Improving access to aged residential respite care

February 2018

About Carers Australia

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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- survey participants from CRCCs and other services who generously gave their time to share their experiences and those of the carers they help, and whose quotes appear throughout the report
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Executive summary

Reasons for the research

Respite care is an essential part of aged care service provision, enabling older people to stay in their own homes for longer and to transition to residential aged care when it becomes necessary. Residential aged care providers are funded by the Government (through the Department of Health) for a set number of residential aged care places. Providers determine the mix of permanent and respite care places they will deliver each financial year.

Reports to Carers Australia and state and territory Carer Associations of difficulties finding residential respite care to support carers of the aged have been increasing, particularly from Commonwealth Respite and Carelink Centres (CRCCs), Commonwealth Home Support Program (CHSP) operators, and other services that offer advisory and support services for family and friend carers. Challenges to offering respite care are also acknowledged by the residential aged care providers, with increased risks of vacancies, greater workloads from consumer turnover and lower subsidies.

In the recently tabled *Legislated Review of Aged Care 2017*, led by David Tune, it was acknowledged that, “Feedback provided from workshops and from submissions was that often consumers and their carers are finding it difficult to access residential respite care”.[1] A number of submitters advised that the practice of using residential respite for potential clients in search of a “try-before-you-buy” experience meant that there was less access for people in genuine need of respite. However, because Department of Health 2015-16 data indicated that 9,000 more people accessed residential respite care since the Living Longer Living Better Reforms (LLLB) reforms were introduced and the number of people using residential respite care post-LLLB reforms who were not in respite care immediately prior to entering permanent care had increased by 4,000, Mr Tune was not convinced that “residential care reforms implemented under LLLB, and the increase in “try-before-you-buy”, have made it more difficult for carers and consumers to access residential respite care”.[2] The Tune review did not explore the effect of hospital transitions and use of other short term residential accommodation in residential facilities on respite availability. It was, however, acknowledged that the use of residential respite care is increasing and patterns of use have changed. The report recommended that the Government, “in the short-term, review the existing respite arrangements to ensure that its objectives are being met”.[3]

Carers Australia has also been aware for some time that, even though reports persist from respite brokers and some residential aged care providers that access to respite care is becoming scarcer, the overarching, raw Department of Health data do not appear to reflect a problem – bearing in mind that this data reflects supply rather than demand.

For this reason, Carers Australia and the state and territory Carer Associations developed and distributed a survey to CRCCs and other services that help family and friend carers to access planned and emergency respite[4]. Key issues examined were:

- the demand for, and availability of, different types of residential respite care
- geographical differences in availability of respite care
- systemic reasons for any issues in accessing respite care, and
- possible improvements to the system to ease shortages.

A total of 112 responses were received from across Australia, with the majority of services operating in regional, rural and/or remote areas (74 per cent), while less than half (44 per cent) operated in metropolitan areas. The survey was not distributed directly to carers.

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[1] Department of Health, Legislated Review of Aged Care 2017, p 63

[2] Department of Health, Legislated Review of Aged Care 2017, p 63

[3] Department of Health, Legislated Review of Aged Care 2017, p 13

[4] Some not for profit residential care providers also completed the survey.

Demand and ease of access to residential respite care

The survey results made it very clear that demand for residential respite care is not being met.

When asked about specified types of respite care, most respondents indicated that they had high or very high demand for emergency respite (74 per cent) and planned residential respite (88 per cent). The only type of respite care with higher demand was in home care (93 per cent), which is generally only offered for a few hours during the day, so is not a substitute for residential care.

None of the survey respondents considered that emergency respite was very easy to access and only 3 per cent considered access to planned respite was very easy. In contrast, 68 per cent considered emergency respite and 66 per cent considered planned respite difficult or very difficult to access.

> *"Many facilities have reduced the number of beds they have available for respite and now hold these as permanent beds. Carers are crying out for emergency respite, but it just doesn't exist in our region."*[5]

> *"Finding emergency respite is the most difficult as it is not always available immediately. At times there is no option but being admitted to hospital."*

> *"Both emergency and planned residential respite is difficult to acquire except in older, run down, smelly facilities that have vacant beds."*

Only 35 per cent of respondents were able to offer respite care most of the time, with a further 46 per cent able to offer respite care some of the time.

> *"Most of the time residential respite is able to be found by ringing around different facilities. However, this is a slow process and frustrating for carers."*

Identified difficulties

When rating reasons for the difficulties accessing residential aged care for the purposes of respite, most respondents identified low availability (81 per cent), high care needs (68 per cent) and affordability (62 per cent) as the most significant barriers.

Respondents identified a range of issues for carers, including the following:

- not enough residential respite care beds, particularly for:
    - low care needs (due to low subsidies)
    - high needs, and
    - dementia specific
- many residential aged care facilities not offering any respite care or only offering a bed when it is between permanent residents
- not being able to get bookings well in advance and for the times they are needed (for example, so carers can plan holidays)

[5] Respondent case studies and anecdotes provided throughout the report are taken from the survey and have been lightly edited for spelling and grammar, but not substance.

- meeting transport needs, particularly relating to distance from home to the aged care facility, including for the carer arranging transport and visits by other family members
- many residential respite providers unable to provide secure settings and/or (enough) trained staff to support dementia and others with high care needs
- minimum stay periods
- delays in ACAT assessments required to access respite care, and
- transfers from hospitals taking up potential respite care beds.

Suggested improvements

Asked to nominate improvements to residential respite, the most common suggestions by respondents included:

- dedicated respite beds
- entry without ACAT, especially in emergencies
- a better/central system for checking availability and making bookings
- dementia specific respite care
- greater flexibility, with suggestions such as longer/shorter stays, advance/short notice bookings, and
- improved affordability.

The two most commonly suggested respite options were for cottage (or cottage style) accommodation and for overnight/weekend respite options.

> *"Cottage style respite works well for people, as it can be tailored to the care needs of the person and this is a more normative program model for many people, rather than a larger aged care setting where there may be one respite bed available."*

Other suggestions included:

- more day respite
- more emergency respite
- more in home respite, and
- secure respite for dementia and others with high needs.

Recommendations

To address the range of disincentives for providers to offer respite care in their facilities, and to improve flexibility of respite options for carers and people with care needs, Carers Australia believes that a combination of measures will be needed to make respite more readily available.

The measures should include:

- requirements for residential care providers to offer some respite care, including through minimum allocations by large facilities
- incentives to support respite care offerings, including changes to the subsidy model so that residential care facilities offering respite care are not disadvantaged
- cottage style and/or other short term residential respite to both alleviate the pressure on residential respite places and, more importantly, give carers and consumers some choice in the types of accommodation that best suits their needs, the length of stay that is needed and an option for care in their local community, particularly in rural, regional and remote locations
- developing host family respite, particularly in CALD communities and in rural, regional and remote locations
- enhancement of home care through CHSP, including through a package to support consumers with high care needs, as recommended in the *Legislated Review of Aged Care 2017*[6]
- a real time respite booking scheme enabling CRCCs, CHSP providers and other brokers to more easily identify and book respite care, and
- measures to improve awareness of the hardship provisions for carers who cannot afford the co-contribution for residential respite.

[6] Department of Health, Legislated Review of Aged Care 2017, p 8

Introduction

The last Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC), conducted in 2015, found that, while nearly 95 per cent of people aged over 65 years live in households, one-third of older people needed assistance with daily activities.[7]

There are approximately 2.7 million family and friend carers in Australia, of whom 860,000 are primary carers. Over 400,000 provide primary care for someone aged over 65 years old. Of carers caring for a partner, over one in five were over 65 years old themselves, and about one third were primary carers. Primary carers caring for a parent are mostly aged 45 to 64 years old (63.7 per cent) and are mostly female.

About a third of all primary carers provide care for more than 40 hours per week on average and 41.5 per cent of older primary carers spent an average of 40 hours or more per week in their caring role. Deloitte Access Economics valued the replacement cost of the care provided by family and friend carers in 2015 at $60.3 billion.[8]

As noted by David Tune in the Legislated Review of Aged Care 2017:

> "It will be essential that, in implementing changes to increase access to high level home care, the government ensure that the existing arrangements for residential respite care meet its objectives, and that there is adequate supply and equitable access to residential respite care for carers and consumers."[9]

While the SDAC indicates that more than half of all primary carers responded that they did not need respite care, given the number of carers in the community, demand is still very high, with respite critical to many carers' own health and wellbeing. Respite options can, in many cases, mean the difference between the capacity of a carer to look after an older person at home, and the need to seek permanent residential aged care accommodation for the person with care needs.

> *"If the Commonwealth wants people to stay at home longer, then carer fatigue must be addressed, to meet the need for the carer to relinquish care temporarily without being consumed with guilt and anguish because of the conditions, environment and standard of care provided to the recipient when they are in the facility."*

This paper presents research that:

- indicates it is becoming increasingly difficult to access aged residential respite care
- discusses the barriers to increasing supply, and
- suggests some policy solutions to make respite care more readily available to carers of older family members and friends.

Detailed survey findings

Background

Residential aged care providers are funded by the Government (through the Department of Health) for a set number of residential aged care places. Providers determine the mix of permanent and respite care places they will deliver each financial year.

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[7] http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features502015?OpenDocument
[8] http://www.carersaustralia.com.au/storage/Access%20Economics%20Report.pdf (commissioned by Carers Australia)
[9] Department of Health, Legislated Review of Aged Care 2017, p 64

Reports to Carers Australia and state and territory Carer Associations of difficulties finding aged residential respite to support carers have been increasing, particularly from Commonwealth Respite and Carelink Centres (CRCCs) and other services that offer advisory and support services to family and friend carers. Challenges to offering respite care are also acknowledged within the residential aged care sector, identifying increased risks of vacancies, greater workloads from consumer turnover and lower subsidies as major disincentives.

The persistence of these reports from services assisting carers to access respite, and acknowledgement from some residential aged care providers that access to respite care is becoming scarcer, persuaded Carers Australia and the state and territory Carer Associations that further investigation was needed.

A survey was developed and distributed, in July 2017, to CRCCs and other services that help family and friend carers with options for planned and emergency respite[10] to identify:

- the demand for, and availability of, different types of residential respite care
- geographical differences in availability of respite care
- systemic reasons for any issues in accessing respite care, and
- possible improvements to the system to ease shortages.

Location of respondents

A total of 112 responses were received from service providers across Australia that support carers and the frail aged with links to respite providers. The table below shows the area of operation for the survey respondents. The two respondents operating in both NSW and the ACT are based in the ACT.

Table 1: State/territory of operation

State/territory	Number	%
Queensland	36	32.1
Victoria	31	27.6
New South Wales	24	21.4
Australian Capital Territory	5	4.5
NSW and ACT	2	1.8
Western Australia	5	4.5
South Australia	5	4.5
Tasmania	2	1.8
Northern Territory	2	1.8
Total	**112**	**100**

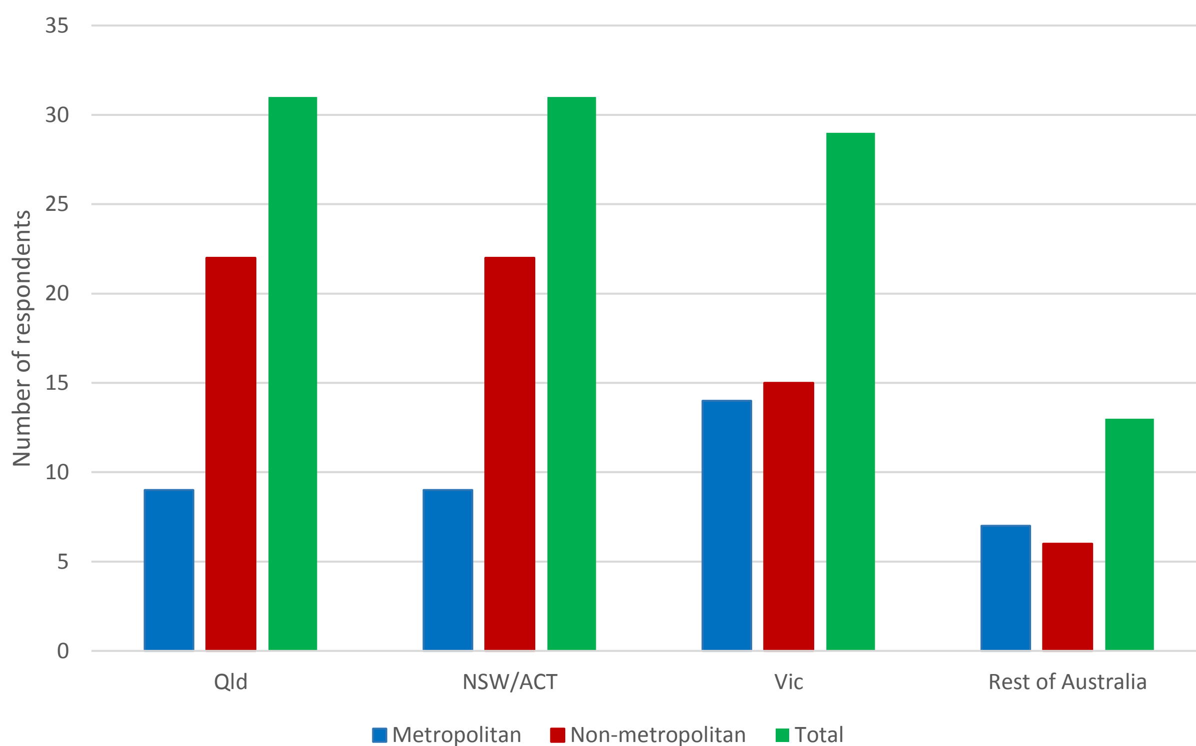
[10] Some not for profit residential care providers also completed the survey.

The response rate was strong in every state and territory and is representative of the number of CRCCs in each jurisdiction. This means, however, that aside from the most populous states of Queensland, Victoria and New South Wales, there were still too few respondents to enable statistical analysis of the other states and territories individually. For this reason, this survey report combines the ACT with NSW into a single “NSW/ACT” category (recognising that the ACT services overlap with NSW), and combines the 14 respondents in WA, SA, Tasmania and NT to form the “rest of Australia” category.

Figure 1 below shows that the majority of respondents operate in regional, rural and/or remote areas (74 per cent), while less than half (44 per cent) operate in metropolitan areas. However, in most jurisdictions, there was a relatively even spread, with responses in Queensland and NSW/ACT dominated by respondents operating in regional/remote/rural areas. There were eight respondents who offered services in both a metropolitan and regional, rural or remote area.

There were too few respondents operating across both metropolitan and rural, regional and/or remote areas to enable meaningful analysis of these services as a separate category. For this reason, comparisons between metropolitan and rural, remote and regional areas (combined into a single “non-metropolitan” category) exclude the eight respondents that operate across both. The eight respondents are included in state/territory based analysis and the broader discussion and case studies.

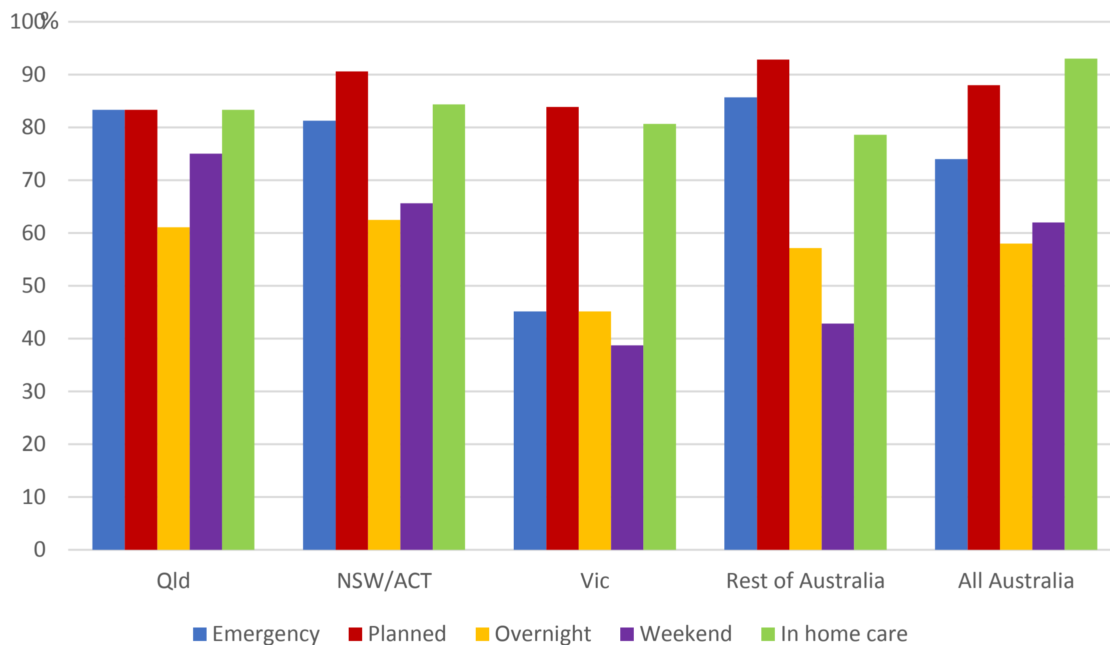
Figure 1: Services’ areas of operation



Demand for respite care

When asked about specific types of respite care for older people, most respondents indicated that they had high or very high demand for emergency (74 per cent) and planned (88 per cent) respite care. The only type of care with higher demand was in home care (93 per cent) , which is generally only offered for a few hours during the day, so is not a substitute for residential care. As can be seen from Figure 2 below, Victorian respondents reported around half the demand for emergency residential respite care than that of other states and territories.

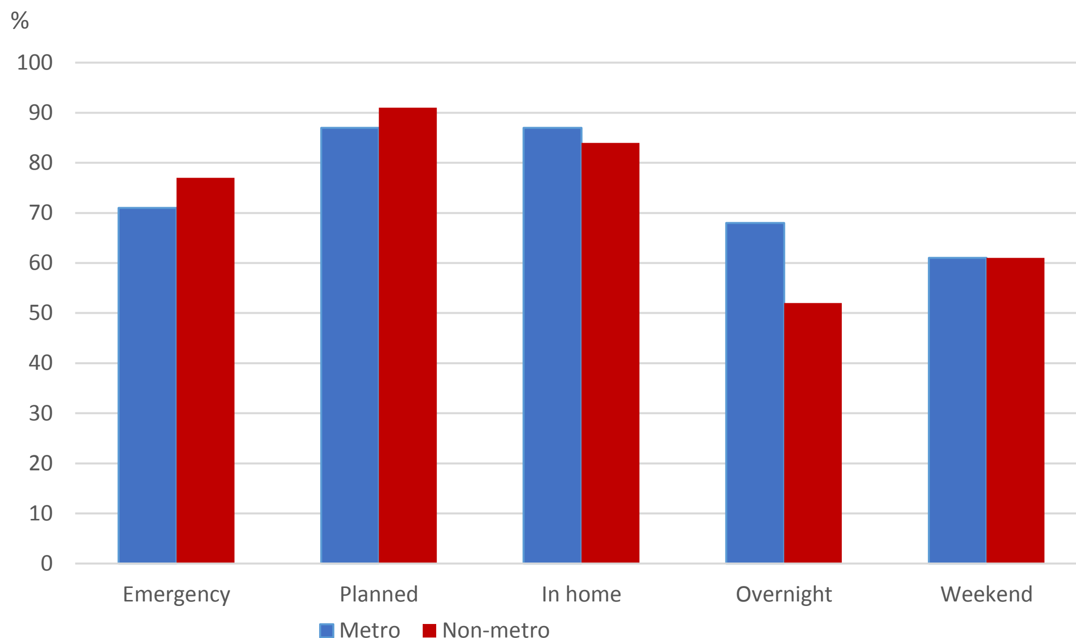
Figure 2: Respite care: demand by state/territory and type



Despite the lower demand, respondents in Victoria were vocal in their concerns, particularly in regional areas, where they reported that respite care had to be booked well in advance and often required long distance travel (mentioning distances of 100 km and 150 km) and, in common with the other states and territories, identified the lack of dedicated residential respite beds as a barrier to residential respite care actually being taken up.

As shown in Figure 3 below, there was little difference in reported high and very high demand for respite care between metropolitan and non-metropolitan locations. The only exception was for overnight care, with 52 per cent of non-metropolitan based respondents reporting high or very high demand, compared to 68 per cent of metropolitan respondents.

Figure 3: Demand for respite care: metropolitan and non-metropolitan areas



Access to respite care

The types of care most rated difficult or very difficult to access by respondents were:

- weekend respite (72 per cent)
- emergency respite (68 per cent)
- planned respite (66 per cent), and
- overnight respite (63 per cent).

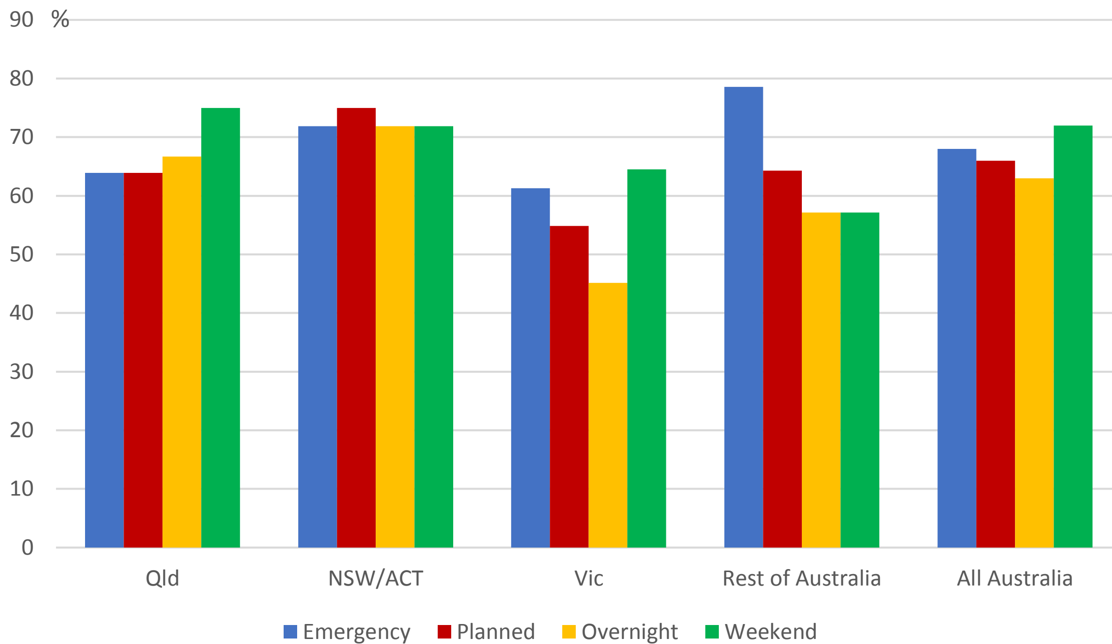
While more than two-thirds of respondents considered emergency respite and planned residential respite difficult or very difficult to access, none of the survey respondents thought that access to emergency respite was very easy and only 3 per cent thought that access to planned respite was very easy.

> *"In [this] area there are only four high level beds and three low level beds for the whole area … My most popular high level facility is booked up to August 2018 – others towards the end of 2017."*

There were some geographical differences in the level of difficulty reported. As can be seen in Figure 4 below, most strikingly there was significantly less difficulty in Victoria (where demand was also lowest) accessing emergency (61 per cent) or planned (55 per cent) respite care than elsewhere, with the greatest difficulty reported in NSW/ACT (72 and 75 per cent respectively).

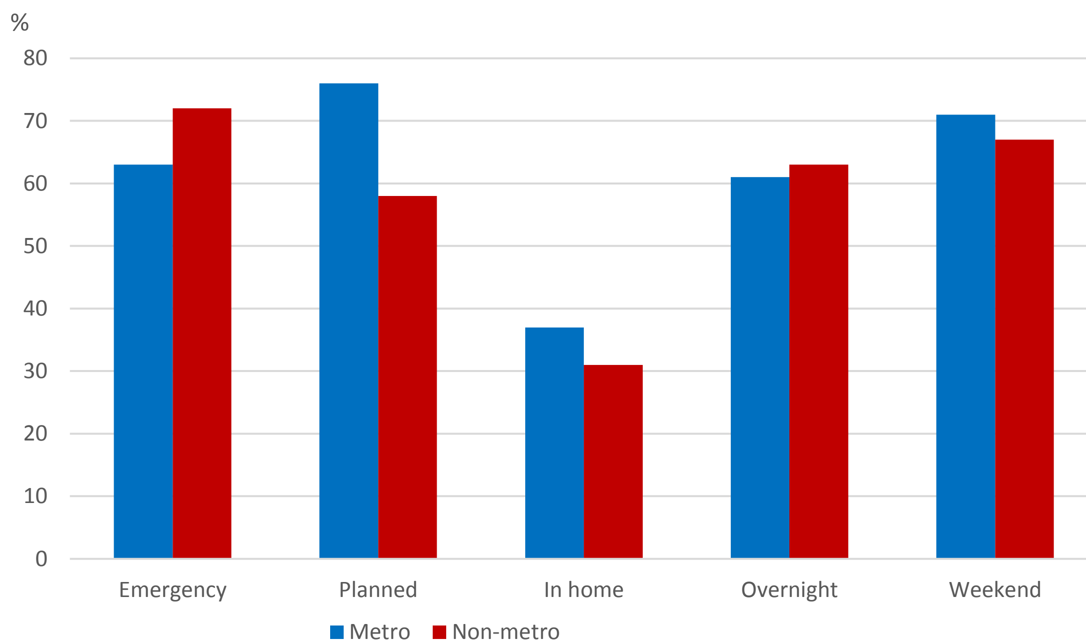
Also notable is that respondents outside the eastern seaboard states found it most difficult to access emergency respite care (79 per cent compared to 68 per cent for the whole of Australia).

Figure 4: Respite care "difficult" or "very difficult" to access by state/territory



Differences in reported access to respite care can also been seen between metropolitan and non-metropolitan locations, most noticeably for planned and emergency respite care. As shown in Figure 5 below, emergency respite care was reportedly more difficult to access in non-metropolitan areas (72 per cent compared to 63 per cent in metropolitan areas), while planned respite care was reported to be more difficult to access in metropolitan areas (76 per cent compared to 58 per cent in non-metropolitan areas).

Figure 5: Difficulty in accessing respite care in metropolitan and non-metropolitan areas by respite type



"I recently assisted a reluctant carer to place his wife in a facility in Rural NSW so he could have a much needed break. Respite was made available for 10 days. However, after three nights, the manager phoned and asked the carer to collect his wife (with dementia) on Friday night by 10 pm because they were short staffed over the weekend. At the same time, he was invited to return her on Monday morning. Consequently, the carer did not return his wife Monday and was very disappointed and let down. Thankfully, we were able to fill this gap the following week by finding in-home respite."

Comparing demand for, with access to, respite care

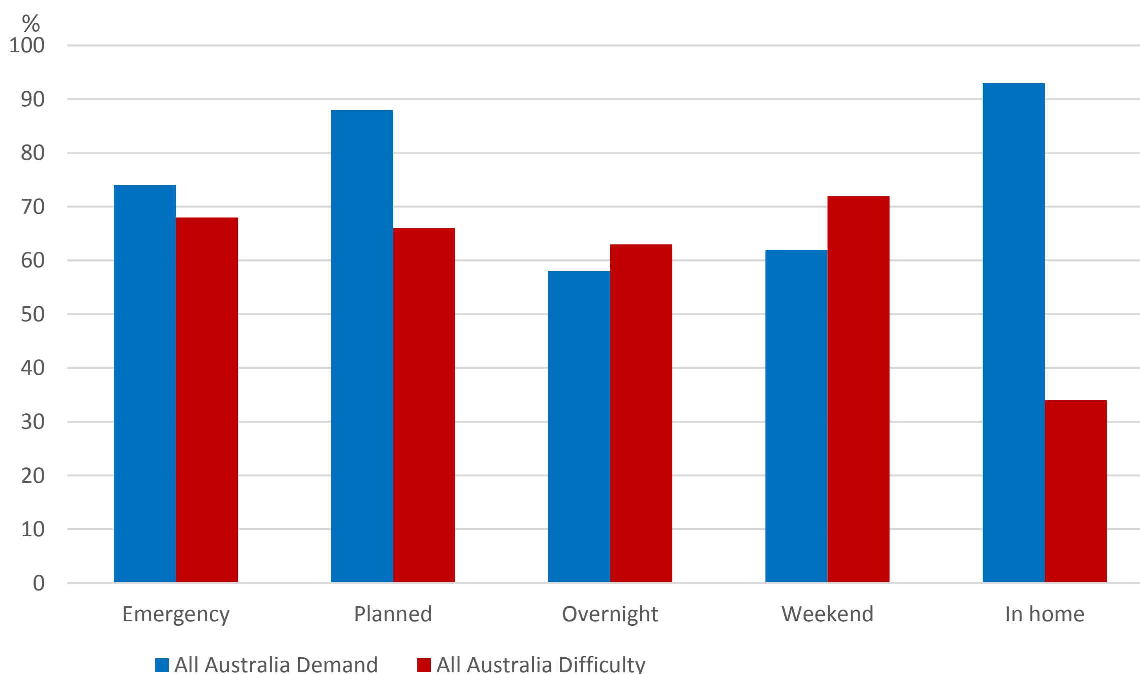
As shown in Figure 6 below, while a high or very high level of demand for in home care respite was reported by almost all respondents (93 per cent), respondents considered it the easiest to access, with more than one-third (approximately 38 per cent) indicating it was easy or very easy, and only one-third of respondents indicating a degree of difficulty (34 per cent). Home care was reportedly most difficult in Queensland (44 per cent saying it was difficult or very difficult).

A high degree of demand and difficulty of access were reported for all forms of residential respite care. While the level of demand varied, with the greatest number of respondents indicating high or very high demand for planned respite (88 per cent), strong uniformity of difficulty of accessing respite (between 63 per cent and 68 per cent difficult or very difficult) was reported across residential care types.

> *"It takes a lot of time and a lot of phone calls. The client and family need to be flexible about going out of town, accepting that emergency respite might be in a facility unknown to the client and a long way from home. A client might end up in a facility that may not be suitable, for example, in a high care facility at a higher cost, when only lower level care at a lower cost is required."*

Interestingly, while Victoria reported the least difficulty across the country in accessing planned respite (55 per cent difficult or very difficult, compared to the average of 63 per cent across the country), demand was similarly high (84 per cent) when compared to the average across the country (88 per cent).

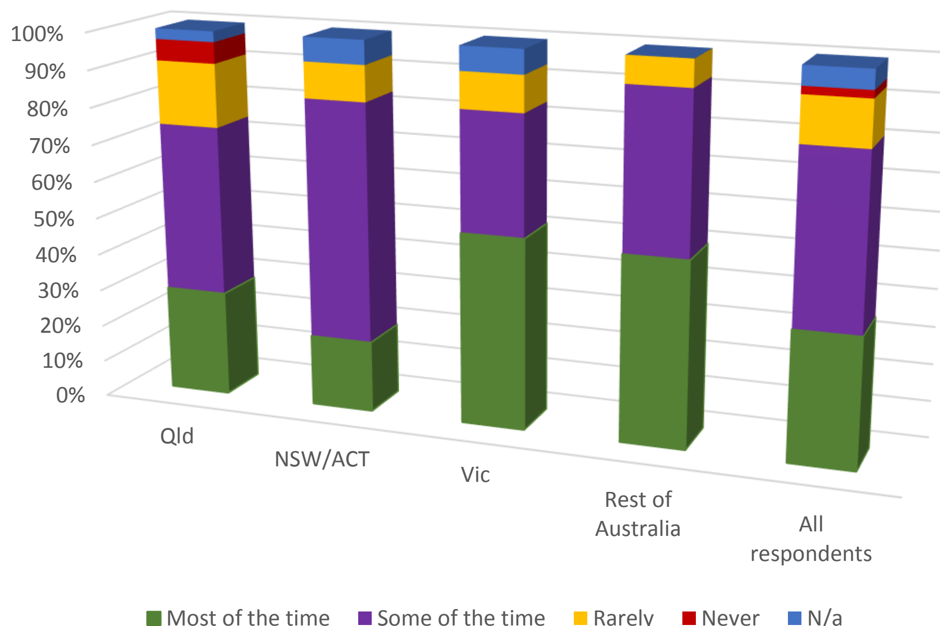
Figure 6: Demand and access to respite care by respite type



Availability of residential aged respite care

As shown in Figure 7 below, around half the Victorian and rest of Australia respondents (52 per cent and 50 per cent respectively) reported that they could offer residential aged respite care most of the time, compared to a much lower 19 per cent in NSW/ACT and 29 per cent Queensland. The majority of respondents reported that they were able to offer respite most of the time or some of the time (35 per cent and 46 per cent respectively).

Figure 7: Ability of services to offer residential aged respite care by location



However, as discussed above, it is clear that around 60 per cent of service providers thought that residential respite could be found with difficulty (some of the time or rarely). Many respondents shared their stories of efforts needed to find respite care and the compromises that have had to be made.

> *"Carer (wife) in a car accident, husband (dementia) in a small rural town. Husband was taken to hospital rehab ward. Daughter arrived to take her father home with her. After two days she was unable to cope, and it took five days to find a residential respite place for her father 30 km away from the family."*

Barriers to accessing residential respite care

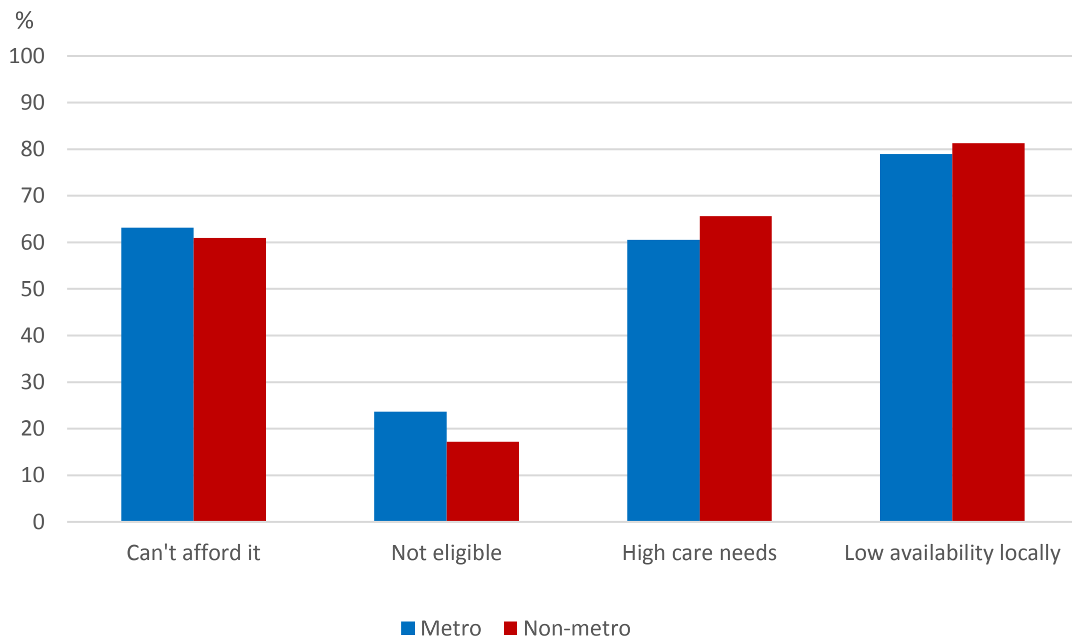
The survey asked respondents to consider the key barriers to carers accessing aged residential respite care by asking the extent of the effect of each of four following factors:

- carers not able to afford respite care
- carers not eligible for respite care
- the high needs of the person receiving care, and
- low availability of residential aged care locally.

Consistent with their other responses, low availability rated as the most significant barrier to residential respite care. Nearly 80 per cent of respondents agreed or strongly agreed that low availability made it difficult to access residential respite care.

As shown in Figure 8 below, there was very little difference in the barriers experienced between metropolitan and non-metropolitan locations.

Figure 8: Barriers to accessing respite care by location

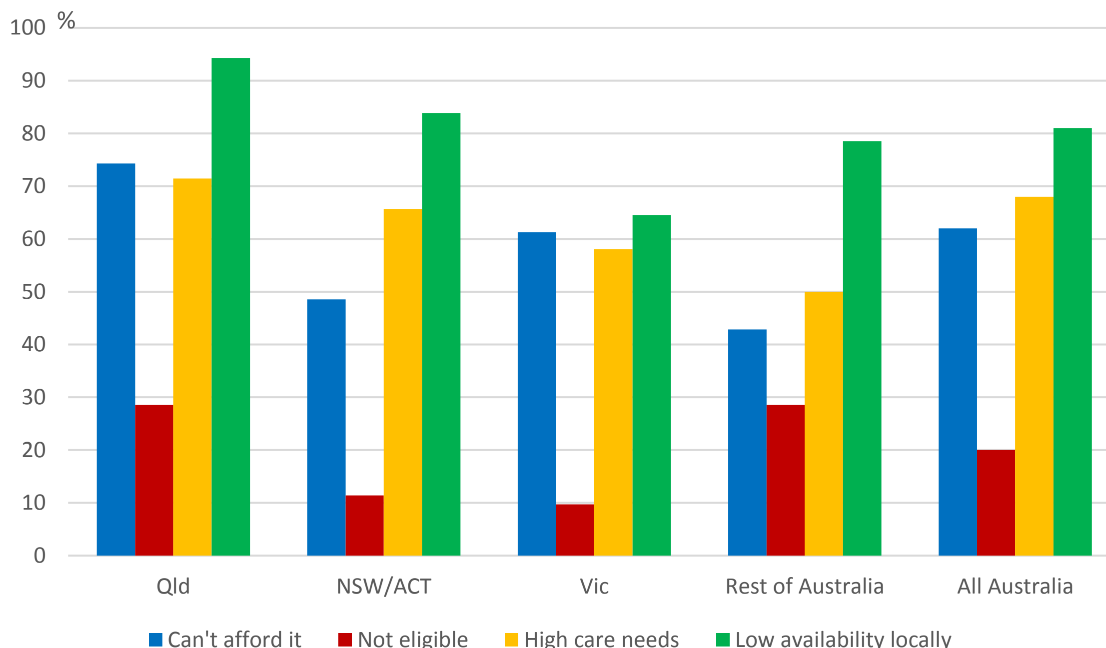


Differences in the extent to which availability was considered a barrier were more evident across the different jurisdictions. As shown in Figure 9 below, while local availability was the biggest issue across the country, the extent of difficulty varied.

While eligibility was not considered a barrier by most respondents (only 20 per cent of respondents agreed or strongly agreed), it was considered a problem by some survey participants.

High care needs and affordability rated similarly in most locations, except in NSW/ACT, where the difference was greatest and 66 per cent of respondents agreed or strongly agreed that high care needs made respite difficult to access, compared to affordability at 49 per cent.

Figure 9: Barriers to accessing residential respite care by state/territory



When specifically asked about accessing respite for people with high care needs, including dementia and behaviours of concern, 64 per cent of respondents felt it was much harder, with a further 19 per cent reporting it harder for people with less complex needs. Only 6 per cent of respondents considered it easier and no one reported it much easier. Responses were consistent across the jurisdictions and in both metropolitan and non-metropolitan areas.

Key barriers to access – common themes

Respondents detailed key barriers to accessing respite in their experience and some common themes emerged across Australia identifying:

- the types of difficulties encountered
- the reasons for those difficulties, and
- how access to residential aged respite care could be improved.

The clear, common themes that emerged included:

- There are not enough residential respite care beds, with some geographical differences in the type of respite beds that were most difficult to access, across:
  - low care (due to low subsidies)
  - high needs, and
  - dementia specific.

  “Facilities are reluctant to accept people with complex high care needs as they don't have the staff with the expertise, nor the ratio required to support these people. Residents object to them intruding into their 'home', and that is understandable. Facilities take a look at the ACAT and often will state they are unable to provide the level of care required.”

  “I have had considerable difficulty in locating residential respite for recipients with an ACCR describing a history of mental health problems, aggression or sexualised behaviour.”

  “People with behaviour issues or physical aggression find it difficult to get beds … people who are obese also face difficulties, due to some facilities not having bariatric equipment.”

- Many residential aged care facilities do not offer any respite care, or only offer a bed when it is vacant between permanent residents.

  “There are limited respite beds available in any facility – usually only one respite bed to about 30 permanent beds.”

  “I’ve been doing this job for nine years and MAC [My Aged Care] has made the last two very frustrating. I had access to 18 beds in the region, and now I have access to five.”

  “Only a few aged care facilities still retain dedicated respite beds, and these are all booked out several months in advance. Occasional short term vacancies pop up in aged care facilities that have had a high turnover of permanent residents. However, they won’t take advance bookings for respite. If a need arises, you have to ring several facilities and get multiple knock backs. Carers cannot plan ahead.”

- Many residential respite providers are unable to provide secure settings and/or (enough) trained staff to support dementia and others with high care needs.

  “A few local residential aged care facilities accept people with dementia behaviours really quickly, but have no dementia expertise or resources and just want the business. They then complain to families about the behaviours. I have had several carers very distressed about this, and it makes them reluctant to book residential respite in the future.”

- Transfers from hospitals are taking up potential respite care beds.

> *"It seems that the need for respite has increased due to requests from hospitals for respite and has affected respite availability for carers in the community who need a break. This has put an added strain on carers as sometimes we cannot meet their requests for a particular home or dates."*

> *"There are issues around placing people into respite when asked by hospital staff. Often a permanent placement is clearly needed, with the CRCC receiving many requests to extend the clients respite when, upon reflection, families come to the conclusion that they cannot continue in their caring roles. Most carers say they don't have the financial capacity to fund the extended respite."*

Where respite can be found, it can involve many compromises and there are great and sometimes insurmountable barriers, as the examples below demonstrate.

- Residential respite cannot be provided in reasonable proximity to the home, which can impose significant transport barriers and make it difficult for carers and other family members to visit the person in respite care.

> *"Carer required respite at short notice for her husband living with advanced dementia as she had received notice of a date for elective surgery. The carer was offered a placement 70 km away and was unable to take it, so did not proceed with her surgery."*

> *"Hospitals push clients out before the family is ready or prepared to support them at home or can find a facility for respite or rehabilitation … Often, because it's a rural area, the client will not be able to find a bed close to home. Usually the vacancy will be in the capital city or another town, with excess travel and causing undue stress."*

- Many places are booked months in advance, while in other places, respite cannot be booked far enough ahead and for the times they are needed (for example, so carers can plan and book holidays).

"A family called into the respite centre to book a high level bed with four months' notice. The only available high level bed was available in eight months' time. The family was forced to cancel the family holiday at great cost and rebook at a time respite could be found."

"Carer needed to go overseas (home) for family reasons so had booked flights a few months out. Had difficulty finding respite for the care recipient, who is fully cognitive but has limited mobility and speech. Carer was concerned about standard of care in aged care facilities, and in-home support was not an option as recipient needs 24 hour care, so it is too expensive. The period (one month) was an issue as, if respite was offered, it was only for two weeks at a time. We eventually secured respite at two different facilities, against the recipient's wishes, which were some distance from each other. Ambulance was the only option for transfer between facilities after the first two weeks. Carer went on trip but was very stressed about the process and amount of effort that was required to get to that point."

- Residential aged care facilities usually impose minimum stay periods, which does not suit many carers, who may need, or prefer, to have shorter and more frequent breaks.

"Some carers advise they are pressured to take a block of two weeks respite care in residential aged care facilities when they require less respite time. This inflexibility is a negative for many families who need respite."

"Residential Respite facilities won't take clients over the weekend and seldom take clients for less than 14 days."

"Many carers advise respite care is too expensive. Some carers advise they are pressured to take a block of two weeks respite care in residential aged care facilities when they require less respite time. This inflexibility is a negative for many families who require respite."

- Delays in ACAT assessments mean that carers are often unable to access respite when they need it.

> *"Facilities will not look at a client until they have the ACAT in hand. MAC is too bound in red tape to respond to an urgent need. It's emotionally stressful now – painful."*
>
> *"ACAT waiting lists have been long. It has become common for carers to contact us regarding unsubsidised beds."*

Flexibility

Respondents also made it very clear that while, with effort, they could mostly find some form of respite care, there were often compromises that made the solutions less than ideal for the carer and consumer. Getting respite care can mean:

- taking care when it is available, rather than when it is needed, making it difficult to plan holidays, attend events and even arrange carers' own medical care, including surgery
- taking set periods of respite, usually in two week blocks, often preventing carers from taking longer breaks (for example for long distance trips, to manage their own health including recovery from surgery or short term contract work) or shorter breaks, where the carer needs a night or two to catch up on sleep or go away for the weekend
- long distance travel, with many services reporting routine distances of 100 km and 150 km between home and the respite care facility, making visits from family members, friends and non-primary carers prohibitive
- transporting the person with care needs from one facility to another when the whole period of respite cannot be accommodated by one provider, which can be very disorientating, especially where the person with care needs suffers from dementia
- the carer is not confident or satisfied that their family member or friend is receiving a high enough standard of care or that they are receiving the right level of care.

Suggested improvements

When asked to nominate improvements to residential respite, the most common suggestions by respondents included:

- dedicated respite beds
- entry without ACAT, especially in emergencies
- a better/central system for checking availability and making bookings
- dementia specific respite care
- greater flexibility, with suggestions such as longer/shorter stays, advance/short notice bookings
- improved affordability.

The two most commonly suggested respite options were for cottage (or cottage style) accommodation and for overnight/weekend respite options. Other suggestions included:

- more day respite
- more emergency respite
- more in home respite
- secure respite for dementia and others with high needs.

Policy response

The research was undertaken because it was becoming increasingly clear from reports across the country that there are systemic issues hampering availability of residential aged care respite places. The extent of the barriers is evident, not only in the survey results themselves, but also by the high response rate which, together with those results, is a clear expression of frustration and exhaustion by service providers.

> *"Carers who regularly utilise residential respite have told me that if they did not have this option their cared for person would be in full time care."*

The survey findings indicate that service providers spend many hours trying to find compromises and workarounds so that carers can get much needed respite. What it means for carers, though, is that, while they can in most cases get some form of respite care, it may not be:

- when they need it or when it suits them best
- the form they need it in
- the period they need it for, or
- in a location that suits them and the person with care needs.

There is a clear need for better support for carers and respite services to meet their needs and to enable older people with care needs to stay in their own homes for longer.

> *"If the Commonwealth wants people to stay at home longer … must address the carer fatigue issue and the need for the carer to relinquish care temporarily without being consumed with guilt and anguish because of the conditions, environment and standard of care provided to the recipient in the facility."*

Table 2 below sets out the daily subsidies paid to residential care providers, based on type of care and the residents' care needs. Taking the lowest rates for low and high permanent care, permanent care subsidies are, as a rule, higher than for respite care. The transitional care subsidy for residential care is highest, with contributions from both Commonwealth and state/territory governments, with a consumer contribution set at 85 per cent of the single rate of the Age Pension. The much lower subsidies are a major disincentive for providers, with the effect especially felt by consumers with low care needs, where the difference can be stark.

Table 2: Daily Government subsidies paid to residential aged care facilities as at 1 December 2017

	Permanent (tabular structure)	Short Term Restorative Care	Transitional Care	Respite (low care)	Respite (high care)
Basic subsidy (daily)	$61.39 to $214.06	$193.34	$350.99*	$45.45	$127.46
Needs supplement	$45.45 to $247.04		$3.99	$37.74	$52.90

* Varies across states/territories. Commonwealth subsidy $198.99 (figure provided based on Victoria).

While a major factor, the low subsidies are not the only disincentive, and other reasons why aged residential care providers may prefer to offer permanent places include:

- use of respite beds to accommodate potential permanent residents ("try before you buy")
- use of respite beds to accommodate people transferred from hospitals
- less likelihood of full occupancy of respite beds than permanent beds and, therefore, less predictability for staffing and other running costs
- additional resources required for respite, including to cover administrative requirements for each person and additional staff support to help them settle in to the accommodation
- an unwillingness to cater for high needs consumers at the risk of reducing income when beds are not fully occupied.

Measures to improve supply of aged respite care

Reform the subsidy model

Residential respite care subsidies should be reviewed, recognising that, currently, daily subsidies for respite care are lower than for permanent care, while providers face additional costs and risks. Providers will be reluctant to increase their respite offerings without compensation to cover the risk of unoccupied beds and the additional work in managing the turnover of occupants to beds, the additional paperwork when consumers enter and leave respite care, and the additional time spent by staff settling in new residents and making sure their needs are met.

Aged care residential care subsidies

There are a number of ways that respite care subsidies could be reviewed to create incentives for providers, including:

- considering options to increase subsidies, for example:
  - increasing the basic daily subsidy for low care respite to the equivalent of the average rate of the basic subsidy for permanent residents with low care needs
  - increasing the basic daily subsidy for high care respite to the equivalent of the average rate of the basic subsidy for permanent residents with high care needs
  - adding a new, "very high needs" category, to be paid at the equivalent of the average rate of the basic subsidy for permanent residents with very high care needs
  - increasing the needs supplement for low care respite to the lowest amount for permanent residents plus 25 per cent (in recognition of higher administrative costs of providing respite care), and/or
  - increasing the needs supplement for high care respite to the highest amount available for permanent residents

- offering compensation for additional costs that can be associated with offering respite care beds, for example by:
  - paying the residential care provider an administration fee to offset the additional work needed to process and settle short term residents
  - including a vacancy factor that can be paid as a direct amount, for example, by calculating an average of two weeks per respite visit and approximately one day's loss per respite consumer (in practice, this could be calculated as an assumed occupancy of 24 x 14 days, with an additional subsidy, paid at the low care rate, for 29 days)
- a health professional undertaking a health assessment of the person with high care needs (in addition to an ACAT) before they enter planned residential respite.

Introducing requirements for residential care providers

Requiring providers to specifically set aside beds for emergency and/or planned respite could increase supply so that carers can access respite when they need it. However, recognising that returns to providers can be affected both by cancellations and other vacancies, and by workload challenges that result from churn, including increased documentation and effort settling in consumers, minimum respite requirements could not be implemented without accompanying increases to subsidies.

Some funding for respite care is built into the formula for payments to residential care providers, with applicants for annual Aged Care Approval Rounds (ACAR) – Government funded aged care places – required to nominate whether to offer short term care, including respite, short term vacancies, and post-hospital recovery (transitional), and how many beds as part of their application. Adjustments are made when subsidies are paid (in arrears).

This option would set a minimum level of respite care for providers, based on the size of the facility. The funding formula would continue to include a premium for each respite bed offered, with providers who offer more than the minimum requirement able to claim an additional or higher premium per bed offered. Providers would still be able to adjust the proportions of respite and permanent care. However, there would be a reduction in the overall subsidy where the provider did not meet a minimum or nominated number of respite nights.

The Tune review has pointed to improvements that would result from allocating residential aged care places directly to consumers, rather than providers.[11] As with other moves to consumer directed care, it is likely that this reform will be made to residential aged care. While the reform would be positive for permanent residents in aged care facilities, another funding solution will be needed for consumers of respite care as a one-off service.

Other respite options

Increasing access to respite is critical for carers, and not only in residential aged care facilities. Other forms of respite are also under pressure, and better access to those alternatives could also help alleviate demand for respite in aged care facilities. Carers Australia would like further exploration of the following measures.

[11] Department of Health, Legislated Review of Aged Care 2017, p 7

Cottage style respite

Increasing the supply of cottage style accommodation offering overnight and weekend respite is the most favoured by carers and consumers and was one of the most called for improvements by survey participants.

Cottages, or overnight/weekend respite in a home-like setting, are often run and operated by community organisations as an addition to day care services. Research conducted by Carers Australia and state and territory Carer Associations indicates there is a high demand for this form of care and a real shortage in availability of short term (overnight and weekend) care, which is usually not offered by residential care providers.

The advantages include:

- the aged person may use the day care facilities, with occasional overnight stays, so are in familiar surroundings with people they know
- overnight stays are in a house, rather than an aged care facility, so it is more normalised than residential respite in an aged facility and may even feel like a holiday for the consumer
- cottages offer dedicated respite care, so there is a known number of beds and respite clients are not competing with people looking for permanent residence
- there is greater flexibility, and can suit carers who prefer to have one or two nights respite more regularly, rather than blocks of respite, or can be used in combination with blocks of care (for example, a carer may have a two week holiday once a year and a night or two break in other months)
- it can take pressure off residential facilities that have competing high demands from consumers seeking permanent residence and those seeking respite care.

The premises are generally funded by state and territory governments, either by building new properties to purpose or retrofitting established properties that have been bought by, or donated to, the state or territory. Funding for operations is provided through grants by the Commonwealth Department of Health's CHSP program.

The main impediments to greater use of cottages are:

- there can be a long lead in time as facilities may need to be acquired, built and/or repurposed
- the initial investment may be high cost, as it may require purchasing land, building or retrofitting for purpose, and funding service delivery
- it needs a high level of coordination and guaranteed Commonwealth funding over a long period to justify the investment.

Carers Australia argues that the benefits to the community and alleviation of pressure on other parts of the aged care health system justify the additional costs. And some of these costs can be reduced through innovative practices, for example through co-location with other services and adopting practices to minimise vacancies, such as allowing city cottages to be occupied by regional (carer/consumer) families travelling together for a hospital stay or break.

The Commonwealth should provide grants to state and territory governments for renting and modifying suitable accommodation and for operating costs. Grants should allow for a range of different models, including leasing state/territory properties to providers to operate using Commonwealth subsidies.

Host family respite

The host family respite program, where a person becomes a paid carer, in their own home, for up to four frail aged clients at any time, offering flexible options for overnight, weekend and other short term respite care, could be extended and better promoted. Host family respite can work particularly well in rural and small communities where the host family and consumer may know each other, and can offer culturally appropriate respite for CALD and Indigenous consumers.

> *"CALD carers are finding it more difficult to find residential respite in a culturally appropriate facility, so end up staying continuously with the family."*

In home care

According to the Carers Australia research, in home care is currently the most accessible form of short term respite and there is a high demand for short term options. It is also favoured by some carers and people with care needs, who prefer to stay at home. This can be particularly important in cases of dementia, where a change of environment can be disorientating and distressing for the person with care needs.

Increasing availability of home care could be used to alleviate demand for other forms of respite, recognising:

- accessibility can be variable, depending on availability of providers
- one-to-one care is the most expensive option, and is not always suitable, and
- it may not be suitable for supporting people with some high care or other specific needs.

Real time booking service

Pressure could be alleviated through an online accommodation service, operating on the same principles as Airbnb, where providers can list their services and take bookings and payments for respite accommodation. This may reduce vacancies in respite care beds and, by association, reduce the disincentive for some commercial providers to offer respite care.

The booking system could either be operated by a private provider, charging for listings in the same way as Airbnb and other similar services, or it could be funded by a Government grant or procurement and operated in the not-for-profit sector.

> *"I have recently introduced a process of sending out an email on every Monday to all the residential facilities with a list of all the residential respite requests we have received for that month. This list is in a table format with details on care recipients assessed level of care and dates requested. This allows facilities to respond quickly if they can accommodate any of the clients."*

Residential aged care providers would only use the service if they considered that there was a financial gain – that is that they could get occupancy of unused beds. Take up by providers may be low if there is little to gain financially; for example, because they have few vacancies.

Accessing hardship provisions

While not related to supply, the research identified financial issues for carers and consumers of respite services. Many low income carers find the co-contributions to the cost of respite prohibitive, as it is an additional cost to their budgets, not a replacement – they will still have normal expenses for rent/housing, power, etc. There are financial hardship provisions for respite care, with government payments to cover the co-contribution component made directly to the facility. However, it is likely that the financial hardship provisions are underutilised, so providers, carers and carers' services could be better informed about their availability.

> *"Residential respite should be made more affordable to pension only recipients."*

Conclusion

To create incentives for providers to offer respite care in their facilities, and to improve flexibility of respite options for carers and people with care needs, Carers Australia recommends that, at a minimum, the subsidies offered to residential care providers should be reviewed to create incentives to offer respite care. Ideally, a combination of measures will be needed to make respite more readily available. The measures should include requirements for residential care providers to offer some respite care ***and*** incentives to support those provisions.

The design of a suite of measures should also incorporate cottage style and/or other short term residential respite. Cottage style respite accommodation would not only alleviate the pressure on residential respite places but, more importantly, give carers and consumers some choice in the types of accommodation that best suits their needs, the length of stay that is needed and an option for care in their local community, particularly in rural, regional and remote locations.