

# YOU DON'T KNOW WHAT YOU DON'T KNOW:

The current state of Australian  
aged care service literacy

September 2018



© National Seniors Australia 2018

National Seniors Australia (National Seniors) owns copyright in this work. Apart from any use permitted under the Copyright Act 1968, the work may be reproduced in whole or in part for study or training purposes, subject to the inclusion of an acknowledgement of the source. Reproduction for commercial use or sale requires written permission from National Seniors. While all care has been taken in preparing this publication, National Seniors expressly disclaims any liability for any damage from the use of the material contained in this publication and will not be responsible for any loss, howsoever arising, from use or reliance on this material.

Publisher NSA ABN 81 101 126 587 ISBN 978-0-06483647-0-2

Suggested citation: Rees, K., Maccora, J. & McCallum, J. (2018). *You don't know what you don't know: The current state of Australian aged care service literacy*. Brisbane: National Seniors.

The Australian Government accepts no responsibility for the accuracy or completeness of any material contained herein and recommends that users exercise their own skill and care with respect to its use. The material in this report may include views or recommendations of other parties, which do not necessarily reflect the views of the Australian Government or indicate its commitment to a particular course of action. A reference to a particular person, organisation, product or service in any part of this report in no way implies any form of endorsement by the Australian Government of that person, organisation, product or service. The Australian Government disclaims to the extent permitted by law all liability for claims, losses, expenses, damages and costs the user may incur as a result of, or associated with, the use of the information contained herein for any reason.

## CONTENTS

---

<b>EXECUTIVE SUMMARY</b> .....	4
Background and purpose.....	4
Data and Methods.....	4
Key Findings.....	4
Conclusion .....	5
<b>INTRODUCTION</b> .....	6
Background.....	6
Purpose .....	9
<b>DATA AND METHODS</b> .....	10
Design.....	10
Data .....	10
Method.....	10
Analysis.....	11
<b>FINDINGS</b> .....	13
1. Expectations of future use of aged care services.....	13
2. My Aged Care literacy.....	16
3. RAS/ACAT assessment experiences.....	27
4. Understanding Consumer Directed Care.....	38
5. Understanding consumer contributions for aged care.....	41
6. Understanding complaints processes .....	45
<b>DISCUSSION</b> .....	57
Some observations overall.....	57
Digital literacy gateway to aged care.....	57
My Aged Care usability .....	57
Complaints and Quality Commissions.....	58
An industry code? .....	59
Literacy among the professionals and care workers.....	59
Consumer willing to pay .....	59
More positive attitudes to aged care services .....	60
<b>CONCLUSION</b> .....	62
<b>REFERENCES</b> .....	63
<b>CURRENT PUBLICATIONS</b> .....	65

## EXECUTIVE SUMMARY

---

### Background and purpose

This study asks whether older Australians have the knowledge, skill and motivation to access aged care services.

National Seniors Australia has conducted a number of research projects into aged care. In 2017, our research provided an early stage analysis of Consumer Directed Care. Earlier in 2018, we reported on the experiences of older Australians receiving home support and home care services, as well as the issues of people providing informal care to family members.

This study considers a further aspect of aged care: service literacy, or the level of understanding that seniors have about the sector, including access to the My Aged Care website and call centre, assessment services, consumer contributions, complaints processes, regulation of the sector, and consumer rights.

### Data and Methods

The National Seniors study reported here was an online survey that collected data from Phase 2 of the National Seniors Social Survey (NSSS) (Wave 7) conducted between 14 February 2018 and 29 April 2018.

A total of 47,280 National Seniors members residing in all states and territories of Australia with an email address were invited to complete the survey, with the survey link being accessible to anyone from the general public who was willing to complete the survey. The survey was also made available to members wishing to complete the survey on paper. A total of 5447 surveys were completed, with 29 surveys completed on paper and included in the sample. Total responses from non-members was 142 or 2.6 per cent.

### Key Findings

- Almost 60 per cent don't expect to deal with aged care issues for family members in the next 5 years;
- Over 70 per cent have never looked at the My Aged Care website, but of those who have, almost 70 per cent found what they were looking for;
- Over 85 per cent have never called the My Aged Care call centre, but of those who have, over 80 per cent indicated that staff were able to assist them with their enquiry;
- For those who've had an assessment for aged care, only half said the process met their expected needs;
- Only 25 per cent of those with experiences of home care had heard of Consumer Directed Care, and 15 per cent of those with no experiences of aged care at home;
- 80 per cent do not understand how consumer contributions for aged care are assessed, but are prepared to pay for aged care in line with their capacity to pay;
- One-third feel there are options available to make a complaint about aged care services, while over 60 per cent have not heard of the Aged Care Complaints Commissioner;

- Only 16 per cent understand the role of the Australian Aged Care Quality Agency, and 19 per cent have heard of the Charter of Care Recipients' Rights and Responsibilities for Home Care.

## Conclusion

As summed up by one National Seniors' member:

***The main problem with age services, you don't know what you don't know. When a problem comes up, one is not too sure of where or how to obtain the right information.***

The findings for this study provide evidence that many Australians over 50 will be caught off-guard by the need to access the aged care sector. The majority of people have very limited aged care literacy, have never viewed the My Aged Care website or called the call centre, haven't heard of Consumer Directed Care, don't understand how consumer contributions are assessed, haven't heard of the Aged Care Complaints Commissioner or the Aged Care Quality Agency, and don't realise there are Charters of Rights for aged care.

After experiencing the aged care sector, one of the main issues is the feeling that complaining about services will lead to retribution. Many who've worked in the sector vow to never use its services if they can avoid it.

The good news is that when people do access the website or call centre, most find what they're looking for or are satisfactorily assisted by My Aged Care staff, however, satisfaction with assessment processes is mixed. National Seniors' members consistently say they are prepared to contribute to the costs of their care but there is a need for greater understanding about exactly what this means.

There is a clear need to increase the aged care literacy of this cohort, to improve the usability of the My Aged Care website, and to educate senior Australians on what they can expect to pay for their aged care so that adequate financial planning can be undertaken. Encouraging more positive views of this life stage is also desirable. There is a potential 'jump start' for improving literacy by learning from and working with initiatives in health literacy already researched and in action.

One way of changing the current negative view of aged care might be to ensure ease of entry into the sector, via the application and assessment processes. While National Seniors' members have reported issues with Home Support and Home Care services in our prior study, the majority express a high degree of positivity about aged care services delivered at home (McCallum, Rees, & Maccora, 2018), and this provides a strong starting point for a change of image for the aged care sector.

## INTRODUCTION

---

### Background

With more Australians living longer with multiple and complex conditions there has been an increased focus on the knowledge, skill and ability of older people to use services to their benefit. Service providers need 'literate', skilled consumers to work effectively and efficiently. The major initiative in service literacy has been in health services with a national survey in 2006 showing that only 41% of Australians 15-75 years of age had adequate or better health literacy skills (ABS, 2008). A new health literacy survey from the Australian Bureau of Statistics (ABS) is currently in the field.

The ability to access and use service information is a fundamental skill which allows people to make informed decisions and helps them to maintain their basic health and self-care. On a broader level, adequate levels of literacy may help to reduce some of the costs in the health and aged care systems, prevent illness and chronic disease, and reduce the rates of accident and death (ABS, 2008).

Aged care service literacy runs parallel to health service literacy but also connects directly when health and aged care services interact, for example during health crises. The key difference is that aged care services tend to be long-term and received in the home or in long-term residential care. The older you are the more likely people are to have more than three health conditions and to be at risk of cognitive impairment. These realities carry implications for effective initiatives to improve aged care service literacy.

This study does not use a composite literacy index but rather the main key items to document the level of understanding of aged care services among Australians over 50, who may be accessing aged care services already, or need services in the future for themselves or their family members. Service literacy has implications not only for a person's involvement in the formal care system, but also for the decisions they make in the home, workplace and community. The level of a person's literacy impacts on tasks such as reading information or accessing My Aged Care, and also affects whether people can function within a consumer-driven care system.

In 2017, National Seniors research provided an early stage analysis of Consumer Directed Care to the Department of Health (McCallum & Rees, 2017), which found that older Australians greatly desire choice and flexibility in aged care but, while support for Consumer Directed Care was high, confidence in the aged care sector was far lower. The study considered that digital literacy can impact access to aged care, and that there was a need for advocacy to enable effective service choice. A further qualitative study in 2017 reported that consumers tend to access aged care under duress, and often feel traumatised by their experiences (Rees, McCallum, & Cantwell, *Be Heard: Snapshots of members' views*, 2017). Consumers reported finding My Aged Care complicated and confusing, and the process time-consuming and frustrating. Once again, the study identified the need for advocacy from someone with knowledge of the sector, both in finding information and completing the assets test.

In *Accentuating the positive: Consumer experiences of aged care at home*, National Seniors reported on experiences of receiving home support and home care services, as well as the issues for people providing informal care to family members (McCallum, Rees, & Maccora, 2018). The report identified a high degree of positivity about aged care services delivered in the home, with strong agreement that workers treated the household with respect, know what they're doing, and are well-trained. Nonetheless a range of issues were identified, including that:

- Services were delivered at times or in ways that were inconvenient to the client;
- There was a lack of continuity of care for dementia patients and poor training levels for dementia care;
- WHS constraints on cleaning caused frustration, and cleaning services were sometimes poor;
- Clients were waiting too long to be assessed, and having to accept a lower level package until a higher one became available;
- Communication from service providers was often lacking;
- Informal caregiving causes physical health effects, stress, and mental exhaustion;
- There is a need for more respite services; and
- Dealing with family dynamics exacerbated the difficulties experienced with aged care services.

This study considers a further aspect of aged care: service literacy, or the level of understanding that seniors have about the sector, including access to the My Aged Care website and call centre, assessment services, consumer contributions, complaints processes, regulation of the sector, and consumer rights. In 2016-17, the Department of Health reported that there were 3.6 million visits to the My Aged Care website, 1.2 million calls to the call centre, 14 Regional Assessment Service (RAS) organisations, and 80 Aged Care Assessment Teams (ACAT) that performed more than 160,000 assessments or reassessments (Australian Government Department of Health, 2017).

With the My Aged Care gateway used as the main access point for aged care services, aged care service literacy interacts closely with physical access of digital technology, and all aspects of digital literacy, including ability and comfort with digital information-seeking. For this reason, digital literacy was a prime focus for the 2018 National Seniors Social Survey and will be reported on more fully in a forthcoming report. The current work builds on National Seniors research on the senior digital divide from 2017. Our prior study found that the National Seniors membership consisted, on the one hand, of a digitally literate cohort, who have email addresses, can complete an online survey, and who signalled daily computer use, and, on the other hand, another group who struggle with some aspects of digital change, have a great desire for computer training, and have cost issues with internet access and buying digital devices (McCallum, Rees, & Maccora, 2017). The study advocated for co-design of products and services with the senior Australians they are intended for, and for alternatives to the digital delivery of information and services to remain available.

In 2017, The Aged Care Industry IT Council (ACIITC) released *A Technology Roadmap for the Australian Aged Care Sector* (ACIITC, 2017) which identified consumer readiness as an issue needing to be addressed if the aged care sector is to fully enable consumer access of digital services:

*Regardless of the extent to which a technological innovation is fit-for-purpose, is well designed, or is likely to significantly enhance quality of life, its adoption requires its end users to be reasonably 'tech savvy' – that is, having digital literacy coupled with confidence in using technology. For older people who have not grown up with ICTs, this can present challenges that must be addressed ...*

*As more people become digitally capable, businesses increasingly assume customers will engage with their products online ... My Aged Care requires access through an online portal and assumes a level of digital capacity that will not be present in many older consumers. For those on the wrong side of the Divide, this brings the consequence of not being informed about what is available, and therefore being unable to make appropriate choices on this basis (ACIITC, 2017).*

Actions called to address lack of consumer readiness included the development of a digital literacy and technology awareness-raising strategies to ensure consumers of aged care have the skills to use technology-based products and services, and are informed about technology-based products and services. They also called for a strategy to address inequitable access of aged care due to disadvantage.

One way the Commonwealth Government is addressing some of these concerns is with the roll out of the *Be Connected Network*, a new digital literacy program for seniors (Good Things Foundation, 2018).

Evidence gathered for this study also provides data on consumer understanding of complaints, regulations, and consumer rights in aged care.

There are Charters of Rights and Responsibilities for the provision of both residential and home care. This study was focused around experiences of home care by members of National Seniors. Thus, respondents were asked about their knowledge of the Charter of Care Recipients' Rights and Responsibilities for Home Care. This Charter describes recipients' general rights, their rights under Consumer Directed Care, privacy, access to complaints procedures, and rights regarding fees. It also outlines the responsibilities of consumers of home care and is available in 18 other languages (Commonwealth of Australia Department of Health, 2017).

The Aged Care Complaints Commissioner resolves concerns about aged care services funded by the Australian Government, including services provided in the home. The Commissioner and staff work with consumers and service providers of aged care in complaints resolution, reporting on



activities to improve aged care services. Complaints can be made over the phone, online, or in writing (Commonwealth of Australia, 2018).

The Australian Aged Care Quality Agency is the accreditation agency for residential aged care homes, assessing 50,000 residents of aged care facilities each year about the quality of care they receive. It also monitors home care and provides compliance information and training to providers. It has recently published the pilot process for new Aged Care Quality Standards (Australian Government, 2018).

Since the NSSS (Wave 7) was conducted, the Government has announced a new Aged Care Quality and Safety Commission, starting from 1 January 2019, which will bring together aged care regulation, compliance and complaints handling. This reform was initiated in response to the Carnell-Paterson review into the failures at the Oakden facility in South Australia and will provide a single point of contact for senior Australians receiving Commonwealth aged care services. Further reforms will include a Serious Incident Response Scheme, a performance rating of providers and a provider comparison tool on the My Aged Care website. National Seniors supports the ongoing reform of the aged care sector in Australia.

## Purpose

This study was designed to gather evidence on the understanding of aged care services by Australians over 50, the cohort the sector is designed to serve. The study asks whether older Australians have the knowledge, skill and motivation to access aged care services.

## DATA AND METHODS

---

### Design

The National Seniors Social Survey (NSSS) (Wave 7) was cross-sectional in design and conducted by National Seniors Research Director, Professor John McCallum using a questionnaire survey of National Seniors members aged 50 and over. The study was approved by the Bellberry Human Research Ethics Committee of South Australia on 31 January 2018, application number 2017-12-981.

### Data

Data in this report were collected in Phase 2 of the NSSS (Wave 7), designed by National Seniors Research staff. The survey was conducted from 14 February 2018 to 29 April 2018. The NSSS Phase 2 asked participants about their experiences, intentions and attitudes across a range of areas including financial planning for retirement, aged care and digital literacy.

Phase 2 of the NSSS was a self-complete instrument, delivered online using the survey instrument, Survey Monkey. For this study, it included the following modules:

- **About yourself**  
A range of questions used to obtain information from respondents about their demographic and socio-economic circumstances.
- **Aged care literacy**  
These questions asked about participants' understanding of My Aged Care and assessment services, Consumer Directed Care literacy, financial literacy regarding fees for home and residential aged care, and their understanding of complaints processes.

### Method

A total of 47,280 National Seniors members residing in all states and territories of Australia with an email address were invited to complete the survey. The survey invitation was emailed and contained a link to the survey instrument. This email link was not restricted to National Seniors members but instead accessible to anyone from the general public who was willing to complete the survey. This meant that the sampling frame was potentially larger than the National Seniors membership with email addresses. Total responses from non-members was 142 or 2.6 per cent of total participant responses.

The age breakdown of National Seniors survey participants and overall members as compared with the Census data is as follows:

**Table 1: National Seniors' members compared with 2016 Census data**

	NSSS survey participants 2018	NSSS 2018 (%)	All NSA members 2018 (%)	Census 2016 (%)
50-59	715	13.2	19.0	37.4
60-69	2124	39.3	37.0	31.3
70-79	1997	37.0	30.5	19.4
80+	563	10.4	13.5	11.9
Total Answers	5446 <sup>1</sup>			

**For this study, Phase 2 of the NSSS included the following questions:**

- Have you personally looked at the My Aged care website or has someone looked at it on your behalf, and did you find what you were looking for?
- Have you called the My Aged Care call centre and were staff able to help with your enquiry?
- Have you had an assessment for aged care services, and did the process meet your needs?
- Have you heard of Consumer Directed Care, the Aged Care Complaints Commissioner, the Australian Aged Care Quality Agency, and the Charter of Care Recipients' Right and Responsibilities for Home Care?
- Do you expect to deal with aged care issues for family members in the next 5 years, and do you understand how consumer contributions for aged care are assessed?

## Analysis

A total of 5447 surveys were completed for the NSSS, a response rate of 11.5 per cent based on the members emailed a link to the survey, although this is difficult to measure given the open access to the survey. The software package Stata was used to analyse the data.

<sup>1</sup> Although N=5446, only 5399 gave their age.

## NATIONAL SENIORS AUSTRALIA

Sample

**Table 2: Basic characteristics of the NSSS sample, 2012-2018 (%)**

	2012	2013	2014	2015	2017	2018
<b>Age (unweighted)</b>						
50-64	48.0	42.2	44.7	43.9	33.3	30.3
65-79	40.9	42.8	43.8	43.3	58.3	59.3
80+	11.2	15.0	11.6	12.8	8.4	10.4
<b>Gender (unweighted)</b>						
Female	54.3	55.9	53.3	54.2	56.2	57.0
Male	45.7	44.1	46.7	45.8	43.8	42.9
Other	-	-	-	-	-	0.1
<b>State (unweighted)</b>						
NSW	29.9	28.8	29.5	30.7	21.8	22.3
VIC	25.8	25.8	25.9	24.7	14.9	14.1
QLD	17.1	18.1	17.4	18.7	42.2	42.4
SA	9.6	9.5	9.3	9.3	4.5	4.1
WA	10.3	11.1	10.1	11.2	8.9	9.0
TAS	4.1	4.1	3.5	3.0	2.5	2.3
ACT	2.2	2.0	2.3	2.0	3.7	3.6
NT	1.0	0.6	0.6	0.4	1.5	2.2
<b>Education (weighted)</b>				<b>(unweighted)</b>		
Not completed high school	52.1	50.1	49.0	42.3	32.2	42.6
Completed high school	47.9	49.9	51.0	57.7	67.8	57.4
<b>Other qualification</b>				<b>(unweighted)</b>		
Yes	-	-	-	-	77.5	79.5
No	-	-	-	-	22.5	20.5
<b>Highest level of qualification</b>				<b>(unweighted)</b>		
Certificate	-	-	-	-	24.8	21.8
Diploma	-	-	-	-	26.1	24.8
Bachelor degree	-	-	-	-	26.5	19.9
Post-grad dip/cert	-	-	-	-	-	14.6
Masters/Doctorate	-	-	-	-	13.2	12.0
Other	-	-	-	-	9.4	6.9
<b>Employment (weighted)</b>				<b>(unweighted)</b>		
Currently in the paid workforce	43.2	41.5	40.3	40.5	27.0	26.6
Not currently in the paid workforce	56.8	58.5	59.7	59.5	73.0	73.4
<b>Country of birth (weighted)</b>				<b>(unweighted)</b>		
Australia	77.6	80.9	80.8	79.6	75.0	76.5
Other	22.5	19.1	19.2	20.4	25.0	23.5
<b>Marital Status (weighted)</b>				<b>(unweighted)</b>		
Married/de facto/living with partner	62.3	63.7	63.6	63.5	63.8	62.7
Divorced/separated/never married/ widowed	36.4	35.8	36.4	36.7	33.0	37.3
Other	1.4	0.5	0.0	-	3.2	-
<b>Total</b>					<b>100%</b>	

## FINDINGS

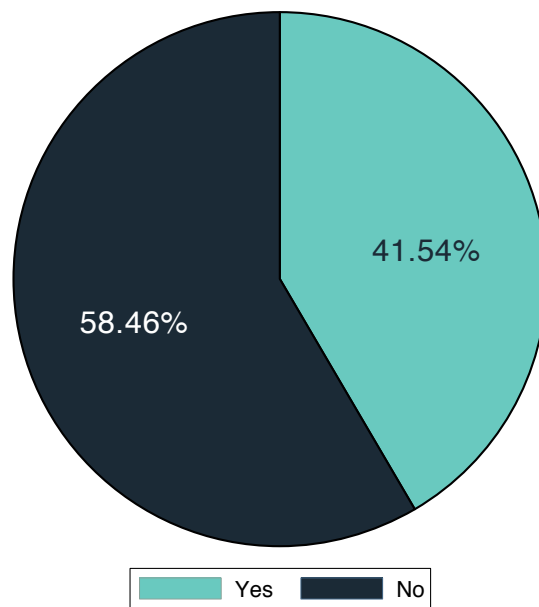
The following chapters present the findings for the National Seniors Social Survey (Wave 7) study on aged care literacy covering six domains:

1. Expectations of future use of aged care services
2. My Aged Care literacy
3. RAS/ACAT assessment experiences
4. Consumer Directed Care
5. Consumer contributions for aged care services
6. Complaints processes

### 1. Expectations of future use of aged care services

**QUESTION:** Do you expect to have to deal with aged care issues for family members in the next 5 years?

**Figure 1:** Expect to deal with aged care issues for family members in the next 5 years (%) (NSSS Wave 7, 2018; N=5072).



**Table 3** Profile of respondents who do and don't expect to use aged care services in the next 5 years (NSSS 7, 2018)

	Yes	No	p-value
<b>gender</b>			<b>0.014</b>
male	43.4	56.6	
female	40.0	60.0	
<b>age</b>			<b>&lt;0.001</b>
50-59	56.3	43.7	
60-69	42.7	57.3	
70-79	34.5	65.5	
80+	43.4	56.6	
<b>education</b>			<b>0.186</b>
certificate	41.5	58.5	
diploma	45.2	54.8	
bachelor degree	43.2	56.8	
postgrad dip/cert	43.1	56.9	
Masters/PhD	47.5	52.5	
other	39.6	60.4	
<b>partnered</b>			<b>&lt;0.001</b>
living with partner	49.9	50.1	
living alone	27.4	72.6	
<b>children</b>			<b>0.016</b>
has children	42.2	57.8	
no children	37.8	62.2	
<b>health</b>			<b>&lt;0.001</b>
excellent	34.3	65.7	
good	41.7	58.3	
fair	47.0	53.0	
poor	53.1	46.9	
very poor	54.2	45.8	
<b>savings value</b>			<b>0.188</b>
less than 50K	41.0	58.9	
50-100K	42.6	57.4	
100-200K	40.7	59.3	
200-300K	42.3	57.7	
300-500K	40.8	59.2	
500-750K	46.6	53.4	
750K-1.5M	44.4	55.6	
>1.5M	41.8	58.2	
don't know	34.7	65.3	

rather not say	40.6	59.4	
<b>employment</b>			<b>&lt;0.001</b>
in paid work	48.2	51.8	
not in paid work	39.5	60.5	
<b>heard of CDC</b>			<b>&lt;0.001</b>
yes	50.1	49.9	
no	39.2	60.8	
<b>prepared to pay</b>			<b>0.706</b>
yes	41.9	58.1	
no	41.2	58.8	
<b>called call centre</b>			<b>&lt;0.001</b>
yes	62.1	37.9	
no	38.2	61.8	
<b>visited website</b>			<b>&lt;0.001</b>
yes	55.5	44.5	
no	35.9	64.1	

Profiling the people who do and don't expect to use aged care services in the next five years is a way of assessing the general aged care literacy of respondents. The non-significant differences were for education level, savings value, and being prepared to pay. All others were graded within variables, for example, as health ratings declined the probability of expecting to use aged care services increased.

The study aimed to find out whether people who know they will need to find out information on the aged care sector in the coming years are literate about how the system works. Table 6 shows that people who do expect to need information on aged care in the next five years are more likely to have consulted the My Aged Care website and call centre, and more likely to have heard of Consumer Directed Care. This also means that people who need aged care services unexpectedly are more likely to access the system with less understanding of how to find the information they need:

*The main problem with age services, you don't know what you don't know. When a problem comes up, one is not too sure of where or how to obtain the right information.*

*Good experiences with My Aged Care, but it is difficult to find out where to go when the need for care is sudden & unexpected.*

One respondent described the process of gaining aged care literacy:

*My mother-in-law is in a nursing home and it took us nearly 3 to 6 months to understand how to access and understand this system.*

Another warned that:

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

With a website and call centre available to begin the aged care journey, one respondent suggested these avenues will not suit everyone:

*How do people go with hearing loss and no computer access?*

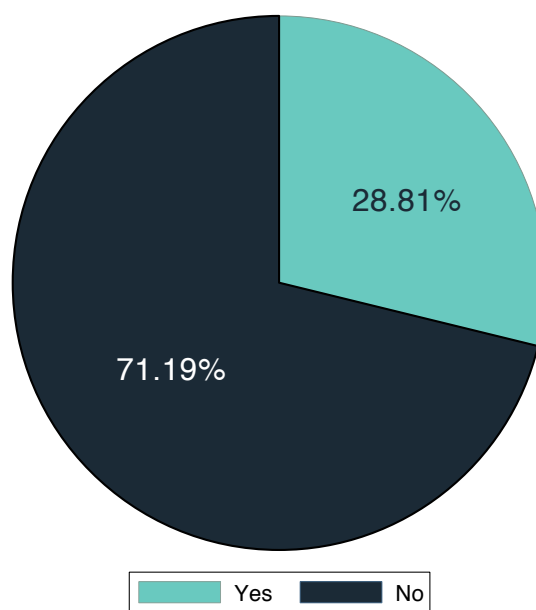
## 2. My Aged Care literacy

---

QUESTION: Have you ever personally looked at the My Aged Care website?

---

Figure 2: Use of My Aged Care website (%) (NSSS Wave 7, 2018; N=5182)





**Table 4: Aged care service literacy – profile of people who have and haven't looked at the My Aged Care website (NSSS 7, 2018).**

	Yes	No	p-value
<b>gender</b>			<b>&lt;0.001</b>
male	20.7	79.3	
female	35.0	65.0	
<b>age</b>			<b>0.013</b>
50-59	28.1	71.9	
60-69	28.2	71.8	
70-79	28.0	72.0	
80+	34.9	65.1	
<b>education</b>			<b>0.050</b>
certificate	27.3	72.7	
diploma	29.1	70.9	
bachelor degree	29.9	70.1	
postgrad dip/cert	34.0	66.0	
Masters/PhD	33.1	66.9	
other	27.6	72.4	
<b>partnered</b>			<b>0.001</b>
living with partner	27.2	72.8	
living alone	31.6	68.4	
<b>children</b>			<b>0.061</b>
has children	28.2	71.8	
no children	31.4	68.6	
<b>health</b>			<b>0.002</b>
excellent	25.0	75.0	
good	28.7	71.3	
fair	32.7	67.3	
poor	30.7	69.3	
very poor	41.7	58.3	
<b>savings value</b>			<b>0.005</b>
less than 50K	33.5	66.5	
50-100K	29.1	70.9	
100-200K	31.1	68.9	
200-300K	32.8	67.2	
300-500K	27.2	72.8	
500-750K	30.8	69.2	
750K-1.5M	26.6	73.4	
>1.5M	24.6	75.4	
don't know	20.0	80.0	

rather not say	27.4	72.6	
<b>employment</b>			<b>0.183</b>
in paid work	27.3	72.7	
not in paid work	29.3	70.7	
<b>heard of CDC</b>			<b>&lt;0.001</b>
yes	51.9	48.1	
no	22.4	77.6	
<b>prepared to pay</b>			<b>0.002</b>
yes	29.9	70.1	
no	24.9	75.1	
<b>called call centre</b>			<b>&lt;0.001</b>
yes	82.9	17.1	
no	19.8	80.2	

Most respondents had not looked at the My Aged Care website. On this question, there is a difference by the Senior Surfer score, unlike for the previous question (Table 3), because digital literacy is now relevant to access information.

From comments received, the process of accessing aged care services has a reputation of being difficult and time-consuming:

*At present my wife and I are managing and would prefer NOT to ask the Govt for help of any type...I consider that the Govt process is FAR too difficult.*

*I understand it would be done when the need arose but the process will take 6 to 8 months! That sounds ridiculous and I would probably die waiting for the package!*

While access of the My Aged Care website is lower than expected for a cohort whose needs the system is designed to serve, the following comment shows that advertising of My Aged Care by the government does serve to increase aged care literacy:

*I only looked at the website out of curiosity when I read about parts of it in the newspaper.*

One respondent's comment shows the level of misunderstanding of the sector among people who haven't accessed it:

*No one I speak to understands it. Everyone has an opinion. I believe overall it cannot be funded and is open to massive corruption and abuse. A friend has obtained a clothes airer for \$450. No one needs the taxpayer to pay for something that expensive.*

Some people put off accessing aged care services as long as they can:

*I will probably not need an assessment until aged 80 plus.*

One respondent said this was a generational trait:

*They are reluctant to ask for help or assistance. It is a generation that does not want to impose, and try to be independent.*

Another blamed digital literacy:

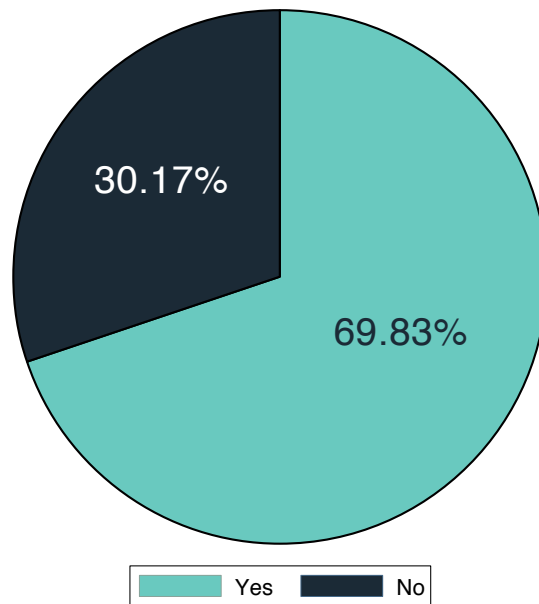
*Access to information is hard if you are not computer literate as everything sends you to a website.*

---

QUESTION: Did you find what you were looking for on the My Aged Care website?

---

Figure 3: Able to find information on the My Aged Care website (%) (NSSS Wave 7, 2018; N=1495)



While access of the My Aged Care website is low at 28.81 per cent of respondents, 69.83 per cent of these said they found what they were looking for. Some commented that the website was difficult for them to navigate:

*Have spent hours perusing MAC website. Is hard to understand.*

*My aged care website is difficult for older people to get information needed. Typical government website.*

*They also need to do more to provide people with information about what care is out there and how to access it. I did not find the My Aged Care site that easy to navigate or find the information I was looking for.*

*Have found the site difficult to work through.*

*Aged Care Website is difficult [impossible] to negotiate - had to ring the phone number although I was registered with My Aged Care to get help with my query.*

Many who find the website hard to use express the difficulty in extreme terms:

*The MAC portal and system is a NIGHTMARE to access and get around.*

*I was able to organise an ACAT for my mum. But MAC is terrible! I don't know how frail and vulnerable people navigate it. Throw in CALD or Indigenous and you have a mess. It is not used friendly.*

*Navigating their website is mind boggling.*

*I am a very competent computer user but the website is an absolute nightmare to use.*

One respondent not only described the website as difficult, but the terminology confusing:

*I found the website confusing. I find the terminology confusing – what is the difference in being assessed, being approved, being granted, being assigned... Very similar words mean different steps in the process.*

Other respondents expressed frustration that the website promises services that aren't available to them in reality:

*I tried unsuccessfully for over 12 months to get assistance with home garden maintenance projects. I found that the suppliers listed and the MAC staff were all useless. Once approached by me the suppliers eventually admitted they were not equipped to do the basic maintenance required. I have tried to take this up with the original assessor but she doesn't reply to my calls. For this area of assistance, the government should be made to take it off their web site. They are just 'jerking people around!'.*

*There were no packages available. The Aged Care Website indicated that various services were available but when these services were contacted they were unable to assist. Very frustrating.*

For one respondent, neither the website or call centre led to adequate assistance:

*No one answers a phone or reply to online request was waste of time filling out online.*

A novel approach, mentioned by one participant, was a class on how to use the My Aged Care website as part of a falls prevention program. This could also work in senior digital literacy courses:

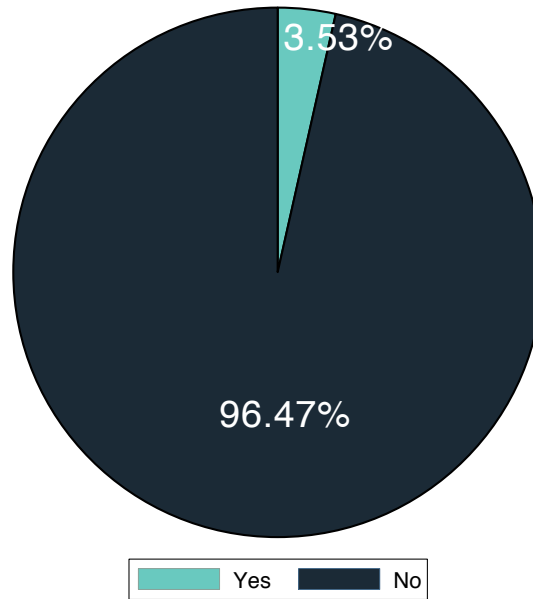
*I did a "Stepping On" Program and we were told about My Aged Care and our homework for that week was to Register for My Aged Care so when we needed help we had an idea of who to call. I tell all my friends and family about it, especially those with mobility or other issues.*

---

QUESTION: Have you asked someone to look at the My Aged Care website on your behalf?

---

Figure 4: Had an intermediary search the My Aged Care website (%) (NSSS Wave 7, 2018; N=5102)

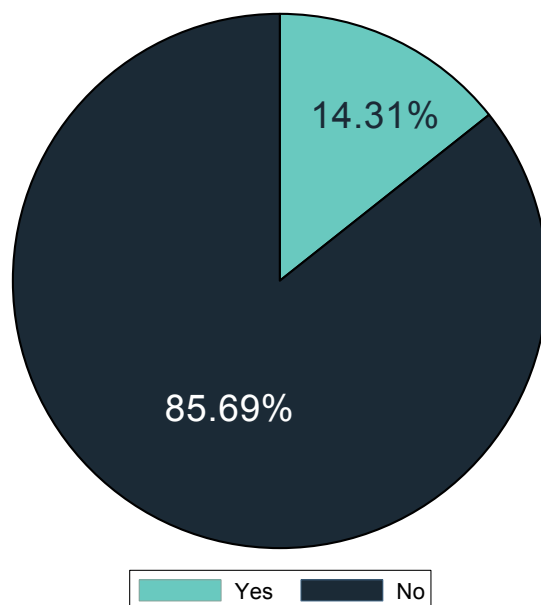


One respondent, who searched My Aged Care for a family member, said it would be impossible for the non-digitally literate:

*As a 60-year-old experienced with IT I have no idea how someone of my mother's status would possibly be able to navigate through the system.*

**QUESTION:** Have you personally called the My Aged Care call centre?

**Figure 5:** Use of My Aged Care call centre (%) (NSSS Wave 7, 2018; N=5157)



**Table 5:** Aged care service literacy – profile of people who have and haven’t used the My Aged Care call centre (NSSS 7, 2018)

	Yes	No	p-value
<b>gender</b>			<b>&lt;0.001</b>
male	9.2	90.8	
female	18.2	81.8	
<b>age</b>			<b>&lt;0.001</b>
50-59	13.6	86.4	
60-69	12.3	87.7	
70-79	14.5	85.6	
80+	22.4	77.6	
<b>education</b>			<b>0.592</b>
certificate	13.6	86.4	
diploma	15.8	84.2	
bachelor degree	14.6	85.4	
postgrad dip/cert	15.6	84.5	
Masters/PhD	12.8	87.2	
other	15.7	84.3	
<b>partnered</b>			<b>&lt;0.001</b>
living with partner	12.7	87.3	

## NATIONAL SENIORS AUSTRALIA

living alone	17.1	82.9	
<b>children</b>			<b>0.684</b>
has children	14.2	85.8	
no children	14.7	85.3	
<b>health</b>			<b>&lt;0.001</b>
excellent	10.8	89.2	
good	12.9	87.1	
fair	20.4	79.6	
poor	20.4	79.6	
very poor	41.7	58.3	
<b>savings value</b>			<b>0.01</b>
less than 50K	18.8	81.2	
50-100K	15.9	84.1	
100-200K	15.6	84.4	
200-300K	13.8	86.2	
300-500K	14.1	85.9	
500-750K	12.7	87.3	
750K-1.5M	11.8	88.2	
>1.5M	11.9	88.1	
don't know	18.6	81.4	
rather not say	12.0	88.0	
<b>employment</b>			<b>0.023</b>
in paid work	12.1	87.9	
not in paid work	14.7	85.3	
<b>heard of CDC</b>			<b>&lt;0.001</b>
yes	22.1	77.9	
no	12.1	87.9	
<b>prepared to pay</b>			<b>0.066</b>
yes	14.7	85.3	
no	12.5	87.5	
<b>visited website</b>			<b>&lt;0.001</b>
yes	41.0	59.0	
no	3.4	96.6	



As expected older people and those in very poor health were more likely to have made the personal call. Women were twice as likely as men to call. There were no significant differences by education, having children, or willingness to pay.

Telephone wait times were thought to be excessive for My Aged Care:

*My Aged care website is a nightmare even for the fully proficient web users. I gave up trying to elicit a response by telephone, the wait time rivals Centrelink.*

*I am told it is better to phone them and to have a lot of time to wait.*

*As a volunteer with Dementia Australia, I often refer people to the website if they are tech savvy. If telling them to call, always warn them that they may be on the phone for some time.*

*Feedback from clients have been mixed.*

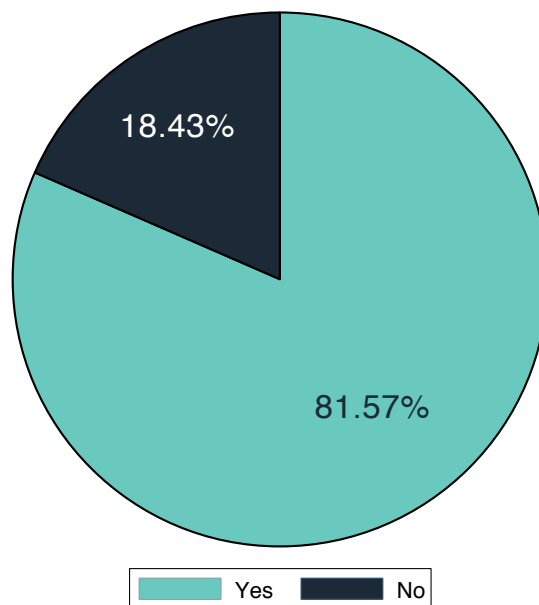
*Call centre...long wait, unfriendly worker.*

---

QUESTION: Were the staff at the My Aged Care call centre able to assist you with your enquiry?

---

Figure 6: Help received from My Aged Care call centre (%) (NSSS Wave 7, 2018; N=727)



Respondents were satisfied with the assistance they received from My Aged Care over the phone. One respondent, however, described a “disturbing and unsatisfactory” encounter in which the call centre operator seemed unwilling to deal with a friend who had difficulty hearing, revealing that a customer-focus is needed:

*I have assisted a friend who needs home based care ... She requested information in writing from the call centre, but they refused and insisted on phone calls only, despite her difficulties with hearing on the phone. The operator spoke too quickly and with a strong accent, making it difficult for both of us to follow her readily and she did not respond well to our request to slow down, stop reading out the script she insisted on repeating when we asked a specific question requiring a more focused answer. It was a disturbing and unsatisfactory encounter from a service intended to assist older people.*

Some calls go unanswered:

*Called My Aged Care but could not get through – then abandoned that line of inquiry.*

Another respondent said the outcome was dependent on the person who answered the call:

*The effectiveness of My Aged Care is heavily dependent on the training and attitude of the staff. Any successful assistance occurred usually after several phone calls to find the right person with the right knowledge and the right attitude.*

Another issue was calling My Aged Care and being directed to the website:

*The My Aged Care site takes a lot of getting used to, when one phones one is constantly referred back to it even though one has phoned because info there was not totally clear.*

One respondent, however, was positive about calling:

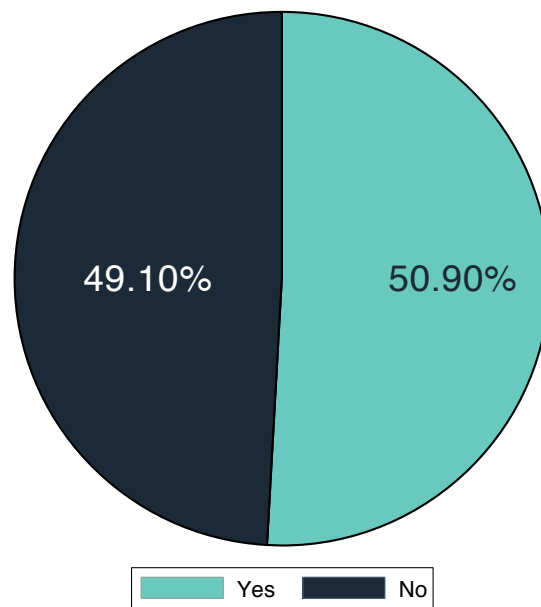
*The people I have dealt with at My Aged Care have only ever been most helpful and kind.*

### 3. RAS/ACAT assessment experiences

**QUESTION:** If you've ever had an assessment for aged care (RAS or ACAT), did the process meet your expected needs?

Just over three-quarters of participants had not had an ACAT assessment, 3843 in total. Those who had had an assessment were divided equally in whether they thought the process met their expected needs.

**Figure 7:** Needs met by aged care assessment (%) (NSSS Wave 7, 2018; N=1222)



Just over 500 participants commented on the assessment process, in ways representative of the overall quantitative result. There were positive and negative opinions, as well as clearly identifiable themes related to aged care assessments, as follows.

## **Positive**

Many respondents said the assessment process met their needs, the assessors were helpful, and they had no complaints. Positive responses ranged from adequate, to good, comprehensive, excellent, or professional. Assessors were described as nice, helpful, co-operative, efficient, caring, patient, considerate and kind. Assessments were deemed accurate, everything was clearly explained, and the process was stress-free and friendly.

Other positive comments included the following:

*Beautiful people.*

*I was very impressed by the kindness and courtesy shown to me.*

*Treated with courtesy and respect.*

*Very satisfied.*

*Was dealt with promptly.*

One reluctant client was treated so well that the assessment went better than expected:

*I did not initiate the assessment. I was in a rehab hospital following a major operation – at age 69 I did not see myself as “old”. But the young man and especially the nurse who interviewed me were so nice – I was quite co-operative.*

Another common feeling was one of relief:

*The help we received was terrific, they could not do enough for us, as we were at our wits end.*

*My parents expressed great relief that they were able to access that service.*

One respondent praised the assessors handling of a dementia patient:

*The people who conducted the assessments are to be commended for the way they handled the difficult situation of my spouse’s dementia.*

Another commented on how perceptive the assessor was of their situation:

*It was very helpful and even though my partner thought he was making a great impression, the assessor could tell what the issues were for both of us.*

For many, the process was efficient and thorough:

*The ACAT team were more than helpful which resulted in getting my uncle to an aged care facility in a relative short period of time.*

*The assessor was very friendly, very thorough and checked back later to see if I was happy with the service provided.*

Another mentioned that the assessment was well-tailored to the needs of the elderly:

*The person interacted well with my 95-year-old mother and made sure she fully understood the procedure and what it was for.*

### Negative

General negative comments were quite strong, calling the assessment useless, stressful, intimidating, inappropriate, and pitiful, one respondent saying they were left unhappy with some aspects of the process.

One colourful description said:

*The Assessor was aggressive and a “Nelly Knowall”.*

A range of comments referenced the confusion or inexperience of the assessor:

*A process that is very confusing & even the people carrying out the assessments say the same.*

*I believe the assessor is most probably too young? None or very little experience?*

*Person was fairly new and did not know difference with shopping and transport assignment.*

One respondent, however, admitted her own understanding was at issue:

*I realised later how little I understood about the process.*

A few said the assessment took too long:

*Very long process takes way too long and confusing for elderly.*

*I felt the assessment interview was far too long, especially for my elderly parents, they were exhausted afterwards.*

Another described the assumptions the assessor made, which weren't helpful:

*They assumed, as a nurse, that I knew what was going on, but I had no idea or expertise in aged care services. Even though I explained this they continued to provide poor information. What concerned me most, is that as a nurse, I had some idea about the processes they tried to explain. Imagine how complicated it is for someone who has had no exposure to this type of service previously.*

### Long wait time

After applying to have an assessment done, many respondents said the wait times were excessive:

*Waiting times are sometimes a problem due to demand for their services.*

*Delays in process are the big problem. Wait for up to 12 weeks for an appointment.*

*Was told that it would be some 18 months before assessment by experts to assess our situation.*

### Assessment was unsatisfactory

Many said the process was unsatisfactory due to the perfunctory nature of the assessment:

*Insufficient time allocated.*

*It took less than 20 minutes and was nowhere near as involved as the first one I'd had. When my partner had an assessment, it took less than 10 minutes!!*

*I was surprised at the lack of depth of questioning which meant they did not get complete information unless I provided it separately. As a result, my mother-in-law was assessed as needing to be in secure dementia accommodation, which was completely inappropriate and terrifying for her. This was evident to the aged care home and they moved her to high level care, out of the dementia ward.*

Some considered that they weren't viewed as a whole person, or that their needs weren't properly recognised:

*I felt that I was not considered in my entirety, only in sections.*

*I wasn't convinced the most important needs were identified and addressed.*

Another surprising incident was the assessment of an Auslan user without an interpreter:

*My father had an assessment in a hospital setting. He was an Auslan user. Despite my strong request that I or an Auslan interpreter be present, it went ahead without an interpreter.*

There were also frustrations caused by digital issues with the system and paperwork being lost:

*The RAS assessment went well. However, the assessor had a lot of trouble getting the assessment loaded into the portal. It took 4 weeks of frustrating phone calls before the problem was fixed. Meanwhile mum's condition was deteriorating.*

*The ACAT paperwork was lost 3 times, and the staff were very dismissive & I got absolutely no help.*

### Services not available

A range of comments related to services not being available despite satisfactory assessment occurring, usually an issue for regional and remote clients:

*I can't get any help because they don't have anyone in my area who can come in and assist me.*

*The assessment met the needs of my husband but the providers did not deliver what was required.*

*What is assessed may not be what the PROVIDER can deliver.*

For some respondents, this resulted in having to make financial decisions or other arrangements:

*I had assessments done for my parents, they lived in a rural area. Care packages were unavailable when they needed them. I had to move them to residential aged care.*

### No services eventuated

After assessment occurred, many respondents said nothing happened:

*Assessor told me that he was going to call me the same afternoon to give me the names of providers in my area. I am still waiting for his call.*

*Months later, nothing happened yet.*

Some of these needed home support services after hospitalisation, but didn't receive it in time:

*I never heard back. Myself and I have heard of others, once you leave hospital you feel dumped!*

*On discharge from hospital following recovery from a serious fall but apart from a Physio other services did not materialise or took so long I had recovered enough so they were almost not needed.*

One respondent said only respite services were offered to a high care client:

*This has achieved nothing, despite my mother being assessed as high care. Utterly inappropriate respite was all that was offered when I needed it.*

When services fail to eventuate, no explanations are offered:

*I fail to understand why assistance was denied.*

*I had an interview with Anglicare and had a couple of visits from tradespeople to give quotes for work to be done but have heard nothing more in over a year. I guessed it was because I don't need help with housework but I really don't know why.*

Lack of services cause distress and other arrangements need to be made:

*My biggest concerns are for two friends with elderly partners who are frail and somewhat demented. They have been assessed at the highest level but 6 months later nothing has happened. They are frantic.*

*The assessment was done and nothing happened. They know who can push themselves to the point of breaking. There is no CARE in Age Care.*

One respondent said that death occurred before services eventuated:

*Process so slow, in the case of my father-in-law, he died waiting for services. Minefield – difficult to help any elderly person.*

Another commented that this situation probably suits the government:

*My mother is 92 years old and now is one of the more than 100,000 people waiting for higher level Home Care Packages. She probably won't live long enough to actually get the package. The govt will be happy with this outcome as more people drop off the list as they die.*



### Assessed as Level 4, received Level 2

Being assessed as needing a Level 4 home care package and receiving Level 2 is a common occurrence, with one respondent describing this as system failure:

*My mother was assessed in March 2017 as needing a level 4 home care package. She was placed in a queue. In February 2018 – ten months later – she was advised that a level 2 home care package was available for her. By this time her condition had deteriorated so much she had been admitted to an aged care facility. In other words, the system totally failed to help her stay in her home.*

*I have been able to get an assessment for my mother and the people who came out were very helpful, she is now on a Level 2 package, only just approved after waiting for a year, although the approval is for a level 4 – she is only getting funding to a level 2 at the moment.*

*Main problem was my mother was assessed as needing level 4 care but commenced at a low level 1 or 2 which slowly progressed to 4 from memory this took over 6 months.*

*The upgrade from Level 2 to Level 4 with dementia took too long... (over a year) to attain.*

One respondent summed up this failure, thus:

*The assessment was for my mother – it would meet expectations if the funding matched the assessment outcome!!!!*

### Difficult process but eventually sorted out satisfactorily

For some, while the entire process of assessment and getting services in place was lengthy, they were eventually satisfied with the outcome:

*Coming home after 3 weeks in hospital, trying to get help with transport, meals, housework ended up being a nightmare. However, it was finally sorted and we are very happy with help arrangements at present.*

*It was a convoluted lengthy process but eventually it met our needs.*

### Difficult process, eventually gave up

One respondent, however, gave up completely:

*I was assessed by My Aged Care but when I went to my local council for help I was told that I had not been registered and I would have to contact My Aged Care again. As the original process had been so complicated I gave up at this point.*

### Hard to get advice

Many clearly don't know where to start when they first need to access aged care:

*The biggest issues are getting appropriate accurate and reliable advice from the various agencies. (including Centrelink, my aged care and the facilities.)*

*I still don't have a number. Am totally confused.*

Some make assumptions:

*I have assumed that as self-funded retirees we remain responsible for ourselves, despite our income falling with the reduced interest rates.*

Others found the assessors didn't have the right information for them:

*Assessor was not fully informed about the transport services in the area. I needed to do my own investigations to find my answers.*

*I had no idea what to expect when the assessor came to interview us. We had to nominate suppliers at this interview. We had choice but because we didn't know anything about any of those on offer we made blind decisions. I would have preferred the opportunity to google around before having to make a decision as important as this.*

*It was a nightmare, lots of forms and very little help. Lots of fees and charges and very little assistance.*

One believes the assessors were trying, but it was still difficult:

*We didn't always understand what we were told, even though they tried to be helpful.*

Another admitted they didn't themselves understand what they were aiming for:

*The interviewer was very competent but I don't think I really understood what I was trying to achieve.*

### Recipient downplayed their needs

It was common for respondents who had been through assessment processes with their parents to comment that they had overstated their abilities and downplayed their needs, and the assessors didn't recognise this:

*My Dad just told the staff what he thought they wanted to hear – he needed more than one assessment...*

*I was with my mother during the aged care assessment and she professed to be capable and healthy when she was not. It was very awkward trying to get through to the assessor that Mum was telling very big lies.*

*Assessment of parents. Found out afterwards and found that they had lied (parents) about needs and capability but felt ACAT would not listen to myself.*

*Getting Mum reassessed was an absolute nightmare. They refused to do it because she had to speak with Mum, who said she was fine! It was organised, but all too late, Mum passed just two days later.*

Others, however, commended the assessors for dealing well with this situation:

*They were really lovely to my dad as he was not thinking he needed it, they coerced him beautifully.*

*My dad overstated his abilities, remembering how he coped before he had a stroke, and I was pleased my prompts were allowed by the team. My mum was graciously dealt with and laughed her way through the questions which obviously showed her dependency.*

One respondent suggested a solution for this issue:

*For my father, the assessors were great but my father lied through his teeth and I had to correct him constantly re his abilities. I would have liked a paper copy for me to fill in prior to their arrival and then they could have compared to his answers. Also, his ability to recall long-term is great but due to strokes affecting short-term and cognition it would have been effective for them to talk more about recent events etc to get a clearer picture of his true situation.*

Another said that seniors need to be assessed earlier:

*I have since strongly recommended to other families that they get ACAT assessments well before an emergency arises and use the respite system wherever possible. My father became a martyr by refusing advice and assistance so I warn others about that as well.*

### Issues for those with poor cognitive function

A few respondents said their parents performed better when the assessor was present, so the assessment misrepresented their abilities:

*Assessment process was never going to give an accurate view of our current situation. People with a mental illness are well able to perform for the short time an assessor is present and then revert to the usual inappropriate behaviour once the assessor has left the premises.*

*When my mother was assessed, she was not her normal self. Because she was very nervous, her blood pressure increased, improving the functioning of her brain. This happened whenever she was tested by a geriatrician or a neurologist also.*

Another respondent didn't think the assessor understood the ways in which poor cognitive function affect the assessment outcome:

*We had an ACAT assessment done for my mother which went well. I have heard since that the ACAT does not take mental capacity into account and that is a great concern. Both my mother and maternal aunt were physically fit - not frail - but their mental health was very problematic and that was where the help was required.*

For one respondent, the assessment led to a diagnosis:

*I discovered I had Dementia...*

### Family members are ignored

Some considered that more notice should be taken of family members:

*Family opinions were not taken into consideration at all in the decisions!!!!*

*Assessors failed to consider the information from family members who were the ones requesting the assessment in the first place. Very unsatisfactory process.*

Sometimes the issues occur due to family dynamics, situations in which family members disagree:

*I asked for my brother to have a second ACAT done as his GP said he could no longer care for himself and was no longer safe for him to drive. It was declined as my brother said he didn't want it.*

Another said that the schedule of family members should be taken into account:

*More consideration should be put in place for the contacting of full time working sons & daughters that cannot just answer a phone when need to on behalf of their parent.*

### Never heard of it/not interested

Many said they had never heard of RAS and ACAT. One thought assessment must only occur in city areas:

*First I have heard of it. I live in the regions this looks like a program for the City slickers.*

Others were not interested or hoping to avoid aged care altogether:

*I am not interested in aged care at all.*

*I hope to avoid this at all costs. If I need help I hope I can pay for it privately.*

### Aged care avoided by people who have worked in the sector

Another interesting response was by those who had worked in aged care:

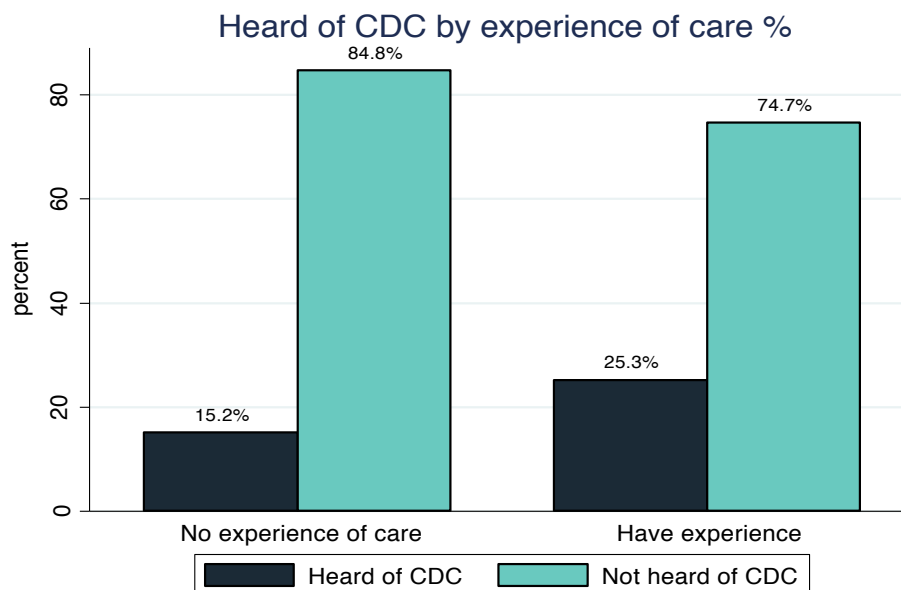
*I worked as a PCA, for 3 years, at different nursing homes, I know what happens and how some staff treat the residents that has put me off.*

*I worked in a nursing home years ago, I will never go to one, unless with dementia & family cannot cope.*

## 4. Understanding Consumer Directed Care

QUESTION: Have you heard of Consumer Directed Care?

Figure 8: Respondents who've heard of Consumer Directed Care (NSSS Wave 7, 2018; N~4250)



As shown in Figure 8, only 25 per cent of NSSS respondents with experiences of home care services had heard of CDC, and 15 per cent of those who had no experiences of aged care services delivered at home. There may be more who have experienced the increased choice options without being able to name the care system change.

Table 6: Profile of people who have and have not heard of CDC (NSSS 7, 2018)

	Yes	No	p-value
<b>gender</b>			<0.001
male	14.8	85.2	
female	27.0	73.0	
<b>age</b>			0.891
50-59	20.6	79.4	
60-69	21.8	78.2	
70-79	22.0	78.0	
80+	21.2	78.8	
<b>education</b>			<0.001
certificate	14.8	85.2	
diploma	19.9	80.1	
bachelor degree	19.9	80.1	

postgrad dip/cert	26.3	73.7	
Masters/PhD	34.8	65.2	
other	20.1	79.9	
<b>partnered</b>			<b>&lt;0.001</b>
living with partner	19.9	80.1	
living alone	24.8	75.2	
<b>children</b>			<b>0.258</b>
has children	21.4	78.6	
no children	23.2	76.8	
<b>health</b>			<b>0.192</b>
excellent	23.4	76.6	
good	21.9	78.1	
fair	20.2	79.8	
poor	16.5	83.5	
very poor	25.0	75.0	
<b>savings value</b>			<b>0.001</b>
less than 50K	18.3	81.7	
50-100K	23.1	76.9	
100-200K	23.7	76.3	
200-300K	23.6	76.4	
300-500K	24.0	76.0	
500-750K	27.1	72.9	
750K-1.5M	20.8	79.2	
>1.5M	23.0	77.0	
don't know	14.3	85.7	
rather not say	19.1	80.9	
<b>employment</b>			<b>0.002</b>
in paid work	25.0	75.0	
not in paid work	20.9	79.1	
<b>prepared to pay</b>			<b>&lt;0.001</b>
yes	23.3	76.7	
no	16.1	83.9	
<b>called call centre</b>			<b>&lt;0.001</b>
yes	33.7	66.3	
no	19.7	80.3	
<b>visited website</b>			<b>&lt;0.001</b>
yes	39.1	60.9	
no	14.6	85.4	

Women were more than twice as likely as men to have heard of Consumer Directed Care, as were people with higher levels of savings, however, this dropped in the very highest saving groups compared to the middle. There were no significant differences by age but there were for education level, a difference which wasn't observed on the previous questions. This is a subject of a chapter in a recent National Seniors report on home support and home care services, *Accentuating the Positive: Consumer experiences of aged care at home* (McCallum, Rees, & Maccora, 2018).

Consumer Directed Care (CDC) attracted some comments from respondents:

*I know what Consumer Directed Care is but the whole thing is so complicated, I feel like switching off.*

There was some knowledge amongst respondents that CDC means that the consumer can change providers:

*Consumer directed care is all well and good but really one can change providers and end up worse off – it all depends on the quality of staff of which there is insufficient. There is a large portion of staff in this industry that do this as a last option and don't have appropriate training and attitude.*

*I believe you change service providers. That is the only thing I know.*

*We're always being told that it's not easy to move from one care facility to another, as you already have a place!!!!*

One respondent was very sceptical about the intention of CDC:

*I think Consumer Directed Care is a marketing ploy which has, at its base, the intent of reducing Commonwealth expenditure on aged care. I believe that the Government is hoping that most people will not call for the support they require or deserve either because they are in denial, don't understand the system or think they are saving the Government money.*

Another regarded CDC as under-resourced:

*The government resources currently allocated to CDC are inadequate. The waiting time for packages is ridiculous, with some packages offered being below the level of care that has been assessed. One then has to wait for a provider that can accommodate the allocated package.*



A Registered Nurse said CDC was poorly understood by those working in the sector:

*Most staff and management do not understand or practice consumer directed care. I work 20 hours per week as a Registered Nurse at age 73. This is still a passion for me as it reduces risks, problems and enhances wellness.*

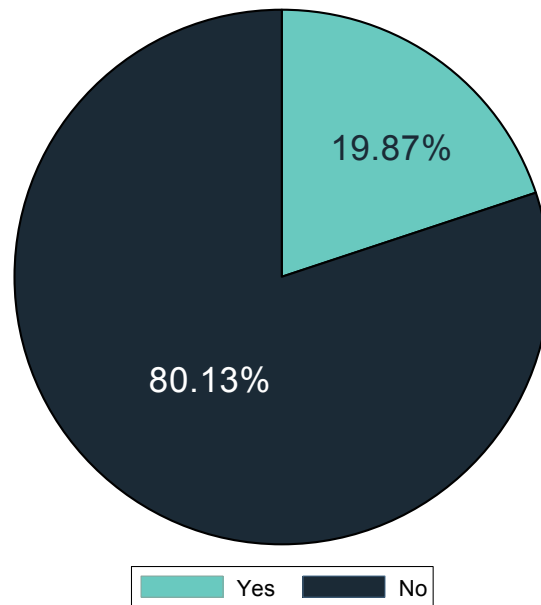
## 5. Understanding consumer contributions for aged care

---

QUESTION: Do you understand how consumer contributions for aged care are assessed?

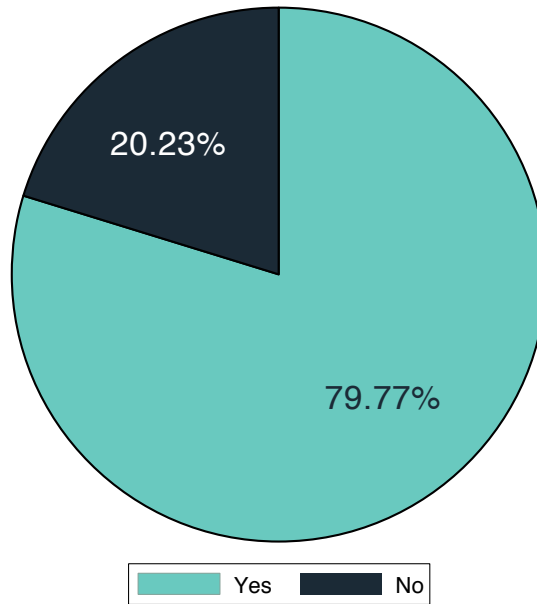
---

Figure 9: Assessment of aged care consumer contributions (%) (NSSS Wave 7, 2018; N=5083)



**QUESTION:** Are you prepared to pay for your own aged care in line with your capacity to pay?

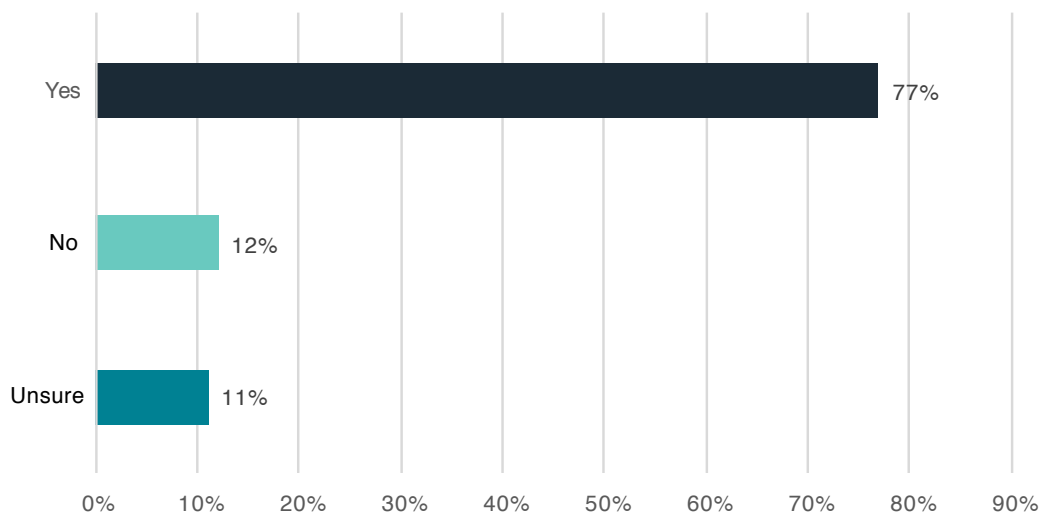
**Figure 10:** Willingness to pay for aged care (%) (NSSS Wave 7, 2018)



As can be seen by a comparison between Figures 10 from 2018 and 11 from 2016, National Seniors members consistently indicate they are prepared to pay for aged care in line with their capacity to pay. Unfortunately, as shown by Figure 9, most don't understand how consumer contributions are assessed.

**Figure 11:** Willingness to pay for aged care (%) (National Seniors member survey, 2016)

Do you agree with the principle that people should contribute to the cost of aged care if they have the means to do so, in line with their capacity to pay?



Some respondents commented on consumer contributions, saying it was difficult to work out:

*I have material on the way aged care costs are determined but it's hard to get one's head around the issues before the situation actually arises.*

One respondent said there was no choice about paying:

*I have said yes, I am happy to pay for aged care, because I do not have any choice, being a superannuation recipient and ineligible for aged pension or any of the associated benefits despite my superannuation pension being barely liveable for a single person.*

Many said it was not a fair system:

*Current means testing for aged care penalises people who've been careful and saved money during their working life. It doesn't seem fair for some to receive free aged care and others have to pay for care. It's not an equitable service for either home care or residential aged care.*

*I feel that the system is not fair. If I am not on a welfare pension, the bulk of aged care payment plus more falls on me. Some of those on the pension do not pay anything extra. So those on government pension pay nothing but those who have worked hard and saved and live independently are asked to pay certain percentage more. As I save the Federal Government \$24,000 in pension, why am I expected to pay additional? The Government should in fact give me a discount as I save them the welfare pension. I am happy to pay my share but not unduly more. The extra co-contribution that I made caused financial hardship.*

*I would reluctantly pay for age care services. I don't receive a pension so I would not like to subsidise the Government further.*

*While I am prepared to pay for my own aged care when it's needed, I object to subsidising sections of the community. I have worked hard during my life and saved for my retirement because we were told there wouldn't be much of a pension by the time we reached retirement age. Self-funded retirees should be given some breaks when it comes to having to pay exorbitant fees for aged care.*

Some respondents took exception to the question, wanting “capacity to pay” defined:

*Depends on how they define ‘capacity’. I would be prepared to contribute but would not want all my savings to be eaten up by my aged care costs. At the moment, the Government policies work on the premise of you dying penniless.*

*What in hell does this mean? Who judges the capacity to pay? Are we prepared to make a co-payment? Absolutely.*

*What do you mean by capacity to pay? This is a loaded question. The expectation of capacity to pay may be too high. Need more detail.*

A few respondents said the assets test was unfair for some:

*The assets test seems very onerous, particularly for small business owners such as family farms.*

*The cost of entering aged care for those with assets is horrific. It is not fair that those who have been frugal and careful in life lose their house and a lot of their savings.*

*I had been prepared to pay for as much of my own care as possible when the time comes however since the Government lowered the Assets threshold in Jan 2017 I am afraid I will not have nearly enough in the ‘kitty’. The reality is that SINGLE people need almost as much as COUPLES to live and this is something that is never discussed.*

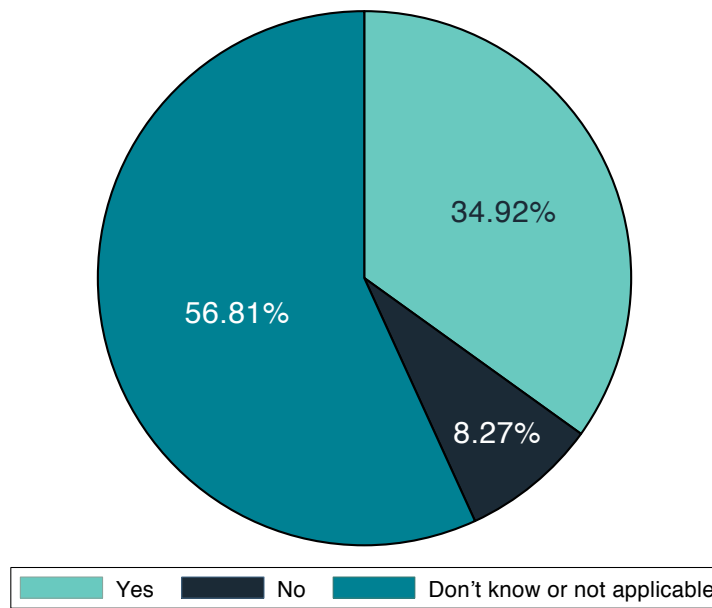
Another said that the process of working out contributions was difficult:

*The process of getting my Father through the Asset Testing and finalising this process was exhausting, costly and very time consuming.*

## 6. Understanding complaints processes

**QUESTION:** Do you feel that there are options available to you for making a complaint if you are not happy with your aged care?

**Figure 12:** Understanding how to make complaints (%) (NSSS Wave 7, 2018; N=5089)



Given the extensive comments on complaints processes, these are reported here across several themes, as follows.

### No need to complain

One respondent said the need to complain never arose:

*In my mother's case when she was at her nursing home for approx. 5 years, not once did we have any need to complain.*

### Yes, aware of complaints channels

Some respondents had already used a range of channels to make complaints, or worked in the sector and understood what to do:

*Have already complained to assessor/provider/aged-care Canberra.*

*I write frequent feedback forms regarding my brother's nursing home experiences and needs. I also send emails to the senior staff as appropriate.*

*I knew which Government departments to complain to when my mother had issues with her medication availability and when she went into care. I will certainly make use of that avenue if and when I may need to for my own care, if I still have capacity. If not my EPA will be set up and they will make representations on my behalf.*

*After working in the system, I have a good idea how it all works.*

One described how to contact the Commissioner:

*There are avenues available on the Commonwealth Department of Health website that direct you how to make a complaint about the level of care provided at an aged care facility e.g. the Aged Care Complaints Commissioner.*

A few said they were confident in their ability to find out how to complain:

*When the time comes, if I end up in aged care and retain my mental agility, I should be able to research and act upon any need to make a complaint if needed.*

### Family would help if needed

Some respondents were confident that family members would help them with advocacy:

*My family live nearby and would advocate if needed.*

### Complaints were resolved

Some mentioned that complaining to providers had worked for them:

*The nursing home has been very understanding and responsive.*

*Have already submitted complaints to management & had them efficiently dealt with.*

Others had successfully taken their complaints further:

*I contacted an aged care complaints service regarding an issue with an appropriate bed-chair for my mother & was given advice which resolved the issue.*

*My mother was treated very badly in aged care facility. We took the case to Human Services and eventually the person was dismissed and lost their aged care licence.*

*We have had to make a complaint to the Aged Care Complaints Commissioner about the care our mother was receiving in a residential aged care facility. For months we were fobbed off - not once were we told about the complaints system or about access to an advocate. When we did make a complaint to the Commissioner & got an advocate involved, the complaint was very quickly rectified.*

### Complaints ignored

A range of responses indicated complaints were ignored, for example they were not taken seriously, rarely reach their destination, were not properly listened to, were to no avail, and nothing was done:

*It has got me nowhere.*

*I have tried in the past without luck.*

*In my mother's case, I/my husband made complaints but nothing changed over several months.*

*It is usually not acted upon!*

*No one is interested.*

*Complaints go down a very deep government hole.*

One respondent blamed understaffing:

*I have friends who had a parent in aged care, and they felt that their complaints were not attended to properly. The main problem, of course, is lack of staff numbers to properly care for people in nursing homes. The number of staff needs to be doubled. It is even worse on weekends.*

Another said their family member had passed away after complaints were ignored:

*Tried with my father's dreadful level of care. No one cared and nothing was improved. He died due to injuries sustained in an aged care facility.*

Another was asked to find another provider:

*When I complained about my mother's care (she had dementia and was in a locked ward) I was told that I had to find a new residential care facility. She had walked out of a locked ward (followed visitors out) and was found at a bus stop a few streets away and the home did nothing so I complained.*

### Doubtful it will help

Many were sceptical about complaints being heard:

*But doubt the efficiency and speed of the system.*

*But I am not sure as to how reliable or effective those options are.*

*But not sure they will be acted on.*

*Complaining only creates an extra hassle and more stress.*

*Better to cancel the service.*

Others pointed out that the elderly are not empowered consumers:

*I'm not convinced consumers are empowered to do this or that the complaint would be followed up in a timely and effective manner.*

*Ineffective as the resident is powerless to move.*

*The problem with making complaints is that the most vulnerable are least able to complain.*

### Unsure how to complain

While many said they weren't sure how to complain, some also believed that frequent changes made it more complex, and others said complaint channels weren't explained to them:

*I am not aware of options, and with the frequent changes of legislation and policy, I think that I may as well wait until it looks like I need some help before investigating it further.*

*Have had major issues with care provider, not told of avenue for complaint.*

*No option to complain was offered to us.*

### Need help to complain

Many said they had no family members to advocate for them, making it particularly difficult to deal with issues when they arose:

*Having to deal with what is an aged care mine field alone is a night mare.*

*I do not like to make a fuss. I do not want to put anything in writing. Fortunately, I still live at home, in the community. I complain rarely, as the service is so good. If I was in residential care I would feel more vulnerable, as I do not have anyone to "bat" for me.*



*I think people who use aged care do not have the ability to complain for themselves and rely on relatives. If they have no children to complain on their behalf this is an issue.*

Some recognised that cognitive decline with make help essential:

*I will probably be able to “vote with my feet” if I am paying for services. But that assumes I retain mental capacity.*

*Think it would be very difficult to complain if you had dementia or some other disease.*

### Complaining is a fraught process

The fear of retribution or repercussions was expressed again and again, for example, by saying complaints have consequences or reprisals, care will be diminished, and frail older people are afraid to “upset the apple cart” or “stir the waters”, which would create a more stressful situation for them:

*If you make a complaint about what you get, guess what you then get?*

*Aged care inhabitants are too afraid to say anything for fear of repercussions. It’s never a confidential process.*

*As a registered nurse when I was working in Aged Care there were many options available to the residents and family members for making a complaint if they were not happy. Many were reluctant to do so as concerned they would be treated badly.*

*Complaints tend to be ignored/glossed over, some people can tend to be nasty following complaints.*

*There are reprisals if a complaint is made.*

*I had complaints about my aunt’s care but felt if I spoke up it would be detrimental to her in my absence. She had dementia and the administration staff played on that.*

*I ran the Residents Rights in Nursing Homes and Hostels Program for the Department of Human Services plus performed Standards Monitoring. There is lip service for making complaints but nobody will dare because the client can receive retribution when nobody is around.*

*I know there are moles in the Dept of Health and Ageing. Any complaints will probably be met with some kind of persecution. I am basing this opinion on what happened to my mother when I complained about various problems in the corporate aged care centre where she was a resident.*

Certainly, being powerless to complain made residential aged care unappealing:

*I have heard that residents are at the mercy of the operators, and have very few avenues for complaint. Going into care would be a last resort as it would be too upsetting seeing others neglected or abused, treated unfairly - and being powerless to get fair treatment for ourselves.*

Some residents ask their family members not to complain:

*I know that my mother is very reluctant to allow me to complain on her behalf or complain herself, she lives in fear that this will come back at her and she will be set upon, stolen from, mistreated, or not get the services any more.*

The dependence created by needing care makes people vulnerable:

*Older people rarely complain, they try to please their carers because they are dependent on them.*

One respondent said this situation created the need for unannounced visits, something announced by the Government in 2017:

*Anecdotal evidence is that aged care residents are not able to make any complaints without negative repercussions on them! I think aged care homes need to have more inspections without notice. I think many residents are treated somewhat poorly, especially re poor quality and quantity food.*

### It's a tick-box exercise

The perfunctory nature of dealing with a complaint was described in various ways, including the following:

*Anytime I contacted I had to deal with a new person, there appeared to be little continuity and all they cared about was "ticking boxes" and covering their own backside.*

*I am aware that, there are channels available to make a complaint, but it is not availability, it is the lack of concern or understanding that one is faced with when you exercise one's rights to make a complaint.*

*Having complained to the support service that provided care to my mother, I am acutely aware that they have an obligation to respond (and did so politely and carefully), but although they changed the worker who attended my mother, they could not meet consumer needs because the service they provided was incapable of providing the skilled staff required for the interventions that my mother required.*

### Providers ignore complaints but should deal with them

Some respondents criticised providers for not dealing adequately with complaints:

*Alzheimer nursing home for my wife for last 6 years. I made suggestions about safety matters and it was suggested that I take my wife to another nursing home. Prior to starting my company in 1976 I had 31 years in senior management in Australian & Canadian companies and am a safety expert so my suggestions were not trivial.*

*Aged care providers need to deal constructively with all complaints, with quick acknowledgement and resolution.*

Others said the prospect of taking it further was unappealing:

*Any complaint is dismissed by the service provider and to take it to the next level is a bureaucratic nightmare designed to discourage anyone from taking it further.*

*Again, if there is a problem off to different departments we go and I'm not going to go through any of that.*

One respondent suggested mandatory display of the Code of Conduct:

*The Code of Conduct for non-registered health carers is not required to be displayed in aged care residential facilities. This is the very place where display should be mandatory.*

Again, understaffing was blamed for lack of provider action:

*When I telephoned the administration of the organisation she understood the situation but said she was having trouble finding suitable staff.*

*My mother has been in a home for six years and I have watched the level of care decline over this time and they have drastically cut staff.*

### Complaints processes seem under-resourced or non-existent

Many said they'd found complaint channels ineffective:

*How! You sit on the phone for (typically) an hour so using that channel is not good. There needs to be more channels to give feedback - good and not so.*

*I have found internal complaint processes for residential aged care are rudimentary and not sincere obtaining the real picture (which often takes some time to understand due to high emotion of complainer).*

*There are options but it is largely ineffective and poorly resourced.*

Another said they are almost non-existent:

*As NOK for an elderly relative living in a High Care facility in NSW I am appalled at what our supposedly "caring" Multi-National companies are getting away with. The complaints system in NSW is virtually non-existent.*

### Getting complaints heard was difficult

People often feel overwhelmed about finding a solution:

*I have experienced problems in aged care for 2 aged care family members. I felt overwhelmed with problems in the system at the time and simply had to deal with them and find the best solution.*

Complaining is regarded as time-consuming and difficult:

*I understand /understood there is/was a complaints process in place but at the time, I was so busy meeting my responsibilities. Making a complaint is a lengthy process, often one must tell one's story to many different people.*

Some are not listened to for legal reasons:

*I lodged a complaint about treatment of friend in Aged Care and they weren't able to help because of Power of Attorney restrictions.*

Many avenues are considered in getting complaints heard:

*I even went to politicians about the terrible care given my mother. Luckily, I owed the home a small amount of money, finally used this to get somewhat of a hearing after fighting them for nearly 4 years.*

### Cynicism

A range of cynical comments about complaining were received:

*It probably would get lost in the fabulous Computer System.*

*It's all lip service. A lot of paper work, a lot of comforting meaningless words.*

*We are from the government and we are here to help ha ha ha!*

### Worried about having to access aged care

Many respondents used the text box comment area for the complaints question to express their anxiety over the prospect of needing aged care, some in the extreme, saying they would rather die or would commit suicide to avoid it:

*Even though I am on the pension I will not sell my house to go into age care facilities. I would rather die i.e. not take my medication.*

*I have little knowledge of the options and would prefer suicide to accessing assistance. Why isn't this readily available to anyone of any age as it should be?*

*The system is overwhelmed. Quite frankly if I get to needing aged care, the only option I would see is suicide.*

*From what we have seen of aged care facilities it is the last place you would want to end your life. Hopefully the assisted dying debate will give people the choice to exit before it becomes necessary to enter an aged care facility.*

*I have seen and look after relatives in the homes. I have a pill that will kill me before [hopefully] it gets to that. I have no intention of ending up in one of those places. I don't fear death, I'm an atheist.*

One respondent considered her father lucky to have died before having to go into a facility:

*I am quite distressed by what I hear in the media about the conditions in care facilities. The facility in which my mother died left a lot to be desired and I see no sign that things have improved in the 15 years since. My father was determined never to be sent to one and luckily died before he got there.*

### Calls for government action

Some respondents considered the government to be at fault in various ways:

*From what I have read in the press Govt's Fed and State are culpable here.*

*There is a long waiting list for people on lower levels of care. The waiting list Australia wide I believe from news reports 44,000. This successful programme is in need of further government funding.*

*Governments are abrogating a responsibility to look after the vulnerable elderly by outsourcing care to greedy private often corporate operators.*

*It is like a dog's mess to me. Too many "cooks" come and see you then no action. Typical public servants.*

One called on more government action:

*Ageing in our society is at the mercy of private enterprise. I would like this statement debated in federal parliament.*

Many respondents made suggestions about what should be done:

*The complaints scheme is hindered by useless standards in aged care, e.g. no staffing levels or skill mix ratios. RN and other AHPs are not made accountable to their regulatory body. Until this happens, complaints will not be reduced or actioned properly.*

*Visits to check for adherence to guidelines and accreditation at aged care facilities should be unannounced and at any time within a 24-hour day. Community visitors should be able to contact random relatives or NOK about their perceptions of the care facility.*

One respondent accused regulatory bodies of caring more about providers than consumers:

*These have been accessed however they are generally unsatisfactory. It is our experience that the various bodies are all about keeping a good relationship with the provider rather than having the person in trouble advocated for appropriately.*

Another respondent, however, considered governments responsive:

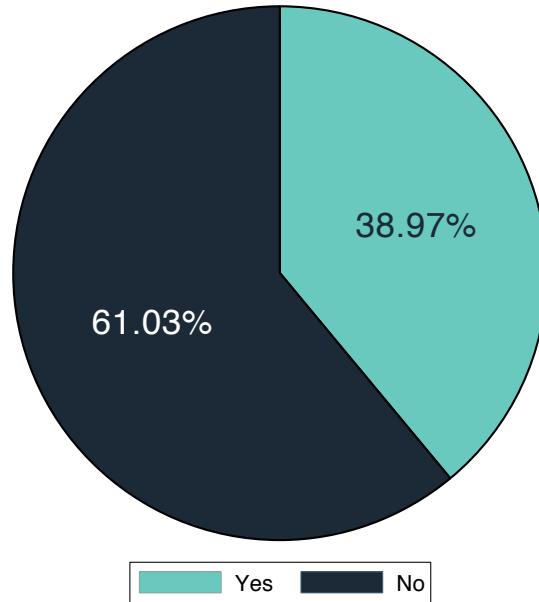
*Writing to Ministers and heads of Departments tends to get results.*

---

Have you heard of the Aged Care Complaints Commissioner?

---

Figure 13: Knowledge of the Aged Care Complaints Commissioner (%) (NSSS Wave 7, 2018; N=5081)



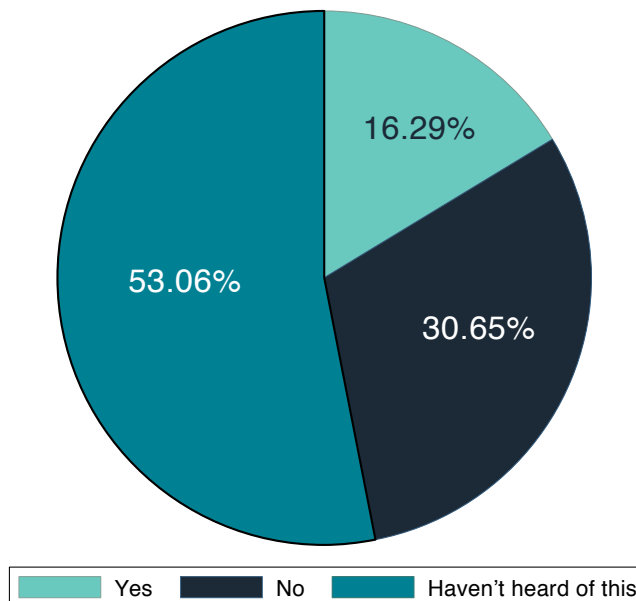
While there was rich articulation of complaints in text comments, only 4 out of 10 had heard of the Commissioner.

---

QUESTION: Do you understand the role of the Australian Aged Care Quality Agency?

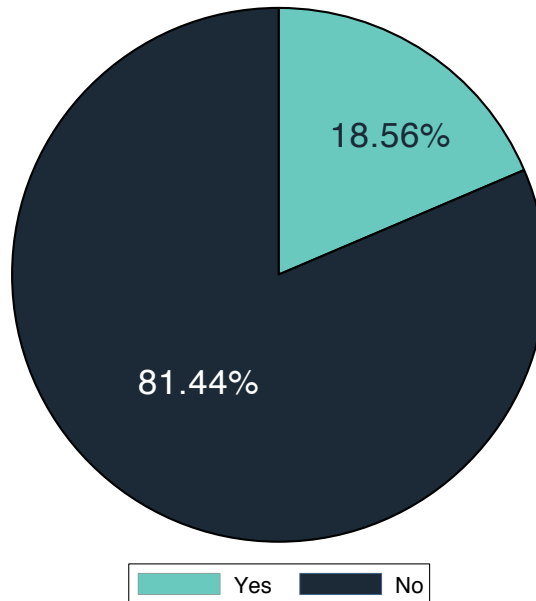
---

Figure 14: Understanding of the Australian Aged Care Quality Agency (%) (NSSS Wave 7, 2018; N=5100)



**QUESTION: Have you heard of the Charter of Care Recipients' Rights and Responsibilities for Home Care?**

**Figure 15: Knowledge of the Charter of Care Recipients' Rights and Responsibilities (%) (NSSS Wave 7, 2018; N=5076)**



A few respondents found out a lot by doing the survey for this study:

*From questionnaire I realise that I am ill-informed about the agencies available for seniors.*

*I am a lawyer and deal with elderly clients all the time and I haven't heard of any of the above????? It is not out there for solicitor's knowledge and we deal with these issues.*

Respondents may be more aware of the issues than the titles of agencies, which could be discovered when needed.

In summary the awareness of the Complaints Commissioner was the highest at 4 out of 10 and this dropped to below 2 out of 10 for the Charter and the Aged Care Quality Commissioner. Given that these two Commissions are being merged through 2019, the issues raised here will carry forward to the new Aged Care Quality and Safety Commission.



## DISCUSSION

This assessment of the state of aged care service literacy in Australia provides evidence of a range of issues and suggests some as items for action. While digital literacy interacts closely with aged care literacy, it will be dealt with more fully in a separate report.

### Some observations overall

Looking across specific items, it was a consistent finding that having children had no significant relationship with actions or knowledge related to service literacy. This was also observed in parts of the recent work on home care services (McCallum, Rees, & Maccora, 2018). It is possibly a characteristic of advanced economies that while children are information providers and advisors for aged care, the system can be used by older people whether they have children or not, and whether or not children decide to help them. It is designed for independence. It is very different situation in new and emerging communities who have an expectation that care will be provided by family at home even for very high need elders (Rees & McCallum, 2018).

Text comments from respondents revealed that people are drawn to the My Aged Care website after seeing promotional advertising. There is then a question about how best to approach families and communities to improve service literacy. Women were twice as likely as men to have looked at the My Aged Care website, called the call centre, or to have heard of Consumer Directed Care. This may be the result of women taking and maintaining responsibility for health and caring roles. This raises questions about the best way to target messages to increase interest in My Aged Care. Would it be to men, who apparently have less understanding of the aged care sector, or to women on the assumption that they are the intermediaries for care information? The latter option would accentuate a feminisation of care which may not fit forthcoming cohorts. It does indicate the need for more carefully targeted messaging in an aged care awareness-raising campaign.

### Digital literacy as the gateway to aged care

Despite the negative reactions of some older Australians to using My Aged Care, digital literacy is undeniably the gateway to service literacy and will become progressively more so. The digital literacy component of the NSSS (Wave 7) provides evidence on senior digital literacy, with many older Australians being impressively capable in using digital devices and accessing digital services. However, low levels of digital literacy and access are known and acknowledged amongst seniors and, hence, many complaints were received about the requirement to go online to access services.

Digital literacy is covered in other National Seniors reports, and we are continuing to work in this area, with a forthcoming report to be released this year presenting a new senior digital literacy score, "The Senior Surfer". This score will be used to analyse the attitudes of older Australians about the use of digital devices and services.

### My Aged Care usability

If the first barrier to improved service literacy is low digital literacy, then the next barriers are the entry point and user experience of the My Aged Care gateway. If initial access is an issue for consumers, this negative experience is known to carry through to affect continuing contact through the website and other channels.

Consumer comments were clear on this issue, expressing disappointment and frustration that government websites in general were so difficult to navigate and interact with. This is a particularly sensitive issue for older consumers with physical or cognitive impairments. These are the people who are most in need of the services offered at My Aged Care but the least able to profit from them due to the inaccessible nature of the online offering. As usability engineer Jakob Nielsen has commented:

*On the Web, usability is a necessary condition for survival. If a website is difficult to use, people leave. If the homepage fails to clearly state what a company offers and what users can do on the site, people leave. If users get lost on a website, they leave. If a website's information is hard to read or doesn't answer users' key questions, they leave. Note a pattern here? (Nielsen, 2012).*

Nielsen's point about 'survival' is especially salient in the context of My Aged Care, which is not a company website, but a government service offering that is directly related to the wellbeing of our older population in Australia.

The use of bureaucratic concepts such as "assessed", "approved", "granted" and "assigned" (p19) is unhelpful to navigating through the site and enhancing the experience on it. Generally, cultures of feedback and continuous improvement are needed across the aged care sector information sources because both usability and experience on the site are not good.

In July, the Government announced a \$61.7 million revamp of the My Aged Care portal to make access easier (Commonwealth of Australia, 2018).

## Complaints and Quality Commissions

Consumer feedback through quality and complaints systems is a key to problem solving and service improvement. Despite the national centralisation of quality issues and complaints, the focus of consumers remains local and facility or service provider focused. In this study, only 39 per cent had heard of the Complaints Commissioner, 19 per cent the Charter of Rights, and 16 per cent of the Aged Care Quality Agency. When National Seniors members were asked whether they'd heard of these agencies in preparatory forum discussions for the survey, they responded by referring to the absence of a State Minister for Ageing.

***You were also asking about Pricing and Complaints Commissioners. Our State doesn't have someone representing Seniors in its ministry. We used to, but they cut it out.***

These matters are first and foremost community and local issues for people, rather than ones they expect to escalate to national and government agencies. This raises the issue of better industry self-regulation.

The 2016-17 Annual Report from the Aged Care Complaints Commissioner reported a 20 per cent increase in the number of complaints from the previous year, seen as evidence that more people now know the Commissioner exists. While more than one million people are receiving aged care in Australia, the Commissioner dealt with only 4,713 complaints (Commonwealth of Australia). Despite the prevalence of complaints being proportionally low (even considering under-reporting), they remain

a lively area for wider community discussion and a strong barrier to more positive attitudes to aged care services. Negative experiences of aged care services have received widespread media attention, which has rightly been essential in driving industry change. There is, however, a need to create greater confidence in the process of making a complaint, and these issues will pass on to the new Aged Care Quality and Safety Commission. Concerns about complaints handling came through clearly in this research, with fear of retribution from residential care staff being the most prominent problem that emerged. The evidence suggests that consumers of aged care are not advised about complaints processes and simply do not know how to go about it.

## An industry code?

A voluntary, self-regulatory industry code, typical of many industry groups, was recommended by the Aged Care Workforce Strategy Taskforce (Australian Government Department of Health, 2018). It is currently a fragmented industry and bringing it together will be a major task. An industry code could become a useful support for regulatory watchdogs and oblige signatories to follow best practice. It would offer an increased level of responsibility and local accountability for complaints and quality issues. As an emerging industry, aged care also needs to plot its own purposes and future from grassroots consumer experiences.

## Literacy among the professionals and care workers

A specific issue, indicating a failure in skill and performance of professionals, came through strongly here, namely the frustration of families not being recognised in assessment processes. This led to inappropriate and, occasionally, dangerous consequences of assessment because of the older person's inaccurate reporting of their health being taken as fact by the assessors. Families describe it here as their elders playing the "martyr" or "telling big lies" to present a brave face. Communication and professionalism of care professionals and workers is already known to be a key factor in health literacy and it is also true for aged care. The previous report on home care indicated that care providers needed to bring active problem solving and creativity into their work to get the most out of consumer directed care (McCallum, Rees and Maccora 2018). This indicates a need for an improved focus on training both in training establishments and in-house. Improvements in providers' skill and communications are fundamental to improving consumer literacy.

Core communication and care planning practices also need better staff training to improve consumer service literacy. This was a major topic in our recent report (McCallum, Rees, & Maccora, 2018). This will necessarily be dealt with at the organisational level and with guidance from the new Aged Services Industry Reference Committee. As the title, 'You don't know what you don't know' suggests, people won't know what to look for if they're not told what's available or if it isn't explained simply and clearly.

## Consumer willingness to pay

Many of the issues needing attention observed here will be accentuated as growth strains funding capacity of the Government. In the 2018-19 budget 20,000 new home care places were funded. While this is a major budget item, as of 31 March 2018, there were over 100,000 people approved for home care on the national queue. Of these, over 54,000 were in a package but waiting for a higher level of

care, and over 53,000 were waiting for a package to be assigned (Australian Government & AIHW, 2018). The constraints on funding are real, from competing budget pressures, which include funding the NDIS, and from workforce limitations. It is difficult to create a trained workforce for 20,000 new places let alone many more. It is also clear that the wages of aged care workers will need to increase with demand and become more competitive.

It is worth noting, then, that 80 per cent of respondents to this survey are prepared to pay for services within their means, but the same number, 80 per cent, don't understand consumer contributions. In a previous 2016 survey, 77 per cent of respondents agreed that they were prepared to pay within their means. In a related development, Treasury, Finance and Social Services Departments are undertaking major reforms of the Retirement Income Systems, in particular, relating to Comprehensive Income Products for Retirement (CIPRs). These take the form of annuities or deferred annuities which enable income to be available across longer lifespans. Older Australians consistently indicate that they want a 'retirement wage', as consistent income across their whole life span. Given that the current superannuation accounts are tax-advantaged deferred wages, it is unacceptable that many retirees live 'mean' through retirement because they can't manage risk well but die with substantial savings. The observation is that, as CIPRs come into place, there needs to be parallel development of the coherence and reasonableness of consumer contributions for aged care, which many consumers currently experience as being unfair.

In 2016, the Aged Care Sector Committee produced the Aged Care Roadmap, which says that:

*Increased consumer choice will be a major change into the future. A fiscally sustainable aged care system that requires consumers to contribute to their care costs where they can afford to do so means that there will be increased consumer expectations for greater choice and control. The ability for consumers to choose who provides care and support will create a more competitive and innovative market (Aged Care Sector Committee, 2011).*

This consumer support and expectation needs to be complemented by clearer protocols for consumer contributions as well a more vibrant private market which Consumer Directed Care is already making a contribution to.

## More positive attitudes to aged care services

Finally, due to continuing bad press, the most underachieved goal of the Aged Care Services Roadmap is the target to create more positive attitudes to aged care services:

*Promote positive societal attitudes about aged care and the benefits of talking about and planning for aged care (Aged Care Sector Committee, 2011).*

It is not a generally held view of Australians of all ages that aged care services will enhance your life. Whilst a significant majority of experiences are good or at least satisfactory, the impact of the worst cases taints the whole aged care service industry. This is also an argument for an industry code. The negative stigma for residential care does not attach to home care (McCallum, Rees, & Maccora, 2018).

Until people feel better about aged care it will remain difficult to encourage the development of service literacy. Given that the negativity arises predominantly from residential care cases, the evidence shows that home care has a generally positive consumer response. Improving access to information and services that are expected to enhance life will potentially improve as more services proportionally are moved into the home. To retain this positivity more attention will need to be given to support, training and respite as more high-level care is provided at home. Connecting to and learning from initiatives in health service literacy such as integrated primary care trials and improving the attention and time given to service communications will also help. There are then many factors affecting Australians' aged care service literacy and it remains a 'work in progress' as these factors are addressed. Active interventions are needed to encourage consumers to have a more interested and detailed knowledge of aged care service types and quality, which is the target of the Aged Care Roadmap.

## CONCLUSION

---

Longevity is increasing and with the baby boomer generation entering retirement, the number of people accessing the aged care sector is rising rapidly, and pressure on the Government to provide and fund the sector is intensifying. Facilitating digital access of services is a current focus of Australian government departments, a necessity for the sake of efficiency and a reasonable aim in a digital age, but a disadvantage for those with lower digital literacy.

National Seniors has previously reported on the digital divide (McCallum, Rees, & Maccora, 2017) and how senior Australians access information (Rees & McCallum, 2018), as well as conducting prior studies of aged care (McCallum & Rees, 2017) (McCallum, Rees, & Maccora, 2018). Information-seeking behaviours and digital literacy affect the access of aged care services. However, in a system experiencing continual change and emerging disruptions it isn't an easy task to be a 'literate' consumer as one might be as a shopper. This must start with professionals and other providers being knowledgeable themselves and communicating clearly and sometimes with creativity on options available.

The findings for this study provide evidence that many Australians over 50 will be caught off-guard by the need to access the aged care sector. The majority of people have very limited aged care literacy indicated by having never viewed the My Aged Care website or called the call centre, having never heard of Consumer Directed Care, not understanding how consumer contributions are assessed, having not heard of the Aged Care Complaints Commissioner or the Aged Care Quality Agency, and not knowing that there are Charters of Rights for aged care.

After experiencing the aged care sector, one of the main issues is the feeling that complaining about services will lead to retribution. Many who've worked in the sector vow to never use its services if they can avoid it. Home care generally escapes this negativity, and it needs to be nurtured as it grows, particularly as it takes more highly dependent people into the services and homes where they are delivered.

The good news is that when people do access the website or call centre, most find what they're looking for or are satisfactorily assisted by My Aged Care staff, however, satisfaction with assessment processes is mixed. National Seniors' members consistently say they are prepared to contribute to the costs of their care but there is a need for greater understanding about exactly what this means.

Changing the current negative view of aged care would be assisted by ease of entry into the sector, via the application and assessment processes. There is a clear need to increase the aged care literacy of this cohort, to improve the usability of the My Aged Care website, and to educate senior Australians on what they can expect to pay for their aged care so that adequate financial planning can be undertaken. Encouraging more positive views of this life stage is also essential.

The succinct comment of a respondent sums this up:

***The main problem with age services, you don't know what you don't know. When a problem comes up, one is not too sure of where or how to obtain the right information.***

This is simple but often forgotten by busy service providers.

## REFERENCES

---

- ABS. (2008, January 9). 4228.0 - *Adult Literacy and Life Skills Survey, Summary Results, Australia 2006*. Retrieved from Australian Bureau of Statistics: [http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4228.0Main+Features12006%20\(Reissue\)](http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4228.0Main+Features12006%20(Reissue))
- ABS. (2008, June 25). 4233.0 - *Health Literacy, Australia 2006*. Retrieved from Australian Bureau of Statistics: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/mf/4233.0>
- ACIITC. (2017). *A Technology Roadmap for the Australian Aged Care Sector*. Adelaide: Aged Care Industry Information Technology Council.
- Aged Care Sector Committee. (2011). *Aged Care Roadmap*. Canberra: Commonwealth of Australia Department of Health.
- Australian Government Department of Health. (2017). *2016-17 Report on the Operation of the Aged Care Act 1997*. Canberra: Commonwealth of Australia.
- Australian Government Department of Health. (2018). *A Matter of Care: Australia's Aged Care Workforce Strategy, Aged Care Workforce Strategy Taskforce*. Canberra: Commonwealth of Australia.
- Australian Government. (2018). Retrieved from Australian Aged Care Quality Agency: <https://www.aacqa.gov.au/>
- Australian Government and Good Things Foundation. (2018). Retrieved from Be Connected: Every Australian online: <https://www.beconnectednetwork.org.au/>
- Commonwealth of Australia. (2018). Retrieved from Aged Care Complaints Commissioner: <https://www.agedcarecomplaints.gov.au/internet/accc/publishing.nsf/Content/Home>
- Commonwealth of Australia Department of Health. (2017, September 19). *Charter of Care Recipients' Rights and Responsibilities - Home Care*. Retrieved from Ageing and Aged Care: <https://agedcare.health.gov.au/publications-and-articles/guides-advice-and-policies/charter-of-care-recipients-rights-and-responsibilities-home-care>
- Good Things Foundation. (2018). *Our Network*. Retrieved from Be Connected: Every Australian Online: <https://www.beconnectednetwork.org.au/be-connected-network>
- McCallum, J., & Rees, K. (2017). *Consumer Directed Care in Australia: Early stage analysis and future directions*. Brisbane: National Seniors.
- McCallum, J., Rees, K., & Maccora, J. (2017). *Bridging the Digital Divide*. Brisbane: National Seniors.
- McCallum, J., Rees, K., & Maccora, J. (2018). *Accentuating the positive: Consumer experiences of aged care at home*. Brisbane: National Seniors.
- Nielson, J. (2012, January 4). *Useability 101: Introduction to Useability*. Retrieved from Nielson Norman Group: <https://www.nngroup.com/articles/usability-101-introduction-to-usability/>
- Office of the eSafety Commissioner. (2018). *Understanding Digital Behaviours of Older Australians*. Subiaco: Ipsos Pty Ltd.
- Park, S. (2017). *Digital Capital*. Palgrave Macmillan.

## NATIONAL SENIORS AUSTRALIA

- Rees, K., & McCallum, J. (2018). *A Little Help from My Friends: getting good advice in the Information Age*. Brisbane: National Seniors.
- Rees, K., & McCallum, J. (2018). *Dealing with Diversity: Aged care services for new and emerging communities*. Brisbane: National Seniors.
- Rees, K., McCallum, J., & Cantwell, J. (2017). *Be Heard: Snapshots of members' views*. Brisbane: National Seniors.
- Thompson, K. M., & Azfal, W. (2011). *A Look at Information Access through Physical, Intellectual, and Socio-cultural Lenses*. OMNES: The Journal of Multicultural Society, 2(2), 22-42.



## CURRENT PUBLICATIONS

---

- McCallum, J. & Rees, K. (2017) *Consumer Directed Care in Australia: Early stage analysis and future directions*. Brisbane: National Seniors. (35 pages) published 18/8/17.
- McCallum, J. & Rees, K. (2017) 'Silver Economy' Consumer Co-design: An Australian Perspective. In *Innovation in Active, Healthy and Smart Ageing Sector* edited by Guangsheng Guo and Jianbing Liu: Beijing Science & Technology Publishing Press 2017 pp 273-283, published 12/9/17.
- National Seniors and Challenger (2017) *Seniors More Savvy about Retirement Income*. Brisbane: National Seniors. (19 pages) published 3/10/17.
- Lamont, A. & Sargent-Cox, K. (2017) *Healthy Ageing: The State of the Evidence and available resources*. Brisbane: National Seniors. (51 pages) published 12/10/17.
- Rees, K., McCallum, J. & Cantwell, J. (2017) *Be Heard: Snapshots of members' views – A report to members from the CEO*. Brisbane: National Seniors. (39 pages) published 2/11/17.
- Earl, J.K., Gerrans, P. and Hunter, M. (2017) *Better ways of assessing cognitive health*. Brisbane: National Seniors. (55 pages) published 9/11/17.
- Rees, K. & McCallum, J. (2017). *Downsizing: Movers, planners, stayers*. Brisbane: National Seniors. (21 pages) published 27/11/17.
- McCallum, J. & Rees, K. (2017). *Growing older, feeling younger*. Brisbane: National Seniors. (24 pages) published 5/12/17.
- McCallum, J., Rees, K. & Maccora, J. (2017). *Bridging the Digital Divide*. Brisbane: National Seniors. (35 pages) published 14/12/17.
- Rees, K. & McCallum, J. (2017). *A Little Help from My Friends: Getting good advice in the Information Age*. Brisbane: National Seniors. (35 pages) published 18/1/18.
- McCallum, J., Maccora, J. & Rees, K. (2018). *Hope for the best, plan for the worst? Insights into our planning for longer life*. Brisbane: National Seniors. (27 pages) published 1/2/18.
- McCallum, J., Rees, K. & Maccora, J. (2018). *Accentuating the positive: Consumer experiences of aged care at home*. Brisbane: National Seniors. (87 pages) published 30/4/18.
- National Seniors & Challenger (2018). *Once bitten twice shy: GFC concerns linger for older Australians*. Brisbane: National Seniors. (31 pages) published 9/7/18.
- Rees, K., & McCallum, J. (2018). *Dealing with Diversity: Aged care services for new and emerging communities*. Brisbane: National Seniors. (30 pages) (14/8/15).
- National Seniors and Retirement Essentials. (2018). *The Centrelink Experience: From 'waiting, frustrating, hopeless' to 'helpful, "friendly, "positive'*. Brisbane: National Seniors. (24 pages) (18/06/18).
- Rees, K., Maccora, J. & McCallum, J. (2018). *You don't know what you don't know: The current state of Australian aged care service literacy*. Brisbane: National Seniors. (68 pages) (26/09/18).

PAGE INTENTIONALLY LEFT BLANK

PAGE INTENTIONALLY LEFT BLANK

# National Seniors

AUSTRALIA

GPO Box 1450, Brisbane Qld 4001

**P:** 1300 76 50 50 **F:** 07 3229 0356

**E:** [info@nationalseniors.com.au](mailto:info@nationalseniors.com.au)

**W:** [nationalseniors.com.au](http://nationalseniors.com.au)