

Submission to the Office of the Inspector-General of Aged Care: 2024: Review of the administration of My Aged Care

June 2024

Carers Australia welcomes the opportunity to respond to this consultation.

We understand that the Office is seeking lived experience engagement with My Aged Care and that the particular focus is on assessment. We have also promoted this consultation to carers of older people in our newsletter and social media, including the specific questions identified in your Office's call for submissions.

Responses from the 2023 national Carer Wellbeing Survey

Carers Australia conducts an annual national Carer Wellbeing Survey in partnership with the University of Canberra. It explores, among other things, carers' access to services and support for themselves and for those they care for.

While the survey covers all carers, a significant number of respondents were carers of older people. Of the 5238 respondents to the 2023 survey, 1511 (29%) identified as carers of someone with dementia and 2079 (40%) reported caring for someone with age frailty.

In relation to My Aged Care, respondents were asked whether:

- the person they care for received formal support packages
- whether they received adequate levels of support to ensure their wellbeing and that of their carers
- time spent navigating the aged care support system and what support would be most useful to help with navigation.

At a broad level:

- Just under 40 percent (39.9%) of carers of frail aged people identified that they had poor access to My Aged Care, 20.9% reported neither good or poor access, and 46.2% reported good access.
- Of carers of people with dementia, 35.5% reported poor access to My Aged Care, 12.4% reported neither good or poor access and 52.1% reported good access.
- 44.1% of carers of the frail aged said that complicated application processes presented a barrier to accessing services, and this was 44.5% who identified as carers of with dementia.

Survey participants were invited to include open-ended responses in relation to particular questions, including the opportunity to comment on their experience of My Aged Care and suggestions on how it might be improved.

We have extracted those responses which included references to the ACAT, noting that assessment is the focus of this consultation. There were many more responses in relation to My Age Care and service delivery more generally.

With respect to assessments, a persistent theme was long waiting times to access initial assessments but, more commonly, the even longer waiting times and difficulty of getting a new assessment when there was a marked decline in the condition of the person being cared for.

Quotes from open ended comments relating to assessment

- *“Currently on a wait list for outcome of ACAT assessment and recommendations for level 4 priority for my mother.
Also currently waiting on an ACAT assessment for my father following on from assessment prior to the ACAT. This process has been extremely frustrating and distressing for my father who shares the caring role of my mother who has medium range vascular dementia diagnosis. Both need additional help to remain in their home and stay together.”*
- *“Need easier access to ACAT needed when asking for a higher level of service. No way of checking when a new review for more support is being looked into. Frustrated at the lack of ability to talk to the relevant ACAT agent to find out how long my mother will be out of pocket with having to pay for her increased services.”*
- *“My Aged Care. I submitted all documents and it took 4 months before I heard that it had been rejected because dr had filled the form in incorrectly. I spent 90 minutes in line waiting to talk to someone to confirm it was just the doctor's information that was needed correctly before applying to be reassessed. Was then told to get dr to complete the form again, submit it online - then call them back to let them know so they could get it assessed. it seems ridiculous that I have to spend up to 3 hours on the phone to get a simple thing done.”*
- *“A straight answer would be appreciated.
Timely responses - it took 18months to be granted funding for level 3 My Aged Care despite being told my husband was entitled to it.
Not received an answer about level 4 funding. Taken 12 months so far!”*
- *“We need a service for those of us who have no idea or experience of aged care.
A service that would walk us through the maze of aged care and the packages available.
My Mum is terminal with a life expectancy of less than 2 months and I have been told that Mum will be dead before they can get an ACAT assessment to raise her to level 4 and get the help she needs myself and other family members are now paying for any services she needs as we are tired of waiting for her service provider to enact anything or even return our calls and emails.”*
- *“Wait times for regional assessments are over 5 months and then another 6 or more months for an ACAT assessment. A call back system that retains your number in the queue like other services,*

eg banks do, would be helpful. If the system wasn't so complicated and service providers at capacity, this system would be able to use and much more easier to navigate."

- *"I don't know much about the services that are offered. Over the years I have learnt about it but it wasn't until I needed it, that I had to learn. I did get help from a My Aged Care advocate, who was extremely helpful in navigating the system and she helped me get an ACAT assessment for my dad. I also had an ACAT done for my mum but unfortunately she passed away last year before she was allocated a Home care package. I still need to get another one done for my dad but I'm getting resistance from the My Aged care staff who tell me that he won't get approved but, as the process is taking so long, I need to get him on the books now so when he does need an accelerated level of care, he can get it and not miss out on a package like my mum did".*
- *"Been on the waiting list for 20 weeks for ACAT. My Aged Care offers no help available, no compassion or empathy and I am sick of telephoning their Agencies, who tell me there is nobody available and they have no FUNDING. So I am sick of telephoning wasting my time and money, and still NO HELP AVAILABLE. Please advise your Aged Care Minister before I do, I am very sick and tired of all this red tape and should be assistance for us even for domestic help, PLEASE."*
- *"I'm very new to this and found it confusing dealing with and understanding the relationships between My Aged Care, ACAT, and Service Providers."*
- *"There needs to be easier access to ACAT when asking for a higher level of service. No way of checking when new review for more support is being looked into. Frustration at the lack of ability to talk to the relevant ACAT agent to find out how long my mother will be out of pocket with having to pay for her increased services."*
- *"Initially, My Aged Care was difficult as I had no previous experience with the system. I researched it, received assistance from our accountancy firm who had an expert in this field, received assistance from our medical team and from Carers Gateway. The ACAT team was very helpful when conducting assessments and treated my mother respectfully and allowed her to retain her dignity. However, it was a complicated process and, even though I am a retired manager of a government department, I found it difficult and at times confusing."*
- *"My Aged Care staff and service providers need to be consistent and accurate in their information. Service providers have no idea how my aged care system works which leads to hours on the phone (on hold for over an hour each time) to ask questions and get codes that they can't give you. Wait times for regional assessments are over 5 months and then another 6 or more months for and ACAT assessment! Even some My Aged Care staff can add codes over the phone and others can't/won't. A call back system that retains your number in the queue like other services eg banks do would be helpful. If the system wasn't so complicated and service providers at capacity, this system would be able to use and much more easier to navigate."*
- *"There is a need to provide an avenue for recipients to contact ACAT directly to update assessments instead of starting from beginning. Have ACAT assessor help with care advice instead*

of all the business providers overlapping duplicating and unable to deliver timely relevant high quality services because of a flawed cost inefficient MAC structure.”

- *“We need one point of contact for MAC. We have RAS, ACAT and now three different providers, navigating and understanding the MAC system is difficult. I need someone to work with me to work out how to get an ACAT assessment and get the best outcome for the person I care for.”*
- *“A straight answer would be appreciated.
Timely responses - it took 18months to be granted funding for level 3 My Aged Care despite being told my husband was entitled to it.
Not received an answer about level 4 funding. Taken 12 months so far!”*
- *“I’m okay but in the area I live I’m the only person who can help the aged persons near me. So far I’ve assisted over eight people to access My Aged Care. Most elderly in rural areas, unless their kids are nearby can’t begin the Aged Care Assessment.”*
- *“Such lengthy process of applying for an ACAT assessment, long wait times for an aged care package and then the incredibly complex process of finding a care provider that meets your needs and has a fee structure you can afford as well as determining whether the person is eligible for financial hardship via Centrelink. I spent days working on this while holding down a full time job. I don’t see how an elderly person could navigate this on their own, especially if they need care due to complex mental health issues and cognitive decline. There are services that will do this but they charge a couple of thousand dollars.”*
- *“The Disability Support for Older Australians program is an abomination and extremely unhelpful. No automated email acknowledgement response, no address, no telephone contact details and only a generic email address for enquiries. Questions go unanswered. They are contemptuous, disrespectful and obstructive. We have been forced to endure and ICAN assessment, directed for further interrogation by an ACAT assessment, been jettisoned from the scrapheap of disability to the garbage dump of aged care and no one gives damn. Directed to seek funding from CHSP (even though totally inappropriate in a regional area) which is to end in June 23, then we will be forced to navigate the Support at Home proposal and their new you beaut assessment. process, all whilst being directed back to the now non existent state supports. Disability support has always been abysmal, but being dumped from access to NDIS is outrageous as the primary issue is disability not age related and there is no support for disability in the aged care arena.”*
- *“The ACAT assessment process really sucks. It’s done once, when you very first realise that the person you love has symptoms and gets a diagnosis. There is absolutely zero provision to have it reviewed over time as your person’s condition worsens. As it is used to access nursing home care and other services, for example “ageing in place” through the Commonwealth, this can result in totally inappropriate care levels or nursing home places being offered. I encountered totally unsympathetic and rude staff who did not understand that with Alzheimer’s an ACAT from seven years ago was now inappropriate for someone in the advanced stages of the disease who needed constant supervision and a locked facility.”*

- *"The process of navigating My Aged Care is complicated. The initial ACAT assessment and assessors was excellent and easy to navigate. It was the process following this which was more difficult".*
- *"We have been up and running for a while now, I had to work it out for myself. Nightmare!!! It would be helpful if ACAT and My Age Care would communicate with each other rather than have us running around like a headless chicken, contacting one agency and trying to implement what they recommend only to be told it is not done this way. As I said, a nightmare. A carer is under enough pressure and is time poor. In the beginning this process caused me undue stress and blood pressure. What I was put through was very unnecessary and effected my health terribly. Having staff who know what they are talking about would be a good start."*
- *"When my husband was assessed by ACAT I was handed a whole pile of written material. One size does not suit all. It is relatively complicated to wade through everything so I haven't bothered."*
- *"I am a dyslexic person who likes to have access to auditory or visual learning adds. After Mum's ACAT assessment I was given a lot of written material in booklet forms. I would have liked to have other forms of format of information."*

General comments on engaging with My Aged Care

If we were to copy all carers' responses in relation to My Aged Care it would take up many pages. The strong themes which emerge from these responses are reflected below.

Wait times

Long wait times were identified for almost every step along the way, whether it is phone connections, waiting for assessments, waiting for services to be accepted by providers and waiting for services to be provided.

These wait times can impact heavily on carers, including carers who navigate the aged care system on behalf of the person they care for. Carers tend to be extremely time poor, especially if they have their own families and/or are employed. And in the meantime, they are the ones who fill in the gaps which are not being filled with paid care and other assistance available through CHSP or Home Care Packages. They report high levels of exhaustion arising from interacting with My Aged Care and, in many cases, they just give up.

A few reported that the person they cared for died before they go an ACAT assessment or before they were able to access services.

Navigation

Almost every comment on My Aged Care included a reference to the difficulties of navigating the system. This included coming in with little knowledge of the aged care system as whole and how it operated, which they thought would have made it easier to engage in the part of the system they were seeking help from. It was suggested that this general information prior to engaging with My Aged Care would be very useful. This should be provided through a booklet (including hard copy for those who find the website difficult to navigate) and perhaps in community forums.

Others complained that they were bamboozled by the use of jargon when they finally were able to connect.

Many complained that they found the website hard to navigate and IT systems hard to navigate in general. This was particularly the case with older carers. A number also said they found filling out the requisite forms difficult.

The need for a case worker from when they first entered the system and to work their way through to actual service delivery was identified again and again. It was thought that inconsistency in the advice they received through engaging with multiple people could be avoided in this way. The advantage of having someone who was familiar with their circumstances and their needs such as a dedicated case worker was also mentioned as an advantage.

Examples:

- *"I don't feel the person who interviewed us this year for My Aged Care was very helpful. There was nothing in the discussion about what My Aged Care is and how it can help, nor any information about future help I may need in the future."*
- *"It is impossible to deal with the Aged Care systems. The wait times on the phone are interminable, the people speak unintelligibly using terms I don't understand, and there's nothing available in the end anyway. But mostly I give up waiting."*
- *"We need more step by step instructions in how to navigate and find the information that you are looking for: .a kind of "Aged Care for Dummies " manual could possibly help. The problem is that there is so much information out there, that you do not know where to begin sometimes, and i found that by reading over and over i managed to find the topic that i was after."*

Fragmented points of contact across the aged care system and across government

As will be apparent from the comments concerning assessment, many respondents drew attention to their frustration in dealing with multiple points of contact between My Aged Care, ACAT assessments and accessing providers.

Lack of connectivity between different agencies involved in aged care was also seen as problem – particularly between the Department of Health and Aged Care and Centrelink, resulting in duplication of effort in providing information.

Examples:

- *Current providers of aged care packages services have knowledgeable & committed staff but their usefulness is limited relating to the lengthy time taken to navigate between the number of responsible bodies in the chain of command eg from My Aged Care to provider, to contracted local service provider. Very slow, inefficient and bureaucratic process and so financial costs to carer are high, equating to poor value and poor results.*
- *"I feel the Government systems could "talk" to each other a little more. I had to notify Centrelink I was the person who could undertake things on my husband's behalf and then had to submit a form to My Aged Care for the same thing! It must be difficult for those with no systems knowledge to work their way through the needs of Govt systems i.e. Centrelink and My Aged Care. A total process review across all Govt services under myGov making things as simple as possible, with simple wording, would be of advantage."*
- *"I have filled in forms to My Aged Care and Centrelink on behalf of my husband I assume I have answered the questions in My Aged Care correctly. No one ever gets back to you to tell you the forms you filled on were okay I had to notify them of changes to our financial situation and have heard nothing, so I just presume that they were okay. Lack of communication is a real worry to me as I will be held responsible if something is incorrect."*

Summary

While the responses to carers of older people gleaned from the 2023 Carer Wellbeing survey do not address all of the questions posed in the consultation material, they do provide lived experience evidence in relation to very long wait times for initial and re-assessments and the consequences for those they care for and themselves as well as difficulties navigating the system at each stage of engagement.

Difficulties with navigating the system, filling out the required forms and understanding the terms used were also a dominant theme – especially for those who struggle with IT. We are aware that when they face barriers in understanding and engagement they often turn to the Carer Gateway providers and other carer service providers rather than My Aged Care for assistance, and it is sometimes provided. However, this is not a core role of carer organisations and shouldn't be required because of failings with My Aged Care.

We hope the outcomes of this consultation will result in the necessary improvements.

About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail aged.

In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represents the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers should have the same rights, choices, and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment, and education.

This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including 'grandparent carers'
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI+)
- Who are living in rural and remote Australia, and
- Who are no longer in a caring role (former carers).

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples and communities as the traditional custodians of the land we work on and pay our respects to Elders past, present and emerging. As an inclusive organisation we celebrate people of all backgrounds, genders, sexualities, cultures, bodies, and abilities.

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