

# CARING FOR OTHERS AND YOURSELF

## 2022 Carer Wellbeing Survey | Full data report

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# Executive Summary

In 2021, 12.8% of Australians aged 15 and older were providing unpaid assistance to a person with a disability, illness, chronic condition, or old-age related frailty (ABS 2022). For Australia's 2.65 million carers (ABS 2019), the responsibility of providing support is a significant part of their day-to-day life.

In 2021, the first Australian *Carer Wellbeing Survey* (2021 CWS) found that Australia's carers are two and a half times more likely to have low wellbeing than the average Australian adult; the

risk of poor wellbeing is higher amongst carers who have more complex, time-consuming or otherwise challenging caring obligations. 54.1% reported that they found being a carer satisfying, but carers were also much more likely than the average Australian to experience significant health problems, loneliness and financial hardship. However, carers with good access to support typically had higher wellbeing and fewer health and financial challenges.

In 2022, the second *Carer Wellbeing Survey* examined whether the wellbeing of Australia's carers changed between 2021 and 2022. It also provided deeper analysis of key aspects of carers' wellbeing and access to support.

## Carer Wellbeing Survey data collection overview

A total of 5,992 Australian carers aged 13 or older participated in the survey. Participants completed the survey online or in a paper form, with options to complete a short or long version of the survey. Participants were recruited through invitations sent by carer service providers and carer representative organisations, social media advertising targeted to carers, and inviting past participants to participate again. All presented findings were statistically weighted to be representative of Australia's carers based on information from the Australian Bureau of Statistics (ABS) *Census of Population and Housing* and *ABS Survey of Disability, Ageing and Carers (SDAC)*.

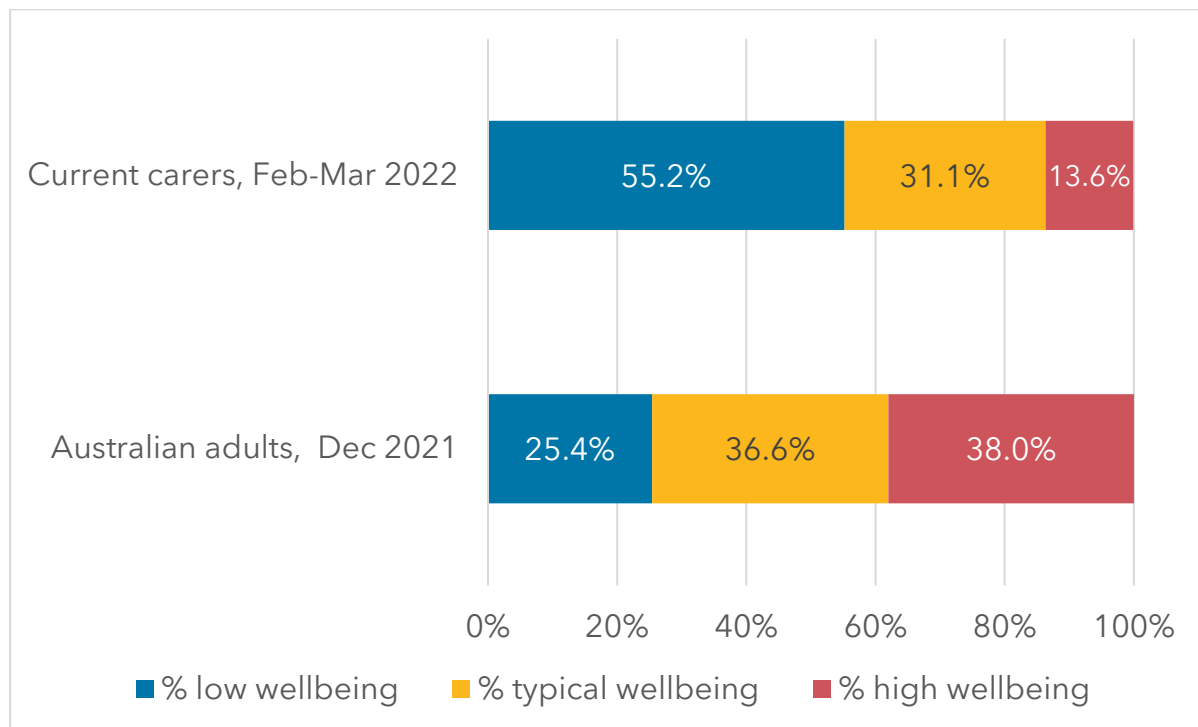
## Wellbeing and health of Australia's carers

Carers continue to be significantly more likely than other Australians to have concerningly low levels of wellbeing, with 55.2% having low wellbeing compared to 25.4% of Australians. Carers are three times *less* likely to have high levels of wellbeing compared to the average Australian. They are slightly less likely to have sufficient wellbeing (meaning the level of wellbeing considered to be associated with mostly positive quality of life) (FIGURE 1).

**What is a carer?** *A carer is a person who looks after someone who has a disability, mental illness, drug or alcohol dependency, chronic condition, dementia, terminal or serious illness; or who is frail or needs care due to ageing. They do this not as their paid job, but as a family member or friend. The Carer Wellbeing Survey focuses on those carers for whom caring represents a significant part of their day to day life - typically at least 10-15 hours per week, and often much more than this.*

Between 2021 and 2022, there was a decline in wellbeing amongst carers aged 35-44, and amongst Aboriginal and Torres Strait Islander carers. There was some improvement in wellbeing amongst carers aged 15-24, and those who had lower levels of caring obligation.

Carers also continued to be at higher risk of psychological distress, with 48.1% experiencing moderate to high levels of psychological distress - almost twice as many as the 25.0% of Australian adults who experience this. Rates of high psychological distress increased between 2021 and 2022 amongst carers aged 25-34 and those who had been a carer for five or more years. They remained high amongst carers aged 35-44, and amongst carers who were unemployed.



**FIGURE E1 THE WELLBEING GAP BETWEEN CARERS AND THE AVERAGE AUSTRALIAN**

While 47.9% of Australian adults report that their health is very good or excellent, only 17.1% of carers report this. Compared to 2021, reports of poor health in 2022 increased amongst carers aged 25-44 and Aboriginal/Torres Strait Islander carers.

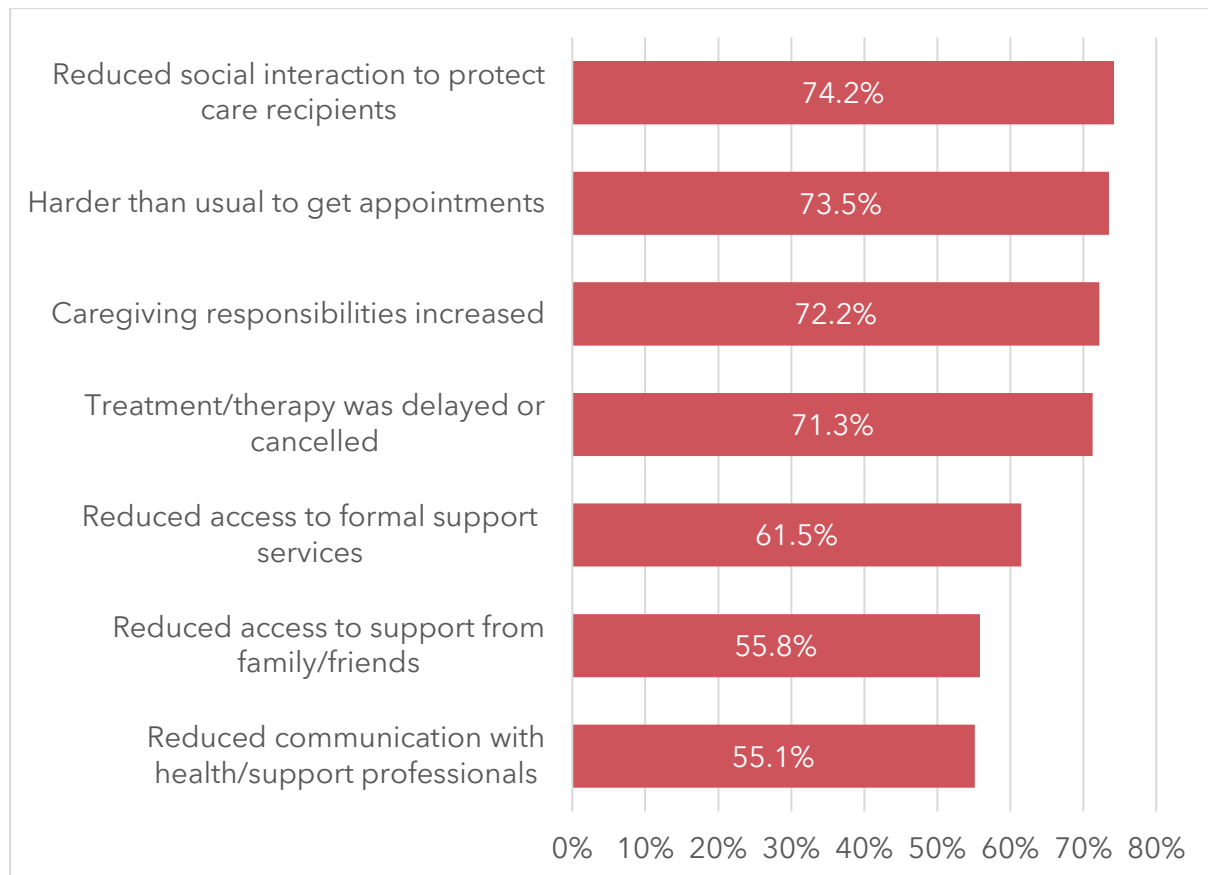
Overall, carers continue to be at very high risk of poor wellbeing and health. That risk appears to have increased somewhat between 2021 and 2022 for carers aged 25-44 and Aboriginal and Torres Strait Islander carers, suggesting some increased wellbeing stressors for these groups.

Carers were **2.8 times less likely to have good/excellent health** (17.1%) compared to other Australians (47.9%)



## Impacts of COVID-19

Carers were impacted in multiple ways by the COVID-19 pandemic, with almost all reporting at least one negative impact. More than 70% reduced their own social interaction to protect the people they cared for and increased their caregiving responsibilities. Similar percentages of carers found it harder to get appointments and maintain treatment/therapy for the people they cared for (Figure E2). A majority reported reduced access to support services and to informal support from family and friends. Carers who encountered increased difficulty communicating with the health and support professionals who helped the people they care for were also in the majority.



**FIGURE E2** NEGATIVE IMPACTS OF COVID-19 FOR CARERS AND THE PEOPLE THEY CARE FOR

The greatest impacts of COVID-19 on carers occurred amongst younger to middle aged carers who were caring for children, Aboriginal and Torres Strait Islander carers, and those caring for people with ASD, ODD or intellectual disability.

However, despite 63.9% of carers reporting they were more isolated in their role as a carer due to COVID-19, and 39.6% struggling to maintain their own wellbeing, 55.5% felt the wellbeing of the people they cared for had been successfully maintained. 60.1% reported that telehealth appointment had been helpful during COVID-19, and 34.9% found increased support payments during COVID-19 helpful.

## Loneliness and social connection

Rates of loneliness increased amongst carers between 2021 and 2022, with a rise in those reporting they were often or always lonely from 35.1% to 39.4% (Figure E3). This was driven by growth in loneliness experienced by carers aged 25-44. This is consistent with the reported impacts of COVID-19 on carers in these age groups, with these groups more likely than other carers to report experiencing increased social isolation due to COVID-19.

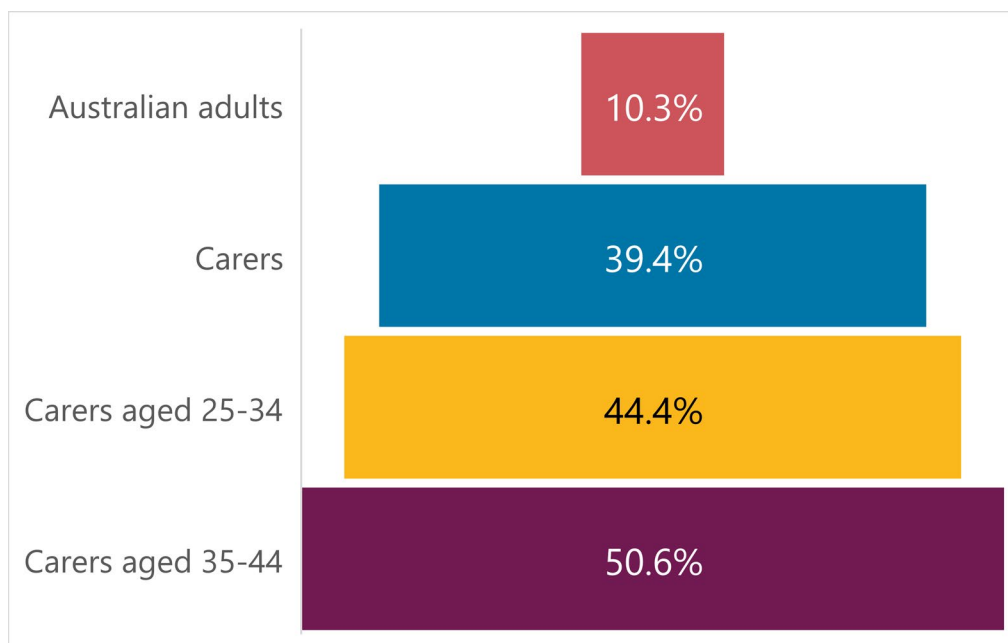


FIGURE E3 RATES OF LONELINESS AMONGST CARERS

## Time use

Having a good balance in time use is important to wellbeing: this involves not just having a good balance between 'work' and 'life', but time to fulfil caring duties, home duties such as housework, self-care, and relaxation (Tomczyk et al. 2021).

85.0% of respondents spent less time than they wanted doing recreational activities, 80.8% did less exercise than they wanted, 78.2% spent less time than desired with family and friends, 75.3% got less sleep than they wanted, and 65.0% spent less time outdoors than they wanted. Carers were much less likely than other Australians to get as much recreational time, exercise, and time with friends as desired.

67.1% of carers reported spending more time caring for family members or friends in the previous four weeks than they wanted to, while 54.1% did more housework than they wanted to. A further 21.5% did less housework than they wanted to.

Carers were almost twice as likely to be under-employed as other Australians: 44.8% of carers who were in the workforce were doing fewer hours of work than desired compared to 23.1% of the Australian workforce. Of these carers, 69.4% said caring was the sole reason for working less than desired.

## Financial wellbeing

In the 12 months to March/April 2022, 54.4% of carers experienced at least one significant financial stress event in the previous 12 months, such as being unable to pay bills on time, going without meals, or having to ask for financial assistance, compared to 32.2% of Australian adults.

Carers were **1.7 times more likely to experience significant financial stress** compared to other Australians.

## Housing, telecommunications and transport

In both 2021 and 2022, more than 70% of carers across Australia reported their home met their needs well, including good access to mobile phone reception and high speed, reliable internet. However, in 2022, 24.1% reported that their home was too small to comfortably accommodate the people who lived in it, indicating overcrowding was a problem for almost one in four carers in 2022 (24.1%). Meanwhile, outside major cities, one in three carers lack good access to high speed, reliable internet (33.8%). This highlights a significant 'urban-rural divide' in access to important infrastructure that many carers need to access supports and services.

Only 39.4% of carers reported that the people they cared for could easily travel to the places they needed to go, such as medical appointments through to social activities, with most experiencing difficulty with transport some or all of the time.

## Employment and study

Managing care responsibilities in the context of employment can make it challenging for carers to participate in the workforce. In the 2016 Census of Population and Housing, only 59.5% of carers participated in the labour force, compared to 66.2% of non-carers. The CWS focuses on carers for whom being a carer is a significant part of day-to-day life. Amongst this group, in 2021, only 66.5% participated in the labour force, while in 2022 69.3% participated in the labour force.

This suggests that labour force participation is lower amongst those carers for whom caring comprises a significant part of daily life. It also suggests labour force participation may have grown between 2021 and 2022 amongst this type of carer, although further data over a longer time period would be needed to establish confidence.

Amongst carers who have paid employment, many work fewer hours than they want to. Most had some flexibility in work hours, with only 22.8% reporting no flexibility. 42.5% had a supervisor who was understanding of their caring obligations. However, only half of working carers felt they could discuss their carer role with their employer/supervisor any time they

needed to (48.1%), and 15.8% had not told their supervisor about their caring obligations. Younger carers were less likely to feel confident they could discuss their caring obligations with their supervisor. Only 32.4% reported that their job was very secure.

Carers who were employed were less likely to have low wellbeing (54.5%) compared to those who were not in the labour force (58.5%), and particularly compared to those who were unemployed (74.7%). This does not account for the many carers who are working less than they would prefer. This population includes both employed carers and those who are not currently in the labour force. Of the 44.8% of carers who reported that they did less paid work than desired in the previous month, 70.8% had low wellbeing.

## Choosing to be a carer

Becoming a carer often occurs unexpectedly, and many carers may have had a limited or absent ability to choose whether they became a carer. In total, 57.8% of current carers reported that they had no choice about whether to be a carer or not, 19.0% said they had little choice, and 14.8% actively decided to take on a carer role and could have chosen not to be a carer.

Carers were least likely to feel they had a choice about becoming a carer if they were aged between 35-54, were a primary carer or cared for three or more people, and cared for a child or grandchild or a person with autism spectrum disorder or an intellectual disability.

Having a choice was associated with better wellbeing: 61.0% of those who actively chose to be carers had typical or high levels of wellbeing, compared to only 35.9% of those who had no choice in becoming a carer, and 42.2% of those who had little choice.

## Benefits associated with being a carer

Despite the challenges that can come with being a carer, 54.1% of carers find being a carer is satisfying. 56.4% said that it contributed to their sense of meaning and purpose, and 51.6% that being a carer is a positive experience. Around two thirds find that being a carer has strengthened their relationship with the person they care for (62.9%) and have learned new skills due to being a carer (68.0%).

However, despite many reporting having some positive experiences associated with being a carer, only 40.0% of carers say they would have no hesitation in encouraging other people to become carers. 37.7% disagreed, and 22.3% were unsure or neutral. This suggests that the complex and challenging impacts experienced by many carers mean they would not recommend others become carers in spite of the positives.

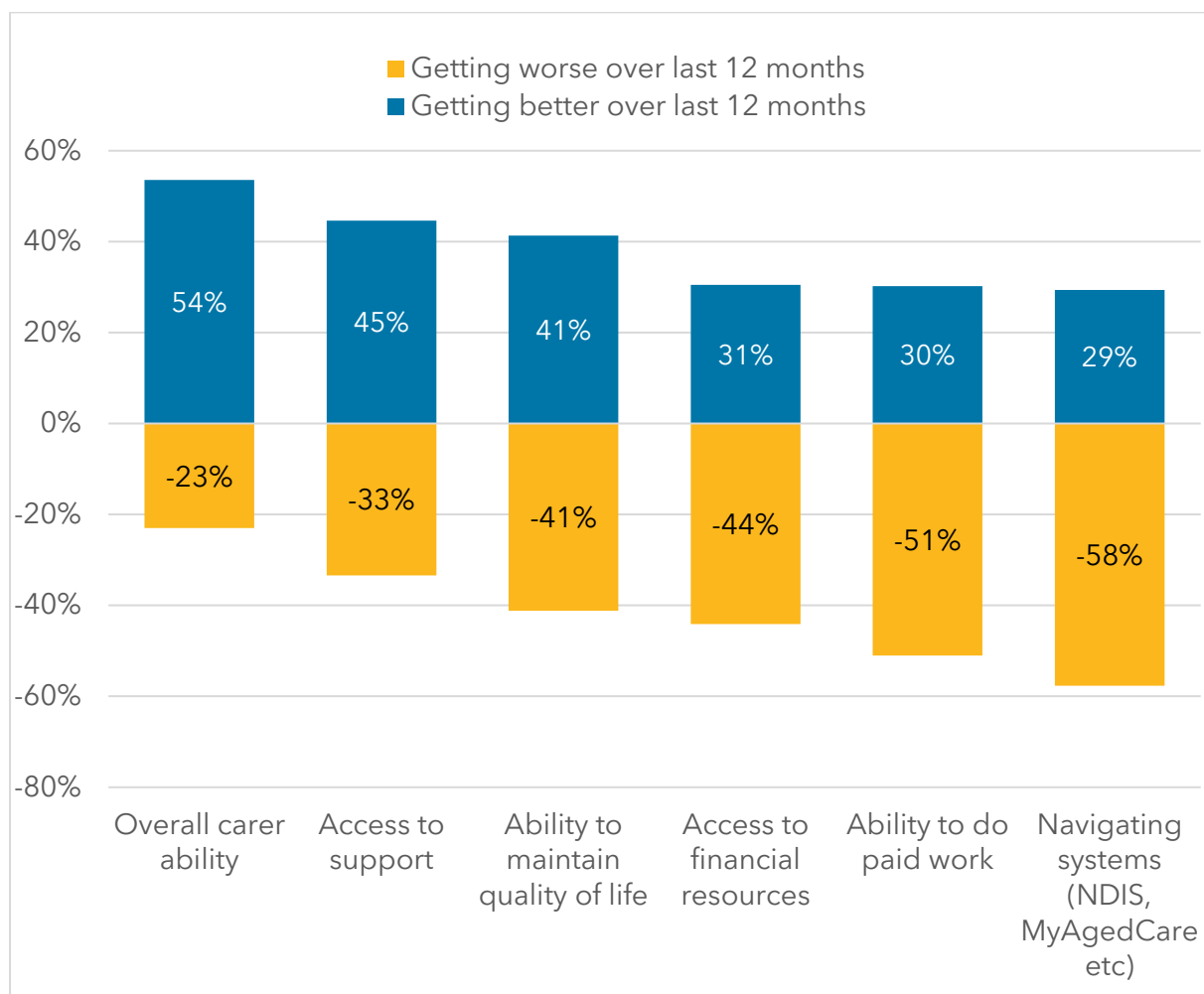
## Challenges and impacts of being a carer

Many challenges are associated with taking on a caring role. They range from worry about the future of the person being cared for (69.8%), to carers lacking time for themselves (62.3%), and financial stress and fears (56.2%). The most commonly experienced negative aspects of being a carer are fearing for the future of the person being cared for, lacking time for yourself, high level of responsibility, and financial stress, all of which are reported by a majority of carers.

## Confidence in carer role

Most carers feel confident to take care of the physical needs of the people they care for (68.4%). However, fewer feel able to readily identify and access services for care recipients (52.9%), or to take care of their emotional needs (47.2%). Only 34.9% feel confident they can cope with the stress of their care-giving activities.

However, many carers felt positive about how their carer skills were changing (Figure E4). 53.6% felt their overall ability as a carer had improved in the last 12 months, while 45.0% felt their ability to maintain their own health had improved. 44.6% that their access to support for their caring duties had improved, although 33.4% reported access to support had declined.



**FIGURE E4** CHANGE IN EXPERIENCE OF BEING A CARER IN THE LAST 12 MONTHS, 2022

On the other side of the picture, carers were more likely to report a decline than improvement in their ability to progress their studies/education (53.4%), ability to navigate systems such as NDIS (57.7%), ability to participate in paid work (51.0%), and access to financial resources (44.1%).

## Access to formal and informal support in role as a carer

When asked if they had access to support from friends and family, in both 2021 and 2022, 28% of carers reported having no access to support, while 20% could easily organise a friend or family member to help out, and 52% could organise help but it would be difficult (FIGURE 24).

In 2022:

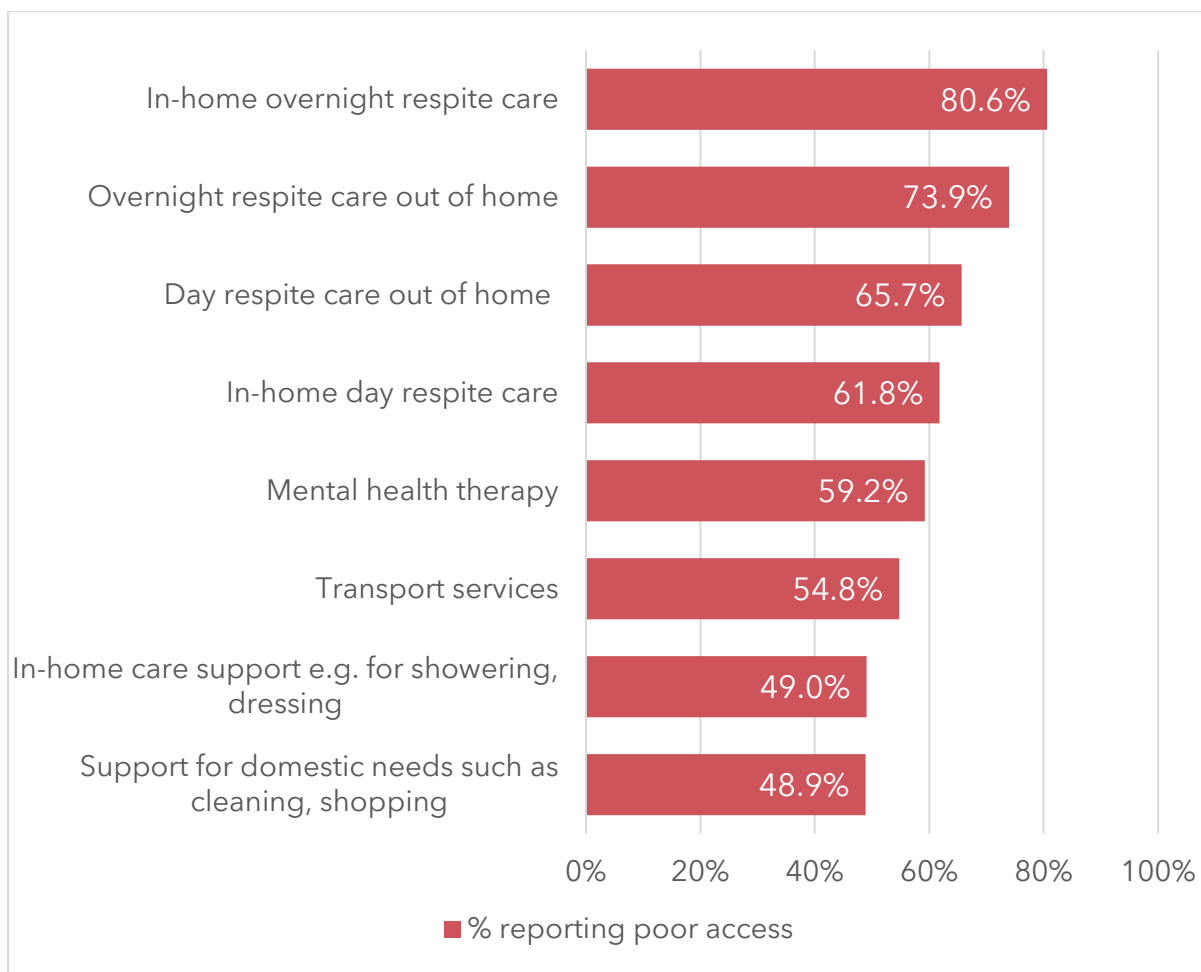
- 61.7% of carers reported they received some support from friends and family in the last 12 months
- 31.6% connected with other carers via peer support groups or other methods
- 29.0% accessed psychological support
- 27.7% used respite care services
- 31.2% accessed financial support for their role as a carer
- 17.4% attended carer training or skills courses.

Male carers were less likely than female carers to access support through carer peer groups or psychological support, and carers aged 65 and older were also less likely to access psychological support services compared to younger carers.

Having access to support was associated with significantly higher wellbeing. Those who had access to support from friends and family were much more likely to have healthy levels of wellbeing, while amongst those providing care to people with high assistance needs, those who had access to respite care, peer support, and financial support within the last 12 months were significantly more likely to have healthy levels of wellbeing.

### Barriers to accessing support

One of the most significant ways carers can reduce the challenges they may otherwise experience is through helping the person they care for access support through available support packages, such as the NDIS and MyAgedCare. However, this is not always easy or possible, with more than half of carers reporting that during the previous 12 months the people they cared for had poor access to transport services, mental health therapy, and different types of respite care (Figure E5).



**FIGURE E5** % CARERS REPORTING CARE RECIPIENTS HAD POOR ACCESS TO DIFFERENT TYPES OF SUPPORT

The biggest barriers carers experienced when seeking access to support services for the people they cared for were:

- lack of funding for the service via NDIS/MyAgedCare or other support packages (a moderate to large barrier for 65.9%)
- difficulty finding high quality services (69.3%)
- complicated application processes (69.5%)
- long waiting times to access services (66.9%)
- lack of local service availability (64.0%)
- difficulty affording services (64.2%)
- staff turnover amongst service providers (63.0%)
- poor coordination between services (61.9%)

Most carers reported experiencing multiple of these barriers, highlighting the complex range of challenges many carers face when seeking to access support services.

Carers living in regional and remote areas were significantly more likely to report that lack of service availability was a large barrier to accessing services, with 53.0% of those living in outer regional and remote areas reporting this compared to 34.6% of those living in major cities.

## Carer experiences with medical professionals and My Health Record

Carers often need to liaise closely with medical professionals as part of their role as a carer.

Overall, 52.9% of carers reported they had good access to information from the medical professionals who provided support to the people they cared for. Amongst current carers, around one in three accessed their own My Health Record (33.9%), while 21.0% accessed the My Health Record of a person they cared for.

## Peer support groups: what works well?

In total, 31.6% of carers reported they had connected with other carers to share experiences and advice within the last 12 months. A common way that carers connect with each other is through attending carer peer support groups. The 11.2% of survey participants who indicated they had been part of a peer support group were asked about their experiences. Almost three quarters found the support group helpful overall (74.6%), found participating in it made them feel more positive (74.0%), gained new ideas and knowledge from others in the group (71.7%), and valued the social connections they made (70.7%). Relatively few reported negative outcomes, although around one in five found the group discussions often left them feeling depressed or down (22.1%) or feel more frustrated or angry about their carer role (17.4%).

## Life after being a carer: experiences of past carers

Past carers who participated in the 2022 CWS were asked how their life had changed since they stopped being a carer. Despite many finding their quality of life improved after their caring role stopped, 51.9% reported they found it difficult to adjust to life after being a carer, and 48.8% had some difficulty building their social life. Just over one third reported difficulty either returning to the workforce or increasing work hours (34.4%). Many (63.5%) felt that having access to psychological counselling, support for education or re-entering the workforce, or support to build new social connections, would be useful to help them to adjust to life after being a carer.

## Conclusions

The 2022 *Carer Wellbeing Survey* highlights the impacts COVID-19 has had for carers, with many experiencing reduced access to support (informal and formal), an increase in caregiving responsibilities, and an increase in isolation due to the effects of the pandemic. This compounds the effects of the relatively limited access to support services already experienced by many carers. Some of these impacts appear greater amongst carers aged 25-44 and carers who are Aboriginal or Torres Strait Islander, for whom health, wellbeing and distress worsened between 2021 and 2022.

Many carers feel positive about how their ability to provide high quality care is changing over time, and more feel that access to support is improving than feel it is declining. However, many also feel that their access to financial support and ability to engage in paid work worsened in the 12 months to March/April 2022. Most feel that navigating support systems such as NDIS and My Aged Care has become more challenging.



The results highlight that many carers feel a sense of meaning and purpose due to being a carer - despite often having little choice in whether or not they became a carer. However, barriers to accessing informal and formal support, lack of free time, and financial stress challenge carers' wellbeing. Addressing these barriers could reduce the significant rates of low wellbeing amongst carers, and create more overall positive experiences of caring. In particular, carer wellbeing is supported by facilitating access to different types of support and creating an environment in which carers can engage in paid employment.

# 1. Introduction

In 2021, the *Census of Population and Housing* found that 12.8% of Australians aged 15 and older were carers (ABS 2022<sup>1</sup>). When examined across all age groups including carers aged under 15, in 2018 it was estimated that 2.65 million Australians in total were carers (ABS 2019). A carer provides unpaid assistance to a person with a disability, mental illness, drug or alcohol dependency, chronic condition, dementia, terminal/serious illness, or old-age related frailty. They do this, not as their paid job, but as a family member or friend. If these 2.65 million carers were replaced by paid workers, the care they provide would cost \$77.9 billion annually, or almost 0.8% of Australia's GDP (Deloitte 2020).

Amongst Australia's carers, 860,000 are 'primary carers', meaning they are the primary person providing assistance to one or more people who need assistance with 'core activities' such as mobility, self-care and communication. Amongst most of this group, as well as for many other carers, caring duties typically make up a significant part of their day-to-day life - as much as or more than a full-time job (ABS 2019).

In April to May 2021, the first Australian *Carer Wellbeing Survey* (2021 CWS) surveyed 5,800 carers to provide a comprehensive picture of the wellbeing of carers, and how wellbeing of carers can be supported. It found that Australia's carers are two and a half times more likely to have low wellbeing than the average Australian adult, with 55% having low wellbeing compared to only 20% of the broader population; and that the risk of poor wellbeing is higher amongst carers who have more complex, time consuming or otherwise challenging caring obligations - many of whom are primary carers. Carers were found to be more likely than those who aren't carers to have significant health problems, and to experience loneliness and financial hardship. Despite this, 54.1% of carers found being a carer satisfying. Most importantly, the findings showed that carers who have access to more support have higher wellbeing. This support may be from family and friends, or from formal care providers; support can also come in the form of support from other carers in peer support groups, or carers having access to training that increases their skills and knowledge as a carer.

The 2021 CWS provided an initial baseline set of measurement from which change over time could begin to be examined. This report presents finding of the second CWS, which was conducted in February to March 2022 (the 2022 CWS). The 2022 CWS was conducted by the University of Canberra's Regional Wellbeing Survey team, and funded by Carers Australia with support from the Australian Government Department of Social Services.

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<sup>1</sup> At the time of release of this report, detailed data on carers was not yet available from the 2021 Census of Population and Housing; a more detailed picture of carers across Australia in 2021 that draws on Census data will be included in a subsequent edition of this report once Census data are available.

The objectives of the CWS are to:

- Understand different dimensions of wellbeing and quality of life of carers and how they are changing
- Understanding how the wellbeing differs depending on the type of carer role a person has, and wellbeing risks associated with different carer roles
- Identify which types of support are effective in supporting the wellbeing of carers and their ability to be an effective and successful carer

The 2022 CWS examined whether and what types of change in wellbeing occurred between 2021 and 2022, and whether some types of carers experienced different wellbeing changes to others. It also included questions about a small number of 'special topics'. These special topics were identified in two ways. First, carers who responded to the 2021 survey were asked to identify areas they would like to see asked about in the survey. Second, areas in which there is a need to understand aspects of carer experiences in more depth were identified both from findings of the 2021 survey, and from discussions with representatives of groups representing carers. Overall, special topics aim to improve understanding of the different factors that can (i) help support and improve wellbeing, or (ii) that present risks to the wellbeing of carers. The special topics included in the 2022 CWS were:

- Carer choice and wellbeing: How many carers take on their caring role as an active choice versus feeling obligated to do so, and is the level of choice involved associated with differences in wellbeing?
- Navigating formal support systems: How easy or difficult do carers find it to access and navigate the formal systems that provide support for carers and for the people they care for, and what are the most common barriers experienced to accessing support?
- Health professionals and health records: To what extent are carers recognised and included in care discussions by health professionals, and how many have access to the My Health Record of care recipients?
- Peer support groups: What types of peer support groups are being accessed by carers, and how useful do they find these groups?
- COVID-19 impacts: How have the effects of the COVID-19 pandemic impacted carers, including their access to support in their caring role, level of social interaction, employment, and access to health services?
- Transport access: How many carers have adequate access to transport needed for caregiving purposes?

In addition to these special topics, the 2022 CWS examined the types of support carers provide to care recipients in greater detail than occurred in the 2021 CWS, including whether the carer provided continuous or episodic care, and whether they provided support for communication, physical activity, transport, communication, managing medications or appointments, study or employment support, social support, and advocacy for the person's needs.

Surveys are, by their nature, a snapshot in time that reflects the impacts of events happening when the survey is conducted. Both the 2021 and 2022 CWS were conducted during the

ongoing COVID-19 pandemic. Both were conducted at times when most Australian jurisdictions did not have significant movement restrictions related to the COVID-19 pandemic. However, many vulnerable people - included many carers and the people they care for - were restricted in their movements because of the pandemic, due to having high vulnerability if they became ill. At the time of the 2021 CWS (April-May 2021), vaccination for COVID-19 was in very early stages of roll-out, with the large majority of Australian not yet vaccinated at the time the survey was conducted. In February-March 2022, when the 2022 CWS was conducted, vaccination rates, as well as uptake of booster shots, was relatively widespread amongst the Australian population, and many movement restrictions had been removed or reduced, with relatively unrestricted interstate and travel, and international travel restrictions in the process of being lifted.

## 2. Methods

The CWS is a survey of Australian carers. A person is eligible to complete the survey if they are aged 13 or older, and provide unpaid assistance to a person with a disability, mental illness, drug or alcohol dependency, chronic condition, dementia, terminal/serious illness; or old-age related frailty. Carers can complete the survey online or using a paper form. Survey participants are recruited through multiple methods, including invitations sent to clients registered with carer service providers, invitations sent to members of organisations who represent carer interests, social media advertising targeted to carers, invitations sent to carers who participate in the national Regional Wellbeing Survey, and an online survey panel. In 2022, there were a total of 5,992 valid responses to the survey, and these are analysed in this report.

The methods used to collect and analyse data in the 2022 CWS are described in more detail in Appendix 1, while additional information on the specific items included in the survey, data weighting and sampling can be found in the CWS User Guide (Schirmer and Mylek 2022).

Throughout this report, all data presented have been weighted to be representative of Australia's carers by gender, age, state/territory, Indigenous status, labour force status, and weekly caring hours, unless otherwise specified. Appendix 1 provides information on the statistical weighting process, with further detail provided in the User Guide.

## 3. Topics examined

The findings of the 2022 CWS are presented in multiple sections. In each section, overall findings for all carers are presented, before comparing findings for different groups of carers to identify differences in their wellbeing and support needs.

Confidence intervals were used to identify where there was a high level of confidence that differences between different groups were likely to be the result of actual differences, rather than sampling variance. A confidence interval, put simply, is a measure of how confident we can be in the results. More accurately, it identifies the boundaries between which the mean value of a given variable would be 95% likely to fall if the survey was repeated multiple times with a similar sample. In all cases, 95% confidence intervals were used.

Findings are presented in several sections that examine the following aspects of carers lives, all of which are important to understanding their wellbeing:

- Overall wellbeing, illbeing, and health (Section 4)
- Impacts of COVID-19 (Section 5)
- Loneliness and social connection (Section 6)
- Time use (Section 7)
- Financial wellbeing (Section 8)
- Housing, telecommunications and transport (Section 9)
- Employment and study (Section 10)
- Choosing to be a carer (Section 11)
- Benefits associated with being a carer (Section 12)
- Challenges and impacts associated with being a carer (Section 13)
- Confidence in carer role (Section 14)
- Access to formal and informal support in role as a carer (Section 15)
- Barriers to accessing support (Section 16)
- Carer experiences with medical professionals and the Digital Health Record (Section 17)
- Peer support groups: what works well? (Section 18)
- Life after being a carer: experiences of past carers (Section 19).

## 4. Wellbeing, illbeing and health

### Wellbeing

The 2021 CWS found that carers had substantially and significantly poorer wellbeing compared to the average Australian, with carers being more than twice as likely to have low levels of wellbeing as adults across Australia.

In 2022, the overall finding was the same, with wellbeing of carers staying stable between 2021 and 2022 (FIGURE 1). This means that carers continue to be more than twice as likely as other Australians to have concerning low levels of wellbeing, with 55.2% having low wellbeing (defined as a score of 60 or less using the Personal Wellbeing Index measure), compared to 25.4% of Australians. Carers are three times *less* likely to have high levels of wellbeing compared to the average Australian, and a little less likely to have typical wellbeing (FIGURE 1).

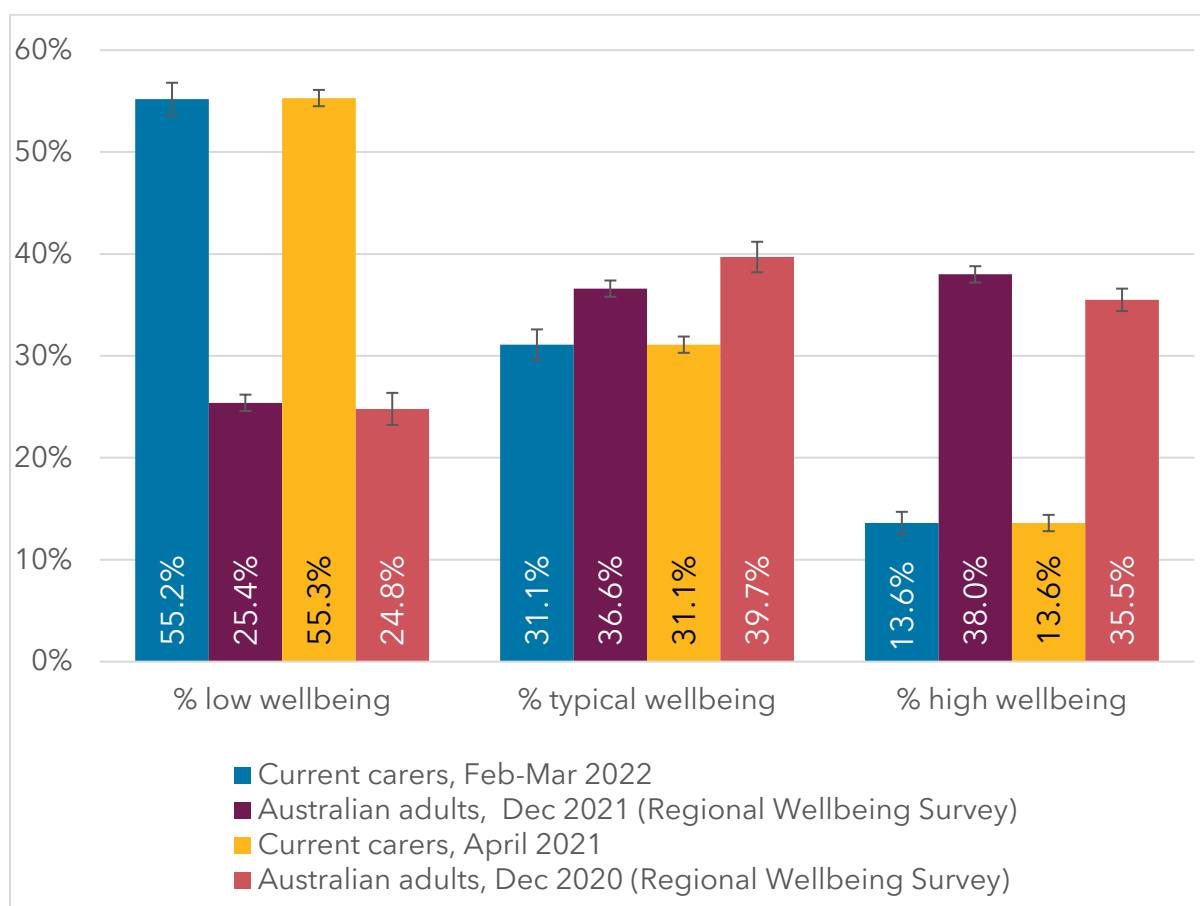


FIGURE 1 CARER WELLBEING 2020-2022

Between 2021 and 2022, key differences in the wellbeing of different carers remained the same: wellbeing was poorer amongst carers who were unemployed, caring for children or grandchildren, caring for multiple people, providing more than 40 hours of caring a week, and

those caring for a person with autism spectrum disorder, drug/alcohol dependency, or mental illness/psychosocial disability (see Appendix 2 for detailed data).

Amongst some groups of carers, wellbeing did change significantly between 2021 and 2022:

- Carers aged 35-44 experienced decline in wellbeing, with the proportion reporting low wellbeing increasing from 54.2% in 2021 and 63.2% in 2022.
- Carers who identified as Aboriginal or Torres Strait Islander also experienced decline in wellbeing, with the proportion with low wellbeing growing from 43.5% to 52.8%
- There was improvement in the wellbeing of carers aged 15-24, with the proportion with low wellbeing falling from 45.4% to 34.2%
- Wellbeing also improved amongst carers who had less than 20 hours a week of caring responsibilities, declining from 47.6% to 36.7%
- Those caring for a person with very high assistance needs also had some improvement in wellbeing, with low wellbeing declining from 63.6% to 55.2% of this group.

In 2021, it was found that those who stopped their caring role typically experienced a gradual increase in wellbeing after ceasing caring, with wellbeing returning to levels similar to the average Australian after a period of time. The 2022 findings again examined this, and found that the proportion of carers with low levels of wellbeing fell from 55.2% amongst current carers, to 48.2% amongst those whose caring role stopped within the last six months, 37.5% amongst those who ceased their caring role between six and 12 months before completing the survey, and 30.3% amongst those who ceased being a carer more than 12 months before completing the survey. This suggests that a year after stopping their carer role, most carers have experienced a recovery of wellbeing back to relatively typical levels, although their rate of low wellbeing (30.3%) still higher than the average of 25.4% across the Australian population at the end of 2021.

Overall, the findings suggest relatively stable wellbeing for most, but not all, groups of carers. Wellbeing typically changes slowly over time: measures of wellbeing do not reflect a person's day to day mood, but instead reflect their long-term quality of life. When changes occur, they tend to occur relatively slowly, and a significant change in wellbeing will usually be triggered by either a major life change, or a slow improvement or decline in important conditions such as a person's finances, housing, workload, or health.

## Illbeing

Measures of wellbeing examine how well the good parts of a person's life are going - how full the glass of wellbeing is. It is also important to look at 'illbeing' - whether a person is experiencing symptoms of distress that indicate the likely presence of significant life challenges. Illbeing and wellbeing often change in relation to each other: when illbeing increases, wellbeing declines, and vice versa.

Illbeing was examined using a measure of psychological distress: the Kessler 10 (K10) psychological distress scale. Similar to wellbeing, there was no significant change in the rate of psychological distress amongst carers: carers continued to have higher than average rates of psychological distress compared to the general population (FIGURE 2). Whereas 25.0% of



adult Australians had moderate to high levels of psychological distress at the end of 2020 (source: 2020 Regional Wellbeing Survey), 49.3% of carers were experiencing these levels of distress in 2021, and 48.1% in 2022.

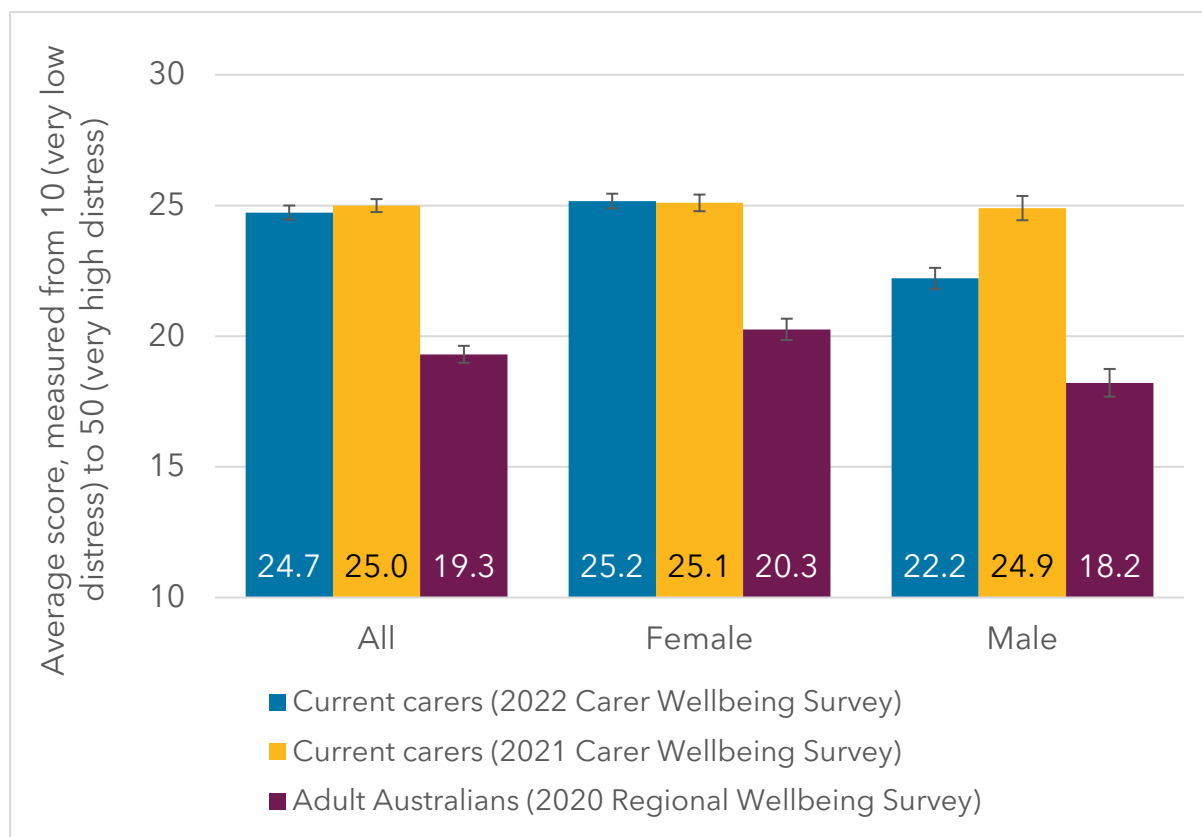


FIGURE 2 CARER ILLBEING, 2021-2022

The rate of moderate to high psychological distress stayed the same for most groups of carers between 2021 and 2022, with a small number of exceptions (see Appendix 2). Rates of moderate-high distress fell significantly amongst carers aged 15-24, those aged 75+, those with fewer than 20 hours of caring responsibilities each week, and those who had been carers for less than 12 months. They grew amongst carers aged 25-34, and those who had been a carer for five or more years.

The carers at highest risk of experiencing high levels of psychological distress in 2022 were (numbers in brackets indicate the proportion with moderate to high psychological distress):

- Carers aged 25-34 (71.0%)
- Unemployed carers (63.1%)
- Carers who identify as LGBTQIA+ (60.3%)
- Carers aged 35-44 (60.3%)

Similar to wellbeing, risk of moderate and high psychological distress is lower amongst past carers, falling from 49.3% of current carers to 40.0% amongst those who stopped being a carer within the last six months, 36.3% amongst those who ceased their carer role six to 12 months previously, and 25.5% amongst those who stopped being a carer more than a year previously - almost identical to the Australian average of 25.4%.

## Health of carers

Across the Australian adult population, in 2021 47.9% of people reported being in very good or excellent health, 30.4% in 'good' health, and 21.7% in fair or poor health (Regional Wellbeing Survey 2021). In contrast, only 17.1% of carers reported having very good or excellent health and 33.1% good health, while 48.6% reported having fair or poor health.

Across the whole population, these findings are the same as 2021, when carers were also found to have more than double the risk of having poor/fair health compared to the general population.

The way general health changed between 2021 and 2022 was, however, different for some groups of carers. In particular, there was a decline in general health amongst those aged 25-34 and 35-44, with a more than 10% increase in the proportion of each of these groups reporting poor/fair health. Similarly, the proportion of Aboriginal and Torres Strait Islander carers reporting poor/fair health increased by more than 10%. This suggests potentially higher health stressors amongst these groups compared to other groups of carers in 2022 when compared to 2021.

## Conclusions

The 2022 findings suggest that across all carers, incidence of low wellbeing, moderate to high psychological distress, and poor health stayed stable between 2021 and 2022. However, there was some change observed in a small number of groups. The groups most likely to have experienced a decline in wellbeing or increase in illbeing or poor health between 2021 and 2022 were carers aged 25-34, 35-44, and Aboriginal and Torres Strait Islander carers. However, for each of these groups there was a negative change in two of the three indicators, not in all three, and it is not known if this represents a long-term trend.

## 5. Impacts of COVID-19

The COVID-19 pandemic has significantly impacted the global community throughout both years of the CWS. Some studies have identified that carers have been at particularly high risk of negative impact, due to the pandemic often adding to challenges experienced when seeking to provide care and support. Studies document impacts including increased loneliness, reduced wellbeing, increased distress and increased uncertainty about the future amongst carers due to the pandemic (see for example Lorenz Dant and Comas-Herrera 2021, Muldrew et al. 2022, Wei et al. 2022). Many carers are caring for people who have higher than typical risk if they become ill with COVID-19, and thus may have put in place additional distancing and isolation measures to reduce risk of transmission. In addition, carers and the people they care for often rely on being able to regularly access health and social services. At times during the pandemic, access to these services was restricted or limited in a range of ways. This included restrictions on the people who could accompany a patient to a health appointment; and limited availability or long waiting times when health services were under particular strain, or when non-essential health services were reduced, due to the impacts of the pandemic.

The CWS was first undertaken a year into the pandemic, with the 2021 CWS collecting data in April 2021. This means that no baseline data are available from the survey prior to the pandemic. To assess the impacts of the pandemic on carers, it was necessary to ask direct questions about those impacts. The 2022 CWS asked carers a number of questions about how the ongoing COVID-19 pandemic had impacted them as a carer, and their ability to access ongoing therapy and support for the people they care for.

As shown in FIGURE 3, the pandemic was associated with significant challenges for many carers, both in terms of their own social contact, and in terms of their ability to maintain support and care for care recipients. Across all carers, just over half - 51.1% regularly had to limit their own social interactions due to one or more people they cared for being at high risk if they became ill with COVID-19, and a further 23.2% sometimes had to do this. Almost half - 49.6% - had a long-term increase in the intensity or amount of their caregiving responsibilities due to COVID-19, and 22.6% sometimes had increase in this. This suggests a significant increase in carer challenges was associated with COVID-19 for half of carers, and a smaller increase in impact for almost another quarter.

This increase in challenges for carers was likely in part a result of reduced access to health and support services: 73.5% of carers reported it was sometimes or regularly harder to get health or social service appointments for the people they cared for due to COVID-19, 71.3% reported treatment or therapy for care recipients being delayed or cancelled (37.4% regularly), and 61.5% reported that access to some types of supports or services such as respite care, cleaning or in-home support reduced for the people they cared for. While 67.9% were able to use telehealth appointments for one or more of the people cared for, this is unlikely to have compensated for the impact of loss of practical support services reported, and 55.8% reported that communication with medical professionals increased in difficulty due to COVID-19 restrictions (for example due to the carer not being permitted to accompany the care recipient to an appointment). Access to informal support also declined during the pandemic: 55.8% of carers reported that at some points during the pandemic, family and friends who usually assisted them could not provide support. One in three carers (35.2%) had

to take some time away from employment or study when a person they cared for was unable to attend school or work and required at home care. Other impacts asked about were experienced by fewer carers, but still by more than one in five: for example, vaccine access was difficult for 27.2% of carers, and 22.7% had difficulty accessing vaccine certificates.

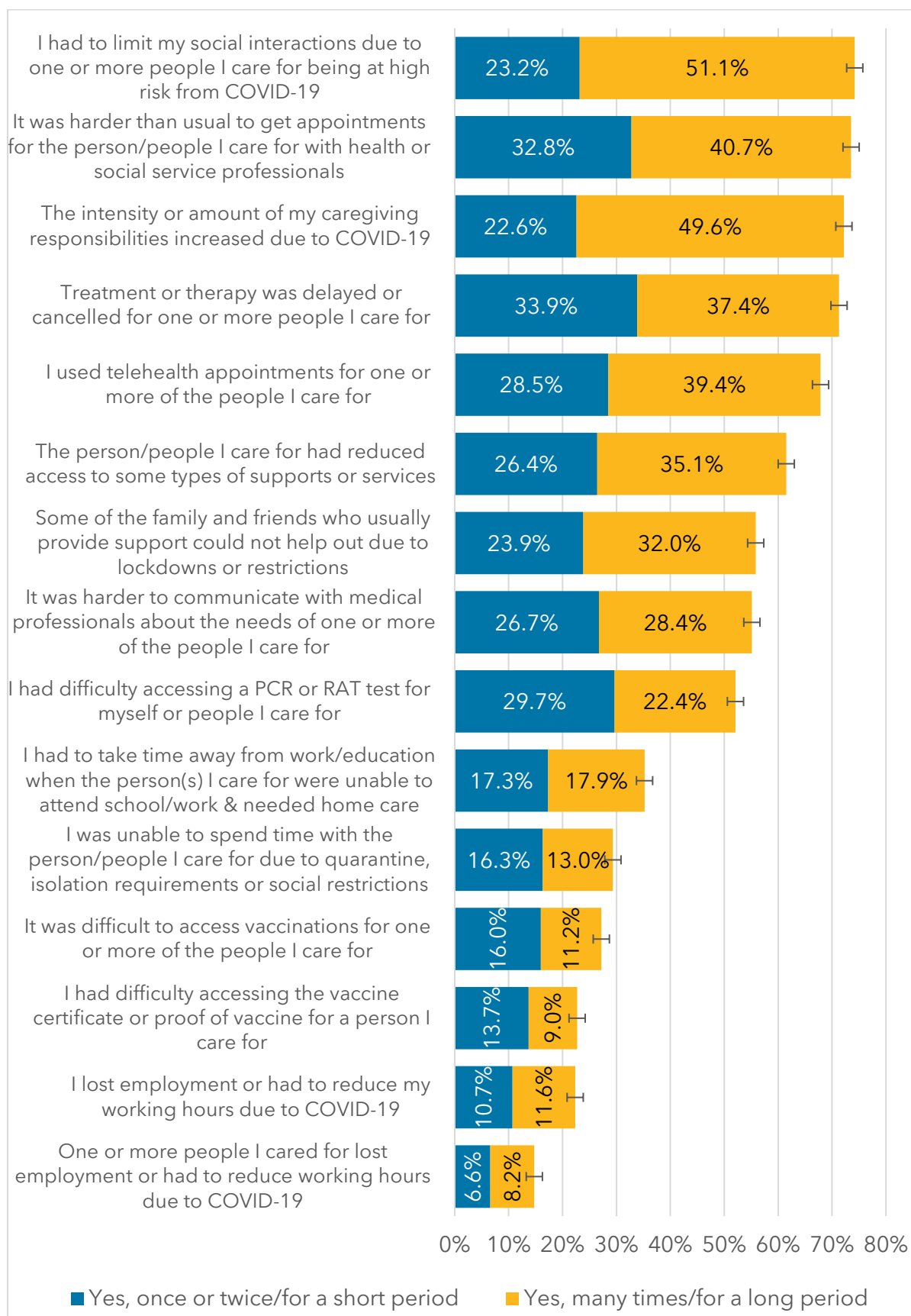


FIGURE 3 COVID-19 EXPERIENCES

Most carers reported that COVID-19 had at least some negative impacts for them in their caring role. However, some were even more likely than others to experience negative impacts. As summarised in Figure 4, the findings suggest the greatest impact of COVID-19 on carers occurred amongst younger to middle aged carers who were caring for children, Aboriginal and Torres Strait Islander carers, and those caring for people with ASD, ODD or intellectual disability.

The carers most likely to report reduced access to support, having to take time away from work or study for their caring role and an overall increase in their carer responsibilities, were those caring for children or grandchildren, for people with ASD, ODD or an intellectual disability, carers aged 25-44, and Aboriginal and Torres Strait Islander carers (Figure 4). A majority of these groups of carers experienced all these things. These groups overlap: carers aged 25-44 are more likely than others to be caring for children, and for people with ASD or ODD, for example. They are also more likely to be engaged in paid work compared to older carers. This is a likely contributor to the reduced wellbeing and increased distress observed amongst carers aged 25-44 and Aboriginal and Torres Strait Islander carers (see previous section).

A slightly different set of carers were more likely than others to lose access to support from friends and family as a result of COVID-19 restrictions or lockdowns: this was most commonly reported amongst Aboriginal and Torres Strait Islander carers, carers aged 25-44, carers living in Victoria, and those caring for a person with a terminal illness. In the case of Victorians, this may reflect the longer period of time Victorians spent with significant travel restrictions and lockdowns compared to those living in other states and territories.

Carers were more likely to report they had been unable to engage in their usual caring duties for a period of time due to COVID-19 if they didn't live with the person they cared for, weren't a primary carer, were caring for a friend or relative other than a close family member, or identified as Aboriginal or Torres Strait Islander.

Amongst carers who were in paid employment or enrolled in a course of study, just over half (50.9% and 51.8% respectively) reported they had taken time off work or study due to COVID-19 related increases in their caring responsibilities.

The higher impacts of COVID-19 on those carers aged 25-44 and caring for children may reflect that many in these groups were at higher risk of having paid work disrupted if their caring obligations increased, and of having an increase in caring obligations during periods of home-schooling.

61.5% of all carers had reduced access to supports and services for care recipient/s

- 78.5% of carers for a person with intellectual disability
- 76.8% of those caring for 3+ people
- 72.1% of ASD carers, and 75.7% ODD carers
- 74.3% of those who help care recipient with work/study
- 72.6% of those caring for a child/grandchild
- 71.1% of carers aged 35-44

35.2% of all carers had to take time away from work or study when people they cared for couldn't study or work due to COVID-19

- 58.8% of carers aged 25-34 and 56.8% of carers aged 35-44
- 54.5% of carers who are Aboriginal or Torres Strait Islander
- 52.7% of ASD carers, and 53.0% of ODD carers
- 55.1% of carers who help care recipient with work/study
- 50.9% of working carers & 51.8% of studying carers
- 50.7% of those caring for a child/grandchild

73.5% of all carers found it harder to get health/social service appointments

- 90.8% of those caring for 3+ people
- 85.2% of those caring for a child/grandchild
- 84.3% of ASD carers and 87.2% of ODD carers
- 84.4% of carers aged 35-44, 83.7% of carers aged 25-34, 81.9% of carers aged 45-54

72.2% of all carers reported an increase in caring responsibilities due to COVID-19

- 89.2% of carers who help care recipient with work/study
- 87.0% of carers who care for 3+ people
- 86.8% of those caring for a child/grandchild
- 85.8% of ASD carers and 86.5% of ODD carers
- 84.5% of carers aged 35-44 & 80.6% of carers aged 25-34
- 84.1% of carers of a person with intellectual disability

55.8% of all carers reported COVID-19 restrictions stopped family and friends being able to help

- 67.7% of Aboriginal/Torres Strait Islander carers
- 65.3% of ODD carers
- 65.2% of carers aged 25-34 & 62.7% of carers aged 35-44
- 64.5% of Victorian carers
- 63.9% of those caring for a person with a terminal illness

71.3% of all carers reported treatment or therapy being delayed or cancelled for people they care for

- 87.6% of carers who help care recipient with work/study
- 86.7% of carers who care for 3+ people
- 84.7% of ASD carers and 85.0% of ODD carers
- 84.5% of those caring for a child/grandchild

29.3% of all carers were sometimes unable to do their caring role due to COVID-19 related restrictions

- 62.1% of carers who live separately to care recipients
- 51.8% of those who are not the primary carer for a person
- 50.0% of Aboriginal and Torres Strait Islander carers
- 48.7% of those caring for a friend or relative
- 44.5% of those caring for 3 or more people

FIGURE 4 EXPERIENCES OF COVID-19 ON DIFFERENT GROUPS OF CARERS

Carers who experienced increased challenges in their caring role due to the effects of COVID-19 were also significantly more likely to have low wellbeing (FIGURE 5). Amongst carers who reported COVID-19 had few or no impacts during 2021 on day-to-day aspects of their carer duties, 36.9% had low wellbeing. This increased to 54.2% amongst carers who reported COVID-19 made two or three aspects of their carer role more difficult on a regular basis during 2021, and to 68.2% amongst those who reported that COVID-19 made multiple aspects of their carer role more difficult on a regular basis.

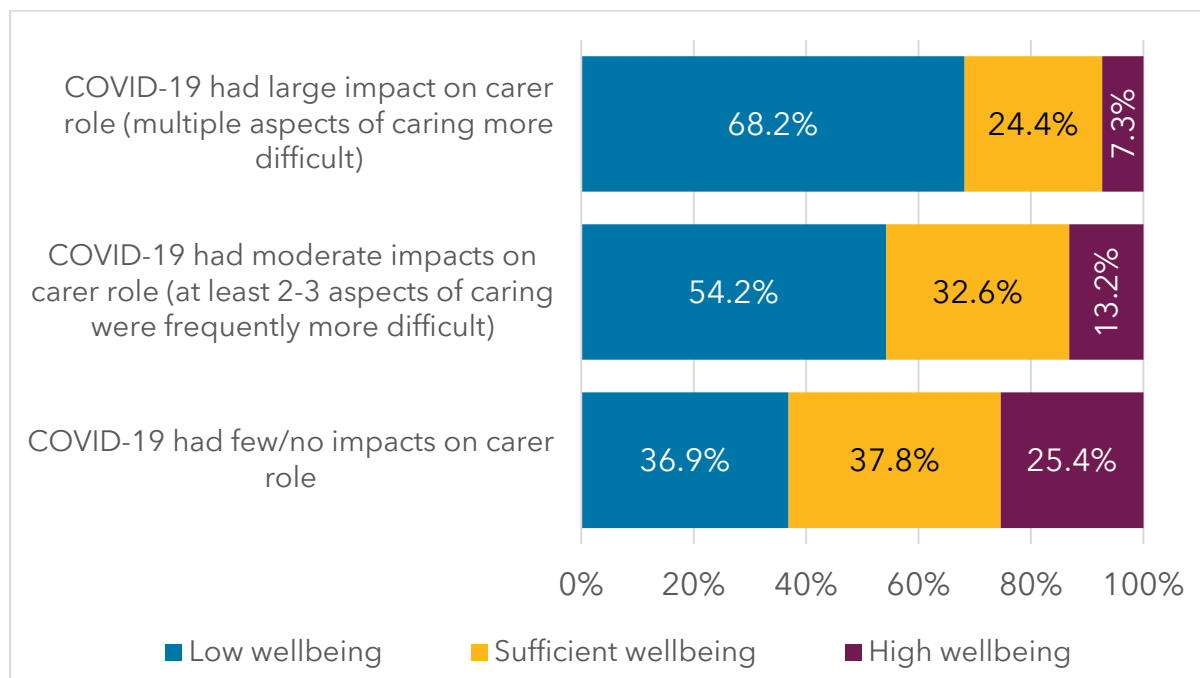


FIGURE 5 WELLBEING OF CARERS BY LEVEL OF IMPACT COVID-19 HAD ON CARER ROLE DURING 2021

Carers were also asked the extent to which they agreed or disagreed with several statements about the impacts of COVID-19 (FIGURE 6). Almost two in three carers - 63.9% - said they felt more isolated than usual in their caring role due to COVID-19, while 39.6% did not feel they were able to maintain their own wellbeing, and 29.9% felt the wellbeing of the people they cared for was not maintained during COVID-19 lockdowns and impacts.

However, 60.1% reported that telehealth appointment had been helpful during COVID-19, 55.5% felt the wellbeing of the people they cared for had been successfully maintained, 40.2% reported they were able to maintain their own wellbeing, and 34.9% found increased support payments during COVID-19 helpful.

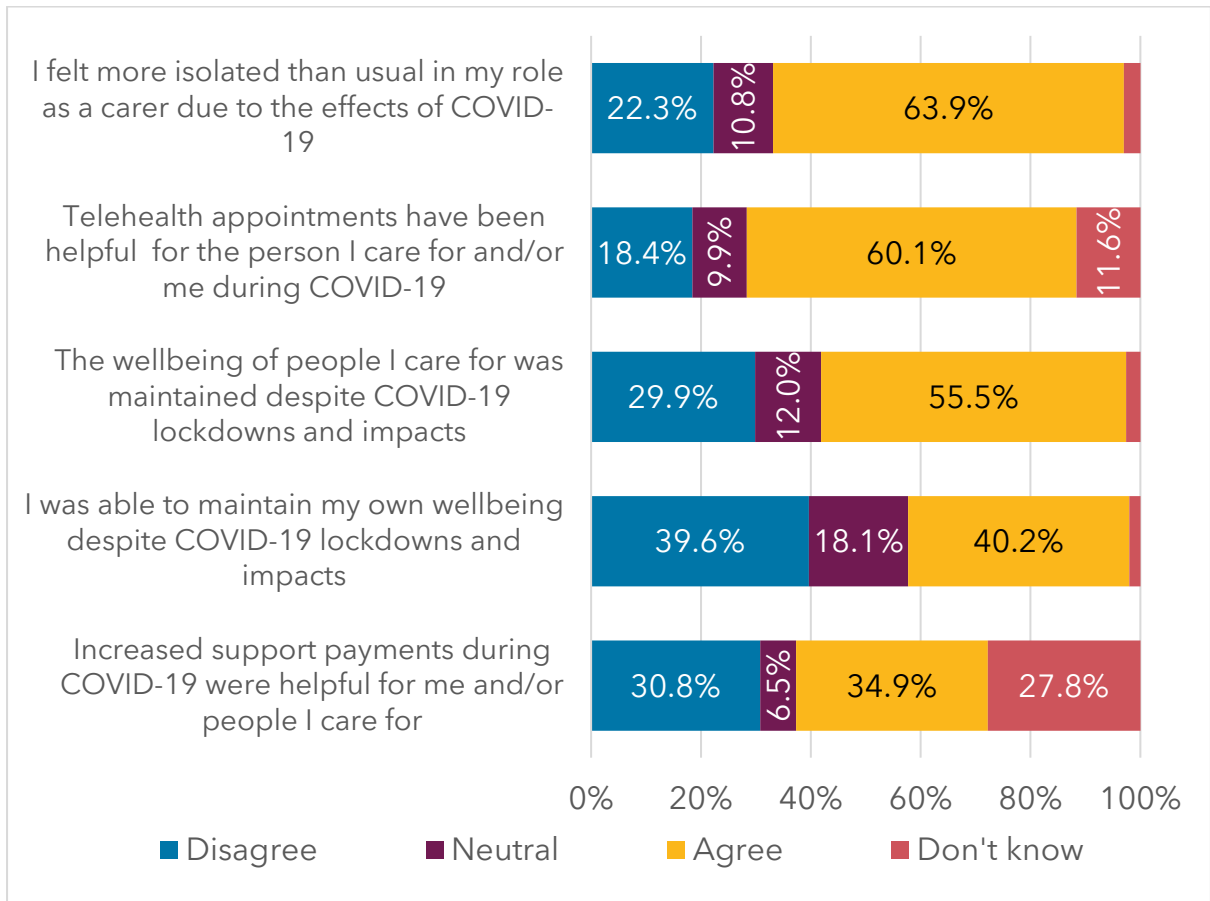


FIGURE 6 IMPACTS OF COVID-19



## 6. Loneliness and social connection

People who experience ongoing social isolation and loneliness are at significantly higher risk of a wide range of physical and mental health disorders (Cacioppo and Cacioppo 2018). As of 2020, one in ten Australians reported feeling lonely always or almost always (10.3%), while 41.3% rarely felt lonely and 48.4% sometimes felt lonely (Regional Wellbeing Survey 2020). Amongst carers, however, loneliness is much more common: in 2022, 39.4% reported they often or always felt lonely, and only 23.6% rarely felt lonely.

Between 2021 and 2022, the rate of loneliness increased slightly but significantly across Australia's carers (FIGURE 7).

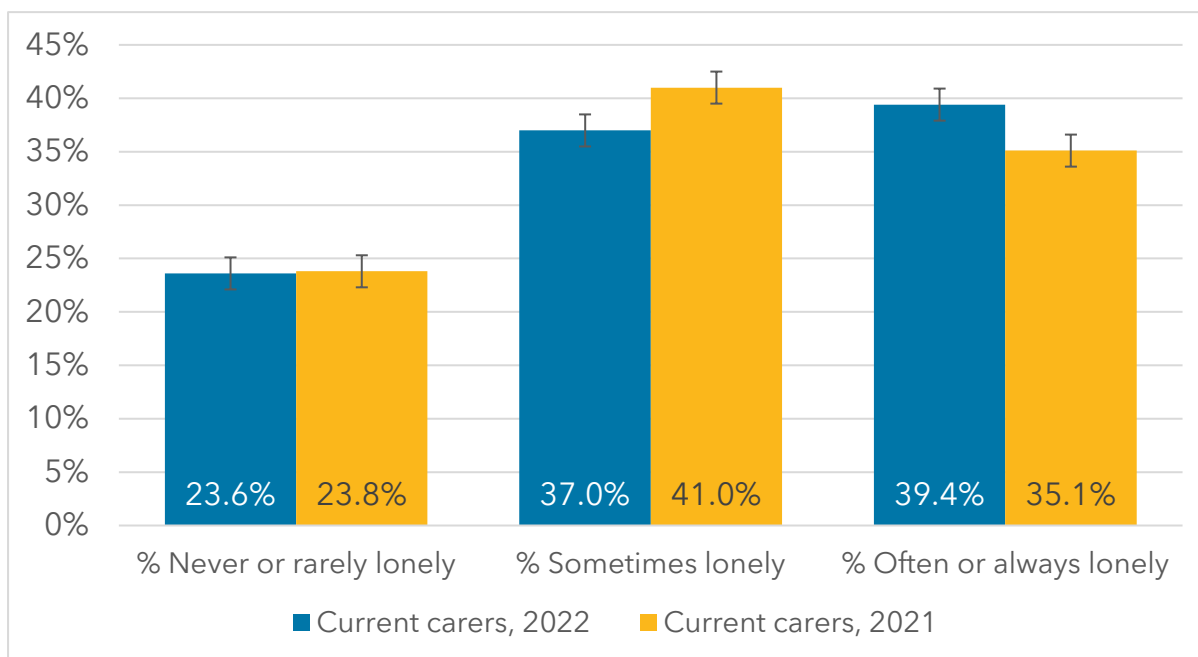


FIGURE 7 LONELINESS IN CARERS 2021-2022

The majority of this increase in loneliness occurred amongst carers aged 25-44: the proportion who often or always felt lonely increased by 9.4% amongst those aged 25-34 (from 35.0% in 2021 to 44.4% in 2022), and by 7.5% amongst those aged 35-44 (from 43.1% to 50.6%). This is consistent with the reported impacts of COVID-19 on carers in these age groups, with these groups more likely than other carers to report experiencing increased social isolation due to COVID-19.

## 7. Time use

Having a good balance in time use is important to wellbeing: this involves not just having a good balance between 'work' and 'life', but time to fulfil caring duties, home duties such as housework, self-care, and relaxation. While research on time use and wellbeing is still developing, there is strong evidence that people who have a poor time use balance in the areas of caring obligations, other unpaid work such as housework, physical activity, and engaging in as much paid work as desired, have significantly poorer wellbeing (Tomczyk et al. 2021).

Carers were asked if, in the last month, they had done more, less, or about as much as they wanted to of a range of activities known to be important to health and wellbeing as part of balanced time use.

Amongst current carers, most - 67.1% - spent more time caring for family members or friends in the previous four weeks than they wanted to, while 54.1% did more housework than they wanted to (FIGURE 8).

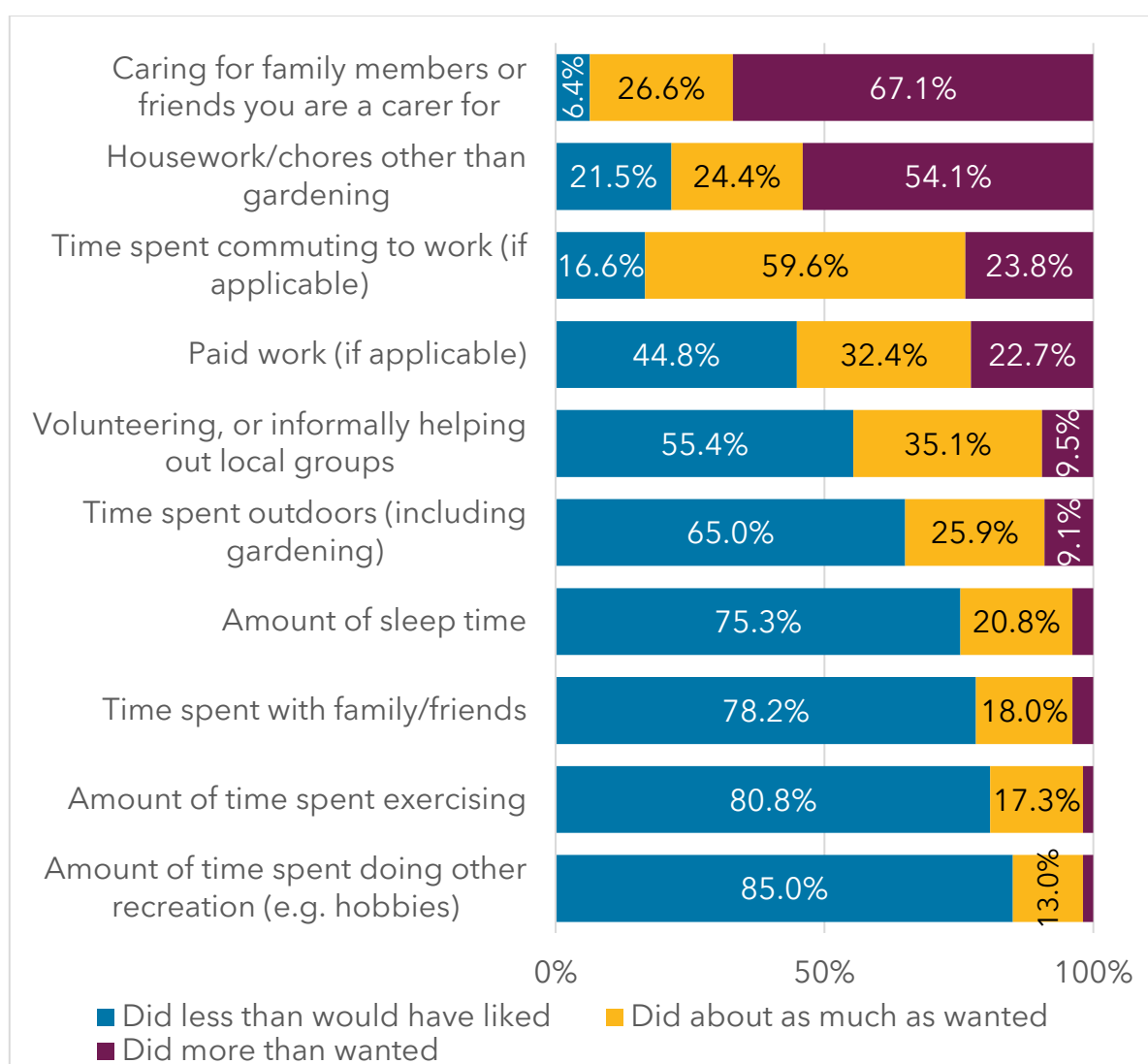
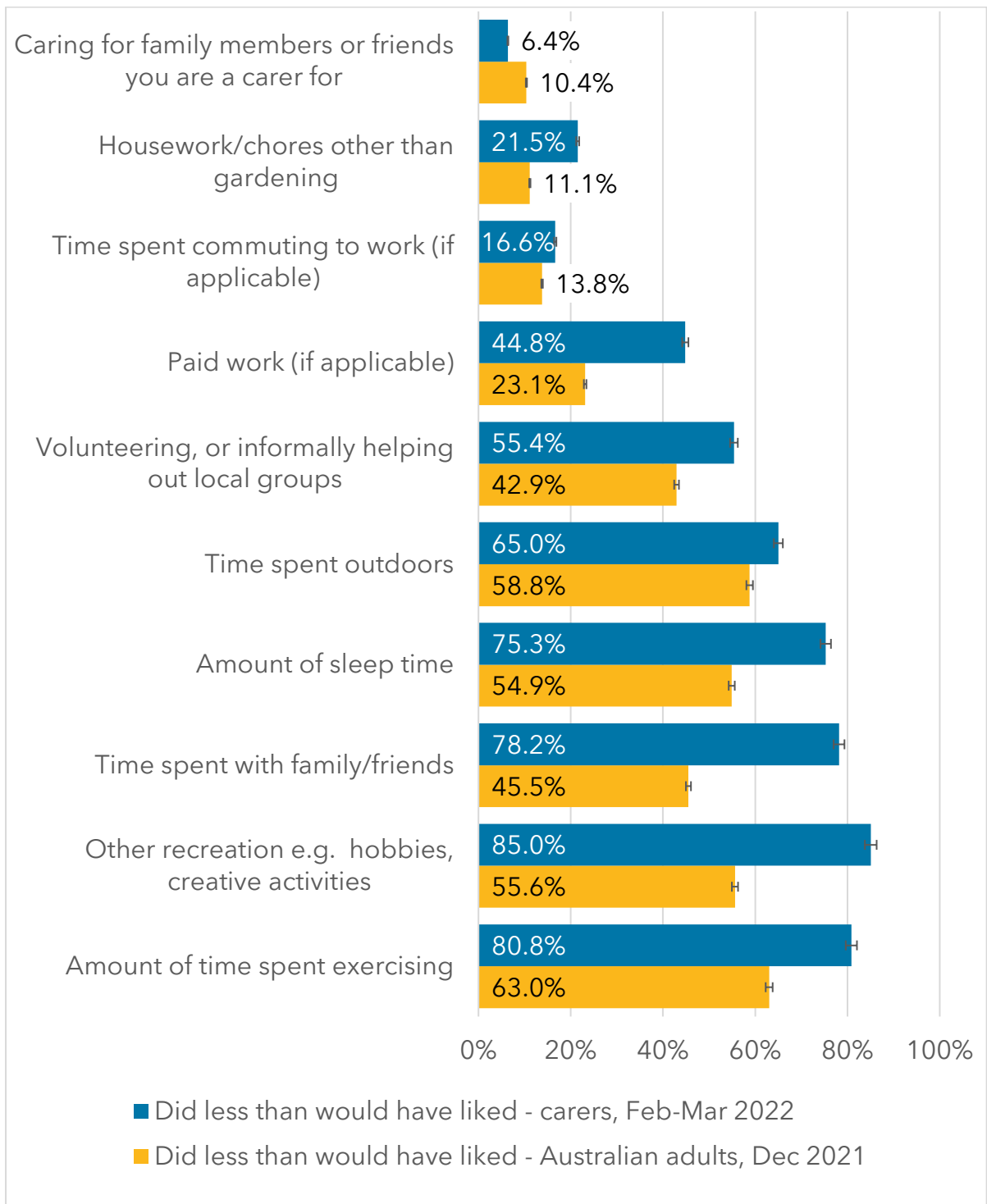


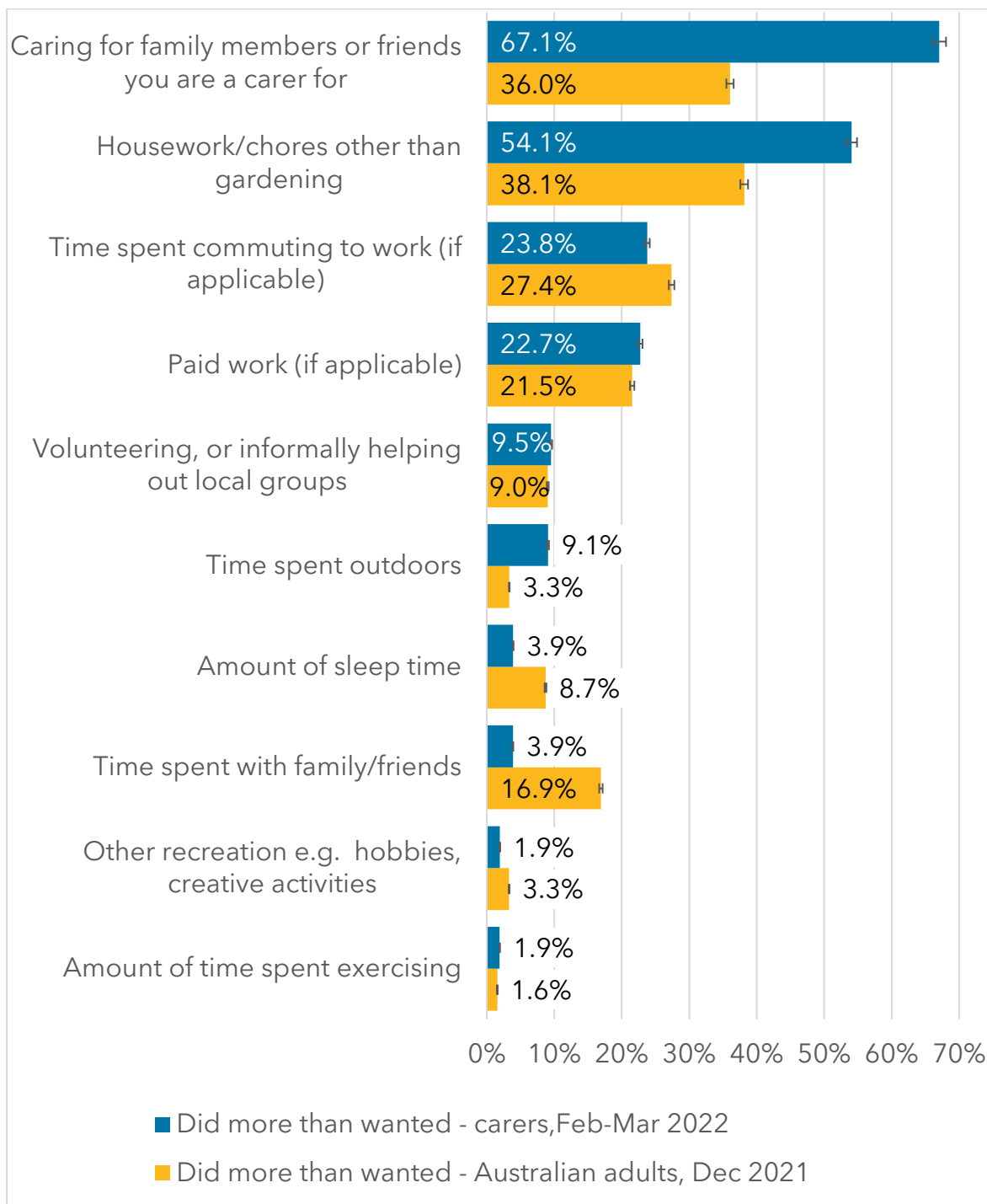
FIGURE 8 TIME USE AMONGST CARERS

A further 21.5% did *less* housework than they wanted to. At the other end of the time use scale, 85.0% spent less time than they wanted doing recreational activities, 80.8% did less exercise than they wanted, 78.2% spent less time than desired with family and friends, 75.3% got less sleep than they wanted, and 65.0% spent less time outdoors than they wanted.

Lacking desired balance in time use is not uncommon: across all Australian adults, most would like to be spending more time exercising, doing recreational activities, and sleeping, for example (FIGURE 9), and just over one third spend more time on caring duties and housework than desired (FIGURE 10). However, carers were more likely than other Australians to report having a poor time use balance. In particular, 85.0% of carers had less recreational time than desired, compared to 55.6% of Australians, 80.8% spent less time exercising compared to 63.0% of Australians, and 78.2% spent less time with family and friends than desired compared to 45.5% of the general population.



**FIGURE 9 TIME USE LESS THAN DESIRED AMONGST CARERS COMPARED TO AUSTRALIAN ADULTS**



**FIGURE 10 TIME USE MORE THAN DESIRED AMONGST CARERS COMPARED TO AUSTRALIAN ADULTS**

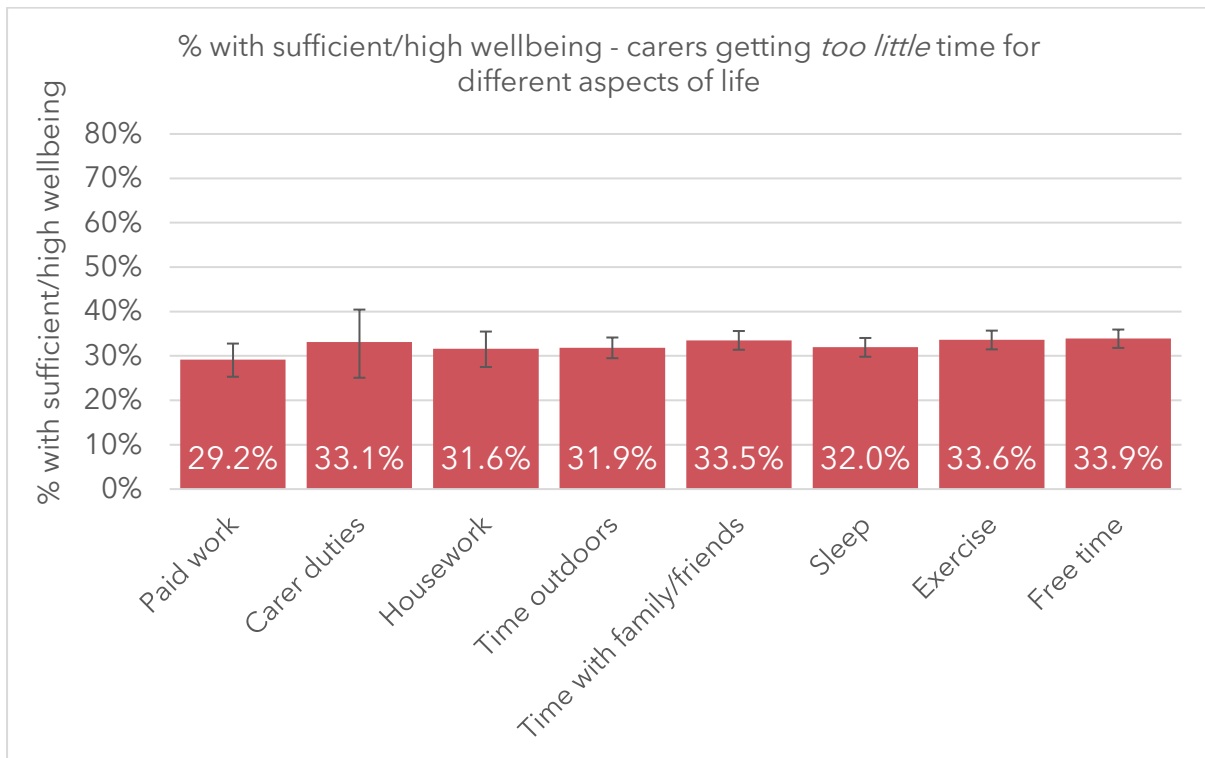
Of those who were working or who wanted to be in paid work, 44.8% of carers reporting they were doing less paid work than desired, compared to only 23.1% of Australians more generally. Carers who reported doing less paid work than desired were asked if this was partly or wholly due to their caring duties:

- 73.6% reported that their caring duties meant they could not do as much paid work as they would have like to in the past month; of these, 69.4% reported that caring was the sole reason, while 4.2% reported that both their caring duties and other factors contributed to them working less than desired.

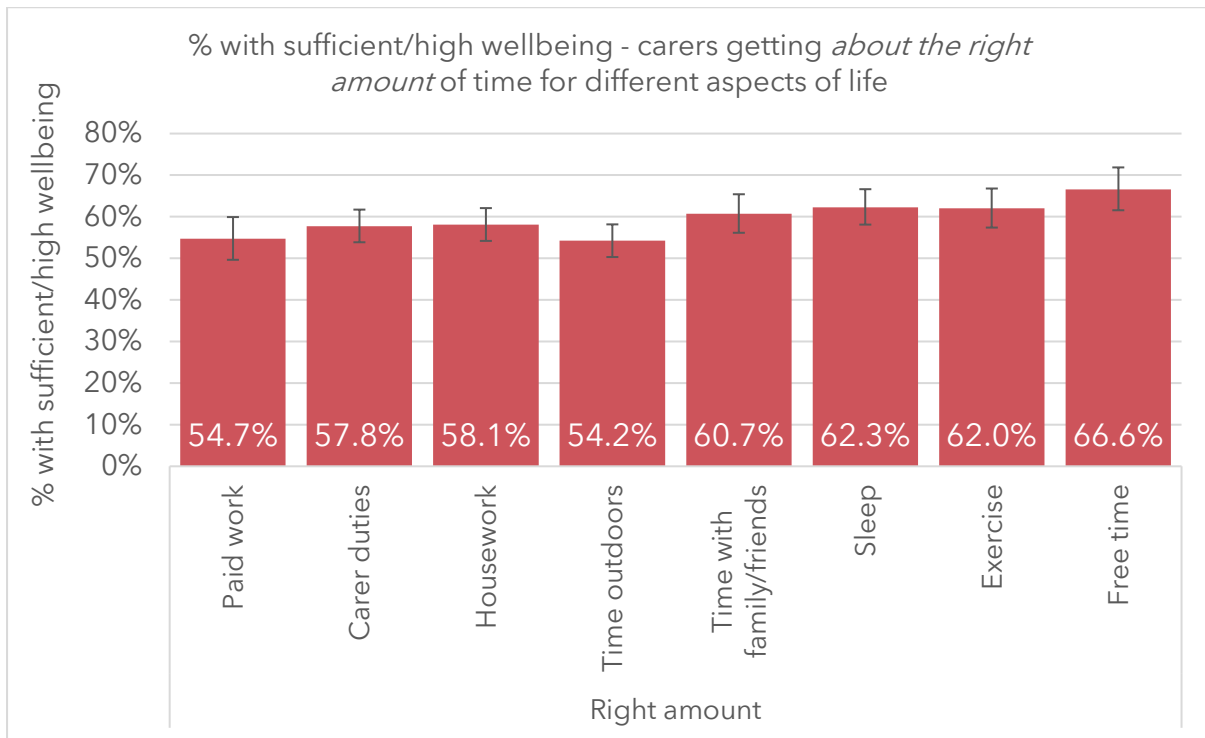
- 30.6% reported that the reason they did not do as much work as desired was partly or wholly due to reasons other than their caring.

The carers most likely to report they were doing less paid work than they wanted to were those who were doing more than 40 hours of caring in a typical week (amongst whom 56.8% were doing less paid work than desired), those who had been a carer for less than a year (56.8%), carers aged 15-24 (55.9%), and those currently studying (55.0%).

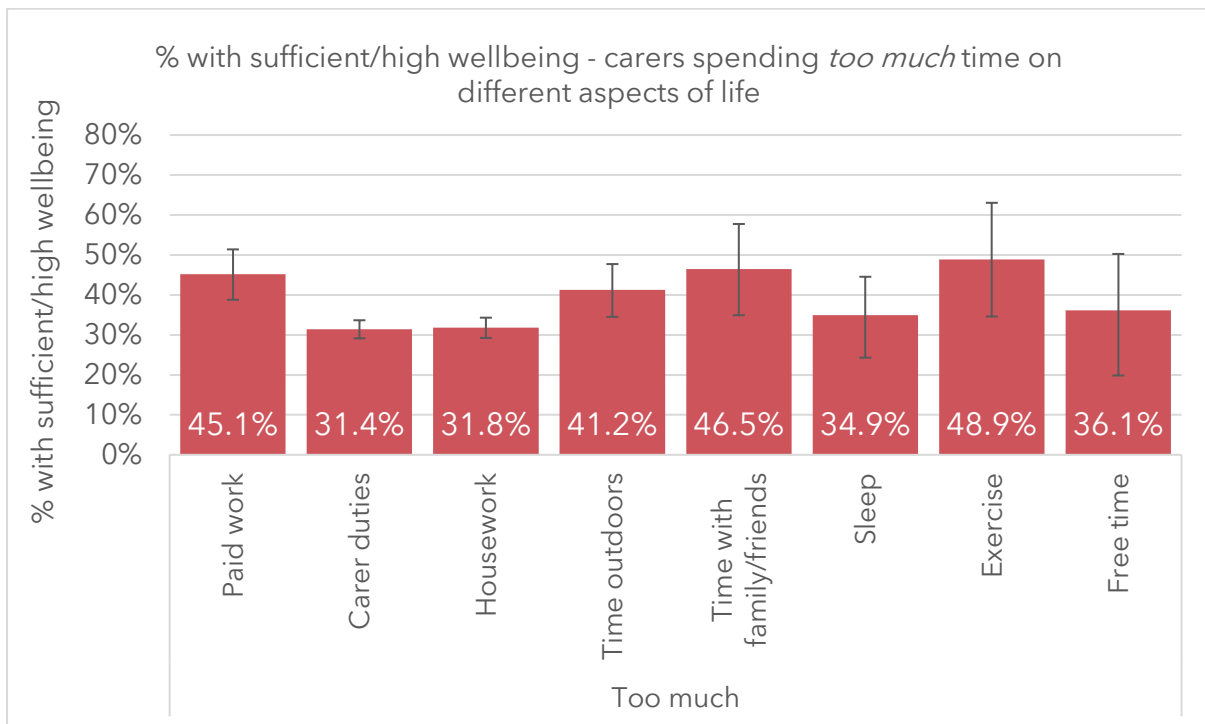
Carers who reported having a good time use balance for any dimension of time use were more likely to have positive levels of wellbeing (whether sufficient or high) compared to those who reported poor time use (FIGURE 13).



**FIGURE 11** RELATIONSHIP BETWEEN TIME USE AND WELLBEING AMONGST CARERS (TOO LITTLE TIME)



**FIGURE 12** RELATIONSHIP BETWEEN TIME USE AND WELLBEING AMONGST CARERS (ABOUT THE RIGHT AMOUNT OF TIME)



**FIGURE 13** RELATIONSHIP BETWEEN TIME USE AND WELLBEING AMONGST CARERS (TOO MUCH TIME)

Having less paid work, carer time, housework time, exercise, sleep, time outdoors or free time than desired was in particular associated with poorer wellbeing. Spending more time than

desired being a carer, doing housework, or having too much free time or sleep time, was also associated with lower likelihood of having positive wellbeing.

Carers who had less free time than they would have preferred during the previous four weeks were twice as likely to have low wellbeing compared to those who reported they had about the right amount of free time (66.1% having low wellbeing compared to 33.4%). Those getting too little sleep were 1.8 times as likely to have low wellbeing, while those getting too little exercise or time with family/friends were 1.7 times as likely to have poor wellbeing. Those who reported doing less paid work than desired were 1.6 times as likely to have low wellbeing, while those with too much paid work were only 1.2 times as likely to have poor wellbeing.



## 8. Financial wellbeing

In the 2022 CWS, more than half of carers – 54.4% – reported that they had experienced at least one significant financial stress event in the previous 12 months, such as being unable to pay bills on time, going without meals, or having to ask for financial assistance. This was slightly lower than the 57.3% who reported this in 2021, although the difference was not statistically significant. Amongst the broader Australian population, in comparison, 32.2% reported experiencing one or more financial stress events in the 12 months to the end of 2021 (Regional Wellbeing Survey 2021).

Similarly, the proportion of carers reporting that their household was poor, just getting along, comfortable, or very comfortable/prosperous stayed stable between 2021 and 2022. However, again this masked some changes occurring amongst different groups of carers: there was an increase in the proportion of carers aged 15 to 44 who reported being poor or just getting along, a decrease in the proportion of those aged 45 to 64 who reported this, and no significant change in financial outcomes amongst carers aged 65 and older (FIGURE 14). This suggests different types of financial pressure and opportunity are being experienced by younger versus older carers.

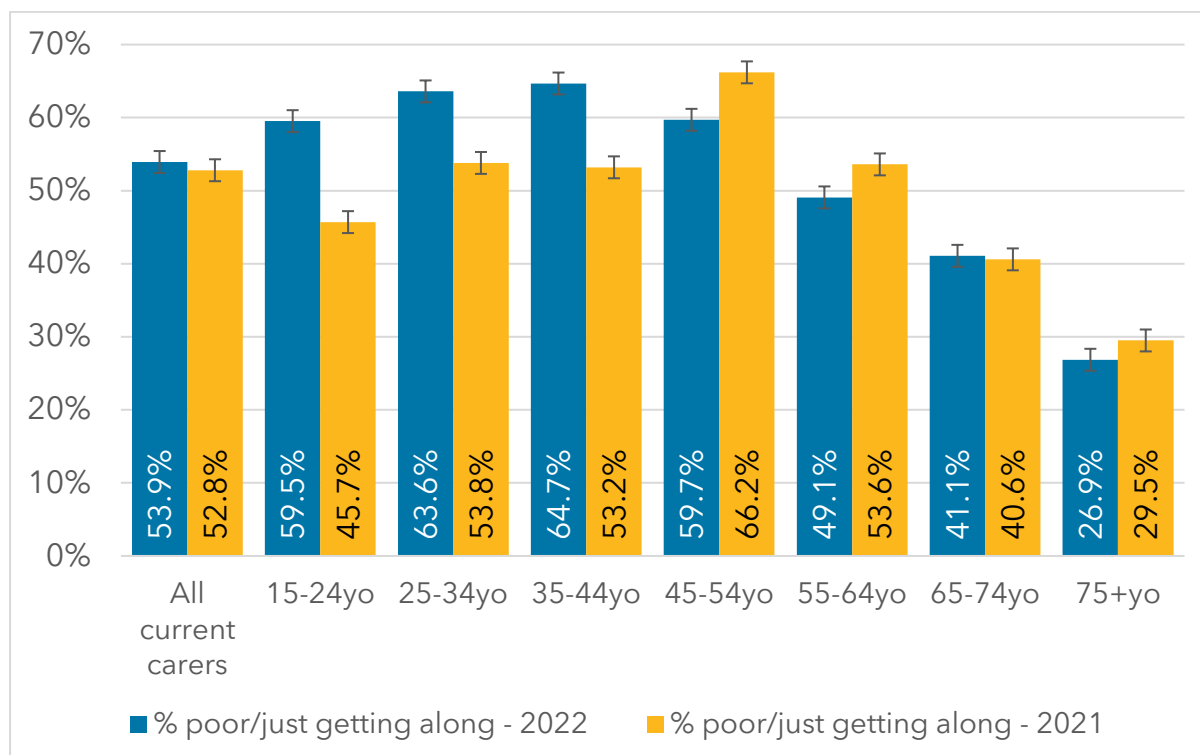


FIGURE 14 FINANCIAL PROSPERITY AMONGST CARERS, BY AGE 2021-2022

The decline in financial wellbeing amongst carers aged 25-44 is consistent with some of the impacts of COVID-19 reported amongst carers in this age range, however this does not explain the decline in financial wellbeing amongst carers aged 15-24, or the improvement amongst those aged 45 to 64.

## 9. Housing, telecommunications and transport

Carers often spend significant time caring for people in their residence, and are also often responsible for either transporting the people they care for to appointments, work or study, or for organising transport. Increasingly, many carers also access appointments online, using services such as telehealth.

All these things mean that the quality and accessibility of a person's housing, telecommunications and transport access can make a big difference to their ability to fulfil caring duties and to have a positive experience as a carer.

In both 2021 and 2022, more than 70% of carers across Australia reported their home met their needs well, they had good access to mobile phone reception, and that they had good access to high speed, reliable internet in their home. In 2022, 24.1% reported that their home was too small to comfortably accommodate the people who lived in it, indicating overcrowding is a problem for almost one in four carers.

While most groups of carers were similarly likely to have good access to internet, there were significant differences depending on where the carer lived:

- 78.2% of carers living in major cities had good access to reliable, high-speed internet
- 68.9% of carers living in inner regional areas had good access
- 66.2% of carers living in outer regional and remote areas had good internet access.

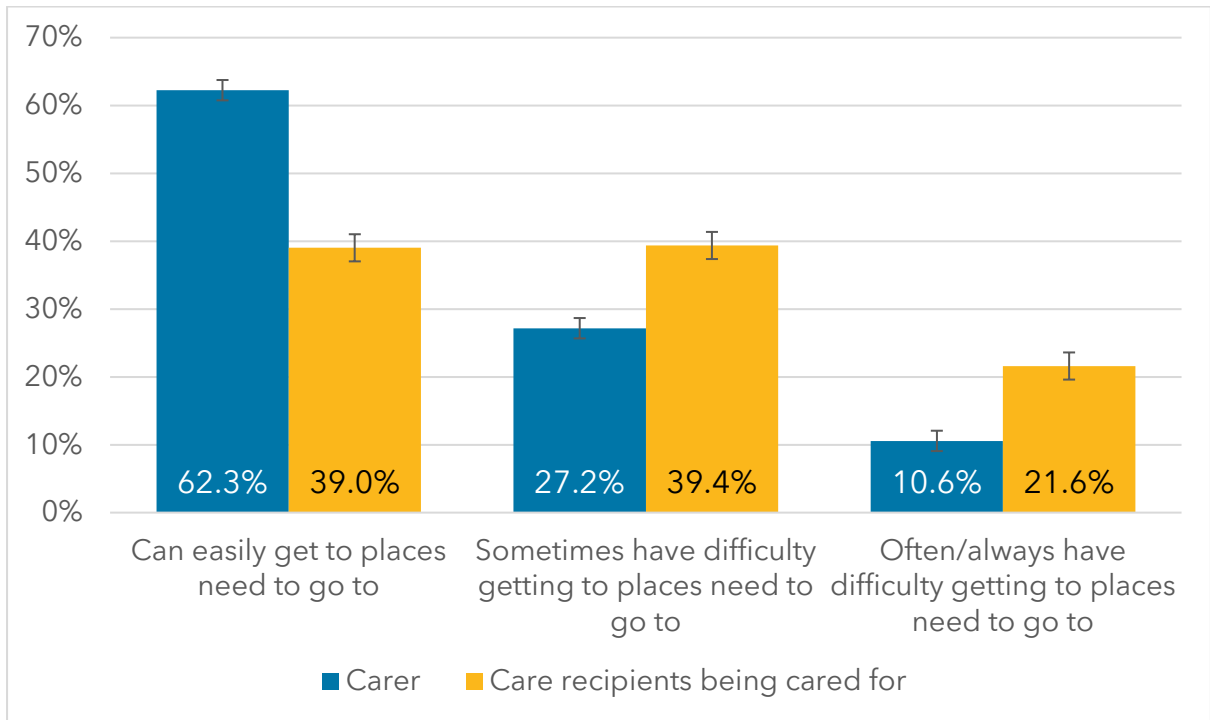
This highlights that there remains a significant 'urban-rural divide' in access to key resources that are increasingly necessary for carers to have access to in order to access and use a range of supports and services. One in three carers living in areas outside major cities lacks good access to high speed, reliable internet.

In 2022, carers were also asked if they had access to devices and spaces needed to access online and telehealth services:

- 82.0% had good access to a personal computer, laptop or tablet
- 69.3% had good access to a private space for using telehealth or online services

This suggests that building capacity for private space to use online services is as important a priority as ensuring that carers and care recipients have access to high speed, reliable internet that can be used to access this type of service. A significant proportion of carers live in homes where it is difficult to have privacy if seeking to have an online appointment: this can limit use of online services such as telehealth appointments.

When asked how easily they and the people they care for could get to the places they need to go to, 62.3% of carers reported they could easily get to the places they needed to - but only 39.0% reported that the people they cared for could easily travel to different places they needed to go (FIGURE 15). This highlights that many carers and care recipients experience challenges with transport, with 39.4% of carers reporting that the people they cared for sometimes had difficulty with transport, and 21.6% that the people they cared for often or always had difficulty with transport.



**FIGURE 15** EASE OF TRANSPORT AMONGST CARERS AND CARE RECIPIENTS

## 10. Employment and study

Being a carer can present challenges to maintaining participation in the labour force. In the 2016 Census of Population and Housing, people who reported providing unpaid assistance to a person with a disability, health condition, or due to old age - carers - were less likely to be in the labour force compared to others. Only 59.5% of carers participated in the labour force, compared to 66.2% of non-carers. This is partly due to carers being more likely to be older than typical retirement age. However, even when examining just those aged 15 to 64 - the ages most likely to be engaged in the labour force - carers were less likely to participate in the labour force, with 76.3% of carers aged 15-64 participating in the labour force, compared to 81.9% of non-carers<sup>2</sup>.

The CWS focuses on carers for whom being a carer is a significant part of day-to-day life. This is somewhat different to the Census, which includes all carers, irrespective of whether their carer role comprises a relatively small or large part of their day-to-day activity. Amongst this group, in 2021, only 66.5% participated in the labour force, while in 2022 69.3% participated in the labour force. This suggests that labour force participation is lower amongst those carers for whom caring comprises a significant part of day-to-day life. It also suggests labour force participation may have grown between 2021 and 2022 amongst this type of carer, although further data over a longer time period would be needed to be confident that this is the case.

In 2021, the CWS results suggested 51.6% of current carers were employed, while 4.9% were unemployed and seeking work, and 43.5% were not in the labour force. In 2022, data from the CWS revealed 52.8% were employed, 5.5% unemployed and 41.7% not in the labour force. While this suggests a possible increase in engagement in paid work, the differences were relatively small across years, and longer-term growth would need to be observed to be confident this represents an upwards trend in employment amongst carers. In total, 15.3% of carers reported being enrolled in a formal course of study in 2022.

Section 7 highlighted that many carers work fewer hours than they want to, with underemployment much more common amongst carers compared to the general population. Reflecting this, many carers reported working part-time hours: 38.4% of those carers who had paid employment worked less than 20 hours a week, 28.4% worked 20-34 hours, 26.8% 35-44 hours, and 6.5% worked 45 or more hours a week.

Flexibility of work hours, understanding of employers, and security of employment remained very similar between 2021 and 2022:

- In 2022, 22.8% of carers did not have flexibility of work hours, while 46.4% had somewhat flexible hours, and 30.9% very flexible hours (compared to 24.4% with no flexibility and 27.6% with very flexible hours in 2021)

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<sup>2</sup> At the time this report was released, employment data for carers were not available from the 2021 Census of Population and Housing.

- 22.7% had insecure employment, 44.9% somewhat secure employment and 32.4% very secure employment in 2022, compared to 29.3% with very secure employment in 2021
- In 2022, 42.5% reported their supervisor was very understanding of their caring obligations, very similar to the 41.3% who reported this in 2021.

These findings suggest that there may have been positive change in some aspects of employment. However, this would need to continue for more than one year to be considered a trend in which employment conditions are improving for carers.

In 2022, carers were also asked whether they had actively spoken with their supervisor about their role as a carer. In total, 48.1% reported they had spoken to their supervisor and could discuss their carer role at any time with them if they needed to; 36.1% had spoken once or twice with their supervisor about their carer role, and 15.8% had not spoken to their supervisor (FIGURE 16).

There were significant differences in the likelihood a carer who was engaged in paid work had spoken with their supervisor about their carer role: those aged 15-24 were least likely to have done this, with 41.4% of this group reporting not having spoken to their supervisor, and only 16.7% that they could discuss their carer role any time they needed to (FIGURE 16). Likelihood of feeling confident to have regular discussions with supervisors about being a carer increased with age, with 67.3% of carers aged 65-74 who worked reporting they could discuss their carer role with their supervisor any time they needed to. Carers were also more likely to discuss their carer role with their supervisor if they were a primary carer, had a continuous caring role, and cared for a person with higher assistance needs (FIGURE 17). These findings suggest that there are significant cohorts of carers who may find it difficult to have a conversation with their supervisor about their carer role.

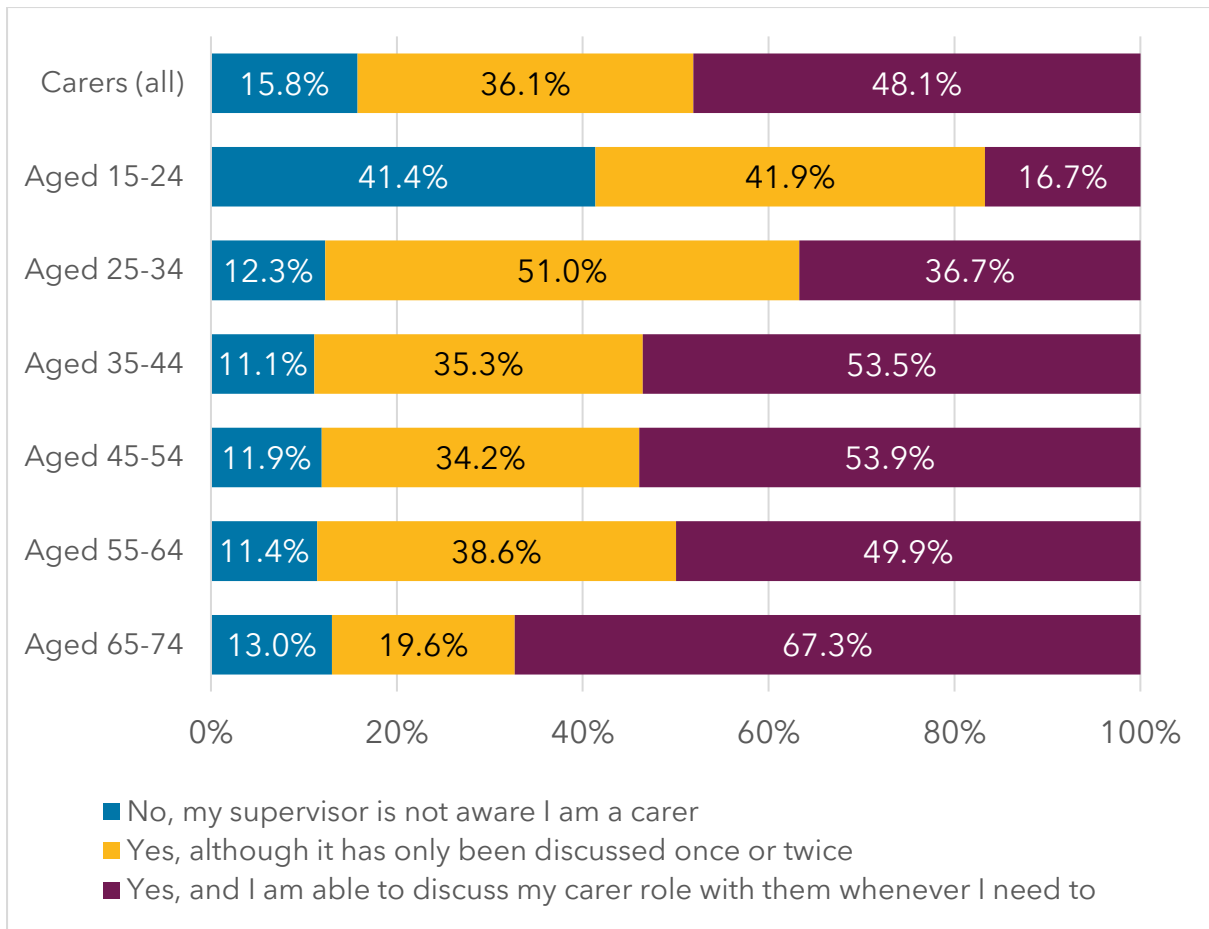
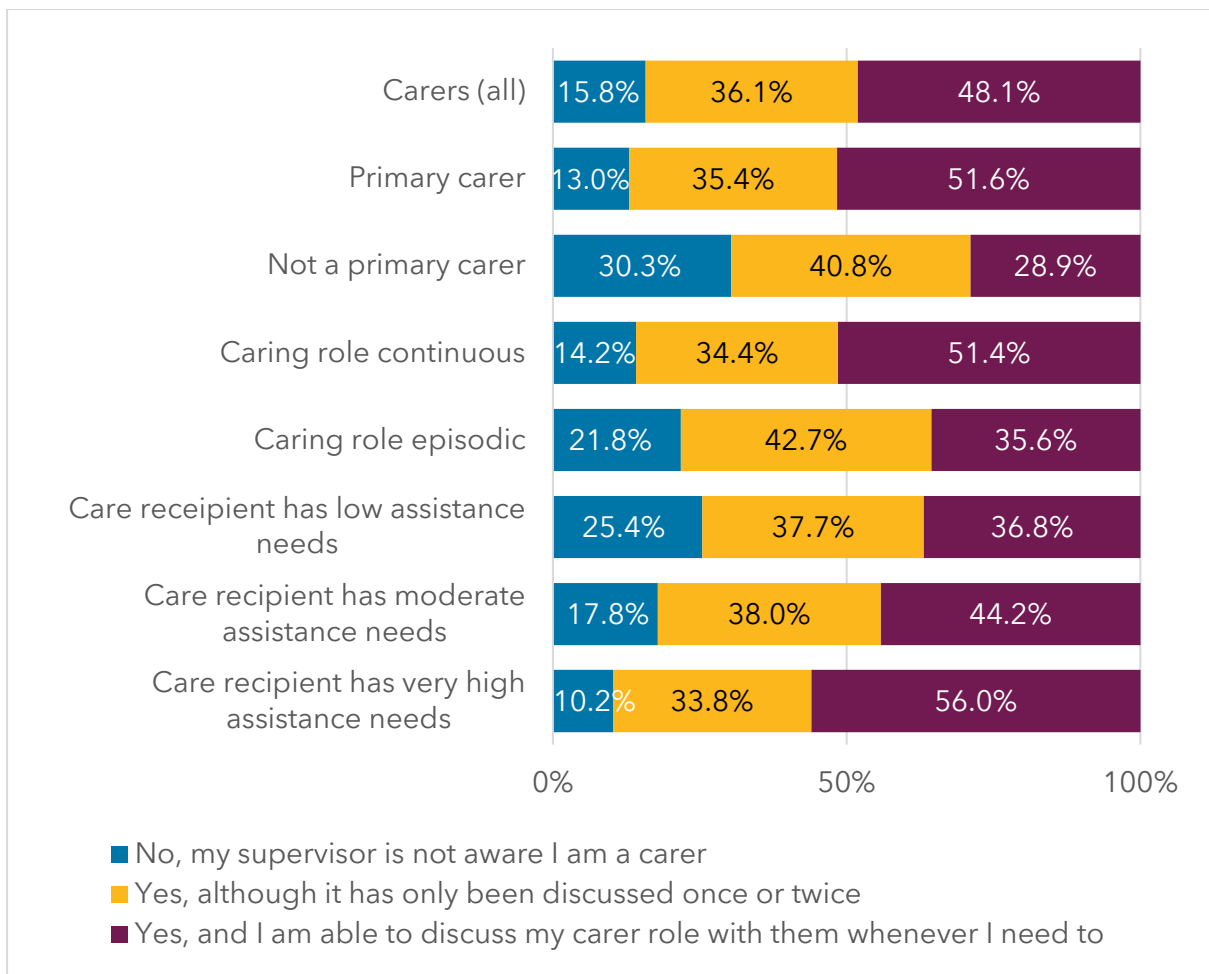
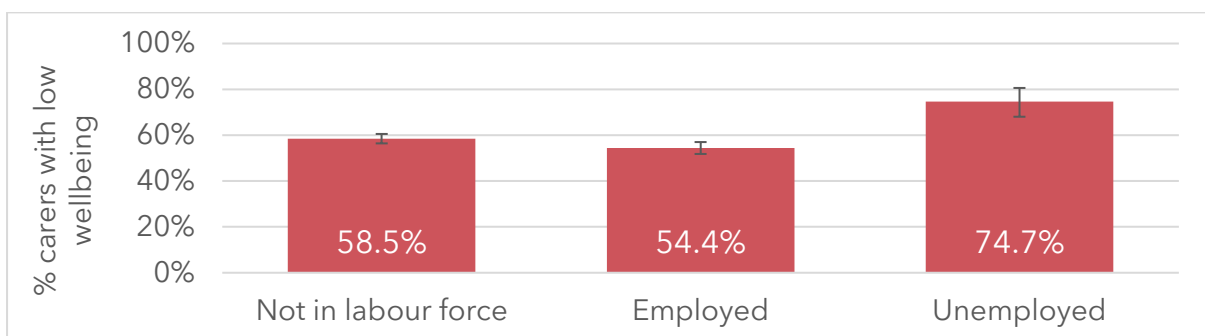


FIGURE 16 SPEAKING WITH WORK SUPERVISORS ABOUT CARING ROLES, BY AGE



**FIGURE 17** SPEAKING WITH WORK SUPERVISORS ABOUT CARING ROLES, BY TYPE OF CARING ROLE

Carers who were employed were less likely to have low wellbeing (54.5%) compared to those who were not in the labour force (58.5%), and particularly compared to those who were unemployed (74.7%) (FIGURE 18). This figure does not account for the many carers - including both some of those who are employed, and some of those not currently in the labour force - who would prefer to be doing more paid work than they currently are. As identified in Section 7, of the 44.8% of carers who reported that they did less paid work than desired in the previous month, 70.8% had low wellbeing.



**FIGURE 18** PROPORTION OF CARERS WITH LOW WELLBEING, BY PARTICIPATION IN LABOUR FORCE

## 11. Choosing to be a carer

Every person's life typically involves a mix of making active choices and responding to circumstances that take life in a direction that may be unexpected, and over which there may be little choice. For example, many people have a reasonable degree of choice in the type of employment and study they choose, or the choice of whether, when or how many children they will have. However, not everyone has freedom to choose the timing or nature of these key life decisions, and a range of factors may result in a person having limited or no choice about key aspects of their life at some points in time.

Becoming a carer is an example of a situation in which many people are asked to respond to challenging circumstances, and may have limited choice. Becoming a carer often occurs unexpectedly, and many carers may have had limited - or in some cases no - choice regarding whether or not they would become a carer. Many carers may feel obligated to take on the duties of caring for a person who is ill, has a disability or is frail - even if it is not something they would have voluntarily chosen to do.

Having choice in life is something known to affect long-term wellbeing: feeling little or no sense of control over important choices in your life is associated with greater risk of poor wellbeing (Lachman et al. 2015), even if the actions you take are things you find meaningful and valuable. Some studies have found that carers who feel little sense of control in their day-to-day role as a carer have poorer wellbeing (Brown 2007). This suggests that it is possible those who took on a carer role involuntarily, or only somewhat voluntarily, may be at higher risk of poor wellbeing than other carers - even if they value and find meaning through being a carer.

In the 2022 CWS, carers were asked whether they had a choice about whether to be a carer. In total, 57.8% of current carers reported that they had no choice about whether to be a carer or not, 19.0% said they had little choice, and 14.8% actively decided to take on a carer role and could have chosen not to be a carer. The remaining 8.4% felt it was hard to say which of those options best described how they came to be a carer.

Different types of carers reported different degrees of choice about becoming a carer. In particular, Aboriginal and Torres Strait Islander carers were more likely than others to report that they actively chose to be a carer. As shown in

TABLE 1 (Appendix 2 provides more detailed data), the carers least likely to feel they had choice in being a carer were:

- Those aged 35-44 (69.6% reporting they had no choice)
- Those aged 45-54 (62.0%)
- Primary carers (59.0%)
- Those caring for three or more people (69.5%)
- Those caring for a person with ASD (75.7%) or ODD (73.6%)
- Those caring for a person with an intellectual disability (68.0%)
- Those caring for a child or grandchild (77.5%).



Carers aged 15-24, and aged 55 and older were slightly but significantly more likely to report that they actively chose to take on a caring role, and could have chosen not to be a carer, with 19% of people in these age groups feeling they had choice, compared to 14.5% or less in other age groups. While the difference is not large, it may suggest that there is greater availability of alternative care options for these carers.

TABLE 1 CHOICE OF BECOMING A CARER, BY GROUP

	<i>I had no choice about whether to be a carer or not</i>	<i>I had little choice about whether to be a carer or not</i>	<i>I actively chose to take on a caring role, and could have chosen not to be a carer</i>	<i>It's hard to say which of these best describes me</i>
Current carers - all	57.8%	19.0%	14.8%	8.4%
Female	60.9%	16.5%	12.5%	10.1%
Male	46.2%	23.2%	23.3%	7.3%
Aged 15-24	46.9%	21.1%	18.6%	13.4%
Aged 25-34	53.3%	20.0%	13.9%	12.7%
Aged 35-44	69.6%	14.0%	8.7%	7.7%
Aged 45-54	62.0%	17.0%	14.5%	6.5%
Aged 55-64	47.4%	21.9%	19.6%	11.1%
Aged 65-74	51.0%	20.5%	19.4%	9.1%
Aged 75+	58.7%	14.0%	18.5%	8.7%
Aboriginal/Torres Strait Islander	41.5%	22.5%	24.2%	11.8%
Not Aboriginal/Torres Strait Islander	57.3%	18.5%	15.1%	9.0%
Not a primary carer	34.5%	30.1%	24.2%	11.1%
Primary carer	59.0%	17.1%	15.2%	8.6%
Currently care for 1 person	54.1%	20.1%	16.0%	9.8%
Currently care for 2 people	61.7%	15.2%	15.9%	7.2%
Currently care for 3 or more people	69.5%	9.8%	15.7%	5.0%
Dementia	46.7%	22.4%	20.4%	10.5%
Old-age related frailty	41.7%	26.7%	21.2%	10.4%
Terminal illness	55.9%	15.1%	21.1%	7.9%
Autism spectrum disorder	75.7%	10.8%	7.0%	6.5%
Other development disorder	73.6%	11.4%	8.8%	6.2%
Mental illness/psychosocial disability	60.7%	17.0%	13.8%	8.5%

Drug/alcohol dependency	49.2%	22.6%	21.6%	6.7%
Physical disability	52.7%	19.6%	18.7%	9.0%
Intellectual disability	68.0%	11.9%	12.1%	8.1%
Chronic non-terminal illness or injury	52.8%	21.8%	15.7%	9.7%
Short term non-terminal illness	51.1%	13.3%	32.4%	3.2%
Other condition	61.9%	13.4%	15.6%	9.0%
Care for child/grandchild	77.5%	9.0%	7.7%	5.8%
Care for partner	58.2%	16.9%	16.2%	8.8%
Care for parent/grandparent	42.6%	25.7%	21.0%	10.7%
Care for sibling	51.9%	21.6%	15.8%	10.6%
Care for friend or other type of relative	29.7%	20.2%	39.2%	10.9%

One commonality amongst carers aged 15-24, and aged 55 and older, is that they are significantly less likely to be caring for children or grandchildren than those aged 25-54. Those who care for a child or grandchild are much more likely to report having little choice in being a carer compared to others groups of carers.

The wellbeing of carers who felt they had more and less choice in becoming a carer was compared (FIGURE 19). Amongst those who actively chose to take on their caring role, wellbeing was significantly higher compared to those who reported having no or little choice: 61.0% of those who actively chose to be carers had typical or high levels of wellbeing, compared to only 35.9% of those who had no choice in becoming a carer, and 42.2% of those who had little choice.

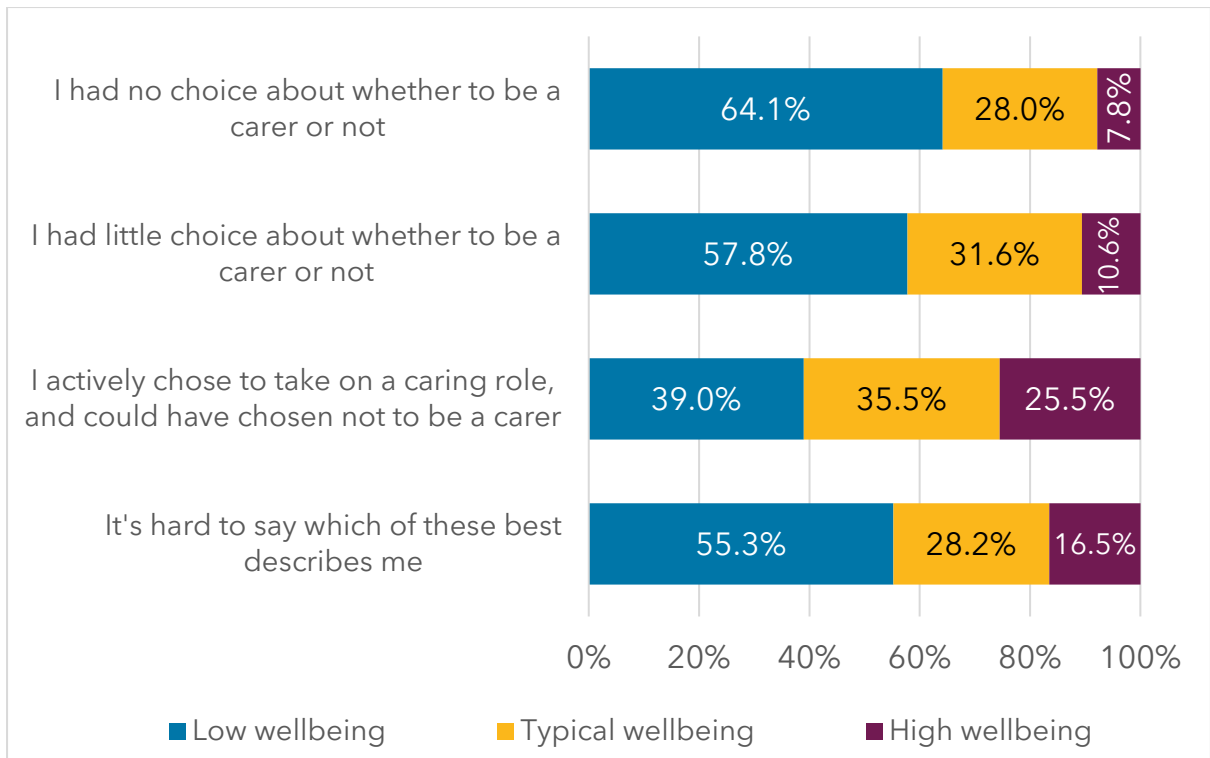


FIGURE 19 CHOICE OF BECOMING A CARER

# 12. Benefits associated with being a carer

In both 2021 and 2022, carers were asked the extent to which they experience positive outcomes as part of their caring role, in the form of finding their caring role satisfying, finding it contributed meaning and purpose to their life, caring being an overall positive experience, strengthened relationships, or learning new skills (FIGURE 20). In 2022, carers were also asked whether they would encourage other people to be carers.

Despite the challenges that can come with being a carer, 54.1% of carers find being a carer is satisfying, 56.4% that it contributed to meaning and purpose, and 51.6% that being a carer is a positive experience. Around two thirds find that being a carer has strengthened their relationship with the person they care for (62.9%) and have learned new skills due to being a carer (68.0%).

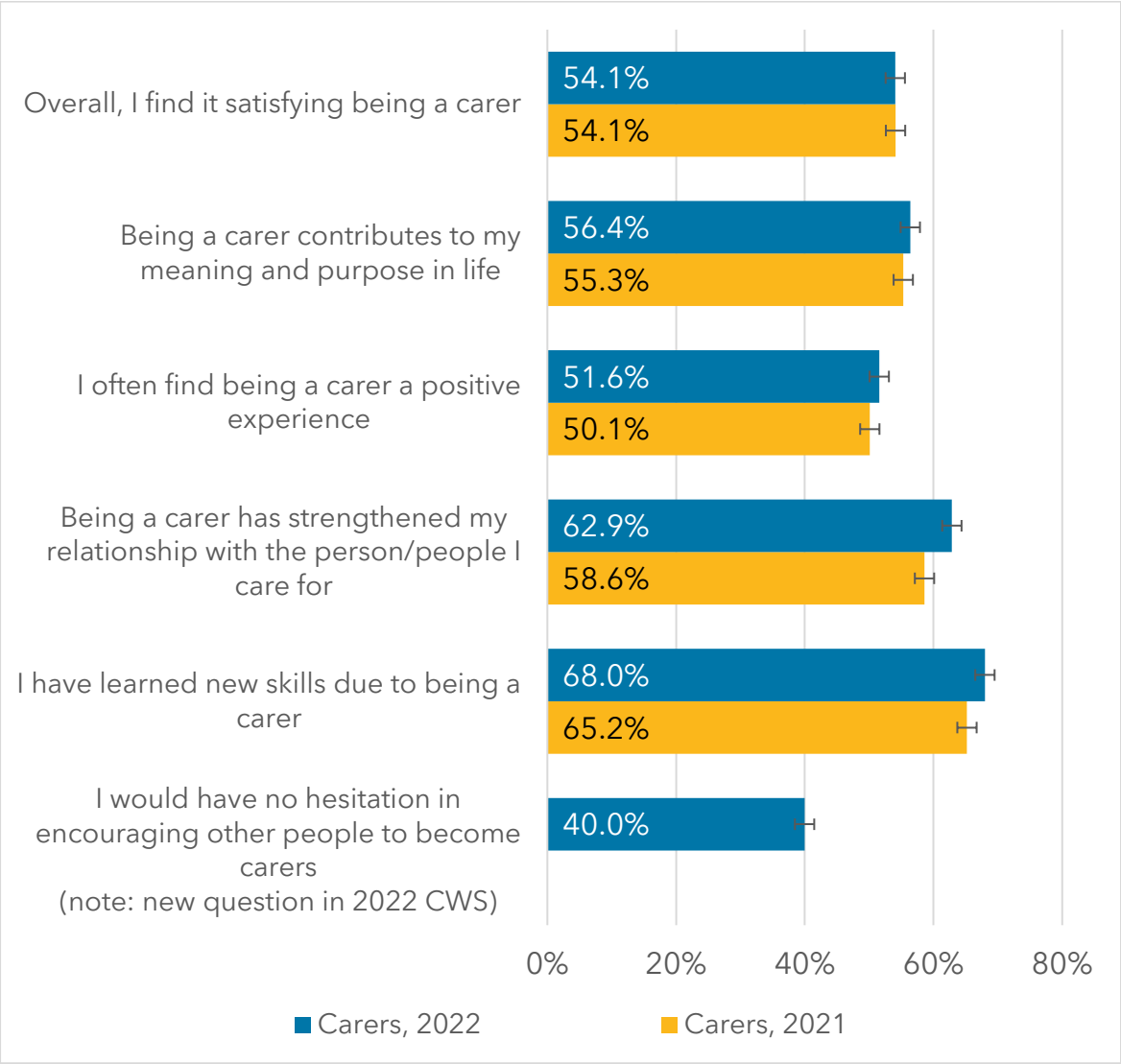


FIGURE 20 EXPERIENCE OF POSITIVE OUTCOMES ASSOCIATED WITH BEING A CARER

Findings were very similar in both years: in 2022 there was a slight, but not statistically significant, increase in the proportion of carers who reported they had learned new skills due to being a carer (from 65.2% to 68.0%), and who felt being a carer had strengthened their relationship with the person or people they cared for (from 58.6% to 62.9%).

However, despite many reporting having some positive experiences associated with being a carer, only 40.0% of carers say they would have no hesitation in encouraging other people to become carers, while 37.7% disagreed, and 22.3% were unsure or neutral. This suggests that despite the positive aspects of being a carer, many of the challenges and impacts associated with a carer role reduce the likelihood that a carer would recommend that others take on a carer role.

The proportion of carers who *disagreed* that they would encourage other people to become carers was relatively similar across most groups of carers. The proportion who *agreed*, however, was higher amongst some groups:

- Past carers (56.7% would recommend others become carers, compared to 40.0% of current carers)
- Male carers (50.5% would recommend)
- Younger carers (60.0% of carers aged 13-14 and 63.4% of those aged 15-24 would encourage others to become carers)
- Aboriginal and Torres Strait Islander carers (52.7%)
- Those who usually speak a language other than English at home (50.2%)
- Those caring for a person with a short-term condition not expected to last longer than six months (60.6%)
- Those caring for a person with a low level of assistance needed (52.2%).

These differences suggest that carers with differing caring obligations form very different views about the benefits and costs of the carer role, as do those from different cultural backgrounds.

## 13. Challenges and impacts of being a carer

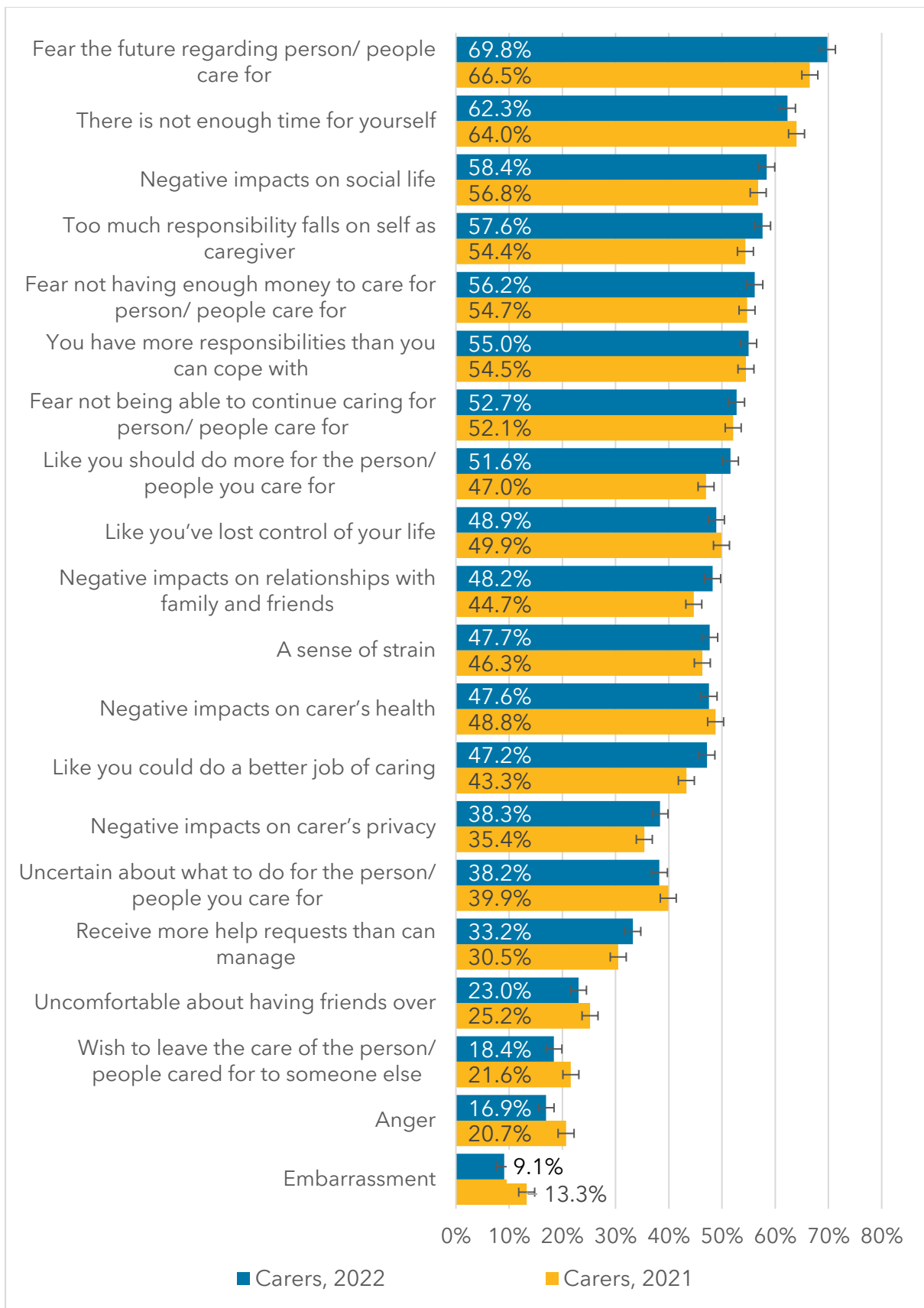
Being a carer can have a range of challenges and impacts. In both 2021 and 2022, the CWS data suggest that the most commonly experienced negative aspects of being a carer are fearing for the future of the person being cared for, lacking time for yourself, high level of responsibility, and financial stress, all of which are reported by a majority of carers (FIGURE 21).

There was almost no change in the types or frequency of experience of different challenges and impacts between 2021 and 2022, although there was a slight increase in the proportion of carers who:

- Felt they should be doing more for the people they cared for (increased from 47.0% in 2021 to 51.6% in 2022)
- Felt they could do a better job of caring (47.2% in 2022, up from 43.3% in 2021)
- Experienced negative impacts on relationships with family and friends (48.2%, compared to 44.7% in 2021)

Conversely, there was a small decline in the proportion of carers who reported wishing to leave the care of a person they cared for to someone else (down to 18.4% from 21.6%), and who reported feeling embarrassment or anger related to the person they cared for or their caring situation.

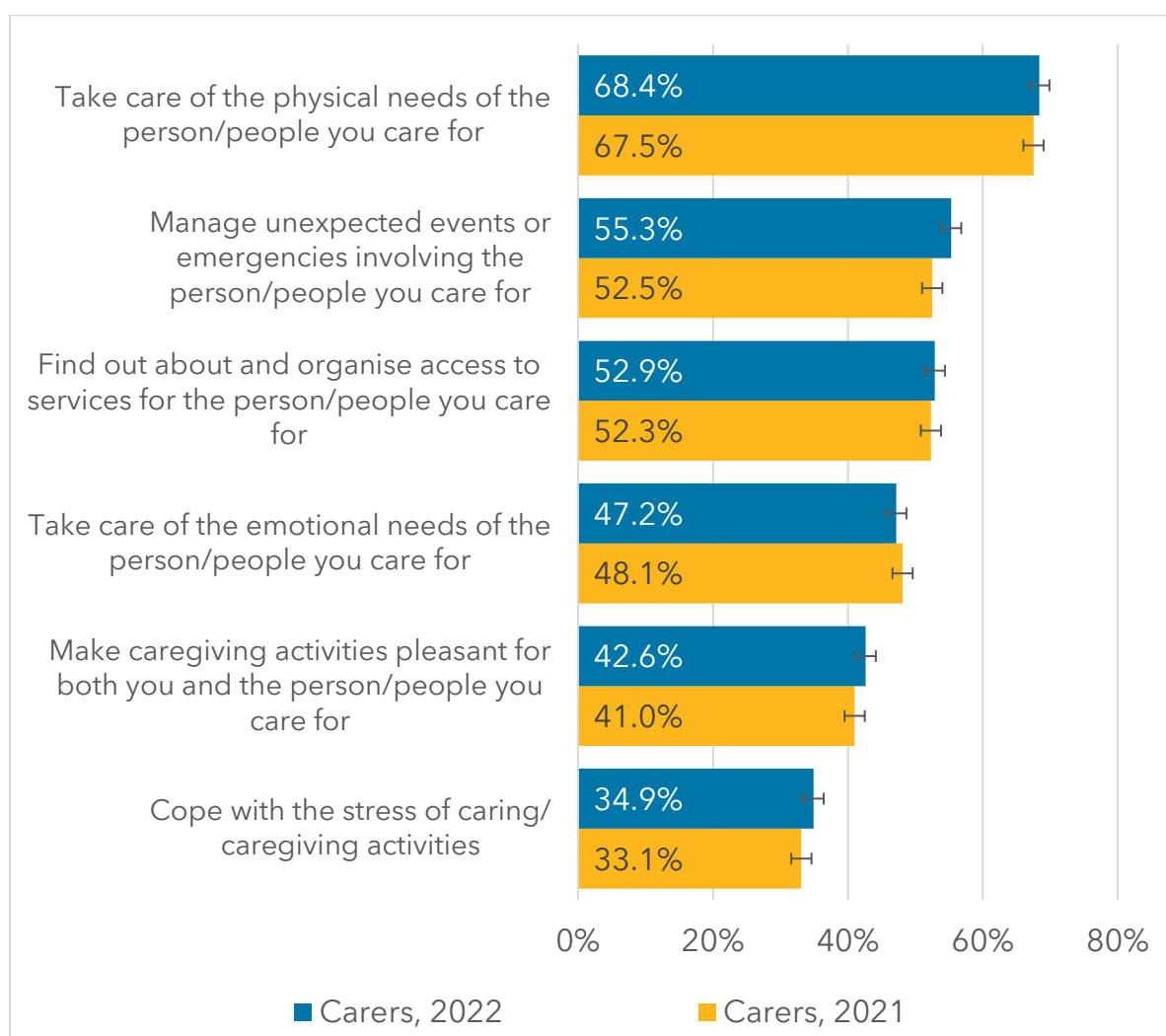
These changes were all small: while statistically significant, it is not possible to identify whether they represent a trend until a further wave of data collection occurs.



**FIGURE 21** PROPORTION OF CARERS WHO REGULARLY EXPERIENCE DIFFERENT TYPES OF CHALLENGE/IMPACT RELATED TO THEIR CARING ROLE

## 14. Confidence in carer role

Carers are asked to take on a role that often involves trying to manage a wide array of activities, all while ensuring both the quality of life of the person they care for, and maintaining their own wellbeing. When asked if they felt confident that they could achieve positive outcomes, in both 2021 and 2022 just over two-thirds of carers were confident they could take care of the physical needs of the people they cared for, just over half were confident they could manage unexpected events/emergencies and find out about and access services. The lowest confidence was held about coping with the stress of caregiving: 34.9% were confident they could cope with the stress of caring activities (FIGURE 22).



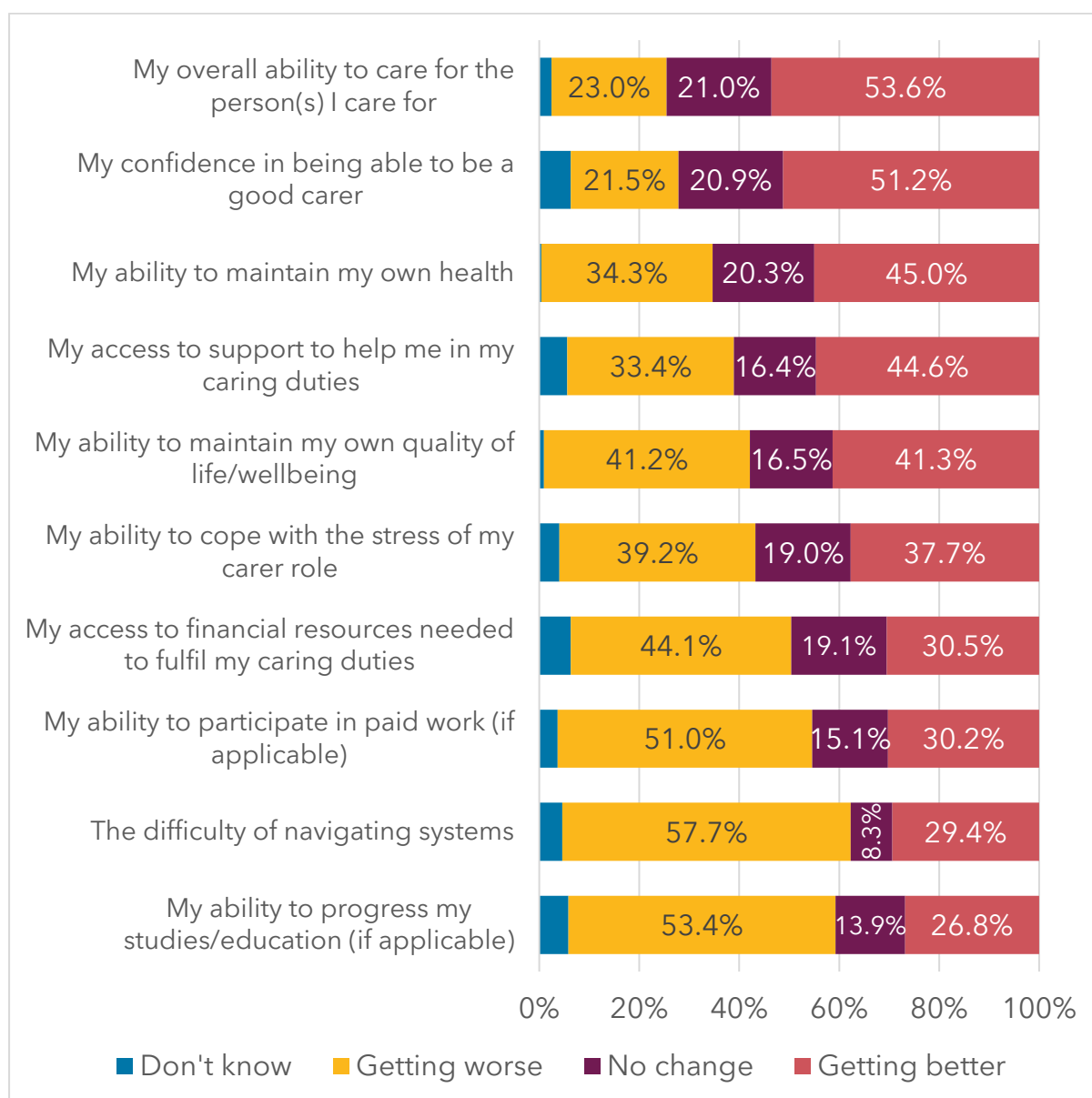
**FIGURE 22** PROPORTION OF CARERS WHO FELT CONFIDENT THEY COULD ACHIEVE DIFFERENT OUTCOMES AS PART OF THEIR CARER ROLE

This picture of relative stability suggests that for many carers, little changed between 2021 and 2022. A somewhat different picture emerges from data on carer’s self-assessment of how different aspects of being a carer had changed for them in the last 12 months. Carers were asked if, over the last 12 months, different aspects of caring had been getting worse, staying about the same, or getting better (FIGURE 23).



More than half of carers reported that their overall ability to be a good carer had increased in the last 12 months, while less than one in four felt it had worsened. More carers reported an improvement in ability to care for their own health (45.0%) than reported declining ability to care for their health (34.3%).

Carers were also more likely to report improvement in access to support for caring than worsening: 44.6% reported that their access to support to help them in their caring duties had increased in the last 12 months, while it had worsened for 33.4%.

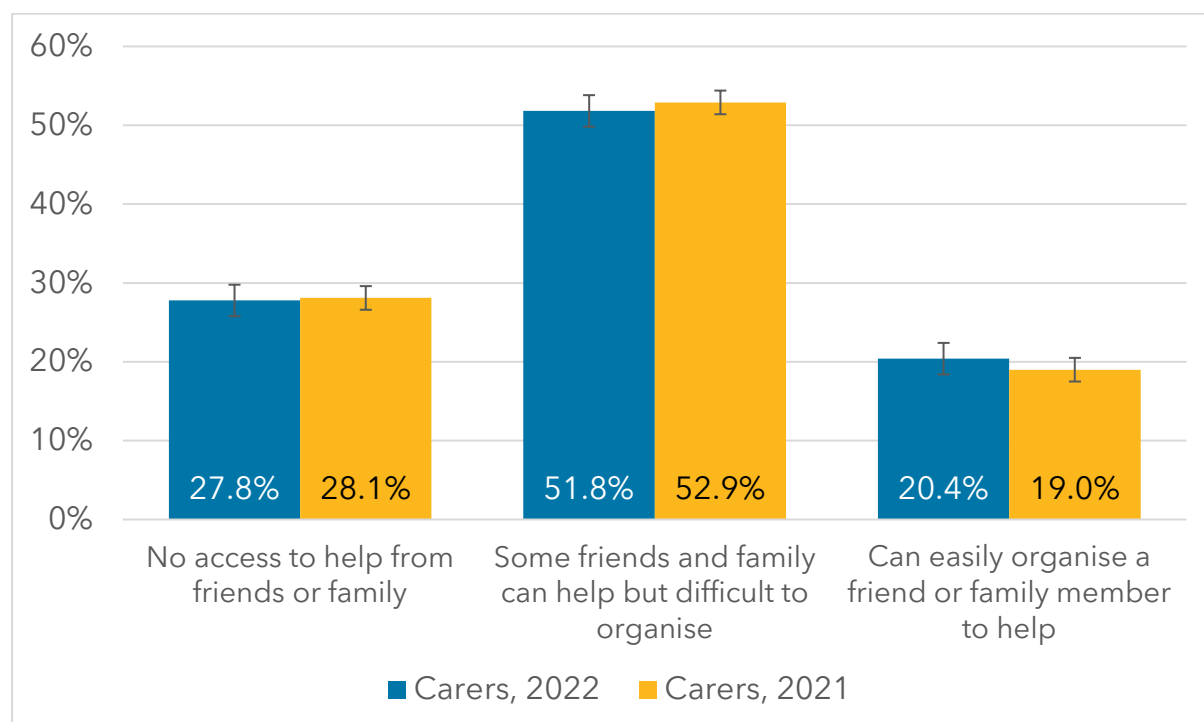


**FIGURE 23** SELF-ASSESSED CHANGE IN CARER CAPABILITIES AND CONDITIONS OVER THE LAST 12 MONTHS

On the other side of the picture, carers were more likely to report a decline than improvement in their ability to progress their studies/education (53.4%), ability to navigate systems such as NDIS (57.7%), ability to participate in paid work (51.0%), and access to financial resources (44.1%).

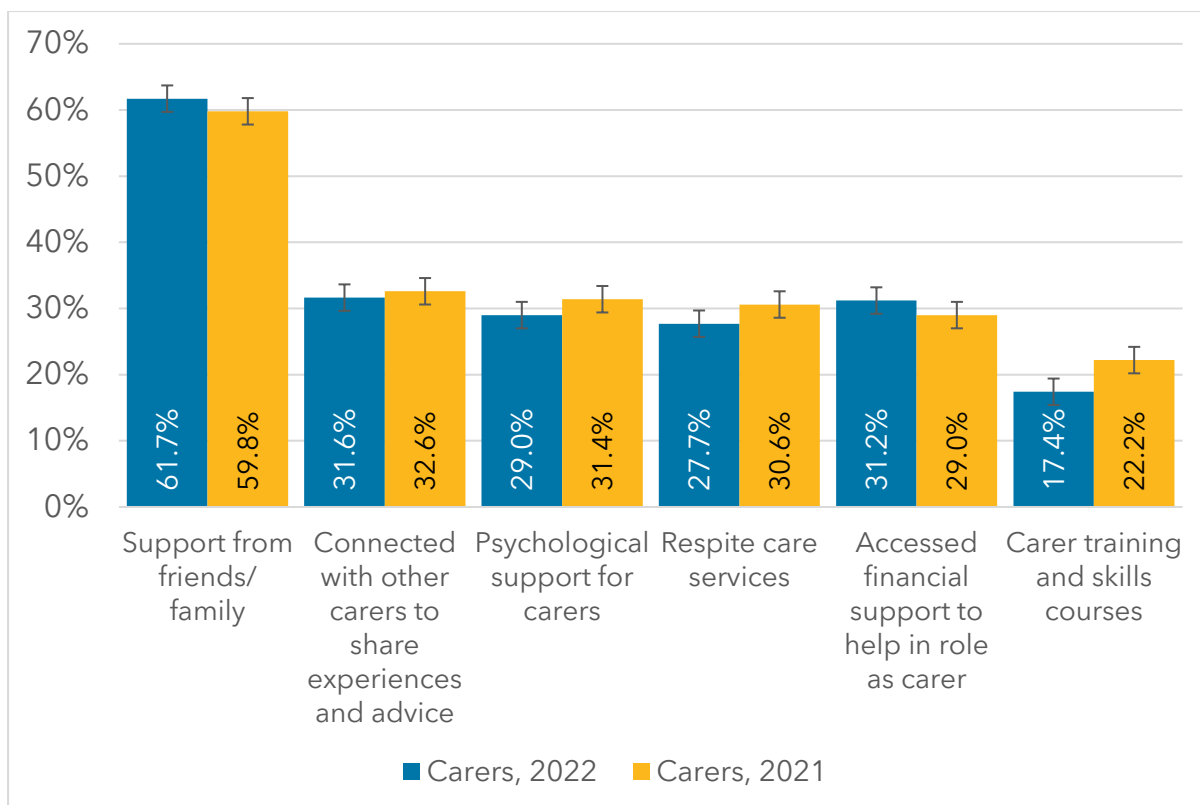
## 15. Access to formal and informal support in role as a carer

When asked if they had access to support from friends and family, in both 2021 and 2022, 28% of carers reported having no access to support, while 20% could easily organise a friend or family member to help out, and 52% could organise help but it would be difficult (FIGURE 24).



**FIGURE 24** ACCESS TO HELP FROM FRIENDS OR FAMILY IN CARING ROLE

Between 2021 and 2022, there was little significant change in the proportion of carers who reported accessing different types of formal and informal support (FIGURE 25). The one significant change was a decline in the proportion of carers who reported accessing carer training and skills courses, which dropped slightly but significantly from 22.2% to 17.4%.



**FIGURE 25** TYPES OF INFORMAL AND FORMAL SUPPORT ACCESSED IN LAST 12 MONTHS

Carers were more likely to access support from friends and family if they were younger, were not the primary carer for the care recipient, had an episodic carer role, had been a carer for 1-2 years, or cared for a sibling (Table 2). They were least likely to have had support from friends and family in the last year if they were a sole carer with high caring obligations (40 or more hours a week or caring and/or caring for three or more people), and if they cared for a child or grandchild.

Carers were more likely to connect with other carers to share experiences and knowledge, e.g. through carer peer groups, if they were Aboriginal or Torres Strait Islander, lived in the ACT, cared for a person with a short-term non-terminal illness or a person with drug or alcohol dependency, or were aged 25-34. Those least likely to connect with other carers were those caring for a person with a terminal illness, for parents/grandparents, male carers, those who had been a carer for less than a year or who lived in an outer regional or remote region of Australia.

Older carers aged 65 and older were less likely to access psychological support compared to others; to a lesser extent, male carers and those caring for a person with intellectual disability were less likely to. Younger carers, Aboriginal/Torres Strait Islander carers, and those caring for people with drug/alcohol dependency, mental illness or short-term non-terminal illness were more likely to reporting accessing psychological support.

**TABLE 2** TYPES OF CARERS MOST AND LEAST LIKELY TO REPORT ACCESSING DIFFERENT TYPES OF INFORMAL AND FORMAL SUPPORT IN THE PREVIOUS 12 MONTHS, 2022

% current carers who accessed this in last 12 months, 2022		Top five groups of carers most/least likely to report accessing support					
Accessed support from friends/family	61.7%	<i>Most likely</i>	Carer aged 15-24 (81.6%)	Secondary carer (81.3%)	Caring role episodic (75.6%)	Carer for 1-2 years (75.5%)	Care for sibling (74.7%)
		<i>Least likely</i>	Sole carer (53.7%)	Care for 3+ people (55.6%)	Care for child/grandchild (55.7%)	Carer for 40+ hours a week (56.0%)	Queensland carer (56.2%)/ODD carer (56.2%)
Connected with other carers to share experiences and advice	31.6%	<i>Most likely</i>	Carer is Aboriginal/Torres Strait Islander (44.1%)	Carer lives in ACT (43.8%)	Short-term non-terminal illness (43.0%)	Care for person with drug or alcohol dependency (40.3%)	Carer aged 25-34 (39.2%)
		<i>Least likely</i>	Care recipient has terminal illness (25.3%)	Carer for <1 year (26.3%)	Male carer (26.6%)	Care for parent or grandparent (27.7%)	Carer lives in outer regional or remote area (27.8%)
Accessed psychological support for carers	29.0%	<i>Most likely</i>	Short term non-terminal illness (51.4%)	Carer aged 25-34 (46.4%)	Care recipient has drug or alcohol dependency (44.0%)	Carer Aboriginal/Torres Strait Islander (43.6%)	Mental illness/psychosocial disability (36.8%)
		<i>Least likely</i>	Carer aged 75+ (21.0%)	Carer aged 65-74 (23.6%)	Carer living in Inner Regional area (25.0%)	Carer of person with intellectual disability (25.5%)	Male carers (25.6%)

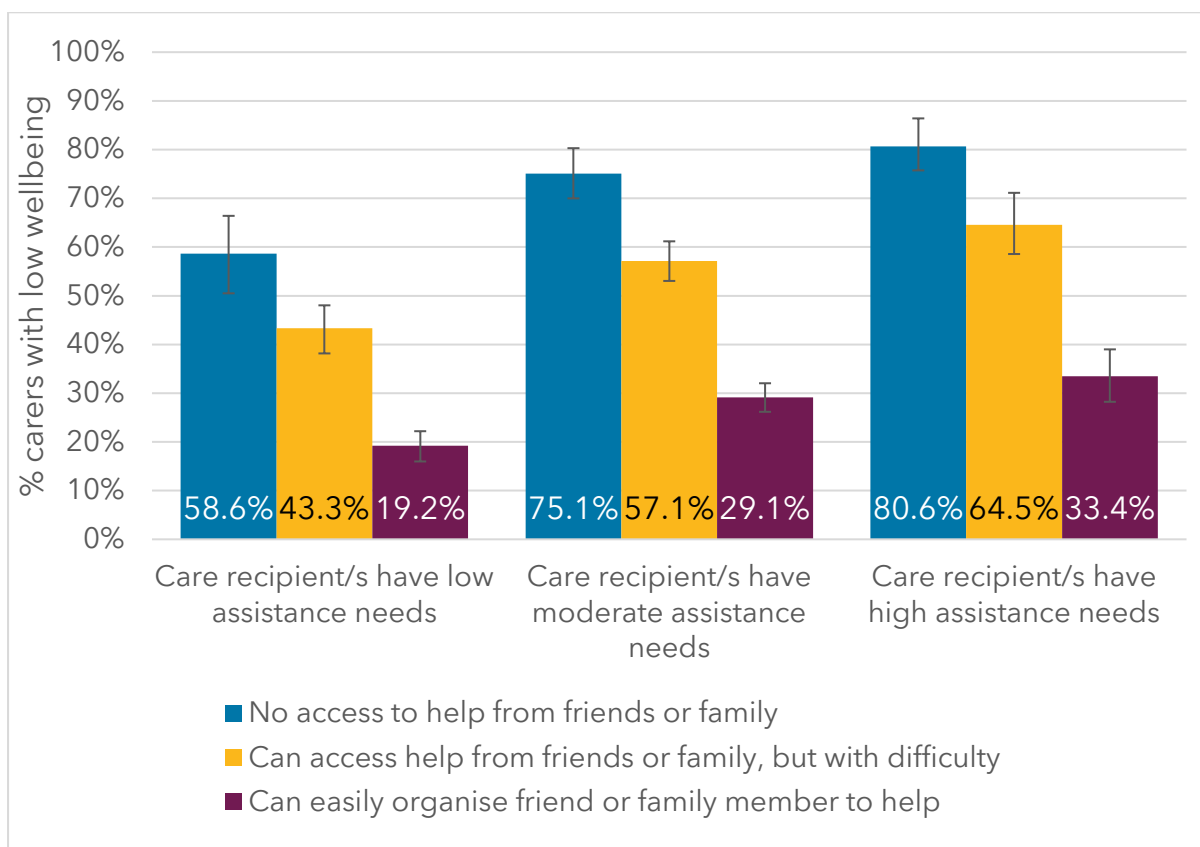
% current carers who accessed this in last 12 months, 2022		Top five groups of carers most/least likely to report accessing support					
Accessed respite care services	27.7%	<i>Most likely</i>	Care recipient has dementia (43.5%)	Care recipient has very high assistance needs (41.7%)	Carer aged 75+ (40.3%)	Carer is not a primary carer (35.0%)	Care recipient has old-age related frailty (34.7%)
		<i>Least likely</i>	Care recipient has low/ moderate assistance needs (16.8%)	Care recipient has varying assistance needs (17.9%)	Mental illness or psychosocial disability (21.4%)	Care recipient has drug or alcohol dependency (21.4%)	Carer aged 35-44 (21.5%)
Accessed financial support to help in role as carer	31.2%	<i>Most likely</i>	Carer aged 15-24 (55.3%)	Carer is Aboriginal/ Torres Strait Islander (43.8%)	Carer currently studying (42.2%)	Short-term non-terminal illness (42.2%)	Care for sibling (41.9%)
		<i>Least likely</i>	Care recipient does not live with carer (19.2%)	Carer for <1 year (24.7%)	Carer aged 65-74 (25.8%)	Caring hours <20 hours per week (26.6%)	Caring role episodic (26.7%), carer 55-64 (26.8%), low/mod assistance needs (26.8%)
Accessed carer training and skills courses	17.4%	<i>Most likely</i>	Carer is Aboriginal/ Torres Strait Islander (32.5%)	Carer living in ACT (29.2%)	Cared aged 25-34 (28.9%)	Short-term non-terminal illness (28.0%)	Care for 3+ people (26.0%)
		<i>Least likely</i>	Carer living in outer regional/ remote location (11.4%)	Carer living in NT (13.4%)	Care recipient has terminal illness (13.6%)	Carer living in Victoria (14.2%)	Has been a carer for <1 year (14.6%)

Respite care was more commonly accessed by those caring for a person with dementia, with high assistance needs or old-age frailty, and by the oldest group of carers aged 75 and over. In addition, those who were not primary carers were more likely than others to report accessing respite care. Respite care was least commonly accessed by carers aged 35-44, those caring for people with low or varying assistance needs, and those caring for people with mental illness, psychosocial disability or drug or alcohol dependency.

Younger carers, carers engaged in study, Aboriginal/Torres Strait Islanders were more likely to report accessing financial assistance for their role as a carer, and carers with lower caring obligations, who had been a carer less than a year, or were aged 65-74, were less likely to receive financial assistance.

Carer training and skills courses were more often accessed by carers who were Aboriginal or Torres Strait Islander, who lived in the ACT, who were aged 25-34 and who cared for three or more people. They were least commonly accessed by those living in outer regional/remote locations and the NT (most of which is outer regional/remote), living in Victoria, or by those caring for a person with a terminal illness or those who had been a carer for only a relatively short time (less than a year).

Carers who had good access to support from friends and family were much less likely to have low wellbeing compared to those who had no or limited access to support from friends of family (FIGURE 26). Amongst those caring for people who had relatively low assistance needs, 19.2% of those with easy access to help from friends and family had poor wellbeing - compared to 58.6% of those with no access to help of this type. Amongst those caring for people with high assistance needs, 33.4% of those with good access to help from family and friends had low wellbeing, compared to 80.6% of those with no access. This highlights the importance of having access to support for the wellbeing of carers.

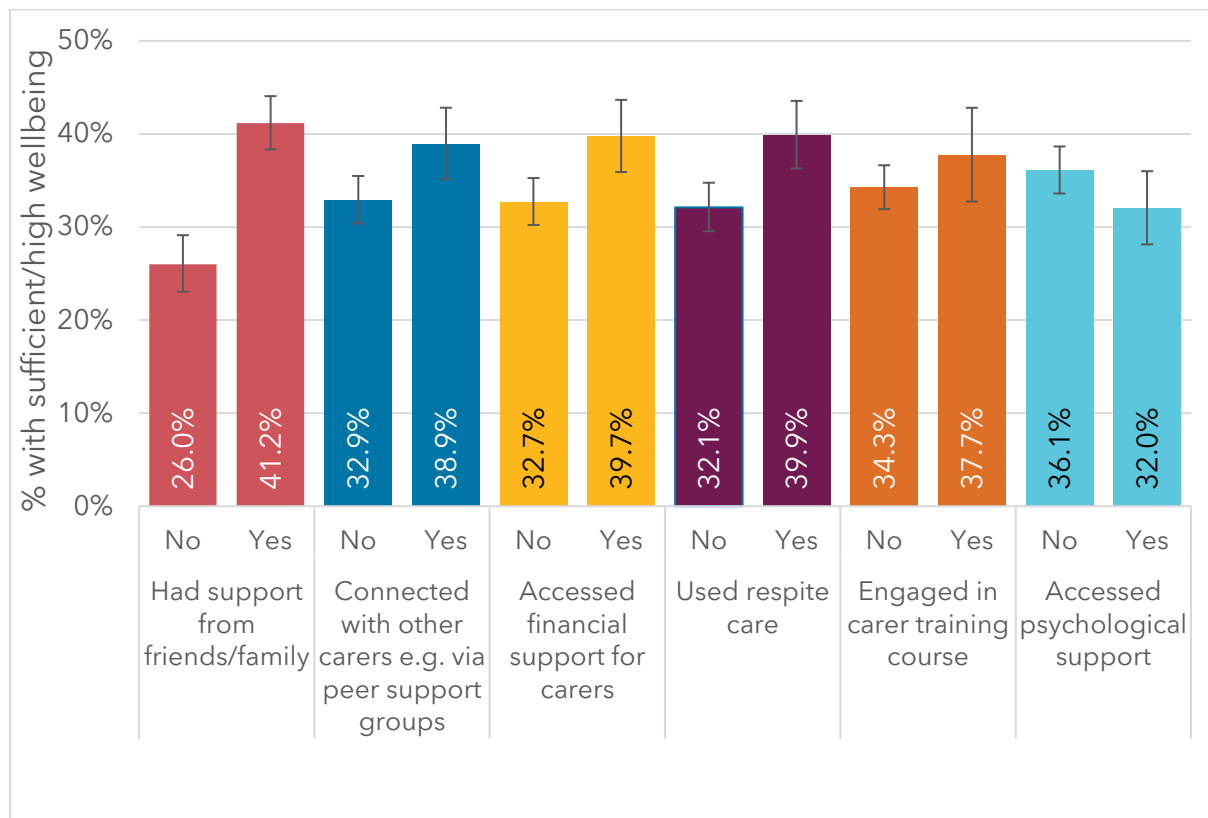


**FIGURE 26** WELLBEING OF CARERS WHO HAD MORE AND LESS ACCESS TO SUPPORT FROM FRIENDS AND FAMILY WHEN NEEDED

Not all carers have access to informal support from family and friends; and amongst those who do, this support may not be sufficient, particularly when a care recipient has complex needs. Access to a range of types of formal supports is important to the wellbeing of many carers. Some types of support are typically accessed when carer wellbeing is low and needs support: for example, carers are more likely to seek psychological support when they are experiencing significant challenges coping with their role as a carer. It is also common to access some types of support when the needs of care recipients become greater - a time when the wellbeing of a carer may be lower due to the demand of the carer role. For example, respite care is often accessed only when there has been a significant increase in the needs of a care recipient, a time when a carer is at high risk of experiencing loss of wellbeing due to the high demands of their caring role.

These complexities mean that observing the impacts of supports on wellbeing of carers is not as simple as identifying whether a carer who has access to these supports has higher wellbeing: given that many carers are more likely to seek formal support when their carer role increases in difficulty or challenge, the effect of formal supports on wellbeing may not be readily observable.

FIGURE 27 compares the wellbeing of carers providing assistance to care recipients with high or very high assistance needs, based on whether they reported accessing different types of formal and informal support in the last 12 months. This focuses on the group of carers most likely to both require support, and whose wellbeing is most likely to benefit from access to support. Amongst those who had support from friends and family, the proportion who had healthy levels of wellbeing (sufficient or high) rose from 26.0% amongst those with no support from family and friends to 41.2% amongst those who received supported from family and friends in the last 12 months. Wellbeing was also significantly higher amongst those who connected with other carers, who received financial support for their carer role, and who used respite care.

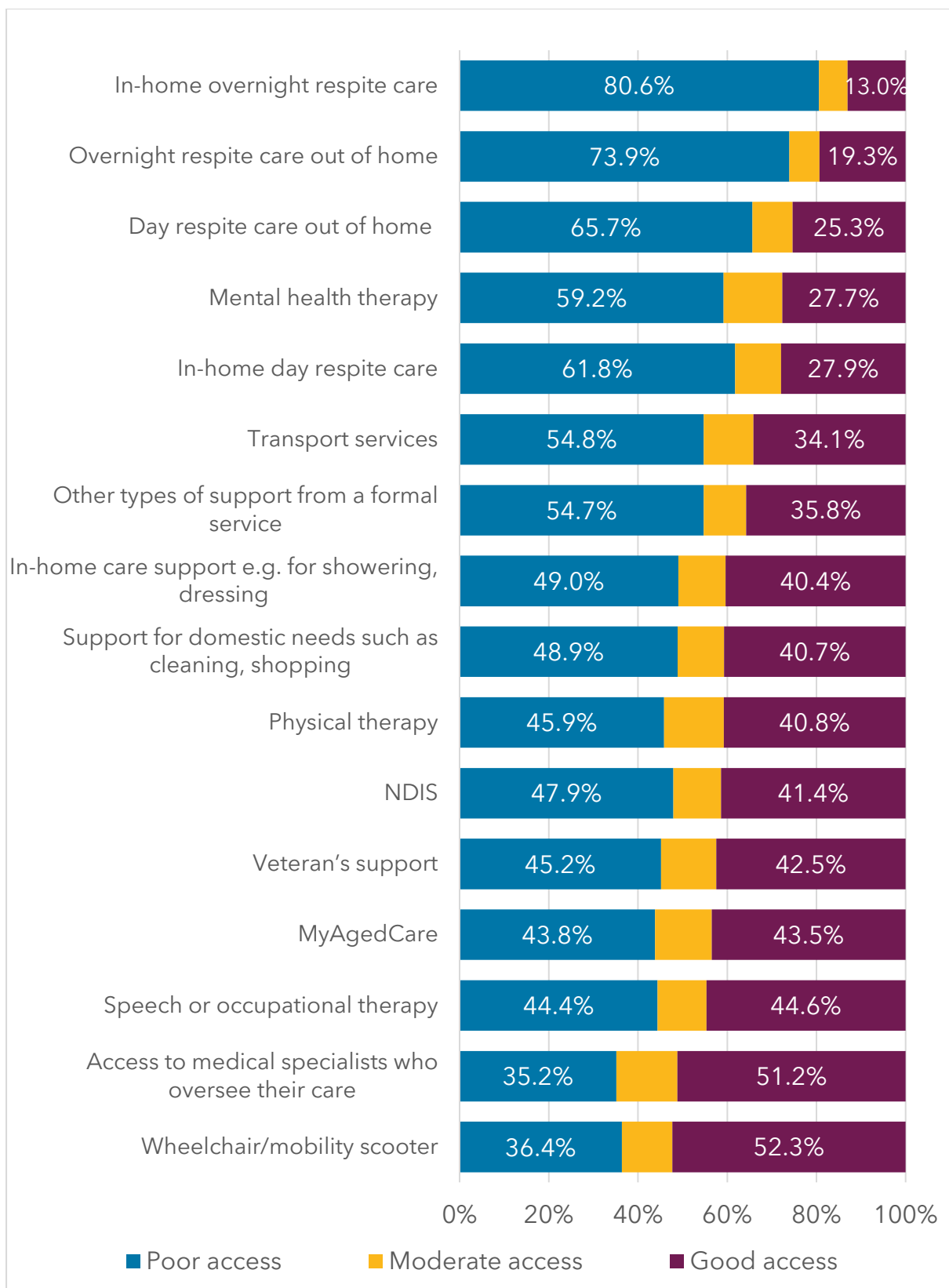


**FIGURE 27** PROPORTION OF CARERS WITH SUFFICIENT/HIGH WELLBEING, AMONGST CARERS PROVIDING SUPPORT TO CARE RECIPIENTS WITH HIGH SUPPORT NEEDS, BY TYPE OF SUPPORTS ACCESSED IN LAST 12 MONTHS



## 16. Barriers to accessing support

One of the most significant ways carers can reduce the challenges they may otherwise experience is through helping the person they care for access support through available support packages, such as the NDIS and MyAgedCare. However, this is not always easy or possible. When asked to rate the extent to which the person or people they care for had good access to a range of types of support, a majority of carers reported poor access to several types of support, particularly respite care, mental health therapy, and transport services (FIGURE 28).



**FIGURE 28** CARER'S VIEWS ABOUT ACCESS OF CARE RECIPIENTS TO DIFFERENT TYPES OF SUPPORT DURING THE LAST 12 MONTHS

More carers reported that the people they care for had poor than good access to many types of support service during the previous 12 months, including in-home care support, domestic

support, NDIS, physical therapy, and Veteran's support. Some carers were more likely than others to report that the people they cared for had poor access to key types of support during the year prior to completing the survey in early 2022 (Table 3):

- Sole carers were more likely than others to report the people they cared for had poor access to in-home overnight respite care, in-home care support, NDIS, and speech/occupational therapy
- Carers aged 35-44 were more likely to report care recipients had poor access to all types of respite care, transport services, in-home care support, MyAgedCare and medical specialists
- Carers of people with ASD or ODD were more likely to report the people they cared for had poor access to most types of respite care, in-home care support and support services for domestic needs
- Carers for people with a terminal illness were more likely to report the person they cared for had poor access to out of home respite care, NDIS, mental health therapy, and speech or occupational therapy
- Carers for people with drug or alcohol dependency were more likely to report their care recipient had poor access to in-home care support, physical therapy, wheelchair/mobility scooter, and medical specialists
- Carers for people with a mental illness or psychosocial disability were more likely to report the person they cared for had poor access to physical, speech and occupational therapy, and wheelchair/mobility aids.

**TABLE 3** CARER'S VIEWS ABOUT ACCESS OF CARE RECIPIENTS TO DIFFERENT TYPES OF SUPPORT DURING THE LAST 12 MONTHS – BY CARER GROUPS

Type of support	% reporting poor access	Top 5 groups most likely to report care recipient has poor access				
In-home overnight respite care	80.6%	Sole carer (87.1%)	Carer aged 35-44 (86.8%)	ODD (85.5%)	ASD (85.2%)	Care for child/ g'child (84.3%)
Overnight respite care out of home	73.9%	Carer aged 35-44 (83.4%)	Terminal illness (81.8%)	ASD (80.7%)	ODD (80.6%)	Carer speaks LOTE at home (79.6%)
Day respite care out of home	65.7%	Carer for <1 year (84.0%)	Carer aged 35-44 (77.9%)	Terminal illness (77.7%)	Chronic non-terminal illness (75.4%)	ODD (75.1%)
In-home day respite care	61.8%	Carer LGBTIQ+ (77.7%)	Carer aged 35-44 (76.7%)	Sole carer (72.6%)	ASD (72.4%)	ODD (71.8%)
Mental health therapy	59.2%	Carer for <1 year (70.2%)	Carer unemployed (67.5%)	Very high assistance needs (67.1%)	Terminal illness (67.0%)	Old-age related frailty (66.5%)
Transport services	54.8%	Carer aged 35-44 (71.4%)	ODD (71.0%)	ASD (66.6%)	Carer provides work/ study support (65.4%)	Care for child/ grandchild (64.1%)
In-home care support e.g. showering, dressing	49.0%	ODD (65.5%)	Carer aged 35-44 (63.1%)	Drug/ alcohol dep. (63.0%)	Sole carer (62.8%)	ASD (62.6%)

Type of support	% reporting poor access	Top 5 groups most likely to report care recipient has poor access				
Support service for domestic needs e.g. cleaning, shopping	48.9%	Carer LGBTIQ+ (68.9%)	Carer aged 25-34 (65.8%)	ODD (63.7%)	ASD (62.6%)	Carer provides work /study support (62.2%)
NDIS	47.9%	Short-term non-terminal (65.5%)	Sole carer (63.0%)	Terminal illness (58.0%)	Drug/ alcohol dependency (56.0%)	Chronic non-terminal illness/ injury (57.5%)
Physical therapy	45.9%	Short-term non-terminal (56.9%)	Care for friend/ relative (55.1%)	Outer regional/ remote area (54.3%)	Drug/ alcohol dependency (54.2%)	Mental illness/ psychosocial dis. (54.0%)
Speech or occupational therapy	44.4%	Short-term non-terminal illness (69.3%)	Old-age related frailty (54.8%)	Sole carer (54.1%)	Terminal illness (52.8%)	Mental illness/ psychosocial disability (52.6%)
MyAgedCare	43.8%	Aged 35-44 (60.0%)	Carers providing work/ study support (57.2%)	Carers currently studying (55.1%)	Aged 15-24 (54.5%)	Mental illness/ psychosocial disability (53.6%)
Wheelchair/mobility scooter	36.4%	Carer unemployed (52.4%)	Drug/ alcohol dep. (50.7%)	ASD (50.6%)	Mental illness/ psycho social dis. (48.4%)	Carer has low-mod assistance needs (46.8%)
Access to medical specialists who oversee their care	35.2%	Drug/ alcohol dep. (47.2%)	Carer unemployed (46.1%)	Aged 35-44 (44.7%)	Care for 3+ people (44.0%)	Carer provides work/ study support (44.0%)

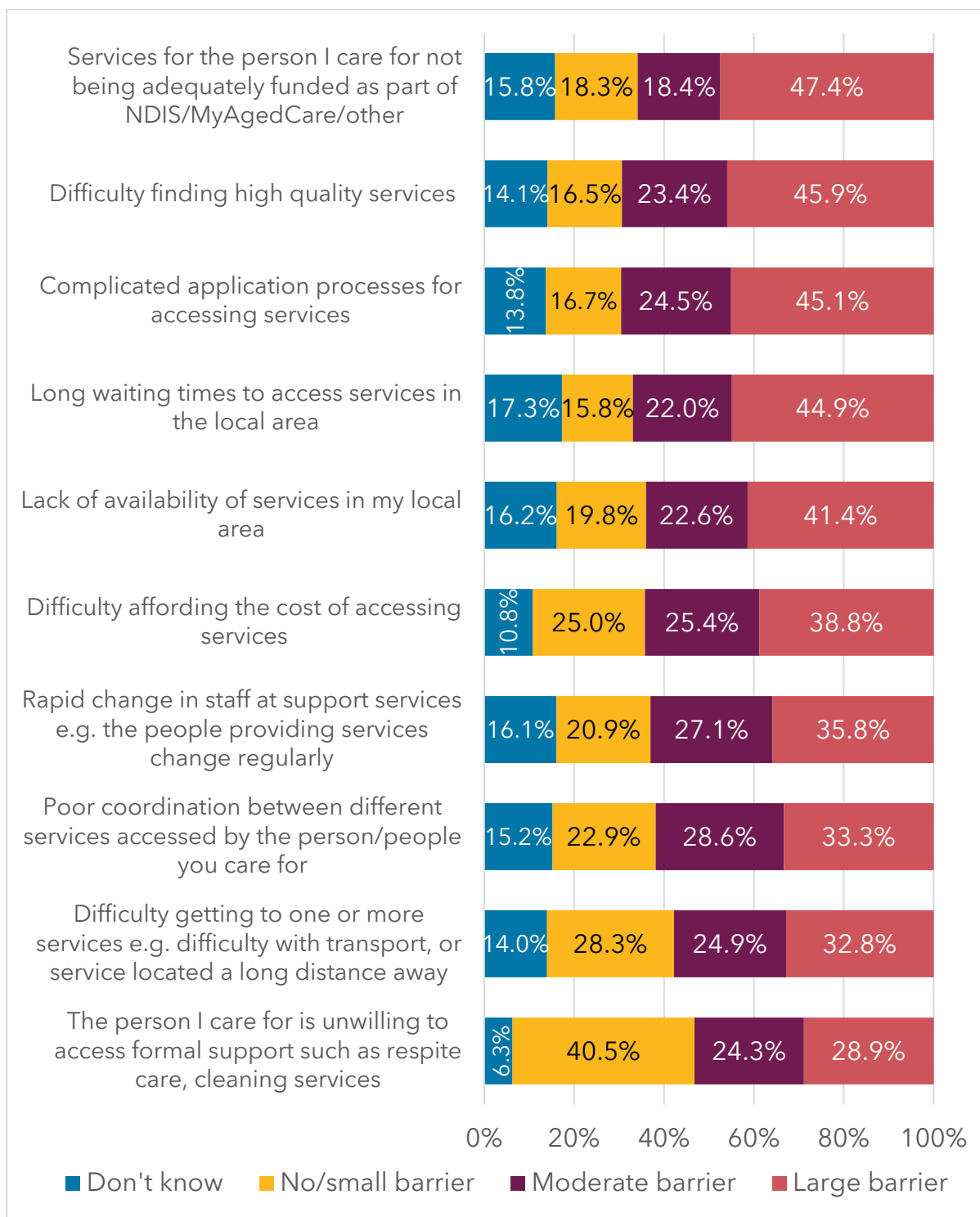
Carers were asked to rate the extent to which several different types of issues presented a barrier to accessing support services for the person they cared for during the previous 12 months, such as respite care, in-home support, cleaning services, or therapy.

As shown in FIGURE 29, the most common barriers experienced in the 12 months prior to March 2022 were lack of funding for the service via NDIS/MyAgedCare or other support packages (a moderate to large barrier for 65.9%), difficulty finding high quality services (69.3%), complicated application processes (69.5%), long waiting times to access services (66.9%), lack of local service availability (64.0%), difficulty affording services (64.2%), staff turnover amongst service providers (63.0%) and poor coordination between services (61.9%).

Carers living in regional and remote areas were significantly more likely to report that lack of service availability was a large barrier to accessing services, with 53.0% of those living in outer regional and remote areas reporting this compared to 34.6% of those living in major cities. Rural carers were also somewhat more likely to report experiencing long waiting times for services compared to those living in major cities.

Most carers reported experiencing multiple barriers addressed in the survey, highlighting the complexities many face when seeking to help the person they care for access support services.

Over half (53.2%) reported that the unwillingness of the person they cared for to access formal support was a moderate to large barrier to accessing services, with more than one in four (28.9%) reporting this was a large problem. This was most common amongst those caring for a person with drug/alcohol dependency (44.9% reporting it was a large problem), a person with a shorter-term illness (40.8%), a person with dementia (36.9%) or a person experiencing mental illness or psychosocial disability (34.1%).



**FIGURE 29** BARRIERS/PROBLEMS EXPERIENCED BY CARERS WHEN SEEKING TO ACCESS SERVICES FOR CARE RECIPIENT

## 17. Carer experiences with medical professionals and the My Health Record

Carers often need to liaise closely with medical professionals as part of their role. Having a good relationship and information exchange with medical professionals can increase the quality of care that people who are receiving care access from carers and medical professionals, improving quality of life.

Digital health records are increasingly used across Australia to store and track records: some carers may access the My Health Record of the person they care for or act as their nominated representative, while others don't.

The 2022 CWS asked carers about their access to information from the medical professionals who support the person or people they care for, and their use of My Health Record.

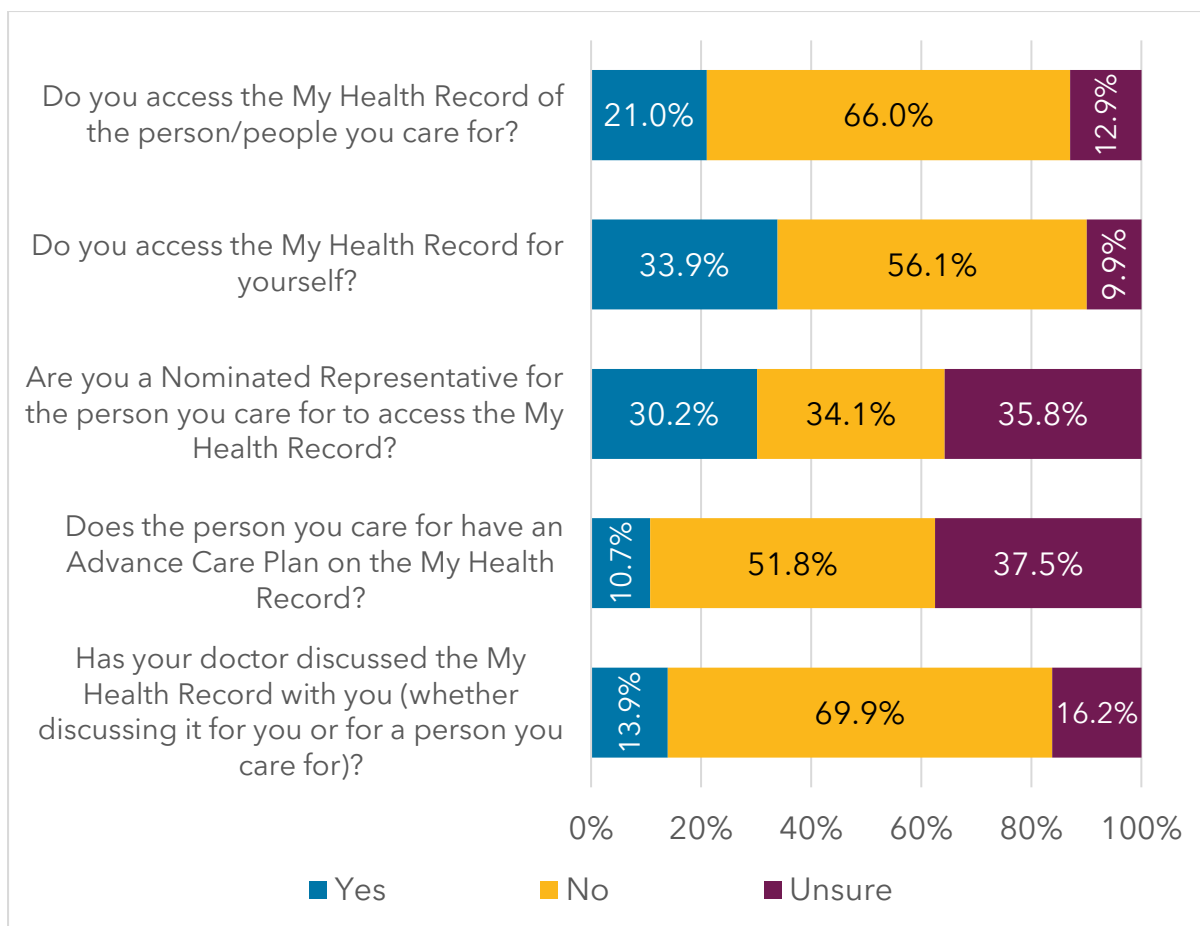
Overall, 52.9% of carers reported they had good access to information from the medical professionals who provided support to the people they cared for, while 35.0% had limited access and 12.2% no access to information from these medical professionals.

Carers were *less* likely to report having good access to information from medical professionals if they:

- were younger
- were Aboriginal or Torres Strait Islander
- usually spoke a language other than English at home
- were not the person's primary carer
- cared for the person episodically
- cared for a person with mental illness or psychosocial disability, and/or
- cared for a person with drug/alcohol dependency.

Amongst current carers, around one in three accessed their own My Health Record (33.9%), while 21.0% accessed the My Health Record of a person they cared for (FIGURE 30). There was significant uncertainty around being a Nominated Representative: 35.8% were unsure if they were a nominated representative for the person they cared for in My Health Record, while 30.2% knew they were and 34.1% were not. Relatively few carers reported that the person they cared for had an Advance Care Plan on My Health Record (10.7%), and only 13.9% had discussed the My Health Record with their doctor.





**FIGURE 30 USE OF MY HEALTH RECORD AMONGST CARERS**

Carers aged 25-34 were the most likely of any age group to access the My Health Record of a person they cared for (34.6%) and be a nominated representative (40.0%), followed by those aged 35-44 (28.1%, 36.3%). Likelihood of using My Health Record in these ways increased amongst carers who had greater caring obligations: for example, only 26.9% of those who spent less than 20 hours on caring duties in a typical week were a nominated representative for a person they cared for, compared to 37.7% of those who had 40 or more hours a week of caring duties. Primary carers were twice as likely to be a nominated representative (32.1%) and access the My Health Record of a person they cared for (22.0%) as those who were not the primary carer for the person (15.3%, 12.3%). Appendix 2 provides further detailed data.

## 18. Peer support groups: what works well?

In total, 31.6% of carers reported they had connected with other carers to share experiences and advice within the last 12 months. These types of connections can occur in many ways: some are informal, with carers simply getting to know each other. However, a common way that carers connect with each other is through attending carer peer support groups. These carer peer support groups can take many forms. For example, some are purely online discussion groups, others meet face to face, and some mix face to face and online interaction. Some groups are facilitated by either an independent facilitator, or a person with lived experience of being a carer.

Carers who indicated they had been part of a peer support group - a total of 674 (11.2%) of the survey participants - were asked about their experiences of the peer support group.

Amongst those who were part of a peer support groups in the previous year:

- 58.8% reported the group was run by a professional facilitator
- 44.5% attended a group facilitated by a person with lived experience of being a carer
- 47.9% were members of groups who sometimes or always had face to face meetings
- 35.6% were members of groups who met online, while 25.6% mostly interacted via online discussions, e.g. in online forums.

When asked about their experiences of peer support groups, most reported that the group had benefits for them (FIGURE 31). Almost three quarters found the support group helpful overall (74.6%), found participating in it made them feel more positive (74.0%), gained new ideas and knowledge from others in the group (71.7%), and valued the social connections they made (70.7%). Relatively few reported negative outcomes, although around one in five found the group discussions often left them feeling depressed or down (22.1%) or feel more frustrated or angry about their carer role (17.4%).

Similar experiences were reported by different carers, irrespective of the type of caring duties they had, or their age, with a small number of exceptions:

- Female carers were more likely than male carers to report that talking to others often made them feel more positive (76.6% compared to 66.3%)
- Carers aged 25-34 were more likely to report feeling depressed or down (42.7%) and less likely to find that talking to others in the group often made them feel more positive (62.1%)
- Those caring for people with very high assistance needs were somewhat less likely to report talking to others made them feel more positive (68.7%).

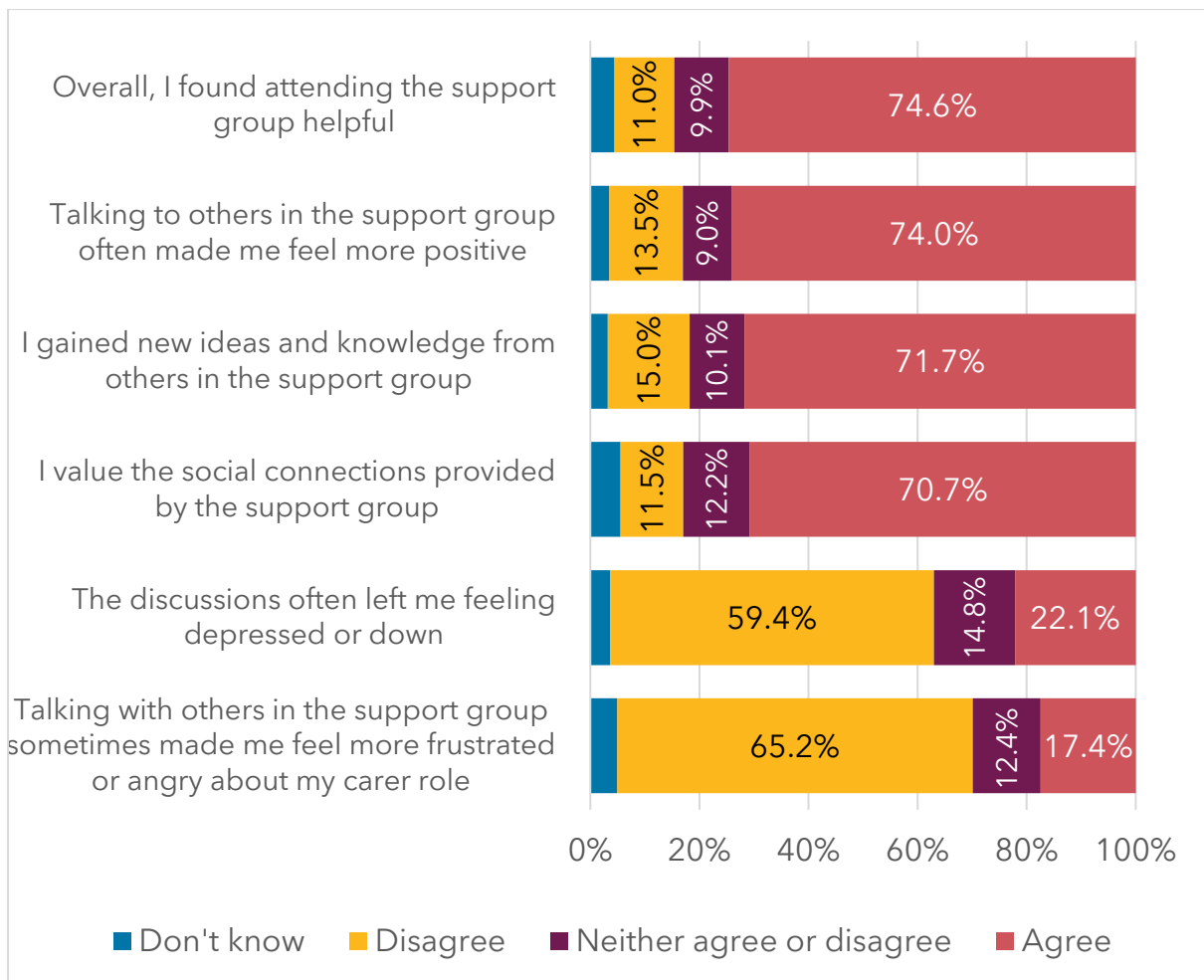


FIGURE 31 EXPERIENCES OF CARER PEER SUPPORT GROUPS

## 19. Life after being a carer: experiences of past carers

Some of the people who participate in the CWS are past carers – people who used to be a carer, but have stopped their caring role in recent months or years. Adjusting to life after being a carer can have its own challenges, but is often associated with positive change in wellbeing: the 2021 CWS found that the wellbeing of past carers was higher as the time since they stopped caring increased, after a year of no longer being a carer, wellbeing had often returned to levels similar to the average adult Australian.

Past carers who participated in the 2022 CWS were asked how their life had changed since they stopped being a carer (FIGURE 32). The responses indicate a wide variety of experiences. For example, while 53.0% reported that their quality of life had improved since they stopped being a carer, for 28.3% it had not. Just over half (52.4%) would take on a carer role again in future, while 25.0% would not, and more than 20% were either unsure or neither agreed or disagreed that they would be willing to be a carer again.

Despite many finding their quality of life improved, 51.9% reported they found it difficult to adjust to life after being a carer, and 48.8% had some difficulty building their social life. Just over one third reported difficulty either returning to the workforce or increasing work hours (34.4%), although 51.7% reported no difficulty with this.

These findings suggest that social challenges are often significant when a person stops being a carer, and that specific support to help a person re-engage socially may be useful for many carers. This was more often a difficulty for past carers than engaging in increased paid work, highlighting the importance of enabling past carers to both re-engage with social networks they may have lost contact with while being a carer, and to make new social connections.

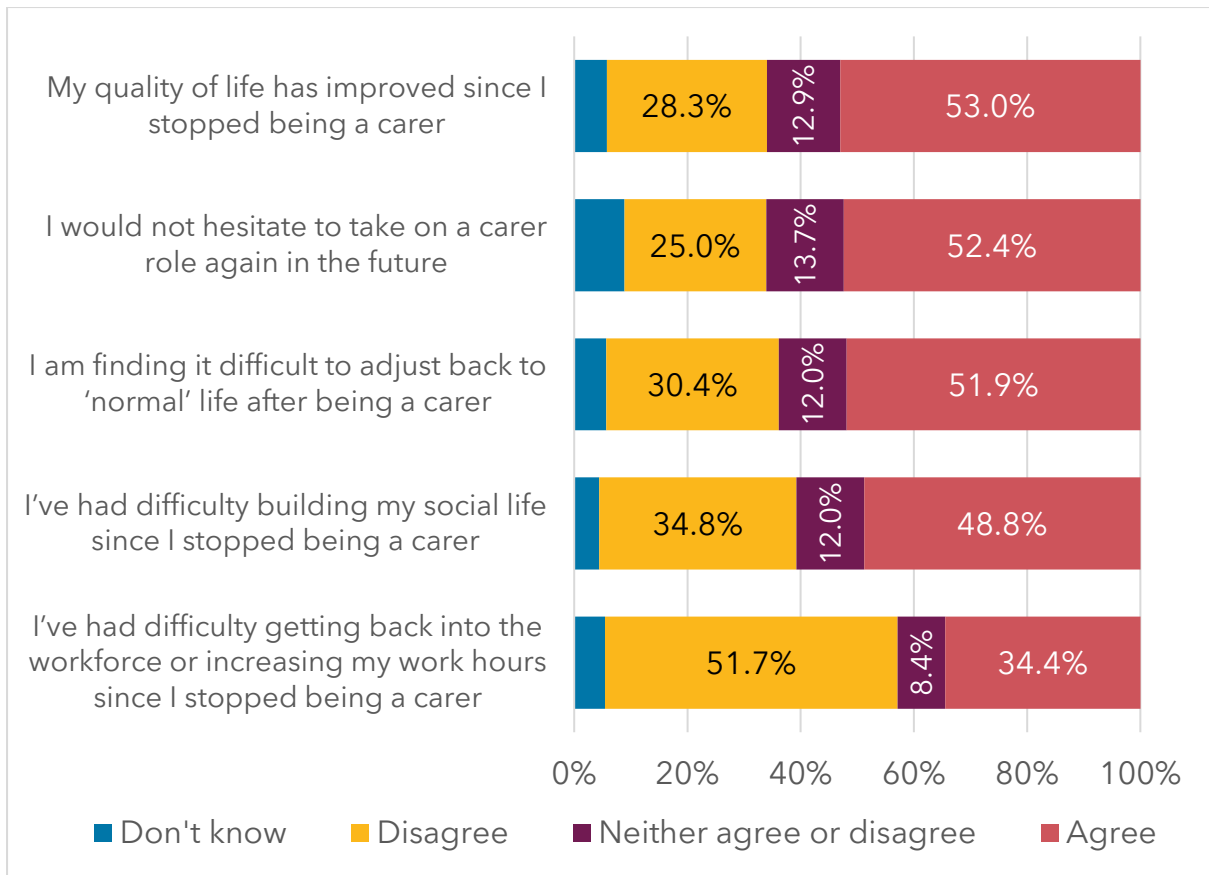
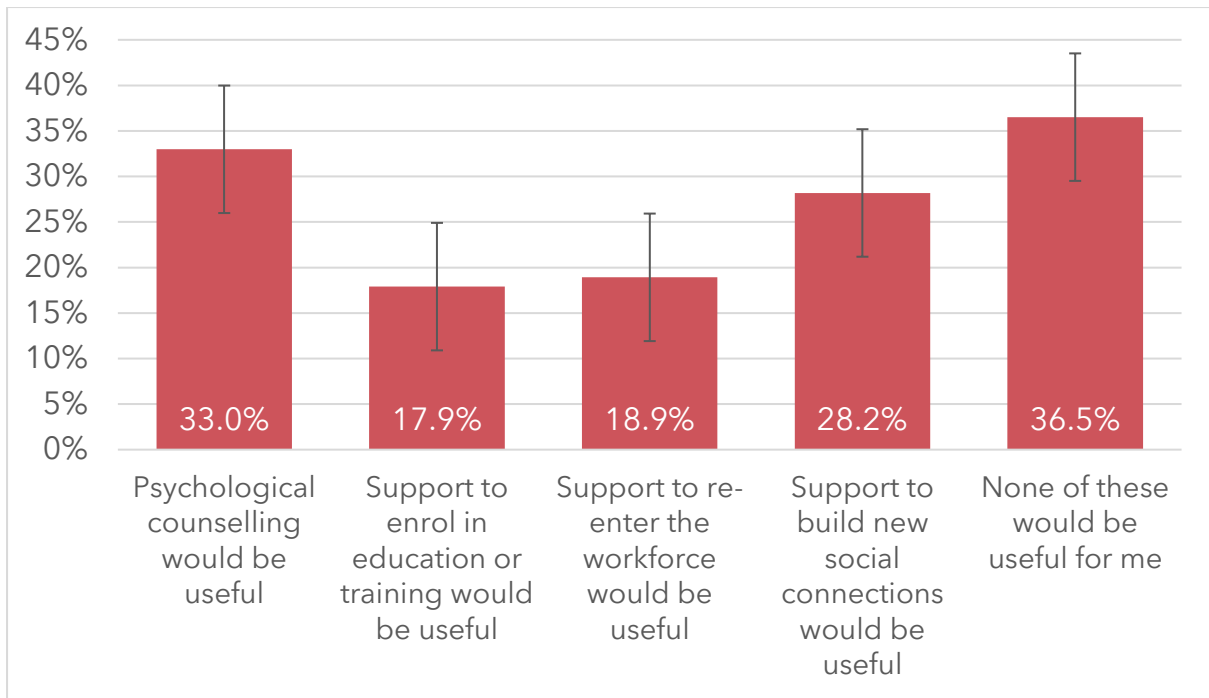


FIGURE 32 EXPERIENCES OF PAST CARERS

When asked what types of supports would be most useful to them after stopping being a carer, 63.5% of past carers said that at least one of psychological counselling, support for education or re-entering the workforce, or support to build new social connections, would be useful (FIGURE 33). Of these different types of support, 33.0% of past carers felt psychological counselling would be useful and 28.2% that support to build social connections would be useful, while 18.9% felt support to re-enter the workforce would be useful and 17.9% would find support to enrol in education or training useful.



**FIGURE 33** SUPPORTING PAST CARERS

## 20. Conclusions

The 2022 *Carer Wellbeing Survey* highlights the impacts COVID-19 has had for carers, with many experiencing reduced access to support (informal and formal), an increase in caregiving responsibilities, and an increase in isolation, due to the effects of the pandemic. This compounds the effects of what, for many, is already relatively limited access to support services. Some of these impacts appear greater amongst carers aged 25-44 and carers who are Aboriginal or Torres Strait Islander, the key groups for whom health, wellbeing and distress worsened between 2021 and 2022. The impacts also appear to be particularly concentrated amongst those who are caring for children and grandchildren, although all types of carers reported a range of negative impacts resulting from the COVID-19 pandemic.

While many carers feel positive about how their ability to provide high quality care is changing over time, and more feel that access to support is improving than feel it is declining, many feel their access to financial support and ability to engage in paid work worsened in the 12 months to March/April 2022, and most feel that navigating support systems such as NDIS and MyAgedCare has become more challenging.

The results highlight that many carers feel a sense of meaning and purpose due to being a carer - despite often having little choice in whether or not they became a carer. However, barriers to accessing informal and formal support, lack of free time, and financial stress all challenge to the wellbeing of carers. Addressing these barriers has potential to reduce the significant rates of low wellbeing amongst carers, and to enable a greater proportion of carers to feel positive about their experience as a carer. In particular, enabling access to different types of support and creating an environment in which carers can engage in paid employment supports the wellbeing of carers. The findings show that carers providing support to care recipients with the highest level of assistance needs have significantly higher wellbeing if they are able to access respite care, financial support, support from friends and family, and if they are able to connect with other carers.

## 21. References

- ABS (Australian Bureau of Statistics). 2022a. Census of Population and Housing: Unpaid work and care data summary, 2021. Released 28 June 2022. Australian Bureau of Statistics, Canberra. Data tables downloaded from: <https://www.abs.gov.au/statistics/people/people-and-communities/unpaid-work-and-care-census/latest-release> Last accessed 16 September 2022
- ABS (Australian Bureau of Statistics). 2022b. Census of Population and Housing: Aboriginal and Torres Strait Islander people data summary. Released 28 June 2022. Australian Bureau of Statistics, Canberra. Data tables downloaded from: <https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-peoples/aboriginal-and-torres-strait-islander-people-census/latest-release> Last accessed 16 September 2022
- ABS (Australian Bureau of Statistics). 2022c. Census Data Packs, 2021, General Community Profile. Australian Bureau of Statistics, Canberra. Data tables downloaded from: <https://www.abs.gov.au/census/find-census-data/datapacks> Last accessed 16 September 2022
- Brown, E., 2007. Care recipients' psychological well-being: The role of sense of control and caregiver type. *Aging and Mental Health*, 11(4), pp.405-414.
- Cacioppo, J.T. and Cacioppo, S., 2018. The growing problem of loneliness. *The Lancet*, 391(10119), p.426.
- Lachman, M.E., Agrigoroaei, S. and Rickenbach, E.H., 2015. Making sense of control: Change and consequences. *Emerging trends in the social and behavioral sciences*, pp.1-16.
- Lorenz-Dant, K. and Comas-Herrera, A., 2022. The impacts of COVID-19 on unpaid carers of adults with long-term care needs and measures to address these impacts: A rapid review of evidence up to November 2020. *Journal of Long-Term Care*, 2021, pp.124-153.
- Muldrew, D.H., Fee, A. and Coates, V., 2022. Impact of the COVID-19 pandemic on family carers in the community: a scoping review. *Health & Social Care in The Community*, 30(4), pp.1275-1285.
- Schirmer, J. and Riyanti, M. 2021. Caring for others and yourself: The 2021 Carer Wellbeing Survey. Report prepared for Carers Australia. Centre for Change Governance and NATSEM, University of Canberra, Canberra.
- Tomczyk, S., Altweck, L. and Schmidt, S., 2021. How is the way we spend our time related to psychological wellbeing? A cross-sectional analysis of time-use patterns in the general population and their associations with wellbeing and life satisfaction. *BMC public health*, 21(1), pp.1-9.
- Wei, G., Diehl-Schmid, J., Matias-Guiu, J.A., Pijnenburg, Y., Landin-Romero, R., Bogaardt, H., Piguet, O. and Kumfor, F., 2022. The effects of the COVID-19 pandemic on neuropsychiatric



symptoms in dementia and carer mental health: an international multicentre study. *Scientific reports*, 12(1), pp.1-11.

## Appendix 1: Methods

This section describes the methods used to collect and analyse data in the 2022 CWS. The CWS User Guide provides more detailed information (Schirmer and Mylek 2022).

### *Questionnaire design*

The 2022 CWS was designed through a multi-step process in which:

- 2021 survey content was reviewed, and measures to be repeated annually identified, as well as any measures requiring amendment
- Carer views about important topics related to carer wellbeing, reported in the 2021 CWS, were reviewed to identify priorities for additional topics
- The initial 2022 CWS was drafted based on both review of the previous year and addition of topics flagged as important by carers who completed the 2021 survey
- Consultation with key stakeholders (Carers Australia and others) was used to revise the content of the initial questionnaire, with two rounds of consultation and revision.
- Pilot testing of the questionnaire was undertaken in two rounds. First, a small group of 20 people (including both carers and representatives of care provider and carer representative organisations) tested the survey and provided feedback. The revised survey was then tested by a sample of 50 carers selected at random from the 2021 CWS sample.
- Final revision of the questionnaire.

The questionnaire included some measures that are asked in other surveys; these are used to enable comparison of carers to the broader Australian adult population. The CWS User Guide documents the source of each set of questions used, including identifying whether the measure is used in other surveys, original sources of the questions, and whether the question was modified for purposes of use in the CWS. Questions designed specifically for the CWS by the project team are also identified.

The 2022 questionnaire asked about the following annual topics, which are examined each year:

- Caring responsibilities, including number of people cared for, length of time the person had been a carer, needs of care recipients and types of support provided to them, typical hours spent on caring responsibilities each week, and whether caring was provided continuously or episodically
- Health and wellbeing of the carer, using several existing validated measures including the Personal Wellbeing Index, general health measure, Kessler 10 psychological distress scale, and loneliness scale
- Challenging life events experienced in last 12 months, including experiencing loss or change of employment, illness, moving house, financial stress, crime, and changes in caring responsibilities
- Quality of time use, assessing extent to which carers had the ability to achieve desired and healthy levels of sleep, caring, work, exercise, and recreation

- Positive and negative experiences associated with being a carer, using both some existing scales (including a modified version of the Caregiver Burden Scale) and a small number of new questions designed specifically for the CWS
- Ability to identify and access both formal and informal support for the person's role as a carer
- Types of formal support accessed, organisations via which these supports were accessed, and level of satisfaction with these supports
- Socio-demographic characteristics of the carer such as age, gender, employment, type of home lived in, and household structure
- Access to mobile phone reception, internet and transport; some waves of the survey may ask about other services as well
- Open-ended questions asking for other comments about role as a carer.

In addition, as noted in the introduction to this report, the 2022 questionnaire included questions about the following topics:

- Carer choice
- Navigating formal support systems
- Health professionals and health records
- Peer support groups
- COVID-19 impacts
- Transport access.

Carers were given the option of completing a shorter or longer version of the survey if they completed it online. This was done to ensure carers who had limited time could still participate in the survey. Online participants were asked if they wished to complete the short or long version, and told how long each was expected to take to complete. The short version of the survey was designed to take 15-20 minutes to complete, while the longer version took 30 to 60 minutes depending on how many questions were applicable to the person completing the survey. Of the online respondents, 64.9% opted to complete the long survey (compared to 69% in 2021), and 35.1% opted to do the short survey (compared to 31% in 2021).

#### *Survey mode*

Participants could complete the survey online or on a paper form. The paper form was sent directly to carers who did not have an email address (see participant recruitment). Carers could also request a paper survey form by calling a free call number displayed prominently in all materials promoting the survey. In total, 2.4% of survey participants (144 respondents) completed the survey using a paper form; the large majority opted to complete the survey online.

The online questionnaire was translated into simplified Chinese, Arabic, Italian and Vietnamese, selected as the highest prevalence languages other than English spoken by carers based on data from the 2016 ABS *Census of Population and Housing*. Those for whom one of these was a primary language could choose to either complete the survey in English or

in Chinese, Arabic, Italian or Vietnamese. Social media advertisements for the survey were also promoted in these four languages.

### *Participant recruitment*

Survey participants were recruited using the following methods:

- Previous participants: Carers who participated in the 2021 CWS and who had given permission to be contacted about future surveys were invited to take part in the 2022 CWS.
- Regional Wellbeing Survey database: All those who identified being a carer in their responses to the nationwide Regional Wellbeing Survey, and who had given permission to be contacted for other surveys, were invited to take part in the 2022 CWS.
- Care provider organisations: Organisations who provide professional services to carers across Australia were asked to email their clients to request their participation in the survey.
- Carer representative organisations: A number of carer organisations around Australia sent emails to their membership inviting participation, advertised the survey on their websites, and promoted the survey on their social media channels.
- Social media advertising: Paid advertising on Facebook and Instagram was used to recruit carers, including some advertising in the different languages the survey had been translated into.

A prize draw incentive was offered to encourage participants to take part in the survey. Prizes offered were gift cards, with winners able to choose their preferred gift card from a list of options that enabled the winner to choose what was most relevant and meaningful to them, from Coles-Myer cards enabling purchase of groceries through to fashion, to Bunnings gift cards.

These recruitment methods aimed to reach as wide a range of carers as possible. Having multiple recruitment methods help to ensure biases resulting from any one method of recruitment were minimised. For example, it was expected that carers recruited via care provider organisations and carer representative organisations may have more complex and challenging caring needs compared to carers recruited via the Regional Wellbeing Survey (RWS) database. Recruiting via the RWS database, social media advertising and online survey panel enabled a wider sample of carers to be reached.

### *Were survey respondents typical of all types of carers?*

In 2021, it was found that the carers who participated in the CWS were mostly those for whom caring represented a significant part of their day-to-day life. Those who provide only occasional care, or for whom caring duties represent a small part of their life (for example, 1 or 2 hours a week), were much less likely to participate. In 2022, similar participation was observed, although the sample of those who undertook fewer hours of caring each week increased.

### *Survey responses*

There were a total of 5,992 valid responses to the survey. Of these, 5,948 completed the English language version of the survey, while 35 completed the Chinese, 7 the Arabic, and 2 the Vietnamese version of the survey. None completed the Italian language version. It is important to note that the survey did include a significant proportion of respondents whose primary language spoken at home was not English: 921 reported that the primary language spoken in their home was not English and, of these, 32 who opted to complete the survey using the English language version reported that Mandarin/Chinese was their primary language spoken at home, 42 spoke Italian at home, 20 spoke Arabic at home, and 13 spoke Vietnamese at home. This suggests that most of those who spoke Italian at home opted to complete the English language version of the survey, as did the majority of Arabic and Vietnamese speakers; only Chinese speakers were as likely to opt to complete the survey in simplified Chinese as they were to complete it in English.

Of the respondents, 1,063 heard about the survey via direct contact from the University of Canberra (being a previous participant in either the CWS and/or the RWS), 1,499 from a care provider organisation, 2,051 from a carer representative organisation, 1013 from social media advertising, 530 via the Qualtrics online panel and 684 through other means including seeing information about the survey on a website, friends or family. Some participants did not specify how they heard about the survey. As noted earlier, 144 completed the survey using a paper form, while the large majority (97.6%) completed the survey online.

### *Survey weighting*

A process of survey weighting was used to enable production of findings that are representative of carers nationally. The weight was developed by first comparing characteristics of the sample to known characteristics of Australian carers from existing data sources. This comparison is shown in TABLE A3. From this, weights were developed to correct for those types of carers found to be over- or under-represented in the survey responses. For example, the 2016 and 2021 ABS Census and the ABS Survey of Disability, Ageing and Carers (SDAC) all suggest that around 40% of carers are male and around 60% female, although estimates vary by 2-3% across these different sources of benchmark data. In contrast, 16.9% of CWS participants in 2022 were male and 83.1% female. Weights were assigned to address this bias: each female respondent was assigned a weight less than 1 so in analysis their response would count as a smaller proportion of the total, and male respondents a weight above 1 so their responses counted as a higher proportion. The weights assigned mean that the weighted sample findings are representative of a carer population that is 39.8% male and 60.2% female, the distribution identified in the 2021 Census of Population and Housing. This weighting process was used to correct for both intentional over-sampling of states and territories with smaller populations, and Aboriginal and Torres Strait Islander population. It was also used to correct oversampling of carers aged 45 and older and under-representation of those carers under the aged of 45; and to address over-representation of carers with 40 or more hours of caring obligations a week in the sample.

Weights were assigned using the 'Rake Weights' command in IBM SPSS Statistics 27. This uses a raking process to iteratively assign weights. Several sets of benchmark categories were

trialled, until a set of weights with suitable statistical properties was achieved. The benchmarks used are specified in Table A2.

Throughout this report, all data presented have been weighted to be representative of Australia's carers by gender, age, state/territory, Indigenous status, labour force status, and weekly caring hours, unless otherwise specified.

**TABLE A3** COMPARING SURVEY RESPONDENT CHARACTERISTICS TO BENCHMARK CHARACTERISTICS OF AUSTRALIAN CARERS

Characteristics of carers		ABS Census, 2016	ABS Census, 2021 <sup>a</sup>	Survey of Disability, Ageing and Carers, 2018-19	2021 Carer Wellbeing Survey	2022 Carer Wellbeing Survey
Gender	Male	39.6%	39.8%	42.7%	19.3%	16.9%
	Female	60.4%	60.2%	57.3%	80.7%	83.1%
Age group	15-24	7.1%	6.4%	1.8%	3.7%	4.4%
	25-34	11.7%	10.5%	7.2%	5.4%	3.6%
	35-44	16.8%	16.6%	10.2%	11.9%	12.2%
	45-54	22.0%	21.7%	13.9%	19.5%	24.2%
	55-64	22.6%	22.7%	21.2%	26.0%	21.4%
	65-74	13.2%	14.3%	21.2%	22.1%	20.3%
	75+	6.7%	7.7%	15.7%	11.4%	13.9%
Gender by age group	Male, 15-24	3.2%	2.9%	0.8%	1.6%	1.3%
	Male, 25-34	4.5%	4.1%	3.6%	1.3%	0.5%
	Male, 35-44	6.4%	6.3%	4.4%	2.0%	1.0%
	Male, 45-54	8.3%	8.2%	5.0%	2.0%	1.8%
	Male, 55-64	8.5%	8.7%	8.3%	3.3%	2.6%
	Male, 65-74	5.4%	5.8%	8.6%	5.1%	4.2%
	Male, 75+	3.2%	3.8%	7.0%	3.9%	5.4%
	Female, 15-24	3.9%	3.5%	1.0%	1.8%	3.4%
	Female, 25-34	7.2%	6.4%	3.6%	3.9%	2.9%
	Female, 35-44	10.4%	10.3%	5.8%	10.1%	11.0%
	Female, 45-54	13.7%	13.5%	8.9%	17.6%	22.3%
	Female, 55-64	14.1%	14.1%	12.9%	22.6%	18.9%
	Female, 65-74	7.8%	8.5%	12.6%	17.0%	16.2%
	Female, 75+	3.4%	4.0%	8.7%	7.7%	8.4%
State/ Territory	NSW	33.1%	30.7%	32.3%	20.1%	18.9%
	Vic	26.2%	27.8%	26.6%	18.2%	22.5%
	Qld	19.0%	19.4%	20.2%	17.9%	19.8%
	SA	7.9%	7.8%	6.9%	11.7%	13.5%
	WA	9.2%	9.3%	8.8%	16.0%	12.4%
	Tas	2.3%	2.4%	3.0%	10.6%	7.7%
	NT	0.7%	0.7%	0.4%	1.9%	1.8%

Characteristics of carers		ABS Census, 2016	ABS Census, 2021 <sup>a</sup>	Survey of Disability, Ageing and Carers, 2018-19	2021 Carer Wellbeing Survey	2022 Carer Wellbeing Survey
ACT		1.7%	1.8%	1.9%	3.6%	3.4%
Aboriginal & Torres Strait Islanders	Aboriginal and/or Torres Strait Islander	2.8%	3.1% <sup>a</sup>	No data	4.2%	4.5%
	Other	97.2%	96.9%		95.8%	95.5%
Language	English usually spoken at home	77.6%	No data	No data	78.6%	82.0%
	Language other than English spoken at home	22.4%			21.4%	18.0%
Labour force status	Employed	54.6%	No data	Primary carers: 55.7%	43.0%	37.0%
	Unemployed	4.9%		Primary carers 4.7%	4.2%	4.4%
	Not in the labour force	40.5%		Primary carers 39.6%	52.7%	58.6%
Weekly caring hours	<20	No data	No data	45.8%	39.8%	39.1%
	20-39			19.3%	13.9%	14.1%
	40+			34.9%	46.3%	46.8%

<sup>a</sup> Estimates of the proportion of carers from the 2021 ABS Census are based on data published in June 2022 on (i) Unpaid work and care data (ABS 2022a), (ii) Aboriginal and/or Torres Strait Islander data summary tables which included information on the number of Aboriginal and Torres Strait Islanders who reported being carers in the 2021 Census (ABS 2022b), and (ii) Census datapacks that provided data by state and territory on number of carers (ABS 2022c).



Table A2 specifies the benchmark categories used to develop statistical weights for the 2022 CWS, and the source of benchmark data used. Note that in some cases a weight is specified for those who did not provide information. The benchmark data source has been adjusted to enable inclusion of those who did not report some characteristics in the weighting; in all cases, the proportion of these unspecified categories does not exceed the non-response reported in the Census.

**TABLE A2 BENCHMARK DATA SPECIFICATIONS USED TO DEVELOP STATISTICAL WEIGHTS**

	<b>Benchmark data source</b>	<b>Benchmark specifications</b>	<b>Variable name in data set and coding</b>
Gender	ABS Census, 2021, adjusted to provide 'other' gender option	Male - 36.4% Female - 57.8% Other/not specified - 5.8%	bGenderWT 2 = Male 1 = Female 3 = Other/not specified
Age groups	ABS Census 2021, adjusted to enable inclusion of those who opted not to respond (included at less than the reported non-response rate in the Census)	13-34 15.9% 35-44 15.6% 45-64 43.4% 65+ 21.0% Age not specified 4.1%	bAgeWT 1 = 13-34 2 = 35-44 3 = 45-64 4 = 65+ 5 = unspecified
State/Territory	ABS Census 2021, adjusted to enable inclusion of respondents who did not report state of residence	NSW 29.2% Vic 26.3% Qld 18.4% SA 7.3% WA 8.8% Tas 2.4% NT 0.8% ACT 1.8% Not specified 5%	bGEOGSTewt 1 = NSW 2 = Vic 3 = SA 4 = WA 5 = Tas 6 = NT 7 = ACT 8 = Unspecified
Language other than English	2016 Census of Population and Housing	Not used to weight as responses close to benchmark Main language at home not English 20.4% Main language at home English 71.6% Unspecified 8%	bLOTEwt 1 = LOTE 2 = Main language English 3 = unspecified
Aboriginal and Torres Strait Islander	2016 Census of Population and Housing	Not used to weight as responses close to benchmark	bATSIwt 1 = ATSI 2 = other/unspecified

		Aboriginal and/or Torres Strait Islander 3.1% Other/unspecified 96.9%	
Labour force status	2016 Census of Population and Housing	Employed 52.1% Unemployed 4.9% Not in labour force 38.0% Not specified 5%	bLFSwt 1 = employed 2 = unemployed 3 = not in labour force 4 = unspecified
Weekly caring hours	Survey of Disability, Ageing and Carers, 2018-19	<20 hours weekly or varied/ hard to say hours 44.3% 20-39 hours weekly 18.3% 40+ care hours weekly 33.4% Unspecified = 4%	bCareHoursWT 1 = < 20 hours 2 = 20-39 hours 3 = 40+ hours 4 = Unspecified

The resulting weight (variable name WTsample) had a small number of extreme weights, with 4.3% of the sample having a weight of 3.01 or higher, with the highest weight being 17.06. The weight was trimmed to reduce risk of outlier responses creating bias in findings, with weights of 3.01 and above trimmed to a weight of 3.00. This resulted in a trimmed weight, WTsampleTRIMMEDmaxwt3.

## Appendix 2: Detailed data tables

Detailed data tables are available as a Microsoft Excel file. To request the data tables, please email [policy@carersaustralia.com.au](mailto:policy@carersaustralia.com.au).