OPAN Older Persons Advocacy Network

The National Aged Care Advocacy Program 2020-2021

Raising the voice of people accessing aged care

OPAN receives funding from the Australian Government Department of Health for the delivery of the National Aged Care Advocacy Program.

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OPAN Older Persons Advocacy Network

opan.org.au | 1800 700 600

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 close to 30 years.

The OPAN Network Member Organisations are:

Australian Capital Territory: ACT Disability, Aged and Carer Advocacy Services (ADACAS)

South Australia: Aged Rights Advocacy Service (ARAS)

New South Whales: Seniors Rights Service (SRS)

Tasmania: Advocacy Tasmania

Northern Territory: Darwin Community Legal Service (DCLS)

Victoria: Elder Rights Advocacy (ERA)

Northern Territory Central: CatholicCareNT (Central Australia)

Western Australia: Advocare

Queensland: Aged and Disability Advocacy Australia (ADA Australia)

OPAN's services support older people and their representatives to address issues related to Australian Government-funded aged care services.

OPAN is funded by the Australian Government Department of Health to deliver the National Aged Care Advocacy Program (NACAP).

OPAN aims to provide a national voice for individual aged care advocacy and promote excellence and national consistency in the delivery of advocacy services under the NACAP. OPAN is an independent body on the side of the older person we are supporting. This independence is a key strength both for individual advocacy and for our systemic advocacy.

ADACAS ADVOCACY

aras aged rights advocacy service inc.

Seniors Rights Service

Advocacy Tasmania

Darwin Community LEGAL SERVICE

ERA Elder Rights Advocacy Supporting your right to quality care

CatholicCare NT

Advocare Empowering People

ADAAustralia Your aged and disability advocates

A Message from the CEO

This report, the first definitive public annual report on the issues seen by aged care advocacy services, shines further light on the experiences of a portion of older people engaging with the aged care system throughout 2020-21. It provides insight into the valuable work of aged care advocates, reinforcing the importance of the role they play in supporting older people to understand and exercise their aged care rights.

The report also demonstrates that despite the challenges presented by COVID-19 during this period, OPAN members were able to adjust and rapidly respond to the emerging needs of over 20,000 older people and their representatives. I would like to acknowledge and thank all members of the network for their ongoing dedication to supporting older people and their representatives to understand and exercise their rights during such uncertain times.

The content of this report has been collated during a period of transition for OPAN. In July 2021, the network introduced a new Minimum Data Set (MDS). Prior to the introduction of this new MDS, each member gathered data using varying systems for categorising and counting advocacy issues, making it challenging to present reliable data on the key aged care advocacy issues experienced across the nation. The new MDS will support members to gather nationally consistent quantitative data and will enable the network to provide strong, evidence based, insights into systemic issues impacting on older Australians. However, the qualitative data within this report remains powerful.

The issues presented in this report have been informed by a thematic analysis of the qualitative data captured in member quarterly reporting throughout 2020-21. This qualitative data includes a number of case study examples that assist in painting a picture of the challenges older people experience engaging with the aged care system.

The advocacy issues presented in this report will not come as a surprise to many, but they are confronting. They closely reflect many of the concerns identified by the Royal Commission into Aged Care Quality and Safety and provide further transparency to the continuing issues within the aged care system, reiterating why investment in and transformation of the aged care system is required.

When reading this report, it is important to note that older people and their families rarely seek advocacy support when they are happy with their aged care services. They engage the support of an advocate when they feel they have been treated unfairly, their concerns have not been understood or heard, or their human and aged care rights have been breached. Rather than seeing this report as a negative criticism of aged care providers and governments, this report should be viewed as an insight to the real life experience of some older people and a useful lens into the service system that can help inform improvements into the future.

We can only improve a system if we recognise that no system is perfect. While there are aged

care providers delivering good care and high-quality services, like all systems aged care is on a journey of quality improvement.

Throughout the year, the Charter of Aged Care Rights has been an important tool in supporting advocacy casework. However, the absence of a human rights based Aged Care Act continues to be a significant barrier to the full realisation of the rights listed under the Aged Care Charter of Rights. An Aged Care Act that is embedded in the rights of older people is required to truly transform the aged care system. We look forward to working with both the Australian Government Department of Health, the Aged Care Quality and Safety Commission and aged care providers to address the ongoing concerns raised in this report and to ensure the voice of older people is heard and respected as the Australian Government works to introduce reforms to the aged care sector

Craig Gear OAM

"We can only improve a system if we recognise that no system is perfect. While there are aged care providers delivering good care and high-quality services, like all systems aged care is on a journey of quality improvement."

Executive Summary

NACAP Advocacy Casework – A Year in Review

Total number of information provisions

11,849

Total number of Advocacy cases

8,826

Total number of elder abuse info and advocacy

2,344

Top Five Presenting Issues in Advocacy Casework by Aged Care Service Type

COVID

- Access to advocacy support.
- Communication with families/ representatives.
- Visitor restrictions in residential care.
- Quality of care concerns.
- Reduced access to social supports.

The Abuse of Older People

- Increased risk of abuse as a result of COVID-19 environment.
- Misuse of Enduring Power of Attorney/Guardian.
- Financial abuse.
- Unwanted admission into residential care.
- Residential care staff with limited knowledge of supported and substitute decision making.

Assessment Services

- Service availability influencing assessment outcomes.
- Phone based assessments.
- Inappropriate triaging of assessment services.
- Wait time for accessing an assessment service.
- ACAT (Aged Care Assessment Team) not assessing older people residing in residential for home care services.

Commonwealth Home Support Program

- Service availability.
- Home care package recipients increasingly accessing CHSP.
- Service provider communication regarding changes to support staff and service times.
- Limited consumer choice, particularly in rural and remote areas.
- Workforce shortages.

Home Care Packages

- Extended waiting periods to receive a package.
- Communication with providers.
- Purchasing goods and services on a home care package.
- Workforce shortages.
- Fees and charges.

Diverse and Marginalised Groups

- Understanding and accessing the system.
- Service availability.
- Culturally appropriate and trauma informed care.
- Family and financial abuse.
- The aged care and housing interface.

Transition Care, Short Term Restorative Care and Respite

- Accessing transitional care from hospital.
- Issues relating to staffing and the quality of care in residential respite.
- Access to respite, particularly during COVID-19.
- Restricted visitation in residential respite due to COVID-19 restrictions.
- Lack of transparency in the communication of possible costs for fully or partially funded respite.

Residential Care

- COVID-19 restrictions.
- Quality of care.
- Care planning.
- Restrictive practice.
- Security of tenure.

Policy Considerations

This report presents on the common issues in aged care advocacy case work in 2020-21. The key themes that have emerged in this report have reinforced the findings and recommendations made by the Royal Commission into Aged Care Quality and Safety in relation to:

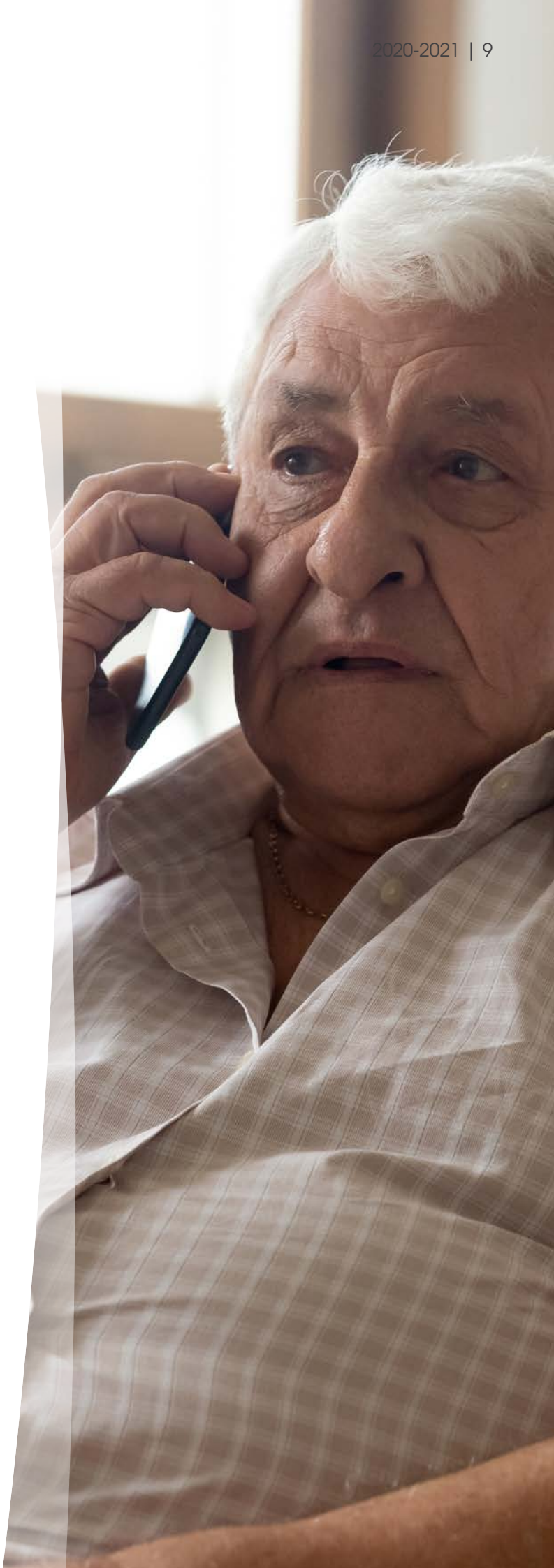
- Knowledge of and access to the aged care system.
- Workforce supply and training.
- An undersupply of home care services.
- Services not adequately meeting the needs of older people.
- The interface between health and aged care.
- A lack of flexibility, choice, and control, particularly for those from diverse and marginalised backgrounds.
- Quality of care concerns, particularly in the residential aged care setting.

OPAN acknowledges that the Australian Government has already commenced plans to address many of the key issues identified by the Royal Commission and reinforced in this report. We urge the Australian Government and the Department of Health to engage with OPAN and most importantly, older people with lived experience of the aged care system in the design and implementation of these necessary reforms.

OPAN recognises that many of these reforms are major and will take time to implement. However, we also note that there are a number of issues, that are currently impacting on older people in a significant way, that could be addressed immediately with consideration of the following recommendations:

- The Department of Health to clearly communicate that if a residential aged care facility is not in a COVID-19 hotspot and not subject to specific public health directives, then visitation rights as well as the rights of a resident to move freely within and outside of a residential care facility must be respected.
- Increased public education the roles and responsibilities of substitute decision makers and the rights of people with substitute decision makers in place.
- The Advocates as Agents pilot, which allows advocates to act as a conduit between the older person and My Aged Care to be maintained as a permanent program.
- My Aged Care staff to receive training on;
  - Triaging assessments.
  - Eligibility requirements for Aboriginal and Torres Strait Islander people.
  - Engaging and working with interpreters.
  - The aged care system and the role and scope of aged care advocacy.
- Phone based aged care assessments to be used as a last resort with video/phone-based assessments only used if a face-to-face assessment is not a viable option.
- Assessment outcomes to be based on the assessed need of the older person and not service availability.
- The aged care workforce to receive training on the following topics;
  - The roles and responsibilities of Enduring Powers of Attorney/Guardians and the supports available to assist people experiencing abuse by their Attorney/ Guardians.
  - Supported decision making.
  - Communicating with aged care consumers
  - Care planning.
  - Culturally appropriate and trauma informed care.
  - Understanding and responding to challenging behaviours.

- Home care package Guidelines to provide clarification for both providers, consumer and advocates about items that are considered excluded as well as the types of evidence the Department considers appropriate to justify the purchase of something that may be considered an excluded item.
- The Department of Health to introduce a pathway for having home care package excluded items approved under exceptional circumstances.
- The Department of Health to introduce a direct line of communication between advocates seeking advice on home care package excluded items.
- The Department of Health to set maximum amount (graded across package levels) that can be spent on administration, case management and package management fees.
- The Department of Health and Aged Care Quality and Safety Commission to re-enforce the importance of clear communication with home care recipients.
- The Aged Care Quality and Safety Commission to monitor care planning processes more thoroughly. Care planning is not picked up in 'consumer experience' reports and should be explored when the Commission engages older people and their family/carers in the quality review process.
- The Aged Care Quality and Safety Commission to gain greater insight into the needs of Aboriginal and Torres Strait Islander communities so they can appropriately measure the cultural competency and inclusiveness of the services.
- Diverse and marginalised groups to be engaged in a co-design process to ensure their needs and issues not captured in the Royal Commission's final recommendations are appropriately addressed.



COVID-19

During 2020-21, COVID-19 restrictions presented new challenges for advocates, particularly when it came to supporting older people in residential aged care facilities to exercise their basic rights under the Charter of Aged Care Rights. OPAN observed that the COVID-19 environment had a particular impact on resident's rights to:

- Safe and high-quality care and services.
- Be treated with dignity and respect.
- Have control over and make decisions about the personal aspects of their care, personal and social life, including where the choices involved personal risk.
- Personal privacy.
- Have a person of their choice, including an aged care advocate, to support them or speak on their behalf.

With access to aged care facilities restricted during periods of lockdown, advocates were unable to connect with residents in person. This experience brought to light the limited number of phones and communication devices available to older people living in residential aged care. Advocates reported that on some occasions they would have to call 5-10 times before they were connected with an older person requiring advocacy support. Maintaining privacy and confidentiality was particularly challenging during this period with many facilities screening calls to residents before taking the phone into their room. Some members observed that this practice occurred more frequently in cases where the resident had an active Enduring Power of Attorney/Guardian in place.

Privacy and confidentiality issues continued to be a concern once restrictions were lifted. One member reported that a provider was reluctant to have advocates visit residents unless the advocate reported everyone they spoke

to whilst at the facility. This created issues with client confidentiality and went beyond what was required under the Public Health Orders in force by the state health department.

Inconsistent application of visitation requirements created ongoing challenges for advocates during the pandemic with members reporting that ever changing health directives where often misinterpreted and applied incorrectly to the detriment of the older person. For example, one member was involved in case where an advocate had been engaged to support a resident through an online tribunal hearing. Upon arrival at the residential care facility, the advocate was advised that they could not enter the premises due to a state health directive. The member had to apply for an urgent exemption and during this process, state health department representatives advised the advocate that there were no restrictions in place preventing the advocate from visiting the facility.

Despite these challenges, members were able to adapt to the continuously changing COVID-19 environment, often providing advocacy support at meetings for care planning and complaints handling purposes via video conference.

Restrictions preventing family, friends, and representatives from visiting residential care facilities presented as one of the most significant COVID-19 advocacy issues. It is widely acknowledged that social connection is important to residents' mental health and wellbeing.

Members across the nation were busy advocating for families and friends to be able to connect with their loved ones in residential care, even if it was only through a viewing window. Advocacy support in this area typically involved multiple phone calls to facility management to discuss the importance of residents connecting with their families and friends.

Where visitation restrictions applied, families and representatives expressed concerns for relatives who had dementia and/or a hearing and vision impairment. For these residents, connection via virtual technology or window visits was often unsuitable. Many residents with dementia experienced behaviour changes, were unsettled, agitated, and confused by a sense of abandonment when their families stopped visiting. Members also reported increased use of restraint during these periods.

The management of a residential care facility would not allow a wife to visit her husband who had advanced dementia. Prior to COVID-19, the wife would visit her husband every day to sit and be with him and assist with toileting and showering him. With the wife's visits restricted, the husband's behaviour had become difficult for the staff to manage, and as a result, they locked him in his room, which agitated him further. An advocate was engaged to support the wife to address her concerns with the facility manager and later the head office and CEO of the residential care facility. At first, the facility resisted changing their visitation policies, but eventually the advocate was able to negotiate for the wife to visit for an hour every day.

In some instances, family members made the decision to remove their loved ones from the increasing risk of COVID-19 by temporarily caring for them in their own homes. In these types of scenarios, advocates played an important role in providing information on leave and security of

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tenure entitlements. However, it was disappointing to find that some providers tried to prevent this from happening purely for financial reasons, rather than being focused on the resident's needs.

A daughter contacted one of our members for advice on taking her mother out of a residential aged care home that was managing COVID-19 positive cases. The daughter had spoken to the management to plead the case to allow her mother to move into her home temporarily to keep her safe whilst the virus was present in the facility. Her father had died earlier in the year and so she was highly concerned about losing her mother too. Facility management would not give permission for her mother to leave stating that if she left, they would not let her back in, and they would give her bed to someone else. The advocate called management to argue the case for the mother to leave temporarily and follow the process of getting tested regularly and to isolate in her daughter's home where they would care for her. The manager was adamant that the mother could not leave as the facility would not get paid if the resident left and the facility would therefore be out of pocket. The advocate discussed options with the daughter, and she decided to continue to pay fees for however long her mother was absent from the facility. As a result, the mother was allowed to reside with her daughter without risk of losing her place in the facility.

Members observed that many residential aged care facilities maintained some very restricted visitation protocols after lockdowns lifted. For instance, some facilities did not permit visitors in the evenings; others did not permit visits longer than one hour. Some would not permit residents to venture out of the facility unless there was a medical reason; others would not allow visitors into the resident's rooms. One provider was not willing to allow a pet dog to visit their owner for fear that the pet would be a possible source of COVID-19.

Older people and their families expressed continued frustration at the inconsistencies and misinterpretations of health directions relating to visitation.

A family member called an OPAN member and stated they had been in an almost continual battle with their parent's residential aged care facility since March 2020 due to COVID-19 restrictions. The caller was concerned because the facility manager had informed her they would consider applying for a restraining order if she and her family continued to complain and seek to visit her parent outside of stated visiting times. Prior to the pandemic, the caller's parent had visits from or went on outings with family members on an almost daily basis. Since the beginning of the pandemic, this had been severely restricted. With the easing of restrictions, the facility had maintained limited visiting hours making it difficult for most family members to visit as often or for as long. An advocate was able to negotiate with the manager and the operations manager of the facility. The facility eventually agreed to allow the family to visit outside of the

prescribed visiting hours and reviewed their organisational decision to continue to enforce the restricted visiting hours. They also reviewed the processes for checking in visitors prior to entry, moving to an online check in system, making it easier for all visitors/families to access and sspend more time with residents.

A resident who was a smoker requested the support of an advocate after management at his residential care facility stopped him from smoking in the grounds outside of the facility. Management had stated that every time he left the building and entered the grounds to smoke, he would be required to go into isolation upon re-entering the building. The advocate supported the client to discuss the issue with the management noting that he was not leaving the grounds, the facility was his home and the resident had been accepted into the facility as a smoker and he had the right to continue smoking. The facility agreed to the client continuing to smoke outside, in the designated spot, without any further isolation requirements.

The introduction of the Industry Code for Visiting Residential Aged Care Homes During COVID19 became a useful advocacy tool used by both advocates and family members self-advocating for visitation rights.

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A resident with Post Traumatic Stress Disorder and dementia, required assistance with taking medication and eating. The resident's daughter who regularly assisted with meals was no longer able to provide support to her father as the facility introduced new visiting times, which finished at 5.30 pm - the daughter had work commitments up until 5.30pm. The daughter contacted an OPAN member, and an advocate emailed her a copy of the Visitors Access Code. The daughter set up a face-to-face meeting with management and referred to the Visitors Access Code. The daughter was very appreciative of the information provided by the advocate and as a result, arrangements were made for her to visit her father after work.

An older woman who had dementia and was legally blind, resided in a facility located in a region with Level 4 COVID-19 restrictions and was unable to receive visits from her daughter, despite the facility being COVID-19 free. Video chats and other forms of virtual technology were not an option for this resident. An advocate provided the daughter with information about the Visitors Access Code and strategies to communicate with the facility. The daughter referred to this resource whilst self-advocating and was eventually able to visit her mother in her room.

An advocate received a call from a very distressed daughter whose mother had gone into palliative care in a residential care facility after a staff member had called to say that her mother was at the end of life. When the family arrived at the facility to say their goodbyes the manager was very reluctant to allow the family of four to enter the facility. They had initiated a rule that permitted only one person, per resident to enter the facility, per day. When family challenged this and requested that they all be allowed to go in and be with their dying mother, the manager refused. The advocate called the facility and discussed the matter with the manager who was unbending on these rules. The advocate quoted the Visitation and Guidelines for Residential Aged Care Facilities, but the manager said their internal visitations rules were the process they followed. However, after further discussion the manager relented and allowed the family to enter the facility to spend time with their mother before she died.

Members reported that visitation issues were even occurring in locations where there were no government directed or public health restrictions in place. Members have observed that these types of scenarios commonly occurred within organisations where a head office based in another state or territory was issuing blanket rules across all sites.

A regionally based facility went into lockdown and restricted visitors from entering the facility and residents from leaving the facility, despite there being no lockdown requirements in force in this regional area. An advocate assisted numerous individuals to address this issue with facility management. The advocate called on the support of the Aged Care Quality and Safety Commission who advised the family that residential aged care facilities can decide whatever restrictions they like to protect residents. The advocate supported the family to raise their concerns with higher level management and finally the restrictions were lifted by the CEO.

During the height of COVID-19 lockdowns, restricted visitations meant families were unable to monitor the health and wellbeing of their family members. Once restrictions lifted, many visiting family members expressed serious concerns about the visible deterioration and decline in their loved ones. Advocates were involved in multiple cases where residents had become depressed, lost weight and had their care needs neglected. These issues often related to restricted access to social supports, basic clinical care and allied health services during the COVID-19 crisis response phase.

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A 95-year-old resident had his dentures lost at the facility. The facility was adamant they were not lost and repeatedly attempted to put dentures in his mouth. The daughter arranged for a dental review where they learnt that the dentures the resident was using belonged to a female mouth. New dentures were ordered. The facility went into lockdown and the dentist advised that he couldn't visit due to lockdown rules when in fact he hadn't had a flu vaccination and therefore couldn't attend. The dentist didn't make the family aware of this. Without teeth, the resident was only able to eat pureed food. Since late March, the resident has lost weight, from 90kgs to 48kgs. The resident is now palliative, bed bound with difficult to manage pressure sores. He has fallen out of bed the last four nights and the facility has advised that they can't install a bed rail due to it being a restraint. They report that they have tried all other measures with a final suggestion by the GP that the resident be prescribed medication "so that he won't feel pain if he falls from bed again".

A family member sought the support of an advocate when their family member, who they had been unable to visit during lockdown, appeared to have an infection in her foot. They reported that the nurses at the facility thought the foot looked fine and would not do anything about it. Eventually the nurses emailed a doctor about the resident's foot and the doctor also advised that the foot looked fine. The family member organised a telehealth appointment with her doctor who advised that they take the resident to hospital straight away. At the hospital it was identified that the resident had gangrene and after having her foot operated on, the resident sadly passed away.

During this period, the Aged Care Quality and Safety Commission closely monitored residential aged care facilities involved in COVID-19 outbreaks. A small number of these facilities failed to meet the aged care accreditation standards and were either sanctioned or closed. Members played an active role at both sanction and closure meetings providing information about advocacy and aged care rights and responsibilities including the resident's right to choose where they will live and the provider's responsibility to maintain the facility until alternate accommodation has been secured for all residents. Advocates also supported several individuals to relocate to alternative residential care facilities.

OPAN members provided significant efforts in connecting with older people and families during lock downs when there was an outbreak. OPAN held numerous resident and family meetings via Zoom when a facility was affected by a COVID-19 outbreak. This practice initiated by OPAN during the first wave of COVID-19 outbreaks in aged care has now seen as best practice with communicating with residents and families during an outbreak in a facility. The approach provides residents and families an open and independent forum to receive updates on outbreak management and to raise their concerns and questions directly with the facility management,

outbreak management team, the Aged Care Quality and Safety Commission and governments directly. Senior Rights Services (OPAN member in New South Wales) have highlighted that communication is vital in ensuring that residents, families and advocates are kept informed and care recipients are reassured they are safe, and that quality of care and services are maintained. Concerns regarding vaccination levels, continuity of care, quality of care, communication, mental wellbeing of residents, physical activity and social isolation were all raised during these meetings. Families also provided positive feedback to the aged care facility staff and management when they believed communication was working well and when confidence in the quality of care was able to be reassured.

OPAN developed an informational newsletter on aged care rights, COVID-19 restrictions and coming out of COVID-19. This newsletter was distributed to every older person in aged care across the country throughout May 2021.

Whilst advocacy support during COVID-19 primarily addressed issues within residential care, advocates were also involved in a number of community-based advocacy cases. Often these cases related to providers withdrawing services to home care consumers, or the consumers cancelling services out of fear that they may contract COVID-19 via their care workers. Members also reported issues with older people accessing household supplies such a groceries and medication. These types of issues were often easily resolved through the provision of information on services offering support with grocery shopping and home deliveries of food and medical supplies.

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Members observed that many providers of the Commonwealth Home Support Program (CHSP) reduced their social support services in response to COVID-19 restrictions. A number of older people shared with advocates that they felt lonely without access to their regular CHSP social supports. Advocates offered to connect several socially isolated people living in the community with services such as Red Cross Telecross service, FriendLine and the COVID-19 Older Persons COVID-19 Support Line, of which OPAN was a partner agency along with COTA, Dementia Australia and National Seniors. Some members have expressed concerns about the longer-term effect of COVID-19 on social clubs catering for older people. A number of these clubs have cancelled all their events until post June 2021 due to concerns about social gatherings and the costs incurred by unexpected event cancellations.

Finally, members reported that their ability to deliver NACAP education were significantly reduced during the peak periods of COVID-19 outbreaks. Members flagged concerns that some residential aged care facilities appeared to be using COVID-19 as an excuse to not allow NACAP education even during periods where the risk of COVID-19 had subsided. Despite this, network members continued to receive an increased number of calls for both information and advocacy support with OPAN's national information and advocacy figures increasing by 10.6% between 2019/20 and 2020/21.

It was noted that extended periods of COVID-19 related lockdowns made it difficult for advocates to travel out to regional, rural, and remote locations as they normally would. Travel restrictions made it particularly difficult for advocates to engage in regular face to face connection with various Aboriginal and Torres Strait Islander communities, and this was likely to impact on building and maintaining relationships between members, community members and organisations.

Digital delivery of education through OPAN's webinar series has seen around 41,000 participants across 70 webinars since the COVID-19 pandemic began. OPAN members have also been providing education online and via Zoom meetings. However, this digital delivery does not suit all older people and it is particularly challenging for the older people to be aware of the webinar and be supported with digital access while in an aged care facility. Some aged care homes, where there is an ability for older people to congregate within the aged care home, are now bringing older people together to watch the webinars or to participate in the meetings directly with members. This practice by aged care providers is welcomed and encouraged. However, older people have advised OPAN and members that their preference is for face-to-face education.

The Abuse of Older People

This year, the COVID-19 pandemic created an environment where older people experienced increased risk of abuse. Community lockdowns, social distancing measures and visitor restrictions in residential aged care resulted in:

- Less social visits from family and friends.
- Less opportunities for older people to connect with people and services outside of their place of residence.
- Increased loneliness and social isolation.
- Increased emotional and financial stress for caregivers and family members.
- Increased reliance on others to purchase and deliver groceries and essential supplies.

Advocates expressed concern about the potential for COVID-19 lockdown abuse, noting that older people may not have had the ability to ask for help if they were confined or socially isolated. Whilst calls for assistance with abuse where lower during peak COVID-19 outbreaks, as restrictions eased, some members observed an increase in calls for information and support.

Common abuse scenarios during the COVID-19 outbreaks included family members moving into the older person's home without their consent and financially abusing and neglecting them by not providing the care they said were going to (often whilst claiming carers payments).

Advocates also observed cases of financial abuse in circumstances where older people relied on others to purchase essential items for them, trusting family members or friends with their bankcards. The misuse of finances in these types of scenarios saw some older people enter financial hardship with unexpected debts to pay.

More broadly, the misuse of Enduring Powers of Attorney and/or Guardianship has been an underlying factor in many abuse related

advocacy cases. Members have witnessed many occasions where the misuse of an Enduring/ Power of Attorney has ended in the abuse of an older person's funds, and their right to autonomy, choice, and wellbeing. Advocacy casework in this area is often complex with factors such as family dynamics and a lack of understanding of varying levels of decision-making capacity in different domains coming into play.

An OPAN member was involved in an ongoing case where a daughter living overseas was misappropriating her mother's funds. The mother was from a Culturally and Linguistically Diverse (CALD) background where English was not her first language. The mother was reluctant to revoke her daughter as Power of Attorney, as she was fearful that her daughter would disown her, never call her or visit her once COVID-19 related travel restrictions were lifted. The mother was in residential care and was unable to continue to afford the fees due to the money being used by her daughter.

One of the most noticeable trends in abuse advocacy case work over the last year has been unwanted admission into residential aged care.

An OPAN member supported a woman who was moved interstate and placed into a residential facility by her daughter. The daughter advised the facility that her mother had dementia and could no longer fend for herself. The residential care facility identified that the woman was distressed with what had occurred and referred her to an OPAN member. An advocate met with the woman and identified that prior to being moved interstate she had lived in the same community for much of her life, was fully immersed in the local community, regularly attended community functions, had community services in place and maintained connections with many close friends. Through discussion with the woman the advocate gradually learned that her three children had a disagreement and their relationships had broken down. Two of the children had joint Enduring Powers of Attorney. The daughter that was not an attorney had explained to her mother that she wanted to be put on the documents because she currently did not have a say on what happened to her mother. The mother went to the solicitor to add her third child to the document; however, a new document was drawn up only in the daughter's name. This is how this woman ended up being moved interstate and placed in a residential care facility. The advocate worked with the woman by arranging a visit to a geriatrician who assessed her as capable of making her own decisions. With the support of an advocate and a solicitor she revoked the current Enduring Power of Attorney and replaced the other two children. A family meeting was arranged for the client with an advocate present to assist in discussing what had happened and the woman's desire to return to her home and community. The following morning the woman drove back to her home to resume her life within her community.

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Cases of unwanted admission into residential aged care have often involved Enduring Powers of Attorney/Guardians placing an older person into residential care following a hospital visit, or an Enduring Power of Attorney/Guardian informing an older person they are attending residential care for a short respite stay and then permanently admitting them into residential care against their wishes. In some instances, the older person's assets and possessions have been sold or given away without consultation or consent.

An OPAN member received a referral from a residential aged care facility with a request that a client wanted support from an advocate to help her through an issue she had with her daughter who was her Enduring Power of Attorney. The daughter had arranged for her to go into the facility suggesting that her mother had advanced dementia and was not able to live by herself anymore. This had occurred after the client was admitted to hospital and was showing signs of confusion and paranoia. The medical team at the hospital had originally thought she had advanced dementia; however, it was later identified that her symptoms were associated with a severe urinary tract infection. After a number of weeks of treatment, the client had regained her clarity, however her daughter had arranged for her to enter the facility on a permanent basis. This was when the case was referred to the OPAN member. When the client met with the advocate, she told the story of how she had arrived at the facility with no clothes, no personal items and no keys to her home. The client had asked her daughter to allow her to go home and collect various possessions that she needed, but the answer was no, you will not go back to the house as it will be sold, and your possessions are being given away to friends and family. As the client's health progressed and started to get better the advocate requested an assessment from a geriatrician. The advocate phoned the daughter and granddaughter for a family meeting to discuss this situation, as the assessment came back from the geriatrician that the client had regained her capacity to make her own decisions. This information upset the daughter and said she would not attend a family meeting. A day later the daughter returned the keys to the client's home, along with a letter stating a withdrawal of the Enduring Power of Attorney. The granddaughter and the client had a meeting with the advocate to organise a trip to the client's home to get what was needed and a decision was made that the granddaughter would become the Enduring Power of Attorney. The advocate continued to support the client and the grand daughter to work out what was going to happen next including accommodation, the client chose to stay as a permanent resident and put sale of her home into the hands of her lawyer.

OPAN members have indicated that the limited availability of home care packages is influencing the ongoing push towards residential care, with many families and their representatives fearful that the older person will be seriously injured or die at home without access to the appropriate supports. Queensland member ADA Australia

notes that many of the older people they have supported in this type of scenario have had some form of cognitive impairment but have still been able to clearly articulate that they want to go back home and are willing to accept any associated risks.

Once in residential care, advocates report that the limited availability of home care packages makes it very hard for older people to return to their homes. Aged Care Assessment Teams in some regions have even informed advocates that they will not assess older people living in residential care for community-based care, as they would be taking a package away from someone already living in the community.

An elderly resident has been in aged care for 6 months, and she wishes to go home. The advocate listened to her story and ascertained that her nephew has Enduring Power of Attorney for financial matters, and he thinks it best she remains in the aged care facility. The resident does not have an appointed Guardian to assist with lifestyle decisions such as accessing aged care. [1] *The woman was quite coherent and expressed herself well during three calls with the advocate. The woman had been assessed as eligible for Level 4 Home Care Package, but none were available in her area, and she cannot manage at home without this level of care.*

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[1] In some jurisdictions Enduring Powers of Attorney are limited to finances with Enduring Powers of Guardianship covering decisions relating to lifestyle which means that an Enduring Power of Attorney cannot legally consent to admission to residential aged care.

At times advocates find it difficult to access and provide advocacy support to older people experiencing family abuse whilst living in residential care, particularly when they have an enacted Enduring Power of Attorney and/or Guardian[2] in place. In many cases, the providers of residential aged care wrongly believe it is their obligation to inform a substitute decision maker when an advocate has been present. This can sometimes make the older person feel fearful or reluctant to access support for concerns relating to their Enduring Power of Attorney or and/or Guardian. [2]

Members have raised concerns about how often residential aged care workers unknowingly support the abuse of residents because they are simply unaware of rights of people who have substitute decision makers in place or of the limits of the different instruments relating to administration and guardianship (which vary across Australia). Advocates also report that staff often have limited understanding of supported decision-making principles and frequently take direction from Enduring Powers of Attorneys or Guardians without engaging the older person in discussions about their views and preferences. In some instances, residential care staff are taking direction from a substitute decision maker who is not authorised to make decisions.

An OPAN member was approached to advocate for a client who had recently experienced a stroke and was living in residential aged care. The client's Power of Attorney (POA) was being very hostile with other family members and had banned them from visiting the client. The advocate organised a meeting with the client and the manager of the facility. At the meeting the advocate informed the manager of the scope of the POA's authority and the rights of the client. [3] The advocate then supported the client to express his wishes regarding other members of his family visiting him. The client's views and wishes were documented, and the staff of the facility now support the client to see all his family and play an active role in ensuring that the POA does not overstep their legal rights.

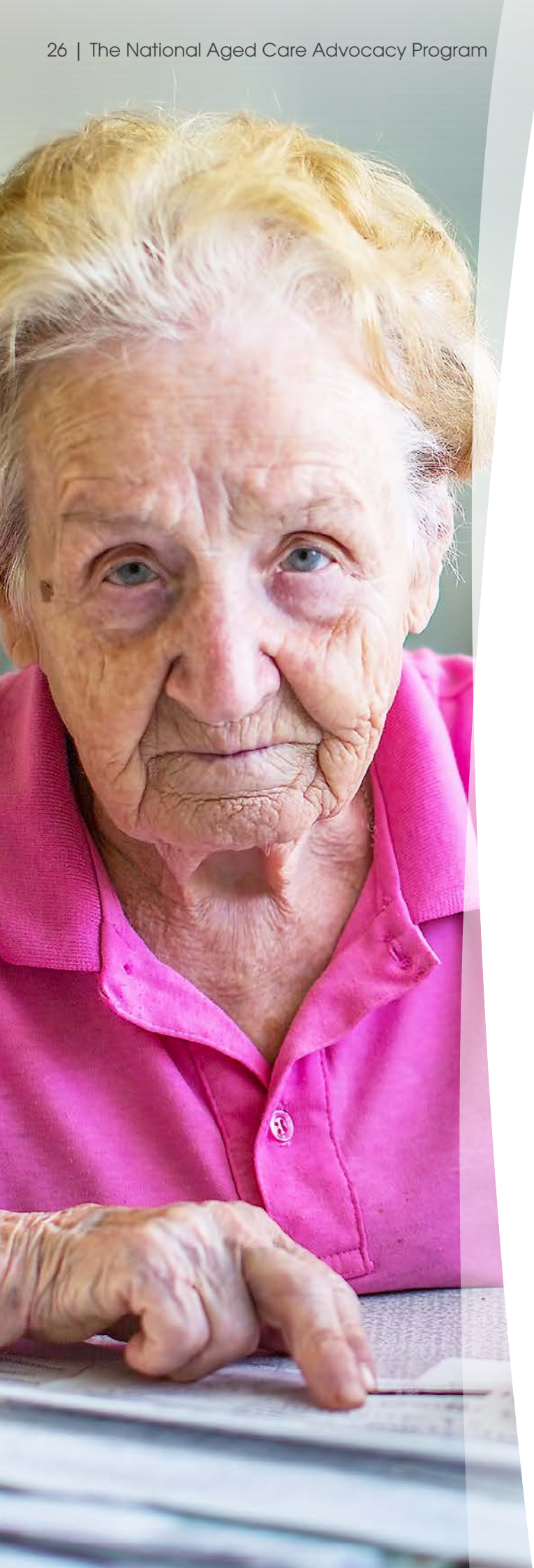
Issues relating to neglect and abuse in residential aged care are an ongoing concern. One member noted that it appears that providers often do not recognise the various forms of abuse occurring within their facilities and only consider the instances requiring compulsory reporting such as unreasonable force and unlawful sexual contact to be abuse. Issues relating to quality of care and neglect are explored in greater detail in the residential care section of this report.

OPAN is hopeful the new Serious Incident Response Scheme (SIRS) will help to shift providers approach to abuse and neglect. Throughout the year OPAN members have been informing advocacy clients about the introduction of the SIRS in April 2021.

A resident had told his family he was hit by a staff member. The family arrived to investigate what may have happened. Staff denied any wrong-doing but there was a deep wound which was bleeding on his ankle and flesh on the walking frame. Staff decided a doctor did not need to be called, but the family insisted, and a GP came and reviewed the injury. The family asked to speak with the care manager who said they would review the time and look at camera footage outside the room. They later told the family there was no evidence of wrongdoing. The advocate provided the resident and his family with information on aged acre rights, incident reporting, duty of care and complaints mechanisms. The advocate encouraged the family member to report the incident to the ACQSC and explained the role of the new Serious Incident Response Scheme starting early 2021. The advocate suggested a letter to the provider requesting for a meeting to discuss the incident, obtain reassurance that staff will be more careful approaching residents and to request a copy of the incident report. The family indicated they felt confident to do this and would get back to the advocate if more assistance and representation was required.

[2] Legislation relating to the powers of Enduring Powers of Attorney and Guardians, and Administrators is state and territory specific.

[3] In some jurisdictions, such as Victoria, Enduring Powers of Attorney have authority to make both lifestyle and financial decisions



My Aged Care

In previous years, advocates have experienced challenges supporting clients with their journey through My Aged Care (MAC). Advocates were often not recognised as a representative of the older person and had limited access to client information available through MAC systems.

In late 2019, the Department of Health and OPAN worked collaboratively to introduce an Advocates as Agents pilot. The aim of this pilot was to provide Advocates with the ability to act as a conduit between the older person and My Aged Care and make it easier for older people to receive the support they need.

The pilot engaged over 70 advocates, Aged Care Navigators and specialist support workers as registered 'Agents' that were able to:

- View and update client information through the My Aged Care client portal on the older person's behalf.
- Speak with, and provide information to, My Aged Care, assessors, and service providers on behalf of the older person.
- Receive information about the older person's progress in the My Aged Care system, for example in an application process.
- Facilitate and enact decisions made by the older person about their aged care assessment and referrals for services.
- Be a point of contact for information on assessment and services.
- Receive letters for older people receiving or applying for home care.
- Receive phone calls on behalf of the older person from My Aged Care or providers.

The Advocates as Agents pilot continued as a valuable service during 2020-21, with advocates reporting the pilot has enabled them to resolve and clarify issues in a timelier manner, and this often resulted in more timely outcomes and positive results for the clients.

Network members also report positive experiences with using the additional support available through MAC case managers, particularly during COVID-19 outbreaks. Advocates found they were often able to achieve greater outcomes for clients when engaging the social work support of a MAC case manager. The MAC case managers were often able to connect the older person to additional emergency supports, referring them directly to a provider without an assessment where possible, and providing supports to the client that were outside the scope of the advocacy role.

Network members report one of the greatest presenting issues relating to MAC over the past year has been older people and their families/ representatives finding the system complex, confusing and difficult to navigate. Members have suggested that this issue is particularly evident in rural and remote areas where internet access is limited and within Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse communities.

Network members are finding that people are often not aware of how to access aged care supports and, in many cases, have not heard about MAC. System navigators have been a great referral point in these circumstances; however, advocates continue to provide information and support to understand and access the aged care system in communities where system navigators do not have a presence. Members report the Advocates as Agent trial has made this process easier.

An older women contacted an OPAN member in need of assistance to access transport services and support in the home. She did not have access to internet and did not have knowledge of the aged care system. An advocate identified that there were no system navigators available in her local area to provide information and support to access the needed aged care services. The advocate arranged to call MAC on three-way call and assisted the woman to answer the questions required. Afterwards the advocate advised the woman to write down the MAC reference number and start to collect information in a file. The woman called again later and noted she was unwell and requested further assistance from the advocate. The advocate used their Advocate as Agent registration to access MAC and continue the process of accessing services.

An older Italian man phoned an OPAN member for assistance. An Italian interpreter was engaged and an assessment over the phone ensued. The man was unsure if he had previously been assessed or whether he was currently receiving any services. In the discussions with the advocate, it seemed that he did have a support worker come once a week, on a day and time that did not suit him. With the client's permission the advocate called MAC as an Advocate as Agent and was informed that the client's

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approval for home care package came through just that day and he could now contact a service provider and engage services. This case was recognised as a good referral to the Aged Care Systems Navigator multicultural trial site in the client's local area. The System Navigators arranged a face-to-face meeting with client to assist him to access services which he needs and chooses.

A client from an Aboriginal and Torres Strait Islander background was looking for support services and did not know where to begin the journey into aged care. She had heard about her local OPAN member from an acquaintance who had been provided information regarding a session on My Aged Care in a local community group. She phoned the member, and an advocate explained the process of signing up with My Aged Care for an aged care package. Being of Aboriginal or Torres Strait Islander descent she was able to enter My Aged Care even though she was under 65 years of age. The advocate supported her to speak to a My Aged Care representative and explained that she will have to have an assessment before she receives a support package. A referral was sent through to My Aged Care enabling an appointment to be made for an assessment. The client has now received a package and is being supported to live as she chooses in her community.

Some advocates and navigators have observed that several Aboriginal and Torres Strait Islander clients aged under 65 years are being declined for My Aged Care (MAC) referrals and aged care assessments until they can provide evidence they have applied for and been declined supports under the NDIS. In these cases, advocates and navigators have contacted My Aged Care or the assessment agencies to find out why they are declining the assessment and request documentary support for their decision. This has resulted in the assessment being completed and the client being referred for aged care services.

Members also reported lengthy delays in MAC arranging Translating and Interpreting Services (TIS) and other interpreting services for clients. One member shared that they waited over 30 minutes while MAC tried to access an interpreter for an Aboriginal man they were supporting. MAC refused to allow the man's daughter to provide this assistance until it become clear they would not be able to source an interpreter for his language group. This delay placed significant stress on a vulnerable older person already struggling to understand the system and the processes involved in accessing the system.

Advocates have highlighted the importance of providing timely and appropriate access to TIS services noting that access to interpreting services can influence whether older persons from diverse backgrounds access aged care services.

An OPAN member worked with a client who advised that English was not their first language. The advocate noted it was difficult to explain the aged care system to this client, but with the help of an interpreter they soon realised the client needed services in place so she could continue to live in her home. The advocate supported the client to apply to MAC and they were assessed and approved for a home care package. As the wait list for home care packages was long, the advocate supported the client to access CHSP funding as an interim measure. The advocated reported that the interpreter was beneficial in the case as the client's understanding of home care was not clear and was critical in their journey in accessing services to assist her to remain living safely in her own home.

Advocates have also stressed the importance of MAC call centre staff being trained in working with interpreters.

Some members have reported that the cost associated accessing care in the community can be a barrier to some clients progressing further with the MAC and accessing aged care services.

We have just started working with several clients from a CALD background and they are all seeking help to get into the My Aged Care system and to understand the 'system'. We are regularly supporting clients to understand the difference between CHSP and HCP. We have found that when MAC and ACAT assessors tell clients that they have to pay daily fees – they are given a figure and the client panics and states that they don't want the assessment or to register with MAC because they can't afford the associated fees. Breaking down the affordability barrier is a big part of the advocacy work we do.

OPAN and OPAN members are pleased with the increased awareness of NACAP and OPAN by MAC staff following the development and delivery of MAC contact centre staff in relation to advocacy and rights in 2020. However, most members have reported that they still receive many inappropriate referrals from MAC. Inappropriate referrals include issues outside of the scope of the NACAP (for example, personal debt). Members have also observed that they often receive referrals when MAC call centre staff are unable to answer general aged care information, or because the caller has become frustrated with MAC. Many older people express frustration at being referred to a service that is unable to assist them.

A 93-year-old man requested an assessment and was advised by MAC that there would be a wait time of a couple of weeks. The man wanted the assessment immediately and didn't understand why he had to wait and so MAC referred him to an OPAN member. The member was unable to assist the man as there is nothing an advocate can do about MAC wait times. The man expressed frustration for being inappropriately referred to OPAN. Advocates have suggested that MAC call centre staff may benefit from some further training around the aged care systems and the role/scope of the NACAP.

Assessment Services

Member reports indicate that the availability of Commonwealth Home Support Program (CHSP) services and home care packages has had an impact on assessment services during 2020-21. Scenarios demonstrating the flow on effect of service shortages include:

- Older people with entry level needs requesting an Aged Care Assessment Team (ACATS) assessment over a Regional Assessment Service assessment because they have heard about the long waitlists for home care packages and want to get on a waitlist for a package as soon as possible.
- Older people with high care needs have been inappropriately referred for RAS assessments and informed that they will be able to access care needs faster through the CHSP. In these circumstances, the older person is later referred for an ACAT assessment. This process means the client participates in multiple assessments.
- Older people referred for a RAS assessment are declined requested CHSP services, and instead are directed to purchase aids or equipment e.g., declined domestic assistance and directed to purchase a particular type of mop and/or vacuum cleaner.
- Older people placed in residential care against their will are unable to access an ACAT assessment to support their return to the community.

Advocates have played an active role in supporting clients to access the assessment and services they need, as demonstrated in the case studies below.

A client from a CALD background with a high risk of homelessness was referred for a comprehensive assessment by both his GP and social workers at the hospital. The client experienced frequent hospital

admissions associated with dietary, lifestyle and medication choices. An advocate was engaged to support the client to register with My Aged Care. The advocate was able to "follow" the referral and when the client was informed, he would only receive a RAS assessment the advocate was able to ensure the referral was returned to the ACAT with support from GP. The ACAT approved the client for High Priority Level 4 home care package and interim high level of support via Short Term Restorative Care (STRC) and CHSP. The Advocate was also able to negotiate with ACAT to also provide an immediate referral code for Assistance with Care and Housing (ACH) to support the client to find alternative safe accommodation.

A Care Leaver/Forgotten Australian with multiple chronic conditions and a history of homelessness was referred to an OPAN member for support to find accommodation and community supports. An advocate referred the client for a comprehensive ACAT assessment. Instead the client received a RAS assessment and was offered CHSP services. The client declined all services offered because he could not meet the service requirement of a fixed address. An advocate was able to assist the client to request and eventually receive the comprehensive ACAT assessment, which he had originally been referred for. The advocate also connected the client with a local organisation to assist with emergency housing. Once housing was established, the client was able to access some CHSP services whilst waiting for a home care package to become available.

In some jurisdictions, advocates report challenges in engaging ACATs to reassess people already receiving a home care package. In Queensland for example, the wait time for an ACAT assessment was extended from 12 weeks to 16 weeks. The Queensland ACAT also stated that they would not accept a referral/reassessment unless documentations such as the client's current care plan, budget, and home care package request forms were provided in advance.

Phone based assessments were identified as another area of concern relating to assessment services. Members report that assessments are increasingly being carried out over the phone and as a result, body language and communication subtleties that are normally captured in face-to-face assessments are being missed. Further to this, communication barriers such as hearing impairments mean that in some cases assessments cannot be completed. In some instances, advocates have had to step in and support people to complete a phone-based assessment.

A couple from a regional community sought face-to-face advocacy support after they were unable to engage with an assessor on the phone due to hearing difficulties. The couple shared that the experience left them feeling frustrated, fearful, and disempowered at a time when they needed to reach out to strangers for help. Having an advocate based in their region meant that the advocate could provide the face-to-face support required to assist the couple to be assessed and access services.

Commonwealth Home Support Program

One of the greatest challenges advocates have identified within the Commonwealth Home Support Program (CHSP) during 2020-21 has been a lack of service availability. Multiple jurisdictions have reported challenges accessing CHSP services, identifying domestic assistance, home maintenance and home modifications as the most difficult services to access.

ADA Australia (OPAN Queensland member) consistently reported that there was no funding and no service availability across almost all CHSP service types in metro, regional and remote areas of Queensland, noting that many older Queenslanders simply had to go without services.

ADACAS (OPAN ACT member) shared stories of clients in the Australian Capital Territory who were in urgent need of CHSP supports but were declined services due to a lack of funding. These clients were being encouraged to contact My Aged Care about a Home Care Package, despite there being a wait time of over a year for Home Care Packages.

ARAS (OPAN South Australia member) expressed concern for older people in South Australia requiring home modifications, reporting a two-year wait time for the occupational therapy (OT) assessments required to access home modifications services. ARAS have observed that lengthy delays in accessing modifications to the home can have a significant impact on an older person's ability to maintain living independently in the community, as home modifications are often adopted as a falls prevention strategy. ARAS note that the long wait times are reportedly due to a scarcity of OT graduates entering the aged care sector, with most finding employment with children's services or NDIS.

In response to these access issues, some South Australian local councils have sought to install grab rails for older member of the community in circumstances where there are immediate safety concerns. Meanwhile, in Queensland, ADA Australia advocates have been trying to assist clients to access volunteer run or state funded services such as Home Assist, however in some areas there are no alternative options available.

Members note the ongoing lack of CHSP services is also impacting on the right of older people to exercise choice in selecting a service provider. This lack of choice is particularly evident in regional and rural communities.

> *An advocate was assisting a client in a very small town to access CHSP domestic assistance services from a new provider, as her current provider was unreliable. MAC suggested three potential service providers in her local area that could assist with domestic assistance. Out of the three suggested service providers, only one of the service providers had CHSP domestic assistance funding available. This service provider was the provider the client was already receiving services from and had deemed unreliable.*

OPAN members often attribute issues with CHSP service availability to the ongoing under supply of Home Care Packages, which sees many older people with medium to high-level needs accessing interim CHSP services for extensive periods, whilst they wait for a home care package to become available. However, it is also acknowledged that in some areas workforce shortages are having a significant impact on the availability of CHSP services.

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Members have also been involved in a number of advocacy cases where a client's regular CHSP staff and service times have been changed by the provider without any client consultation.

A client who had been receiving regular weekly CHSP services from the same worker for over five years was informed, by their worker on their last visit, that the provider was changing how they scheduled services and would be introducing a new worker. This change occurred without consultation with the client. The OPAN member received several complaints from clients of the same provider about similar issues - change to care without consultation. The provider informed these clients that there would be no exceptions and all planned changes would take effect as part of the provider's long-term plan to reduce the travel between workers and clients. The OPAN member was able to support a small number of clients to retain their regular workers and services, after a protracted complaints investigation by the Aged Care Quality and Safety Commission. During the period of investigation, several care recipients withdrew their complaints and accepted the changes, citing concerns about possible retribution from the provider.

A CHSP support worker informed a client that they would no longer support them to go shopping and from now on, the client would have to provide the worker with a shopping list that they would action. The client tried addressing concerns about these changes with their provider, but the provider would not return their calls or respond to emails. An advocate was able to contact the service provider who advised they were facing significant staff shortages and had made the decision to roster staff for "essential" services only. The advocate informed the provider that these types of decisions should be discussed in consultation with clients and with appropriate written notification provided before the changes are implemented. The advocate also highlighted that the provider had an agreement with their funder to provide a range of services, which should meet the standards outlined in the CHSP Guidelines. The provider agreed to review the proposed changes and the client had their shopping service reinstated.

OPAN and its members are concerned that some older people have started to consider a move into residential aged care, as they cannot manage without access to reliable home supports. It should be noted that this level of concern has been observed in both metro and regional locations.

Home Care Packages

Extensive waiting periods for home care packages have been a well-documented concern over recent years. This trend has continued in 2020-21 with members reporting they received many calls relating to older people being unable to access the level of care and support appropriate to their assessed need.

Many older people reported frustration over home care package wait lists, whilst their informal carers expressed desperation when discussing the challenges they faced in supporting a friend or family member to remain living independently with minimal support from the aged care system. Numerous people received interim level home care packages, but often these interim packages have been inadequate in meeting their needs.

Many reported that their needs became greater whilst waiting for a home care package and they did not know what to do or who to contact for help. Members have observed that numerous older people have accessed residential aged care prematurely because community care options are simply not available to them.

Mrs H's husband died suddenly in 2019. Prior to this time Mr and Mrs H were living independently, were in good health and did not use any support services. They preferred to be independent and were active in their community. Mr H, a fit and active 85-year-old, had been performing many domestic duties, shopping, and cleaning because Mrs H was experiencing cognitive loss and was living with osteoporosis and a lung condition. When Mr H died, an ACAT assessment determined that Mrs H was eligible for a Level 4 home care package.

As no package was available, and alternatives were not suitable/affordable, Mrs H entered residential aged care. Mrs H's son expressed that he believed his mother could have remained at home with support from a home care package. My Aged Care offered Mrs H a Level 1 Home Care Package, 6 months after Mrs H entered residential care. This low-level package did not offer an appropriate level of care to support Mrs H's return to her own home.

OPAN members in some state and territories have reported that Aged Care Assessment Teams are pre-empting the unavailability of high-level home care packages and are only approving people for low level packages despite them having high level needs. In some circumstances, advocates have found it difficult to have the ACAT agree to reassess for higher levels of care.

Members across the nation have noted an increase in advocacy cases relating to home care package excluded items. Members report some providers interpret the home care package guidelines 'excluded items' section to the detriment of the older person's health and well-being. If requested items are not specifically listed in the Guidelines many providers are not approving the item for purchase, even if the item is essential in meeting the client's health needs and has been appropriately assessed and/or recommended by a qualified health professional. In these types of scenarios, the approval process can be long and drawn out and older people have expressed that they feel they have to 'fight' to be heard and have their needs met.

A client had difficulties receiving the medical bed that suited her needs. She has now been approved for the bed she wants but it has been a lengthy and distressing process ensuring the occupational therapist and the service provider would listen to her needs and approve the bed she needed.

A 94-year-old gentleman was told that the package funds could not be used to pay for a new set of dentures and that he would have to go on the public dental wait list. The wait list for public dental is currently 4 years.

A full-time carer requested that home care package funds pay for a trolley to move heavy equipment and waste associated with the care recipient's renal care. The request was denied by the provider who considered the trolley as a benefit to the carer not the older person.

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A woman on a Level 2 home care package needed new hearing aids and because she has a condition which limits hand movement and dexterity, she requested the new devices to be provided from her package. The provider would only approve the standard aids, but the caller knew that the standard range would not suit her as she has difficulty changing the batteries. The provider offered to include changing batteries twice a week with her home visit. The woman argued that the batteries stop working at any time and cannot predict when this may occur and cannot be without her hearing. An advocate gained approval to call the provider and discussed the home care package Guidelines and the client's right to consumer directed care and support to maintain her independence. A call was also made to Hearing Australia who reported that some providers will not approve aids that clients have been assessed as needing, and others do and suggested the best option was to change to a home care package provider that will support their needs.

Some home care package recipients were advised by their provider that their package funds could no longer be used to pay for certain items that were included previously. Others have been placed in a difficult situation whereby their provider originally said yes to a particular item being purchased but when the funds were required, or a reimbursement sought, the provider changed their mind and deemed the item as an excluded item. Unfortunately, some of these cases have impacted on the care recipient's security of tenure.

A client had been receiving services from a provider for over 4 years and had made a number of purchases for equipment during this time. After an accreditation visit, the provider changed the process for purchasing from the package, introducing the need for allied health assessment prior to any purchases for equipment. The client was approved to purchase a replacement TV and washing machine by both an occupational therapist and the provider. However, when the client purchased the items, the provider refused to pay a reimbursement, stating the items were in excess of the client's needs. An advocate was able to assist the client to achieve a full reimbursement for the purchased items after a protracted discussion with provider and investigation by the Aged Care Quality and Safety Commission. A second occupational therapy assessment and report (costing the client's package $500) and a home visit by a coordinator was required as part of the process. During this 10-week process, the provider repeatedly refused to recognise the client's right to an advocate and tried to terminate the client's agreement. The advocate was able to reassert the client's rights and security of tenure.

A client wanted to have their bathroom turned into a wet room as their health was declining and their bathroom was not suitable. This issue had been going on for 3 years before the client sought advocacy support. The original occupational therapy assessment suggested a modification that would cost $25,000 however the client was told by the provider they could get their own quotes as they were from a licensed builder. This was also stated at a meeting where the advocate was present. The client had saved over $10,000 in his Level 1 Home Care for the bathroom renovation. The client came with quotes for $10,000 for the provider to approve. The provider requested a meeting with the client and asked that the client's advocate not attend but the advocate still attended. At the meeting the provider's major modifications team said that by using a builder the client had sourced himself, the building work would not have warranty and so they would not approve the modification. The provider then claimed that they had never informed the client that they could use their own quotes. The issue has since gone to the Aged Care Quality and Safety Commission who have indicated that the case should result in a positive outcome for the client.

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Members report that providers are increasingly advising advocates that the "department" have said no to particular requests. One provider put in writing to a member that they have been advised by the department that they now need to "hold evidence of reasons for the consumer not understanding the HCP guidelines" the provider then went on to state that this is difficult as it "depends on consumer's perspective versus the provider's perspective". Some providers have taken a particularly strict stance on excluded items following quality audits.

We have been involved in several cases where service providers have been deemed non-compliant for approving items outside of the scope of the home care package program, and as a result they will no longer approve anything that isn't specifically listed as an approved item in the home care package Guidelines. We are finding it much harder for clients to have items in their package approved that are specifically listed in the guidelines but are meeting the client's health needs and have been appropriately assessed and recommended by a health professional. Such items have included specialised skin emollients, taxi vouchers, particular hearing aids, membership to a gym for the purpose of accessing hydrotherapy and fixing a wheelchair hoist which assists to get the vehicle into the car.

Issues with staff was another top advocacy issue in the home care package space during 2020-21. Common themes relating to staffing have included a lack of consistency in support staff, frequent changes to case managers/coordinators, and a lack of communication from managers/coordinators. The examples below are typical of a number of advocacy cases in this area.

A client stated he had been trying to contact his case manager, but they didn't return his calls or emails. He later found out they were on leave and the relief case manager had not been informed of his calls. Client stated he has had several case managers since he took up his package and it was difficult to communicate with all of them.

An advocate was engaged to provide assistance to meet with a home care package provider and request that a particular support worker be banned from visiting a client due to suspected abuse of the older person. After this request was made the support worker in question was reassigned to work with the client again after just one week had passed. The client reported that the support worker was rude and ignored the client's interactions when providing support.

Members have identified workforce shortages as an underlying issue associated with the lack of consistency in support staff and frequent changes in case managers/coordinators. Members have expressed concern that workforce issues are starting to result in home care providers not being able to fulfil client care plans. It appears that there are a number of providers who do not have enough support staff or contracted services on their books to meet the assessed needs of older people requiring care. Some home care package providers are declining to accept new clients due to the lack of support staff available to provide the service. OPAN member, ERA has heard of older Victorians

having to wait an additional 4-6 weeks for home care package services to commence due to there being insufficient numbers of support staff available to deliver personal care, shopping assistance and basic cleaning services etc. ERA note that CHSP top up services are not available to fill the gaps, as the CHSP faces similar workforce challenges.

Some members have noticed a trend in Home Care Providers referring to staff shortages as the underlying reason for terminating a client's home care package. Members such as ADA Australia in Queensland and ERA in Victoria have flagged concerns that some providers may be using sector wide workforce shortages as an excuse to apply security of tenure provisions to clients that have a history of being challenging to support. Members are particularly concerned that there is no documented requirement in the home care package Security of Tenure provisions to ensure providers support clients to engage a new home care package provider.

Issues relating to home care package fees, charges and statements continue to be raised within advocacy case work across the nation. Concerns relating to high case management and package management charges are frequently raised with many older people alarmed at the administration and case management costs associated with their package.

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A care recipient rang an OPAN member to say that they were going to contact their local MP to complain about the little amount of funds that were made available in a Level 1 home care package once the service provider had taken out their monthly charges. The caller reported the government subsidy for the Level 1 home care package was $9,000, however package management charges were $426 per month, care management charges of $149.00 per month and case management costs of $98.00 per month, making total charges for the month $673.00. This amounted to $8076.00 being taken out of package per annum leaving approximately $900 to pay for direct care services. When the care recipient questioned the home care package provider on the high cost of fees and charges the provider justified it by saying "well, we have to pay staff, pay for cars, and pay rent".

Members have also received an increasing number of referrals relating to the out-of-pocket costs associated with home care package fees and charges. In many cases care recipients have incurred a debt due to poor communication and/or a service provider refusing to pay or reimburse an item they previously approved for purchase.

An advocacy client was informed by a provider that they had exceeded their home care package budget by over $10,000 and would have to reduce services and/or make additional payments to bring the budget back to surplus i.e., pay the outstanding amounts back. An advocate was able to negotiate a full waive of the "outstanding" amount after reviewing the statements, service schedule and care plan. During the investigation, it was found the client was using a 1-person assist mobility aid during daily services and the provider had been sending two staff to assist. After discussion, the provider agreed this was an organisational decision and the client had not been informed about this or the potential costs involved in having a second person assist daily. In the end, the client decided to change providers and has since received a refund of surplus funds from the former provider.

A client had purchased a 'hospital style' bed privately before changing service providers. He was informed verbally by his Care coordinator that the new service provider would reimburse him from the packaged funds in monthly instalments. A partial payment was made, no written contract was drawn up and the care coordinator resigned.

The client was left out of pocket around $3000. The new service provider refused to reimburse as:

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- *The original purchase was made before the client was signed up to the package.*
- *There was no contract or care plan written up to show that there would be reimbursement.*
- *No documentation from the coordinator that subsequently resigned.*

The client has since transferred to another service provider, and he has been fully reimbursed.

Many clients have found the terms and conditions relating to fees and charges, and service providers invoicing processes difficult to understand and at times distressing.

An older person contacted an OPAN member stating that she had been receiving invoices for several months indicating an ever-increasing debt. Two different care coordinators had managed her Level 4 home care package over a period of approximately 9 months, but neither was able to explain satisfactorily how the debt arose. Both coordinators had urged her to pay off the debt or move to another provider where the fees "might be cheaper". The older person expressed a reluctance to change service providers due to her high degree of satisfaction with the support workers. The debt had reached $3,000 and the older person stated that she could not reconcile her accounts. She sought support from an

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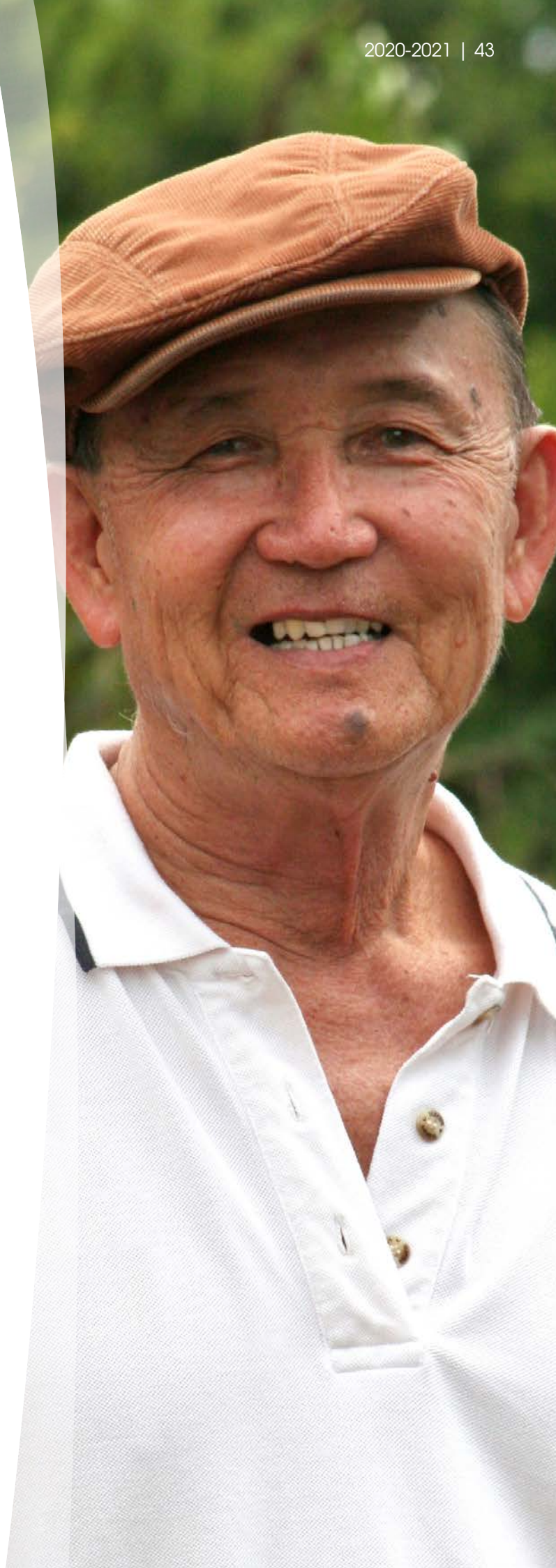

advocate stating that she had been losing sleep because she had always been good at managing her personal finances. The advocate offered the older person support to meet with the service provider. A preliminary meeting was held between the older person and the advocate where the older person highlighted a number of apparent discrepancies in her invoices and statements. With the client's consent the advocate spoke with the care coordinator who stated that the client previously had a surplus in her budget, so she bought a recliner chair. At the same time, services increased to manage a wound. This resulted in a monthly 'overspend'. The current care coordinator stated that she had attempted to explain the situation to the client and had suggested that she embark on a repayment plan. The care coordinator escalated the situation to her team leader. The advocate convened a meeting between the client and the team leader. At the meeting the advocate and client highlighted issues with the invoices and statements (e.g., terminology that was confusing, code numbers being listed rather than descriptions of services, no indication of whether a dollar amount was owing or was a credit, timetables/care plans and statements with different time notations, and no dates on documents). The advocate discussed the service provider's responsibility to provide the client with information about her care and services in a way she understood, and their responsibility to work in partnership with the client. The advocate indicated that this did not appear to happen during the previous care coordinator's tenure, and as a result the client had been placed in a risky financial situation. The advocate suggested that as an act of good will the service provider could waive the debt and review the care plan to ensure the home care package budget was not overspent. The Team Leader took this proposal to her supervisor, who agreed to waive the debt. A new care plan was developed.

A client requested some short-term additional services and was informed this would not be possible due lack of funding available in their package. The client currently received a level 3 home care package and was waiting for a level 4 package. The client called an OPAN member with her daughter who explained their concerns about not being able to afford a short-term increase in services whilst the daughter was on holiday for two weeks. They were concerned because other people they know appeared to be able to afford additional services at short notice. The advocate was able to request a current statement from provider and review the clients service levels. The advocate was able to identify and inform the client and daughter that the service provider was charging for a 30-minute medication prompt each morning, 7 days a week and this was using up most of the package funds. The advocate was able to explain the statement and show how much the medication prompt was costing and how the hourly rate varied on weekends and public holidays. The client

and daughter were surprised at this and stated the worker only stayed for about 10-15 mins at the most each morning and they had no idea this was so expensive. The advocate was able to support the client to request a care plan review and request evidence of the attendance times for the medication prompts. The provider agreed to review of medication prompt times and in recognition of lack of clarity – no written quote or information was provided to the client to ensure client understood how the package funding was going to be allocated – the provider agreed to reimburse package for time not delivered by support worker during the "30 minute" medication prompt. This reimbursement allowed for some short-term increases in services as originally requested. The client and daughter stated they would investigate other providers in the future to see if they could find a more cost-effective service.

A number of clients have contacted OPAN members distressed at the increasing costs of fees and charges for home care services. Older people and their families are increasingly weighing up the benefits of purchasing services through CHSP or privately due to the increasing costs of Home Care Packages, with several clients electing not to accept a package of care at all. Members have also observed an increasing number of enquiries regarding self-managing home care packages because the rising cost of case management and brokerage fees are affecting the level of care that can be accessed.

Transition Care, Short Term Restorative Care and Respite

Overall, members report positive experiences with the supports delivered through the Transition Care and Short-Term Restorative Care Programs. Advocates are often involved in connecting older people to these programs after a hospital stay or an incidence of functional decline and generally report that care recipients have welcomed the supports provided under these programs. However, it appears the services are not well known or utilised by the acute health system, driving people to inadequate care at home and functional decline or leaving people with limited choices regarding home or residential aged care.

The most common issue observed within these programs has been difficulties accessing transitional care in the home following a hospital admission. Advocates have observed that ACAT assessors are often encouraging clients to enter residential respite from hospital rather than transition care in the home, due to the lengthy waitlists for high-level Home Care Packages. Access to home care packages is often necessary to support ongoing care in the community once the transitional programs cease.

The move into residential respite is often promoted without discussion about other alternative options such as transitional programs and state-based post hospital supports. Members report that this practice sees many older people entering residential care prematurely, as residential respite often progresses to permanent placement. Advocacy clients that have found themselves in permanent residential care following a hospital admission have expressed feelings of having no choice or control over what was happening to them. These feelings are heightened when the older person looks to leave residential care and face challenges in accessing an ACAT assessment to support their move back into the community.

Increased access to both transitional care programs and higher-level home care packages are essential to ensure older people have more choice and control following a hospital admission and can avoid premature entry into residential aged care.

Members report advocacy cases relating to respite care during 2020-21 have primarily involved:

- Issues relating to staffing and the quality of care in residential respite.
- Access to respite, particularly during COVID-19.
- Restricted visitation in residential respite due to COVID-19 restrictions.
- Lack of transparency in the communication of possible costs for fully or partially funded respite.

Members noted that the COVID-19 environment introduced new challenges relating to residential respite with some residential care facilities not offering respite due to COVID-19 lockdowns. In addition, there have been many cases dealing with deteriorating mental health due to the restricted visitation during the COVID-19 lockdowns.

An advocate was engaged to support an older person access residential respite. When the residential care facility advised they were not accepting new respite admissions due to COVID-19, the advocate referred the facility to the appropriate state-based health directives that stated there were no restrictions preventing a person being admitted into an aged care home during lockdown. When access was granted for 2 weeks respite, the older person was advised that they would be in isolation for 14 days, even though they had isolated at home prior to the admission, had not been in contact with anyone, and was not from a known hot spot. The older person's family were concerned about the mental health of their father, but after exploring alternative respite options, they decided that the family needed a break from caring and residential respite was the best available option.

Planned respite care appeared to be difficult to book, even when COVID-19 restrictions were lifted. The predominant concerns raised through advocacy has been lack of access to respite, respite fees and charges, and a lack of transparency in the communication of possible costs for fully or partially funded respite.

A caller requested assistance to find respite for a parent who was a full-time carer for their spouse. The caller noted that their parent's Home Care package provider had informed them they would have to pay "hundreds of dollars" for respite. The case manager who had provided this information had also directed caller to the old Commonwealth Respite and Carelink Centre website and provided an out-of-date brochure. An advocate was able to the assist caller by explaining the new process for accessing residential or home-based respite and the expected costs and assisted the caller to locate a referral code from the service provider, who now agreed to help the parents to access respite.

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Residential Care

Quality of care concerns were identified as a common theme in advocacy casework in residential aged care during 2020-21. The list of issues relating to quality of care were extensive and included concerns relating to delays in calls for assistance, understaffing, food and nutrition, access to health and wellbeing services and poor clinical oversight. OPAN members have shared case studies that clearly demonstrate how unaddressed quality of care concerns, particularly those involving substandard clinical care, can quickly escalate and have a devastating effect on residents.

We have been working with a client in a residential care facility who has had an injury on his foot that has now developed into a necrosis. This man was in so much pain with this injury a meeting had to be held with the management and staff about correct pain management. On one occasion during a visit the man told the advocate he was still waiting for his pain medications which were three hours late. During the advocate's visit, a staff member came into his room and said she had forgotten his pain medications, but he could take them now. This incident was reported to the management. A written complaint was made to both facility management and the Aged Care Quality and Safety Commission.

Inadequate care planning has been identified as an underlying issue in many advocacy cases relating to quality of care. Care plans are an important resource for informing aged care staff about an older person's needs, goals and preferences and how they can be provided with individualised and responsive care.

The Aged Care Quality Standards (Standard 2) stipulate that assessment and care planning should focus on optimising health and wellbeing in accordance with the resident's needs, goals and preferences. Despite this quality directive, OPAN members have been involved in numerous residential care cases where care plans have been inaccurate and have not been reflective of the individual's care needs. In some circumstances, OPAN members have even seen care plans that appear to be describing a completely different person to the resident they are supporting.

Members report that in many cases, it is evident that care plans have not been developed in consultation with the older person or their family/representatives. Members note that care recipients and their families/representatives have also raised concerns about the lack of engagement in the care planning process, with some flagging they have never been involved in a care plan review, despite living in residential care for several years.

Advocates have flagged concerns that external factors may be influencing the quality-of-care plans in residential care. Some have suggested that the exclusive use of care planning software, featuring standardised terminology can make it challenging for some providers to develop individualised plans with nuanced interventions. Others have questioned whether descriptions of resident's physical ability, cognisance, behaviour, and dependence on staff have been exaggerated for funding purposes.

Throughout the year, advocates have provided many residents and their families/representatives with information about their rights when it comes to care planning and have:

- Supported older people to access their care planning records.
- Called on providers to actively engage the older person and their families/representatives in care planning and review processes.
- Reminded providers to seek consent before actioning a care plan.
- Requested care plan reviews and associated assessments (including assessments from relevant health professionals).

An advocate was engaged in a case where a resident was left lying in bed most days, was not being wheeled out to the common areas, not being showered due to lack of staff, their false teeth were constantly left out and they were not being supported to sit up in bed so they could see the television. The resident was not mobile and relied on staff for every aspect of her daily living. The resident's family members were upset when they visited the resident and observed the apparent lack of care. An advocate assisted with lodging a complaint to the Aged Care Quality and Safety Commission. As a result of the complaint a care plan review was requested. The advocate will support the resident and her daughter at this review.

In response to the increasing number of cases relating to care planning, South Australian member, ARAS developed a 'Your Care Plan' brochure outlining items that should be included in a care plan and what care recipients and their families/representatives can do if a care plan does not reflect the personal needs of the consumer. The brochure has been well-received resource informing residents of their care planning rights and options.

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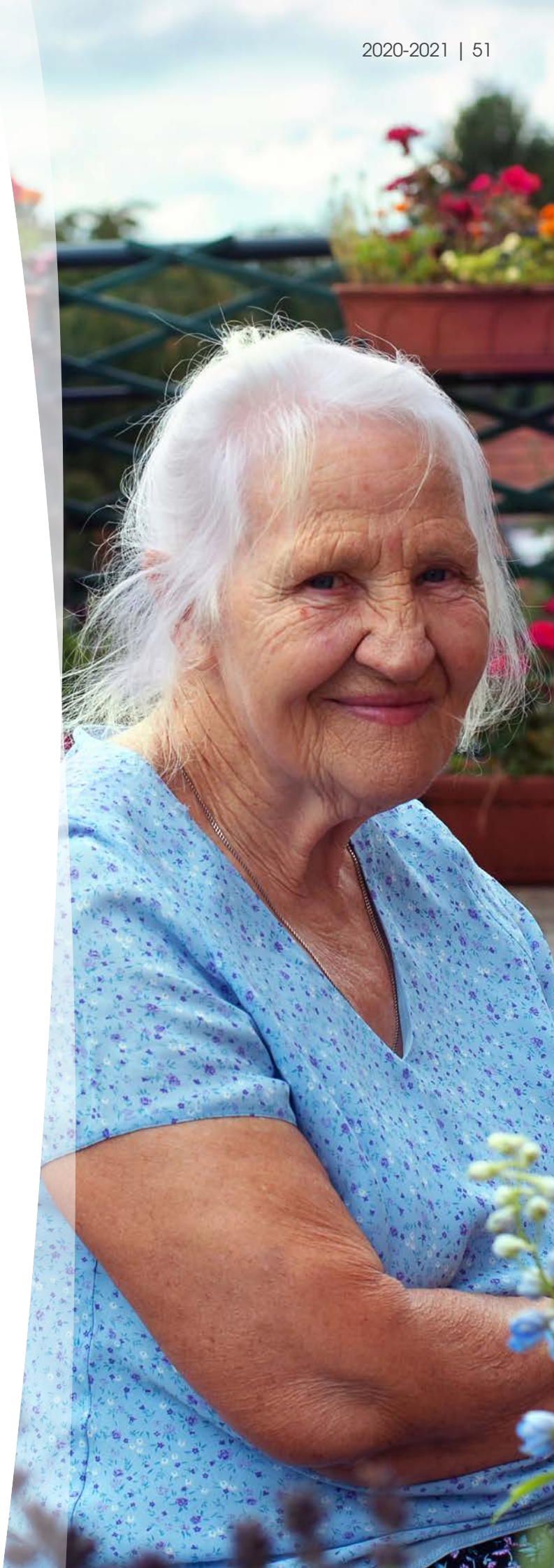
The use of restraint is another concerning theme that emerged within advocacy case work in residential aged care. Chemical restraint appears to be the most common form of restraint raised with OPAN members, with most cases of chemical restraint featuring residents that have been described by their provider as verbally aggressive. Advocates have observed that in many of the restraint cases the aged care staff seem to be inappropriately equipped to explore underlying factors influencing a residents' behaviours, have not considered alternative approaches to restraint and in some cases have not sought the consent of the resident's guardian for the use of chemical restraint.

A resident with dementia was being verbally aggressive and the aged care provider considered the resident to be placing others at risk. The resident was refusing a PRN (as needed) antipsychotic injection, so the provider decided to send the resident to the hospital where they were forcibly given the injection, a very distressing experience for the resident. Once stable the resident was discharged back to the residential facility who requested the GP refer the resident to the Geriatric Evaluation and Management (GEM) ward for further assessment. The resident's daughter did not agree to the GEM ward referral as she was concerned it would cause her parent further undue distress. The advocate contacted the provider and discussed other possible options for in house assessment and treatment which had not been considered. Dementia Support Australia became involved, and an effective behaviour management strategy was developed and did not include injecting medication.

The family of a resident with a cognitive condition and aggressive behaviours contacted an OPAN member to discuss concerns about over medication. They explained that staff at the facility had been administering PRN psychotropic drugs to the resident against the wishes of the appointed guardian. The resident was hospitalised for a review of behaviour and medications and during this time developed delirium. The family expressed concerns that the staff at the aged care facility had contributed to the resident's behaviour as they had been withholding food, raising their voice at the resident and to each other and these actions had potentially triggered the resident to react. An advocate listened to the family and discussed potential options for addressing their concerns. The advocate assisted by attending a meeting with the guardian and aged care provider. The advocate was able to empower the guardian to speak about their concerns. The advocate was able to support the conversation when required, referring to the Charter of Aged Care Rights and Aged Care Quality Standards where appropriate. The advocate continued to work with the guardian to explore other options including moving the resident to another dementia-specific facility, seeking the second opinion of another gerontologist, and accessing supports from Dementia Australia.

An Enduring Power of Attorney approached an OPAN member in relation to the treatment of their father in a residential care facility. The EPOA was concerned about the level of chemical restraint the staff were using on her father without her consent. The EPOA had serious concerns that her father was being sedated to the point that he was non-responsive and was soiling himself, causing his incontinence pads to overflow consistently. When she was able to support him, she found that he had dried faeces stuck to his skin. When questioned, the staff explained that her father had shown signs of aggressive behaviour and needed to be sedated. The daughter stated that there was an agreement with the facility that they would call her whenever her dad became aggressive, and she would approve or deny sedation as his EPOA (as this was happening often). The advocate offered to speak with the Care Manager of the facility, but the EPOA was happy to discuss options with the advocate and self-advocate. The EPOA advocated for a GP review of her father's medications and as a result the father no longer shows signs of aggression. It was identified that the aggression was associated with untreated pain.



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Over the past 12 months, advocates have been involved in many cases relating to resident security of tenure. It has been disappointing to observe that in some cases security of tenure has been threatened in response to residents standing up for their rights.

A resident has been threatened with eviction after she spoke up for other residents too afraid to voice their concerns. An advocate listened to the resident and discussed a plan of action. The advocate supplied the resident with information on the Charter of Aged Care Rights, the Aged Care Quality Standards, providers responsibilities around security of tenure guidelines under the Aged Care Act 1997 and a brochure for the Aged Care Quality and Safety Commission. After received this information the resident was able to read and comprehend her rights and discuss her options with the manager. In the end the resident swas erved with a notice to vacate.

Much like the issue of chemical restraint, security of tenure cases have frequently involved residents experiencing behaviours associated with either a cognitive and/or mental health condition. In many cases, the aged care staff are not equipped with the knowledge or skill to respond to these behaviours in an appropriate manner.

"In many cases, the aged care staff are not equipped with the knowledge or skill to respond to these behaviours in an appropriate manner."

A provider conducted a mini mental assessment, determined that an older person with a formal diagnosis of dementia was in fact competent. Using this assessment, the facility determined that the resident should be held accountable for lashing out at another resident who had wandered into his room and started touching his belongings. An advocate supported the resident's family to address security of tenure concerns, noting that a mini mental assessment is not a sufficient tool for determining the resident's capacity in circumstances where a misdiagnosis could be potentially very harmful to the older person, placing their security of tenure at risk.

An older person with dementia was hospitalised with delirium. The provider was willing for them to return to the facility, but they told the family that they would need to pay for one-on-one care to manage the older person's behaviours until a suitable alternative accommodation could be found. The provider appeared oblivious to the cause of delirium and the impact of their neglect in contributing to it.

In circumstances such as these, advocates have played an important role in informing care recipients of their rights in relation to security of tenure, as well as the service provider's responsibilities.

A resident who had a congenital intellectual disability had been living in an aged care facility for a number of years. Recently the resident slapped a staff member at the facility. The resident's guardian stated that it is likely that the resident had been provoked. Management at the aged care facility informed the guardian that the resident might have to move to another facility because staff could not manage the resident's behaviour. The resident reportedly had not previously displayed such behaviours. An advocate discussed with the resident's guardian the aged care facility's responsibilities in relation to staff training, meeting the resident's care needs, investigating the incident and any medical reasons that might have contributed to the 'out-of-character' behaviour, consulting with medical experts about managing any challenging behaviours, and the resident's rights in relation to security of tenure. The guardian used this information to self-advocate.

Advocates continue to support the older person's security of tenure but often find families are so disappointed with the provider's attitude, lack of understanding and complete inability to care for their relative that they decide on their own accord to seek alternate accommodation arrangements. This often presents as another challenge for the older person with dementia, as they must adjust and settle into another new environment.

Diverse and Marginalised Groups

Throughout the year, OPAN members across the nation provided advocacy support to over 5000 people from diverse and marginalised groups including:

- People from Aboriginal and/or Torres Strait Islander communities.
- People from culturally and linguistically diverse (CALD) backgrounds.
- People who live in rural or remote areas.
- People who are financially or socially disadvantaged.
- People who are veterans of the Australian Defence Force or an allied defence force including the spouse, widow, or widower of a veteran.
- People who are homeless, or at risk of becoming homeless.
- People who are care leavers (which includes Forgotten Australians, former child migrants and Stolen Generations).
- Parents separated from their children by forced adoption or removal.
- People from lesbian, gay, bisexual, trans/transgender, and intersex (LGBTI) communities.

The advocacy issues raised were often similar to those presented in other sections of this report however, many of the cases involved added layers of complexity associated with language, cultural factors, family and community dynamics and/or elements of social disadvantage.

For example, members reported many older people, and their families found the aged care system complex, confusing and difficult and navigate. Members observed that for people from diverse and marginalised groups these feelings were often intensified by additional factors such as:

- Poor internet access within rural and remote communities.
- A mistrust of government services such as

MAC amongst Aboriginal and Torres Strait Islander people, Care Leavers and/or people from LGBTI communities.

- Language and communication barriers for people from Culturally and Linguistically Diverse or Aboriginal and Torres Strait Islander backgrounds.
- Confusion about the interface between Department of Veterans' Affairs and My Aged Care.
- Difficulties understanding and navigating the differences between the NDIS and My Aged Care.
- Financial stress associated with the mention of aged care fees and charges.
- No fixed address to register for aged care services.
- No access to a phone for engagement with MAC.

Members reported that people from diverse and marginalised groups also experienced the same range of issues documented under the CHSP and Home Care Package sections of this report. Advocacy issues in these areas were often heightened by other influencing factors. For example, OPAN's Victorian member, ERA reported financially disadvantaged people living in regional, rural, and remote communities were at greater risk of facing challenges and barriers to purchasing needed "excluded' services and items under a home care package. ERA has observed that there are older people in rural and remote communities who are not eating a sufficient quantity or quality of food due to now having to contribute from their own limited funds to the food component of delivered meals. ERA noted that for some older people, living in regional areas, the pension does not stretch far enough to cover market value rent, the rising cost of food in rural communities or the long distances travelled to attend medical appointments, social outings, and shopping. Issues with home care package fees and charges can significantly add to the financial stress experienced by people from diverse and marginalised groups.

A socially and financially disadvantaged Aboriginal client living in a remote community called an OPAN member in relation to their CHSP service. The caller advised that her CHSP provider was still taking fees direct from her Centrelink payment despite the provider providing written notice a month earlier advising that they were cancelling the services. The provider had taken $28 per week out of her Centrelink payment until it amassed to over $600. An advocate assisted the client to speak to their provider but due to the providers internal policies they would not speak to the client as the client could not remember the mobile number they registered with the provider and the date of birth the client provided was different to what the provider had on file for the client. With the assistance of an advocate the client was able to speak to their provider and the finance department within the organisation. The provider admitted the error and agreed to refund the client. The client was asked for their bank details but was unable to give them and with the clients consent the client's daughter provided her bank details to the provider organisation for the refund. After a week the client confirmed that they had not received the funds. The advocate assisted the client to call the provider again and the provider stated that they were unable to make the refund to the client's

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daughter. The organisation had made no attempt to contact the client about this and were unable to explain why they took the daughter's bank details in the first place given this was outside of their policy. With the consent of the client a local organisation was contacted to assist the client to obtain her bank details to provide to the service provider. The advocate then assisted the client to provide her bank details for the refund. The client contacted the advocate a week later and confirmed the refund had been received.

Members also supported a number of people to address specific issues relating to culturally appropriate care across both community based aged care programs and residential care.

An OPAN member was contacted by the daughter and carer of an Aboriginal Elder who was disappointed and disheartened by how her home care package was being managed, identifying many issues with communication and the quality of services. The advocate spoke to the client and their daughter about their concerns and in the process, they noted that there were a number of other Elders in the community who were experiencing the same challenges with this service provider and asked the advocate to talk with the other Elders in the community and their carers. A meeting was held a week later with 15 Aboriginal Elders and some carers attending. The group identified a number of common issues regarding service provision and communication but also raised concerns that the service provider was not culturally sensitive or flexible enough to respond to the cultural needs of Aboriginal Elders (for example: transport options for Elder to return to country for cultural respite or funerals). It was agreed the advocate would write a letter to the service provider on their behalf and request a meeting.

Members noted that access to care staff with appropriate language skills in residential aged care was an ongoing issue for both Culturally and Linguistically Diverse and Aboriginal and Torres Strait Islander residents. They also reported that language barriers were particularly heightened during COVID-19 restrictions as it was difficult to engage interpreters to meet with clients face to face during this time.

Members also highlighted the need for residential care providers to receive education on trauma informed care noting that it is very apparent in some cases that staff are quick to label an older person as "difficult" without consideration of other influencing factors.

"Access to care staff with appropriate language skills in residential aged care was an ongoing issue for both Culturally and Linguistically Diverse and Aboriginal and Torres Strait Islander residents."

A resident who has had her security of tenure threatened on numerous occasions over the past 6 years has now been diagnosed with a serious, degenerative condition for which she required palliative care. The residential care provider indicated that staff did not want to provide this level of care to the resident as it is a challenge working with a person who is not grateful, who complains and who berates them for not doing things correctly. The resident engaged an advocate, and during the advocacy process disclosed that she had grown up in an orphanage and had experienced severe domestic violence in her adult life. The advocate noted that an understanding of this history may provide the facility staff with some perspective and compassionate understanding. The resident did not consent to the advocate sharing details of their historical trauma with the provider. Instead, the advocate encouraged the provider to train staff in trauma informed care in the hope that they may gain some understanding that most people who have reached 80 years of age and over will have experienced some form of trauma in their life.

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CHSP and home care workforce shortages continued to have a significant impact in rural and remote communities across the nation. Access to a localised workforce is often limited in isolated rural communities and support workers are often traveling long distances from regional town centres to deliver care and support to older people living int these communities. Members note that the higher travel and administration costs associated with delivering a home care package in a rural or remote community means the older person has less funds available for provision of direct care services. In some circumstances premature entry into residential aged care occurs because community care programs are simply not able to meet the basic needs of older people living in rural and remote communities.

Catholic Care, OPAN's member based in Alice Springs, reported that workforce issues are huge and this impacts on service availability. Catholic Care has observed that whilst those who live in town are often able to access a range of services, Aboriginal Elders living outside of town with a home care package often only receive breakfast at the aged care community centre, have their blanket washed and receive a packed lunch or dinner to take home.

Some members have heard of positive scenarios where local health services such as allied health and palliative care services have worked together with families to provide a certain level of support to try and keep ageing family members in their homes for as long as possible. However, this often means families are travelling long distances to provide the support, with many changing their work arrangements to provide the care needed. OPAN member, Darwin Community Legal Centre (DCLC) identified a growing need for training for community members on informal caregiving that touches on topics such as accessing carers payments and meeting the basic care needs of older community members.

Family and financial abuse was identified as a significant issue of concern arising in advocacy case work within Aboriginal and Torres Strait Islander communities. Often these types of cases involved housing issues, complex family and community dynamics and family members taking and using bank/basic cards from Elders. Members report that these cases are often very complex and require a case management approach and collaboration with other community-based services.

An OPAN member received a call from a social worker at a hospital concerned about an elderly Aboriginal man who was living in squaller in a remote community. This man had been picked up by an ambulance after he had collapsed in the toilet at his home. The paramedics found the man malnourished, having ulcerated feet and laying in his own faeces. His bed was a mattress on the floor that was soaked in urine. The man agreed to advocacy support and through discussion with the man it was identified that his family had been taking his key card and was spending all his Centrelink money. With the client's permission, the member advocated for the man to go into an aged care facility and for protections to be put in place with the bank so his family could not access his funds. The family did try to take him out of the aged care facility under the guise of taking him shopping but this soon stopped. He is now eating well, has 24/7 care and is enjoying good health.

OPAN member, Darwin Community Legal Centre, reported that a lack of residential aged care facilities in remote areas means that many older people are forced to relocate away from family and Country as their needs increase. Throughout the year members servicing rural and remote communities with large Indigenous populations worked closely with a range of stakeholders to support a number of Elders to return to Country for palliative care.

The interface between housing and aged care has also emerged as a common theme in advocacy casework in 2020-21 with referrals often coming from public housing. These types of cases appear to be occurring more frequently amongst people who are socially and financially disadvantaged and Aboriginal and Torres Strait Islander people. In many cases advocates have been able to support clients to maintain their tenancy with increased support from CHSP or a home care package.

An Aboriginal client was at risk of homelessness due to not meeting property standards for community housing. The client was receiving CHSP services including fortnightly cleaning but also required support with home maintenance. With the client's permission, an advocate was able to investigate the services being provided by their CHSP provider and identified they were receiving approximately 20-30 minutes of very limited cleaning duties e.g., washing dishes and sweeping front and back verandah. The advocate contacted MAC and found the client had a referral for home maintenance but hadn't accessed it due to concerns about the cost. The advocate assisted the client to connect with another provider who agreed to provide 1.5 hours cleaning weekly until property standard met (approx. 6 weeks) and to provide monthly home maintenance. The client also agreed to referral to the Community Visitors Program (CVS) program to assist with social isolation and loneliness.

A socially and financially disadvantaged client who was prematurely ageing was living in community housing in a remote regional area and was receiving a level 4 home care package. The client was referred to an OPAN member by a Community Housing officer with concerns the client's tenancy was at risk due to their inability to meet property standards. When an advocate met with the client, it was identified that the client had some continence issues and was also struggling to get himself out of bed. The advocate was able to liaise with the service provider to support the purchase of a new queen size bed/mattress to replace the heavily soiled existing one, suitable mattress protection to prevent ongoing soiling and arrange the trial of a bed rail and bedside commode. The advocate was also able to assist the client to access ongoing home maintenance and increase in fortnightly cleaning to weekly to support the client to meet the required property standards.

Throughout the year OPAN members made numerous referrals to the Assistance with Care and Housing Sub-Programme, although it was noted that the Programme's availability was limited in some regions.

Conclusion

This report has presented on the common issues in aged care advocacy case work during 2020-21. Findings in the report provide insight into the challenges many older people experienced engaging with the aged care system during this period. Key themes that have emerged in the report across the various aged care programs included:

- Knowledge of and access to the aged care system.
- Workforce supply and training.
- An undersupply of home care services.
- Services not meeting the needs of older people.
- The interface between health and aged care.
- A lack of flexibility, choice and control, particularly for those from diverse and marginalised backgrounds.
- Quality of care concerns, particularly in the residential aged care setting.

These findings largely reflect the findings of the Royal Commission into Aged Care Quality and Safety and reaffirm why investment in and transformation of the aged care system is required.

OPAN has welcomed the Australian Government's commitment to investing $17.7 billion into an aged care reform package. Many of initiatives under the Australian Government's five year, five pillars of reform plan aim to address issues identified in this report. OPAN recognises that the transformation journey will take time and looks forward to working with government, agencies and aged care providers during the transformation journey.

Whilst we recognise that many of these reforms are significant and will require time to design and implement, this report highlights that there are number of issues, currently impacting on older people in a significant way, that require immediate attention. An extensive list of recommendations have been documented in the Policy Considerations section of this report, and we urge the Australian Government to give these recommendations due consideration as they have the potential to immediately improve the aged care experience for many older people, if implemented in a timely manner.

Every day, OPAN members are supporting older people to have their voice heard on issues relating to their aged care rights and services.

Every day, OPAN members are supporting older people to have their voice heard on issues relating to their aged care rights and services and at the national level, OPAN facilitates the National Older Persons Reference Group (NOPRG) a representative group supporting the voice of older people to be heard by in government consultations, aged care sector conferences and in the media.

OPAN would welcome the opportunity to support the Australian Government and the Department of Health to engage older people with lived experience of the aged care system in the design and implementation of necessary sector reforms.

Acronyms

ACAT	Aged Care Assessment Team
ACQS	Aged Care Quality Standards
ACQSC	Aged Care Quality and Safety Commission
ACRC	Aged Care Royal Commission
ACSA	Aged and Community Services (Aged Care Provider Peak)
ADAA	Aged and Disability Advocacy Australia (ADA Australia): OPAN member in Queensland
ADACAS	ACT Disability, Aged and Carer Advocacy Services: OPAN member in the ACT
ARAS	Aged Rights Advocacy Service: OPAN member in South Australia
ATSI	Aboriginal and Torres Strait Islander
CALD	Culturally and Linguistically Diverse
CCNT	CatholicCare NT: OPAN member in Northern Territory
CHSP	Commonwealth Home Support Program
DCLS	Darwin Community Legal Service: member of OPAN in Northern Territory
DOH	Department of Health (Federal)
EPA/EPOA	Enduring Power of Attorney
EPG	Enduring Power of Guardianship
ERA	Elder Rights Advocacy: OPAN member in Victoria
GEM	Geriatric Evaluation and Management
GP	General Practitioner
HCP	Home Care Package
LGBTI/LGBTIQ+	Lesbian, Gay, Bisexual, Trans, Intersex and/or Queer plus other identities
MAC	My Aged Care
NACAP	National Aged Care Advocacy Program: the program OPAN is funded under
NDIS	National Disability Insurance Scheme
OPAN	Older Persons Advocacy Network
OT	Occupational Therapist
POA	Power of Attorney
PRN	Pro Re Nata (as needed or not scheduled)
RN	Registered Nurse
RACF	Residential Aged Care Facility
RAS	Regional Assessment Service
SDM	Supported Decision Making
Member	Service Delivery Organisation: how OPAN members are referred to
SIRS	Serious Incident Response Scheme
SRS	Seniors Rights Service: OPAN member in NSW

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 People

CatholicCare NT

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