned. To achieve this, the employers have to offer permanent employment, workable rostered hours on and off and strong long-term incentives for career advancement and stability. The government is desperate for women to return to the workforce - the above surely is the means of opening the way […] Each hub created joins together and becomes a well run aged care facility.”*

Another person who had visited numerous facilities felt this model worked well:

> *“The best we found were the ones made up by Pods of about 30 self-contained rooms with communal TV, dining, and outdoor areas in each Pod. Their main kitchen supplied all Pods. The nursing and domestic staff [knew the residents] and the residents had confidence in the staff and were happier. […] [Each] pod can be sealed off from the rest”*

This model of multiple “hubs” or “pods” may be compatible with the further suggestion to have retirement villages on the same site as residential facilities. A retirement village could comprise one or more of the hubs or pods. Further to that, a concern people often have is that residential care effectively breaks up couples if one partner must enter and the other doesn’t need to. One person suggested a second facility for loved ones be provided on the same site as a care facility, so that partners, friends or family of residents can live close and *“provide support and personalise care as required”*.

Several people said mixed age communities were desirable. Options proposed included older people being housed in mixed age suburb communities and aged care residences being attached to early learning centres so that older people can interact with children. A few people mentioned the system of offering free accommodation to select university students to live in an aged care facility alongside older residents, perhaps exchanging some labour for a reduced higher education debt:

> *“It is my belief that small residential aged care units placed in family communities next to schools and pre-schools and shopping centres where people can engage in community living as members of community family -*

*villages, community gardens, playgrounds, horticulture, restoration projects, where different age groups and different races can work and play together - are the way to go. Where people belong, feel valued and can be useful watching children play, picking up rubbish, talking to the baker……. Not being alone watching television!!!!!!!!!”*

Many older Australians would like the opportunity to try a residential aged care facility before they commit to it. Respondents mentioned different kinds of temporary stay, including short respite stays to relieve home carers, short holidays before a person needs residential care, and trials prior to applying to move in. One person suggested a trial model whereby people can get used to aged care over time by living in a facility a few days per week, and at home for the rest, then increasing it gradually. Some respondents shared the benefits of trial periods for their loved ones entering care:

*“[my sister] asked Mum if she would like to go into aged care facility for the week which she agreed. She enjoyed the experience and this type of thing happened over a period of 6 mths or so. Then one day she fell and injured herself and was in hospital for a few days […] Not long after that Mum decided to go to the home for good[...] So her casual visits allowed her to check the place out and so also made friends during those stays, so it wasn't as traumatic as if she turned up and moved in as a stranger.”*

## 2.4. Facilities that enable ageing in place

Our next theme speaks to the fact that some residential facilities do not currently provide services for residents with high care needs. This is a problem for many older people.

The survey results show that older Australians are worried about needing increasingly higher levels of care as they age and desire more certainty about how they will be cared for. For many respondents, this means facilities should be designed to enable ageing in place, so people do not have to move after entering a facility. Other respondents suggested linking facilities on the same site, such as building residential care facilities adjacent to (and associated with) retirement villages, so residents do not have to move far to receive higher levels of care. The ideal is to avoid the need for residents to have to search, apply and wait for a new residence when their needs change, and to then adjust to that new place, especially when they may lack the full capacity to do so:

*“1. I think more lifestyle and retirement villages should have residential aged care facilities on site - to keep people in their communities once they have made the change from their home to Village. Change is much harder as we get older. 2. Residential aged care should be integrated into the community - some new ones are in the same buildings as child care, shops*

*etc 3. Information about the costs of Residential Aged Care should be clear and processes as fast as possible - e.g. if I move from a Village into integrated residential aged care who will manage the change - selling the Village home, paying for the RAC etc especially if the resident doesn't have children or other family."*

A further implication of this is that all facilities must be equipped to provide specialist care for people with dementia, people with different kinds of disability, and people with terminal illness, including people who want to access voluntary assisted dying (VAD) provisions.

Respondents expressed different opinions about how and where to best accommodate people with dementia. Some feel strongly that it is desirable to have sections of facilities dedicated to care for those with severe dementia, and for all residents to be accommodated close to others with the same cognitive abilities as themselves. They argued that this would also enable staff to specialise better. A concern was raised that people with a milder level of dementia may find it stressful to dwell alongside people with severe dementia, making graded (separate) dementia wards desirable:

*"There needs to be totally different physical residential care facilities / properties for people suffering acute dementia / Alzheimer's to those elderly persons who are just physically impaired to care for themselves on a full time basis. No mixing of dementia / Alzheimer's patients with those persons in Residential care that are unable to physically care for themselves. It is not good for either to be in a mixed environment, with the yelling, singing out and sometimes physical assaults that occur."*

*"I would like to see specialist aged care facilities provided where there were levels of services provided. Have a home like aged care facility for people that are able to look after themselves quite adequately and then another facility that specialises in looking after people that have health issues and need assistance on a regular basis. Thirdly have aged care facilities for the infirm and dementia type person that needs full time care with perhaps an attached hospice. By hav[ing] grades of aged care facilities you can then have staff that are trained specifically for the type of aged care services provided and not have general staff that try to be all things to the various level of aged care needed."*

However, other respondents prioritised ageing in place with the ability to access care support irrespective of the level of need, implying people with severe dementia will routinely be accommodated in rooms adjacent to people with no cognitive decline.

*“Ageing in place would be really important to me - I saw my father go downhill every time he was moved within a facility to a different room.”*

*“Centres need to be more focused on care in place models instead of clients having to move somewhere else when they become ill or their everyday needs become more involved. For this to be effective, there has to be realistic TRAINED staff to client ratios in place, whether private or government or community or religious based. I also, personally, believe that a smaller type of facility is much more comfortable and home like than the modern, sprawling, large type of places that become homes to hundreds of people, and are mostly privately owned, built and run for maximum profit these days. Individuals just seem to be a little overlooked when changes in their support needs start to occur, because of staffing issues in places where hundreds of people live.”*

Respondents asserted the need for facilities and staff to accommodate the needs of people with different types of disability, including people who are blind or have limited vision, people who are deaf or have limited hearing, people who require mobility assistance, and people who have difficulty communicating with others. Since people cannot necessarily predict whether they will be living with disability in the future, nor the level or type of disability, all residential facilities should ideally be designed to accommodate a range of future potentialities.

## 2.5. Flexible, home-like living quarters that maximise freedom and control

The layout and fittings of private rooms is of primary importance to older people when considering residential aged care. Once again, survey respondents overwhelmingly agreed that rooms should feel like home rather than like an institution. Along these lines, one asked the rhetorical question, *“Are institutions there for the individuals whose “home” it is – or are the residents there for the benefit of bureaucracy?”*

Most people want to have their own room not share with another person, especially a stranger. An ensuite bathroom is a desirable trait for residents’ rooms for similar reasons of privacy, conflict avoidance, cleanliness, and fostering a home-like environment:

*“If the time comes, I would prefer privacy, my own room and ensuite. I know that such facilities are available, but at a price.”*

*“single rooms should be in the majority of complexes followed by rooms with two beds for couples or two single persons sharing. Larger rooms should be avoided at all costs as 4 bed rooms or larger should be a thing of*

*the past, No privacy, too impersonal and can lead to tensions between residents. The aim should be to maximize a persons remaining quality of life and enjoyment of life not the opposite.”*

Respondents would like residents to be granted generous levels of control over their room’s environment that allow them to:

- stay hydrated including at night,
- control the temperature in their rooms via an air conditioning system,
- control the lighting with different brightness options,
- install a landline telephone if they desire one,
- have privacy when desired, for example by closing and locking doors, and
- play music in their rooms without worrying about disturbing others.

Privacy is an issue several respondents raised, expressing a desire for residents’ privacy to be fully respected, with no one entering their room unnecessarily. One person observed that when walking along a corridor it is natural for people to glance into others’ rooms, causing residents to close their doors and isolate themselves. They suggested a different door configuration could address this issue. However, for others, open doors are an important measure to minimise the risk of abuse.

People want to be able to decorate their rooms in personalised ways and bring some furniture and personal items from home. As one person asked, *“what will happen to all my treasures?”*

Respondents also want plenty of room to store personal items brought from home, including secure storage for any precious or valuable items. Space to store larger items such as motor scooters and wheelchairs, and in some instances cars, is needed to retain mobility.

People prize having a view of gardens from one’s room, and ideally direct access to an outside area, for example via a balcony:

*“Larger rooms and suites with a lounge and bedroom and ensuite. Rooms with views of at least a garden - shrubs etc.”*

*“Myself I would like my own room, Be able to get outdoors if I could manage on my own, if only to sit in the fresh air. Have access to food and drink when I wanted it.”*

Room size and layout matter. Some respondents expressed the desire for semi-separate areas in their rooms for study, hobbies or making a cup of tea, and more space in their room to pursue activities that require it such as knitting, sewing and puzzles. The possibility of

having two living spaces (a bedroom and lounge room) was also raised, to make the private space less like a hospital room and to enable residents to entertain visitors comfortably:

> *"Older citizens want to maintain their dignity and privacy. All Residential homes should consist of single rooms only, no shared rooms. These rooms should be large enough to fit several items of personal furniture, and large enough to have areas ie TV viewing area, place for a tea making facility, small table for meals and craft etc"*

While people do not generally want to share living quarters with strangers, it is important to some that couples be able to share a room or dwell in adjoining or interconnected rooms. This also applies to siblings and other pairs of people who want to live together. For many people, allowing pets is extremely important, out of love for them and concern for their welfare. One respondent explained their situation like this:

> *"It would be lovely if an aged person could bring their likely equally old furry companions with them to help them settle into their new home. It would also continue to encourage the aged person to walk as their furry companion will still be needing their ritual walk/toilet breaks. Yes, I know that some aged care residences don't have outdoor areas, but perhaps there could be some built in relevant regions that do and the aged person and their pets could at least enjoy what time is left to them together. I know I have an 8 year old maltese x toy poodle who quite happily spends her time snuggled on my lap when we're not out ministering to the street folk and riding on our mobility scooter. I fear having to enter residential aged care as disability continues to encroach on my abilities, as I'll have to find another home for my constant companion, she'll likely think I've abandoned her as she is a rescue to begin with."*

Another emphasised the importance of allowing pets to visit:

> *"My daughter-in-law's grandfather went into a nursing home and we took on his dog, Sam. Her grandfather was happy that Sam had a good home to go to, however it would have been good if visits could have occurred as Sam had made him happy for 8 years."*

The use of new technologies in aged care facilities was flagged by a few people to solve known problems. One person suggested rooms make use of voice recognition technology so that residents can call for help if they are immobilised and can even interact with their television and so forth via voice commands if they have mobility difficulties. Technologies such as button-controlled showers designed for seated use or toilets with a built-in bidet were also suggested, to give residents more independence in personal care.

## 2.6. More home-like meals and tailored food choices

Food quality has been a prominent theme in public discourse about aged care and accordingly is very important to older Australians when seeking aged care. What people want re food is fairly straightforward.

People would like meals to be more *“home cooked”* in style and quality. This would entail kitchen staff catering to diverse food tastes spanning many cultures, ensuring food is nutritious, and being transparent about nutrition planning. Some residents require attention to dietary preferences, needs and allergies, so individual meal plans are necessary. Examples include one respondent whose arthritis responds poorly to processed foods, so they need a diet of fresh fruit, vegetables, and meat, and vegetarians who want nutritionally appropriate vegetarian meals *“which are not meals without the meat component removed”*. One survey respondent was concerned to ensure very ill people’s meal options are appropriate.

People want their food to be appealing to eat. They want meals that resemble what they are used to eating and to be able to suggest menu items, or at minimum to always be offered options to choose between. While insufficient food is a concern for some, others are worried about being fed large servings having been raised to eat everything on one’s plate, so both adequacy and flexibility in serving sizes is desirable.

Older Australians would also like more flexibility with mealtime scheduling rather than schedules revolving around staff rosters. They want to be able to choose whether to eat in their room or in a communal area, they want an end to meals and drinks served in plastic containers and ideally to have attractive crockery, plus they want access to quality leisure foods such as good wine and coffee. They want the freedom to eat fruit or make a cup of coffee or tea for themselves outside of rostered times or even to prepare their own small meals.

*“The resident complains about the food. Endlessly. There is lots of polite listening. But no change. CALD people cope with it worst - many places can't supply basics like rice as a staple for Asian residents of the Arabic style bread.”*

*“Access to preparing own meals e.g communal kitchen area, including somewhere to make a sandwich, salad, your own toast which does occur with low level care situations”*

Older Australians generally find it unacceptable for food to be prepared offsite, mass produced and uniform. Most people want meals prepared on the premises. One person argued for rules about food donations from local farms and home gardens to be relaxed.

## 2.7. Opportunities for socialising, appropriate activities and community engagement

When asked about their informational needs when considering aged care in the other follow-up survey question, many survey respondents said they would want to ask residential facilities about specific services, programs, spaces and equipment they offered within communal spaces for residents’ entertainment, and for assisting residents with tasks beyond bodily care. This list of items grants us some insight into what older Australians want in aged care communal spaces; it includes a hairdresser, nail technician, pool, library, games room, music room, movie theatre, and dancing and exercise space. People also mentioned the need for a technology room containing computers and internet access.

Respondents want to ensure the facility they enter offers lots of activities for mental and emotional stimulation including educational programs. They want to be able to pursue the activities they enjoyed throughout their life, including through regular outings to cafes, external facilities, or natural places such as beaches, and in-bound services to support their hobbies while at home in the residence. A library service to deliver books to avid readers was one suggestion.

Older Australians want activities that are *“commensurate with people’s intelligence”* and interests rather than *“mindless craft or activities that would be better in a child-care centre”* as one person put it. The opportunity to bake a cake, make jam, clean a car, polish silver, or do other practical tasks was mentioned by a few survey respondents as desirable activities that could also enhance socialising opportunities among residents and contribute to the functioning of the facility. Seating residents in front of a loud communal television was identified by many as an undesirable activity too common in aged care.

> *“Most of the problem with placing older people into residential care is connected with some concept they are useless in any other aspect. This is far from the case. Bookkeepers, accountants, cooks, gardeners, landscapers, administrators, cleaners, and many other skills are available in these individuals and could be harnessed in order to actually run the facility. With this aspect lessening the employment factor, a consideration could be given after assessment and consequent appointment, making it less of a financial burden and providing a much needed function for these people. Early death, after retirement, is attributed to a lack of purpose in life. Many people, after having worked a lifetime and subsequent retirement, die within six months of that retirement because all their sense of purpose, sadly, has been associated with their employment. A sense of being able to contribute to the `community' of the old age facility is something which needs to be factored in.”*

*“Afternoon tea on some days cooked by a resident.....smell the scones baking! that will bring residents together.”*

Several respondents noted that most aged care facilities don’t currently introduce residents to each other or actively encourage friendships. This kind of promotion of in-house socialising and social groups would be desirable. Some feel it could be achieved with structured socialising activities such as a happy hour or residents taking it in turns to set the agenda for dinner conversation, though others acknowledged not everyone likes *“structured fun”* or socialising.

Respondents highly value gardens for fresh air and, ideally, for residents to have the opportunity to engage in gardening tasks. Enclosed, shaded gardens for people with dementia to wander in safely are also desirable. Respondents noted that deciduous and other seasonal plants are important to help residents identify the seasons, and sensory gardens are desirable for people who have limitations in one or more senses. Where a residential facility is organised as a group of smaller buildings, one respondent suggested that each could be individualised in appearance for easy recognition, with different plantings and colours.

Designing communal spaces to resemble the outside world was suggested as a strategy for making them more home-like, for example dining rooms that are more like cafes or restaurants and walkways like malls or covered roads. People want aged care residents to be treated as adults not children in terms of building aesthetics. For example, one suggested replacing the stuffed toy aesthetic of some residences with fresh flowers.

Well-signed toilets close to all areas throughout a facility are desirable. Measures to ensure facilities do not smell unpleasantly of urine and food are also important to people:

*“All aged care places should smell good - most don't and smell of urine”*

*“When I have visited any aged care residence the smell of food always pervades the area and to me this is rather revolting”*

Many survey respondents expressed their desire for residential aged care facilities to engage more meaningfully and actively with the wider community, both to reduce stigma about old age and needing care, and to highlight the value of aged care workers. They suggested forging community connections and being more open with facilities to enable prospective residents to become familiar with them and normalise them. Respondents would like facilities to support residents to continue their volunteer involvement in community groups and general community participation. Several suggested facilities partner with specific community groups and school groups to provide activities for residents that are genuinely stimulating and therapeutic, and generally for group members to visit facilities and spend time with residents:

*“In regional areas, articles from local facilities in community media telling us what’s going on, changes in their rules, etc. Some of these information items can appear in in-house newsletters for residents, but engagement with the wider community can be lacking.”*

*“partnerships' with [ethnic] groups could provide opportunities for companionships and visits and projects such as recording memoires.”*

*“Care facilities should be encouraged to provide organised therapy groups - physical exercise, crafts, link to local Mens Sheds or CWAs or local groups that could provide access for residents.”*

One person suggested regular visits from school students who could pair up with residents under a ‘buddy’ system or share technological skills with residents in exchange for residents’ wisdom, thoughts, life stories and lessons about patience. They emphasised the value of residents having something to look forward to, with one writing:

*“My grandmother used to always say – ‘Never underestimate the goodness of anticipation. You can dine out on it for days at time and it can be just as nourishing as food.’”*

## 2.8. Facilities for visitors, travel and online communication

Access to the outside community is important for older Australians when considering residential care and was the topic of many comments. Respondents emphasised the importance of residents having meaningful human contact whether from people visiting them or from them participating in the world. This was a prominent concern for some because of the impact of COVID lockdowns on residents. Some mentioned the desirability of guaranteeing good access for visitors, even during pandemics, *“to maintain wellbeing and feelings of connection and worth”.*

People want access to transport to be able to shop and visit people, whether public transport close by or transport provided by the facility. It is also important to people that others can visit residents at the facility, so facilities need ample parking for visitors. Visits that involve opportunities to pat animals are desirable:

*“Being permitted visitors at odd hours or being able to be taken outside the facility to go shopping or for a cuppa was one [of my mother’s] great delights and always generated much interest with her colleagues when she returned.”*

Respondents would like to see supports for residents without friends and family including volunteer visitor schemes (some of which currently exist) and programs for assisting

residents to purchase toiletries and other goods. They also want greater carer attention paid to residents who do not like to socialise with others in the facility to ensure they are supported and have enough intellectual stimulation. People want to ensure that couples have ample opportunity for time together, given at present it is effectively a separation if one goes into care while the other does not.

The pandemic has increased people’s awareness and use of online video conferencing and chat technologies such as Zoom. Residential facilities should ideally incorporate internet access for every room, a computer lab equipped with devices that have communication apps installed to serve those residents who do not have their own digital equipment, and staff who can assist with using the technologies and digital security:

*“Given the rise in the use of virtual meetings via the internet I think there is potential for some of the aged care facilities to make these services available to their clients so they have easy communication with friends and family.”*

*“parking and access for visitors and options for social outings and recreational activities. Facilities to provide communication with family (terminal, writing desk)”*

*“Residential care should include a staff member to assist with technology problems to avoid scams.”*

## 2.9. Increased staff numbers and improved pay and conditions

Older Australians want mandated higher numbers of staff per resident at all times of day and on all days of the week including public holidays. Within this they want enough carers to support nursing staff so that staff roles are better differentiated, for example so that nurses are not given cleaning and cooking duties. At the same time, they want administrative staff and others not directly involved in caring duties to be trained in aged care, so they are more part of the care team. They want staff who are fully vaccinated, and police screened.

Respondents want to see staff numbers high enough that carers (or other specialised staff) can devote at least a standard minimum amount of time per day to each resident that includes concerted attention to their quality of life, exercise and leisure activities, and time to stop for a chat. They also want enough staff to be able to respond to residents’ needs such as toileting in a timelier manner than at present. The need for staff to be available to assist residents with eating and drinking was highlighted by several respondents. They discussed the fact that some older people physically cannot feed themselves, drink by themselves and/or cut up their own food, so they will (and do) become severely dehydrated or malnourished if no one helps them. A respondent who had become familiar with

approximately 20 local aged care facilities through their work with aged care clients discussed this problem and its further repercussions, writing:

> *“I saw residents who were almost starved to death. They were given meals but they needed assistance to eat them. Because there was no staff to do this, a superficial assessment was made that they were not hungry and the food was taken back. This happened to my mother in aged care who became severely dehydrated and very thin, until the situation was drawn to the supervisor's attention. Because no one checks their fluid intake there is a widespread epidemic of urinary tract infections - often undiagnosed and residents do not disclose!”*

Many respondents mentioned that aged care workers are frequently underpaid, undervalued and overworked, and they want this addressed with much better pay, conditions, recognition, and consideration for their health and wellbeing given their work can be difficult. They want to see aged care facilities staffed by quality, qualified people, and for aged care work to become more professionalised with career pathways, rather than ‘just a job’. Ultimately, they would like to see reduced numbers of casual workers or none, and instead stable staff in each facility so that residents are supported by people they know. They want staff who are caring and empathetic by nature and thus naturally drawn to the profession. They also highlighted the need for strong communicators who can work with any language barriers and communication-related disabilities or conditions such as hearing loss to engage properly with residents’ needs:

> *“Once my father passed away leaving mother by herself in the nursing home for a further 4.5 years, my wife and myself travelled 1000km from NSW to [town in Queensland] to visit her every 6-8 weeks. In those weeks when we weren't present visiting her, we rang at least twice a week to talk with her and to determine from the staff as to her physical and mental condition and if she needed anything e.g. clothing, personal hygiene articles, sweets, chocolates etc., etc. On numerous occasions when ringing, we spoke with casual registered nurses, casual nursing assistants, very, very few of them knew my mother personally or what her condition or needs were. Often, I would hear the flicking through pages by the registered nurse, who come back to me and tell me, "Yes, she's okay." When questioned if she was in need of anything, very often received the reply, "I don't know, I'm only a temp here, please wait until I find someone who might know." All the foregoing commenced happening after the nursing home was taken over by a company that had many nursing homes on their books. Prior to this, the nursing staff were wonderful, they had been at the home long term, they all knew my parents and were always*

*able to provide me with the information about them and their needs. Since the takeover by the new company, over a period of about 2 years, almost all the long term staff had left the home, with most of the new staff being made up of casuals, including the Registered Nurses. This tells me that the new operators were not treating their staff as well as they should and that their significant focus was on maximising profits which occurred at the expense of long term dedicated staff and more particularly, the resident seniors. In short, the personable and knowledge aspect of the home had almost disappeared."*

One person described a vision for a highly supportive working environment for staff that would also benefit residents:

*"Staff should form a strong team, with exchange of experiences, care for each other, and openness for new ideas. Respect for each other, profound training, compassion should be key issues"*

## 2.10. Specialised healthcare staff and flexible access to health professionals

Respondents expressed interest in improving the ways that residential facilities handle residents' medical and health needs, beyond the routine aspects handled by carers and duty nurses. They want to see staff trained in care for people with dementia and other conditions associated with cognitive decline; trained in palliative care, end of life support and VAD guidance; and trained to use methods other than psychoactive medication to assist and manage residents. They also want more staff training in managing mental health and well-being, skin conditions, incontinence, and using disability aids and equipment.

Respondents want choice and control over their health providers, including the ability to continue visiting external GPs and other health professionals, with transport assistance. But they also want to ensure that those who cannot travel to see external providers, or people who do not have a pre-existing relationship with external health professionals, can regularly access in-house appointments with a GP, and visits from health providers such as podiatrists, physiotherapists, diversional therapists and dentists. Some expressed concern that aged care residents often have wounds or other medical issues not noticed by carers, and doctors are not always readily available within some facilities. They want all residents to have regular health and wellbeing check-ups by professionals to ensure their medical needs are addressed. They want medical aspects of care to be planned in discussion with residents and families, to be periodically reviewed, and for a robust system to ensure medication is administered correctly. Some would like a GP in residence:

*"Resident Doctors within the aged care facility, who are ultimately responsible for client care standards."*

*"Integration of residential care with the health-care system to ensure that residents have access to necessary comprehensive care eg general practitioners, physiotherapy, podiatry, dental, audio, counselling, psychiatry."*

Some also asserted the need for residents to have access to mental health professionals on a more permanent (not visiting) basis. Respondents often noted the emotional and psychological stress involved in transitioning to aged care and the urgent need for this to be both recognised and addressed through continuing (not short-term) mental health support:

*"Mental health and wellness services/programs that are private and confidential if necessary, interesting and enjoyable and best practice - which is to say ongoing and structured, involving psychoeducation and day to day skills education to minimise depression, anxiety, trauma, grief and loss. As the younger aged (ie people now in their mid 60's or younger) enter residential aged care, they will have different attitudes to counselling and other wellness supports than people who are now in the 80's. Still, literature and discussions etc should be aimed at normalising some wellness issues as we age - with an aim of ensuring the best wellness possible. This should include close collaboration with physical specialists - everything from GPs to physios and OTs. Regular, multi-professional wellness/enablement reviews should be conducted on each person to check for example, the interaction of medications on mood, physical activity and the like with 'prescriptions' for managing such issues."*

Some people advocate having a chemist on the premises of aged care facilities, both for immediate medication needs and to provide toiletries and other products to residents.

## 2.11. Facilities catering to diverse people, through care and culture

Older Australians are aware that the aged care system must take diversity seriously in its culture, workforce and facilities. That requires empowered involvement by diverse community members in designing and delivering aged care.

In general, respondents agreed it is important that aged care staff can speak residents' primary language. On this note, they highlighted the importance of training a diverse and diversity-embracing workforce to care for the great diversity of older people in Australia. Respondents want staff to have effective diversity training for supporting residents who are

LGBTI+; who belong to religious, linguistic, and ethnic minorities; and who are survivors of violence:

> *"Staff to be professionally informed about working with people from diverse backgrounds including LGBT&. Staff to be professionally informed about working with people who have a trauma background including domestic violence; and historic sexual abuse. Staff to be professionally informed about working compassionately with people who have dementia. Staff to be professionally informed about working inclusively with people of diverse faiths; racial and national backgrounds"*

More than that, they support an aged care workforce that is itself diverse in all these ways and diverse in age, to ensure all older people get the care they need. As one person put it:

> *"Minister Wyatt's push for more Indigenous youth to be inspired to work in the Social Services be given legs. Only by careful training can youth, mainstream, multicultural, indigenous, be nurtured to see value and satisfaction in work in the aged care area for their parents and grandparents."*

Another respondent shared the story of her mother who in old age has reverted to her first language (French) although she is fluent in English, so needs a bilingual carer to understand her. Diversity in carer teams' gender is important to some people who for various reasons do not want to receive personal care from a person of another gender.

In contrast to this, other respondents were concerned about older people who have not had much exposure to human diversity until entering aged care. They highlighted English proficiency as a desirable staff trait for such residents both to ensure good communication if residents only speak English, but perhaps also because some older Australians are not used to hearing the many accents that Australians use to speak English, so they mistake an unfamiliar accent for low English proficiency or simply have trouble understanding speech in different accents. One self-identified white respondent expressed prejudice against non-white carers, so facilities will need to take care of staff from minority ethnic communities and language groups to avoid subjecting them to this kind of hostility. While it is illegal and inappropriate to discriminate based on ethnicity, languages spoken, migration status and "race", and National Seniors does not endorse it, for the sake of completion we report that a small number of our respondents said or implied they would prefer to be cared for by people who meet their ethnically narrow definition of *"Australian"*.

A further suggestion for ensuring care is appropriately targeted is for governments to incentivise employing *"people in their senior years who have more patience and*

*understanding"*, rather than relying on younger staff who haven't experienced ageing. Respondents noted that this would require changes to Age Pension rules about paid work.

Beyond the socio-political diversity of the Australian population, respondents emphasised the fact that older people are simply different from each other in a variety of ways. Many respondents held a strong view that aged care services should recognise older people's diverse needs and backgrounds and tailor care for each accordingly, constantly adapting to their needs at the time. They want to ensure aged care residents to have the freedom to make their own decisions to the full extent of their capabilities, to decide what to wear, when to eat or shower, how to organise their days, and how to be addressed by staff. They want to be able to leave for periods of time if they want to, to take holidays for example. People want residents to be respected, to be talked to not talked about as if they were absent, and to be listened to when discussing their health and capabilities. They want staff to remember and acknowledge that residents are not just care recipients but have lived lives and contributed to the world; as one person put it: *"the people in their care have been doctors, scientists, farmers, builders, musicians and everything in between and they need to be treated with respect and dignity."* One respondent would like to reframe residential care in a way that *"Acknowledge[s] that it is not about chronological age and that care is not provided because of age"*, perhaps to avoid ageist assumptions that can lead to disrespect. Respondents do not want the religious affiliation of a facility to restrict residents' freedom of choice. They want any rules to be communicated clearly.

Respondents value the opportunity to have some control over the kinds of people they live with. In some cases that is because of larger concerns such as safety, for example some women want to be housed separately from men especially at night, while a transgender respondent was concerned that they would be completely unable to find a place where they would be treated respectfully. Beyond safety it is a matter of preference to be able to live with like-minded people. As one respondent put it:

> *"I'm not interested in shopping trips to the local mall. I want people with whom I can have a challenging discussion about politics, discuss societal norms, be conversant about culture and be aware that the most difficult sudoku is just about knowing strategies, not rocket science. I need to know if there will be people at my place of care with whom I can connect."*

## 2.12. Management accountability and measures to prevent abuse

Older Australians want providers to be held accountable for the welfare of clients in their care and for the realistic promotion of their facility. Partly this entails transparent communication about corporate management structures and history (discussed in Appendix IV). The suggestion was also made for management to involve residents in running the

facility, on the board or in other capacities, to enhance representation and to help residents feel that they are contributing to their community.

*"a residents committee who could speak to and for the rest of the occupants would be welcomed."*

*"Have residents be involved in helping in the running of the place, even in small things so they can feel useful."*

Respondents also articulated the need for facilities to institute systems for residents and care staff to report issues and make complaints without fear of retribution. Older Australians want to ensure they are consulted about their care and have a say in matters concerning them. They want transparent, open communication between providers and loved ones of residents and an easy system for reporting issues, including a residents' committee. They want an advocate for residents, families, and residents' representatives to turn to in time of need, to make complaints or have problems addressed without fear of recrimination, and a similar body for staff. A quarterly meeting in which residents and their loved ones can raise any issues with an independent entity, with facility management and staff not present, was another suggestion. They would also like a day-to-day contact who is available to update family and friends on a resident's situation and well-being:

*"I think it would be a good idea if all age care facilities had a quarterly meeting with all the residents. With no one from the care facility, but from an independent entity. This would give the residents a chance to speak freely of any problems within the facility."*

*"There should be a body whereby employees can feel comfortable to whistle blow their concerns if a company is failing and not have the fear that their position would be in jeopardy."*

Given their heightened awareness of reports of neglect and abuse in the aged care sector, older Australians want measures in place to protect the safety of both residents and staff. Some suggested the need for two carers to be present for any personal care attendance, and for regular wellbeing checks for residents. Respondents want more government inspections and for those inspections to be unannounced, so the facility does not have the opportunity to cover up transgressions and problems. They want inspections to evaluate care quality, not just compliance with regulations. They also want greater enforcement of minimum standards and meaningful penalties for breaches. They noted that the Royal Commission has outlined what needs to change, so what is now required is enforcement of this, accreditation of facilities, and constant scrutiny to ensure above-minimum standards are always maintained:

*"There should be unannounced spot checks by authorities on aged care facilities; of course they are all up to scratch when undertaking a formal review!"*

*"on one occasion I contacted the Queensland Aged Care Commissioner, (I think this is the correct title), to complain about the staff losing two pair of mothers glasses, 4 hearing aids, TV remote control etc., which also indicated to me that no one was taking a personal interest in my mother and her belongings. I was advised that they had already programmed their visit to the nursing home in the forthcoming weeks, a fact of which they had already signalled to the nursing home. This of course, meant that when the inspection did occur, that everything would be made ready by the nursing home to ensure they received a favourable report. All these type of inspections should be made at random, without any prior notification to the nursing home."*

Some survey respondents also expressed a desire for CCTV cameras to be installed in residents' rooms, or at least for a resident or a loved one empowered to make decisions for them to be permitted to install a camera in their room. However, other respondents mentioned the privacy risks of this so were not in favour of it:

*"Recommend CCTV cameras to for continued surveillance not only of residents but the staff as abuse is rife this area of aged care."*

*"There's no accountability by Aged Care Facilities they are not monitored and they should all have camera's in the residents rooms. The reason they give for lack of cameras is privacy. This is rubbish it would give the Residents security which they dont have now. My Mother (97) is in Aged Care and has been for over a year now and we have to go there every day to make sure that Mum is safe. This is disgraceful."*

*"I am hesitant to suggest 'Camera's' in Aged Care Facilities as nobody likes being 'watched', but may be an Assessment Scheme from time to time could be made on Staffing capabilities."*

## 2.13. The ultimate ideal: A happy, joy-filled life in old age

Beyond this wish list, several survey respondents offered more abstract, inspirational visions of what residential aged care should be to make it something to look forward to, not something to fear. Their comments inadvertently draw attention to the fact that the current emphasis is mostly on meeting basic needs rather than aiming any higher, and that people

entering residential care often rapidly decline because their outlook is so bleak. Thoughts on alternatives to the current philosophy included these quotes:

> *“Residential care should not be about how many beds can we get on this block but about light, sunshine, gardens, bright and happy experiences involving everyone especially young people.”*

> *“Residential care could become a place where one feels as close to "home" as possible, where they can thrive physically, emotionally and spiritually for their latter years.”*

> *“The FINAL DAYS of "one's life" should NOT be consumed with a feeling of failure and deprivation, but filled with pleasure and pleasant surroundings and people. I don't think that that is TOO MUCH TO ASK.”*

# Q3. Information, guidance and assistance needs when accessing aged care

## Q3. Section map

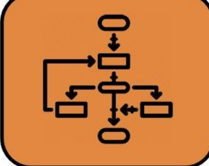
To return to this map at any point, click the Q3 map icon at the bottom of any page.

5 information, guidance & assistance NEEDS

Information about specific residential aged care facilities

Effective strategies for communicating with older Australians

Guidance navigating processes and the aged care system



Professional services to protect welfare of care seekers

Public communication to encourage aged care planning

## Q3. Results

The final survey question we asked older Australians about aged care was: what information, guidance and assistance should be easily available to people when they need residential aged care? The question yielded 598 responses for analysis after blank and ‘I don’t know’ type answers were eliminated.

Once again, the open response format meant many of the submitted responses were quite complex and multi-dimensional. Nonetheless, from this, we were able to identify five primary needs for providing guidance, assistance and information about residential aged care. They are:

- The need to provide comprehensive, transparent information about every residential aged care facility to enable consumers to make informed decisions (Section 3.1).
- The urgent need to enhance, streamline and simplify communication about aged care to ensure all guidance, assistance and information is accessible and appropriate for people needing care (Section 3.2).
- The need to create process-oriented guidance tools to help people navigate the aged care system as a whole (Section 3.3).
- The need for consumers to have access to professional services to ensure their welfare is taken care of when planning and entering aged care (Section 3.4).
- The need to implement government-sponsored communication strategies to change public perceptions of aged care and encourage aged care planning (Section 3.5)

### 3.1. Information about facilities to enable informed decisions

The first need we identified is the need for comprehensive, transparent information about each specific residential aged care facility to be made available to consumers, so that they can make informed choices when considering applying to a facility. Many respondents expressed interest in this kind of information, so it is clearly of primary importance to older Australians. They collectively suggested well over 100 different characteristics of aged care facilities that they would want information about. They made it clear that this kind of information must be presented in a consistent way from one provider to the next to facilitate comparisons:

> *“Need to have something like a Product Disclosure Statement on a spreadsheet where all costs and all services can be compared. Needs to be audited and published by Govt. department so that the information provided by the suppliers can be relied on. I have recently been looking at places with my Mum, and whilst the brochures and the walk-around are interesting, extracting the information that we need is nearly impossible.*

*Unless we ask the correct question, we are not getting all the information we need to make a decision. The "marketing speak" in the brochures is difficult for some older people to read between the lines and understand what is really being said. So brochures in plain English with consistent headings are really needed for comparisons to be made.”*

*“Need quality info on RAD [refundable accommodation deposits], daily fees, optional fees, facilities available in an easy to read spreadsheet. I found it very difficult to get quality info from nursing homes. It took several calls to each of many possible places to get info on daily fees, and whether fees were for extra services, or whether they were optional or compulsory. Websites were not clear about services available, RADs and daily charges. A common format would have been very useful. […] RADs seemed to be extremely high and seemed to range from $300,000 to $900,000, with little chance for any negotiation, and then daily fees seemed to be compulsory, not optional for extra services. All very confusing for a novice. A clear government website explaining the whole process would have been helpful.”*

To condense the wealth of characteristics that people want information about into a manageable format, we sorted all of them into a detailed 15-point list. The 15 points are:

1. Costs and financial implications for prospective residents
2. Care levels and the range of care services available
3. Staff qualifications, ratios, roles, pay and conditions
4. Additional medical, health and well-being support
5. Availability, application processes, contracts and trial options
6. Room environment, personal belongings and sharing spaces
7. Communal areas and activities
8. Food and water
9. Facility routines
10. Visitors, transport, communication technologies and isolation
11. Facility culture, diversity and resident relationships
12. Turnover statistics and incident records
13. Corporate management, organisation, budget details and history
14. Accountability to residents and loved ones, and conflict resolution
15. Summary reviews and ratings.

Each of the 15 points contains multiple sub-points that consumers want information about so these headings are only indicators of the details that comprise them. Because of the amount of detail each involves and the resultant length of the list, we have placed the full

version of the list in Appendix IV of this report rather than merging it here with the main text. Its placement in an Appendix should not be read as a gesture to downgrade its importance but rather a recognition of its high practical value.

Providers, governments, advocates and consumers alike are urged to engage with the full list and to use it when communicating about aged care. The comprehensive nature of the list makes it a handy practical tool for aged care providers and governments to use when producing information packs for prospective residents. It could also be a useful checklist for consumers or their advocates when considering a facility.

## 3.2. Enhancing communication with aged care consumers

Beyond their specific interest in detailed information about residential aged care facilities, numerous respondents made suggestions for improving the way that governments, providers and others communicate with consumers about aged care. In other words, it is not just the information that matters, it is the way the information is presented. Enhancing communication is therefore the second need we identified.

Clear communication is especially important in the aged care domain because the current system is extremely complex, to the point where even experts have trouble understanding it. This is particularly the case for topics such as application procedures and aged care costs which are notoriously difficult. Poor understanding of these high-stakes topics, and poor communication about them, can have serious ramifications as some comments illustrated:

*"having my Mother placed in a nursing home because of her increasing Dementia, was a nightmare situation. I had no idea where to get information. No Public Health Dept for Aged Care seemed to exist. I picked up information sporadically, through chance conversations with other people who had gone through the same situation before me. They also told me that they had gone through the same experience as I had. Neither Hospital nor GP offered any information, nor seemed to care."*

*"The most confusing aspect of Residential Aged Care is the finance side of the process. It is confusing for me even though I worked in an accountant role in aged care before I retired."*

*"Before I retired from work I was a Financial Information Services Officer working for Centrelink. As such I provided detailed explanations about all Centrelink benefits but especially the Age Pension. This also entailed providing information about residential aged care. Unfortunately the financial aspects of residential care are so complicated that no one else in our large Office had any understanding of them and I was the specialist.*

*However even I found the rules very complex and I regularly had to consult our internal Help Desk to resolve difficult questions. Hence, the most first essential change the government should make is to simplify the final assessment. As a result of these complexities I found that the aged care residences did not really understand their fees and charges, and many people were being wrongly charged. This is because relatives and carers have no way of checking whether the fees are correct or not. As many of the aged care residences are now run by national operators, people making fee inquiries had to deal with corporate call centres who are often quite abrupt and not at all helpful.”*

Communication about all aspects of aged care must urgently be improved for everyone’s sake. To achieve this, our respondents recommend instituting a one-stop-shop and case worker model for handling the aged care process from start to finish and employing language styles and mediums appropriate and accessible to aged care consumers.

### 3.2.1. A one-stop shop and case worker approach

A comment many respondents made consistently in response to this survey question was the desire for a “one-stop shop” for aged care support. Older Australians want a single service they can contact for assistance with every step in the aged care process, much like they would contact a single solicitor or accountant service for legal or financial advice. One person framed this as the need for a *“retirement specialist”*. People differed in who they thought should provide this one-stop-shop service – variously mentioning the Federal Government; Centrelink; the state, territory, or local government; government endorsed independent agents; and RN-based community services – but they were largely in agreement that it should be free for all, fully transparent, highly regulated, receiving no commissions, staffed by experienced/qualified people, and with a clear frame of reference:

*“I think there are many areas where information can be obtained, such as National Seniors, MyGov, providers […] but it would be good to have a "one stop shop" where all guidance, assistance and information is centralised.”*

*“It would be good if there was a “one-stop shop” that could offer all service providers a platform to supply their particular information to the person requiring care (and maybe a significant or support person). At the moment I think private companies, state government agencies, local government agencies and federal agencies all have to be considered at their individual level? I’m thinking about something like a Generic website that you can add different accounts to e.g myGov and Taxation, Medicare, etc. MyAged are maybe already doing this? […] Even a service shopfront*

*at shopping centres would be good, in much the same way that we have e.g Optus who can provide various services and products in one place."*

*"A one stop phone number or website, even to just start the process! Not all oldies are computer literate or have family that can help!"*

*"There needs to be a centralised contact (not just a website) that can give all the latest information and requirements to qualify to go into residential aged care. It needs to be comprehensive and cover who qualifies, costs, paperwork needed, who to see to arrange it, types of care available, different levels of care and who to contact if you need to actually talk to someone to get the information explained in person. It also needs to be in different languages to allow for those from NESB backgrounds. Not everyone understands the complexities of using a website."*

*"A one stop information and guidance centre where all people concerned, including family, can obtain unbiased information and follow through. This service should be focused on the individuals needs and not the organizations"*

Some respondents acknowledged that aged care brokers currently exist but are often expensive or hard to find, so want this service to be free and accessible:

*"A financial adviser whom my friend visited (my friend was supposed to be talking to his wife who was a 'specialist' in finding suitable placements for aged) spent a good hour probing my friend's finances seeming to only be interested in having her as a client for the cost of $3000 a year! We need unbiased guidance from people employed by government without an ulterior motive!"*

*"When we were in a situation where we needed guidance, assistance and information for our mother, we found what was out there completely overwhelming, disconnected and not interested in meeting our needs particularly. The government side of things was 'do this, go there, fill this form' and then every interaction was with a different person. Each provider side of things was 'we can do this, we can do that, fill this form here, sign there, pay that' but then vague on how it connected with the pension or government funding or when it would be available and told us to wait. We were lost and confused and didn't know what to do. Eventually and by word of mouth, we found a private consultant who charged a low, one off fee who consulted with us about who we were, what was our context, and asked us what we wanted. She explained in*

*detail all the ins and outs of both private and government options and then proposed and negotiated several options for us. Over time, and keeping us connected and informed at all times, we found what we needed. My mother has been very well cared for ever since. This was a wonderful experience and one that I wish for all."*

At the same time, people generally do not want the one-stop shop to take the form of a call centre where they must wait in a long queue, register for a call back or press multiple buttons to select options. They want to speak to a person straight away upon initial contact and ideally to have a case worker type arrangement with one person over many years. They don't want to have to explain their situation multiple times. They do want someone looking out for them throughout the process of seeking, choosing, and accessing aged care. Ideally that case worker would liaise with government bodies and other organisations on the care seeker's behalf and would accompany them to appointments as well as providing information:

*"Each person needs a case manager. The case manager needs all options and timing of situation. How when where why..."*

*"To be assigned one person to deal with and not having to repeat your story over and over to a different person each time you have a question."*

*"Before I put my wife into respite care (with a view to permanency) it was difficult visiting aged care/dementia facilities trying to decide on which facility was right for her. I found it extremely difficult getting support and working through my aged care, assessment teams, dementia Australia etc and sometimes I wished i could have had a trustworthy person to advise me through the process and act on my behalf as a sort of champion if you like, e.g a case worker"*

*"Get rid of the website which expects the elderly to navigate through to organise care! There needs to be an RN based community service that is a one stop shop for aged care prior to requiring admission to an aged care facility. This community service should oversee all aspects of the services required- from home care to community transport and organising referrals etc as needed. One phone call from the person needing care should see their all needs met."*

For several reasons it is important that case workers be based in different regions of Australia. Many people would like to be able to speak to their case worker face to face, including through home visits for people with mobility issues, not just to be sent information packs (though if relevant, information packs sent by case workers are also

desirable). They also want their case worker to have on-the-ground local knowledge relevant to their area, meaning they cannot be centrally located elsewhere:

*"I've found that older people understand and process issues better when it is discussed with them in person. This could be an option incorporated into My Age Care for families to access."*

*"A call centre with staff experienced and knowledgeable about Federal subsidies and income/assets test and how to make the transition from home to residential aged care. Staff need to make home visits, assist in filling out necessary paperwork and submitting it to relevant authorities. Aged residents may have mobility issues or no way of viewing aged care centres so they can meet staff there, view facilities and make informed decisions. This is where the team of experts could take the elderly on tours of facilities and also be up to date with vacancy rates and costs of entry."*

*"Advice per state which is clearly indicated for the particular state - rules vary and this is very confusing. List of all state facilities, location, levels of care provided etc. There is not a one stop shop."*

*"Moving into aged care is a very stressful time for the elderly and their families. Some local friendly face to talk to in order to discuss options, availability and costs would help."*

People are aware of the need for the one-stop-shop case workers to be specially trained in communicating with elderly people appropriately. Desirable traits respondents mentioned include patience, acceptance of the fact that older people might talk a lot and might not understand things initially, the ability to go over some information repeatedly, and awareness of conditions that affect many older people's ease of communication, such as limited hearing or slow speech. The case workers also need to have a positive attitude towards the diversity of older people and to recognise people as unique individuals so they can appropriately tailor assistance:

*"Ideally there should be a department of people who are specially trained in this area. For many older people trying to find out information by going through the Internet or looking it up online as we are always told to do is absolutely impossible. Somebody that people can talk to and ask questions from makes it so much simpler. Ideally these people would be trying to talk slowly, clearly and patiently with older folk who sometimes have poor hearing and cannot understand highly accented speech. The rules that apply to going into full time care are extremely complex. Explaining this to older people need someone with patience and sympathy. Many older folk*

*don't even know which questions to ask to begin to find out what is going to happen to them."*

*"Perhaps a person appointed to walk them through the steps, and let the people who need residential age care to set the pace."*

Care seekers would also like follow-ups once a person enters care to check if their expectations have been met. A few respondents mentioned a specially appointed "government carer" or Official Visitor acting in this capacity. Respondents recognised a need for an appropriate external person to be available to hear complaints. In essence they want a means of checking if a person is well treated, to ensure no one falls through the cracks, and to make sure guidance and assistance don't end when a person passes through the facility gate. The case worker approach would meet this need.

### 3.2.2. Communication language, format, and mediums

In addition to the strong support for an aged care one-stop shop and a case worker approach to aged care assistance, basic principles of understandable communication are also a priority for respondents.

Respondents would like information to be provided in plain, everyday language free of jargon, with short digestible paragraphs. It should be translated into multiple languages by fluent native speakers, so all can access it. Support from visual aids, applied examples and cost calculators is desirable.

*"All written information to be in "plain English", eg, no lawyer speak or jargon."*

*"Clear and concise wording that is able to be understood by the average person. A pathway of instructions that is easy to follow."*

*"perhaps something which makes contracts both plain english and a visual aide so that there can be (no?) doubt everyone knows what the provisions mean from a financial perspective."*

*"Flow chart on the process. Easy access to see availability. Quick calculator to estimate costs/out of pocket expenses"*

People want information delivery to be friendly not officious, and to consider a person's emotional, mental health and cognitive needs. But they are also wary of marketing techniques and the risk of being deceived by shiny brochures, so want communication that treats care-seekers as intelligent decision-makers, *"without the fluff and sparkles"* as one person put it. They also want to ensure that, even when information is provided in accessible language, it has been vetted by legal professionals. As discussed bove, people

ultimately want transparency and truth, and accessible language is a necessary tool for delivering that. As one person said:

*“Seniors are very often rendered speechless and powerless - blinded by complicated language. I have been a disability advocate and parent advocate in my working roles (over 12 years) and language used to include people in their journeys is vital to getting good outcomes for those who require assistance.”*

Beyond those basics several people suggested presenting information in different ways to make it more understandable and fit for purpose. Knowing that people have different preferences and abilities with communication mediums – and that younger people will often be seeking accommodation for older people as well as older people searching for themselves – respondents variously suggested brochures, booklets, books, magazines, podcasts, videos, and websites as accessible mediums for different people, as well as live delivery at events such as seniors’ festival show days. They emphasised the importance of information being delivered via different routes once it has been produced, including hardcopy collateral (such as brochures) made available via newsagencies, post offices, GP surgeries, hospitals, Centrelink/Medicare offices, and local government, to ensure it reaches people with low computer skills, and for electronic materials to be communicated via newsletters from recognised aged care bodies and advocacy organisations. They suggested combinations such as brochures plus websites or booklets plus face-to-face meetings. One person explained that a printed booklet with guidance and information is useful so the contents can be retained well into the future, whereas other delivery modes and mediums cannot so easily be revisited later. Any chosen approaches should be piloted with older people to ensure they are fit for purpose.

*“Personal face to face assistance for discussing options and process as well as printed information booklets that are written in plain English and easy for everyone to understand.”*

*“We did visit a local care home and had all the financial implications explained to us. But we got nothing in writing and, as that was a few years ago, we have forgotten much of it. An easily understandable printed guide would be good.”*

*“Any information needs to be spoken or in booklet form - not on-line. Those with Alzheimer's or other cognitive decline must be able to go over and over the information and find it easily. The information needs to be provided on a regular basis.”*

*“Easy read material and easy access to obtain the reading material - Example - in all newsagencies or post offices to have free reading material on how to enter and what residential age care will cost.”*

*“Often, too, it is younger family members who have to guide their loved ones into aged care, so it is important that guidance is available to this cohort of people, as well as to those of us who might need this one day. Information should be available in many forms, including on-line, in books, magazines, podcasts and videos.”*

As noted above and as detailed in Appendix IV, people want consistency in how aged care information is presented, especially information about specific facilities, to make comparisons straightforward. First and foremost, people want financial information presented in a consistent way so they can compare different facilities’ inclusions and exclusions. Some felt a standardised tick sheet for comparisons would be useful so people can prioritise their personal preferences. One person argued for comparison information to be regulated by government with consistent headings:

*“The "marketing speak" in the brochures is difficult for some older people to read between the lines and understand what is really being said. So brochures in plain English with consistent headings are really needed for comparisons to be made.”*

A refinable, searchable database that shows available aged care places with search options and comparison options was also suggested. However, some respondents were wary that existing comparison sites are often hard to navigate, so it would have to be well designed:

*“A one-stop shop website, with information on how to access aged care; clear information on pricing; list of facilities, with a map based search option and a side by side comparison option.”*

*“There are a number of Age Care Review sites with varying degrees of convenience in navigating. I don't want to have to trawl through information on each facility, I want a website […] with a Low Care Price, High Care Price & Overall Performance Rating to help narrow down my search so I can then concentrate on reviewing what specific facilities in my locality are good or not so good for”*

Knowing how complex the system is and the sheer amount of information that is possible, some respondents noted information should be streamlined and simplified to help them navigate it, while others want as much information as possible in one location (e.g. a website) along with someone available to help explain it and sift through it with them. As part of this, some respondents desire information tailored to the individual based on their

circumstances. They do not want to be redirected to legislation and regulations and left to fend for themselves with it; they want help understanding whatever it is they need to know. Again, these needs reinforce the benefits of a case worker approach.

*“Regarding information, care is needed to not overwhelm the patient who might have some mental disability which causes them to not be overwhelmed. So, in toto, this requirement is closely connected to the assistance they require--if no informed (worthwhile) family advice is available, the information that needs to be provided involves all aspects, and provided in a way which will be comprehended by the patient--if that requirement is met, there is no limit to the information that should be readily available by independent sources.”*

The number and complexity of forms was a cause of complaint for several respondents:

*“Paperwork that is simpler. My family and I have completed the paperwork for our parents and we found it difficult. We are well educated so I don't know how people not well educated can manage. The information provided and required is not always clear - being quite confusing.”*

*“Paperwork is a huge problem and the assumption that everyone has access to the internet and the associated skills is understated. ESL and literacy needs more attention when trying to access Governments sites and assistance.”*

People suggested relevant forms should always be available for download to avoid surprises, and forms should be simplified and not ask for the same information repeatedly. One person described accessing care for their mother as *“gut-wrenching and emotionally debilitating for her and us”*, and that this *“was compounded by the never-ending questions and completing reams of forms - many signed and never seen again.”*

Finally, while careful communication practices are important, all the communication in the world is no substitute for a good system that empowers recipients of aged care, and a good system is in turn much easier to communicate about. One person articulated the communication needs in this space as follows:

*“No Lies. No Sales pitch. The decision should involve the person going into residential aged care, that should be mandatory. Too often the person involved doesn't even know what the family/concerned regulatory body are doing to them when placing them into care, until it happens. Don't put everything on the internet! Post information, call people, call on people - go old school; try to reach those people who aren't computer literate, or mobile phone savvy. I think the word guidance is great, but I feel the*

*greatest resource is an Aged Care Home that I would want to live in. The best information etc is word of mouth among the aging community about wonderful homes to go to. The best assistance is providing clean, happy, well staffed, well funded, not smelly, with good food Age Care Homes."*

## 3.3. Guidance tools to help consumers navigate the aged care system

The discussion of the one-stop-shop, case worker proposal shows that many respondents need help navigating the processes involved in accessing aged care, not just to be handed a stack of information. There are several reasons for this, including the overabundance and complexity of information currently available, the widespread negative opinion about residential aged care we discussed in Part A of this report, and the limited ability of some older people to access and process existing information for themselves.

There are also lots of different kinds of decision to be made when accessing aged care, so people want help with different aspects of the process. These include choosing between aged care options, understanding financial impacts, planning out the timing of each step in this process, dealing with requirements of providers and government services, managing the practicalities of moving, and making decisions for loved ones to enter residential aged care. These are all domains in which people need guidance and assistance from experts. Whether the case worker approach or another approach is instituted to provide this assistance, these are some of the areas those experts should be trained in.

### 3.3.1. Aged care options

While care seekers highly value their freedom to make aged care decisions for themselves, many also want independent, expert guidance when choosing between aged care options. They want open discussion about the pros and cons of each option, even in regions where few options are available. As one person put it:

*"In the area I live in the options for aged care are limited so guidance is low, assistance is only offered at a point where the person seeking help has no say in the matter and therefore it is safe to say that information to make a very personal decision about your own future is revealed AFTER someone else has decided on your behalf. I'm sure that most of us "elderly" would just love to decide for ourselves. We are capable, generally, of doing just that!!"*

Confusion about how the aged care system works is rife. At the macro level some people simply want to know where to start in planning for aged care and considering options. Respondents' suggestions for resources to help orient people to the system included: clear

and concise pathways of instructions; flow charts of the whole process; a roadmap with attention to assessment, costs, what to look for and more; and a list of dos and don'ts.

> *"A simple step by step guide to the process from prior to ACAT to getting a bed in residential care. Simple explanation of the costs. Assistance for those who do not have anyone to help the negotiate the process. An advocate to ensure homes do not take advantage or give poor explanations"*

> *"What's lacking?? RESOURCES at the first stage. We had no previous knowledge of Respite Care, Transition Care or Aged Care or an understanding of the differences between these care service providers. […] It would so helpful if Social Workers could immediately direct family members to a comprehensive VIDEO resource which CLEARLY explains how the Governments, State and Federal define these facilities and support services within them and how to access them. […] Phone assistance provided by Myagedcare was excellent so long as I asked the right comprehensive and clear questions. Not every one has those skills. I suggest a more interactive role be taken by telephone support staff such as honing in on purpose of the enquiry and sending support weblinks via email to the most relevant resources. […] different government service departments are not linked. For example I was referred from Myagedcare to the ACAT team Sunshine Coast for one enquiry and then Centrelink for another. What's lacking?? An overall explanation of the different key players involved in Aged Care, even in visual chart form this would be helpful. For example what's the role of MyAgedCare, DVA, ACAT, Centrelink and individual aged care facilities in the transition process to respite or permanent aged care."*

People also want assistance to help them decide in advance whether home care is an option, what technology and environmental modifications might help them stay at home, how to transition from home care to residential care and what to expect from residential care. They want practical dot point summaries of options and higher-level philosophical considerations of how Australian society manages its aged care system, for example:

> *"What are the actual costs of going/not going into Aged Care -- morally, ethically, financially, spiritually? What modelling on the above is available and where and by whom?"*

> *"The different types of residential care available. What the differences mean for them as far as care goes. Someone they can contact for an*

*unbiased view of their options who will give advice depending on their physical, emotional and psychological needs."*

### 3.3.2. Financial implications

People also need to know how different choices may impact their financial circumstances. In the first instance, they would like to be informed about any available government subsidies and financial assistance for accessing aged care, the impact of using these on the services and facilities a resident can access for free or for fees, and whether any gap between the subsidy and the costs will be covered by the Age Pension. Some respondents wondered if entering aged care would, in some circumstances, lead to them losing their pension. Consumers also need information about the financial impact of their assets on care costs and means tests inclusions. They need information about how their assets will be evaluated if they are co-owned by a partner or child, and any impacts that will have on their (or their relative's) financial status:

*"If I jointly own my own home, how much will it cost to enter Care and how will this affect my partner who wishes to remain in our home? The person remaining will still have the same running costs for the home but will have a reduced income (pension) available. How can I access a Care Facility without mortgaging or affecting our home?"*

*"We have a couple of sons with health problems, and we help them out financially - neither is in paid employment. One has serious mental health issues and the other is diabetic. We worry that an investigation would regard such gifts [as] part of our assets on entry to residential aged care."*

Respondents flagged the need for targeted information to be provided for people without independent funds who have fewer choices, and people without family and other supports who must make decisions alone. They seek training for advocacy organisations such as National Seniors on how to guide people on who to talk to, the procedures to follow, and factors such as costs, time frames and key decisions.

### 3.3.3. Timing

Many respondents mentioned the important issue of timing. They seek guidance as to when they should make each decision in this process. For example, when should a person start looking for a residential aged care facility? When do they have to commit to it after finding a suitable place? A proposed timeline for answering key questions like these is a desirable form of guidance for care seekers.

The context for these questions includes the awareness that most people enter aged care under critical and urgent circumstances. As a result, they are unlikely to get a place in their

preferred facility with respect to factors such as location; a welcoming atmosphere for their culture, gender, or sexual orientation; or the facility's commercial or not-for-profit status. If they are gravely ill or affected by cognitive difficulties, they may be in no position to even express their wishes let alone have them met.

For these reasons some respondents recommended that older people should start planning for aged care earlier. One compared planning for aged care to planning for a child to enter selective preschools and schools – it is something best set up well in advance. Specific recommendations included:

- discussing wishes with trusted others;
- testing facilities with respite stays, open day attendance and even volunteering;
- accessing counselling and financial advice to discuss options and work through emotional responses;
- putting your name on a waiting list;
- giving older loved ones information about residential aged care over a period of months prior to them accessing it, to get them used to the idea and give them the chance to ask questions and find out more.

Making advice on these matters widely available is another kind of guidance that is needed.

*"If there had been some sort of macro vision, illustrating a flowchart from the time of the decision of entry into an aged care facility, displaying all the steps along the way, including all the documentation required, this would have greatly eased Mum's introduction. Including, providing a checklist which would help the person/family member chart progress and anticipate issues before they necessarily arose."*

*"A simple step by step guide to the process from prior to ACAT to getting a bed in residential care. Simple explanation of the costs. Assistance for those who do not have anyone to help the negotiate the process. An advocate to ensure homes do not take advantage or give poor explanations. Simple paperwork that doesn't repeat itself eg asks the same question just in a different way"*

### 3.3.4. Transitioning to residential aged care

Having decided (or been forced) to enter residential aged care, people then need practical assistance with the system's processes. That includes assistance to complete forms and paperwork, and guidance on how to organise oneself for this. It also includes advice on what to consider, ask, ask for and demand from a provider; and help determining what residents are entitled to, what they will likely need, and what they are willing to pay for. Case workers

must be trained in assisting with these processes. Pre-produced information such as websites and brochures should cover all these points.

At a more personal level, people asked for practical guidance on what to take with them into residential aged care, and technical advice on how to preserve and organise photos and memorabilia if they cannot take everything with them. As one person asked, *"what will happen to all my treasures?"* Homeowners seek independent (not for profit) assistance with selling their current residence. People need assistance to get money back from any furniture and other assets they must dispose of when moving or downsizing. People want help with inspections and moving. The timing of all of this is a point of anxiety, so people seek step-by-step advice on how the transition will happen. Should people find their residential facility unsuitable once in, they would like help transferring to another facility.

*"Essential that detailed information on how the transition to residential care would happen, step by step, not just for the person entering care, but for the family as well. eg- transportation from home to care, financial costs, partner and family consideration."*

*"Help in selling their property and disposing of excess contents. This advice should be independent of real estate people"*

*"When it came to moving my friend into a retirement village, the physical move cost a lot, and in the end we had to take her perfectly good furniture and goods to the tip because the Salvos wouldn't take it, the Recycling depot was full and it cost her a fortune for the removalists. Downsizing is a nightmare and young people can't buy from downsizes at a garage sale because they can't afford transport costs. Support from local government would have been a boon."*

### 3.3.5. Assistance for loved ones of a care recipient

Respondents identified the fact that family members and friends of people needing care can find it very difficult to put their loved one into residential care or to persuade them to enter care, even if their level of need seems to warrant it and they are unable to make their own decisions, for example because of cognitive limitations. It is especially hard if the person needing care feels bullied and loses trust in the loved one. Respondents expressed the need for a third party to help them make key decisions, specifically with three aspects of this.

The first is help determining when aged care is needed, so carers don't just carry on caring for a person at home if they can't cope. This would require easier access to the person's medical information, and help understanding that information, so the family members or friends can make an informed decision.

*"A couple of years ago my Mum's doctor told me that my mum shouldn't be living at home. She was furious with him. She refuses to talk about this subject with me, doesn't tell me if her doctor has raised the issue again and will not agree to me talking to her doctor. Even if I did talk to her doctor what can I do without her permission? Worrying about her keeps me awake at night. I don't know where to start or whom to talk to. Is her doctor even correct? Are there more services she could receive at home? Has the council (she gets cleaning) assessed her recently to see if she needs more? My Mum has anxiety, agoraphobia and an unusual dietary requirement so moving her to aged care could actually be harmful. She's also getting dementia. But as far as I can tell none of these conditions are being managed by her doctor so she's certainly not improving. I think she needs a case manager. Someone who visits her and talks things over with her. Make recommendations. Liaise with her doctor and other service providers. Mum will listen more to an outsider than she will listen to me."*

The second aspect is guidance on how to explain to a loved one the decision to put them into care in a way that helps them understand the situation and accept it more easily, including implications such as selling their home to pay for care.

*"Many people who need residential care do not want it and their families are the meat in the sandwich between a Medical recommendation, necessity and common sense. The needs of the family and Carers needs to be made equally important as the patient. Counselling should provided to assuage any feelings of guilt or inadequacy."*

The third aspect is advice on advocating on behalf of a loved one once they are in care, understanding what they are going through when transitioning to aged care, and how to best support them through the transition period.

Family and friends can also face practical problems when sorting out their loved one's affairs because of the need to continually explain their situation to different businesses and bureaucracies. The suggestion was made to centralise information about people's power of attorney status or similar, to make these tasks easier:

*"all the logistics of moving my sister into higher care were very frustrating. Just think about all the accounts she held for electricity, internet, foxtel, chemist, phone, bank, Electoral, post office, Centrelink, MyAgedCare etc etc. to name but a few. There needs to be a central registration point where, once you are registered as POA/Guardian, everyone else just references it, like another QR code. At the moment, even government agencies haven't got their act together. I had to register separately for*

*MyAgedCare and Centrelink as a representative. Why? Not only that but getting certified copies of documents during lockdown? Get real. With a central registration point, you do it once."*

## 3.4. Professional services to protect aged care consumers' welfare

Even if they have all the information they need and adequate guidance through the system, care seekers will likely need additional professional services and other kinds of assistance to proceed with accessing aged care. Respondents suggested that providers and/or governments should directly refer clients to relevant professional services in their region, rather than merely making the general suggestion that clients should seek legal and financial advice. The kinds of service and assistance respondents mentioned included:

- Expert legal assistance to prepare key documents such as a will, power of attorney and advance care directive, and to advise on any contracts with providers.
- Expert financial guidance to work through costs associated with the move, tailored to the individual's circumstances, perhaps in conjunction with a social worker.
- Advocacy services, including the Guardianship Board and Public Trustee for those without family or friends supporting them, and an independent body to ensure elderly people have not been coerced to enter residential aged care. Note that a case worker approach may successfully serve these needs in many cases, being able to answer questions, hear problems and refer people to senior advocates, guardians or trustees if needed.

*"All too often the family members will agree with anything - just so that they can get their elderly relatives into the care and responsibility of others. […] Without exception, the final decision should be of the aged person - unless it is upon the advice of medical practitioners […]. An independent body to issue advice, information and guidance is the best possible solution. A free 1800 number, and offices available to all. It also should be mandatory that, the facility offering residency, should be compelled to make sure that all enquiries also include the details of this service. So many elderly people feel like that they are a burden on those around them, and they can agree to things that they don't fully believe in, but will do so, just to keep the peace. But, knowing that there is an independent body that they can go to, will remove the pressure, and offer the opportunity to talk more freely."*

Respondents also emphasised the importance of accessing counselling services at various points along the way with different specialisations, from financial counselling to grief counselling to emotional counselling for those who are arranging care for a loved one. They noted counselling should be ongoing to help people with transition periods, not just one off

or short term. Mental health wellness programs should be developed with mental health professionals, medical specialists and others and should incorporate regular reviews of a care recipient's wellbeing once they are in care.

*"When persons are forced into the need of residential age care persons are usually upset and confused. Professional counselling service required before entering residential age care."*

Beyond such formal support services, respondents are also concerned to ensure that new residents feel okay on a day-to-day basis and have a "comfort person" to talk to during the transition and once in residential aged care. One suggestion for the comfort person role was for existing residents to mentor new residents during the first few months, to provide moral support and a friendly ear. This model could be formalised within facilities:

*"I think that not only do people need information about the financial aspects of residential aged care but also information on what it's like living in residential aged care. As a volunteer pastoral care person I've noticed that new residents find it very hard to get used to living in an institution so I think mentors should be available during the process of the move into residential aged care and then for the initial few months."*

*"All the professionals in age care and support services can be as supportive as possible but it is not the same as talking and connecting with a resident who is already in residential care! Just because a person is in residential care does not mean they have lost their ability to help the system to relate to new residents. There are many residential care clients who could be used to help new residents to settle or be advised about coming into care and smooth the transition. This does not seem to be used and it could be a powerful tool if use correctly."*

## 3.5. Communication strategies to shift public attitudes to aged care

The final informational and guidance need we identified from the survey responses is the need for governments to institute longer term communication strategies to change public attitudes to aged care, to enhance Australians' understanding of ageing, and to encourage people to start planning for aged care sooner rather than later.

### 3.5.1. Raising awareness of the need to plan

Respondents were acutely aware that many people put off aged care planning until it is too late for them to have a genuine choice. Several suggested the government create mass advertising campaigns to raise awareness of the reality that these decisions must be made, and to normalise them so that people who are currently *"too proud"* to seek help feel okay

about doing so. A key message suggested by one respondent was: preparing for aged care doesn’t resign you to dependence and decline; rather, planning for the right kind of dependence on support services can help you remain independent as you age. The ideal would be to raise awareness in all Australians’ minds about where to go for aged care planning and how to advise an older person needing care:

*“Information is vital, so the Govt should create a themed program on residential age care, making us aware of all that is involved, perhaps like a 'slip, slop, slap' ad exposing us to the reality that decisions do have to be made.”*

*“Age care Homes seems to only [be] addressed and offered to the poor, some family feel ashamed if parent/s are put in the care if age care environment instead of staying at home with family/s. The result: many old people stay at home lonely and frightened.”*

*“None of the aged care recommendations include the importance of preparing people by improving their longevity awareness well before they are likely to require aged care (residential or home). Informed preparedness is likely to empower them to remain productive and healthier in the community for much longer, and shorten their period of dependency in aged care (per AIHW research).”*

*“We become more different from each other with age, not more alike. By understanding and responding personally to these differences well before they become dependent, people are more likely to make properly informed choices to delay and minimise the likelihood of their requiring aged care.”*

As well as a mass advertising campaign, respondents made other suggestions to meet this need. One idea is to send all pensioners not in aged care an annual needs test, to help with assessment of people who, by themselves, won’t notice that they need care. Another is to send everyone over 60 information about residential aged care (perhaps through MyGov, or when receiving their annual flu shot), and giving them the option of having a conversation with a social worker or similar about future pathways. This ties in with a case worker approach to care communication.

### 3.5.2. Open discussion about aged care

Several respondents wrote about the value of increasing open public discussion about aged care. This would include open, honest public seminars on both the benefits and pitfalls of residential aged care, aimed at older people who may need care and at younger family and friends who might be called on to assist someone to access aged care. People want open acknowledgement of the realities of the aged care industry (even putting aside the extreme

horrors of neglect and abuse), for example the fact that many carers are in the industry simply because they need to earn a living, not because of an inherent desire to care as such. People would also like an acknowledgement that residential aged care does not suit everyone, and that the changes entailed in moving into residential aged care can be extremely distressing. One person raised the point that veterans of foreign wars may face specific stresses when being cared for by people who they believe are from the countries they fought in or against and that this should be acknowledged. We note that carers may find such situations equally stressful. Increasing awareness of carers' experiences in the aged care sector may be equally helpful both for promoting public understanding of aged care and for improving it to everyone's benefit.

A few respondents were attuned to the fact that increasing numbers of Australians now live until they are very old, into their 90s and past 100. They felt the Australian community needs to better understand the implications of this for care. Suggestions for measures responding to this included specific training for people working in aged care on how to care for people over 90, and events to increase older Australians' informed preparedness for longevity such as Zoom webinars, films, and talks at Senior Citizen Centres and festivals.

> *"In previous times it was rare to see 100 year olds and 90 year olds were not too obvious, not these days. These folk require more staff to help them individually in their very advanced age. Age care workers need to be recognised as persons of status. These workers not only look after the frail elderly but very often are the caring connection to their families. I would like to see more information on growing VERY old, facilities available and involvement of families and friends"*

People also want to dispel negative myths about present-day aged care. As part of normalising aged care and opening it to public scrutiny, respondents suggested aged care facilities build more active, positive relationships with local community groups to encourage visits and greater understanding of how they operate. One respondent shared the stress experienced by their mother prior to entering aged care because of prevalent myths that were far afield from the reality, and the happy ending to the story once their mother entered a good quality aged care facility:

> *"My elderly mother was one of the residents in the nursing home I worked in. Before she needed care she lived with me and had an absolute terror of nursing homes. Her vision of them was of old people tied in chairs calling for the nurse and urinating where they sat. Also long wards with 60 beds or more, so when she had to go into care she was very upset and crying. I think guidance, assistance and information are very good tools used in informing future residents but this needs to start perhaps when aged care*

*gets involved. All the information could be given to them over perhaps 12 months. I found over the time I worked in aged care, many patients on admission had no idea of where they were going and why. My Mother went into a new facility with her own room with ensuite bathroom and ended up loving her stay."*

# Discussion

The findings from the Royal Commission into Age Care Quality and Safety are the catalyst for sweeping reforms to the age care system in Australia. The goal is to shift focus from the processes, systems and organisations providing care to the people who receive care. A new human rights and consumer-focused age care act will come into effect from the 1st of July 2023. This act will place the rights of older people to live self-determined and meaningful lives at the centre of all age care systems and activities.

The Government recognises that older Australians, their families and carers have a critical role in designing and implementing a new age care system. Listening to and incorporating the views, experiences and wisdom of those using the system will ensure it delivers a high quality of life and person-centred care to older people. The Commonwealth Department of Health is the main organisation responsible for implementing the Royal Commission recommendations and for reaching out to older people and the community at large for input.

One of the barriers to engaging with potential consumers of residential care specifically is general community aversion to 'ending up' in residential care. According to research conducted by Roy Morgan for the Aged Care Royal Commission, 80% of older people want to stay living in their own home and most would prefer support to be provided by family and friends. If higher levels of care are required, people's preference is to use paid home help from aged care providers.[7] Estimates from the Royal Commission's residential aged care survey conducted in early January 2020 showed approximately 39% of people in residential aged care experience neglect and/or abuse.[8] The Royal Commission also documented experiences of sexual abuse and assault with 50 instances occurring in residential care each week.[9] Given these figures alone, it is not surprising that the prospect of entering residential care causes fear and dread in older people and their families.

Negativity towards residential aged care was apparent in the free text responses to the NSSS-9 survey question asking about the effects of reported abuse and neglect on age care planning. Of the 1,300 people who provided a free text comment, most shared negative views that had been prompted or reinforced by reports. About 25% of commenters said they would never enter residential care or were strongly against it while a further 19% said

[7] Roy Morgan Research. What Australians Think of Ageing and Aged Care [Internet]. Royal Commission into Aged Care Quality and Safety; 2020. Report No.: 4.
[8] The Royal Commission into Aged Care Quality and Safety. Experimental estimates of the prevalence of elder abuse in aged care facilities. 2020 Dec. Report No.: 17
[9] 'Aged care royal commission hears there are around 50 sexual assaults a week of residents nationally' https://www.abc.net.au/news/2020-10-22/aged-care-royal-comm-told-of-50-sex-assaults-a-week/12801806

reports of abuse had increased their worries and fears. Many told stories of frustrating and painful residential care experiences endured by family members, spouses and friends.

A sense of powerlessness underpinned much of the negativity respondents expressed toward residential care. People felt helpless to change the systemic issues causing neglect and inadequate care. Respondents mentioned inadequate staffing and resources, lack of management accountability, lack of choice in care options and provider business models that were incompatible with caring for frail elderly people. Those who had worked in age care swore they would never enter it themselves because they had had seen first-hand the challenges in providing good care. As one respondent bleakly pointed out, abuse was inevitable in the age care system: *"problems with aged cared are endemic and have been since time began-- there will always be aged abuse no matter where in the home or in care places."*

Sadly, as reported in Appendix II, 71 people said they would prefer to die than enter residential care. This is a poignant manifestation of the powerlessness and despair people feel towards a system that has caused significant emotional pain and trauma to many older Australians and their families. It is these people's views and lived experiences that need to be heard so previous mistakes are not repeated and residential care is a welcome and viable option for those who need it.

Focusing on the negative sentiments surrounding residential age care is not to deny the high quality and compassionate care provided by many if not most staff and management. As some commenters mentioned, the widespread media reports of abuse unfairly undermined those individuals and organisations providing excellent care often in very challenging circumstances.[10] Nonetheless, an overall strong aversion to entering residential care needs acknowledging as the context in which consumers are being asked for input to reform the system. There is the risk that people may lack motivation to expend effort and energy contributing to an outcome they are determined to avoid. The following quote from the Interim Report of the Royal Commission captures the essence of current sentiment:

> *"People do not usually enter residential aged care willingly. They often do so with great trepidation. They fear loss of autonomy, of individuality, of control over their own lives. They fear ceasing to be a person with distinct needs and preferences, with an emotional and intellectual life and freedom to do what they want, when they want to do it."*[11]

[10] Appendix III presents positive sentiments about residential care.

[11] Commonwealth of Australia. Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect [Internet]. 2019 Oct.

To help counter potential unwillingness to think about residential care, one of our follow up questions to the NSSS-9 asked people to take an aspirational approach to changing the system. Respondents had the opportunity to re-imagine residential care as providing quality of life, comfort, security and enjoyment, rather than focusing on what is currently wrong and unacceptable. When people imagined residential care as a desirable option, they still identified current flaws in the system, but also provided rich and valuable insights into the practical ways older people's rights, dignity and value should be upheld. Although some individual facilities already offer many of the features and options described, standards are inconsistent and as noted by the Royal Commission, good care occurs in spite of rather than because of the system.[12] In their responses, people focused on ways residential care could be 'as close to home as possible' which meant ways to enjoy socialising, freedom of movement and personal routines, good food and home-style décor, the freedom to express cultural, sexual and gender identity and options for activities that were enjoyable, meaningful and personally relevant.

One of the most prevalent ideals expressed was that there needs to be a complete shift to a not-for-profit model of providing care. People strongly believed that providing good care was incompatible with providers making profits. However, it is also the case that some not-for-profit and government care facilities have mismanaged funding and placed other interests above those of residents. One of the features of well-managed and ethical organisations is that these providers can and do invest funds into continual improvement of their care facilities and culture, and attract highly qualified staff, all of which are good outcome for residents regardless of whether providers are for profit or not.

The assumptions about provider profit being at the expense of quality care are understandable. Historically providers were the gatekeepers of care and they had limited accountability for how funds were allocated and administered. The Royal Commission has recommended a fundamental shift by government and its bureaucracy to place the people receiving care at the centre of the system rather than the system being provider focused. A new system aims to ensure all age care providers, whether for profit or not-for profit, practice transparency and accountability through good governance and stringent oversight by independent age care authorities and advisory bodies.

Some respondents made suggestions for system improvements that have already occurred or are in progress. For example, the unannounced inspections of residential care facilities proposed by some are now in place and a star rating system to compare residential care homes on a common set of indicators is expected to be available from the end of 2022. As

[12] Commonwealth of Australia. Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect [Internet]. 2019 Oct

the system evolves, clear communication about associated reforms is needed so older people and the broader community are kept abreast of the changes occurring. Hopefully this will slowly build trust and optimism amongst the people requiring residential care that the current issues causing concern are being gradually addressed.

Follow-up participants gave complex and multi-dimensional responses to the question we asked about their needs for information, guidance and assistance when accessing age care. A common theme was that people wanted comprehensive, transparent and understandable information made readily available about all residential aged care facilities. As one person put it, *"Unless we ask the correct question, we are not getting the answers we need to make a decision."*

Another high priority for respondents was understanding the financial repercussions of moving into age care, especially when they need to sell their house to do so. Evaluating or comparing residential care facilities requires understanding of how income, assets and age care entitlements are connected. The lack of support and services to assist with understanding the financial complexities of age care was a major source of angst amongst respondents. People are being asked to make judgements about their capacity to afford future living costs and charges often under time pressure and without really understanding the options presented. It is no wonder that respondents placed such a high priority on access to clear, independent and consistent information about the financial commitments associated with accessing residential care.

Respondents' need for clear communication was paramount. Information is not useful if it cannot be accessed, understood or applied. Although the My Aged Care portal has aimed to improve useability since it was launched in 2013, it is a stressful and frequently opaque system for users to navigate. Older users can struggle when attempting to access and interact with information online, especially if they have disabilities such as cognitive impairment, visual impairment, or conditions that affect dexterity such as Parkinson's Disease. The need for frequent phone communication in conjunction with the online system or as complimentary to it is particularly frustrating for those with hearing or speech impairments.

A 'one-stop shop' or case-worker approach was consistently mentioned as a solution to the complexities of navigating the residential care entry process. Older Australians want a singleservice they can contact for assistance that must be free, fully transparent, highly regulated, receiving no commissions, staffed by experienced/qualified people, and with a clear frame of reference. From 2019 until June 2021, the Commonwealth Government trialled four Aged Care System Navigator programs that were implemented through Council Of The Ageing (COTA) and its 30 partner organisations. Although NSSS-9 follow-up respondents did not mention knowing about the navigator services, the trials show Government acknowledges the challenges older people face when trying to access the aged

care system as it is currently presented. Data and feedback from the Navigator trials are in accord with the communication preferences described by NSSS-9 respondents, that face-to face assistance and guidance is particularly valuable, especially for hard to reach or diverse groups.[13] During 2021 and 2022, the Commonwealth Government is expanding face-to-face support and assistance in 325 Services Australia centres, and aged care specialists in 70 additional service centres.[14] These measures do not capture the case worker style support that respondents wanted, but do go some way to helping people navigate across the complexities of the financial and funding component of residential aged care access.

Typically, most middle-aged and older people avoid actively thinking about or planning for their long-term care needs. Needing care does not sit well with most people's goal of 'ageing successfully' because it signals decline, loss of autonomy and moving closer to the end of life. In a previous study by National Seniors using NSSS-9 data we found that 90% of people thought they may use age care services in the future, but only 20% had investigated care options and even fewer (14%) had planned for age care costs.[15] Most (47%) said they would think about it when they needed it. Follow-up respondents in the present study identified lack of planning as adding to the stress and difficulty in accessing residential age care. They pointed out that the process is usually crisis-driven, for example, through death of a carer or an incapacitating fall.

When thinking about guidance and information needs, people asked Government to create public awareness campaigns directed to all sectors of the community to normalise preparation for age care and remove the stigma of seeking and receiving care. They suggested providing specialist age care services supporting the mental health of family members and older people entering age care to acknowledge it as a transition in life rather than its end.

The aspirational sentiments expressed by respondents show it is possible that residential age care could be transformed from being a fearful prospect and the option of last resort into the service older people deserve; a service offering quality of life, comfort and compassion. Only then will residential care become *"a place where one feels as close to "home" as possible, where they can thrive physically, emotionally and spiritually for their latter years."*

[13] https://www.health.gov.au/resources/publications/evaluation-of-the-aged-care-system-navigator-measure-final-report

[14] https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/report-endorses-value-of-new-face-to-face-aged-care-navigation-services

[15] Hosking D, Minney A, McCallum J. Planning for aged care costs: Hesitancy, ignorance and denial. National Seniors Australia; 2021.

# Appendix I – Methods and demographic traits of the surveyed samples

## Methods

National Seniors Australia is a not-for-profit, non-government advocacy organisation for Australians aged 50 years and over. Every year, National Seniors conducts an online survey of older Australians’ behaviours and views across a range of topics relevant to lifestyle, health, and wellbeing. The survey is open to members and non-members aged 50 plus from all states and territories. The survey is made available on the National Seniors website and circulated via a member online newsletter and in the quarterly magazine.

The 9th National Seniors Social Survey (NSSS-9), on which this report is partly based, was approved by the NHMRC accredited Human Research Ethics Committee of Bellberry Limited (APP 2020-12-1319). It asked a range of demographic questions in addition to questions about topical concerns and all questions were optional. The survey was open from 15 February 2021 to 1 March 2021. Anonymous and non-identifiable responses were collected online via the survey tool Survey Monkey. In total, 5430 people participated in the survey.

As detailed in the Introduction, one question we asked in the NSSS-9 was “Have the reports of neglect and abuse in the aged care system affected your aged care planning or decisions?” The wording of this question broadly referred to ‘aged care’ in general, not any specific aspect of it. Nonetheless, almost all survey respondents who left text comments for that question seemed to interpret it as solely or primarily referring to neglect and abuse in residential aged care. Only a few people commented on problems with other aged care services such as home care. For this and other reasons, we decided to restrict the scope of this report to residential aged care, so we did not deeply analyse the few survey comments about other forms of aged care.

In October 2021 we prepared the short follow-up survey discussed in the Introduction. It had just two open response questions focused specifically on residential aged care (see Introduction for wording), plus gender and age demographic questions. We emailed an invitation to participate in this follow-up survey directly to the 1603 NSSS-9 participants who had indicated on the survey that they were open to being contacted for follow-up research and who provided an email address. In doing this we acted in accordance with the conditions of our ethics approval for NSSS-9, and responses to the follow-up survey were not traceable to individuals except in a few cases when respondents identified themselves within their written answers.

Of the 1603 contacted, 634 (39.6%) accepted the invitation to participate within the two-week window the survey was open (19-31 October 2021), by answering one or both follow-up questions in SurveyMonkey. An additional participant responded by sending our team

answers to the questions via email after the survey had closed, and these responses were also incorporated into the analysis.

A pre-defined data cleaning protocol was used to remove duplicate responses prior to analysis. All statistical calculations were performed in Stata (version 15.1). However, we restricted statistical methods to descriptions of the surveyed samples, not analysis of trends. The answers to the main NSSS-9 question were not particularly informative in that regard, as discussed in Section 3 above, and the questions inviting comments yielded data too multi-dimensional to analyse statistically with any reliability.

We analysed text comments from the primary and follow-up surveys using the thematic analysis framework described by Braun and Clarke.[16] One National Seniors Research Officer analysed all the comments and produced a draft analysis. A second Research Officer examined the data before and after the first Research Officer’s analysis, to ensure the themes we reported were an appropriate and comprehensive representation of the views expressed. We discussed any discrepancies and agreed on a consensus thematic approach. Themes were identified through inductive analysis, that is, data were coded without reference to an explicit pre-existing theoretical framework. The analysis was guided by a critical realist approach which aimed to summarise and reflect participants’ views as accurately and objectively as possible, without reading other layers of meaning into them. Emphasis was placed both on highlighting common ideas expressed by large numbers of participants and on describing the diversity of ideas present, some of which were expressed by fewer people. The researchers acknowledge the influence of their pre-existing theoretical knowledge and understandings on the themes identified from the data.

Quotes from survey participants were selected to illustrate the variety of ideas expressed by the cohort and also commonly articulated ideas. Sometimes this entailed reproducing only part of a person’s comment if the rest was not relevant to the theme. We endeavoured to reproduce each selected quote verbatim whenever possible.

In a small number of cases, we omitted or altered part of a quote for clarity and indicated this with square brackets []. In additional cases, minor typos and obvious spelling errors were corrected for readability but without using square brackets to indicate we did this. Quotes were only corrected in this way if there was no ambiguity about the participant’s intended meaning in the part of the quote that was corrected. All other phrasing idiosyncrasies were retained in the quotes.

[16] Braun V & Clarke V (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3:2, 77-101, doi:10.1191/1478088706qp063oa.

## Demographic traits of the surveyed samples

This section of the Appendix provides a demographic overview of those who responded to the original NSSS-9 survey question and those who participated in the follow up survey.

*Appendix Table 1. Demographics of NSSS-9 participants who responded to the question "Have the reports of neglect and abuse in the aged care system affected your aged care planning or decisions?"*

| *Responders: n=5166* | *Number of responders* | *Percentage of responders* |
|---|---|---|
| *****10-year age group*** | | |
| *50-59* | 313 | 6.1 |
| *60-69* | 1622 | 32.5 |
| *70-79* | 2393 | 47.0 |
| *80+* | 725 | 14.2 |
| ******†Gender*** | | |
| *Women* | 2817 | 54.9 |
| *Men* | 2295 | 44.7 |
| ***State of residence*** | | |
| *NSW* | 1187 | 23.1 |
| *VIC* | 840 | 16.3 |
| *QLD* | 1894 | 36.9 |
| *WA* | 459 | 8.9 |
| *SA* | 317 | 6.2 |
| *TAS* | 122 | 2.4 |
| *ACT* | 238 | 4.6 |
| *NT* | 76 | 1.5 |
| ******Highest level of education*** | | |
| *Year-10* | 909 | 18.5 |
| *Year-12 or diploma* | 2053 | 41.7 |
| *Tertiary degree or higher* | 1957 | 39.8 |
| ***Self-reported health*** | | |
| *Excellent/good* | 3851 | 75.4 |
| *Fair* | 1054 | 20.6 |
| *Poor/very poor* | 201 | 3.9 |
| *****Partnered*** | | |
| *Yes* | 3087 | 61.6 |
| *No* | 1920 | 38.3 |
| ***Employment*** | | |
| *Employed* | 985 | 19.5 |
| *Unemployed* | 103 | 2.0 |
| *Retired* | 3960 | 78.4 |
| ***Home ownership*** | | |

| | | |
|---|---|---|
| *Own outright* | 3882 | 79.6 |
| *Own with mortgage* | 539 | 11.0 |
| *Don't own a house* | 455 | 9.3 |
| ****Accessed age care services in previous 5-years*** | | |
| *Yes, for self or partner* | 887 | 17.3 |
| *Yes, for family or friend(s)* | 553 | 10.8 |
| *Yes, for self/partner AND family or friend(s)* | 64 | 1.2 |
| *No age care services accessed* | 3600 | 70.2 |

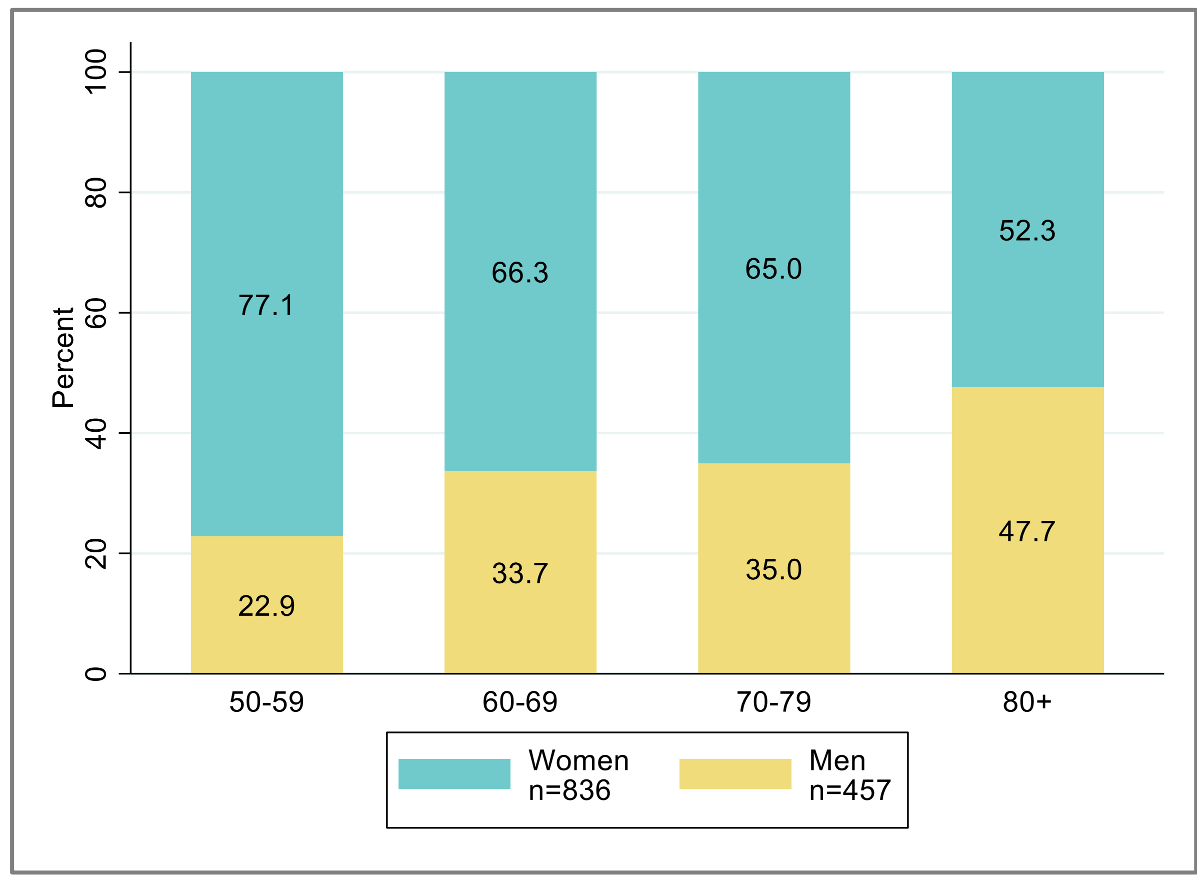
*†Three people identified as non-binary, three identified as other gender, 13 preferred not to specify their gender and 16 did not answer the gender question.*

*Statistics for Chi-square test of difference between those who commented and did not comment on effects of reports of neglect and abuse on age care planning: * Significant at p≤.05 ** Significant at p≤.01 ***Significant at p≤.001*

There were some statistically significant differences in the demographic makeup of the commenters versus those who responded to the question but did not leave a comment. Significantly higher proportions of commenters were:

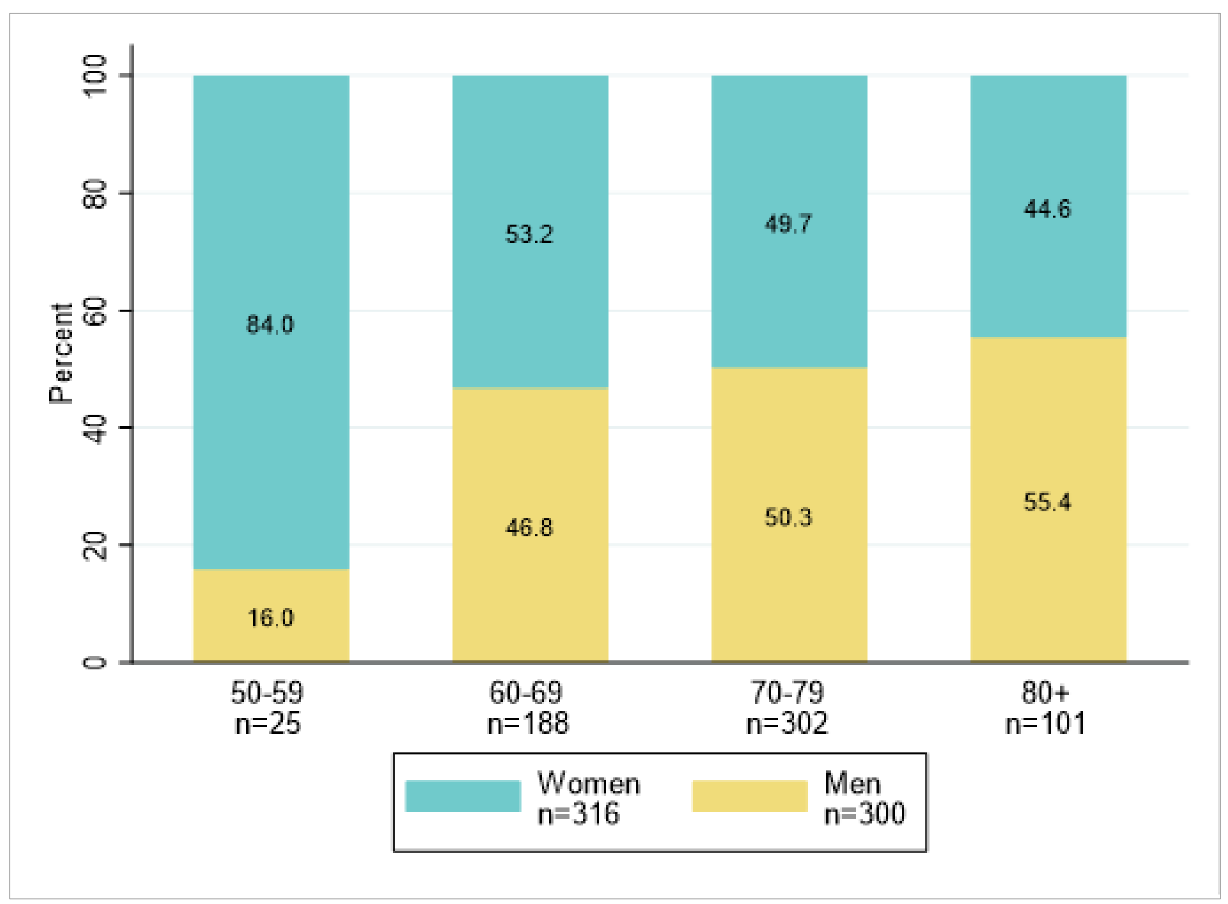
- Aged between 60 and 79 (compared to being under 60 or 80-plus)
- Women
- More highly educated
- Not partnered
- People who had previously accessed age care services for themselves or others.

The two figures on the following pages graph the proportions of women and men in each age group for the NSSS-9 commenters and the follow-up sample. Note age group and gender are the only two variables of demographic information collected for the follow-up so other demographic comparisons cannot be made.




*Appendix Figure 1. Proportions of women and men within 10-year age groups for the NSSS=9 subsample who commented on the effects that reports of abuse had on their age care planning; n=1305.*

*Two people identified as non-binary; one person preferred not to specify their gender. Age and/or gender information missing for n=57.*




*Appendix Figure 2. Proportions of women and men within 10-year age groups for the age care sentiment follow-up sample; n=619.*

*One person identified as non-binary; two people preferred not to specify their gender.*

*An additional 29 people provided age and gender information, but no text comments. These were excluded.*

# Appendix II – Commenters who would prefer death over residential aged care

*For readers experiencing distress after reading about this topic, we have included the contact details of crisis support lines on the last page of this report. We urge readers feeling anxious, depressed or in crisis to access mental health support.*

Seventy-one of the 1305 survey respondents who wrote comments said they would prefer to die than to enter residential aged care, with two thirds of these stating they would take their own lives if residential aged care was the only alternative. Seventy-one people represents over 5% of commenters and over 1% of all those surveyed in NSSS-9. Although the sentiment was expressed by a statistical minority of respondents, even that small number suggests it is shared by many seniors. Given there are around 8 million Australians over the age of 50, 1% of this population amounts to about 80,000 people and 5% is around 400,000.[17] So if our survey results are broadly representative of Australian seniors’ views, they indicate an alarming degree of fear about residential aged care. Even if our survey results are not representative, 71 people who said they preferred to die than enter residential aged care is still too many to ignore. We note that in Australia and elsewhere the 85+ age group has the highest age-specific suicide rate for men, and suicide risk increases across the life course, so seniors’ statements of intent to take their own lives should not be dismissed as mere hyperbole.[18]

Given their seriousness, we believe these sentiments should be discussed more concertedly and openly by policy makers, the general population, and researchers. It should never be the case that a person would prefer to die than to access care. It is a damning indictment on the residential aged care sector that anyone would feel this way, indicating how deeply in crisis the Australian aged care system is.

To emphasise the seriousness of this, we here reproduce further comments from our surveyed respondents who expressed a preference for death over aged care, beyond those we included in the main text. We do this in the hope that it will drive home to the broader population how acutely the reality of this situation impacts many older Australians. We also hope to encourage productive conversations to address this issue and to radically reform

[17] Number from 2016 census. id. Demographic Resources: Australia: Five year age groups. Collingwood (Vic): .id. 2021 [cited 2021 September 16]. Available from: https://profile.id.com.au/australia/five-year-age-groups
[18] Everymind. Life in Mind Suicide Prevention: Older adults. Newcastle (NSW): Everymind. 2021 [cited 2021 July 6]. Available from: https://lifeinmind.org.au/about-suicide/suicide-across-the-lifespan/older-adults; Suicide Prevention Resource Center. Older Adults. Oklahoma City (OH): University of Oklahoma Suicide Prevention Resource Center. 2021 [cited 2021 July 6]. Available from: https://www.sprc.org/populations/older-adults; Conejero I, Olié E, Courtet P, Calati R. Suicide in older adults: current perspectives. Clinical Interventions in Aging. 2018;13:691-699. DOI:10.2147/CIA.S130670.

the aged care sector, so that future generations of seniors will no longer feel that becoming dependent on others for care with age is a fate worse than death.

Forty-seven people said they would take their own lives rather than enter residential aged care. Some statements clearly represent firm intent in this direction, though others may represent extreme negative sentiment rather than firm intention. Their comments, in addition to those included in the main text (above), were:

*"All hell will freeze over before I […] will go into an aged care home or hospital. What with the experience of COVID where people are isolated from friends and family to the examples of shithouse meals and physical abuse and outright neglect, I think I'll pass on it. I will just have to have a drink of weedkiller or similar when the time comes that I need institutionalised care."*

*"At the moment I really have no intention of spending time in an aged care facility. I don't want the owners of such facilities to slowly drain my hard earned savings. I'd rather go for a walk to my local park and put a revolver to my head."*

*"Avoid residential aged care if possible. Would prefer euthanasia"*

*"Better to end life before I have to go into aged care and get treated like a piece of crap."*

*"Deplorable, unsafe, boring places with no respect for human rights. We will explore home care and voluntary euthanasia if things get worse."*

*"Euthanasia is preferable to aged care homes"*

*"Euthanasia is preferable to some of what we hear is going on in these institutions and all for the sake of the mighty $$$"*

*"Hopefully we will be able to 'use an end of life' method before needing Care facility."*

*"I have considered the possibility of suicide if I am unable to look after myself. I don't want to go into other accommodation."*

*"I have no desire to enter aged care. It sounds very poorly regulated and rather cruel. The deaths in aged care during covid and the reported responses of the aged care minister and his either denial or apparent lack of interest and knowledge about what was and is going on in many of the homes, makes me feel very angry. It seems aged Australians are of no*

*value and are dispensable. I plan to take my own life when I can no longer care for myself.”*

*“Frankly I'm determined not to go into a nursing home. I was a Registered Nurse for years and did agency shifts in a few nursing homes years ago. I was shocked and appalled, and vowed I'd rather just commit suicide than allow myself to be admitted to a nursing home. However, I realise that the time may come when I no longer have the intellectual capacity, nor physical ability, to even carry out my plan. It's all very well to joke to friends that I plan to overdose on champagne, or book a one-way trip to Switzerland and Dignitas. The reality is that I may have a stroke or some other condition which would see me lose control over my own life. It's a terrifying thought and I don't want to ever be treated like those poor residents I saw, semi-conscious, with PEG tubes in place, and just curled up in foetal positions waiting to die. You wouldn't do that to an animal, so why should it be allowed for humans?”*

*“I had already decided that suicide was a better option than going into any aged care facility. I have a nursing background and I have seen the neglect and ageism. The use of unregulated workers and lack of registered nurses translates into neglect.”*

*“Home care package yes fine if I can get any help but would prefer it provided by local government or public hospital linked service. Do not believe value for money is delivered by profit driven providers. Nursing home? I am naturally introverted and self sufficient, hate crowds. Would only consider a facility linked to a public hospital not a church or profit taking organisation. Actually after providing for my relative and pets (if any are left) I’d rather access voluntary euthanasia.”*

*“I don't plan on using aged care. I am a member of EXIT International and plan to exit via suicide assist when I feel my health deteriorating.”*

*“I feel as though I would end my days as a worn out old person in a bed that will be very quickly filled if i pass on. I would be looked after by people that talk to me as though I was in the way. I would sooner end my life, my way, by my own hand, than get in the way of a mob of strangers in Canberra, as they do not care about the elderly people, If I was to find myself homeless with no help from Canberra, nor the state, why would I want to go into some grubby age care? NO. Old age comes to most of us, and if you do not have a big pot of money, be prepared to be an old person that is in the way.”*

*“I hope NEVER to enter a residential aged care facility. Would far prefer voluntary euthanasia!!”*

*“I live in a rural area and I believe that the Nursing Home beside the small independent living unit village I live in is a very good one and extremely well run, clean and never has a "smell" about it when you enter, I was so horrified to hear the way people were treated I am considering euthanasia very very seriously.”*

*“I really would not like to go to an aged care centre, if I am not well enough to look after myself I would rather not be here. I do believe in Voluntary Euthanasia”*

*“I used to visit aged care facilities as an allied health professional and too often what I witnessed appalled me. I have no intention of ending up in an aged care facility. Plan to take euthanasia option if necessary- if in any position to choose”*

*“I will end my own life before I go into an aged care facility to be starved, neglected & abused by unsympathetic 'carers' who are there for the money & not the welfare of the clients. It seems that this type of treatment is more the norm rather than isolated cases. The supervising staff who are supposed to oversee the staff appear to also shirk their responsibilities, so no aged care home for me.”*

*“I will never go into care, I will walk into the ocean first!”*

*“I will stay away from aged care and will do all in my power not to be caught up in it to the point of ending my life before being taken to one.”*

*“I will stay home whatever it takes. I would prefer to end my life rather than enter one of those ghettoes”*

*“I would hope i don't have to go into aged care. Hoping assisted dying legislation will have passed by the time I need it !!!”*

*“I would prefer to die of cancer or commit suicide than move into one of those death camps.”*

*“I would rather have euthanasia”*

*“I would rather use voluntary euthanasia than go into an aged care facility.”*

*"I would sooner contemplate a suicide exit or pact than be deposited in what is quintessentially a human knackery."*

*"I would sooner take my own life than go into an aged care facility"*

*"I'd rather hasten my end than go into aged care"*

*"If I need care I will kill myself rather than go into a nursing home or have untrained strangers who know nothing about me coming into my home to take care of me."*

*"I'm a health worker. I will be aiming for VAD before I have to go with Aged Care Options."*

*"I'm not impressed by what has been reported concerning mistreatment of elderly patients by staff in these aged care facilities. […] The more i think about it, I like the USA system where guns are freely available and one can blow one's brains out before needing to undergo this stage in life!"*

*"Knew about it from employment as a registered nurse back in the 70's. Talking to people at lawn bowls and U3A, we know it is no better than it was back then. So not surprised, BUT KNOW WE ARE NOT GOING THERE. Euthanasia/suicide is a much better option for us."*

*"My goal is to live at home for the rest of my life, and not be in any form of residential care. I have discussed this with my adult children and they have undertaken to support me in home based care if needed. I also aim to maximise my ability to live at home by the type of housing (single storey) and design of interior of house that I live in. The goal to live at home (and not in an aged care facility or retirement village) is based on personal preferences that suit my personality etc, and also on recent experience with my frail aged mother in a retirement village then needing to move into aged care (she passed away about two years ago). We were fortunate that the facility we found was a good one (compared to many of the stories in the media), however it was still not ideal by any means and not something I want to or probably could endure as I get older. I would rather live better and not longer if that is the choice I end up needing to make."*

*"My mother is currently in an aged care facility. I find the system: profits before people and only consideration for their investors, to be disgraceful. I will make the appropriate arrangements to end my life before I need to go into aged care."*

*"No other option if we have to use it. Had family members in aged care 15 years ago and in recent years. It's always been bad situation, understaffed, neglect etc. Many [inquiries], royal commissions, don't improve greed of providers. Hope we die before we have to go into one or euthanasia is legalised so we can use that."*

*"Not interested in going into a 'waiting to die' facility and eating crap food and never getting a regular shower. I prefer to be 'put down'."*

*"Suicide looks to be a good option if there is no legal option to terminate one's life by the time I need aged care."*

*"Relying on the govt to regulate aged care is fine in principle, but is there as a safety net only. It's about personal reliance rather than Govt assistance for me. I would ideally prefer wider access to VAD which is extremely narrow, and be able to self-fund private care with nominated friends overseeing it. There are issues either way. Its up to me to try and work it out before I reach that stage with my personal community of people. Not easy, but reality is better than relying on the govt. Who knows what services will be available in 20 years."*

*"Until the Governments, be they State first, then Federal see common sense and pass laws such as "Dying with Dignity." or approve organizations like "Exit International." Then sadly to say these sorts of neglect and/or abuse issues will continue for the elderly that have really no control over their functions. Yes, it is very sad, but put yourself in the [carers'] position on a daily basis."*

*"Will stay in my own home as long as possible, utilising aged care services, rather than go into a nursing home. Euthanasia/suicide sounds an attractive alternative when I can no longer look after myself!"*

*"Yes, do not ever plan to go into age care system. Assisted death is my way to go, no sitting around in nursing home for me with staff rushed off their feet, meals trucked in, no kitchen on site, no proper nursing care, would rather be dead."*

Twenty-four people expressed a less imperative version of the sentiment, saying they (or a loved one) hoped to die prior to requiring residential aged care. A few expressed this as a positive wish to age in place for the remainder of their lives, but others stated a specific preference for death over residential care.

*“I want to remain in my own home till I drop off my perch, so have been making the necessary changes to enable me to manage my disabilities within the home and already access home care as a disability pensioner.”*

*“prefer to be in my own home as long as possible, then die”*

*“I want to be able to live my life out at home, then just curl up and die”*

*“I understand how the staffing of these establishments can cause some angst between the staff and the residents. I understand that pressure and tiredness may impact the staff and their residents to the extent that some [may] rely upon physical abuse to get the job done. I read about these outrages from time to time and try to keep an open mind when it comes to my time to make a decision. In the mean time I look forward to living my life at home and hopefully my next and final stop will be with my late wife at the local cemetery, in many years away.”*

*“Present government policy of outsourcing these services inevitably result in poor performance by the profit driven contractors. There have been shocking examples of insufficient trained staff, lack of empathy for residents, poor value for money, and incompetent facility management. My wife (87 yo) has said she will go out of this house in a box; I must acknowledge her wishes but the day after the box leaves, the house will go on the market!”*

*“I would do whatever I could to avoid having to go into a nursing home. I would rather die quickly of natural causes in my own home [than] lie in a nursing home waiting to die.”*

*“Makes one aware of how alone one is. highlighted shortfalls during Covid. Makes one want to pass away at home in one’s sleep.”*

*“It makes us want to stay and die at home when we get older and need more care”*

*“Certainly don't want to end up in an aged care facility. Hope to just drop dead before I get to that stage.”*

*“the costs of aged care housing are exorbitant and the fear of wasting our savings on institutions that take control of our finances causes us to hope to avoid hopefully until we die.”*

*“An absolute NO to going into any aged care facility. Would rather die in my own home than be a vegetable in one of those facilities.”*

*"and my own experience with relatives who have been in aged care facilities. i would rather die than be in one of these places."*

*"I would rather die than go into a nursing home, […] far too many issues for them to manage with any sort of kindness or care."*

*"Historically our/my experience has repeatedly shown the potential for institutional abuse in environments that are understaffed, not appropriately trained. Just 2 of many reasons why I think I'd rather slit [my] wrist, metaphorically speaking"*

*"I agree with the person who said she would rather die than end up in aged care facility"*

*"I have had relatives and friends in a nursing homes. Nursing homes will be the last resort people are treated worse than dogs. I would prefer to die than go in a home"*

*"I have a written paper officially signed that I do not want to live on if I ever need a wheel chair or cannot look after myself."*

*"I hope I die before I have to go into care"*

*"Live in aged care LAST RESORT I'd rather be dead, my position before COVID and reinforced by COVID"*

*"I have no confidence in Residential Aged Care while it is arranged to make a profit for the owners rather than care for the residents. I have told my family I would prefer to die if I get that sick."*

# Appendix III – Positive experiences of aged care

While it is critical to redress neglect and abuse in the aged care sector and people’s fears about that, it is also important to acknowledge the good work done by aged care workers. For this reason, we here include the additional positive comments from respondents about their experiences with aged care, over and above those we were able to include in the body of the report. People shared these positive comments even where they saw room for improvement or problems still to be resolved.

Most of these remarks were made by family members and friends of care recipients:

> *“I have been very fortunate in finding an aged care facility for my wife that is quite excellent - coupled with the services (for which I pay) of a gifted Carer who sees my wife several days a week.”*

> *“My experience with my late husband in 4 different respite aged care residential over two years have all been good. Final decision making for permanent residency did not cause me any difficulty. Sadly, it became necessary after looking after my husband at home for 15 years with Parkinsons. My own health was deteriorating and DR's recommendation Permanent Residency for him. Excellent care, beautiful staff and RN's always available for any discussion. As was the Residential Manager. Any falls were reported to me immediately by telephone. Food was excellent, activities good and I cannot fault this nursing home. All medical records kept up to date. [Name of provider in Perth WA.]”*

> *“We saw my wife's father in residential care. He had dementia. The treatment he got was great and we were well satisfied. He has passed away now. As is typical with the plethora of 'media' that abounds, some of these tales are blown out of all proportion !”*

> *“My parents and father in-law have been in aged care facility and have all been treated well. At times there are issues (eg lost clothing, seeing my parents clothing on other residents.) My parents were self funded. We were constantly (weekly) asked to replace Dads diabetic testing strips apparently carers used Dads on other residents if they run out.”*

> *“[My answer comes] From experience where my mum's care and service has improved her life. She is [happier] and has the care she required, Mum suffers from Dementia and 24 hours care is required. We are so grateful for the nursing home she's with, our loved ones are really cared [for] and loved there.”*

*"Although the press reports many instances of neglect etc., my experience of residential aged care for our parents has been very positive. I believe the overall standard of care is high, although some reforms around staffing etc are required. There is a need for the system to encourage self-sufficiency amongst older people as well as ensuring care provision for all who need it."*

*"I work in aged care and in 40 years I have not seen anything to the extent that has been reported. I feel saddened by the media hype about adverse events because I know these events are not widespread. The media do not however report all the good stories about aged care. Very one sided. My mother is in residential care and she is well cared for. She says she feels safe and I know the staff treat her well."*

*"My mother spent the last two years of her life in an aged care home in Launceston, and the quality of care she received was mostly pretty good. If I ended up facing that option down the track, I would hope for the best"*

*"My wife's mother was in a nursing home for about 3 years and experienced excellent care. We live in a rural community and our local nursing home has an excellent reputation"*

*"My parents were in care till they died...and they received the best of care!"*

*"I feel we chose well in mum's in home, then respite and now residential care. We all liaise with facility and she gets visited regularly by either children, siblings, friends"*

*"We have had nothing but good experiences with my mother's aged care facility."*

*"We have recently put mother into aged care the care is very good and we would not consider anything less."*

*"My mother had a very good aged care experience and I visited her a couple of times a week for 4 years up until her death."*

*"we live in a small town and my mother-in-law is in an aged care facility which I visit very regularly and I haven't seen or heard any bad reports about either of the aged care homes in this area."*

*"Any experience I have had with others in aged care/nursing homes has been positive. I have had a number of family members involved in the past few years. The worst is the loss of things, including clothing when labels*

*drop off or clothes get ruined in the wash. Generally I have found them clean, staff generally helpful and kind. Most staff do not have english as a first language and are probably not prepared well enough for their role, although much of this is covered by their kindness.”*

*“I have many friends in aged care and while they don’t like being dependent they claim they are well cared for”*

*“My experience with my friends sees no evidence of aged care abuse. As a retired health practitioner I am familiar with what to expect and what to ask regarding aged care.”*

*“The private home my friend has selected to move to when necessary has a very good reputation and we have no worries.”*

*“Yes and no. I have a relative and friend both in aged care. These two people have had no trouble with the aged care system and can not fault the care that they get at the homes they are in. If you are to do so it is better if you are able to nip the trouble in the bud early and it is able to be sorted. I am not saying there has […] been no problems but it does need to be brought to the attention of the management sooner rather than later.”*

Some people reported positive experiences with residential aged care even while stating that they would prefer not to enter residential aged care themselves:

*“My 92 year old husband passed away in Aged Care, was well looked after and I couldn't complain about anything, but I wouldn't want to be in such a regulated system if I could stay in my own home with some help.”*

*“Hope i never have to experience it however friends who are in residential care are happy and do seem to be well looked after. They are not suffering from dementia or severely disabled.”*

*“It really isn't something I want to have to do but realistically have to think it is likely in the future. I would much prefer to stay in my own home and have home care than go into a nursing home. My elderly mother was in a nursing home from late 2012 to early 2016 and I would not want to have to go through what she went through even though I think she was pretty well cared for.”*

*“The general consensus is to stay away from the sector for as long as possible - however recent interactions with a non-profit residential home for my father were wonderful.”*

*"I visit people regularly in an excellent Aged care facility. I plan not to live there when unable to enjoy life."*

Others had mixed experiences with some good and some bad aged care facilities:

*"I do know that there are good aged care facilities, but the inhumanity of the bad ones really scare me."*

*"My father was in aged care 4/5 years ago. I saw good and bad in the residences he was in. One I'd recommend, the other I wouldn't. We had the Situation of a client smoking in their room and the provider didn't seem to care even though smoking was banned in the rooms. My father was in a room next door. Fortunately 11 months later they were closed down by the fire brigade because the fire sprinklers weren't operational. I did ask this question of the provider, and of course was told all was well."*

*"Although my late husband had excellent care, including palliative care, in an Age Care home, it is frightening to think that if I am ever cognitively or physically compromised I could be neglected, bullied, harassed or assaulted. When researching suitable care for my late husband I noted there was a big difference in registered/enrolled nursing staffing levels per resident at various Care homes. The carers who look after the daily needs of frail and unwell residents need to be far better educated and trained to deal with challenging situations. In my view people in this vulnerable state should be looked after in a specialised unit even if this means they need to be moved from their current accommodation."*

*"both my mum & dad were armed forces, so they got pretty good care. but once my mum had to wait 2 weeks in public care for a place with RAAF & that was shocking for us the kids. really bad what i saw."*

*"The only good care facilities I have seen were run by a couple of different churches."*

Some positive comments also came from aged care workers and volunteers:

*"I worked in age care for 5 years and saw mostly wonderful caring people"*

*"I have previously worked in aged care as Lifestyle & Leisure cert.IV employee and have never seen or experienced any such abuses. Only to confirm the occasional delay of toileting at shift changeovers as there weren't enough staff to cover these times. Generally nurses and carers are wonderful but could be assisted more. ie meal times and above."*

*"I volunteer in a nursing home and have never seen any mistreatment of residents. Having said that there are never enough staff and residents often have to wait for attention."*

*"My partner is an aged care nurse in a nursing home. Residents get fantastic care. Government meddling in the sector has the potential to make aged care financially devastating for those involved"*

*"i worked in age care for over 30 years, where i worked there was never any neglect or abuse that i witnessed. Have heard about some terrible things happening, those aged care homes have been shutdown or sanctioned. I would know what to look for if we changed our minds."*

# Appendix IV – Information consumers want about each residential facility

Many of those who responded to the follow-up survey question about guidance, assistance and informational needs commented that they would like easy access to honest, transparent information about each residential aged care facility in their region to aid them in making decisions about which facility to enter. This is information they want upfront, to inform their decisions, not after accepting a place in a care facility.

However, the respondents who answered the survey question in this way varied considerably in which characteristics of facilities they want information about. To manage the complexity inherent in this set of answers, we sorted the characteristics into a 15-point list. Each of the 15 points contains several subpoints. Aged care providers, governments and other bodies are urged to consider attending to all parts of this list when putting together information for prospective aged care residents. Consumers and their advocates may find it a handy checklist when considering a facility.

In the interests of brevity, we have not included verbatim quotes from survey participants as supporting evidence for these many points. If the supporting evidence is required, it can be obtained from National Seniors upon request.

**1 Costs and financial implications for prospective residents**

Costs was the theme most often raised by respondents. Respondents were highly concerned about the lack of clarity and transparency regarding the costs of residential aged care. Some, including people who have worked in the system, expressed much frustration at this.

Respondents collectively identified a wide range of cost-related information that they want to access easily when making aged care choices. Information from facility providers should include:

- any refundable and non-refundable costs for securing a place;
- any interim costs while holding the place but prior to moving into the facility;
- any non-refundable costs for entering a facility or exiting a facility;
- regular, ongoing and maintenance fees during residency;
- whether such regular fees continue if a resident temporarily enters hospital or goes away on holiday;
- a list of provided services that are free to all residents, and a list of any services that are paid for individually;
- different care and service options available for different fee levels;
- any hidden and incidental costs covered or not covered by upfront or regular fees such as for incontinence pads, haircuts, hearing aids or podiatry;

- how costs would differ if a couple was to enter a residential facility or independent living property together rather than one person entering alone;
- whether and how the provider will implement cost increases over time;
- taxes on any of these transactions;
- timeframes to make these payments including penalties for late payments.

In addition to these, a highly important cost care-seekers want to know about is the amount of any refundable bonds that are held by the provider for the duration of residency. They want information on arrangements for refunding the bonds to residents who leave or the beneficiaries of residents who die, and the amount the provider will keep in these circumstances. Under the current system, respondents said they want more information about RADs (refundable accommodation deposits), including why they vary between different facilities, and any options for negotiating the amounts.

Those entering independent living facilities and retirement villages want to know what maintenance they are responsible for paying for and arranging and which the facility will take care of; any preferred contractor arrangements; expectations around obtaining quotes; and waiting times for upgrading structures and infrastructure.

**2 Care levels and the range of care services available**

When considering a facility, respondents desire information about the different levels of care it provides (e.g. low, medium or high care); whether the costs for care increase with higher needs; the ability to vary care levels and costs; the triggers used to identify the need for higher levels of care and how higher care conditions such as dementia are diagnosed by associated staff; whether there are provisions for residents to age in place for the duration of their lives or if they must move to a different site for higher levels of care; and back up services when the facility cannot provide a service and how a resident can access them.

People also want to know if the facility provides services for people with specialist needs, such as people with dementia, people with different kinds of disability, and people with terminal illness; the levels and kinds of training staff have for supporting people in those circumstances; and the quality of any palliative care services. They want to know the facility’s policy regarding residents who wish to access voluntary assisted dying (VAD) provisions, and whether VAD counselling is available through the facility.

**3 Staff qualifications, ratios, roles, pay and conditions**

The staffing situation is another high priority for people seeking aged care. They want to know about the qualifications and expertise of all staff including kitchen staff, cleaners, and management as well as carers and medical staff. They seek information on the training staff have had in specialist areas such as geriatric care, palliative care, wound care, nutrition, and caring for people with Alzheimer’s Disease or Parkinson’s Disease. They want to know the

ratios of all staff to residents; caring and nursing staff to residents; and registered nurses (RNs) to residents. They want to know how many carers and how many RNs are on duty at night and during the day.

Respondents are highly concerned about the pay and conditions under which aged care staff work, so would like information on that when deciding on a facility. They want to know whether staff are paid above award wages; the numbers of full time, part time, casual and agency workers; the services that are provided by third parties; and policies and practices around staff diversity. They are interested in staff safety, OHS plans, staff vaccination rates, and infection control protocols.

**4 Additional medical, health and well-being support**

Numerous respondents identified their need for information about how the facility handles residents' medical and health needs beyond the routine aspects handled by carers and duty nurses. They want to know if they would be assisted to access external medical providers such as their own GP or allied health providers including alternative medicine providers; how the facility would accommodate specialist diets and supplements recommended by health providers; and if the facility has regular visits from a GP for those without their own GP, and from health providers such as podiatrists, physiotherapists, diversional therapists, and dentists. They want to know whether the facility provides routine checks to find out if residents need specialist health and well-being services such as podiatry, physiotherapy, diversional therapy, or dentistry, and if there is a chemist on the premises.

They also want to know how the facility manages emergency medical assistance that is serious but doesn't require an ambulance, such as a wound, infection, or illness. They seek clarity on what the procedures are for care in the case of serious illness, and under what circumstances a person would be hospitalised or would remain in their residence.

Mental health support is another prominent concern, with respondents wanting to know if the facility provides mental health, psychological and counselling support to residents, including through non-healthcare professionals, such as a chaplain.

**5 Availability, application processes, contracts and trial options**

Respondents said they want at-a-glance information about vacancies currently available in facilities they are considering; how long they would be likely to wait to be offered a place; any eligibility criteria; medical and legal documents required; and the best methods of applying and communicating with the facility about an application. For example, one respondent had been told to phone a particular facility every day to secure their loved one a place. People also need to know what arrangements are possible after securing a place but before moving in, while raising funds to pay for it (for example by sale of a private home).

People want easy to understand versions of any contracts they must sign, and for any legal rules and obligations to be clearly spelled out, such as their obligations on leaving a facility and any exit or entry requirements. They also want to know the details of property titles when entering independent living arrangements. They want clear lists of mandated inclusions and what is not included in the service they are signing up for, and for any special needs services to be detailed in writing.

To consider a facility, many respondents would like to know if it offers respite trial periods to "try-before-you-buy"; how much that would cost; and whether the facility has a cooling off period if a person secures a place but later decides to leave. In this circumstance, they need to know before entering a facility what the cooling off period is, which fees will be refunded when they leave, what amount or percentage providers will keep, and any other information about their contractual obligations should they decide to leave.

**6 Room environment, personal belongings and sharing spaces**

Care seekers want information about the room they will stay in as a resident, including the room size and configuration; their ability to make the room more home-like; what is included in the standard fittings such as internet access, a television and television recording device; rooms' security and safety features including lockable storage furniture or a safe; rules about privacy; rules about music; heating and cooling equipment and a resident's level of control over it; access to their own landline phone; any direct access to outside areas; and the physical condition of the building. They also need to know how much space is available for storage of their personal items both in their room and elsewhere, for example whether (and where) they would be able to store a car, mobility scooter or wheelchair. They want information on what furniture is built-in and what can be replaced with their own furniture, including electronic equipment such as televisions.

Some respondents discussed sharing a room and would want to know whether they can choose to have a room to themselves in a residential aged care facility or would have to share with one or more others. They also want to know if they would have an ensuite or shared bathroom. In the case of any shared rooms, people want to know how the facility would manage a situation where a resident did not get along with a roommate.

Conversely, some respondents mentioned they would like to know whether a facility can accommodate couples in the same room, interconnected rooms or adjoining rooms. Others would want to know about a facility's rules on keeping pets. One person said they would ask if carers or other family members can live with them on site, or if they can stay over for a night.

**7 Communal areas and activities**

Respondents generally mentioned wanting information on facilities’ shared spaces, programs, entertainment, and assistance with tasks beyond bodily care. They want to know if facilities have in-house services and equipment such as a hairdresser, nail technician, pool, library, games room, or music room, and the type of outdoor areas and gardens on the premises, as well as information about access to all these outside business hours. They seek information about entertainment, activities, social gatherings, and excursions provided by the facility, including both formal and informal activities, any activities oriented towards “brain stimulation” and any physical exercise options. They want to know about activity programs designed for people with cognitive conditions like dementia. They want to know if staff are available to assist them with technical tasks such as using their phones or computers and accessing the internet.

**8 Food and water**

Care seekers are highly concerned about the provision of food in residential aged care and want to access information about that prior to choosing a facility. They want to know what kinds of meals are provided; how much choice they have over what to eat; whether they can eat in their rooms or must go to a communal area; whether the facility accommodates specialised diets; if mealtimes are set or residents can eat on demand; whether they can suggest items for the menu; and whether they have access to leisure foods such as quality alcohol and coffee.

They also want information about the behind-the-scenes aspects of food, including the facility’s nutrition track record; whether it develops individual meal plans; if the meals are prepared on site or at a central external kitchen; and the expenditure per meal per resident. Some respondents want information on how the facility ensures residents are hydrated and have access to water in their rooms including at night.

**9 Facility routines**

In addition to food routines, care seekers are also interested in other routines of each facility they are considering. These include the daily and weekly scheduling of laundry, cleaning, and personal care regimes; the process for managing medication; and the degree of personal freedom within routines such as whether residents can sleep in. Generally, they want to know about the degree of autonomy and freedom they would have in the facility and any restrictions on their activities.

**10 Visitors, transport, communication technologies and isolation**

Access to the outside world is important for care seekers and was the topic of many comments. People want to know about a facility’s rules regarding visits by family members and friends including the flexibility of visiting hours and vaccination requirements, and any

rules about residents leaving the facility to visit others. They want information about transport options and costs, including access to local public transport; any transport provided by the facility for shopping trips and other outings; and how close the facility is to services such as shops and medical care. Care seekers also want information on assistance or equipment for communicating with others online, such as video calling facilities.

Some respondents are concerned for residents who do not have visitors but who may need assistance with tasks beyond the minimum routinely provided by the facility. They asked who will buy such residents clothing, toiletries and so on if they cannot travel themselves. They seek information about the special care a facility would provide to residents in this situation, including company for the lonely and occupational therapy to devise activities for them to avoid boredom.

**11 Facility culture, diversity and resident relationships**

Care seekers want information about the philosophy and culture of each residential aged care facility they are considering, to ensure they are a good fit and that they will not feel isolated or marginalised there. That information includes whether a facility welcomes and embraces diversity in sexual orientation, gender, culture, ethnicity, and religion; if it is specifically targeted to one or more demographics or groups; or if it has options for some internal separation of groups (for example, gender separation options or requirements). They also want to know whether and how a facility can accommodate the needs of people with different types of disability, including people who are blind or have limited vision, people who are deaf or have limited hearing, people who require mobility assistance, and people who have difficulty communicating with others.

Aside from that kind of organisational information, people want to know about the social norms of the facility that have evolved by chance with resident composition, including levels and kinds of social interaction between residents, and any dominant political views held by the population. They are interested in facility policies and norms regarding consensual sex and intimate relationships between residents, both existing relationships and new ones.

**12 Turnover statistics and incident records**

Some metrics are of key interest to respondents as indicators of what happens within a residential aged care facility. Respondents expressed interest in information about staff turnover rates and resident turnover rates, and the reasons why people have left (as a proxy for the facility's quality and priorities). They seek transparency about the number of falls residents have suffered, hospital admissions and other incidents in the past 12 months, and the facility's performance and compliance track record on any measures aged care facilities are evaluated on. Some want to know if there are surveillance technologies in place, or if any are needed, such as CCTV in rooms to protect against abuse.

**13 Corporate management, organisation, budget details and history**

Care seekers want transparent information about how facilities are managed. When considering a facility, they would like to see up-to-date budget information including easy to understand summaries of the facility's sources of income, the costs it incurs by providing its services, a breakdown of those different expenditure areas, any profits generated, and how profits have been spent. The profit-making aim of some facilities was a concern to many respondents, so clear information about whether a provider operates for profit or not-for-profit is important to them.

People want access to audit summaries; information on solvency; historical corporate information such as the umbrella and parent organisations the facility has had during the past decade; past and present names of any businesses associated with the facility; information about the board of management and CEO; and information about any other facilities owned or managed by the same people or organisation.

**14 Accountability to residents and loved ones, and conflict resolution**

Care seekers are interested in the role of residents and loved ones in facility management, including whether there is a commitment to self-determination and listening to the agency of a person needing care; whether the facility has a charter of residents' rights; the role residents can play in decision-making processes for the facility and for their own care; and the role of residents' family and friends in helping manage life in the residence.

Accountability is a further consideration, with respondents wanting to know about any communication plans and practices in place for keeping loved ones aware of how things are going in all aspects of a resident's life; details of an emergency contact within the facility for residents to contact and/or for loved ones to contact to enquire on residents' behalf; whether care standards for each resident are written out with a checklist for staff; how residents' care plans are implemented; and who ensures such written directions are followed.

Care seekers also want to know about facilities' complaints processes for residents, staff and loved ones. As part of this they seek historical information about complaints, including a transparent list of complaints and records of complaint resolution.

They want to hear whether and how a facility plans for continuous improvement and shows its respect for residents in practice, through actions responding to residents' experiences and views.

**15 Summary reviews and ratings**

Finally, as well as wanting to drill down into the nitty-gritty detail of items included in the previous 14 points, respondents identified their desire to have access to at least four kinds of overarching review:

- Official ratings of the facilities by a government-sponsored or independent agency, that give an at-a-glance indication of both a facility's quality of service and its value for money, plus recommendations of good facilities. The comparison was made to the recommendations Choice makes for other kinds of product and service.
- Honest, comprehensive resident reviews of facilities including commentary on matters such as privacy, care, restraints, medical issues and more.
- Honest, comprehensive staff reviews of facilities, with protections in place for any staff to speak out, including protection for whistle-blowers.
- The care seeker's own observations of a facility, gained from open days at facilities that allow open chats with willing residents and staff, the opportunity to eat in the dining room and participate in activities, and a tour of all areas including kitchens (while respecting residents' privacy).

# Support lines if you are feeling distressed

If reading this report has raised issues of anxiety, stress or personal crisis for you, support and counselling are available from these services, or find others at https://www.healthdirect.gov.au/mental-health-helplines.

**Lifeline – 24/7 crisis support and counselling**

Telephone support and counselling 24 hours a day, 7 days a week 13 11 14
Crisis text service 12pm to 2am (Sydney time) 0477 13 11 14
Online chat service 7pm to 2am (Sydney time) https://www.lifeline.org.au/crisis-chat/

**Suicide Call Back Service – 24/7 crisis counselling if you are feeling suicidal**

Telephone counselling 24 hours a day, 7 days a week 1300 659 467
Online chat 24 hours a day, 7 days a week https://www.suicidecallbackservice.org.au/
Video chat by appointment, details at website

**Friendline – 24/7 non-crisis service for anyone feeling lonely or who just wants to chat**

Telephone chat 10am-8pm, 7 days a week 1800 424 287
Online chat 1pm-5pm Tue/Wed/Thu (at the page, select region) https://friendline.org.au/

**Beyond Blue – short-term counselling, info and referrals about depression and anxiety**

Telephone advice 24 hours a day, 7 days a week 1300 22 4636
Website, including access to online chat https://www.beyondblue.org.au/

**QLife – support and information for LGBTI people of all ages**

Telephone support 3pm-12am (local time, Australia wide) 1800 184 527
Webchat service 3pm-12am (local time, Australia wide) https://qlife.org.au/resources/chat

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