OPAN Older Persons Advocacy Network

OPAN Submission to

The Office of the Inspector General of Aged Care - Review of My Aged Care

Contents

About OPAN

Formed in March 2017, the Older Persons Advocacy Network (OPAN) is a national network comprised of nine state and territory organisations that have been successfully delivering advocacy, information and education services to older people across Australia for over 30 years. Our members are also known as Service Delivery Organisations (SDOs). The OPAN SDOs are:

ACT	ACT Disability, Aged and Carer Advocacy Services	SA	Aged Rights Advocacy Service (ARAS)
NSW	Seniors Rights Service (SRS)	TAS	Advocacy Tasmania
NT	Darwin Community Legal Service	VIC	Elder Rights Advocacy (ERA)
NT	CatholicCare NT (Central Australia)	WA	Advocare
QLD	Aged and Disability Advocacy Australia (ADA Australia)		

OPAN is funded by the Australian Government to deliver the National Aged Care Advocacy Program (NACAP). OPAN aims to provide a national voice for aged care advocacy and promote excellence and national consistency in the delivery of advocacy services under the NACAP.

OPAN's free services support older people and their representatives to understand and address issues related to Commonwealth funded aged care services. We achieve this through the delivery of education, information and individual advocacy support.

OPAN is always on the side of the older person we are supporting. It is an independent body with no membership beyond the nine SDOs. This independence is a key strength both for individual advocacy and for our systemic advocacy.

OPAN works to amplify the voices of older people seeking and using aged care services and to build human rights into all aspects of aged care service delivery.

OPAN acknowledges the lived experience, wisdom and guidance provided by members of the National Older Person's Reference Group (NOPRG) and others in preparing this submission. We also acknowledge the many individual advocacy cases that have helped shape this submission.

About NOPRG

The National Older Persons Reference Group (NOPRG) consists of 36 people ranging in age from 50–93 living across Australia and with a range of experiences with aged care,

including receiving home care packages, living in residential care, being a current or previous carer or being a person living with dementia. There is a broad mix of diversity representation including Aboriginal and Torres Strait Islander peoples, those that are culturally, ethnically and linguistically diverse, lesbian, gay, bisexual, transgender, intersex and queer people and other sexuality, gender and bodily diverse (LGBTIQ+) people and communities (LGBTQI+), people with disability, Forgotten Australian's, people at risk of homelessness, people living in residential aged care homes, and people living in remote, rural and regional areas. NOPRG members have strong community connections and networks, providing feedback based on their own consultation with community.

Introduction

OPAN members provided 36,904 instances of information and advocacy support to older people, their families and representatives in the 2022-23 financial year representing a 36 per cent increase from the previous year. Of these cases 28% related to care access, including understanding and engaging with My Aged Care, assessment wait times and service availability. These issues have been raised previously by OPAN in the last two National Aged Care Advocacy Program (NACAP) Presenting Issues reports. Older people continue to find the aged care system confusing and difficult to navigate. They still experience issues engaging with My Aged Care and continue to face long wait times for aged care assessments.

Many of the older people assisted suggested there is not enough information, education or promotion of My Aged Care to the general public. Aged care advocates have observed that a lack of accessible information on the role of My Aged Care and the type of aged care services makes it increasingly difficult for some older people to begin the journey of accessing aged care. OPAN members have noted that it is particularly important for information to be made available to older people who do not have internet access or who are unable to effectively use online services.

Awareness of My Aged Care

Understanding the aged care system continues to be problematic for many older people and their families or representatives. A large proportion of older people assisted by aged care advocates to access aged care throughout 2022-23 said they had no prior knowledge of My Aged Care, the Commonwealth Home Support Programme (CHSP) or the Home Care Packages Program. OPAN members report that many people accessing aged care for the first-time experience high levels of confusion when trying to understand the range of available aged care options, the process for accessing the various types of aged care services and the associated fees and charges.

In consultation with members of OPAN's NOPRG it was very clear that there was mixed knowledge about My Aged Care. Some were assisted by social workers in the hospital, who provided information and helped them navigate the system. Others had no knowledge and eventually found My Aged Care through perseverance, though they then found the website and architecture, "both *frustrating and hard to use*". Others who were actively engaged in other ways in aged care knew about My Aged Care and then assisted others to learn about it. Members also noted that some older people heard about My Aged Care via word of mouth or by attending information sessions run in the community.

Particular concern was raised in regard to diverse and marginalised groups who may have more difficulty learning about and navigating My Aged Care. It was proposed that there needs to be different ways of informing these groups and outreaching through services that support or engage with them. One person suggested that if at 50 you can get sent your "bowel cancer" kit why not at 65 – 70 you get your "Aged Care Kit" that gives you all the whys and how's of aged care.

"Well, I didn't know anything about it. I had a stroke, and I was in hospital and a social worker very kindly put me on the road and … took me by my hand. And then it was followed up when I went into rehab, post stroke. So, I was taken hand in glove all the way. I can't believe that I didn't know a thing about it. I was a 55-year career nurse '.

"A lot of word of mouth has gone on or they've gone to the sessions at the Wollongong Library and found out about it there. And so that that's how people are finding out about it."

"I get constant phone calls from people wanting to know where do they go now? So, the first thing they do is come to my house and have a cup of tea and we go through everything that they need to do."

"We're not just looking at one facet, even trying, of course, the most difficult group of people to meet are the homeless people. To get people, you know who need to know about my age care, particularly women over the age of 55 who are homeless and there are more and more of them than any other demographic."

Accessing My Aged Care

OPAN members report that the complexity of the aged care system often prevents or delays older people's access to aged care services. There are numerous steps required to gain approval for aged care services and then further steps to begin receiving aged care. Communication about these steps is not always clear or easily discerned and this often leads to stress and frustration for service users. It has been suggested by OPAN members that communication from My Aged Care should be less official, less repetitive and made easier to read for older people and their families. Communication processes must be improved for older people without support, internet connection and those living with disability, including hearing, vision, and memory loss.

NOPRG members noted how difficult it was to navigate the My Aged Care website. This included not being able to find relevant information. Some, again, had support from social workers or health professionals to navigate My Aged Care. Concern was raised regarding those that had no, or limited, ability to use technology either because of cognitive decline or dementia, lack of experience or people to support their use or lack of affordability of technology such as phones, computers and tablets.

People were still wanting and needing information and communication delivered face to face. While some knew of the Aged Care Service Officers within Services Australia, it was noted that to access them you had to have accessible, affordable and reliable transport and this was not always available. Alternatively for people living in remote areas the Services Australia office was not within easy travelling distance. However, those that had used ACSOs found them very helpful and informative.

People also noted similar frustration with using the phone line. Noting that often it was the "luck of the draw" whether you received good help or no help. Some NOPRG members have developed a strategy whereby if they are not getting the help they need they hang up and ring again, in order to speak to someone else who may provide greater support.

"Alright, I knew about my age care. But I still found it quite frustrating … [and] really difficult to navigate."

"Not hard to get registered, but the website is crap for finding information."

"This person's parents needed support. But they had no ability to access technology. They just really were sitting at home with [the] husband [living] with dementia. The GP practise nurse was most helpful. That was just lucky. But in the end the adult son has

had to take it over because his parents just wouldn't have [been able to]. I don't know what would have happened to them."

"Through my aged care and a lot of them can't use the computer, they're still waiting for stuff face to face."

"I use the phone rather. I looked at the website a couple of times and thought this is hopeless, and so then I did what I have done with Centrelink for years. I would ring and ask questions and if the person was hopeless, I'd thank them very much and I'd ring back later and I'd keep ringing until I got the person who actually had the information I needed."

Issues with availability/reliability of the My Aged Care system or phone line

Over 2022 - 2023, both advocates and older people have experienced a range of challenges communicating with My Aged Care over the phone. There have been periods where the wait time to get through to a My Aged Care contact centre staff member has been up to, and in some instances, above 30 minutes. There were many cases where older people and their family members simply could not wait that long due to health conditions or caring responsibilities. There were some occasions when advocates and older people persisted with the wait time, but the phone call was cut off when they eventually reached the contact centre.

OPAN SDOs report that MAC referrals that have been out of scope for NACAP over recent months have included referrals for people

- seeking financial advice.
- wishing to contest the outcome of Services Australia means/asset assessments
- with a disability seeking advocacy support for issues unrelated to aged care service provision.
- who have experienced theft (not aged care related).

Advocates will generally redirect the client to the appropriate referral pathway, however, many callers' express frustration at the number of calls they need to make before they receive the assistance they need. This highlights the potential need for further training on NACAP scope and exploration of alternative referral pathways for issues that are out of scope for NACAP.

OPAN SDOs also report regularly receiving referrals for matters that MAC should be able to address in the first instance. Examples include MAC referring older people to Advocacy because

- they have CHSP referral codes and don't know what to do next.
- they don't know what their current aged care status is
- MAC was unable to identify what the older person needed from them
- they have CHSP referral codes but cannot find any services with availability
- they are agitated because they have to wait 6 months for a home care package to become available
- they have received a referral for a particular service type and want to know what providers deliver that service in their area.
- they are NDIS funded but are over 65 years old and want to clarify their eligibility for aged care.

It would be less onerous for the older person, if MAC contact centre staff could provide relevant information about eligibility, and accessing services, including service lists in the first instance rather than referring to Advocates.

Where there are no available CHSP services in the client's area it would be useful if the MAC contact centre staff could provide intel on service availability and waitlists or the option to be assessed for a low-level home care package instead. Of course, Advocates can provide information on these topics, but an older person should be able to get all this information from one spot. It is stressful and frustrating for them to have to call multiple organisations to get all the information they need. It is even more frustrating when they are referred to Advocacy and then the advocate has to reconnect them back to MAC.

Some of the above examples may highlight some potential training opportunities for MAC Contact Centre staff. For example, training on

- how to identify a client's aged care status
- how to communicate effectively and identify client need. (advocates noted this often just takes time and using language that the older person can relate to).
- how to engage in difficult conversations (i.e. there is a long wait list for services and unfortunately there is very little that can be done)
- how to problem solve (i.e. there is no CHSP service available but we could get you assessed for an HCP)
- how to engage with angry callers. (offering an inappropriate referral only makes them angrier and more frustrated with the system).

We have also received some case examples from advocates highlighting other potential knowledge gaps for MAC Contact Centre Staff. Examples include MAC contact centre staff

- Not advising callers who had money and possessions stolen (not aged care related) to call the police. Instead, they were referred to an OPAN member.
- Providing definite answers about home care package included/excluded items or telling older people they can access anything they need from a home care package. This later leads to confusion and conflict with providers.
- Advising clients experiencing homelessness that they won't be able to access a home care package (this is a reoccurring issue from last year).

The case example below provides details on a recent interaction with an older person experiencing homelessness. In this case example, there were concerns about how the MAC contact centre staff engaged with the older person and the accuracy of the information provided.

> An Advocate was calling regarding a vulnerable client who required an ACAS assessment. The client is homeless, suffering from elder abuse and going through cognitive and physical decline. In addition, his carer and ex-daughter-in-law cannot care for him anymore as she herself is also going through multiple stressful events.
>
> The duration of the call was 50 minutes. This included being put on hold for a few lengthy periods and being asked the same basic questions as if the operator was not listening. The operator's tone came across as belittling with some of the advice incorrect, including that the client would not be eligible for a home care package as he did not have a home to live in. There were inappropriate questions asked heightening the client's emotional state. The urgency of an ACAS assessment did not seem to be understood despite the Advocate advising on the reasons. No doubt, this call could be listened to on a recording. Please note, that the client consented to have this complaint raised about his interaction with My Aged Care.

NOPRG members highlighted the difficulties of the My Aged Care online system. One person gave an example of the limitations of using the digital application for an assessment. They explained that they helped someone complete the online form but the person was "*knocked out on the online application because we answered all the questions in a way that demonstrated he could perform [tasks] well*." The person has MS and the GP recommended they apply for an assessment as overtime their abilities will deteriorate. It was noted that this forced people to go to the "worst case scenario" and was considered quite humiliating for the person.

Assessment Wait Times

Wait times for both Regional Assessment Services (RAS) and Aged Care Assessment Teams (ACAT) continue to be a concern. In some areas, older people are waiting up to

three months just to receive an initial contact from a RAS or ACAT assessor let alone an assessment. Concernedly, one OPAN SDO reported a six-month wait for an ACAT assessment for some locations. These wait times are adversely impacting older people urgently in need of care. Sadly, while OPAN is not linking causality, some older people have died while waiting for an assessment.

Time frames vary across the nation, with regional, rural and remote areas appearing to experience more noticeable delays. One OPAN SDO has observed that the delays in accessing an assessment in regional, rural and remote areas often align with the availability of services in these areas. It has been suggested that assessments are not being prioritised in these areas because there are simply no aged care providers with capacity to support an older person's identified needs after the assessment.

Advocates have provided support throughout 2022-23 to ensure older people receive timely access to the appropriate level of assessment. Advocates have noted that older people receiving CHSP are often automatically referred by My Aged Care to RAS for reassessment even when the older person identifies a significant increase in need and specifically requests an ACAT assessment. This can lead to further delays for the older person, as the RAS often makes an internal referral to ACAT and the older person commences a new waiting period. These wait times coupled with time spent in a national queue and waiting for a service to be available means that older people are left without necessary care and support for significant periods of time.

Some NOPRG members agree that there is a lengthy wait for assessment, often exacerbated by a lack of providers once the assessment is complete. As one person stated, "*trying to get assessment took months and months and progression through the system was both very slow and local providers were almost negligible when I, got to that stage*." Another person noted that while it took some time to get assessed, when they eventually were assessed the progression to services moved reasonably well.

However other members provided a more positive story, with one member saying that "*my first assessment was fantastic. It was done by clinical staff from the local hospital and we're operating the RAS. They understood my needs and they projected their recommendations forward. The next assessment was that even higher level and again they looked at what else needed for the future*."

In the Report on Government Services 2024, Table 14A.29 in the data tables, wait times in 22-23 were the longest ever recorded. People at the 90th percentile were waiting 98 days+ from referral for assessment.[1]

[1] Productivity Commission, Report on Government Services 2024, https://www.pc.gov.au/ongoing/report-on-government-services/2024/community-services/aged-care-services

Often assessment wait times depend on where the person lives with those in more remote and rural areas often having far more extensive wait times. This does not mean that metropolitan or large regional areas are all uniformly better, as again where the person lives within those areas also impacts access to assessment.

"I'm hearing that it's still taking a long, long time for assessments to be done. And … there are now businesses, or there have been for a while, facilitating helping people get through and for a fee, of course. But yeah, I'm still hearing there's a long, long wait for the assessment to actually take place. There are some codes and some emergency situations that in those cases you can possibly get through a little sooner, but it's still from what I hear not acceptable."

Assessment Processes

Advocates have observed that older people living with vision or hearing impairment often find it more difficult to access aged care information. Advocates have been involved in cases where people who are legally blind have been sent detailed letters about their assessment outcomes and the next steps for accessing care that they could not read. Advocates have also been involved in cases where people living with hearing loss are unable to communicate with My Aged Care over the phone and have sought the support of an advocate to progress their access to care.

Advocates note that delays can also be experienced when an older person misses a call from an assessor calling to book a visit. This often occurs because the older person is suspicious about answering unknown phone numbers, or the assessor does not leave a message with return contact details. Improved communication processes between assessors and older people must be prioritised with the introduction of the single assessment system for aged care from 1 July 2024.

OPAN SDOs continue to raise concerns over the continuation of assessments over the phone in some areas. Assessments over the phone often make it difficult for older people to communicate their care needs and consequently, many are not approved for the appropriate levels of care. Advocates regularly provide support to older people at assessments to ensure they understand the process and are supported in communicating all their care needs.

Advocates and NOPRG members have reported that in some cases assessors do not appear to be appropriately skilled in adequately assessing an individual's needs and taking into consideration important factors such as chronic health conditions, carer stress and trauma histories.

NOPRG members also noted that some people refer themselves directly into residential aged care, due to long wait times for home care services.

"In my own case, I admitted myself to residential aged care because I just couldn't manage after a long period of hospitalisation. I just couldn't manage anymore and for most of the residents, families I've spoken to a lot of the residents have been admitted in similar circumstances and my age care doesn't have doesn't seem to apply a big part in their decision making."

"I think the assessment process was really, really, really difficult for me. The RAS worker just minimised my back issues without any sort of knowledge whatsoever. And I felt like I had to fight for an ACAT assessment".

You know, what's your worst day or what's the worst time of the day. It's like I was getting out of bed, barely being able to walk first thing in the morning, but by 2:00 o'clock in the afternoon when he saw me, I probably wasn't too bad. So, I had on the one hand my GP wanting to actually have me admitted to hospital because she was concerned that I couldn't look after myself. And then a my age care assessor, thinking there was nothing wrong with me. So there really is a problem there."

"And they must be making decisions for themselves, just as people who are managing earlier stages of dementia, they have the right to be able to be heard and heard clearly, and I don't believe this digitalised process that we've got is going to support that. So, I'm very, very concerned".

Conclusion

Awareness of, accessing and navigating My Aged Care remains problematic for many older people. As noted above 28% of older people assisted by OPAN SDOs and reinforced by the direct lived experience of NOPRG members, said they had difficulties in accessing aged care. Awareness of My Aged Care remains low in the general community with people relying on advocates, social workers and other health professionals to connect them and navigate My Aged Care. The My Aged Care website remains problematic with information remaining hard to find. There are serious concerns around the knowledge and understanding of My Aged Care call centre staff.

Long wait times continue for assessment, with concerning issues around information and communication in general, but especially for people who are living with a vision or hearing impairment.

My Aged Care is not well promoted or explained and there is an urgent need to improve community awareness and knowledge about My Aged Care. In tandem the My Aged

Care website needs to be made easier to navigate and the phone centre staff need to be upskilled in assisting older people who call them and in providing relevant and accurate information.

OPAN and NOPRG look forward to the findings of this review and to seeing improvements within My Aged Care and Assessments.

OPAN Older Persons Advocacy Network

OPAN member organisations by state or territory:

ADACAS ADVOCACY

Advocacy Tasmania

ERA Elder Rights Advocacy
Supporting your right to quality care

Seniors Rights Service

Darwin Community LEGAL SERVICE

ADAAustralia
Your aged and disability advocates

aras
aged rights advocacy service inc.

Advocare
Empowering older people in WA

CatholicCare NT

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