



## Respite Care Roundtable

### Record of Meeting

Prepared for Australian Government Department of Social Services

December 2023

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## Introduction

Carers Australia is the national peak body representing Australia's unpaid carers, advocating on their behalf to influence policies and services at a national level. This includes facilitating efficient and effective discussion with the Australian Government. In 2023, these activities include holding biannual consultation roundtables. The roundtables bring together a wide range of stakeholders including carers, support organisations, service providers, government representatives and advocacy groups.

The topics to be discussed are determined in collaboration with the Department of Social Services (DSS) based on identified needs. Following each roundtable, a record of the meeting is to be provided to DSS, followed by a public brief made available on the Carers Australia website.

The November 2023 Respite Care Roundtable was the second consultation roundtable held by Carers Australia. The first being the Carers & Employment Roundtable hosted in May 2023, the outcomes of the roundtable can be accessed on the [Carers Australia website](#).

## Background

### Who are carers?

More than one in ten Australians are carers who provide unpaid care and support to family members and friends with a disability, chronic health conditions, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail and aged (SDAC, 2018).

Carers Australia uses the term 'carer' as defined by the Commonwealth Carer Recognition Act 2010 (the Act). We do however include alcohol and other drug issues to acknowledge this is often a comorbidity.

The terms 'informal carer', 'unpaid carer' or 'family and friend carer' are also often used by organisations, government and the community to describe a carer. These terms may be used to assist in providing context and to differentiate between other types of care.

### What is Respite Care?

Respite care or respite is an alternative care arrangement with the primary purpose of providing an organised, temporary break both for the carer and the person they care for. Respite can vary in length, with options available for both short- and long-term services and can be provided in multiple different contexts.

Some examples include:

- In-home respite
- Centre-based day respite
- Overnight or weekend respite

- Residential respite care
- Transition care

**On 21 November 2023, the Respite Care Roundtable was held in Canberra.**

Its purpose was to begin discussions on how the upcoming National Carers Strategy may address the challenges faced by Australia's 2.5 million unpaid carers when trying to access respite care.

*A full list of all participants can be found in Appendix B.*

Representatives were invited from a variety of sectors and organisations, including government, service provision, community advocacy, and individuals with lived experience of caring. On the day more than 30 participants attended and the event opened with an address from the Department of Social Services and a presentation by Carers NSW. All attendees were provided with a Background Paper prior to the Roundtable. The background paper highlighted recent data on barriers to respite for carers and previous research and advocacy that has been undertaken by the National Carers Network on respite access.

*A copy of this Background Paper can be found in Appendix C.*

It was recognised amongst the groups that targeted carer support, including respite care, is integral to the sustainability of a healthy care relationship, and currently various barriers to accessing appropriate and timely respite care exist.

As a group, the provision of accessible, appropriate, and timely respite care was identified as a necessary and impactful support service for both carers and the individual they care for, however a diverse range of supports and services must be made available for all carers to adequately recognise and address the diverse and bespoke needs of carers.

The Roundtable was facilitated by Gordon Denoon, National Director of Programs at Carers Australia, and the event consisted of one presentation, shared carer lived experience and three discussion sessions. The day was opened by reading aloud a letter from the Hon. Amanda Rishworth MP, Minister for Social Services by Lucy Tatchell, Acting CEO of Carers Australia. The roundtable was held as a guided discussion around three key topics with a focus on group discussions.

*See Appendix A for the full statement.*

### **National Carers Strategy**

The Department of Social Services representative provided round table participants with context around the Ministerial announcement of the development of a new National Carers Strategy. The

strategy will build consensus and coordinated action by the Commonwealth and in partnership with the States and Territories to better support Carers in their roles. The Strategy is intended to be launched towards the end of 2024, following extensive consultation in the sector. The strategy will also be informed by lived experience of carers.

## Presentation

### Building the respite evidence base

To provide attendees with a brief overview of the National Carer Networks (the Network) past advocacy and research activities addressing respite, Sarah Judd-Lam, Executive Manager of Policy, Development and Research at Carers NSW presented on how the Network has built an extensive respite evidence base for over a decade.

The presentation outlined the key milestones impacting national respite policy since the 2008 House of Representatives Inquiry into better support for carers<sup>1</sup>. The timeline included the introduction of the Commonwealth Carer Recognition Act 2010, the development, implementation, and lapse of the 2011-2014 National Carer Strategy, introduction of the National Disability Insurance Scheme and more recently, introduction of the Carer Gateway and ongoing aged care, mental health, and disability reform.

Throughout these measures, the Network has undertaken extensive research and consultation to better understand what good respite looks like and the barriers faced by carers in accessing respite across systems and portfolios. Broadly, respite care is accessed by carers through one-of-four sectors – mental health, disability, aged care, or carer-supports. Each of these sectors has dealt with its own reforms and changes over time which have both positively and negatively impacted carer experiences with respite.

Analysis has identified several key findings in research that remain consistent amongst state and national comparison. These include:

- Respite services are critical to certain groups of carers, especially those with a significant caring load that cannot easily share their responsibilities with others.
- Despite evident demand for services to support breaks from caring, uptake is relatively low because many carers are not aware of respite services, have had prior negative experiences or are unable to access them.
- A range of barriers prevent carers from accessing respite, from a lack of services that meet their needs, lack of timely respite, through to guilt about taking a break.



<sup>1</sup> <https://aphref.aph.gov.au/house/committee/fchy/carers/report/index.htm>

- A mismatch between what carers need and how respite services are structured impacts uptake as well as effectiveness and perceived value.
- Access to respite results in measurable positive outcomes for carers.

These findings have been used to develop the Networks position on the provision of respite across Australia.

- The carers we work with tell us that respite services are of critical importance, and that the supply of respite does not meet demand.
- We need to expand the evidence base on the demand for respite, and the uptake, effectiveness, and perceived value of respite.

[Access Presentation here.](#)

### Lived Experience Voice

Throughout the day, several carers shared their experiences of accessing respite care. The lived experience group included mental health carers, carers from culturally and linguistically diverse (CALD) backgrounds and veteran carers, carers living with disability and carers for more than one individual ('sandwich' carers). Their experiences, coupled with those shared by other participants in attendance, reiterated the necessity of flexible and inclusive respite care.

Many of the experiences shared included reflections on how access to respite has changed over time, including how the establishment of new services has changed the way community and government provide respite, specifically how it is accessed. This was particularly the case for those who had experience caring for someone who was a participant in the National Disability Insurance Scheme (NDIS). In general, the view was expressed that access to, and quality of respite has tended to decrease.

The introduction of the NDIS was largely viewed as an immensely negative change for carers and their experiences accessing support and being recognised. Common themes were identified from the shared experiences including a large decrease in funding for carer specific supports such as respite. A notable example being the NDIS' absorption of funding available for non-government organisations (NGOs) through the National Respite Development fund, which existed from 2008 to 2019.

Additionally, many carers noted the evolution away from a medical model of care to a person-centred approach has manifested as a sole focus on the participant, consumer or patient. This in turn has led to a rejection of the needs and rights of informal supports such as family, carers and kin. This has brought a fundamental change in the way respite services are accessed, as it is now most common for respite to be viewed solely as a service for the individual requiring care and not for the carer. The impact of this is detrimental to carers, as their needs including accessibility and appropriateness are not considered when planning or participating in respite.

*“The process of accessing respite and most other carer services is traumatic, it is like a scab being pulled off an unhealed wound”. – Lived Experience carer*

### Describing a good respite system

Attendees were asked to describe what they considered to be a good respite system.



Figure 1: Key features of a good respite system

### Workshop: Barriers to accessing respite care

The first workshop focused on identifying whether the barriers to accessing respite care captured in past research, advocacy and policy by the National Carer Network were still relevant and accurate in modern context. The purpose of this was to understand whether the rich evidence base that had been shared in the earlier presentation, could still be used in the upcoming development of the National Carers Strategy and throughout advocacy in other policy reforms such as the NDIS Review and consultation for a new Aged Care Act.

Generally, the group agreed that the evidence base was still relevant. However, a range of key issues were repeatedly identified by participants, including:

### Current barriers to accessing respite care

1. **The process of inquiring into or accessing respite is often complex and discouraging and many carers do not have the time, resourcing or energy to navigate this process.**
2. **Many carer supports, including respite, are not sensitive to diverse ethnic groups. Services for First Nations carers and kin may not be appropriate for individuals from CALD backgrounds.**
3. **Many carers are required to repeatedly explain, contextualise or justify their need for respite during the inquiry or application process and this is often triggering and emotionally traumatic.**
4. **Eligibility requirements for respite often inadequately reflects the needs of carers. Specifically in how education and employment are viewed as luxury or personal-care time, instead of a right.**
5. **Mental health carers face added barriers or complexities in accessing support services, due to the acute nature of their care needs and the stigma associated with mental illness.**
6. **Inconsistency in service availability between different geographical areas, including that some metropolitan areas face the same service limitations as regional and rural communities.**
7. **Lack of trust or confidence in the provision of quality respite services to the care-recipient because of high-staff turnover in facilities, poor work conditions and insufficient training.**

It was also noted that diversity in carer support services is needed as respite is not always the most appropriate or important support that carers might need. For example, carers of individuals receiving palliative care might not wish to spend additional time away from the person receiving care. In these instances, financial or emotional support are often considered a higher priority.

### Workshop: Priority actions for the National Carer Strategy

The second workshop involved participants working in smaller groups to discuss priority actions for the upcoming National Carer Strategy. Groups were encouraged to consider a variety of options including the re-establishment or continued funding of existing support programs, options for consultation and engagement in Strategy development, and principles for the design or implementation of new services.

The primary priority actions agreed on by the group have been listed below.



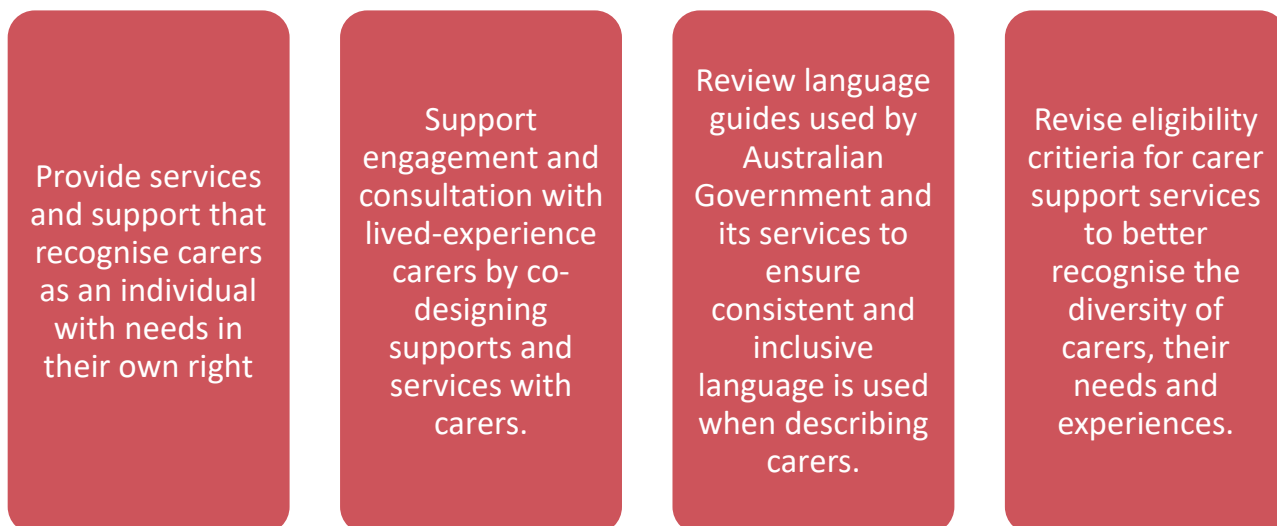


Figure 2: Identified priority actions for the National Carer Strategy

In sharing back these priorities, several attendees raised concerns about the lack of recognition given to the extensive research and development work undertaken to support the development of the previous National Carer Strategy, and the ongoing advocacy by the National Carer Network. It was widely agreed that this information and the learnings from its implementation must be used to minimise time spent researching what is already known. In addition to the 2011-2014 National Carer Strategy, examples of past activity that were recommended for consideration during the development of the upcoming Strategy include:

- Productivity Commission Inquiry into Carer Leave Final Report
- Senate Select Committee on Work and Care Final Report
- Royal Commission into Aged Care Quality and Safety
- Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability
- Pending release – Independent Review into the National Disability Insurance Scheme
- Pending release – Standing Committee on Social Policy and Legal Affairs Inquiry into the recognition of unpaid carers
- Carer Wellbeing Survey Reports
- National Carer Survey Reports
- Productivity Commission Inquiry into Mental Health
- 2016 National Carer Network Survey of carers respite needs
- 2017 National Carer Network Survey of brokerage organisations

Overall, it was widely agreed that greater clarity regarding the purpose and role of the National Carer Strategy was needed to inform the identification of appropriate priorities. It was the opinion of many participants that the Strategy would work best as a framework or action plan for how carer inclusive practices can be actioned across the various systems and portfolios that carers interact with – health, social services, employment, education, defence etc. The identification of this led was explored in more depth in the following workshop session.

### Workshop: Enabling greater cross-system and portfolio collaboration

As identified earlier in the day, carers and their advocates regularly label navigation issues as a persistent barrier to accessing support services. The extent of this issue has been recognised by the Australian Government and in response, the development of a framework has been committed to as part of the National Carer Strategy. This framework is intended to enable greater coordination of carer policy across government portfolios.

As a group, participants were asked to share what they thought to be principal characteristics of a framework from enabling cross-system and portfolio collaboration.

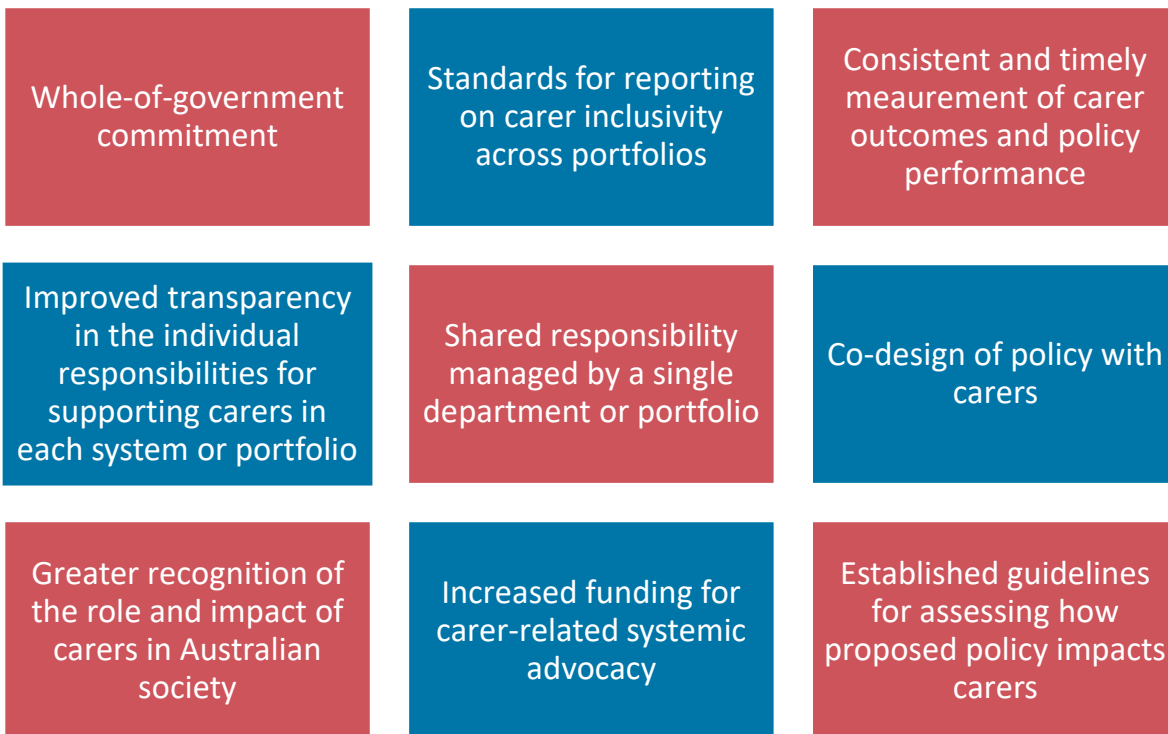


Figure 3: Principles to enable greater cross-portfolio collaboration on carer policy

In addition to these features, attendees called for the upcoming National Carers Strategy to work harmoniously with other government policy strategies and frameworks, specifically those with direct influence on carers such as the Australian Disability Strategy, National Autism Strategy, Early Years Strategy, and Employment Whitepaper. When discussing examples of best practice for past government strategies and frameworks it was recommended the National Mental Health Workforce Strategy be considered a positive example of how a whole-of-government approach could be utilised to establishing accountability for working towards a carer-inclusive Australia.

Finally, it was agreed the Strategy, accompanying framework and all other policy and programs initiatives related to carers must adequately recognise that interactions with multiple systems and portfolios is a reality of being a carer. Efforts to minimise the impact of this reality should be focused on ensuring no carer falls between the cracks and that government services and the responsible

departments communicate internally to limit the burden placed on carers and the individuals they care for when access support services.

### **Summation and Next Steps**

Facilitator, Gordon Denoon along with Carers Australia National Director of Policy, Courtney Love, provided a summation of the key discussion themes and welcomed final remarks and commentary from participants.

The themes identified in this paper may be used to inform the development of the National Carers Strategy by the Australian Government Department of Social Services, as well as informing advocacy and activities undertaken by Carers Australia.

## Appendix A



It is with regret I am unable to join you today as part of the Respite Care Roundtable hosted by Carers Australia.

I appreciate the representational and policy leadership roles that Carers Australia plays in relation to unpaid care, and continue to appreciate their advocacy. Carers Australia's ability to harness relationships across the unpaid care sector is demonstrated by the broad representation at today's Respite Care Roundtable.

The Albanese Labor Government values the immense contribution of Australia's 2.65 million carers, and we acknowledge the importance of respite for carers, to support them to sustain their caring role and maintain their health and wellbeing. Which is why I referred an inquiry into the recognition of unpaid carers to the House of Representative Standing committee on Social Policy and Legal Affairs, and more recently, in National Carers Week, I announced the development of a new National Carer Strategy

Importantly, the discussions you have today will feed into the development of this Strategy, which will provide the opportunity to develop a nationally consistent and committed agenda for carers, intersecting across multiple sectors and agencies including health, mental health, aged care, veterans and disability.

The Strategy will provide a framework for the co-ordination of carer policy across Government, and recognise the integral role of carers in supporting the sustainability of the care and support economy. To inform the development of the Strategy, we will undertake national consultation and engagement with carers, care recipients, peak bodies and service providers and state and territory jurisdictions to ensure that the needs of carers across Australia, including regional and remote Australia, are addressed by the strategy

I look forward to hearing about the outcomes from today's session. I wish you all a successful event.

Yours sincerely

Amanda Rishworth MP  
Minister for Social Services  
Federal Member for Kingston

## Appendix B

### Respite Care Roundtable participants

Name	Organisation
Josh Fear	Palliative Care Australia
Louise Faulkner	Wellways
Virginia Wilson	Wellways
Felicity Benedetti	Department of Health and Aged Care
Richard Newman	Carers Association of WA
Katrina Armstrong	Mental Health Carers Australia
Debra Nicholl	Elder Rights Advocacy
Ann-Clare Fitzgerald	Services Australia
Jessica Johnson	Carers ACT
Cassandra Platts	Dementia Support Australia
Sarah Judd-Lam	Carers NSW
Sarah Bone	Carers Queensland
Judith Abbott	Carers Victoria
Deborah Ryan	Carers NT
Kylie Miskovski	Dementia Australia
Peter Heggie	National Mental Health Consumer Carer Forum
Rhiannon Brodie	National Disability Insurance Agency
Karen Carey	Carer
Joanna Bartholomaeus	Carer
Eileen McDonald	Carer
Gordon Denoon	Carers Australia
Courtney Love	Carers Australia
Ayesha Sarfraz	Carers Australia
Rebecca White	Department of Social Services
Lydia Ross	Department of Social Services
Claudia Verskroot	Department of Social Services
Kartika Medcraft-Smith	Department of Social Services
Helen Roben	Carers Australia
Lucy Tatchell	Carers Australia

### Respite Care Roundtable

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## Respite Care Roundtable

Tuesday 21 November 2023

On October 19<sup>th</sup>, the Albanese Government [announced](#) it would be fulfilling its election commitment by investing \$3.8 million to deliver a National Carers Strategy.

The Respite Care Roundtable will provide relevant stakeholders with an opportunity to begin discussions on how the Strategy may address the challenges faced by carers when accessing respite.

Following the Roundtable, Carers Australia will develop an Outcomes Paper highlighting the key discussion points and ideas from the day. This paper will be provided to the Department of Social Services for consideration in the consultation for and development of the Strategy and will be used to inform Carers Australia's advocacy and engagement regarding respite care.

**Discussion will be focused on how the National Carers Strategy can recognise respite care, address the barriers to access, and include meaningful outcomes and performance measures.**

#### Background

##### *Who are carers?*

More than one in ten Australians are carers who provide unpaid care and support to family members and friends with a disability, chronic health conditions, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail and aged (SDAC, 2018).

Carers Australia uses the term 'carer' as defined by the Commonwealth [Carer Recognition Act 2010](#) (the Act).

We do however include alcohol and other drug issues to acknowledge this is often a comorbidity.

The terms 'informal carer', 'unpaid carer' or 'family and friend carer' are also often used by organisations, government and the community to describe a carer. These terms may be used to assist in providing context and to differentiate between other types of care.

##### *What is Respite Care?*

Respite care or respite is an alternative care arrangement with the primary purpose of providing an organised, temporary break both for the carer and the person they care for. Respite can vary in length, with options available for both short- and long-term services and can be provided in multiple different contexts. Some examples include:

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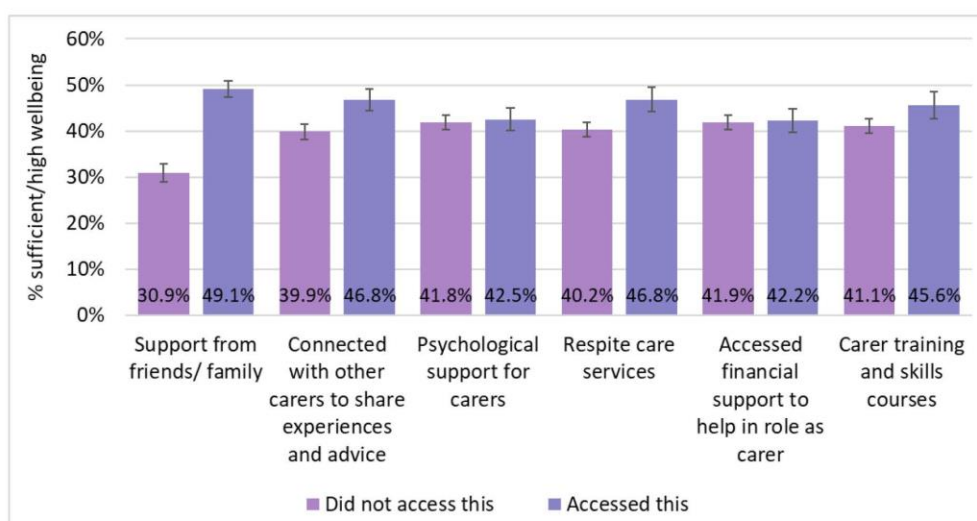
### Status of Australia's carers

According to the Australian Bureau of Statistics' 2018 [Survey of Disability, Ageing and Carers](#) (SDAC), 2.65 million Australian's provided ongoing assistance for someone with disability or older people.<sup>1</sup> Of these, 861,600 (or 3.5% of all Australians aged 15 years and over) were primary carers – i.e., the carer who provided the most care assistance.

Carers can be at either end of the age continuum, noting that in 2018 there were 235,000 'young carers' aged 12 – 25 years and almost 230,000 over 65. There will be differing experiences in duration of care – those who are new to the role, those who care for a comparatively short-term and those caring for more than 20 years. Caring is often not a choice, but in some cases it will be. In 2018, the three most common reasons primary carers gave for taking on a caring role were a sense of family responsibility (70%), emotional obligation (47%) and ability to provide better care than anybody else (46%).

The [2023 Carer Wellbeing Survey](#) (CWS) found that 49.8% of carers surveyed reported that their ability to maintain their own quality of life was getting worse. Additionally, the past 3 years of CWS findings consistently demonstrate that carers spend more time than desired on caring duties and housework/chores, and significantly less time than desired in paid work, volunteering, exercising, sleeping, and spending time with friends and family - all things that contribute to wellbeing.

The findings also show that accessing respite care is one of the six main factors associated with higher wellbeing for carers.



**Figure 1 Proportion of carers with sufficient/high wellbeing amongst carers did and did not access different supports in the past 12 months**

Despite these findings, when comparing 2021 and 2023 data about the different types of formal supports carers accessed to assist them, the only significant changes were a decline in the proportion of carers who reported respite care services. From 30.6% in 2021, to 27.7% in 2022 and 26.8% in 2023.

<sup>1</sup> The Survey of Disability, Ageing and Carers defines disability as a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activity. This includes sensory, intellectual, physical, psychosocial, head injury/stroke/acquired brain injury, long-term conditions which impact on everyday activities)

## Respite Care Roundtable

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The carers least likely to report access to respite care services were those aged 35-44 (16.8%), Sole carers (17.2%), carers for a person with low-moderate assistance needs (19.3%), those aged 45-54 (20.5%), and carers living in the ACT (22.3%).

These findings are also consistent with other research. The [2022 National Carer Survey](#) found that, like previous years, the largest unmet need reported by carers was for planned and emergency respite services (Figure 32). For planned respite services, the unmet need (27.0%) is twice as high as the rate of use among respondents (13.8%); for emergency respite, unmet need (24.4%) is four times the rate of use (6.1%).

### *Barriers to respite care*

Consistent with the 2022 CWS findings, in 2023 the most common barriers experienced in the 12 months leading up to March 2023 were:

- a. difficulty finding high quality services (43.9% reporting this as a large barrier),
- b. complicated application processes (42.9%),
- c. long waiting times to access services (42.9%),
- d. lack of funding for the service via NDIS/My Aged Care or other support packages (40.2%)
- e. lack of local service availability (40.1%).

Most carers reported experiencing multiple barriers while accessing care, highlighting the complexity of the process.

The 2021 paper [Repositioning respite within consumer directed service systems](#) developed by Carers NSW Policy and Research team on behalf of the Carer Respite Alliance (CRA), outlined 5 key barriers experienced by carers when accessing respite: availability, accessibility, appropriateness, and affordability.

In application these barriers can range from unawareness of appropriate options to choose from with regard to the needs of the carer or care recipient. Appropriateness can relate to cost, location, timing and level of care or other factors. This has been identified as a particular barrier for carers of people with dementia, carers of people with complex needs, carers from CALD backgrounds and carers living in regional and rural areas.

The importance of respite has been highlighted in the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, the 2020 Productivity Commission Inquiry into Mental Health, and the 2021 Royal Commission into Aged Care Quality and Safety. Further, the findings from these processes have consistently noted the cessation of funding for previous programs such as Mental Health Carer Respite Services, difficulty accessing respite (particularly community-based cottage respite) through the Carer Gateway, issues with aged care respite pathways (both community and residential) or palliative care-specific respite options, and very limited access to carer respite via the NDIS.

Equitable access and early referral to respite care, both planned and emergency, and across residential and community settings, overnight and day options, is critical to ensure sustainability of care relationships, and the health and wellbeing of carers.