CARING FOR OTHERS AND YOURSELF

The 2021 Carer Wellbeing Survey

Centre for Change Governance and NATSEM, University of Canberra

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Carers Australia

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Introduction

One in ten Australians – 2.65 million people in 2018 – are carers. If these carers were replaced by paid workers, the care they provide would cost $77.9 billion annually, or almost 1% of Australia's GDP (Deloitte 2020). Almost one million of these are 'primary carers' who have caring duties that make up a significant part of their day-to-day life – for many, being much more than a full time job (ABS 2019).

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.

Carers are responsible for taking care of the welfare of large numbers of vulnerable Australians, providing often challenging and complex caring duties. Past studies have found carers often have lower wellbeing than the average Australian (Schirmer et al. 2016, Carers NSW 2020). We need to know more about how to support the wellbeing of carers, ensuring they have a high quality of life while providing quality of life to the people they care for.

The national *Carer Wellbeing Survey* is addressing this gap. Through an annual survey of Australia's carers, it will build a comprehensive picture of the wellbeing of carers, and how it can best be supported. This report gives findings from the first *Carer Wellbeing Survey*, which surveyed 5,800 carers across Australia during April and May 2021.

Who are Australia's carers?

According to the 2016 ABS Census of Population and Housing, almost half of Australia's carers (45%) are aged between 45 and 64, and 62% between 35 and 64 (Figure E1). Around 20% are aged 65 and older, and 19% are younger than 35. Around 60% of Australia's carers are female, and 40% are male.

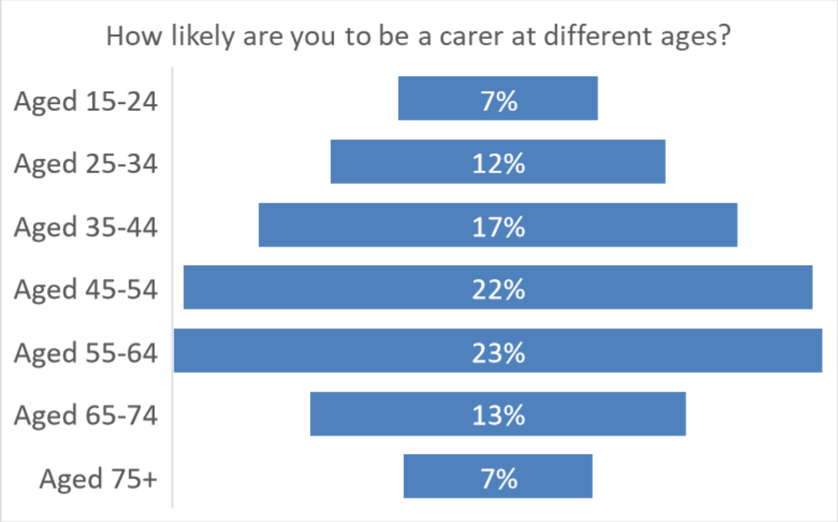


Figure E1: % Australians who are carers, by age group (data source: ABS 2016 Census of Population and Housing)

Carer Wellbeing Survey data collection

The *Carer Wellbeing Survey* was designed in collaboration with Carers Australia. Carers could complete the survey online or using a paper form, and the survey was available in English, simplified Chinese, Arabic, Italian and Vietnamese. As many carers have limited time, they could choose to do a shorter 5-10 minute version of the survey, or a longer version, with 69% choosing to do the long version. Survey participants were recruited through inviting all carers in an existing national survey database to participate, as well as inviting those registered with care providers across Australia, and members of carer's representative organisations, to take part. In addition, social media advertising and online survey panel recruitment were used, and those who participated in the survey could enter a draw to win one of several gift card prizes. 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. A process of survey weighting was used to enable production of findings that are representative of carers nationally. 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.

Wellbeing of Australia's carers

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 (Figure E2).

The wellbeing 'gap' becomes larger as carers get older, and wellbeing is poorest amongst carers aged 45 to 54, amongst whom 66% have low wellbeing.

Carers are at greater risk of low wellbeing if they have more complex, time consuming or otherwise challenging caring obligations: 60% of those caring for a person who needed high or very high levels of assistance with daily functioning had low wellbeing, compared to 38% of those caring for a person with relatively low daily assistance needs.

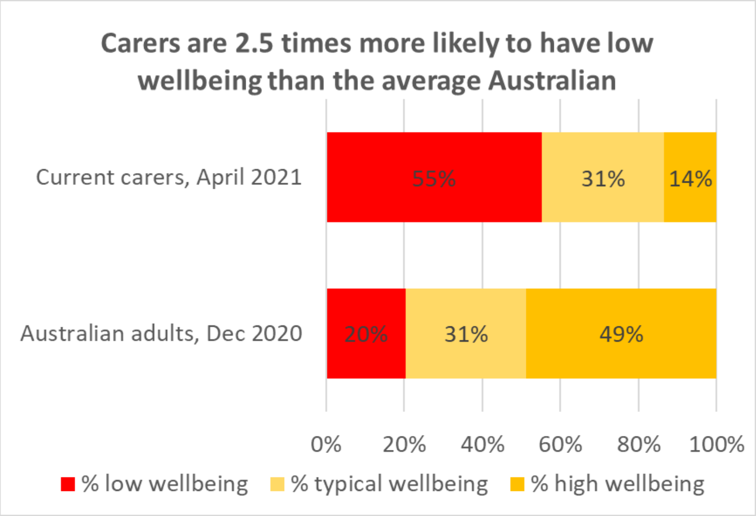


Figure E2 The wellbeing gap between carers and the typical Australian

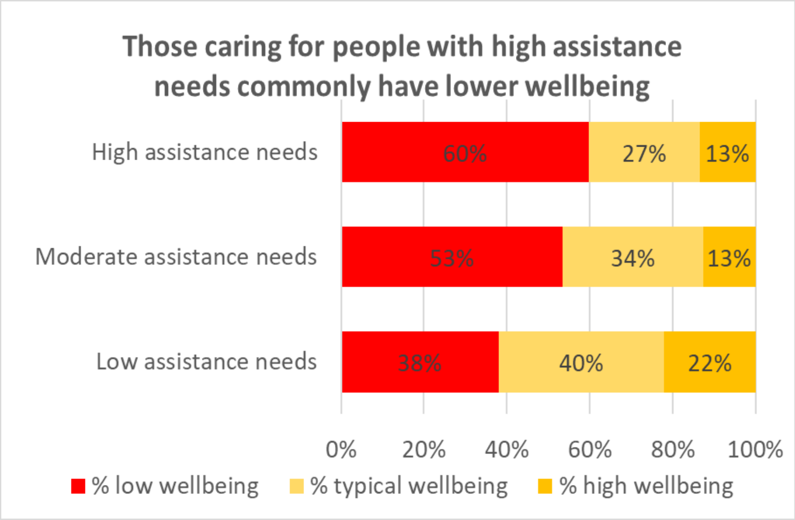


Figure E3 Difference in wellbeing of those caring for people with different levels of daily assistance needs

The wellbeing of carers tend to decrease the longer a person has been a carer, and increase once a person ceases having caring obligations.

Low wellbeing was also more common amongst those caring for a person with autism spectrum disorder (ASD), other development disorders, mental illness/psychosocial disability, drug/alcohol dependency or intellectual disability, and amongst those caring for a child or grandchild.

Psychological distress

The measures of subjective wellbeing presented above examine levels of positive wellbeing. It is also important to examine measures of 'ill being', such as psychological distress. Carers have significantly higher rates of psychological distress than the average Australian. In 2020, the average psychological distress score for Australian adults was 19.3 out of a possible 50. In contrast, the mean score amongst carers was 25.0.

Across all age groups of carers there was a significant 'distress gap' with significantly higher distress levels among carers compared to the average Australian adult. This gap was greatest for carers aged 30 to 44, whose average psychological distress was 6.7 points higher than that of the general population. Younger carers and those with high caring obligations are at greater risk of high psychological distress. So are those caring for a person with a terminal illness, autism spectrum disorder, development disorder, mental illness, drug/alcohol dependency or intellectual disability.

Health of carers

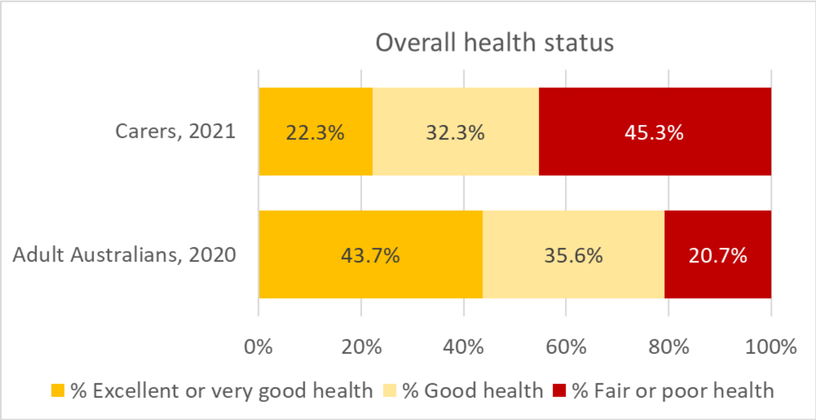


Figure E4 Self-rated health of carers compared to the Australian population

Many carers are managing challenging health problems while also caring for others. Forty-five per cent of carers have poor health, compared to 21% of adult Australians, and 46% have one or more disabilities, health conditions or injuries that restrict their everyday activities. In general, carers are twice as likely to have poor health as other Australians of similar age. Carers with more challenging caring obligations are more likely to have poor health, as are female carers, carers aged 45 to 54, and those caring for a person with ASD, development disorder, mental illness or intellectual disability.

Loneliness and social connection

Having positive social connection with others is important not just for a person’s mental health and wellbeing, but also for their health: a range of physical health issues are more common amongst those who experience high levels of loneliness. Given this, it is important to understand whether carers are able to have the same levels of social connection as other Australians.

Carers are three times as likely as the average Australian to regularly experience loneliness

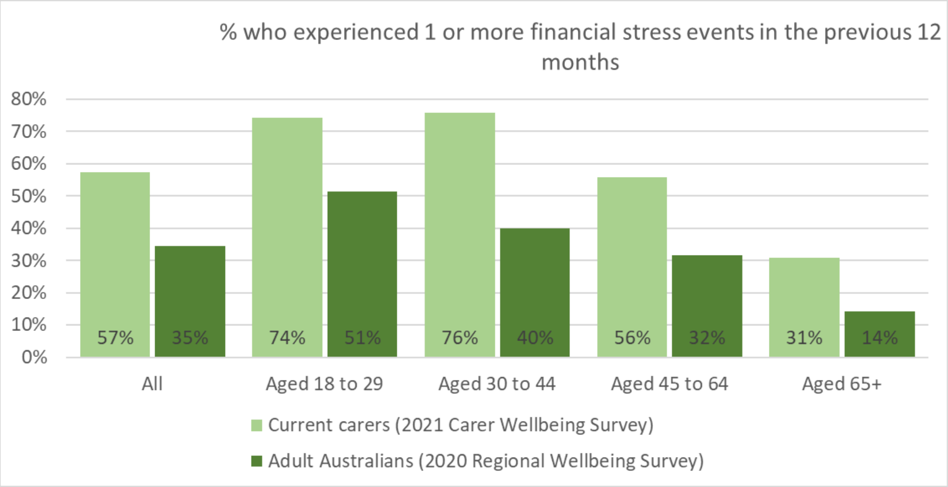
35% of carers often or always feel lonely

Carers were three times as likely as other Australians to regularly experience loneliness, with 35% often or always feeling lonely compared to 11% of Australians.

More than 44% of those caring for a person with high assistance needs, ASD, a development disorder, mental illness or intellectual disability, were frequently lonely. More than 40% of carers aged 35 to 54, and female carers, were regularly lonely. Carers who were older, cared for a person with lower assistance needs, and who spent fewer hours a week caring for others, were less likely to be lonely.

Household finances

On average, carers have poorer financial wellbeing compared to the typical Australian, particularly those aged under 45. More than half of all carers – 52.8% - reported that their household was either very poor, poor or just getting along financially, compared to 33.8% of Australians. Fifty seven per cent of carers had experienced at least one major financial stress event in the last 12 months, such as being unable to pay bills on time, going without heating or cooling, having to delay important purchases, or having to ask for financial help from friends and family. This compared to 35% of Australians more generally in 2020. Three quarters of carers aged under 45 had experienced at least one financial stress event (Figure E5).



Carers were also more likely than average to have experienced one or more financial stress events if they were Aboriginal or Torres Strait Islander; cared for a person with high assistance needs; cared for two or more people; cared for someone with a terminal illness, ASD, other development disorder, intellectual disability, mental illness, or drug/alcohol dependency; or were caring for a child or grandchild.

Housing and telecommunications

Having access to suitable housing and telecommunications can support the quality of life of both carers and the people they care for. Almost one in three carers reported that some parts of their home were difficult to access due to disability or health problems (32.6%), an issue which can reduce effectiveness of the home as a place for high quality caring for both carer and care recipient. Carers who were younger, male, Aboriginal/Torres Strait Islander, or usually spoke a language other than English at home were more likely to report this. Most carers (79.3%) had good mobile phone reception at their home, and almost three-quarters (74.3%) had access to high speed, reliable internet in their home.

Figure E5 % carers experiencing one or more financial stress events

Employed carers

Carers are less likely to be employed than other Australians. Overall, 51.6% of Australian carers were employed, while 4.9% were unemployed and seeking work, and 43.5% were not in the labour force. Carers were more likely to have paid employment if they were younger, and had fewer caring obligations. They were less likely to be in employment if they were older, or had high caring obligations. The longer a person is a carer, the less likely it is that they will be participating in the labour force (Figure E6): 47% of those who had been a carer for five years or more were employed compared to 61% of those who had been a carer for less than a year. When asked if their employer was understanding of their caring obligations 17.2% reported they were not very understanding, 41.6% that they were somewhat understanding, and 41.3% that they were very understanding. Younger carers were more likely than other employed carers to report their employers were not very understanding.

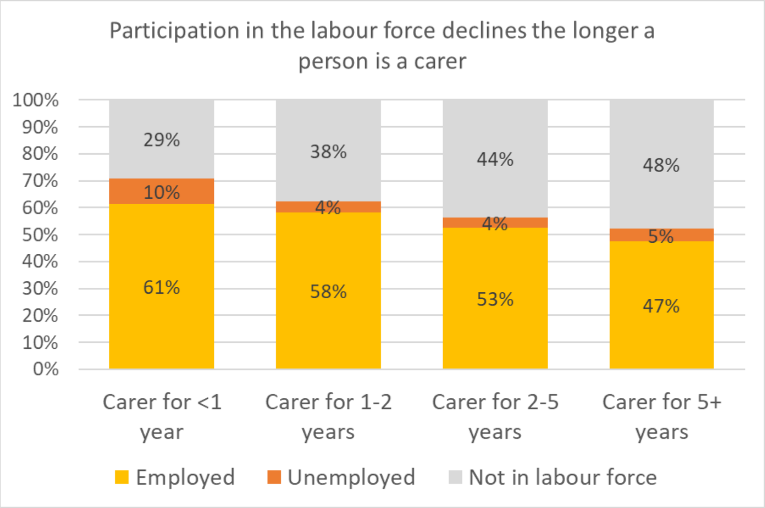


Figure E6 Proportion of carers in the labour force, by number of years they had been a carer

Benefits experienced by carers

Overall, 54.1% of carers found being a carer satisfying, while 26.9% did not. Carers were less likely to find their carer role satisfying if they were female, aged 45-54, or caring for a person experiencing mental illness or drug/alcohol dependency. Those aged 35 to 44 were more likely to report finding being a carer satisfying than other age groups (59.2%). Many carers – 58.6% - felt that being a carer had strengthened their relationship with the people they cared for, while just over one in four (27.1%) disagreed with this. Those caring for a person with dementia, or with drug/alcohol dependency, were less likely to feel their relationship had strengthened than others (50.5% and 47.4% respectively).

Challenges and burdens experienced by carers

Almost all carers reported experiencing multiple types of challenges related to their role as a carer (Figure E7). In particular, 67% regularly feared for the future of the people they cared for; 64% did not usually have time for themselves; between 50% and 57% experienced negative impacts on their social life, finances, and level of control over their life; and more than 40% experienced negative impacts on their own health, and relationships.

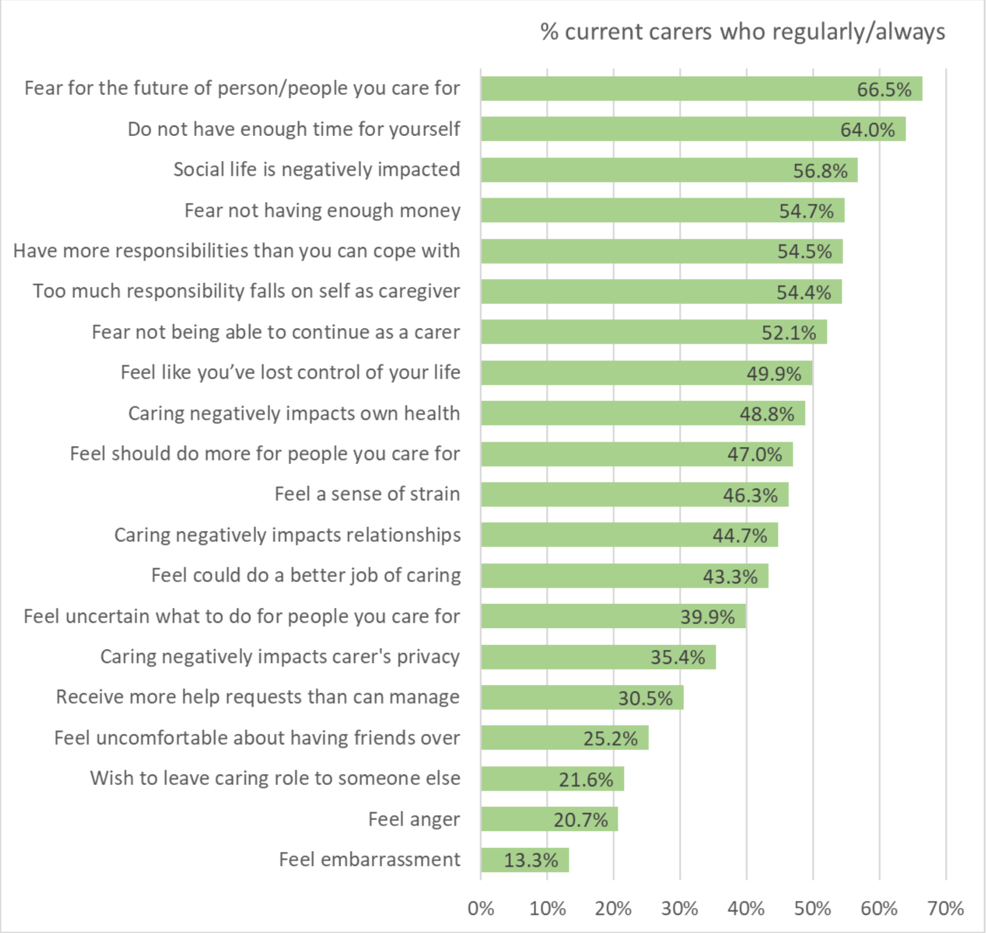


Figure E7 Common challenges experienced by carers

Despite these challenges, very few regularly wished to leave their caring role to someone else (22%), felt anger (21%) or felt embarrassment (13%).

When asked to describe the challenges they experienced in accessing services for the person they cared for, common issues identified by carers were:

- Difficulty finding out about available support services
- Long waiting times to access services
- Lack of availability of services in their local area
- Services being reduced or changed when the person they cared for shifted to NDIS
- Lack of skilled and experienced staff providing services
- Difficulty accessing funding to enable them to access services.
- Complex and confusing processes for accessing support

Confidence in carer role

Supporting the wellbeing of the people they care for requires multiple skills. When asked how confident they were in being able to meet the needs of the people they cared for:

- 67.5% of carers were confident they could provide for physical needs
- 52.5% were confident they could handle unexpected events or emergencies
- 52.3% were confident they could identify and organise access to services needed
- 48.1% were confident they could provide for emotional needs
- 41.0% were confident they could make caregiving activities pleasant
- 33.1% were confident they could cope with the stress of care giving activities.

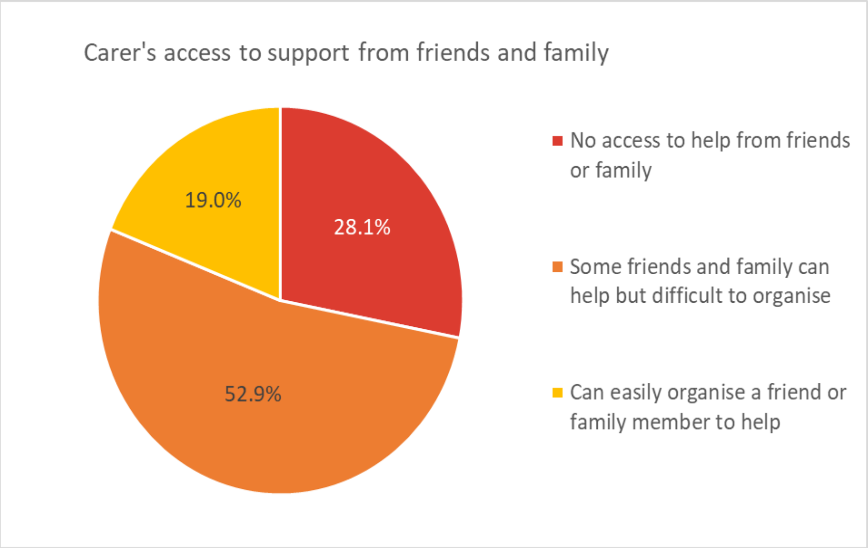


Figure E8 Access to support from friends and family

Access to support from family and friends

Only 19% of carers are able to easily organise a friend or family member to help them in their carer role if they are ill or need a break (Figure E8). More than one in four (28%) have no access to this type of support. Carers aged 45 to 54 were less likely to have access to support than younger or older carers.

In total, 60% had accessed some support from family and friends in the previous 12 months.

Formal supports accessed in previous 12 months

Beyond family and friends, the most common types of supports carer had accessed in the previous 12 months to help them in their caring role were:

- 33% received support from carer support groups or forums
- 31% accessed psychological support for their role as a carer
- 31% accessed respite care services
- 29% received some form of financial support, such as Carer Payment or Carer Allowance
- 22% accessed carer training and skills courses of some type.

Most carers who have access to support are moderately to highly satisfied with the support they received in the last 12 months. However, between 10% and 18% are dissatisfied with the supports accessed. This increases to 23% who are dissatisfied with the financial support they have received.

Carers who have more support have higher wellbeing

Having access to support – whether from family, friends or formal care provision services - is associated with higher wellbeing, particularly for carers who are caring for one or more people with high assistance needs. Amongst those caring for people with high assistance needs – the group at greatest risk of low wellbeing – wellbeing was 10 to 11 points higher if the carer had access to support from family and friends or respite care, and also higher if they had financial support, and access to peer support or training/coaching.

Discussion and conclusions

The first *Carer Wellbeing Survey* has confirmed that carers across Australia are at high risk of poor wellbeing, high psychological distress, and poor physical health. Multiple factors are likely to be contributing to this higher risk. In particular, carers experience much higher levels of social isolation and financial stress than other Australians, as well as often experiencing lack of time for self-care, and a range of complex challenges fulfilling their role as a carer.

Some carers are at higher risk of poor outcomes than others: in particular, carers aged 35 to 54, female carers, those with high weekly caring hours, who have been a carer for many years, care for multiple people, care for a child or grandchild, or care for a person with ASD, development disorder, mental illness/psychosocial disability, intellectual disability, or drug/alcohol dependency. Many of these types of carers have limited access to help from friends and family in their role as a carer, and rely on having access to formal supports.

Many carers have poor access to both informal support from family and friends, and formal support from care service providers. Those who do have access to these types of support have significantly improved wellbeing cared to those without support. This highlights the importance of continuing to identify ways of increasing the availability of both informal and formal support for Australia’s carers.

1. Background

More than 2.5 million Australians provide what is often labelled 'informal' care to people who need assistance due to having a disability, old age, long-term illness or addiction. As of 2018-19, there were an estimated 2.65 million carers in Australia, representing around 10.8% of the population. Of these, 0.86 million were primary carers, meaning they were the primary person responsible for providing assistance to one or more people who needed assistance with core activities related to mobility, self-care and/or communication. A further 1.78 million other carers either assisted primary carers, or provided care to people with fewer assistance needs (ABS 2019).

As of 2020, it was estimated that these carers provide care that would cost $77.9 billion if provided formally by paid care workers. This represents 0.8% of Australia's GDP, and 10.6% of the formal health care budget in Australia (Deloitte 2020).

Despite the significant contribution and large numbers of carers in Australia, relatively little is known about their wellbeing. A large survey of carers conducted nationwide in 2020 found that on average, carers had much lower wellbeing compared to the average Australian, and higher rates of psychological distress (Carers NSW 2020).

This report provides findings of the first national *Carer Wellbeing Survey* (CWS), conducted in 2021. The 2021 CWS was conducted by the University of Canberra's Regional Wellbeing Survey team. It is funded by Carers Australia with support from the Australian Government Department of Social Services.

The CWS aims to understand how the wellbeing of carers is changing over time through an annual survey of carers with results analysed to enable a representative picture of carers across Australia. Specifically, it aims to:

- Understand different dimensions of wellbeing and quality of life of carers and how they are changing. Wellbeing is a broad term, and many things affect a person's quality of life, from their own health to their standard of living and their social networks. The survey examines multiple aspects of wellbeing to better identify which of these are more and less likely to be higher and lower amongst carers.
- Identify whether particular types of caring roles are associated with higher than typical stresses on wellbeing: for example, whether caring for people with different types of needs is typically associated with better or poorer wellbeing.
- Identify whether particular carers are more vulnerable to low wellbeing than others, for example those of different ages, engaging in the workforce, or with health problems of their own.
- Identify which types of carer support best help support the wellbeing of carers and their ability to maintain quality of life for both the person/people they care for and themselves.

This survey adds to the growing body of evidence regarding the needs of carers, joining the national survey conducted by Carers NSW (Carers NSW 2020) and reports on wellbeing of carers produced previously (Schirmer et al. 2016). These existing surveys have pointed to a need for continued investment in better understanding the wellbeing challenges and needs of carers. The CWS seeks to address this need.

The CWS was conducted for the first time in 2021. As such, this report provides an initial baseline from which change over time can be examined. The survey will be repeated annually, providing opportunity to understand how the wellbeing of carers is changing over time.

Surveys are by their nature a snapshot in time that reflects the impacts of events happening at the time the survey is conducted. The 2021 CWS collected data during April and May 2021. This means it was collecting data in the context of the ongoing impacts of the COVID-19 pandemic. During April to May 2021, 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 due to the pandemic, due to having high vulnerability if they became ill. 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.

2. What is a carer?

In this study, a carer is defined as *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*. In most studies, a person is considered a carer if they have provided, or expect to provide, care for six months or more. Carers do not need to live in the same household as the person or people they care for. A person who cares for children is only considered a carer if one or more of the children they care for has a long-term health condition or disability as per the definition above.

This definition is consistent with the definition used in other surveys and studies. However, within this broad definition, there are some differences in how carers are identified. For example, the Australian Bureau of Statistics (ABS) *Census of Population and Housing* does not define the length of time a person has been a carer for, simply asking if in the last two weeks a person spent 'time providing unpaid care, help or assistance to family members or others because of a disability, a long term health condition or problems related to old age' (ABS 2016).

The ABS *Survey of Disability, Ageing and Carers* (SDAC), meanwhile, differentiates between primary and other carers, with primary carers defined as 'a person who provides any informal assistance (help or supervision) to people with disability or older people (aged 65 years and over). The assistance must be ongoing, or likely to be ongoing, for at least six months' (ABS 2019). The SDAC further defines a primary carer as someone aged 15 or over for provides assistance for one or more core activity needs of:

- Mobility e.g. physical movements
- Self-care e.g. dressing, toileting, eating, drinking, and/or
- Communication.

The SDAC defines all carers who do not meet the definition of a primary carer as 'non-primary carers'. This study includes both those carers defined as primary and non-primary carers in the SDAC. Both primary and non-primary carers may provide non-core forms of assistance including assistance with:

- Health care
- Cognitive or emotional tasks
- Household chores
- Property maintenance
- Meal preparation
- Reading or writing
- Transport.

Many studies use the term 'informal carers', to reflect that they focus on those people who provide care not as their formal paid employment, but as a family member or friend to the person being cared for. Throughout this report, the term 'carer' is used to mean an informal carer who provides unpaid care, with the only financial payment received (if any) being government carer support payments such as the Carer Payment or Carer Allowance, or financial grants to support purchasing items needed by carers. A person who provides paid caring services in the course of their paid employment is not considered to be an informal carer, and is not included in the group referred to as ‘carers’ in this report.

3. Carers in Australia: numbers and types

The CWS aims to understand the quality of life carers have and how their caring obligations affect their quality of life, and the extent to which they have access to effective supports in their role as a carer. This section provides a brief overview of what is currently known about carers in Australia from existing data.

Three recent sources of data were drawn on to profile Australian carers:

- The ABS Survey of Disability, Ageing and Carers (DSAC): in this survey, 21,983 households were surveyed in 2018-19 and those with disabilities and carers residing in the households asked questions about these roles. Data produced include information on types of caring responsibilities and hours spent providing care (ABS 2019).
- The Australian Bureau of Statistics (ABS) *Census of Population and Housing* (Census): the CPH asks all households in Australia to report whether members of their households are carers, using the definition provided in Section 2. This enables examination of carers by their socio-demographic characteristics, such as age, gender and language spoken at home. However, the Census does not identify information about the types of caring role a person has, hours spent caring, or other information (ABS 2016, 2018).
- The 2020 National Carer Survey (NSW Carers 2020). The National Carer Survey sampled a large number of carers across Australia. This survey provides important insights into aspects of carer's experiences that are not available from other sources of data. However, the sample collected is not weighted to provide nationally representative findings, meaning this data source cannot be used to estimate numbers of carers by type at a national scale.

The 2019 ABS DSAC estimated that across Australia, 10.6% of those aged 15 and over were carers, of which 3.5% were primary carers (defined as a person who provided primary care for a person needing assistance with one or more core activities related to mobility, self-care or communication), and 7.1% not primary carers (either not providing the main care for a person, or providing care not related to core activities) (ABS 2019). In addition, a further 0.2% of the population were carers who were younger than 15 (Figure 1). The ABS Census had a similar estimate, with an estimated 12.5% of all Australians aged 15 and over identified as being carers, with a carer defined as a person who spent time in the two weeks prior to the Census 'providing unpaid care, help or assistance to family members or others because of a disability, a long-term health condition or problems related to old age' (ABS 2018).

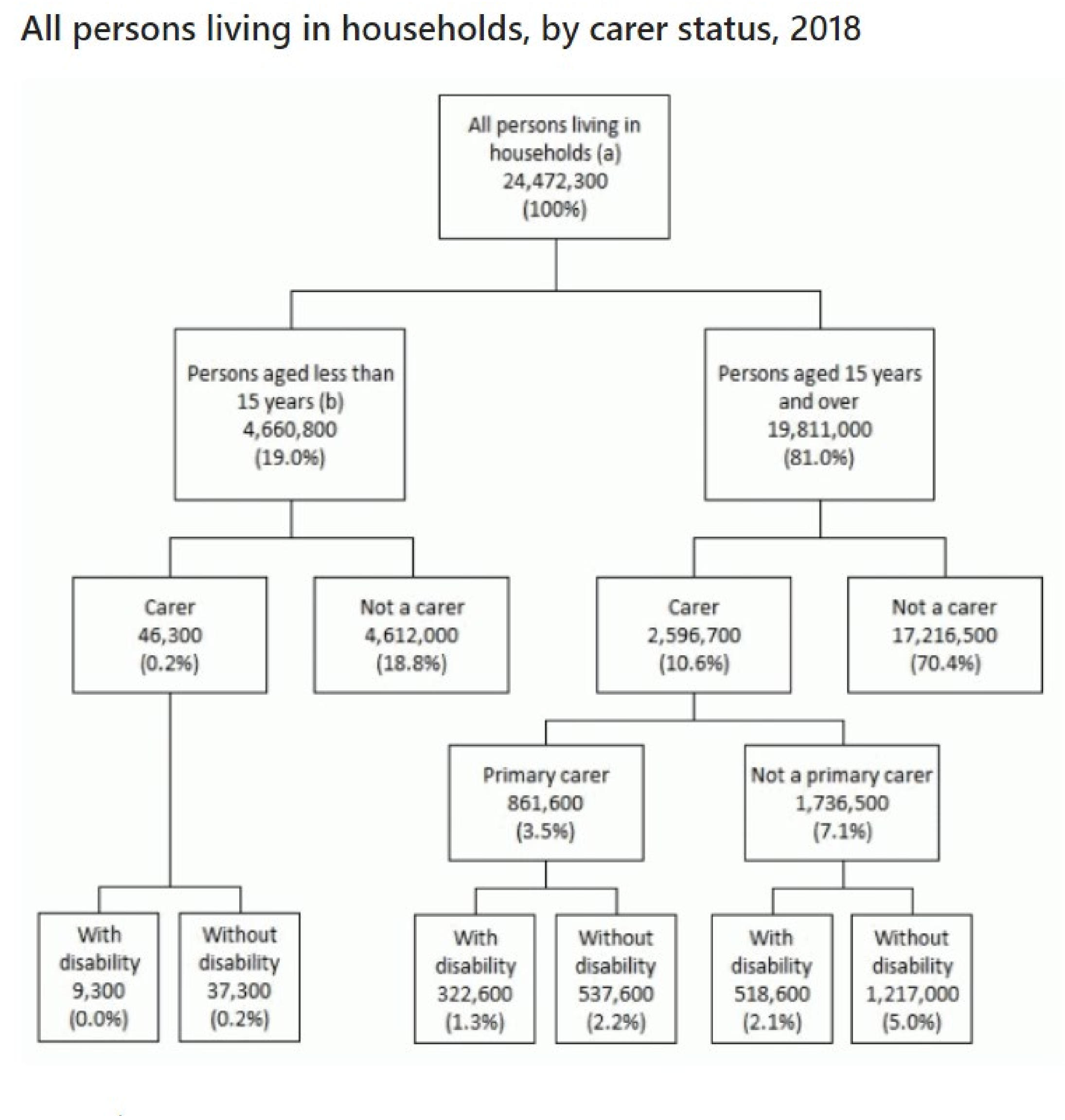


Figure 1 Estimates of the carer population in Australia, Survey of Disability Ageing and Carers (Source: ABS 2019)

Women are more likely than men to be carers, at all stages of life (Figures 2 and 3). While there is some difference in estimates between the Census and the SDAC, the proportion of people who are carers is highest amongst those aged 45 to 74, particularly for women, and lowest amongst those aged under 35.

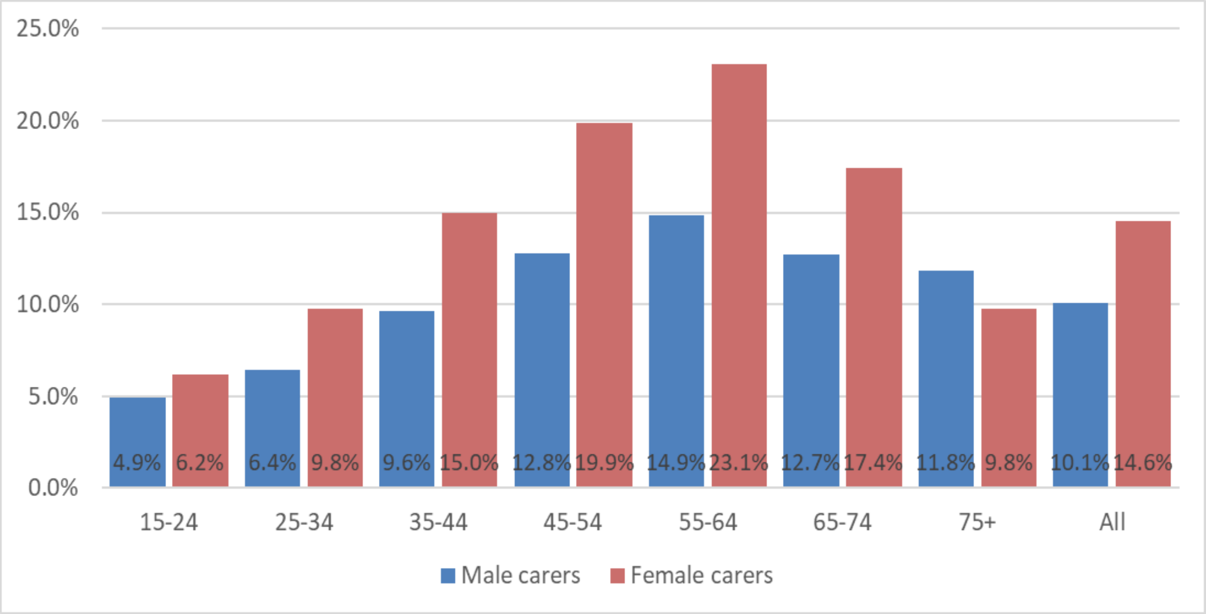


Figure 2 Proportion of population who are carers, by age and gender – 2016 ABS Census (ABS 2018)

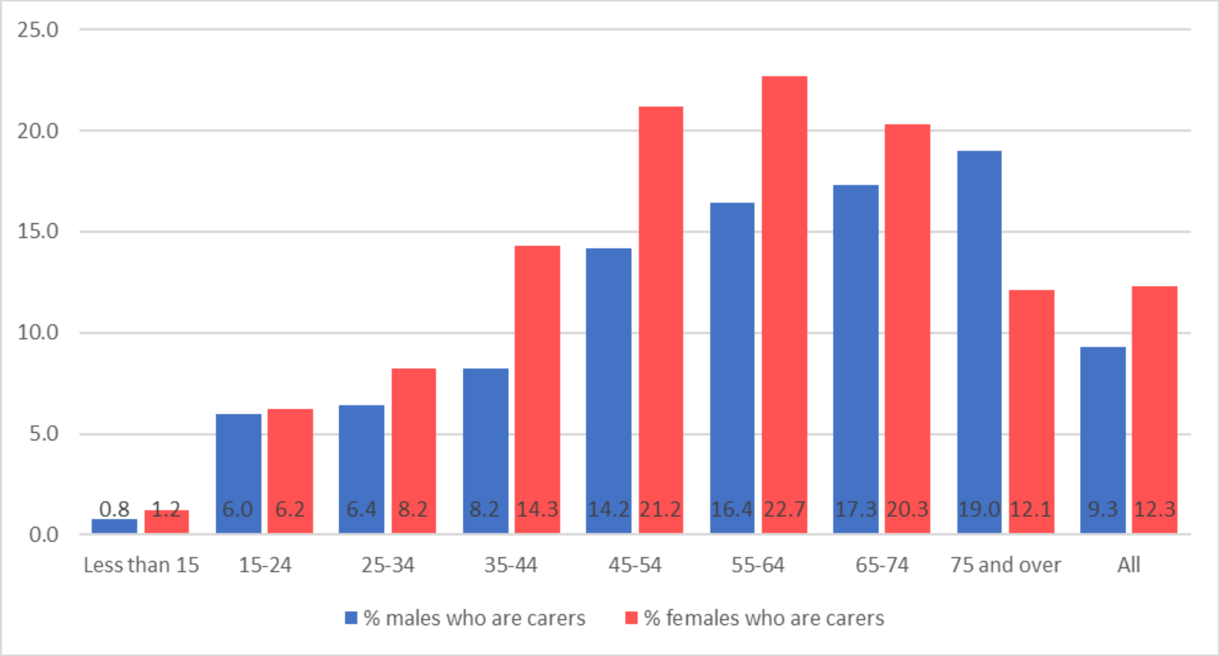


Figure 3 Proportion of population who are carers, by age and gender – 2018-19 SDAC (ABS 2019)

The differing proportion of people who are carers means that 60.4% of all carers are female, and 39.6% male. Of all carers, less than 20% are aged 15-34, while over 40% are aged between 45 and 64 (Table 1).

Table 1 Proportion of carers in different age groups, by gender

	ABS Census (ABS 2018)		ABS SDAC (ABS 2019)	
Age group	**Male carers**	**Female carers**	**Male carers**	**Female carers**
15-24	3.2%	3.9%	3.6%	3.6%
25-34	4.5%	7.2%	4.4%	5.8%
35-44	6.4%	10.4%	5.0%	8.9%
45-54	8.3%	13.7%	8.3%	12.9%
55-64	8.5%	14.1%	8.6%	12.6%
65-74	5.4%	7.8%	7.0%	8.7%
75+	3.2%	3.4%	5.0%	3.8%
All age groups	39.6%	60.4%	42.7%	57.3%

Carers therefore have quite different characteristics to those of the general Australian population. This is important when considering their wellbeing, as studies of wellbeing have identified that wellbeing typically follows a ‘U-shaped’ curve through the life: younger people have higher wellbeing; wellbeing then declines and reaches a low point between the aged of 35 and 55, before wellbeing levels increase again, typically being high through to at least the age of 70. There is more conflicting evidence regarding wellbeing beyond the age of 70 (Blanchflower 2021). This existing evidence, combined with data on prevalence of caring responsibilities at different points in a person’s life, suggests that many people are likely to be carers at the point in life where wellbeing is already likely to be lower than at other stages of life. It is important to identify whether the caring role changes this typical pattern of wellbeing through the lifespan.

4. Methods

This section briefly describes the methods used to collect and analyse data in the 2021 CWS. A detailed report documenting the specific methods used in each wave of the survey, providing the survey questionnaire items and other relevant information will be produced and added to each year (Schirmer and Miranti 2021).

Questionnaire design

The CWS questionnaire, was designed in a multi-stage process:

- Existing carer survey instruments were reviewed for potential inclusion in the survey, including validated scales relevant to understanding wellbeing of carers.
- Proposed questionnaire content was developed by the research team.
- 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 80 carers selected at random from the Regional Wellbeing Survey database of carers (see participant recruitment section).
- Final revision of the questionnaire.

The questionnaire was designed to collect data that would enable comparison of carers to the broader Australian adult population. To do this, several measures of health and wellbeing used in multiple existing Australian and international surveys were included in the instrument. In addition, some existing carer survey instruments were drawn on to measure aspects of wellbeing specific to carers, particularly carer burden. Some questions were designed specifically for the survey, and were asked for the first time in the 2021 survey.

Each year, the CWS will repeat key measures, enabling measurement of change over time. Each year the CWS will also include ‘special topics’ that investigate specific aspects of carer wellbeing in more depth, with these special topics varying each year.

The questionnaire asked about the following topics:

- Caring responsibilities, including number of people cared for, length of time the person had been a carer, needs of care recipients, and typical hours spent on caring responsibilities each week
- 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 (see Schirmer and Miranti 2021 for documentation of scales used).
- 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
- Open-ended questions asking about overall challenges experienced in accessing support as a carer, and about other topics carers wanted to have recognised and examined in the CWS in future.

Many carers have very limited time, and may be unable to complete a long questionnaire. Given this, the questionnaire was designed to give carers choice regarding the length of survey they wished to complete. Those completing the survey online (the majority of participants) were asked if they wished to complete a shorter or longer version of the survey. The short version of the survey was designed to take 5-10 minutes to complete, while the longer version took 15 to 30 minutes depending on how many questions were applicable to the person completing the survey. In total, 69% of respondents opted to complete the long version of the survey, while 31% opted to complete the short version of the survey.

Survey mode

Participants could complete the survey online or on a paper form. The online survey used the Qualtrics online survey platform. 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*. The paper form was sent directly to some 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.

Participant recruitment

Survey participants were recruited using the following methods:

- Existing database: An existing database of carers held by the University of Canberra was used to recruit participants. This was the Regional Wellbeing Survey database: the Regional Wellbeing Survey is an annual survey, in which all participants are asked to identify whether they are a carer. Of the 21,000 people surveyed in 2020, all those who identified they were carers and gave permission to be contacted for a subsequent survey were invited to take part in the survey.
- 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 further recruit carers.
- Online survey panel: The Qualtrics online panel service was used to recruit a sample of carers.

A key goal of participant recruitment was to ensure sufficient sample to enable reporting for every Australian State and Territory. This required deliberate over-sampling in States and Territories with smaller populations, specifically in the Northern Territory, Australian Capital Territory, and Tasmania. Similarly, carers identifying as Aboriginal and/or Torres Strait Islander, and from other culturally and linguistically diverse backgrounds, were deliberately over-sampled to ensure it would be possible to specifically analyse the experiences of carers in these groups. The sampling done via the online panel, social media advertising, and carer organisations was designed to result in a sample that achieved sufficient representation of these regions and groups to enable analysis of their experiences.

A prize draw incentive was offered to encourage participants to take part in the survey. Multiple studies have found that providing incentives both increases participation in surveys, and when designed appropriately, can reduce the impacts of some types of survey response bias. In particular, incentives can reduce the risk of salience bias – the risk of over-representation of those with a very strong interest in a topic and under-representation of those with little or no interest (see for example Singer and Ye 2012). All those who completed the survey could enter a draw to win one of several prizes. 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?

The definition of carers given earlier in this report is inclusive of the full range of people who have a role as a carer, from those with very limited caring obligations who may not view themselves as being a carer, through to those with very high caring obligations for whom their primary role is being a carer for one or more other people.

While the definition of carer used in this survey covers this full spectrum, it was expected that a survey calling for participation of carers may be more likely to achieve participation from those carers for whom caring is a significant part of day to day life, and less likely to achieve participation of those for whom caring is an occasional or relatively insignificant role. Thus the sample was expected to be largely composed of carers who have a caring role that comprises a significant part of their day to day life, and to largely exclude those who have a relatively limited caring role that is a minor part of their life compared to other activities.

This hypothesis was tested by comparing the characteristics of carers from the RWS database who were invited to complete the survey, with those who chose to respond to this invitation. This comparison identified that, amongst those invited from the RWS database, those who chose to respond were typically carers with more significant caring obligations (for example, higher numbers of caring hours per week, or who were the person primarily responsible for care). Those who chose not to respond were predominantly those who were secondary carers with a limited role in providing caring duties, or who otherwise had a caring role that did not take up a significant part of their day-to-day life.

This means that the findings presented in this report should be considered to be representative of 'carers with significant caring obligations' – meaning carers for whom their caring role is a significant part of their day-to-day life. The sample largely excludes those who provide a very small number of hours of caring each week, for example those assisting for 2-3 hours a week as a secondary carer.

Survey responses and weighting

Survey responses were cleaned to remove invalid and duplicate responses. After this process, there was a total of 5,808 valid responses to the survey. Of these respondents, 1,010 heard about the survey via the RWS database, 1,170 from a care provider organisation, 1,530 from a carer representative organisation, 1,005 from social media advertising, 530 via the Qualtrics online panel and 250 from other methods such as a person hearing about the survey via friends or family. Some participants did not specify how they heard about the survey.

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 2. 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 ABS *Census* found that 39.6% of carers were male and 60.4% were female, while the 2018-19 SDAC found that 42.7% were male and 57.3% female. When compared to this known distribution, CWS survey respondents were biased to female carers, with 80.7% of respondents being female and 19.3% male. To address this, the weighting process assigned each female respondent 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 40.7% male and 59.3%. 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.

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 2 Comparing survey respondent characteristics to benchmark characteristics of Australian carers

Characteristics of carers		ABS Census, 2016	Survey of Disability, Ageing and Carers, 2018-19	2020 Carer Wellbeing Survey respondents
Gender	Male	39.6%	42.7%	19.3%
	Female	60.4%	57.3%	80.7%
Age group	15-24	7.1%	1.8%	3.7%
	25-34	11.7%	7.2%	5.4%
	35-44	16.8%	10.2%	11.9%
	45-54	22.0%	13.9%	19.5%
	55-64	22.6%	21.2%	26.0%
	65-74	13.2%	21.2%	22.1%
	75+	6.7%	15.7%	11.4%
Gender by age group	Male, 15-24	3.2%	0.8%	1.6%
	Male, 25-34	4.5%	3.6%	1.3%
	Male, 35-44	6.4%	4.4%	2.0%
	Male, 45-54	8.3%	5.0%	2.0%
	Male, 55-64	8.5%	8.3%	3.3%
	Male, 65-74	5.4%	8.6%	5.1%
	Male, 75+	3.2%	7.0%	3.9%
	Female, 15-24	3.9%	1.0%	1.8%
	Female, 25-34	7.2%	3.6%	3.9%
	Female, 35-44	10.4%	5.8%	10.1%
	Female, 45-54	13.7%	8.9%	17.6%
	Female, 55-64	14.1%	12.9%	22.6%
	Female, 65-74	7.8%	12.6%	17.0%
	Female, 75+	3.4%	8.7%	7.7%
State/ Territory	NSW	33.1%	32.3%	20.1%
	Vic	26.2%	26.6%	18.2%
	Qld	19.0%	20.2%	17.9%
	SA	7.9%	6.9%	11.7%
	WA	9.2%	8.8%	16.0%
	Tas	2.3%	3.0%	10.6%
	NT	0.7%	0.4%	1.9%
	ACT	1.7%	1.9%	3.6%
Aboriginal & Torres Strait Islanders	Aboriginal and/or Torres Strait Islander	2.8%	No data	4.2%
	Other	97.2%		95.8%
Language	English usually spoken at home	77.6%	No data	78.6%
	Language other than English spoken at home	22.4%		21.4%
Labour force status	Employed	54.6%	Primary carers: 55.7%	43.0%
	Unemployed	4.9%	Primary carers 4.7%	4.2%
	Not in the labour force	40.5%	Primary carers 23.3%	52.7%
Weekly caring hours	<20	No data	45.8%	39.8%
	20-39		19.3%	13.9%
	40+		34.9%	46.3%
Weekly caring hours by gender	Male, <20	No data	48.4%	44.8%
	Male, 20-39		20.4%	14.6%
	Male, 40+		31.3%	40.5%
	Female, <20		44.8%	38.6%
	Female, 20-39		18.7%	13.7%
	Female, 40+		36.5%	47.7%

5. Findings

The findings of the 2021 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 whether different types of carers have differences in their wellbeing and support needs. Table 3 describes the groups of carers that are compared.

Not every difference between groups of carers will be significant: some differences, particularly small ones, are more likely to be the result of sampling variance than of significant differences between groups. 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 tells you the boundaries between which, statistically, 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 general, confidence is higher if there is a large sample size and little deviation in responses (for example, almost all people answered ‘4’ on a scale of 1 to 7). Confidence is lower if there is a small sample size and high deviation (for example, equal numbers of people answered 1, 2, 3, 4, 5, 6 and 7 on the 7-point scale). In all cases. 95% confidence intervals were used. While confidence intervals provide a useful way of understanding how reliable the results are likely to be, they are not perfect. Confidence interval calculations assume that data are normally distributed, and a representative sample has been achieved. If these conditions are not met, the confidence interval may not be an accurate representation of confidence.

As large amounts of data are presented in this report, rather than presenting confidence interval ranges (which would require increasing the length of the report substantially), **bold** numbers are used in tables to indicate where 95% confidence intervals indicate that a particular group of carers differ significantly to the average Australian carer. When figures are presented, error bars are used to show the confidence interval ranges. The full sets of data tables underpinning these results, including specific confidence interval ranges, are available from the authors on request.

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 and psychological distress (Section 5.1)
- Health (Section 5.2)
- Loneliness and social connection (Section 5.3)
- Financial wellbeing (Section 5.4)
- Housing and telecommunications (Section 5.5)
- Employment (Section 5.6)
- Benefits associated with being a carer (Section 5.7)
- Challenges and burdens associated with being a carer (Section 5.8)
- Confidence in carer role (Section 5.9)
- Access to formal and informal support in role as a carer (Section 5.10).

Table 3 Groups of carers compared in this report

Carer group	Categories compared (total sample size provided in brackets)	
Current carers	All	
Current carers - by gender[1]	Male Female	
Current carers- by age group	Aged 15-24 Aged 25-34 Aged 35-44 Aged 45-54	Aged 55-64 Aged 65-74 Aged 75+
Current carers by typical weekly caring hours	<20 hours per week 20-39 hours per week 40+ hours per week	
Current carers – by cultural background	Aboriginal/Torres Strait Islander Usually speaks language other than English at home Usually speaks English at home	
Current carers – by state/ territory[2]	New South Wales Victoria Queensland South Australia	Western Australia Tasmania Northern Territory Australian Capital Territory
Current carers – by number of people cared for	Care for one person Care for two people Care for three or more people	
Care recipient caring needs[3]	Dementia Old-age related frailty Terminal illness Autism spectrum disorder Other developmental disorder Mental illness/psychosocial disability	Drug/alcohol dependency Physical disability Intellectual disability Chronic non-terminal illness or injury Short-term (<6 months) illness/injury
Care recipient level of assistance required	Low needs Low-moderate needs Moderate needs	High needs Very high needs
Care recipient residence	Care recipient resides with carer Care recipient lives elsewhere	
Carer relationship with care recipient	Care for child/grandchild Care for partner Care for parent/grandparent	Care for sibling Care for other relative or friend
Length of caring responsibility	Carer for 5 or more years Carer for 2-5 years Carer for 1-2 years Carer for <1 year	
Labour force status	Employed Unemployed (actively looking for work) Not in labour force	
Primary carer	Primary carer for one or more people Not primary carer for any person	
Sole carer	Sole carer with no assistance Carer with assistance	
Past carer	All Ceased caring in last 6 months Ceased caring 7-12 months previously Ceased caring more than 1 year ago	

[1] The sample of non-binary carers achieved was too small to report findings for non-binary carers.

[2] The sample achieved in the Northern Territory was small compared to other States and Territories and confidence is often low in findings for the NT as a result of this low sample size.

[3] In many cases, the person or people cared for had more than one of these caring needs.

5.1 Wellbeing and distress

The wellbeing of carers was examined using two commonly used measures of subjective wellbeing:

- Global Life Satisfaction: This is measured using a single question in which a person is asked to rate their satisfaction with their life as a whole from 0 (completely dissatisfied) to 10 (completely satisfied). Answered are then calculated as a score from 0 to 100. This measure allows a person to evaluate their life as a whole based on what is most important to them.
- Personal Wellbeing Index: This is a 7-item measure in which a person rates their satisfaction with seven aspects of their life, using a scale from 0 (completely dissatisfied) to 10 (completely satisfied). The seven aspects of life they rate are their standard of living, health, what they are currently achieving in life, personal relationships, how safe they feel, feeling part of the community, and their future security. The 7 items are combined into a scale scored from 0 to 100 using a standardised methodology (IWB 2013).

These two measures of wellbeing are both commonly used to measure wellbeing both in Australia and internationally. This regular use means there is robust information on how to best use and interpret these measures, including how they can be compared across different surveys. In particular, it is know that average scores vary depending on whether a person completes the survey by talking to another person (e.g. by a phone interview or face to face), or as a self-complete survey (online or on a paper form). This ‘survey mode effect’ has been shown to be important for any wellbeing measure, with people who answer questions online or on a paper survey without directly interacting with another person likely to give slightly more negative ratings of wellbeing and quality of life, and those who answer questions asked by an interviewer (by phone or face-to-face) likely to give slightly more positive ratings, although findings vary depending on the measure and the mode being compared (Christensen et al. 2014, Dolan and Kavetsos 2016).

As the CWS is conducted using a self-completion approach, findings on wellbeing should only be compared to other data sources that also use self-completion surveys to collect data. They are not comparable to data collected using a phone survey or face to face interview, which will result in higher wellbeing scores. Given this, findings here are compared to those from the Regional Wellbeing Survey (Schirmer et al. 2021) which surveyed 20,000 people across Australia in late 2020, using the same survey modes to collect data as were used in the CWS. This provides a valid comparison.

Australian carers (those currently caring for one or more people) had an average wellbeing score of 53.1 for Global Life Satisfaction and 54.6 for the Personal Wellbeing Index. These scores indicate high prevalence of low wellbeing amongst carers. Across Australia, the average adult in 2020 had a mean score of 70.4 for both Global Life Satisfaction and the Personal Wellbeing Index (Schirmer et al. 2021). Across Australia, 27.0% of adults had a low wellbeing score in 2020; in comparison, 55.3% of carers reported low wellbeing. This means that carers have significantly lower wellbeing than the typical Australian. In particular, carers are twice as likely as the average Australian adult to have low levels of wellbeing. As shown in Figure 4, there is a 15.8 point ‘wellbeing gap’ between carers and the typical adult Australian. This gap is present for carers in all age groups but appears to increase with age, ranging from a gap of 11 points amongst those aged 18 to 29, to 21.7 points for those aged 65 and older.

Figure 4 Wellbeing of carers in April/May 2021 compared to adult Australians in Nov/Dec 2020 – by age group

There is a larger wellbeing gap for female carers compared to male carers (Figure 5): female carers had wellbeing 18.8 points lower than the average for adult women across Australia, while male carers had wellbeing that was on average 14.3 points lower than the typical adult Australian male in 2020.

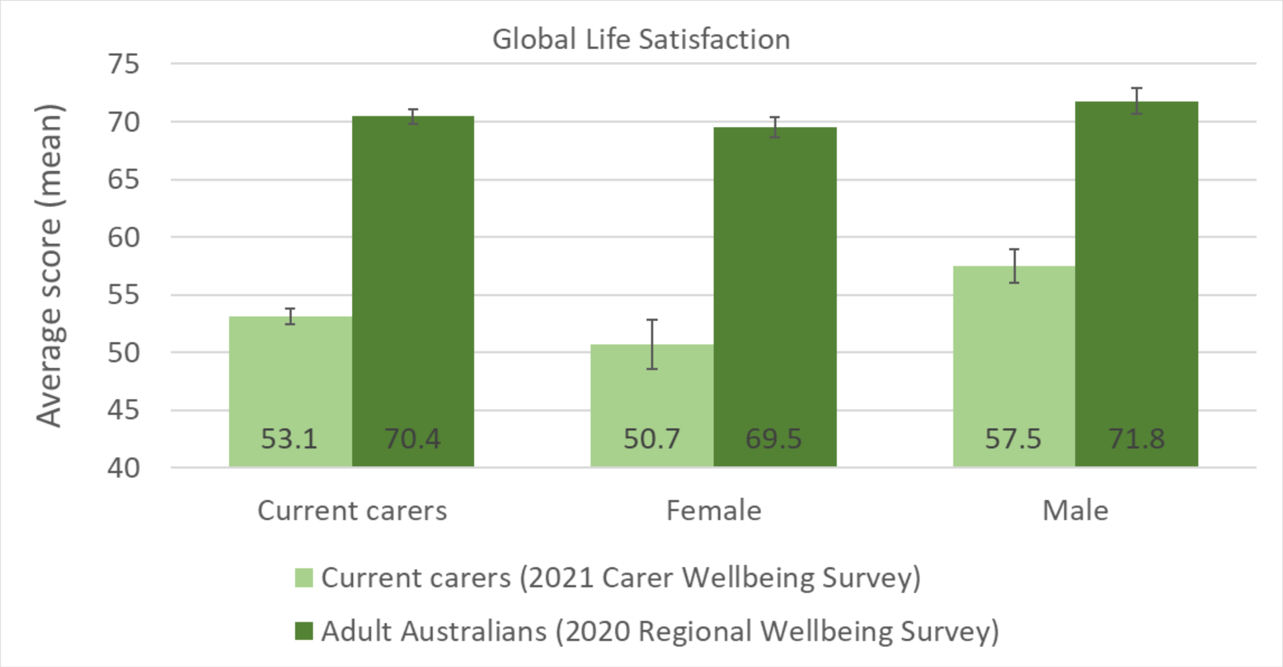


Figure 5 Wellbeing of carers in April/May 2021 compared to adult Australians in Nov/Dec 2020 – by gender

Detailed data on the wellbeing of different groups of Australian carers is provided in Tables 4 and 5. These tables demonstrate that those with more demanding caring obligations in general are more likely to have low wellbeing. For example, those who were not a primary carer had wellbeing 10 points higher than those who were a primary carer. This is consistent with differences in findings for the carers participating in the CWS and the broader set of people with caring obligations in the Regional Wellbeing Survey. Carers who participated in the Regional Wellbeing Survey – who as noted in the previous section include a large proportion of carers for whom their caring role is a relatively small proportion of their daily or weekly life – had higher wellbeing on average than CWS participants. The RWS carers had an average wellbeing score of 63.1 (Schirmer et al. 2021), higher than the average score of 53.1 amongst the CWS participants for whom caring was a significant part of daily life. Both the differences between those with greater and lesser caring obligations in the CWS, and between the sample of all carers including those with minor caring obligations in the RWS, and those in the CWS, highlight that greater caring obligations are often associated with poorer wellbeing for the carer.

These findings are consistent with past studies. The 2020 National Carer Survey measured the Personal Wellbeing Index, and found carers of all types (including past carers and current carers) had a mean wellbeing score of 57.2. While this finding suggests higher wellbeing than that found for current carers in 2021, this difference is likely due to differences in the types of carers included in the two figures. The National Carer Survey average score of 57.2 is the average for both current and past carers who responded to that survey. The CWS score of 53.1 includes only people who at the time of the survey were active carers; those who had been carers in the recent past are not included in this group, with findings for past carers presented separately in Table 5. As shown in Table 5, past carers have significantly higher wellbeing than current carers, suggesting that once the caring role ceases, wellbeing increases. Thus it is important to measure the wellbeing of current carers and past carers separately.

The findings also provide evidence consistent with the argument that the lower wellbeing of carers is likely to in large part be a consequence of the impacts of their caring obligations. As shown in Figure 6, wellbeing scores tend to decrease the longer a person has been a carer, and increase once a person ceases having caring obligations. By the time a person has had more than 12 months since they stopped being a carer, wellbeing levels are close to the average for all adult Australians.

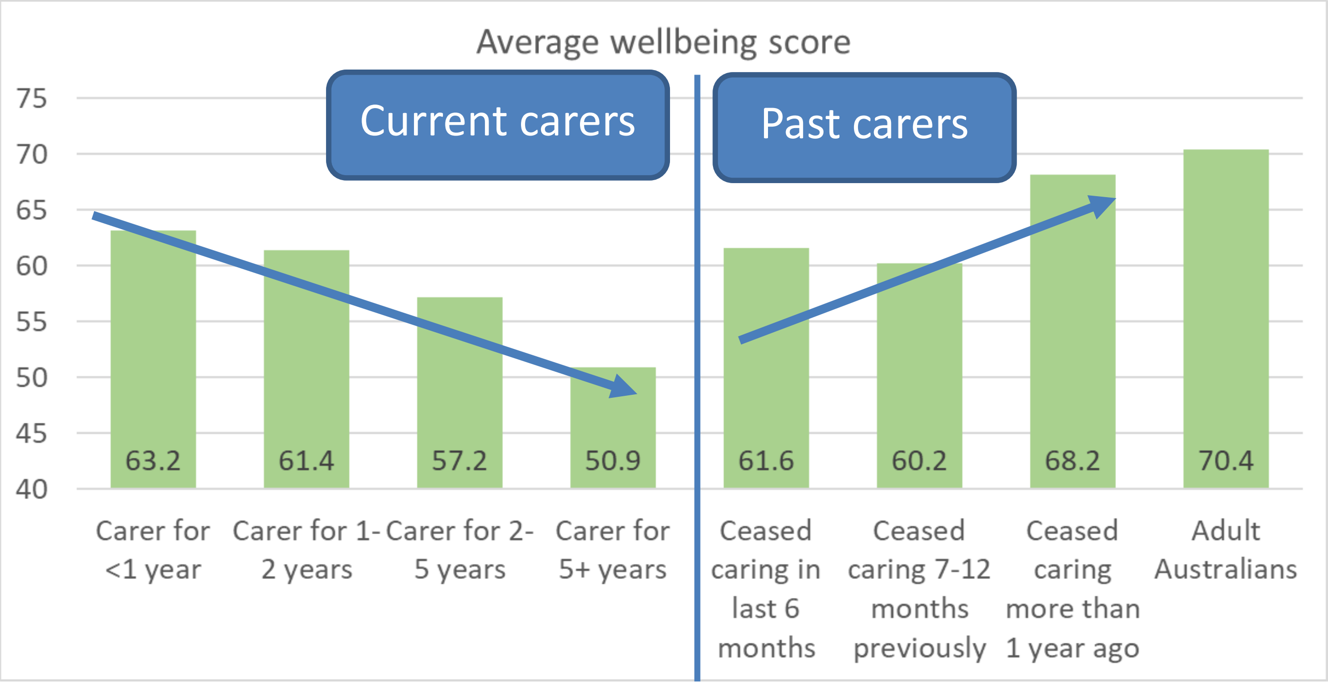


Figure 6 Average levels of subjective wellbeing by length of time person has been a carer

As shown in Tables 4 and 5, wellbeing varied significantly depending on the type of carer. Low wellbeing was more common amongst carers who had:

- higher caring obligations in the form of high caring hours, being a primary or sole carer, or being a carer for a longer period of time
- those caring for a person with autism spectrum disorder (ASD), other development disorders, mental illness/psychosocial disability, drug/alcohol dependency or intellectual disability
- those who care for a child or grandchild
- those who care for a person with high or very high assistance needs, and
- carers who were unemployed.

Low wellbeing was less common amongst carers who:

- were male
- were aged 15-24 or 65 and older
- had lower caring obligations (fewer hours and/or having assistance in their role as a carer)
- had been a carer for a shorter period of time
- were employed
- cared for a person with relatively low assistance needs.

These findings suggest that some types of caring are likely to have a greater impact on a person's wellbeing than others. It is particularly concerning that longer periods of being a carer are associated with decline in wellbeing. The importance of having access to support is clear: carers with limited access to support or assistance, and with higher weekly caring hours, have significantly poorer wellbeing than the average.

Table 4 Carer wellbeing (a)

		Wellbeing – Global Life Satisfaction	Wellbeing – Personal Wellbeing Index	Wellbeing – Personal Wellbeing Index		
Group	**Category**	**Mean score (measured 0-100)**	**Mean score (measured 0-100)**	**% low wellbeing (score <60)**	**% typical wellbeing (score 60-79)**	**% high wellbeing (score 80+)**
Australia	Australian adults – carers & non-carers	70.4	70.4	20.4%	30.9%	48.7%
All current	Current carers	53.1	54.6	55.3%	31.1%	13.6%
Gender	Female	50.7	52.5	**58.9%**	30.8%	**10.3%**
	Male	**57.5**	**58.4**	**47.4%**	33.5%	**19.1%**
Age	Aged 15-24	55.2	**60.1**	**45.4%**	35.9%	**18.7%**
	Aged 25-34	55.4	54.5	56.1%	32.3%	11.6%
	Aged 35-44	**56.2**	54.7	54.2%	30.1%	15.6%
	Aged 45-54	**48.6**	**48.8**	**65.5%**	**26.0%**	**8.5%**
	Aged 55-64	51.3	53.3	57.9%	30.2%	11.9%
	Aged 65-74	55.0	**59.6**	**46.7%**	**36.8%**	16.5%
	Aged 75+	58.7	**65.7**	**35.4%**	**38.1%**	**26.5%**
Typical caring hours per week	<20 hours/week	**56.3**	**58.9**	**47.6%**	**35.8%**	**16.6%**
	20-39 hours/week	**57.2**	**57.1**	52.4%	31.8%	15.9%
	40+ hours/week	**46.5**	**47.3**	**67.4%**	**24.4%**	**8.2%**
Cultural and language diversity	Aboriginal/Torres Strait Islander	56.4	**59.7**	**43.5%**	36.8%	19.8%
	Not Aboriginal/Torres Strait Islander	53.1	54.5	55.0%	31.7%	13.2%
	Usually speak language other than English at home	53.9	55.7	55.6%	29.7%	14.7%
	Usually speak English at home	53.1	54.2	54.6%	32.4%	13.0%
State/ Territory of residence	NSW	53.5	55.0	55.2%	29.1%	15.7%
	Vic	54.1	55.2	51.6%	34.5%	13.9%
	Qld	51.2	**50.5**	**62.5%**	28.8%	**8.7%**
	SA	55.1	55.8	54.3%	31.4%	14.3%
	WA	55.0	56.0	51.3%	36.6%	12.1%
	Tas	59.1	**60.1**	46.9%	34.3%	18.8%
	NT	62.2	61.6	46.4%	32.9%	20.6%
	ACT	54.4	56.4	48.8%	38.8%	12.3%
Primary carer	Primary carer	**50.3**	**51.1**	**61.2%**	28.7%	**10.1%**
	Not a primary carer	**60.4**	**62.8**	**38.5%**	**40.9%**	**20.5%**
Sole or assisted carer	Sole carer	**48.4**	**49.4**	**64.1%**	27.7%	**8.2%**
	Assisted in caring role	54.4	55.4	53.4%	32.5%	14.1%
No. people currently caring for	Currently care for 1 person	54.9	**56.1**	52.4%	32.8%	14.8%
	Currently care for 2 people	**50.3**	**51.6**	**61.7%**	27.7%	10.6%
	Currently care for 3 or more people	50.0	**48.9**	60.9%	30.8%	**8.3%**
Caree residence	Caree lives elsewhere	**59.2**	**62.0**	**38.4%**	**44.4%**	17.2%
	Caree lives in home	**51.1**	**51.5**	**60.6%**	28.6%	**10.8%**
Length of time being a carer	Carer for 5+ years	**50.4**	**50.9**	**61.5%**	**27.4%**	**11.1%**
	Carer for 2-5 years	**56.0**	**57.2**	51.1%	32.7%	16.2%
	Carer for 1-2 years	**57.8**	**61.4**	**44.6%**	**39.8%**	15.6%
	Carer for <1 year	**62.0**	**63.2**	**40.7%**	37.3%	**21.9%**

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 5 Carer wellbeing (b)

Group	Category	Wellbeing – Global Life Satisfaction	Wellbeing – Personal Wellbeing Index	Wellbeing – Personal Wellbeing Index		
		Mean score (measured 0-100)	Mean score (measured 0-100)	% low wellbeing (score <60)	% typical wellbeing (score 60-79)	% high wellbeing (score 80+)
Care recipient disability, illness or injury type	Dementia	53.3	56.5	52.2%	33.7%	14.1%
	Old-age related frailty	54.5	56.2	52.1%	32.8%	15.1%
	Terminal illness	51.6	53.8	57.2%	30.0%	12.9%
	Autism spectrum disorder	**49.9**	**48.6**	**65.2%**	**26.0%**	**8.8%**
	Other development disorder	**47.6**	**47.1**	**68.8%**	**22.6%**	**8.6%**
	Mental illness/psychosocial disability	**48.0**	**48.2**	**65.2%**	**27.3%**	**7.5%**
	Drug/alcohol dependency	50.0	**51.1**	**62.1%**	29.7%	**8.2%**
	Physical disability	53.2	53.5	55.2%	32.6%	12.3%
	Intellectual disability	**48.4**	**48.1**	**65.2%**	**25.9%**	**8.9%**
	Chronic non-terminal illness or injury, 6 months+	52.2	**52.1**	57.2%	34.6%	**8.2%**
	Short term non-terminal illness	50.4	58.3	50.2%	31.3%	18.4%
Type of care recipient	Care for child/grandchild	**50.2**	**49.9**	**63.8%**	28.1%	**8.0%**
	Care for partner	54.0	56.0	52.9%	33.8%	13.4%
	Care for parent/grandparent	54.2	55.8	53.0%	32.4%	14.6%
	Care for sibling	55.2	55.7	54.1%	26.5%	**19.4%**
	Care for friend or other type of relative	**60.8**	**58.9**	**40.8%**	**41.1%**	18.1%
Level of assistance needed by care recipient	Low assistance needs	**62.4**	**65.4**	**31.1%**	**41.7%**	**27.1%**
	Low-moderate assistance needs	**57.6**	**61.1**	**43.5%**	**36.3%**	**20.2%**
	Moderate assistance needs	54.6	55.1	56.1%	33.0%	**10.9%**
	High assistance needs	51.5	**51.3**	**60.2%**	29.9%	**10.0%**
	Very high assistance needs	**49.0**	**49.6**	**63.6%**	**25.0%**	11.4%
Labour force status	Employed	**57.4**	**58.2**	**47.8%**	**35.8%**	**16.4%**
	Unemployed	**44.8**	**44.9**	**75.6%**	**19.7%**	**4.7%**
	Not in labour force	**49.4**	**51.5**	**60.3%**	28.7%	**11.0%**
Past carers	Past carers - all	**63.0**	**64.1**	**40.3%**	**36.0%**	**23.7%**
	Ceased caring in last 6 months	**58.3**	**61.6**	**45.7%**	32.9%	**21.4%**
	Ceased caring 7-12 months previously	**59.3**	**60.2**	50.4%	31.2%	18.3%
	Ceased caring more than 1 year ago	**67.4**	**68.2**	**31.3%**	**38.9%**	**29.8%**

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

The measures of subjective wellbeing presented above examine levels of positive wellbeing. It is also important to examine measures of 'ill being', such as psychological distress. Psychological distress was measured using the Kessler 10 (K10) psychological distress scale. This measure asks a person to identify how frequently they have experienced 10 different symptoms of psychological distress in the last four weeks, on a scale from 1 to 5, with 5 being the most frequent. The score across these items is summed to result in a total score from 10 (low/no distress) to 50 (very high distress). This can then be grouped to identify those likely to be well in terms of their mental health related to distress, those likely to have a mild mental disorder related to distress, those likely to have a moderate mental disorder, and those likely to have a severe mental disorder (Andrews and Slade 2001).

Figure 7 compares the average psychological distress scores of carers in April/May 2021 to those of adult Australians in 2020. Carers have significantly higher rates of psychological distress than the average Australian. In 2020, the average psychological distress score for Australian adults was 19.3 out of a possible 50 (Figure 7, Schirmer et al. 2021). In contrast, the mean score amongst carers was 25.0, much higher than the average for the broader population. Across all age groups of carers there was a significant 'distress gap' with significantly higher distress levels among carers compared to the average Australian adult. This gap was greatest for carers aged 30 to 44, whose average psychological distress was 6.7 points higher than that of the general population.

As shown in Figure 8, female and male carers had similar average levels of distress. In the general population, in contrast, men typically have somewhat lower psychological distress levels on average compared to women. This suggests that being engaged in the role of a carer may have impacts on psychological distress that result in higher levels of distress irrespective of gender.

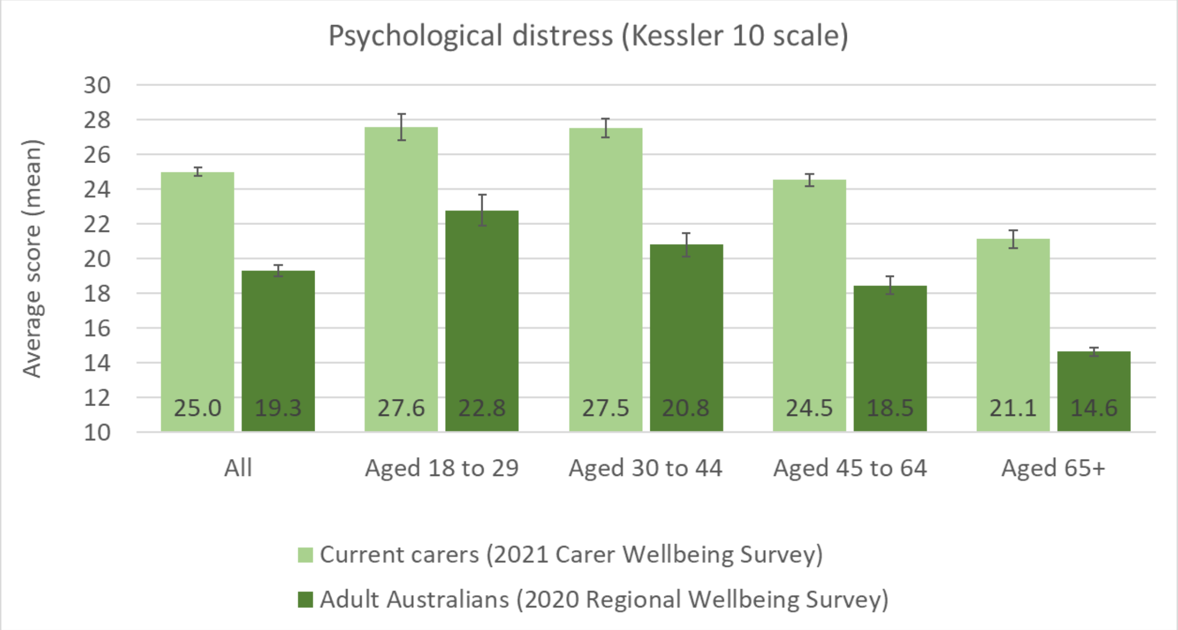


Figure 7 Psychological distress of carers in April/May 2021 compared to adult Australians in Nov/Dec 2020 – by age group

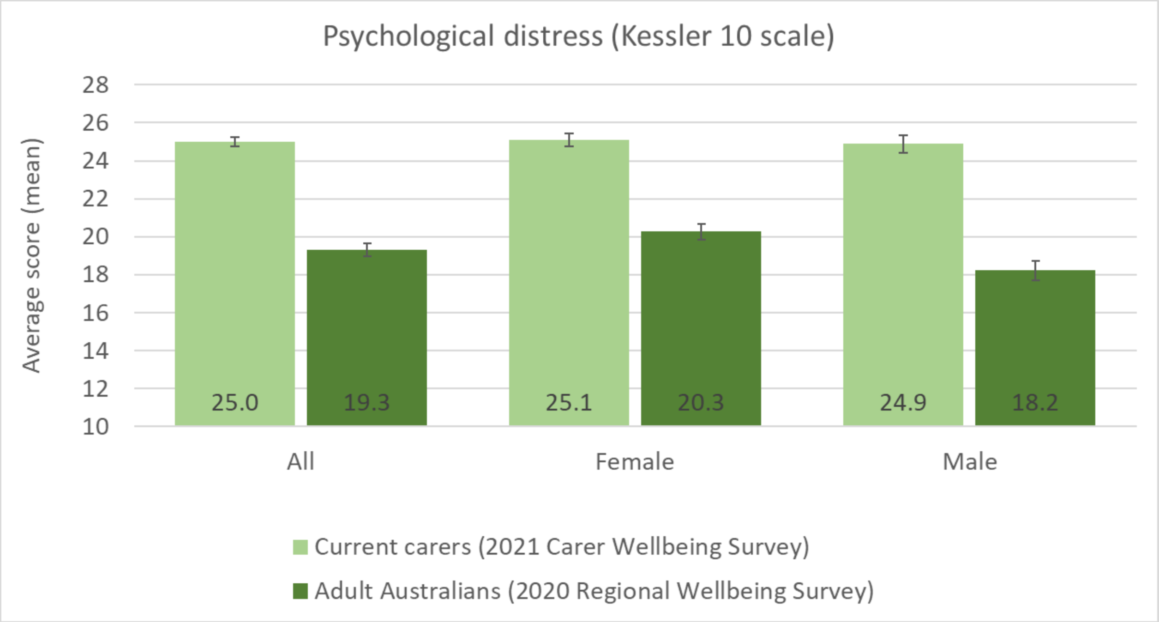


Figure 8 Psychological distress of carers in April/May 2021 compared to adult Australians in Nov/Dec 2020 – by gender

While high levels of distress were observed across all types of carers, some carers were more likely to have high distress than others. Tables 6 and 7 compared distress levels amongst different groups of carers. High distress was particularly prevalent in carers aged under 45, and less prevalent amongst those aged 55 and older. Those with high caring obligations in terms of caring hours, number of people cared for, and assistance needs of the people cared for, had higher distress on average than other carers. So did those who cared for people with specific caring needs: those caring for a person with a terminal illness, ASD, development disorder, mental illness, drug/alcohol dependency or intellectual disability had higher distress on average than others. Carers who were unemployed also had higher distress than average.

Distress was lower amongst past carers, although still higher than the average distress experienced across the Australian adult population.

Table 6 Psychological distress (a)

		Psychological distress	Psychological distress			
Group	**Category**	**K10 mean score (measured 10-50)**	**Likely to be well (score 10-19)**	**Likely to have mild mental disorder (score 20-24)**	**Likely to have moderate mental disorder (score 25-29)**	**Likely to have severe mental disorder (score 30+)**
All current	Current carers	25.0	31.2%	19.6%	18.8%	30.5%
Gender	Female	25.1	29.1%	21.3%	19.5%	30.1%
	Male	24.9	33.8%	**16.4%**	17.6%	32.2%
Age	Aged 15-24	**27.8**	**20.4%**	15.2%	18.4%	**46.0%**
	Aged 25-34	**27.5**	**19.6%**	**15.4%**	**29.2%**	**35.9%**
	Aged 35-44	**27.5**	**22.3%**	16.6%	18.3%	**42.8%**
	Aged 45-54	**25.8**	**25.9%**	21.4%	18.8%	33.9%
	Aged 55-64	**23.5**	**38.5%**	21.0%	16.0%	**24.6%**
	Aged 65-74	**21.5**	**44.4%**	23.4%	17.7%	**14.5%**
	Aged 75+	**20.4**	**52.5%**	20.7%	15.1%	**11.8%**
Typical caring hours per week	<20 hours/week	**24.2**	**34.8%**	19.2%	18.1%	27.9%
	20-39 hours/week	25.0	31.4%	19.9%	20.0%	28.7%
	40+ hours/week	**26.1**	**26.2%**	19.9%	18.9%	**35.0%**
Cultural and language diversity	Aboriginal/Torres Strait Islander	**29.0**	**20.4%**	19.7%	14.7%	**45.3%**
	Not Aboriginal/Torres Strait Islander	25.0	31.0%	19.4%	19.0%	30.6%
	Usually speak language other than English at home	25.2	28.0%	21.6%	17.3%	33.0%
	Usually speak English at home	25.0	31.6%	18.9%	19.2%	30.3%
State/ Territory of residence	NSW	25.2	30.3%	19.2%	18.5%	32.0%
	Vic	25.3	29.5%	21.7%	16.1%	32.7%
	Qld	25.8	27.6%	16.1%	22.7%	33.6%
	SA	23.9	35.4%	21.1%	18.3%	25.2%
	WA	**23.9**	35.7%	19.5%	20.5%	**24.4%**
	Tas	**22.4**	40.9%	21.3%	17.0%	20.7%
	NT	23.7	43.3%	17.3%	11.3%	28.1%
	ACT	23.4	38.8%	17.4%	19.9%	23.9%
Primary carer	Primary carer	25.5	28.8%	20.3%	19.0%	31.9%
	Not a primary carer	**22.3**	**41.4%**	20.4%	16.4%	**21.8%**
Sole or assisted carer	Sole carer	25.1	29.9%	20.8%	19.4%	29.8%
	Assisted in caring role	25.0	30.8%	19.9%	18.0%	31.3%
No. people currently caring for	Currently care for 1 person	**23.8**	**35.4%**	19.6%	19.2%	**25.8%**
	Currently care for 2 people	**27.1**	**22.3%**	20.1%	20.1%	**37.6%**
	Currently care for 3 or more people	**27.0**	26.2%	18.4%	17.1%	**38.4%**
Caree residence	Caree lives elsewhere	**23.2**	**39.3%**	19.1%	18.0%	**23.6%**
	Caree lives in home	25.5	28.7%	19.5%	19.4%	32.4%
Length of time being a carer	Carer for 5+ years	25.2	28.9%	21.3%	18.5%	31.3%
	Carer for 2-5 years	24.8	34.3%	18.2%	17.5%	30.0%
	Carer for 1-2 years	**23.3**	36.7%	22.4%	18.5%	**22.4%**
	Carer for <1 year	24.2	36.4%	15.6%	19.0%	28.9%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 7 Psychological distress (b)

		Psychological distress	Psychological distress			
Group	Category	K10 mean score (measured 10-50)	Likely to be well (score 10-19)	Likely to have mild mental disorder (score 20-24)	Likely to have moderate mental disorder (score 25-29)	Likely to have severe mental disorder (score 30+)
Care recipient disability, illness or injury type	Dementia	25.1	30.7%	19.9%	19.9%	29.5%
	Old-age related frailty	24.4	33.7%	20.5%	18.4%	27.4%
	Terminal illness	**27.3**	**21.3%**	**14.6%**	**24.9%**	**39.1%**
	Autism spectrum disorder	**27.9**	**20.3%**	16.6%	21.6%	**41.5%**
	Other development disorder	**28.0**	**19.4%**	18.6%	17.5%	**44.5%**
	Mental illness/psychosocial disability	**27.0**	**23.9%**	17.9%	19.7%	**38.5%**
	Drug/alcohol dependency	**27.4**	**24.5%**	**13.1%**	19.8%	**42.6%**
	Physical disability	24.7	32.1%	20.6%	18.7%	28.5%
	Intellectual disability	**26.9**	**23.9%**	20.2%	17.3%	**38.6%**
	Chronic non-terminal illness or injury, 6 months+	24.8	31.7%	22.7%	**14.8%**	30.8%
	Short term non-terminal illness	25.5	27.9%	15.1%	25.8%	31.3%
Type of care recipient	Care for child/grandchild	**26.1**	**24.8%**	20.1%	20.9%	**34.1%**
	Care for partner	**23.9**	**35.4%**	20.3%	19.7%	**24.7%**
	Care for parent/grandparent	25.7	29.2%	19.1%	19.1%	32.6%
	Care for sibling	**26.8**	**22.6%**	17.5%	23.4%	36.5%
	Care for friend or other type of relative	**22.7**	**44.5%**	19.1%	**11.8%**	24.6%
Level of assistance needed by care recipient	Low assistance needs	**22.0**	**48.8%**	15.9%	15.7%	**19.7%**
	Low-moderate assistance needs	**23.4**	**39.9%**	18.4%	16.9%	**24.8%**
	Moderate assistance needs	24.4	31.2%	20.0%	**22.5%**	**26.4%**
	High assistance needs	25.7	30.1%	16.8%	19.0%	34.1%
	Very high assistance needs	**26.8**	**22.5%**	22.5%	17.8%	**37.3%**
Labour force status	Employed	25.0	31.0%	19.4%	19.1%	30.4%
	Unemployed	**28.6**	**15.3%**	14.1%	22.9%	**47.7%**
	Not in labour force	24.7	32.4%	20.2%	17.9%	29.6%
Past carers	Past carers - all	**22.6**	**43.2%**	19.3%	**15.0%**	**22.5%**
	Ceased caring in last 6 months	23.8	37.6%	19.3%	15.5%	27.5%
	Ceased caring 7-12 months previously	**23.6**	36.3%	16.8%	21.7%	25.2%
	Ceased caring more than 1 year ago	**19.3**	**58.3%**	21.0%	**7.7%**	**13.0%**

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

5.2 Health of carers

The overall health of carers was examined by asking them to self-rate their overall health, and identifying whether they have a long-term disability, health condition or injury that restricts every day activities.

Figures 9 and 10 compare the overall health of carers to that of the broader Australian population. The measure of general health use for this is one commonly used in Australian and international surveys, in which the person is asked to rate their overall health at the moment on a five-point scale: they can rate their health as excellent, very good, good, fair or poor. This self-rating is a global assessment that will typically reflect both a person's physical and mental health. This measure is used in a range of surveys internationally, and in Australia is used in surveys including the ACT General Health Survey and the Australian Bureau of Statistics National Health Survey (ABS 2018). The general health measure is also included in the Regional Wellbeing Survey and the HILDA survey, making it one of the most widely used general health measures in available Australian datasets.

Carers overall report poorer health than the average Australian: the risk of having poor health is more than double that of the general population. Across Australia, in 2020 43.7% of Australians reported having excellent or very good health, 35.6% good health, and 20.7% fair or poor health (Figure 8). Amongst carers, only 22.3% reported excellent or very good health, 32.3% good health and 45.3% fair or poor health (Tables 8 and 9). Amongst women, the proportion reporting fair/poor health rose from 23% in the general population to more than double this – 51.2% - amongst carers. Men also had a doubling of risk of fair/poor health if they were carers, increasing from 18.2% of the general population to 37.9% of carers. Almost half of carers – 45.8% - report that they themselves have one or more disabilities, health conditions or injuries that restrict their everyday activities.

The health gap between carers and the general population was greater for those aged 30 to 44, amongst whom carers were 2.5 times as likely to report fair/poor health as the broader population (Figure 10). Carers aged 45 to 64 were 2.1 times as likely to report fair/poor health, those aged 65 or older 1.9 times as likely, and those aged 18-29 1.8 times as likely to.

Some types of carers were more likely than others to report poor/fair health (Tables 8 and 9). Fair or poor health was more commonly reported by:

- female carers
- those aged 45-54
- those with high caring obligations
- those who cared for a person with high or very high assistance needs
- those who were primary/sole carers
- those who had been a carer for a longer period of time, and

- those who cared for a person with ASD, development disorder, mental illness or intellectual disability.

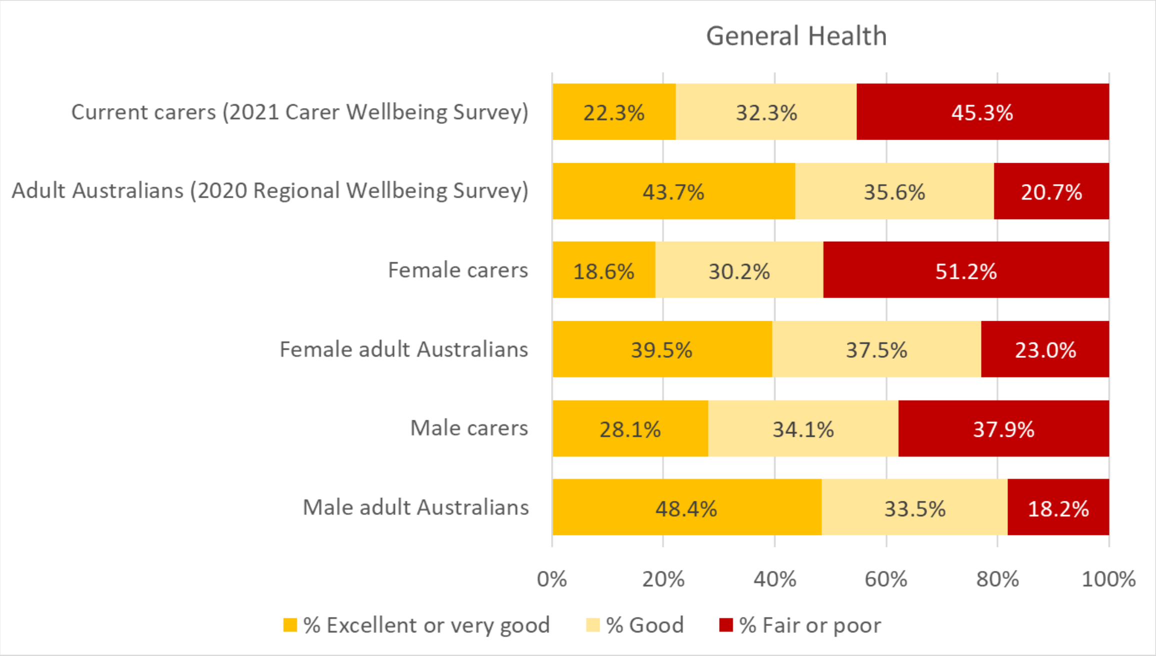


Figure 9 General health of carers in April/May 2021 compared to adult Australians in Nov/Dec 2020 – by gender

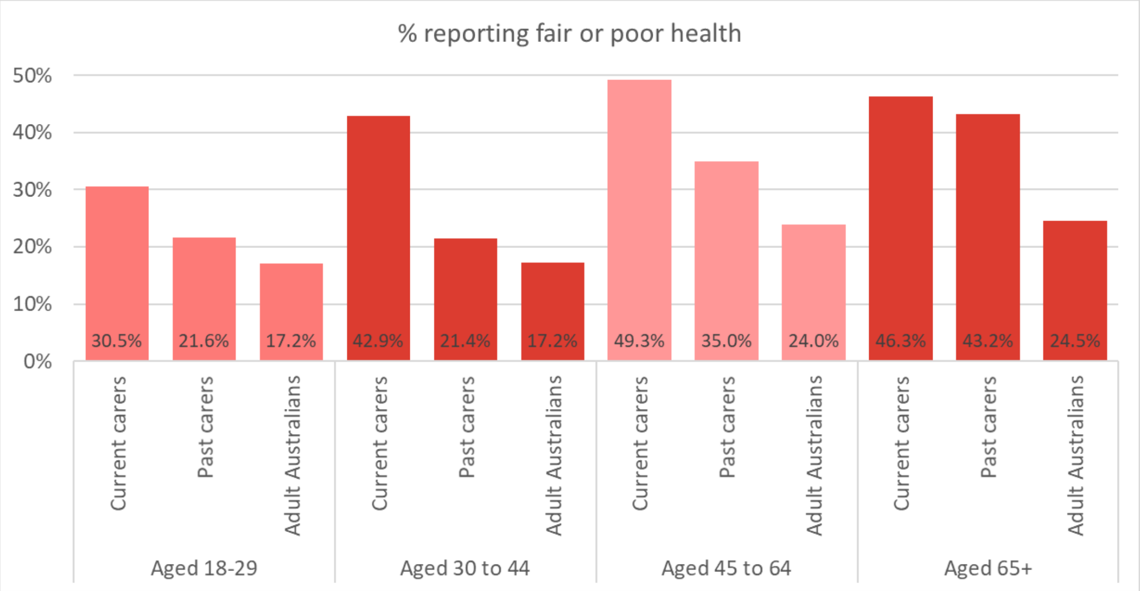


Figure 10 General health of carers in April/May 2021 compared to adult Australians in Nov/Dec 2020 – by age group

Table 8 Overall health (a)

		General health			Carer has long term disability, health condition or injury restricting everyday activity?	
Group	**Category**	**% Excellent or very good**	**% Good**	**% Fair or poor**	**% Yes**	**% No**
All current	Current carers	22.3%	32.3%	45.3%	45.8%	54.2%
Gender	Female	**18.6%**	30.2%	**51.2%**	45.1%	54.9%
	Male	**28.1%**	34.1%	**37.9%**	45.5%	54.5%
Age	Aged 15-24	**39.4%**	32.0%	**28.6%**	44.4%	55.6%
	Aged 25-34	**28.2%**	33.9%	**37.9%**	40.7%	59.3%
	Aged 35-44	25.0%	31.2%	43.8%	45.5%	54.5%
	Aged 45-54	**16.3%**	31.7%	**51.9%**	42.9%	57.1%
	Aged 55-64	19.8%	32.5%	47.7%	47.1%	52.9%
	Aged 65-74	21.1%	33.7%	45.3%	48.5%	51.5%
	Aged 75+	21.3%	32.7%	46.0%	**55.7%**	**44.3%**
Typical caring hours per week	<20 hours/week	**26.1%**	34.2%	**39.7%**	42.4%	57.6%
	20-39 hours/week	26.1%	34.3%	**39.6%**	46.3%	53.7%
	40+ hours/week	**14.8%**	28.5%	**56.7%**	**50.2%**	**49.8%**
Cultural and language diversity	Aboriginal/Torres Strait Islander	**41.8%**	25.7%	**32.4%**	**57.5%**	**42.5%**
	Not Aboriginal/Torres Strait Islander	21.5%	31.9%	46.6%	45.0%	55.0%
	Usually speak language other than English at home	22.6%	31.5%	45.8%	42.7%	57.3%
	Usually speak English at home	21.6%	32.0%	46.5%	46.3%	53.7%
State/ Territory of residence	NSW	**26.2%**	32.3%	41.5%	42.9%	57.1%
	Vic	23.9%	30.0%	46.0%	43.6%	56.4%
	Qld	**14.7%**	33.4%	**51.9%**	**54.0%**	**46.0%**
	SA	**15.3%**	33.0%	51.7%	50.7%	49.3%
	WA	20.2%	31.9%	47.9%	40.1%	59.9%
	Tas	24.1%	33.2%	42.6%	47.7%	52.3%
	NT	16.0%	48.4%	35.6%	**23.6%**	**76.4%**
	ACT	14.4%	32.0%	53.5%	49.4%	50.6%
Primary carer	Primary carer	**17.7%**	30.2%	**52.1%**	**49.1%**	**50.9%**
	Not a primary carer	**32.6%**	32.0%	**35.4%**	**34.0%**	**66.0%**
Sole or assisted carer	Sole carer	**14.2%**	30.5%	**55.3%**	48.7%	51.3%
	Assisted in caring role	24.3%	30.3%	45.4%	45.9%	54.1%
No. people currently caring for	Currently care for 1 person	22.2%	35.5%	42.3%	**41.6%**	**58.4%**
	Currently care for 2 people	24.9%	**25.2%**	49.9%	**52.3%**	**47.7%**
	Currently care for 3 or more people	**15.7%**	30.4%	**53.9%**	**54.4%**	**45.6%**
Caree residence	Caree lives elsewhere	33.5%	32.6%	**33.9%**	40.1%	59.9%
	Caree lives in home	**19.0%**	30.0%	**51.0%**	48.8%	51.2%
Length of time being a carer	Carer for 5+ years	**16.4%**	**28.9%**	**54.7%**	**50.5%**	**49.5%**
	Carer for 2-5 years	26.0%	36.4%	**37.6%**	**40.5%**	**59.5%**
	Carer for 1-2 years	**28.3%**	**39.9%**	**31.8%**	**30.1%**	**69.9%**
	Carer for <1 year	**33.6%**	**41.0%**	**25.3%**	40.1%	59.9%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 9 Overall health (b)

		General health			Carer has long term disability, health condition or injury restricting everyday activity?	
Group	**Category**	**% Excellent or very good**	**% Good**	**% Fair or poor**	**% Yes**	**% No**
Care recipient disability, illness or injury type	Dementia	**29.8%**	30.2%	**40.0%**	**41.2%**	**58.8%**
	Old-age related frailty	25.1%	34.8%	**40.2%**	42.9%	57.1%
	Terminal illness	23.9%	37.6%	**38.4%**	**52.9%**	**47.1%**
	Autism spectrum disorder	21.3%	**26.4%**	**52.3%**	**54.1%**	**45.9%**
	Other development disorder	**14.4%**	27.6%	**58.0%**	**56.0%**	**44.0%**
	Mental illness/psychosocial disability	**16.1%**	28.5%	**55.5%**	**56.6%**	**43.4%**
	Drug/alcohol dependency	26.6%	26.6%	46.9%	**58.5%**	**41.5%**
	Physical disability	19.3%	32.4%	48.2%	47.9%	52.1%
	Intellectual disability	**16.4%**	**26.6%**	**57.1%**	**51.0%**	**49.0%**
	Chronic non-terminal illness or injury, 6 months+	**17.7%**	29.9%	**52.4%**	49.4%	50.6%
	Short term non-terminal illness	**38.3%**	36.0%	**25.7%**	51.3%	48.7%
Type of care recipient	Care for child/grandchild	**16.4%**	29.8%	**53.8%**	**50.8%**	**49.2%**
	Care for partner	**17.5%**	**36.6%**	45.9%	**51.3%**	**48.7%**
	Care for parent/grandparent	**28.0%**	32.2%	**39.8%**	**38.0%**	**62.0%**
	Care for sibling	**30.0%**	27.8%	42.1%	44.5%	55.5%
	Care for friend or other type of relative	**33.7%**	29.2%	**37.1%**	49.1%	50.9%
Level of assistance needed by care recipient	Low assistance needs	**36.4%**	32.9%	**30.7%**	41.0%	59.0%
	Low-moderate assistance needs	**27.1%**	37.5%	**35.4%**	44.1%	55.9%
	Moderate assistance needs	22.1%	34.5%	43.4%	44.0%	56.0%
	High assistance needs	20.0%	31.7%	48.3%	46.6%	53.4%
	Very high assistance needs	**18.1%**	**27.8%**	**54.2%**	48.3%	51.7%
Labour force status	Employed	**27.8%**	33.7%	**38.5%**	**37.9%**	**62.1%**
	Unemployed	**14.7%**	35.3%	50.0%	**58.5%**	**41.5%**
	Not in labour force	**15.5%**	29.5%	**55.0%**	**53.0%**	**47.0%**
Past carers	Past carers - all	**35.3%**	35.4%	**29.4%**	**30.0%**	**70.0%**
	Ceased caring in last 6 months	**30.3%**	35.6%	**34.2%**	**31.1%**	**68.9%**
	Ceased caring 7-12 months previously	**33.4%**	32.8%	**33.8%**	**32.7%**	**67.3%**
	Ceased caring more than 1 year ago	**38.4%**	34.8%	**26.8%**	**29.0%**	**71.0%**

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

5.3 Loneliness and social connection

Being able to build and maintain positive social connection is increasingly recognised as a critical factor contributing to a person's wellbeing and health. High levels of social isolation and loneliness are associated with increased incidence of a wide range of physical and mental health disorders (Cacioppo and Cacioppo 2014). There is strong and growing evidence that:

> 'Loneliness can lead to various psychiatric disorders like depression, alcohol abuse, child abuse, sleep problems, personality disorders and Alzheimer's disease. It also leads to various physical disorders like diabetes, autoimmune disorders like rheumatoid arthritis, lupus and cardiovascular diseases like coronary heart disease, hypertension (HTN), obesity, physiological aging, cancer, poor hearing and poor health. Left untended, loneliness can have serious consequences for mental and physical health of people. Therefore it is important to intervene at the right time to prevent loneliness…' (Mushtaq et al. 2014)

Levels of loneliness were measured using a well validated three-item loneliness scale in which survey respondents are asked (i) How often do you feel you lack companionship, (ii) How often do you feel left out, and (iii) How often do you feel isolated from others. Response options for each item are (i) Never, (ii) Hardly ever, (iii) Occasionally/sometimes, (iv) Often, or (v) All of the time, scored from 1 (Never) to 5 (all the time). The mean scores of the three items are combined to form the index of loneliness. This loneliness scale is used in a number of studies, some of which use slightly different variants of the response scale, but which have all shown good characteristics for the scale (see Hughes et al. 2004, Matthews-Ewald and Zullig 2013, Snape and Martin 2018). While not known to be used in key long-term surveys in Australia currently, this measure was included in the Regional Wellbeing Survey from 2020.

Carers were three times as likely as other Australians to regularly experience loneliness. In 2020, 11.1% of Australians reported feeling loneliness often or all the time (Schirmer et al. 2021). In contrast, 35.1% of carers reported often or always feeling lonely (Tables 10 and 11). Carers were even more likely than the typical carer report high levels of loneliness if they:

- were female
- were aged 35 to 54
- had high caring hours per week (40+ hours)
- were a primary or sole carer
- cared for more than one person
- cared for a person with ASD, another development disorder, mental illness or intellectual disability
- cared for a person with high or very high assistance needs, or
- cared for a child or grandchild.

Carers were less likely to report frequently feeling lonely if they were:

- aged 65 and over
- had fewer than 20 hours of caring obligations a week
- were not primary carers
- had been carers for less than a year

- cared for someone with old-age related frailty, or
- cared for a person/people with lower levels of assistance needs.

Some of the greater differences in loneliness related to the needs of care recipients. As shown in Figure 11, almost half of carers who cared for a person with ASD, other development disorders, or intellectual disability, reported often or always feeling lonely, as did 44% of those caring for a person experiencing mental illness or psychosocial disability.

This highlights a need to provide targeted support to carers whose caring obligations may mean they are at greater risk of social isolation.

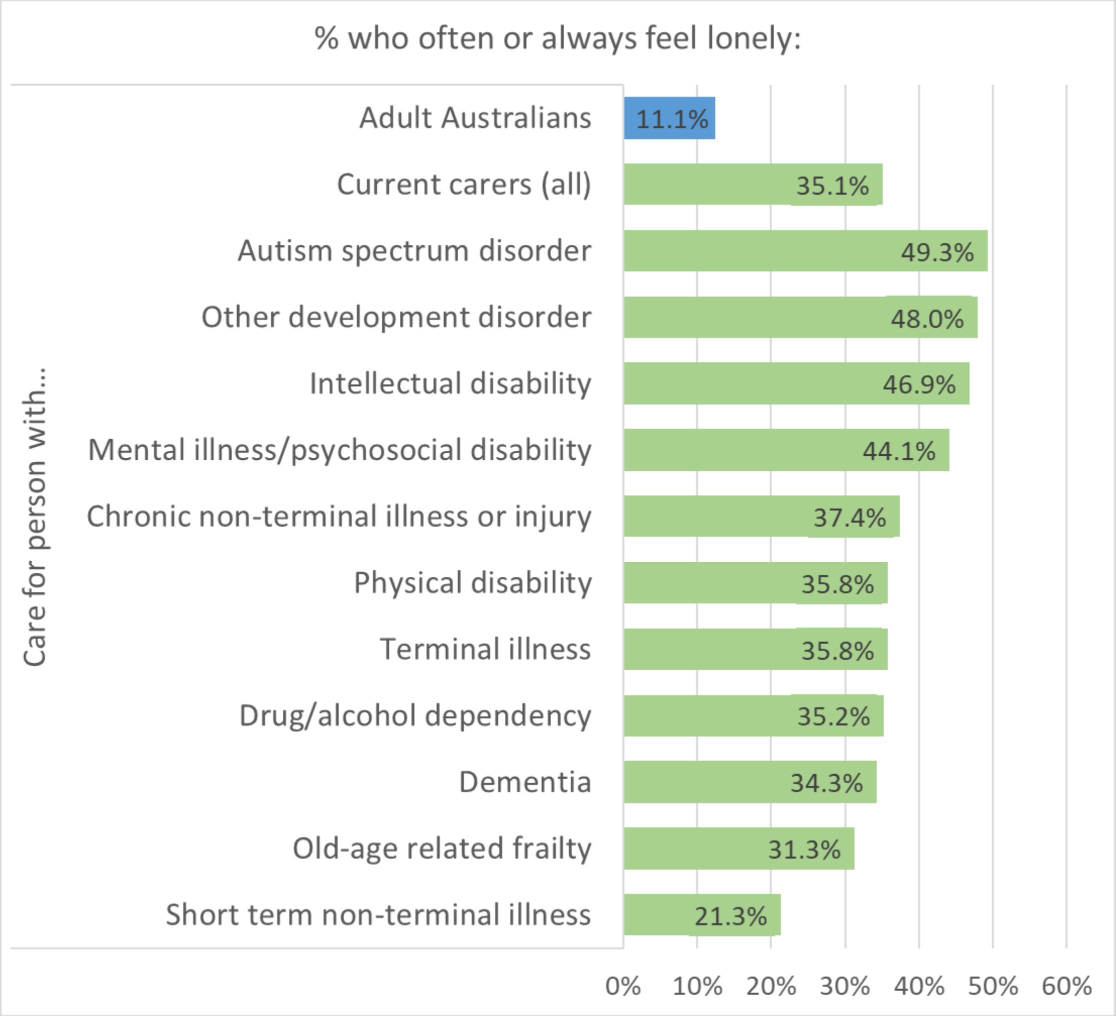


Figure 11 Proportion of people who often/always feel lonely, by care recipient caring need

Table 10 Loneliness and social connection (a)

		Satisfaction with personal relationships	Satisfaction with feeling part of your community	Loneliness scale		
Group	**Category**	**Mean score (measured from 0-10)**	**Mean score (measured from 0-10)**	**% Never or rarely lonely**	**% Sometimes lonely**	**% Often or always lonely**
All current	Current carers	5.2	5.1	23.8%	41.0%	35.1%
Gender	Female	**5.0**	**4.8**	**20.3%**	39.7%	**40.0%**
	Male	**5.7**	**5.6**	**29.1%**	42.2%	**28.7%**
Age	Aged 15-24	**6.1**	**6.0**	23.6%	**53.1%**	**23.3%**
	Aged 25-34	5.5	4.9	22.6%	42.4%	35.0%
	Aged 35-44	5.2	5.1	**17.6%**	39.3%	**43.1%**
	Aged 45-54	**4.6**	**4.6**	**19.8%**	38.2%	**42.0%**
	Aged 55-64	5.0	4.9	26.0%	39.4%	34.6%
	Aged 65-74	5.5	**5.5**	**30.9%**	42.6%	**26.6%**
	Aged 75+	**6.4**	**6.0**	**37.0%**	41.6%	**21.4%**
Typical caring hours	<20 hours/week	**5.7**	**5.6**	**30.1%**	43.5%	**26.4%**
	20-39 hours/week	**5.5**	**5.5**	23.9%	43.6%	32.4%
	40+ hours/week	**4.4**	**4.1**	**15.3%**	**36.1%**	**48.6%**
Cultural and language diversity	Aboriginal/Torres Strait Islander	5.7	**5.9**	15.9%	39.2%	44.9%
	Not Aboriginal/Torres Strait Islander	5.2	5.0	23.8%	40.7%	35.5%
	Usually speak language other than English at home	5.2	5.3	24.2%	43.1%	32.8%
	Usually speak English at home	5.2	5.0	23.4%	39.9%	36.8%
State/ Territory of residence	NSW	5.3	5.2	23.6%	41.0%	35.4%
	Vic	5.3	5.2	23.7%	41.1%	35.2%
	Qld	**4.7**	**4.5**	20.8%	37.6%	**41.6%**
	SA	5.5	5.0	28.1%	39.9%	32.0%
	WA	5.3	5.2	21.7%	44.5%	33.7%
	Tas	5.8	5.5	31.7%	38.3%	30.0%
	NT	6.1	5.6	38.1%	28.8%	33.1%
	ACT	5.3	5.0	25.2%	38.1%	36.7%
Primary carer	Primary carer	**4.8**	**4.7**	**19.8%**	38.7%	**41.5%**
	Not a primary carer	**6.0**	**6.1**	**32.1%**	**47.5%**	**20.4%**
Sole/ assisted carer	Sole carer	**4.5**	**4.5**	20.7%	37.5%	**41.7%**
	Assisted in caring role	5.3	5.2	21.9%	41.7%	36.4%
No. people currently caring for	Currently care for 1 person	5.3	5.2	**26.7%**	41.9%	**31.4%**
	Currently care for 2 people	5.1	4.8	**17.7%**	39.8%	**42.5%**
	Currently care for 3 or more people	**4.7**	**4.4**	21.2%	**33.1%**	**45.7%**
Caree residence	Caree lives elsewhere	**6.1**	**6.1**	**32.7%**	46.4%	**20.9%**
	Caree lives in home	**4.8**	**4.7**	**20.0%**	39.5%	**40.5%**
Length of time being a carer	Carer for 5+ years	**4.9**	**4.7**	**20.5%**	38.8%	**40.7%**
	Carer for 2-5 years	5.5	**5.4**	26.8%	43.3%	29.9%
	Carer for 1-2 years	**5.6**	**5.9**	27.8%	45.3%	26.9%
	Carer for <1 year	**6.1**	**5.9**	**32.9%**	41.6%	25.5%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 11 Loneliness and social connection (b)

		PWI – Satisfaction with personal relationships	PWI – Satisfaction with feeling part of your community	Loneliness scale		
Group	**Category**	**Mean score (measured from 0-10)**	**Mean score (measured from 0-10)**	**% Never or rarely lonely**	**% Some-times lonely**	**% Often or always lonely**
Care recipient disability, illness or injury type	Dementia	5.2	5.2	25.2%	40.6%	34.3%
	Old-age related frailty	5.3	**5.3**	**28.3%**	40.4%	**31.3%**
	Terminal illness	5.3	5.1	**18.6%**	45.6%	35.8%
	Autism spectrum disorder	**4.7**	**4.5**	**14.5%**	**36.2%**	**49.3%**
	Other development disorder	**4.5**	**4.3**	**12.1%**	39.9%	**48.0%**
	Mental illness/psychosocial disability	**4.7**	**4.5**	**16.9%**	39.0%	**44.1%**
	Drug/alcohol dependency	5.1	4.8	**17.3%**	47.5%	35.2%
	Physical disability	5.2	4.9	23.7%	40.5%	35.8%
	Intellectual disability	**4.6**	**4.3**	**15.3%**	37.7%	**46.9%**
	Chronic non-terminal illness or injury, 6 months+	**5.0**	**4.7**	22.4%	40.2%	37.4%
	Short term non-terminal illness	5.5	5.6	28.3%	50.4%	**21.3%**
Type of care recipient	Care for child/grandchild	**4.8**	**4.6**	**16.7%**	39.7%	**43.6%**
	Care for partner	**5.5**	5.1	24.8%	44.5%	**30.7%**
	Care for parent/grandparent	5.3	5.3	25.1%	40.3%	34.6%
	Care for sibling	5.5	5.4	30.5%	40.6%	28.9%
	Care for friend or other type of relative	**5.8**	**5.7**	**38.6%**	35.9%	**25.5%**
Level of assistance needed by care recipient	Low assistance needs	**6.5**	**6.3**	**42.9%**	39.1%	**18.0%**
	Low-moderate assistance needs	**6.0**	**5.9**	**34.7%**	39.6%	**25.6%**
	Moderate assistance needs	5.1	5.2	24.1%	**46.0%**	**29.9%**
	High assistance needs	**4.9**	**4.6**	**19.2%**	38.3%	**42.5%**
	Very high assistance needs	**4.7**	**4.4**	**15.6%**	38.3%	**46.1%**
Labour force status	Employed	**5.5**	**5.6**	25.6%	42.4%	32.0%
	Unemployed	**4.4**	**4.3**	**11.9%**	44.5%	**43.7%**
	Not in labour force	**5.0**	**4.5**	22.5%	38.1%	**39.3%**
Past carers	Past carers - all	**6.3**	**6.0**	**42.1%**	38.8%	**19.1%**
	Ceased caring in last 6 months	5.6	**5.6**	**32.5%**	**51.0%**	**16.5%**
	Ceased caring 7-12 months previously	**6.0**	**5.8**	**35.8%**	44.1%	**20.2%**
	Ceased caring more than 1 year ago	**6.9**	**6.4**	**56.6%**	**28.3%**	**15.1%**

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

5.4 Household finances

On average, carers have poorer financial wellbeing compared to the typical Australian. Financial wellbeing was examined using two measures. Both measures are used in a number of Australian surveys, including the Household Income and Labour Dynamics in Australia (HILDA) survey, some Australian Bureau of Statistics (ABS) surveys, and the Regional Wellbeing Survey. Using these measures ensures findings from the CWS can be compared to the broader Australian population.

The first measure examined experience of household financial stress. Survey participants were asked if, in the last year, they had experienced any of three types of financial stress events: having to delay or cancel non-essential purchases; being unable to pay bills on time; or going without meals or being unable to heat or cool their home. Whereas 34.5% of Australians experienced one or more of these financial stress events in the past 12 months as of the end of 2020, 57.3% of carers reported this (Figure 12).

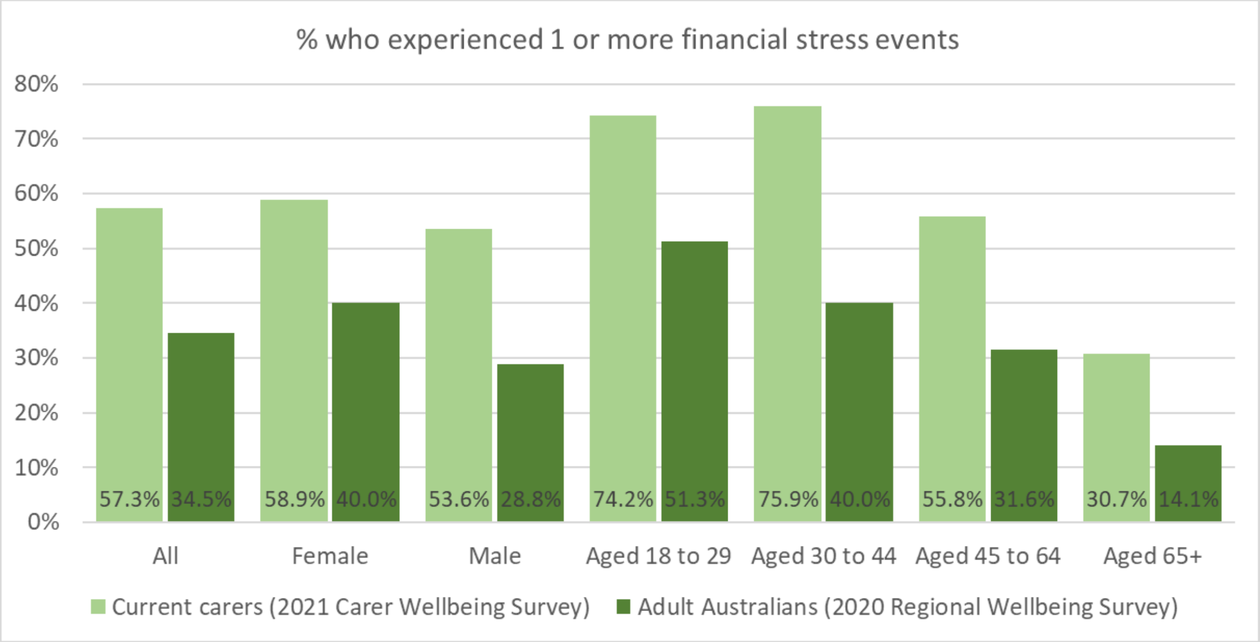


Figure 12 Financial stress of carers in April/May 2021 compared to adult Australians in Nov/Dec 2020 – by gender and age group

While all types of carers reported poorer household finances than the average Australian, some reported greater financial stress than others (Tables 12 and 13). Carers were more likely than average to have experienced one or more financial stress events in the last 12 months (such as being unable to pay a bill on time, going without heating or cooling, going without meals, or delaying non-essential expenses) if they:

- were younger, particularly aged under 55
- were Aboriginal or Torres Strait Islander; lived in Queensland
- cared for two or more people
- cared for someone with a terminal illness, with ASD, other development disorder, intellectual disability, mental illness, or drug/alcohol dependency
- cared for a person with high assistance needs
- cared for a child/grandchild.

Table 12 Household financial position (a)

Group	Category	% experienced 1 or more financial stress events last 12 months	Self-rated household financial prosperity			
			Poor/ very poor	Just getting along	Comfortable	Very comfortable/ prosperous
All current	Current carers	57.3%	13.2%	39.6%	36.3%	10.9%
Gender	Female	58.9%	13.3%	**43.3%**	35.5%	**7.9%**
	Male	53.6%	13.3%	**32.7%**	38.0%	**16.0%**
Age	Aged 15-24	**72.5%**	12.9%	32.8%	37.1%	**17.2%**
	Aged 25-34	**79.4%**	**19.6%**	34.2%	34.3%	11.9%
	Aged 35-44	**73.8%**	**18.1%**	35.1%	34.0%	12.7%
	Aged 45-54	**68.2%**	**18.4%**	**47.8%**	**25.7%**	**8.1%**
	Aged 55-64	**44.7%**	**8.8%**	**44.8%**	36.5%	9.8%
	Aged 65-74	**36.9%**	**5.6%**	35.0%	**48.1%**	11.3%
	Aged 75+	**17.5%**	**1.8%**	**27.7%**	**57.3%**	13.3%
Typical caring hours per week	<20 hours/week	52.7%	**9.9%**	36.2%	**40.6%**	13.3%
	20-39 hours/week	60.3%	16.5%	37.2%	34.4%	12.0%
	40+ hours/week	60.7%	15.8%	**45.8%**	**31.4%**	**7.0%**
Cultural and language diversity	Aboriginal/Torres Strait Islander	**87.0%**	16.5%	32.5%	28.4%	**22.5%**
	Not Aboriginal/Torres Strait Islander	56.4%	13.2%	39.8%	36.5%	10.5%
	Usually speak language other than English at home	60.0%	13.7%	40.5%	38.1%	**7.6%**
	Usually speak English at home	56.6%	13.0%	39.4%	35.7%	11.8%
State/ Territory of residence	NSW	53.0%	11.8%	37.7%	37.5%	13.0%
	Vic	59.2%	12.6%	41.0%	33.1%	13.4%
	Qld	**64.3%**	**18.1%**	43.1%	33.4%	**5.4%**
	SA	55.6%	14.6%	41.6%	36.9%	7.0%
	WA	56.7%	10.5%	37.5%	42.8%	9.2%
	Tas	46.2%	7.1%	38.1%	41.0%	13.8%
	NT	61.1%	9.3%	42.9%	36.2%	11.7%
	ACT	**38.6%**	13.2%	**25.1%**	49.3%	12.4%
Primary carer	Primary carer	58.6%	15.3%	**43.6%**	**31.6%**	9.4%
	Not a primary carer	**44.9%**	**5.6%**	**30.2%**	**49.2%**	15.0%
Sole or assisted carer	Sole carer	59.9%	**18.0%**	**45.6%**	**29.2%**	**7.2%**
	Assisted in caring role	54.3%	10.8%	38.8%	37.8%	12.7%
No. people currently caring for	Currently care for 1 person	**50.5%**	11.2%	37.0%	**40.8%**	10.9%
	Currently care for 2 people	**68.3%**	15.5%	43.9%	**29.5%**	11.2%
	Currently care for 3 or more people	**73.4%**	**22.2%**	45.1%	**26.0%**	**6.7%**
Caree residence	Caree lives elsewhere	**49.4%**	13.4%	**31.5%**	41.7%	13.4%
	Caree lives in home	58.2%	14.3%	43.1%	**32.2%**	10.5%
Length of time being a carer	Carer for 5+ years	59.6%	15.2%	**44.4%**	**32.2%**	**8.2%**
	Carer for 2-5 years	53.0%	10.5%	35.1%	39.1%	**15.3%**
	Carer for 1-2 years	**47.3%**	**7.0%**	**27.2%**	**53.7%**	12.1%
	Carer for <1 year	52.7%	12.5%	35.7%	41.5%	10.2%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 13 Household financial position (b)

			Self-rated household financial prosperity			
Group	**Category**	**% who experienced 1 or more financial stress events last 12 months**	**Poor/ very poor**	**Just getting along**	**Comfort-able**	**Very comfort-table/ prospe-rous**
Care recipient disability, illness or injury type	Dementia	**44.2%**	**9.5%**	35.2%	40.3%	**15.0%**
	Old-age related frailty	**50.8%**	11.5%	38.3%	39.3%	10.9%
	Terminal illness	**69.0%**	15.2%	35.5%	36.9%	12.5%
	Autism spectrum disorder	**71.9%**	**17.1%**	42.3%	**29.9%**	10.6%
	Other development disorder	**74.4%**	**20.9%**	**46.0%**	**26.6%**	**6.5%**
	Mental illness/psychosocial disability	**69.3%**	**18.5%**	**45.5%**	**28.9%**	**7.1%**
	Drug/alcohol dependency	**75.0%**	**22.1%**	45.2%	**21.6%**	11.1%
	Physical disability	55.4%	13.1%	41.9%	36.3%	8.7%
	Intellectual disability	**66.1%**	**18.1%**	41.9%	31.6%	8.4%
	Chronic non-terminal illness or injury, 6 months+	56.8%	14.7%	**45.6%**	**31.3%**	8.5%
	Short term non-terminal illness	68.3%	21.0%	30.7%	40.6%	7.7%
Type of care recipient	Care for child/grandchild	**66.7%**	14.9%	**43.9%**	**31.8%**	9.4%
	Care for partner	**49.8%**	11.3%	38.9%	39.6%	10.2%
	Care for parent/grandparent	56.7%	13.8%	37.2%	38.0%	10.9%
	Care for sibling	60.2%	16.0%	34.3%	32.8%	**16.8%**
	Care for friend or other type of relative	65.0%	**19.0%**	37.4%	33.6%	9.9%
Level of assistance needed by care recipient	Low assistance needs	**46.6%**	13.1%	**27.3%**	43.1%	**16.5%**
	Low-moderate assistance needs	**49.6%**	11.4%	34.3%	38.2%	**16.1%**
	Moderate assistance needs	55.0%	**10.1%**	40.5%	39.6%	9.8%
	High assistance needs	**64.4%**	**17.0%**	38.7%	36.0%	8.3%
	Very high assistance needs	58.9%	15.2%	43.5%	**31.7%**	9.7%
Labour force status	Employed	57.1%	**9.3%**	**36.0%**	**40.2%**	**14.5%**
	Unemployed	**77.2%**	**27.9%**	**48.7%**	**20.8%**	**2.7%**
	Not in labour force	55.4%	**16.0%**	42.7%	33.7%	**7.6%**
Past carers	Past carers - all	53.8%	11.0%	35.0%	39.4%	**14.6%**
	Ceased caring in last 6 months	**44.3%**	**5.1%**	38.9%	43.7%	12.3%
	Ceased caring 7-12 months previously	**68.4%**	17.9%	40.4%	32.7%	9.0%
	Ceased caring more than 1 year ago	**45.4%**	**7.3%**	**29.5%**	**46.3%**	**16.8%**

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Financial stress events were less commonly reported by the following types of carers:

- Those aged 55 or older
- Those who were not primary carers
- Those who cared for one person (rather than multiple people)
- Those who had been a carer for a shorter period of time, and
- Those who cared for someone with dementia, old-age related frailty or a physical disability.

Tables 12 and 13 in particular show significant differences in financial stress between age groups. Amongst the general population, risk of experiencing financial stress events is highest amongst young adults, and progressively decreases for older age groups. The same is true for carers; however the financial stress gap between carers and the broader population varies depending on the age group. Carers aged 18-29 were 1.5 times more likely than average to experience financial stress, those aged 30-44 were 1.9 times more likely to, those aged 45 to 64 1.8 times more likely to, and those aged 65 and older were 2.2 times more likely to experience financial stress.

Female carers were somewhat more likely to experience financial stress events than male carers (58.9% compared to 53.6%), however the gap between men and women is smaller for carers than in the general population, with 40.0% of all adult women reporting financial stress events compared to 28.8% of all men. This suggests that taking on a caring role is associated with increased risk of financial stress irrespective of gender.

The second measure of household finances asked carers to self-rate their household financial position using a common measure of household financial wellbeing which is used in a range of surveys, including HILDA survey and the Regional Wellbeing Survey. Participants were asked ‘Given your current needs and financial responsibilities, would you say that you and your family are...’ and able to respond (i) Very poor, (ii) Poor, (iii) Just getting along, (iv) Reasonably comfortable, (v) Comfortable or (vi) Prosperous. carers also reported lower levels of financial wellbeing than other Australian. More than half of all carers – 52.8% - reported that their household was either very poor, poor or just getting along financially, compared to 33.8% of Australians (Figure 13, Tables 12 and 13). Amongst female carers, this rose to 56.6% (compared to 37.3% of adult females across Australia), while amongst male carers 46.0% reported this (compared to 30.3% of adult males).

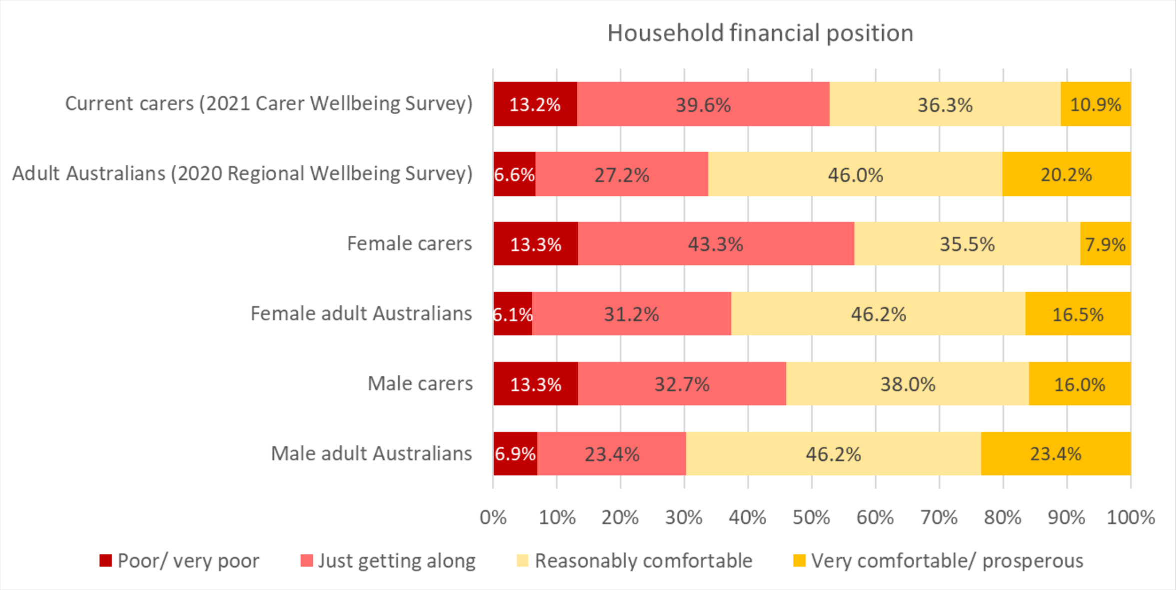


Figure 13 Self-rated household financial position of carers in April/May 2021 compared to adult Australians in Nov/Dec 2020 – by gender

Rates of financial difficulty were highest amongst carers aged 45 to 64: amongst this group, 59.2% reported a household financial position that did not reach the point of being ‘reasonably comfortable), compared to 53.2% of those aged 30 to 44, 49.5% of those aged 18-29 and 36.9% of those aged 65 and older (Figure 14). Carers aged 30 and older were 1.5 times more likely to report a challenging household financial position than others of equivalent age.

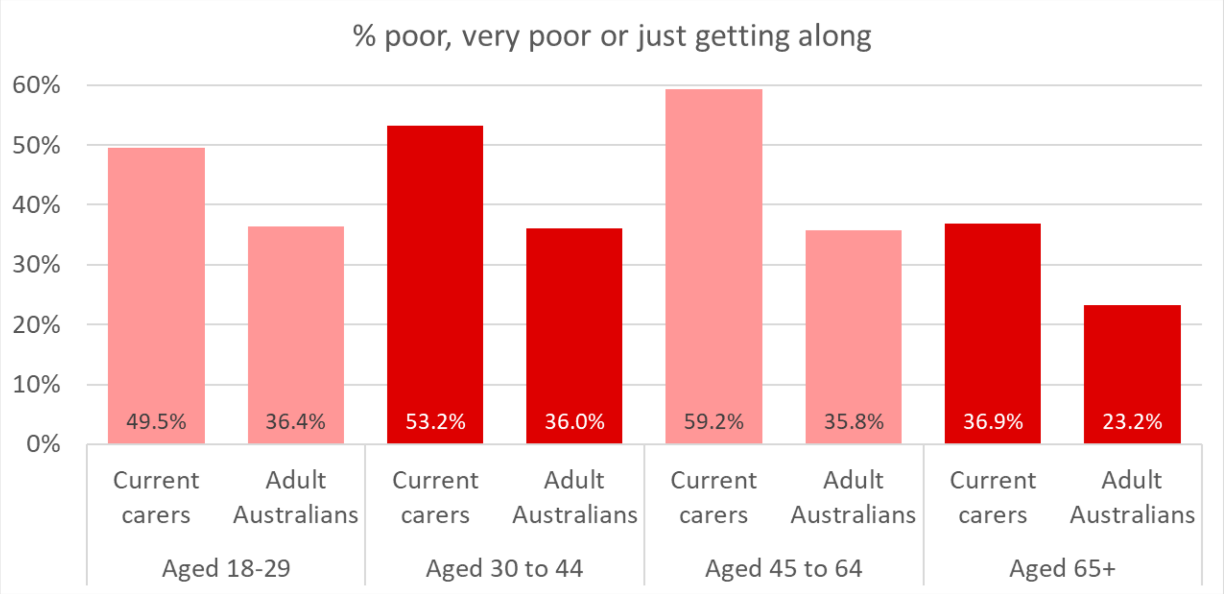


Figure 14 Proportion of carers and adult Australians reporting their household is poor or just getting along financially, by age group

5.5 Housing and telecommunications

Having access to suitable housing and telecommunications can support the quality of life of both carers and the people they care for. Carers were asked if they found it difficult to access or use some parts of their home; if their home met their needs well; and if they had good mobile phone reception and access to high speed, reliable internet from their home (Tables 14 and 15).

Almost one in three carers reported that some parts of their home were difficult to access due to disability or health problems (32.6%), an issue which can reduce effectiveness of the home as a place for high quality caring for both carer and care recipient. Carers who were younger, male, Aboriginal/Torres Strait Islander, or usually spoke a language other than English at home were more likely to report this. However. 74.1% felt their home overall met their needs well. Carers were less likely to report their home met their needs well if they were a primary or sole carer, cared for three or more people, or were caring for a person with a terminal illness. They were more likely to feel their home met their needs well if they cared for a person with relatively low assistance needs.

Most carers (79.3%) had good mobile phone reception at their home, and almost three-quarters (74.3%) had access to high speed, reliable internet in their home.

Table 14 Access to suitable housing and telecommunications (a)

Group	Category	% who found it difficult to access or use some parts of home due to disability/ health problems	% who reported that overall, their home met their needs well	% who had good mobile phone reception at their home	% with access to high speed, reliable internet at home
All current	Current carers	32.6%	74.1%	79.3%	74.3%
Gender	Female	**29.2%**	72.8%	78.9%	72.7%
	Male	**38.1%**	76.2%	80.7%	76.8%
Age	Aged 15-24	**47.6%**	74.8%	72.9%	77.7%
	Aged 25-34	**39.8%**	**68.0%**	**72.5%**	72.9%
	Aged 35-44	**38.3%**	75.4%	**83.5%**	**81.9%**
	Aged 45-54	31.1%	71.9%	77.3%	**69.3%**
	Aged 55-64	**25.4%**	74.5%	77.9%	70.5%
	Aged 65-74	27.9%	77.8%	**84.8%**	78.4%
	Aged 75+	31.5%	77.8%	**87.5%**	76.3%
Typical caring hours per week	<20 hours/week	31.7%	75.9%	80.3%	75.4%
	20-39 hours/week	32.5%	74.8%	79.3%	76.7%
	40+ hours/week	33.9%	71.1%	78.0%	71.6%
Cultural and language diversity	Aboriginal/Torres Strait Islander	**49.1%**	67.1%	73.3%	73.3%
	Not Aboriginal/Torres Strait Islander	32.2%	74.3%	79.5%	74.3%
	Usually speak language other than English at home	**39.9%**	73.1%	78.7%	71.1%
	Usually speak English at home	30.6%	74.3%	79.5%	75.2%
State/ Territory of residence	NSW	33.7%	73.5%	77.7%	73.7%
	Vic	36.2%	75.2%	81.3%	76.3%
	Qld	31.0%	73.2%	**73.4%**	**69.4%**
	SA	28.5%	76.1%	**86.7%**	77.4%
	WA	26.9%	72.7%	79.7%	74.3%
	Tas	36.3%	75.9%	87.2%	79.5%
	NT	42.2%	74.6%	79.3%	72.2%
	ACT	**19.5%**	75.0%	83.8%	79.2%
Primary carer	Primary carer	**29.2%**	**70.9%**	77.2%	72.4%
	Not a primary carer	29.7%	**81.7%**	79.3%	75.1%
Sole/assisted carer	Sole carer	28.7%	**69.6%**	77.6%	**69.8%**
	Assisted in caring role	29.8%	74.6%	77.4%	75.3%
No. people currently caring for	Currently care for 1 person	30.3%	75.9%	81.2%	76.7%
	Currently care for 2 people	35.7%	73.6%	**74.0%**	**69.3%**
	Currently care for 3 or more people	31.7%	**64.8%**	79.2%	70.3%
Caree residence	Caree lives elsewhere	29.2%	77.5%	77.8%	78.7%
	Caree lives in home	31.7%	71.8%	77.4%	71.9%
Length of time being a carer	Carer for 5+ years	30.3%	**70.8%**	**76.3%**	**70.1%**
	Carer for 2-5 years	30.7%	76.8%	**84.0%**	**78.7%**
	Carer for 1-2 years	38.6%	82.5%	**86.5%**	**85.0%**
	Carer for <1 year	32.4%	77.5%	82.1%	79.8%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 15 Access to suitable housing and telecommunications (b)

Group	Category	% who found it difficult to access or use some parts of home due to disability/ health problems	% who reported that overall, their home met their needs well	% who had good mobile phone reception at their home	% with access to high speed, reliable internet at home
Care recipient disability, illness or injury type	Dementia	33.6%	77.7%	79.1%	73.3%
	Old-age related frailty	31.2%	75.9%	79.6%	72.9%
	Terminal illness	38.2%	69.1%	**73.4%**	72.4%
	Autism spectrum disorder	35.6%	71.8%	**75.3%**	72.5%
	Other development disorder	33.6%	70.1%	76.1%	**68.3%**
	Mental illness/psychosocial disability	31.4%	70.6%	76.2%	70.9%
	Drug/alcohol dependency	34.4%	70.2%	79.2%	76.8%
	Physical disability	31.8%	73.2%	79.3%	72.4%
	Intellectual disability	34.4%	70.3%	77.2%	**67.6%**
	Chronic non-terminal illness or injury, 6 months+	29.8%	75.5%	76.3%	73.6%
	Short term non-terminal illness	43.8%	**56.7%**	**54.8%**	**62.2%**
Type of care recipient	Care for child/grandchild	30.4%	71.1%	77.4%	73.1%
	Care for partner	31.9%	75.1%	78.6%	73.9%
	Care for parent/grandparent	33.0%	76.4%	79.1%	73.9%
	Care for sibling	34.2%	73.9%	**71.5%**	69.7%
	Care for friend or other type of relative	37.7%	75.4%	**85.0%**	77.7%
Level of assistance needed by care recipient	Low assistance needs	34.3%	**84.0%**	83.5%	78.7%
	Low-moderate assistance needs	29.6%	73.3%	79.6%	75.9%
	Moderate assistance needs	**25.5%**	76.1%	79.3%	75.7%
	High assistance needs	36.3%	72.4%	79.1%	76.0%
	Very high assistance needs	**37.6%**	72.3%	78.9%	**69.9%**
Labour force status	Employed	33.7%	76.8%	79.9%	76.1%
	Unemployed	30.0%	**65.6%**	**69.8%**	70.5%
	Not in labour force	31.5%	71.9%	79.9%	73.0%
Past carers	Past carers - all	30.3%	**80.8%**	77.0%	76.8%
	Ceased caring in last 6 months	34.3%	79.9%	76.9%	74.2%
	Ceased caring 7-12 months previously	26.7%	75.4%	73.3%	70.3%
	Ceased caring more than 1 year ago	**22.0%**	**87.1%**	76.4%	**80.8%**

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

5.6 Employed carers

Being a carer can present challenges to maintaining participation in the labour force. Overall, 51.6% of current carers were employed, while 4.9% were unemployed and seeking work, and 43.5% were not in the labour force (Tables 16 and 17). Rates of employment amongst carers aged 15 to 64 – the ages in which it is most common for a large proportion of the population to be in paid employment – were compared to rates of employment in the Australian population as of May 2021 (Figure 15). This shows that while the youngest group of carers (aged 15-24) had similar rates of employment to non-carers in that age group, from age 25 onwards, carers are less likely to be employed than others of their age.

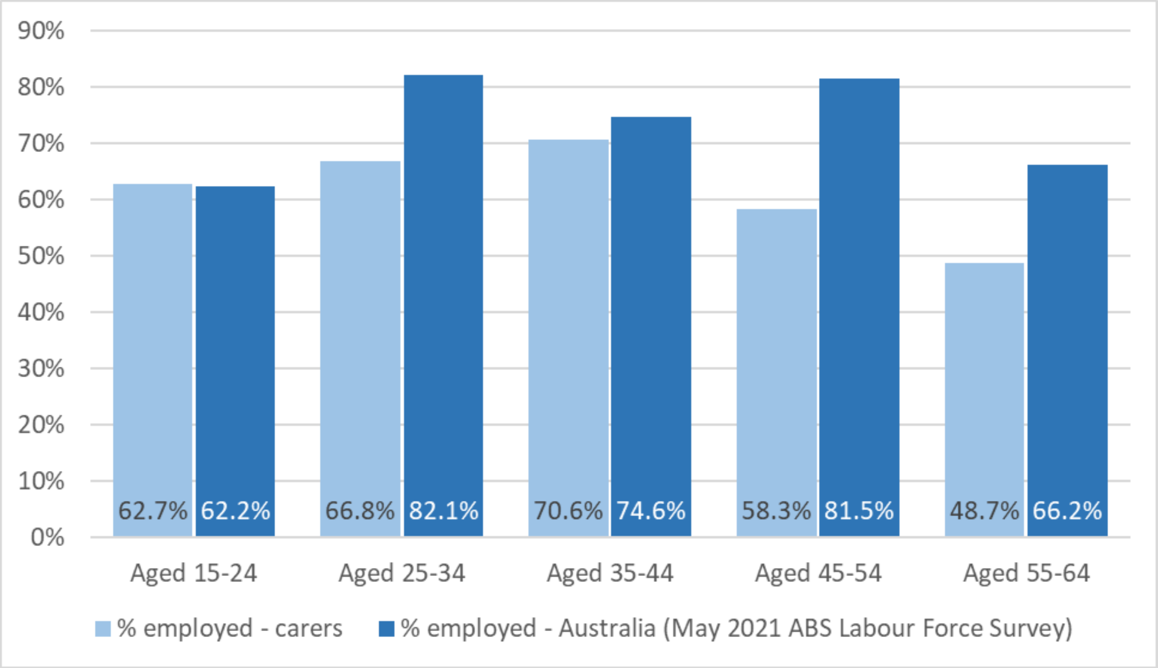


Figure 15 Proportion of different age groups who are employed – comparison of carers to the broader population by age group

Carers were more likely than average to be employed if they were:

- younger (aged 25 to 44 in particular)
- identified as Aboriginal or Torres Strait Islander
- had less than 40 hours of caring obligations weekly
- lived in Victoria
- were not a primary carer
- had assistance in their caring role
- cared for someone with a shorter-term illness, or
- cared for someone with low assistance needs.

Carers were less likely than average to be employed if they were:

- older
- had high caring obligations in terms of both caring hours per week and the assistance needs of the people cared for
- cared for a person with a physical disability, or
- were the primary/sole carer.

The likelihood of a carer being employed was lower amongst those who had been carers for a longer period of time: 47.4% of those who had been a carer for five years or more were employed compared to 61.4% of those who had been a carer for less than a year.

Carers who were employed were asked about the flexibility and security of their work, and whether their employer was understanding regarding their caring obligations (Tables 16 to 19).

Of those carers who were employed, a quarter – 24.4% - had no flexibility in their work hours, while 48.0% had somewhat flexible work hours, and 27.6% had very flexible work hours. The flexibility of work hours did not differ significantly between most types of carers.

Of those carers with employment, 22.1% reported their job was very insecure, 48.5% that it was somewhat secure, and 29.3% that it was very secure (Tables 18 and 19). This did not vary significantly between most types of carers.

When asked if their employer or supervisor were understanding of their caring obligations 17.2% reported they were not very understanding, 41.6% that they were somewhat understanding, and 41.3% that they were very understanding. Younger carers were more likely than other employed carers to report their employers were not very understanding (23.5% of those aged 15-24 and employed, and 25.7% of those aged 25 to 34).

Table 16 Engagement in paid work, and flexibility of work hours (a)

		Current labour force status			Employed carers – flexibility of work hours		
Group	**Category**	**% employed**	**% unemployed**	**% not in labour force**	**Not flexible**	**Somewhat flexible**	**Very flexible**
All current	Current carers	51.6%	4.9%	43.5%	24.4%	48.0%	27.6%
Gender	Female	50.2%	4.7%	45.1%	26.7%	46.0%	27.3%
	Male	53.7%	5.1%	41.2%	19.0%	53.7%	27.3%
Age	Aged 15-24	**62.7%**	**10.8%**	**26.5%**	13.0%	**67.2%**	19.8%
	Aged 25-34	**66.8%**	7.2%	**26.0%**	27.8%	47.4%	24.7%
	Aged 35-44	**70.6%**	5.6%	**23.9%**	30.3%	47.0%	22.7%
	Aged 45-54	**58.3%**	4.9%	**36.8%**	19.8%	54.0%	26.2%
	Aged 55-64	48.7%	5.4%	45.9%	26.3%	43.9%	29.8%
	Aged 65-74	**21.9%**	**0.7%**	**77.4%**	18.7%	**22.4%**	**58.9%**
	Aged 75+	Too few respondents to report					
Typical caring hours per week	<20 hours/week	**57.9%**	5.9%	**36.2%**	21.6%	51.7%	26.8%
	20-39 hours/week	**60.2%**	4.7%	**35.1%**	23.7%	44.7%	31.6%
	40+ hours/week	**38.1%**	3.6%	**58.4%**	29.7%	44.6%	25.7%
Cultural and language diversity	Aboriginal/Torres Strait Islander	**71.9%**	5.8%	**22.3%**	21.9%	55.4%	22.6%
	Not Aboriginal/Torres Strait Islander	51.1%	4.8%	44.0%	24.6%	47.6%	27.9%
	Usually speak language other than English at home	54.1%	6.0%	39.9%	21.9%	49.2%	28.9%
	Usually speak English at home	50.9%	4.5%	44.5%	25.2%	47.6%	27.2%
State/ Territory of residence	NSW	55.7%	4.9%	**39.4%**	19.9%	52.9%	27.1%
	Vic	**56.5%**	3.6%	39.9%	25.5%	47.4%	27.1%
	Qld	**40.3%**	6.7%	**53.0%**	25.9%	38.4%	35.7%
	SA	**37.7%**	4.3%	**58.0%**	32.0%	43.4%	24.6%
	WA	52.3%	5.8%	41.9%	29.5%	53.2%	**17.3%**
	Tas	47.9%	4.2%	47.8%	32.2%	40.7%	27.1%
	NT	66.1%	3.9%	29.9%	14.3%	32.6%	53.0%
	ACT	62.6%	1.4%	36.0%	19.6%	44.9%	35.5%
Primary carer	Primary carer	**46.8%**	4.8%	**48.4%**	23.6%	47.7%	28.7%
	Not a primary carer	**68.9%**	3.1%	**28.0%**	22.4%	53.9%	23.7%
Sole or assisted carer	Sole carer	**39.3%**	5.3%	**55.4%**	22.4%	43.9%	33.7%
	Assisted in caring role	**58.3%**	4.0%	**37.7%**	23.8%	51.3%	24.8%
No. people currently caring for	Currently care for 1 person	51.9%	4.5%	43.5%	23.8%	49.8%	26.4%
	Currently care for 2 people	53.0%	6.1%	41.0%	23.2%	44.7%	32.1%
	Currently care for 3 or more people	54.4%	3.3%	42.2%	21.9%	49.8%	28.3%
Caree residence	Caree lives elsewhere	**68.9%**	5.2%	**25.9%**	19.4%	57.0%	23.6%
	Caree lives in home	**48.0%**	4.4%	**47.6%**	24.4%	46.7%	28.9%
Length of time being a carer	Carer for 5+ years	**47.4%**	4.8%	**47.8%**	27.9%	43.1%	28.9%
	Carer for 2-5 years	52.5%	4.0%	43.5%	21.1%	55.2%	23.7%
	Carer for 1-2 years	**58.3%**	4.1%	37.5%	**11.8%**	46.2%	**42.0%**
	Carer for <1 year	**61.4%**	**9.6%**	**29.0%**	26.3%	55.6%	18.2%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 17 Engagement in paid work, and flexibility of work hours (b)

		Current labour force status			Employed carers – flexibility of work hours		
Group	**Category**	**% employed**	**% unemployed**	**% not in labour force**	**Not flexible**	**Somewhat flexible**	**Very flexible**
Care recipient disability, illness or injury type	Dementia	50.5%	4.3%	45.2%	21.0%	48.7%	30.3%
	Old-age related frailty	54.5%	4.9%	40.7%	21.9%	55.6%	22.6%
	Terminal illness	56.0%	7.0%	**37.0%**	19.3%	59.6%	21.1%
	Autism spectrum disorder	**59.4%**	5.5%	**35.1%**	24.7%	47.3%	28.0%
	Other development disorder	54.2%	5.0%	40.8%	26.3%	45.8%	27.9%
	Mental illness/psychosocial disability	52.7%	4.6%	42.7%	28.2%	43.9%	27.9%
	Drug/alcohol dependency	55.5%	**8.2%**	**36.3%**	16.4%	51.0%	32.6%
	Physical disability	**44.5%**	4.9%	**50.6%**	23.7%	51.1%	25.3%
	Intellectual disability	48.1%	5.4%	46.5%	23.3%	50.6%	26.1%
	Chronic non-terminal illness or injury, 6 months+	48.3%	3.3%	**48.4%**	24.6%	46.7%	28.7%
	Short term non-terminal illness	**72.8%**	1.3%	**25.9%**	**42.3%**	51.8%	**5.9%**
Type of care recipient	Care for child/grandchild	**56.3%**	3.7%	40.0%	28.3%	44.4%	27.2%
	Care for partner	**40.5%**	**2.9%**	**56.6%**	20.4%	45.9%	33.8%
	Care for parent/grandparent	**58.5%**	6.6%	**34.9%**	21.0%	54.9%	24.0%
	Care for sibling	54.8%	**9.7%**	35.5%	28.2%	33.0%	38.9%
	Care for friend or other type of relative	**59.2%**	6.5%	**34.3%**	25.3%	54.3%	20.3%
Level of assistance needed by care recipient	Low assistance needs	**63.8%**	4.5%	**31.7%**	23.7%	57.0%	19.3%
	Low-moderate assistance needs	**61.6%**	3.2%	**35.2%**	24.7%	49.1%	26.2%
	Moderate assistance needs	55.7%	5.4%	**38.9%**	19.0%	49.7%	31.3%
	High assistance needs	50.0%	5.5%	44.5%	25.2%	41.5%	33.4%
	Very high assistance needs	**43.4%**	4.5%	**52.1%**	25.8%	51.8%	22.4%
Past carers	Past carers - all	**57.9%**	**10.7%**	**31.4%**	27.8%	50.6%	21.6%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 18 Security of employment and flexibility of employers (a)

		Security of employment			Extent to which supervisor/ employer understanding of caring obligations		
Group	**Category**	**Insecure**	**Somewhat secure**	**Very secure**	**Not very**	**Somewhat**	**Very understanding**
All current	Current carers	22.1%	48.5%	29.3%	17.2%	41.6%	41.3%
Gender	Female	22.7%	47.6%	29.7%	17.0%	43.0%	39.9%
	Male	20.8%	50.2%	29.0%	17.2%	38.2%	44.6%
Age	Aged 15-24	18.3%	56.1%	25.6%	**23.5%**	27.9%	48.6%
	Aged 25-34	23.7%	50.6%	25.7%	**25.7%**	33.5%	40.8%
	Aged 35-44	21.9%	48.8%	29.4%	14.6%	42.5%	43.0%
	Aged 45-54	24.3%	51.5%	24.3%	16.3%	49.9%	33.8%
	Aged 55-64	19.3%	46.3%	34.4%	14.1%	41.3%	44.6%
	Aged 65-74	26.4%	**29.6%**	**44.0%**	21.5%	26.2%	52.3%
	Aged 75+	Too few respondents to report					
Typical caring hours per week	<20 hours/week	17.4%	50.3%	32.3%	18.2%	39.1%	42.7%
	20-39 hours/week	22.6%	47.6%	29.7%	18.2%	47.6%	34.2%
	40+ hours/week	**29.3%**	46.3%	24.4%	14.7%	41.0%	44.2%
Cultural and language diversity	Aboriginal/Torres Strait Islander	26.3%	38.6%	35.0%	19.1%	30.1%	50.8%
	Not Aboriginal/Torres Strait Islander	22.0%	49.0%	29.0%	17.2%	42.1%	40.7%
	Usually speak language other than English at home	24.9%	52.2%	22.8%	17.4%	**31.7%**	**50.9%**
	Usually speak English at home	21.3%	47.4%	31.3%	17.1%	44.6%	38.3%
State/ Territory of residence	NSW	23.2%	48.2%	28.6%	18.1%	40.6%	41.3%
	Vic	19.7%	51.8%	28.5%	17.8%	40.2%	42.0%
	Qld	26.1%	45.7%	28.2%	12.4%	44.7%	42.9%
	SA	24.8%	40.9%	34.3%	21.3%	42.1%	36.5%
	WA	20.7%	48.8%	30.5%	16.1%	47.2%	36.7%
	Tas	30.6%	42.9%	26.6%	28.1%	32.2%	39.6%
	NT	13.9%	64.6%	21.4%	10.8%	39.6%	49.6%
	ACT	15.3%	39.2%	45.5%	10.6%	37.3%	52.1%
Primary carer	Primary carer	24.5%	47.6%	27.9%	17.2%	43.0%	39.8%
	Not a primary carer	**9.8%**	52.9%	37.3%	17.9%	36.9%	45.2%
Sole or assisted carer	Sole carer	26.2%	44.3%	29.5%	16.7%	41.1%	42.2%
	Assisted in caring role	19.4%	50.9%	29.7%	17.7%	42.2%	40.1%
No. people currently caring for	Currently care for 1 person	20.1%	48.4%	31.5%	17.2%	42.3%	40.5%
	Currently care for 2 people	23.6%	49.9%	26.5%	17.2%	42.0%	40.8%
	Currently care for 3 or more people	29.1%	48.4%	22.6%	18.9%	38.1%	43.0%
Caree residence	Caree lives elsewhere	18.7%	49.5%	31.8%	18.2%	46.5%	35.3%
	Caree lives in home	22.5%	48.4%	29.1%	17.2%	40.7%	42.1%
Length of time being a carer	Carer for 5+ years	25.8%	46.4%	27.8%	17.3%	44.0%	38.7%
	Carer for 2-5 years	17.6%	50.5%	31.8%	22.3%	35.5%	42.3%
	Carer for 1-2 years	14.3%	53.0%	32.6%	**7.1%**	46.6%	46.3%
	Carer for <1 year	19.5%	54.7%	25.8%	14.0%	35.6%	50.4%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 19 Security of employment and flexibility of employers (b)

		Security of employment			Extent to which supervisor/ employer understanding of caring obligations		
Group	**Category**	**Insecure**	**Somewhat secure**	**Insecure**	**Not very**	**Somewhat**	**Very underst-anding**
Care recipient disability, illness or injury type	Dementia	21.3%	46.6%	32.1%	22.4%	44.0%	33.6%
	Old-age related frailty	20.7%	54.0%	25.3%	21.4%	44.5%	34.1%
	Terminal illness	26.8%	51.6%	21.5%	16.3%	36.0%	**47.7%**
	Autism spectrum disorder	28.7%	44.6%	26.7%	18.2%	42.7%	39.2%
	Other development disorder	28.3%	45.9%	25.8%	17.6%	47.3%	35.1%
	Mental illness/psychosocial disability	**30.5%**	47.0%	**22.5%**	22.8%	41.6%	35.6%
	Drug/alcohol dependency	29.7%	49.5%	20.8%	23.0%	42.9%	34.1%
	Physical disability	18.9%	51.4%	29.7%	17.6%	42.0%	40.5%
	Intellectual disability	26.1%	47.7%	26.2%	18.4%	39.4%	42.3%
	Chronic non-terminal illness or injury, 6 months+	19.3%	52.0%	28.7%	18.0%	40.8%	41.2%
	Short term non-terminal illness	**42.3%**	53.0%	**4.7%**	30.1%	34.1%	35.9%
Type of care recipient	Care for child/grandchild	27.8%	43.2%	29.0%	18.9%	40.9%	40.1%
	Care for partner	22.4%	44.3%	33.2%	13.1%	37.5%	49.3%
	Care for parent/grandparent	19.5%	54.1%	26.4%	19.9%	41.8%	38.3%
	Care for sibling	21.8%	56.6%	21.6%	9.1%	57.1%	33.8%
	Care for friend or other type of relative	23.4%	46.7%	29.9%	20.7%	36.8%	42.5%
Level of assistance needed by care recipient	Low assistance needs	**5.9%**	58.2%	35.9%	12.6%	46.0%	41.4%
	Low-moderate assistance needs	23.9%	43.2%	32.9%	17.7%	47.7%	34.7%
	Moderate assistance needs	20.2%	49.4%	30.3%	16.6%	39.7%	43.7%
	High assistance needs	26.1%	52.8%	**21.0%**	15.2%	40.9%	43.9%
	Very high assistance needs	23.3%	44.3%	32.4%	22.1%	39.5%	38.4%
Past carers	Past carers - all	26.7%	47.0%	26.3%	**2.8%**	24.9%	**72.3%**

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

5.7 Benefits experienced by carers

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, and finding being a carer an overall positive experience (Tables 20 and 21). They were also asked if being a carer had strengthened their relationship with the person or people they cared for, and whether they had learned new skills due to being a carer (Tables 22 and 23).

Overall, 54.1% of carers found being a carer satisfying, while 26.9% did not. The remainder neither agreed or disagreed that being a carer was satisfying.

Female carers were less likely than male carers to report experiencing most types of benefits including finding being a carer satisfying (49.5% of female carers compared to 62.2% of men), as were those aged 45 to 54 (47.3%), and those caring for a person with mental illness (49.7%) or drug/alcohol dependency (40.7%). Those aged 35 to 44 were more likely to report finding being a carer satisfying than other age groups (59.2%). Very similar findings were identified when carers were asked whether being a carer contributed to their meaning and purpose in life.

Slightly fewer, however, reported that they often found being a carer a positive experience: 50.1% agreed with this statement and 31.5% disagreed. Female carers were less likely to agree and male carers more likely to; those who were Aboriginal or Torres Strait Islander were more likely to agree, and those caring for a person with mental illness or drug/alcohol dependency less likely to (43.2% and 41.5% respectively).

Many carers – 58.6% - felt that being a carer had strengthened their relationship with the people they cared for, while just over one in four (27.1%) disagreed with this. Those caring for a person with dementia, or with drug/alcohol dependency, were less likely to feel their relationship had strengthened than others (50.5% and 47.4% respectively).

Almost two thirds of carers – 65.2% - reported that they had learned new skills due to being a carer. Those was somewhat less common amongst those who cared for a person with dementia (58.6%), and those caring for a partner (57.8%, with many of those caring for partners who had dementia). Learning new skills was more common amongst those who cared for a person with ASD (73.0%), other development disorder (76.9%) or intellectual disability (74.6%), as well as amongst those caring for a child or grandchild (71.0%).

Table 20 Benefits of caring: satisfaction, meaning and positive experience (a)

Group	Category	Overall, I find it satisfying being a carer		Being a carer contributes to my meaning and purpose in life		I often find being a carer a positive experience	
		% disagree	% agree	% disagree	% agree	% disagree	% agree
All current	Current carers	26.9%	54.1%	28.1%	55.3%	31.5%	50.1%
Gender	Female	29.2%	**49.5%**	30.7%	**51.5%**	**35.3%**	**44.1%**
	Male	**23.0%**	**62.2%**	**23.1%**	**62.7%**	**24.5%**	**61.1%**
Age	Aged 15-24	20.7%	59.5%	**20.4%**	**63.5%**	**16.5%**	55.6%
	Aged 25-34	26.3%	56.3%	25.1%	59.7%	29.3%	48.7%
	Aged 35-44	**21.1%**	**59.2%**	**22.2%**	**62.8%**	27.9%	**56.6%**
	Aged 45-54	**33.4%**	**47.3%**	**34.1%**	**50.1%**	**38.8%**	**43.9%**
	Aged 55-64	28.7%	54.1%	28.9%	52.5%	31.4%	50.0%
	Aged 65-74	25.3%	54.7%	30.1%	51.0%	32.2%	49.1%
	Aged 75+	21.4%	56.2%	27.2%	57.4%	30.7%	54.1%
Typical caring hours per week	<20 hours/week	25.2%	55.0%	26.3%	54.9%	29.6%	49.9%
	20-39 hours/week	24.6%	56.2%	26.4%	59.7%	29.1%	**55.8%**
	40+ hours/week	30.5%	51.6%	31.4%	53.3%	**35.4%**	47.2%
Cultural and language diversity	Aboriginal/Torres Strait Islander	23.4%	62.4%	21.7%	58.8%	**20.8%**	**65.2%**
	Not Aboriginal/Torres Strait Islander	26.9%	53.9%	28.0%	55.4%	31.7%	49.7%
	Usually speak language other than English at home	25.0%	55.5%	24.6%	59.2%	30.4%	54.3%
	Usually speak English at home	27.3%	53.5%	28.9%	54.3%	31.9%	48.8%
State/ Territory of residence	NSW	26.6%	53.8%	27.6%	54.1%	32.2%	51.0%
	Vic	29.5%	52.7%	29.8%	55.6%	32.2%	47.3%
	Qld	27.6%	52.9%	28.5%	56.1%	31.9%	49.4%
	SA	**20.6%**	**61.5%**	24.7%	60.8%	26.9%	55.7%
	WA	23.6%	53.5%	27.6%	52.6%	30.5%	50.4%
	Tas	22.7%	57.8%	21.6%	60.9%	26.0%	53.6%
	NT	12.6%	68.8%	15.2%	64.2%	19.7%	62.6%
	ACT	34.9%	46.1%	33.2%	46.8%	42.3%	42.1%
Primary carer	Primary carer	29.1%	52.0%	30.2%	53.0%	**35.2%**	**46.3%**
	Not a primary carer	22.1%	55.7%	26.5%	55.5%	25.8%	54.5%
Sole or assisted carer	Sole carer	28.8%	52.6%	31.3%	51.4%	**35.9%**	46.2%
	Assisted in caring role	27.7%	52.5%	28.4%	55.0%	32.4%	48.3%
No. people currently caring for	Currently care for 1 person	27.1%	53.5%	29.4%	54.3%	32.5%	49.4%
	Currently care for 2 people	27.5%	53.5%	26.1%	54.4%	32.6%	47.1%
	Currently care for 3 or more people	25.9%	58.4%	26.0%	61.0%	27.9%	54.4%
Caree residence	Caree lives elsewhere	24.5%	53.4%	25.2%	54.8%	29.1%	49.5%
	Caree lives in home	28.8%	52.4%	30.5%	53.1%	**34.8%**	46.9%
Length of time being a carer	Carer for 5+ years	28.0%	53.7%	27.8%	55.2%	32.7%	49.3%
	Carer for 2-5 years	27.6%	53.4%	29.0%	54.6%	32.9%	47.8%
	Carer for 1-2 years	21.8%	54.9%	27.3%	55.0%	**24.1%**	**57.1%**
	Carer for <1 year	22.8%	57.9%	28.3%	57.7%	26.2%	54.7%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 21 Benefits of caring: satisfaction, meaning and positive experience (b)

		Overall, I find it satisfying being a carer		Being a carer contributes to my meaning and purpose in life		I often find being a carer a positive experience	
Group	**Category**	**% disagree**	**% agree**	**% disagree**	**% agree**	**% disagree**	**% agree**
Care recipient disability, illness or injury type	Dementia	30.2%	49.5%	32.1%	50.8%	35.7%	48.5%
	Old-age related frailty	**22.7%**	57.0%	25.4%	58.1%	**27.2%**	53.8%
	Terminal illness	26.7%	55.4%	25.8%	60.0%	32.1%	47.0%
	Autism spectrum disorder	30.1%	52.1%	27.5%	55.7%	34.9%	46.7%
	Other development disorder	29.9%	51.2%	29.6%	56.0%	34.7%	48.1%
	Mental illness/psychosocial disability	**32.1%**	**49.7%**	**32.1%**	**51.0%**	**37.5%**	**43.2%**
	Drug/alcohol dependency	**38.1%**	**40.7%**	34.5%	48.5%	**40.1%**	**41.5%**
	Physical disability	25.8%	56.3%	27.4%	56.4%	30.9%	50.8%
	Intellectual disability	27.5%	53.8%	27.3%	55.3%	33.0%	50.3%
	Chronic non-terminal illness or injury, 6 months+	27.6%	54.2%	31.0%	53.8%	34.5%	49.6%
	Short term non-terminal illness	25.9%	55.9%	25.8%	57.0%	31.4%	54.1%
Type of care recipient	Care for child/grandchild	29.1%	51.6%	29.6%	54.5%	33.3%	47.5%
	Care for partner	29.4%	51.8%	31.5%	**51.0%**	**35.9%**	46.4%
	Care for parent/grandparent	23.9%	55.6%	25.1%	58.0%	28.7%	51.9%
	Care for sibling	28.3%	53.3%	24.4%	53.9%	32.8%	45.6%
	Care for friend or other type of relative	**19.0%**	**68.0%**	**17.3%**	**68.8%**	**17.4%**	**68.6%**
Level of assistance needed by care recipient	Low assistance needs	27.4%	57.9%	26.7%	52.7%	26.2%	52.6%
	Low-moderate assistance needs	26.6%	52.7%	29.9%	53.7%	30.1%	48.4%
	Moderate assistance needs	24.4%	54.9%	26.4%	54.2%	31.4%	47.4%
	High assistance needs	28.4%	53.8%	28.8%	56.8%	31.9%	53.2%
	Very high assistance needs	29.4%	52.3%	29.8%	55.8%	**36.0%**	47.9%
Labour force status	Employed	25.5%	55.3%	26.8%	56.7%	30.0%	50.8%
	Unemployed	**38.1%**	47.9%	34.6%	49.7%	**39.7%**	47.8%
	Not in labour force	26.6%	53.3%	28.3%	54.8%	32.0%	50.0%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 22 Benefits of caring: relationships and skills (a)

Group	Category	Being a carer has strengthened my relationship with the person/people I care for		I have learned new skills due to being a carer	
		% disagree	% agree	% disagree	% agree
All current	Current carers	27.1%	58.6%	20.6%	65.2%
Gender	Female	**30.5%**	**54.7%**	22.4%	64.1%
	Male	**21.6%**	**64.5%**	**16.6%**	68.1%
Age	Aged 15-24	22.2%	59.7%	**11.9%**	72.6%
	Aged 25-34	23.4%	64.6%	**14.7%**	67.5%
	Aged 35-44	**22.6%**	**65.8%**	**14.5%**	**75.7%**
	Aged 45-54	28.8%	55.2%	21.8%	66.7%
	Aged 55-64	28.9%	57.1%	24.1%	**60.6%**
	Aged 65-74	30.6%	54.5%	**28.2%**	**55.8%**
	Aged 75+	29.3%	55.8%	20.6%	60.0%
Typical caring hours per week	<20 hours/week	26.1%	58.7%	21.5%	63.0%
	20-39 hours/week	27.3%	60.4%	18.7%	68.6%
	40+ hours/week	28.4%	57.5%	20.6%	66.2%
Cultural and language diversity	Aboriginal/Torres Strait Islander	23.7%	60.6%	15.0%	65.1%
	Not Aboriginal/Torres Strait Islander	27.3%	58.4%	20.5%	65.4%
	Usually speak language other than English at home	25.0%	61.9%	19.0%	68.8%
	Usually speak English at home	28.0%	57.4%	21.0%	64.2%
State/ Territory of residence	NSW	28.0%	58.2%	20.0%	66.9%
	Vic	27.1%	59.0%	21.1%	62.1%
	Qld	27.4%	57.7%	20.4%	66.9%
	SA	24.2%	60.4%	18.4%	69.1%
	WA	26.8%	57.2%	21.1%	63.7%
	Tas	22.2%	65.0%	19.9%	66.8%
	NT	24.2%	54.6%	21.1%	61.0%
	ACT	33.7%	51.7%	27.8%	60.8%
Primary carer	Primary carer	29.8%	56.3%	21.8%	64.0%
	Not a primary carer	23.7%	60.3%	17.6%	68.5%
Sole or assisted carer	Sole carer	29.3%	56.5%	**25.5%**	**60.5%**
	Assisted in caring role	28.7%	57.0%	17.6%	68.1%
No. people currently caring for	Currently care for 1 person	28.1%	57.5%	21.3%	63.7%
	Currently care for 2 people	27.9%	58.2%	21.1%	66.1%
	Currently care for 3 or more people	22.5%	62.6%	**14.7%**	**72.4%**
Caree residence	Caree lives elsewhere	25.1%	58.6%	18.4%	64.3%
	Caree lives in home	29.7%	56.4%	21.7%	64.6%
Length of time being a carer	Carer for 5+ years	27.3%	59.4%	18.7%	67.4%
	Carer for 2-5 years	28.5%	55.6%	**25.2%**	**60.6%**
	Carer for 1-2 years	25.1%	55.6%	20.7%	66.6%
	Carer for <1 year	23.9%	**65.4%**	21.5%	59.9%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 23 Benefits of caring: relationships and skills (b)

		Being a carer has strengthened my relationship with the person/people I care for		I have learned new skills due to being a carer	
Group	**Category**	**% disagree**	**% agree**	**% disagree**	**% disagree**
Care recipient disability, illness or injury type	Dementia	**32.2%**	**50.5%**	**27.1%**	**58.6%**
	Old-age related frailty	25.8%	59.2%	**24.2%**	61.8%
	Terminal illness	29.6%	56.5%	23.1%	62.9%
	Autism spectrum disorder	26.1%	61.1%	**14.6%**	**73.0%**
	Other development disorder	27.5%	60.2%	**12.4%**	**76.9%**
	Mental illness/psychosocial disability	**31.3%**	55.2%	20.0%	67.3%
	Drug/alcohol dependency	**37.6%**	**47.4%**	22.9%	64.2%
	Physical disability	27.2%	59.5%	22.4%	64.8%
	Intellectual disability	26.0%	62.4%	**13.5%**	**74.6%**
	Chronic non-terminal illness or injury, 6 months+	27.1%	59.0%	24.0%	63.4%
	Short term non-terminal illness	34.9%	61.0%	14.6%	57.9%
Type of care recipient	Care for child/grandchild	25.9%	60.9%	**14.8%**	**71.0%**
	Care for partner	**33.1%**	**51.9%**	**27.5%**	**57.8%**
	Care for parent/grandparent	24.9%	58.6%	22.5%	63.9%
	Care for sibling	29.3%	55.3%	16.6%	68.5%
	Care for friend or other type of relative	**20.0%**	**71.6%**	**13.7%**	**74.0%**
Level of assistance needed by care recipient	Low assistance needs	23.5%	59.1%	23.0%	63.2%
	Low-moderate assistance needs	26.1%	58.0%	23.3%	**58.1%**
	Moderate assistance needs	29.5%	55.8%	21.0%	64.7%
	High assistance needs	27.4%	59.3%	20.2%	64.7%
	Very high assistance needs	27.4%	59.6%	18.5%	**70.0%**
Labour force status	Employed	26.3%	59.4%	**17.3%**	68.1%
	Unemployed	**39.0%**	**49.1%**	27.2%	60.0%
	Not in labour force	26.9%	58.2%	23.2%	62.7%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

5.8 Challenges and burdens experienced

5.8.1 Overall challenges and burdens experienced

Carers can experience many burdens. The *Caregiver Burden Scale* (Zarit et al. 1980) was included in the survey. This scale asks multiple questions about different types of burden a carer may experience, asking them how often they feel or experience a range of burdens associated with their caring role, on a five point scale from never (0) to nearly always (4). It is then possible to score total carer burden by summing the scores for each type of burden.

While the total carer burden scale is important, it is also important to understand which types of burden are more and less common amongst different types of carers. Figure 16 identifies the burdens that carers were more and less likely to report experiencing on a regular basis. The most common burdens carers reported experiencing on a regular basis were fear for the future of the people they cared for (66.5% of carers), and not having sufficient time for themselves (64.0%). Between 50% and 57% regularly experienced negative impacts on their social life, fear of not having enough money, overload of responsibilities, and concern about whether they could continue providing care. Almost half reported that they regularly felt they had lost control of their life, their own health was negatively impacted by their caring duties, they wanted to do more for the people they cared for, and/or an overall sense of strain. Tables 24 to 31 provide detailed results for each of the items asked in the *Caregiver Burden Scale.*

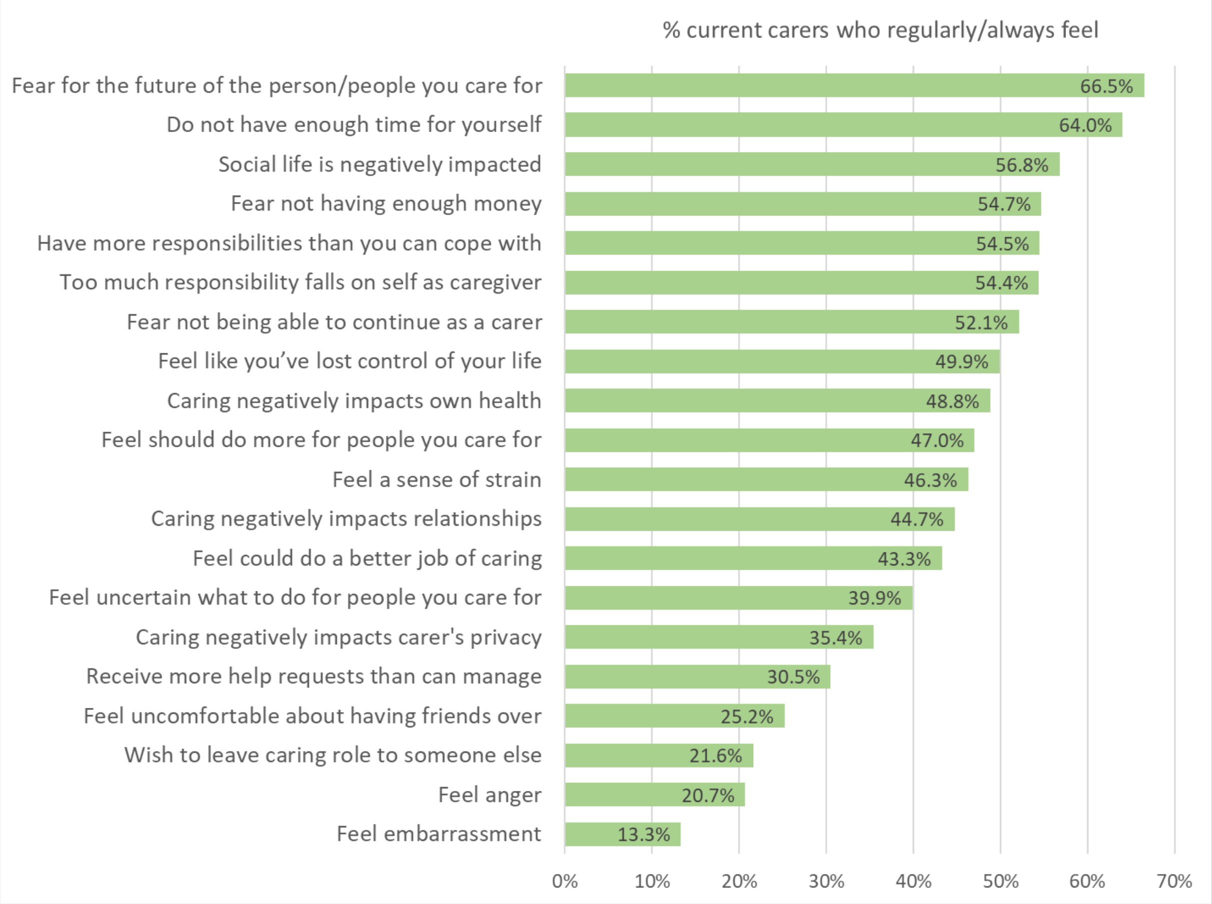


Figure 16 Burdens carers reported experiencing regularly

5.8.2 Lack of time, coping with caring, and knowing what to do

The first questions in the Caregiver Burden Scale asked about carer's ability to have time for themselves, and feeling able to do a good job of caring (Tables 24 and 25). Overall:

- **Having time for yourself:** 64.0% of current carers regularly or always felt they did not have enough time for themselves, particularly female carers (68.6%), those aged 35-44 (72.5%) and 45-54 (72.6%), those with high caring hours (75.3%), caring for three or more people (74.9%), primary carers (68.7%), and those who cared for people living in the same home (68.5%). It was also higher than average amongst those caring for people with ASD (74.9%), development disorders (78.0%), and intellectual disability (69.4%), caring for a person with high (71.3%) or very high (74.7%) assistance needs, and caring for a child/grandchild (71.8%).
- **Being able to cope with caring responsibilities:** 54.5% of carers felt they have more responsibilities than they can cope with, particularly female carers (60.9%), those aged 35-44 (68.8%, 45-54 (62.7%), those with 40 hours or more caring obligations weekly (63.0%), primary carers (58.8%), and those caring for two (68.0%) or three or more people (65.3%). It was also higher than average amongst those caring for people with terminal illness (63.8%), ASD (68.7%), development disorders (73.0%), mental illness/psychosocial disability (66.2%), intellectual disability (64.4%), or for any person with high (61.9%) or very high (65.6%) assistance needs, for a child/grandchild (66.0%), and those who were employed (60.0%).
- **Having control over your life:** 49.9% often felt they had lost control of their lives. This was more common amongst female carers, those aged 35 to 54, and those with higher caring obligations in terms of hours, number of people cared for and being a primary carer. It was also high amongst those caring for people with terminal illness (58.4%), ASD (57.5%), other development disorders (63.8%), mental illness/psychosocial disability (58.1%), drug/alcohol dependency (57.7%) and intellectual disability (56.8%), those caring for a person with very high assistance needs (59.9%), and those caring for a child or grandchild (66.0%).
- **Knowing what to do as a carer:** Fewer carers – 39.9% - regularly or always felt uncertain about what to do for the person or people they cared for. This was more common amongst carers aged 35-44 (45.1%), Aboriginal/Torres Strait Islander carers (51.3%), those caring for a person with a mental illness/psychosocial disability (49.1%), drug/alcohol dependency (48.2%), or for a child/grandchild (44.3%).
- **Feeling you should do more as a carer:** 47.0% regularly/always felt they should do more for the person or people they cared for, particularly those aged 35-44, those caring for two people, those caring for a person with ASD (59.0%), other development disorder (59.4%), mental illness/psychosocial disability (52.2%), intellectual disability (56.7%), a person with very high caring needs (52.2%), those a child or grandchild (55.6%), and amongst those carers who were employed (52.7%).
- **Feeling you could do a better job of caring:** 43.3% felt they could do a better job of caring, particularly those aged 15-24 (56.1%) and 35-44 (52.9%), those who identified as Aboriginal or Torres Strait Islander (58.6%), those caring for two or more people (49.8%), those caring for a person with ASD (52.6%), other development disorder (51.3%), mental illness/psychosocial disability (48.3%), intellectual disability (49.5%), with very high caring needs (48.6%), those caring for a child or grandchild (49.9%), and those who were employed (49.0%) or unemployed and looking for work (57.1%).

Table 24 Carer challenges experienced: time, responsibilities, control and competence (a)

Group	Category	% who regularly or always feel					
		There is not enough time for yourself	You have more respons-ibilities than you can cope with	Like you've lost control of your life	Uncertain about what to do for the person/ people you care for	Like you should do more for the person/ people you care for	Like you could do a better job of caring
All current	Current carers	64.0%	54.5%	49.9%	39.9%	47.0%	43.3%
Gender	Female	**68.6%**	**60.9%**	**54.8%**	41.4%	47.7%	43.4%
	Male	**56.6%**	**44.0%**	**43.2%**	39.0%	45.3%	43.8%
Age	Aged 15-24	**55.1%**	52.9%	**37.9%**	41.6%	50.6%	**56.1%**
	Aged 25-34	**54.9%**	51.8%	47.4%	45.3%	50.7%	48.7%
	Aged 35-44	**72.5%**	**68.8%**	**56.7%**	**45.1%**	**59.1%**	**52.9%**
	Aged 45-54	**72.6%**	**62.7%**	**57.3%**	44.0%	51.4%	45.7%
	Aged 55-64	65.1%	51.6%	50.6%	36.2%	43.8%	40.5%
	Aged 65-74	**55.5%**	**41.9%**	**42.7%**	34.7%	**35.3%**	**31.5%**
	Aged 75+	**49.1%**	**31.4%**	**32.7%**	**27.8%**	**27.9%**	**28.2%**
Typical caring hours per week	<20 hours/week	**55.9%**	**48.7%**	46.2%	39.6%	46.3%	43.1%
	20-39 hours/week	63.0%	52.9%	**43.0%**	40.8%	44.9%	43.2%
	40+ hours/week	**75.3%**	**63.0%**	**58.6%**	39.8%	49.1%	43.7%
Cultural and language diversity	Aboriginal/Torres Strait Islander	64.9%	57.0%	55.6%	**51.3%**	57.6%	**58.6%**
	Not Aboriginal/Torres Strait Islander	64.3%	55.0%	50.4%	40.3%	46.6%	43.2%
	Usually speak language other than English at home	61.6%	55.1%	45.4%	38.5%	44.9%	40.7%
	Usually speak English at home	65.1%	54.7%	52.1%	41.1%	47.5%	44.4%
State/ Territory of residence	NSW	62.0%	57.2%	49.8%	41.3%	47.1%	46.6%
	Vic	67.4%	54.7%	51.0%	40.9%	47.0%	43.4%
	Qld	64.7%	55.3%	**56.4%**	41.7%	48.4%	41.1%
	SA	63.1%	53.0%	47.4%	37.8%	45.3%	38.8%
	WA	65.4%	50.1%	47.6%	38.0%	45.1%	42.0%
	Tas	60.9%	47.3%	40.2%	33.0%	45.3%	38.9%
	NT	49.4%	38.9%	**30.7%**	**20.9%**	37.3%	34.5%
	ACT	66.7%	55.4%	49.6%	48.7%	46.1%	44.9%
Primary carer	Primary carer	**68.7%**	**58.8%**	**55.2%**	41.0%	46.8%	44.0%
	Not a primary carer	**53.8%**	**45.8%**	**41.4%**	42.2%	51.6%	49.9%
Sole or assisted carer	Sole carer	65.8%	56.3%	54.0%	42.8%	44.4%	43.2%
	Assisted in caring role	67.8%	57.9%	52.9%	39.7%	49.9%	46.1%
No. people currently caring for	Currently care for 1 person	62.6%	**49.0%**	47.4%	39.5%	**43.7%**	42.2%
	Currently care for 2 people	65.4%	**68.0%**	**56.6%**	43.9%	**55.6%**	**49.8%**
	Currently care for 3 or more people	**74.9%**	**65.3%**	**56.9%**	35.7%	50.8%	42.5%
Caree residence	Caree lives elsewhere	**57.4%**	52.2%	46.2%	44.8%	51.5%	46.8%
	Caree lives in home	**68.5%**	**58.0%**	**54.7%**	40.5%	46.7%	44.4%
Length of time being a carer	Carer for 5+ years	65.7%	**58.2%**	**53.7%**	40.1%	47.0%	42.8%
	Carer for 2-5 years	65.3%	**49.7%**	46.9%	37.8%	49.5%	44.4%
	Carer for 1-2 years	61.6%	49.9%	**42.0%**	42.3%	41.3%	41.0%
	Carer for <1 year	**50.0%**	**46.2%**	**39.4%**	41.2%	46.1%	46.4%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 25 Carer challenges experienced: time, responsibilities, control and competence (b)

		% who regularly or always feel					
Group	**Category**	**There is not enough time for yourself**	**You have more respons-ibilities than you can cope with**	**Like you've lost control of your life**	**Uncertain about what to do for the person/ people you care for**	**Like you should do more for the person/ people you care for**	**Like you could do a better job of caring**
Care recipient disability, illness or injury type	Dementia	68.1%	55.2%	53.3%	41.5%	43.5%	43.6%
	Old-age related frailty	**60.1%**	**50.0%**	47.6%	37.7%	45.3%	41.8%
	Terminal illness	63.8%	**63.8%**	**58.4%**	40.2%	49.6%	39.8%
	Autism spectrum disorder	**74.9%**	**68.7%**	**57.5%**	43.2%	**59.0%**	**52.6%**
	Other development disorder	**78.0%**	**73.0%**	**63.8%**	40.6%	**59.4%**	**51.3%**
	Mental illness/psychosocial disability	67.6%	**66.2%**	**58.1%**	**49.1%**	**52.2%**	**48.3%**
	Drug/alcohol dependency	65.8%	61.4%	**57.7%**	**48.2%**	45.6%	43.5%
	Physical disability	64.5%	53.1%	52.2%	**35.8%**	45.1%	40.9%
	Intellectual disability	**69.4%**	**64.4%**	**58.3%**	37.8%	**56.7%**	**49.5%**
	Chronic non-terminal illness or injury, 6 months+	62.0%	57.1%	48.2%	38.2%	44.2%	42.2%
	Short term non-terminal illness	**50.7%**	53.3%	40.7%	36.5%	39.6%	44.9%
Type of care recipient	Care for child/grandchild	**71.8%**	**66.0%**	**56.8%**	**44.3%**	**55.6%**	**49.9%**
	Care for partner	61.5%	50.9%	48.7%	36.3%	**39.2%**	**36.6%**
	Care for parent/grandparent	61.8%	53.1%	49.3%	40.6%	47.8%	44.2%
	Care for sibling	57.6%	59.6%	46.4%	33.6%	46.0%	45.9%
	Care for friend or other type of relative	**56.7%**	**39.2%**	**36.2%**	**29.9%**	44.0%	40.2%
Level of assistance needed by care recipient	Low assistance needs	**44.5%**	**32.3%**	**31.6%**	38.6%	46.2%	47.3%
	Low-moderate assistance needs	**48.5%**	**42.0%**	**42.0%**	35.6%	**40.4%**	39.3%
	Moderate assistance needs	63.3%	52.6%	48.9%	40.7%	44.6%	42.7%
	High assistance needs	**71.3%**	**61.9%**	53.0%	40.8%	49.1%	42.0%
	Very high assistance needs	**74.7%**	**65.6%**	**59.9%**	42.1%	**52.2%**	**48.6%**
Labour force status	Employed	66.6%	**60.0%**	50.5%	42.7%	**52.7%**	**49.0%**
	Unemployed	61.7%	54.9%	55.9%	**50.2%**	46.8%	**57.1%**
	Not in labour force	62.4%	**49.1%**	49.8%	37.4%	**40.7%**	**36.6%**

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

5.8.3 Feeling strain, anger, embarrassment or uncomfortable

When asked about burden related to feeling a sense of strain, anger, embarrassment or feeling uncomfortable having friends over (Tables 26 and 27):

- **Feeling strain:** 46.3% regularly or always felt a sense of strain, particularly carers with 40 or more hours a week of caring obligations, caring for two people (55.9%), caring for a person with dementia (56.6%), ASM (52.2%), development disorder (51.8%), mental illness (56.6%), or drug or alcohol dependency (58.4%), or for any person with very high assistance needs (55.9%).
- **Feeling anger:** 20.7% regularly or always felt anger. This was more common amongst carers aged 15-24 (31.0%), those who identified as Aboriginal or Torres Strait Islander (33.7%), those caring for a person with dementia (25.3%) and those carers who were unemployed and seeking work (28.7%).
- **Feeling embarrassed:** Relatively few carers - 13.3% - regularly or always felt embarrassment. This was more common amongst male carers (17.6%), carers aged 15-24 (29.8%) and 35-44 (17.8%), who identified as Aboriginal or Torres Strait Islander (27.0%), caring for two people (17.4%), caring for a person with a terminal illness (20.2%) or drug/alcohol dependency (21.6%), and carers who were employed (16.0%).
- **Feeling uncomfortable having friends over:** 25.2% regularly or always felt uncomfortable about having friends over. This was more common amongst younger carers, with 37.4% of carers aged 15-24, 35.3% of those aged 25-34, and 32.9% of those aged 35-44 reporting this, whereas amongst those aged 65 to 74 only 14.4% reported this, and only 12.3% of carers aged 75 and older. This was also more common amongst carers identifying as Aboriginal or Torres Strait Islander (37.6%), and those caring for two people (33.3%). Carers were more likely to feel uncomfortable having friends over if they cared for a person with ASD (36.1%), mental illness (34.3%), drug/alcohol dependency (42.8%), high assistance needs in general (30.4%), or if the carer was unemployed (35.6%).

Table 26 Carer challenges experienced: negative emotions and difficulty having friends over (a)

		% who regularly or always feel, when with the person/people they care for…			
Group	**Category**	**A sense of strain**	**Anger**	**Embarrass-ment**	**Uncomfortable about having friends over**
All current	Current carers	46.3%	20.7%	13.3%	25.2%
Gender	Female	49.2%	19.4%	**10.9%**	25.0%
	Male	42.9%	23.3%	**17.6%**	25.3%
Age	Aged 15-24	**36.8%**	**31.0%**	**29.8%**	**37.4%**
	Aged 25-34	41.3%	24.0%	16.8%	**35.3%**
	Aged 35-44	48.3%	24.7%	**17.8%**	**32.9%**
	Aged 45-54	50.8%	22.5%	13.6%	26.5%
	Aged 55-64	48.0%	18.2%	**10.0%**	**21.2%**
	Aged 65-74	46.9%	**15.7%**	**7.5%**	**14.4%**
	Aged 75+	**34.1%**	**9.1%**	**4.8%**	**12.3%**
Typical caring hours per week	<20 hours/week	43.4%	22.4%	13.9%	23.2%
	20-39 hours/week	43.2%	22.0%	14.2%	27.7%
	40+ hours/week	**52.0%**	17.9%	12.2%	26.7%
Cultural and language diversity	Aboriginal/Torres Strait Islander	44.7%	**33.7%**	**27.0%**	**37.6%**
	Not Aboriginal/Torres Strait Islander	47.0%	20.6%	13.0%	24.9%
	Usually speak language other than English at home	43.7%	22.1%	11.8%	21.6%
	Usually speak English at home	47.9%	20.3%	13.7%	26.4%
State/ Territory of residence	NSW	48.0%	23.0%	15.9%	26.2%
	Vic	47.1%	22.4%	15.1%	25.8%
	Qld	49.2%	20.5%	11.3%	26.1%
	SA	40.5%	**14.9%**	**7.4%**	20.7%
	WA	45.6%	**15.4%**	**8.1%**	25.0%
	Tas	41.4%	15.5%	7.5%	19.2%
	NT	29.0%	10.1%	17.5%	24.1%
	ACT	46.1%	14.5%	**4.9%**	16.9%
Primary carer	Primary carer	47.3%	20.1%	12.5%	25.9%
	Not a primary carer	45.3%	18.1%	**7.5%**	**18.3%**
Sole or assisted carer	Sole carer	46.8%	20.7%	11.1%	25.5%
	Assisted in caring role	47.2%	19.2%	12.6%	24.4%
No. people currently caring for	Currently care for 1 person	**42.9%**	19.8%	12.2%	**22.0%**
	Currently care for 2 people	**55.9%**	**24.9%**	**17.4%**	**33.3%**
	Currently care for 3 or more people	48.0%	17.3%	**9.2%**	29.6%
Caree residence	Caree lives elsewhere	48.9%	18.5%	9.4%	**14.9%**
	Caree lives in home	46.8%	20.1%	12.3%	26.6%
Length of time being a carer	Carer for 5+ years	47.4%	18.9%	13.2%	26.9%
	Carer for 2-5 years	46.4%	22.2%	14.3%	**21.2%**
	Carer for 1-2 years	42.7%	23.9%	10.4%	26.7%
	Carer for <1 year	42.6%	26.2%	14.5%	23.2%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 27 Carer challenges experienced: negative emotions and difficulty having friends over (b)

		% who regularly or always feel, when with the person/people they care for…			
Group	**Category**	**A sense of strain**	**Anger**	**Embarrass-ment**	**Uncomfortable about having friends over**
Care recipient disability, illness or injury type	Dementia	**56.6%**	**25.3%**	14.8%	23.3%
	Old-age related frailty	47.1%	19.3%	11.0%	23.6%
	Terminal illness	49.6%	24.8%	**20.2%**	30.8%
	Autism spectrum disorder	**52.2%**	21.8%	15.6%	**36.1%**
	Other development disorder	**51.8%**	21.5%	17.1%	**33.4%**
	Mental illness/psychosocial disability	**56.6%**	22.6%	13.0%	**34.3%**
	Drug/alcohol dependency	**58.4%**	36.2%	**21.6%**	**42.8%**
	Physical disability	45.7%	18.1%	10.8%	23.4%
	Intellectual disability	48.1%	17.4%	13.3%	28.7%
	Chronic non-terminal illness or injury, 6 months+	47.1%	17.1%	**7.0%**	**19.4%**
	Short term non-terminal illness	39.9%	27.2%	18.4%	31.2%
Type of care recipient	Care for child/grandchild	49.5%	19.4%	14.1%	**29.3%**
	Care for partner	45.0%	22.0%	11.1%	21.9%
	Care for parent/grandparent	48.6%	21.1%	12.9%	26.0%
	Care for sibling	39.9%	20.0%	14.8%	31.6%
	Care for friend or other type of relative	**36.3%**	18.1%	13.5%	24.6%
Level of assistance needed by care recipient	Low assistance needs	**34.6%**	18.4%	14.0%	**18.9%**
	Low-moderate assistance needs	**34.0%**	19.7%	13.2%	**17.9%**
	Moderate assistance needs	44.8%	22.2%	12.0%	23.9%
	High assistance needs	49.6%	20.9%	14.2%	**30.4%**
	Very high assistance needs	**55.9%**	20.3%	13.1%	28.8%
Labour force status	Employed	48.0%	23.7%	**16.0%**	26.6%
	Unemployed	53.5%	**28.7%**	12.7%	**35.6%**
	Not in labour force	45.4%	**16.8%**	**10.4%**	23.0%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

5.8.4 Impacts on social life, relationships, health and privacy

Caring can have many impacts on a person's social life, relationships, health and privacy (Tables 28 and 29). When asked about this:

- **Impacts on social life:** 56.8% felt their caring responsibilities regularly or always negatively impacted their social life. This was more common amongst carers aged 45-54 (65.3%), those with 40 or more hours spent caring weekly (70.1%), those who were primary carers (63.2%) or sole carers (61.5%), those who cared for two people (62.4%) and those who cared for a person living in the same home as them (63.5%). Social life was more likely to be negatively impacted if a person cared for someone with dementia (61.7%), ASD (66.8%), development disorder (67.5%), mental illness (61.5%), intellectual disability (66.0%), or with high (64.2%) or very high (72.8%) assistance needs; and amongst those caring for a child/grandchild (63.6%).
- **Impacts on relationships with family and friends:** 44.7% felt their caring responsibilities regularly or always negatively impacted their relationships with family and friends. This was higher for female carers than male carers (48.2% compared to 38.6% for men), amongst carers aged 35-44 (52.6%) and 45-54 (53.8%), with 40 or more hours of caring obligations a week (56.5%), who were primary carers (49.4%), cared for two people (53.7%) or three or more people (51.6%), or for a person living in their home (50.0%). Relationships were also more likely to be negatively impacted amongst carers caring for a person with a terminal illness (54.1%), ASD (58.0%), development disorder (61.1%), mental illness (54.7%) or intellectual disability (54.7%), or for any person with high (55.1%) or very high (59.4%) assistance needs. Those caring for children or grandchildren were also more likely to report this (54.0%).
- **Impacts on carer's health:** 48.7% felt their caring responsibilities regularly or always negatively impacted their health. This was more common amongst female carers (52.3%) than male carers (43.8%), and amongst carers aged 35-44 (58.6%) and 45-54 (57.6%), those with 40 hours or more a week of caring obligations (56.1%), who were primary carers (53.6%), caring for two people (57.9%), or for a person living in their home (52.3%). Carers were more likely to report negative impacts on their health if they cared for a person with ASD (60.0%), development disorder (61.5%), mental illness (60.2%), intellectual disability (54.9%), or any person with high (58.7%) or very high (58.5%) assistance needs. Those caring for a child or grandchild were also more likely to report negative impacts on health (56.9%).
- **Impacts on carer's privacy:** 35.4% felt their caring responsibilities regularly or always negatively impacted the level of privacy they had. This was more common amongst carers aged 35-44 (43.2%) and 45-54 (40.2%), with 40+ weekly caring hours (45.7%), who identified as Aboriginal or Torres Strait Islander (47.2%), cared for two people (42.9%); and amongst those who cared for a person with ASD (47.4%), development disorder (49.5%), mental illness (42.6%), or intellectual disability (44.4%), or more generally for a person with high (41.2%) or very high (46.3%) assistance needs, and/or for a child or grandchild (44.3%).

Table 28 Carer challenges experienced: negative impacts on social life, relationships, health and privacy (a)

		% who feel that their caring responsibilities and duties regularly or always negatively impact…			
Group	**Category**	**Social life**	**Relationships with family and friends**	**Carer's health**	**Carer's privacy**
All current	Current carers	56.8%	44.7%	48.8%	35.4%
Gender	Female	60.0%	**48.2%**	**52.3%**	38.2%
	Male	**52.1%**	**38.6%**	**43.8%**	**30.3%**
Age	Aged 15-24	**42.8%**	39.7%	**35.6%**	37.6%
	Aged 25-34	**49.5%**	**38.0%**	48.3%	31.2%
	Aged 35-44	61.8%	**52.6%**	**58.6%**	**43.2%**
	Aged 45-54	**65.3%**	**53.8%**	**57.6%**	**40.2%**
	Aged 55-64	57.0%	44.1%	46.6%	36.8%
	Aged 65-74	**50.7%**	**36.6%**	**40.7%**	**28.0%**
	Aged 75+	**48.0%**	**27.8%**	**28.5%**	**14.9%**
Typical caring hours per week	<20 hours/week	**46.4%**	**35.8%**	**43.0%**	**28.3%**
	20-39 hours/week	57.6%	44.8%	49.5%	33.7%
	40+ hours/week	**70.1%**	**56.5%**	**56.1%**	**45.7%**
Cultural and language diversity	Aboriginal/Torres Strait Islander	52.3%	49.4%	46.9%	**47.2%**
	Not Aboriginal/Torres Strait Islander	57.4%	44.7%	49.4%	35.0%
	Usually speak language other than English at home	52.0%	46.0%	47.4%	35.3%
	Usually speak English at home	58.8%	44.4%	49.8%	35.0%
State/ Territory of residence	NSW	57.1%	43.1%	47.0%	35.8%
	Vic	59.0%	45.4%	50.4%	34.0%
	Qld	59.3%	47.6%	**54.3%**	38.6%
	SA	53.4%	41.6%	46.8%	31.5%
	WA	59.5%	48.7%	49.5%	34.6%
	Tas	**43.2%**	37.1%	41.1%	29.5%
	NT	**32.1%**	32.3%	**26.4%**	35.3%
	ACT	47.0%	43.3%	57.4%	27.9%
Primary carer	Primary carer	**63.2%**	**49.4%**	**53.6%**	38.4%
	Not a primary carer	**43.2%**	38.5%	**31.4%**	**23.0%**
Sole or assisted carer	Sole carer	**61.5%**	46.9%	52.2%	38.4%
	Assisted in caring role	60.0%	**49.0%**	49.6%	34.8%
No. people currently caring for	Currently care for 1 person	55.0%	41.9%	**45.0%**	32.2%
	Currently care for 2 people	**62.4%**	**53.7%**	**57.9%**	**42.9%**
	Currently care for 3 or more people	62.1%	**51.6%**	54.4%	41.1%
Caree residence	Caree lives elsewhere	**44.0%**	**36.2%**	**42.1%**	**22.1%**
	Caree lives in home	**63.5%**	**50.0%**	**52.3%**	**38.9%**
Length of time being a carer	Carer for 5+ years	59.1%	47.3%	51.3%	**39.1%**
	Carer for 2-5 years	54.9%	41.0%	46.4%	**29.5%**
	Carer for 1-2 years	58.4%	45.5%	47.1%	**29.2%**
	Carer for <1 year	**42.2%**	**35.3%**	**39.2%**	32.6%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 29 Carer challenges experienced: negative impacts on social life, relationships, health and privacy (b)

		% who feel that their caring responsibilities and duties regularly or always negatively impact…			
Group	**Category**	**Social life**	**Relationships with family and friends**	**Carer's health**	**Carer's privacy**
Care recipient disability, illness or injury type	Dementia	**61.7%**	48.3%	49.2%	35.9%
	Old-age related frailty	55.2%	43.5%	45.2%	32.8%
	Terminal illness	61.5%	**54.1%**	54.2%	36.0%
	Autism spectrum disorder	**66.8%**	**58.0%**	**60.0%**	**47.4%**
	Other development disorder	**67.5%**	**61.1%**	**61.5%**	**49.5%**
	Mental illness/psychosocial disability	**61.3%**	**54.7%**	**60.2%**	**42.6%**
	Drug/alcohol dependency	59.9%	47.0%	51.9%	41.3%
	Physical disability	58.8%	46.0%	49.6%	35.7%
	Intellectual disability	**66.0%**	**57.6%**	**54.9%**	**44.4%**
	Chronic non-terminal illness or injury, 6 months+	54.8%	46.1%	51.5%	35.2%
	Short term non-terminal illness	46.9%	34.1%	**34.0%**	43.3%
Type of care recipient	Care for child/grandchild	**63.6%**	**54.0%**	**56.9%**	**44.3%**
	Care for partner	56.7%	**40.1%**	46.4%	**26.4%**
	Care for parent/grandparent	56.9%	44.4%	47.5%	38.1%
	Care for sibling	**43.4%**	43.3%	46.8%	32.8%
	Care for friend or other type of relative	**40.8%**	**35.4%**	**37.1%**	**25.3%**
Level of assistance needed by care recipient	Low assistance needs	**32.6%**	**22.8%**	**32.7%**	**18.0%**
	Low-moderate assistance needs	**35.7%**	**27.4%**	**32.9%**	**21.9%**
	Moderate assistance needs	55.8%	41.4%	45.2%	32.8%
	High assistance needs	**64.2%**	**55.1%**	**58.7%**	**41.2%**
	Very high assistance needs	**72.8%**	**59.4%**	**58.5%**	**46.3%**
Labour force status	Employed	55.7%	44.3%	48.7%	35.1%
	Unemployed	57.2%	47.9%	55.3%	41.7%
	Not in labour force	59.0%	44.6%	49.1%	34.0%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

5.8.5 Coping with caring requests, responsibility, and planning for the future

Carers were asked how often they felt they received more help request than they could manage, had too much responsibilities, feared the future, not having enough money or not being able to continue their caring role, or wished to leave the care of the person or people they cared for to someone else (Tables 30 and 31). Overall findings had similarities to many of those for other types of burden, reported on previous pages:

- **Having more help requests than the carer can manage:** 30.5% of carers regularly received more help requests than they could manage. This was more common for carers aged between 25 and 54 (35% or higher), who were employed (34.3%), caring for two people (43.6%) or three or more people (43.3%). It was also higher for those caring for a person with a terminal illness (40.5%), ASD (42.0%), development disorder (38.7%), mental illness (38.8%), or drug or alcohol dependency (44.8%), or for any person with high (37.6%) or very high assistance needs (35.9%)
- **Feeling too much responsibility falls on the carer:** 54.4% of carers regularly or always felt that too much responsibility fell on themselves as the caregiver. This was much more common amongst female carers (63.0%) than male carers (39.8%), amongst carers aged 35-44 (64.4%) and 45-54 (64.2%) compared to those of other ages, and amongst carers with 40 hours or more weekly caring obligations (63.2%). Those who were the primary carers were also more likely to report this (59.8%), and were those caring for two people (66.1%) or three or more people (64.8%). Those who had been a carer for five years or more were much more likely to report this (58.7%) compared to those who had been a carer for less time – for example, 41.2% of those who had been a carer less than a year felt too much responsibility fell on them. It was also higher for those caring for a person with ASD (67.4%), development disorder (67.1%), mental illness (64.4%), intellectual disability (62.8%) or drug or alcohol dependency (61.7%), or for any person with high (65.9%) or very high assistance needs (65.7%). Those caring for a child/grandchild (64.9%) or who were unemployed and looking for work (66.5%) were also more likely to report this than average.
- **Fearing for the future of the person/people cared for:** Most carers – 66.5% - regularly or always fear for the future of the person or people they care for. This was more often the case for men than women, for carers aged 45-54 and those with high caring obligations in the form of high caring hours, being a primary carer, or caring for more than one person. Fear for the future was also higher the longer the person had been a carer, increasing from 52.8% of those who had been a carer for less than a year to 70.3% amongst those who had been a carer for five or more years. It was also higher for those caring for a person with ASD (79.0%), development disorder (78.5%), mental illness (75.0%), drug/alcohol dependency (79.5%) or intellectual

disability (77.0%), very high assistance needs (77.6%) and those caring for a child/grandchild (77.7%).

- **Fearing not having enough money to care for the people being cared for:** 54.7% of carers fear not having enough money to continue caring for the people they are responsible for. This was again most common amongst carers aged 35 to 54, those with 40 or more hours of caring obligations weekly, primary and sole carers, and those caring for more than one person. This was more common amongst those caring for a person with ASD (69.9%), development disorder (72.7%), mental illness (66.5%) or intellectual disability (66.4%), or for a person with high (62.4%) or very high assistance needs (63.2%). Those caring for a child/grandchild were more likely to report this (64.2%) than those caring for partners, parents, siblings or friends, as were those who were unemployed and looking for work (68.4%).
- **Fearing not being able to continue caring for the people being cared for:** 52.1% of carers regularly or always fear they may not be able to continue caring for the people they care for. This was higher amongst carers aged 45-54 (57.7%), those with 40 or more hours of caring obligations weekly (62.1%), and was higher for those who had been a carer for a longer period of time. It was particularly high amongst those caring for a child/grandchild (60.2%), for a person with ASD (63.9%), development disorder (61.8%), mental illness (59.5%), intellectual disability (67.3%) or for any person with very high assistance needs (63.2%).
- **Wishing to leave caring obligations to someone else:** Only 21.6% of carers reported they regularly or always wished to be able to leave the care of the person or people they cared for to someone else. However, this still represents slightly more than one in every five carers. This was higher amongst young carers – those aged 15-24 (30.5%) and 25-34 (28.5%), those who were employed (30.1%) and amongst Aboriginal and Torres Strait Islander carers (33.3%) (many of whom are also in younger age groups). It was also higher amongst secondary carers (27.5%). However, the group for whom this was higher than any other were those caring for a person with mental illness/psychosocial disability (35.0%).

Table 30 Carer challenges experienced: obligations and fear for the future (a)

Group	Category	% who regularly or always feel					
		Receive more help requests than can manage	Too much responsi-bility falls on self as caregiver	Fear the future regarding person/ people care for	Fear not having enough money to care for person/ people care for	Fear not being able to continue caring for person/ people care for	Wish to leave the care of the person/ people cared for to someone else
All current	Current carers	30.5%	54.4%	66.5%	54.7%	52.1%	21.6%
Gender	Female	31.8%	**63.0%**	**71.1%**	57.7%	53.9%	19.2%
	Male	27.8%	**39.8%**	**58.8%**	**49.8%**	48.7%	24.2%
Age	Aged 15-24	**21.9%**	47.2%	**55.8%**	50.8%	45.6%	**30.5%**
	Aged 25-34	**37.3%**	**47.3%**	61.6%	53.2%	46.5%	**28.5%**
	Aged 35-44	**44.1%**	**64.4%**	70.1%	**66.6%**	49.2%	23.1%
	Aged 45-54	**35.2%**	**64.2%**	**72.3%**	**67.8%**	**57.7%**	22.4%
	Aged 55-64	**25.9%**	53.4%	66.4%	51.0%	54.0%	19.7%
	Aged 65-74	**20.4%**	**46.3%**	64.4%	**39.9%**	49.9%	17.7%
	Aged 75+	**13.6%**	**33.6%**	**58.9%**	**29.1%**	51.7%	**11.3%**
Typical caring hours per week	<20 hours/week	28.6%	**47.5%**	**61.1%**	**47.7%**	**46.5%**	23.2%
	20-39 hours/week	33.9%	54.9%	63.1%	52.5%	47.5%	25.2%
	40+ hours/week	31.1%	**63.2%**	**75.7%**	**65.3%**	**62.1%**	**17.4%**
Cultural and language diversity	Aboriginal/Torres Strait Islander	39.2%	52.5%	68.2%	62.7%	51.2%	**33.3%**
	Not Aboriginal/Torres Strait Isla.	30.3%	54.7%	66.5%	54.5%	51.9%	20.9%
	Usually speak language other than English at home	26.6%	57.3%	66.7%	54.5%	53.8%	19.2%
	Usually speak English at home	31.7%	53.9%	66.7%	54.9%	51.6%	21.3%
State/ Territory of residence	NSW	32.5%	53.1%	67.3%	53.7%	52.4%	23.1%
	Vic	30.4%	57.8%	68.9%	54.1%	50.7%	22.9%
	Qld	32.4%	56.4%	63.8%	**61.9%**	55.4%	20.7%
	SA	25.0%	50.4%	62.9%	53.1%	48.4%	**11.4%**
	WA	25.6%	54.3%	67.4%	52.9%	51.6%	17.9%
	Tas	25.4%	42.5%	61.4%	44.6%	48.0%	13.8%
	NT	26.2%	47.3%	61.1%	50.2%	47.3%	15.0%
	ACT	24.3%	53.7%	69.8%	45.8%	50.4%	15.3%
Primary carer	Primary carer	31.4%	**59.8%**	**70.0%**	**60.4%**	**55.8%**	20.6%
	Not a primary carer	27.8%	**45.4%**	64.1%	**40.8%**	52.4%	**27.5%**
Sole or assisted carer	Sole carer	28.5%	57.3%	69.1%	**62.9%**	54.6%	19.4%
	Assisted in caring role	33.1%	**58.6%**	69.4%	53.8%	56.0%	23.2%
No. people currently caring for	Currently care for 1 person	**24.6%**	**49.7%**	63.7%	**50.6%**	49.9%	20.2%
	Currently care for 2 people	**43.6%**	**66.1%**	**74.6%**	**60.5%**	56.5%	**26.6%**
	Currently care for 3 or more people	**43.3%**	**64.8%**	70.1%	**70.3%**	57.7%	18.0%
Caree residence	Caree lives elsewhere	33.4%	54.0%	67.5%	**47.1%**	49.4%	26.1%
	Caree lives in home	30.6%	**58.7%**	69.6%	**59.8%**	**56.4%**	20.7%
Length of time being a carer	Carer for 5+ years	31.3%	**58.7%**	**70.3%**	**59.0%**	**56.8%**	20.3%
	Carer for 2-5 years	29.0%	50.1%	65.1%	**47.9%**	**47.3%**	21.9%
	Carer for 1-2 years	25.8%	48.6%	**57.6%**	49.7%	45.9%	25.1%
	Carer for <1 year	34.6%	**41.2%**	**52.8%**	48.9%	**38.6%**	26.7%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 31 Carer challenges experienced: obligations and fear for the future (b)

		% who regularly or always feel					
Group	**Category**	**Receive more help requests than can manage**	**Too much responsi-bility falls on self as caregiver**	**Fear the future regarding person/ people care for**	**Fear not having enough money to care for person/ people care for**	**Fear not being able to continue caring for person/ people care for**	**Wish to leave the care of the person/ people cared for to someone else**
Care recipient disability, illness or injury type	Dementia	30.3%	57.3%	64.2%	**45.8%**	51.9%	20.2%
	Old-age related frailty	31.8%	54.9%	**59.1%**	**47.9%**	**47.0%**	23.4%
	Terminal illness	**40.5%**	57.7%	69.8%	58.1%	48.6%	23.1%
	Autism spectrum disorder	**42.0%**	**67.4%**	**79.0%**	**69.9%**	**63.9%**	19.5%
	Other development disorder	**38.7%**	**67.1%**	**78.5%**	**72.7%**	**61.8%**	**25.5%**
	Mental illness/psychosocial disability	**38.8%**	**64.4%**	**75.0%**	**66.5%**	**59.5%**	**35.0%**
	Drug/alcohol dependency	**44.8%**	**61.7%**	**79.5%**	60.2%	58.6%	19.4%
	Physical disability	29.6%	55.9%	65.8%	55.7%	53.6%	22.9%
	Intellectual disability	32.0%	**62.8%**	**77.0%**	**66.4%**	**67.3%**	19.1%
	Chronic non-terminal illness or injury, 6 months+	30.0%	57.0%	68.4%	59.4%	51.6%	22.6%
	Short term non-terminal illness	33.8%	43.3%	**54.5%**	**34.5%**	44.3%	22.0%
Type of care recipient	Care for child/grandchild	**36.4%**	**64.9%**	**77.7%**	**64.2%**	**60.2%**	**18.2%**
	Care for partner	**25.6%**	**49.7%**	64.7%	53.4%	49.0%	23.6%
	Care for parent/grandparent	33.5%	55.8%	**61.8%**	**50.2%**	48.3%	24.1%
	Care for sibling	30.9%	51.2%	67.6%	55.0%	56.4%	21.1%
	Care for friend or other type of relative	33.8%	**42.0%**	**55.0%**	47.9%	49.0%	23.9%
Level of assistance needed by care recipient	Low assistance needs	**20.5%**	**34.1%**	**58.5%**	**38.7%**	**42.5%**	19.5%
	Low-moderate assistance needs	**18.7%**	**37.5%**	**55.7%**	**38.5%**	**39.7%**	19.2%
	Moderate assistance needs	29.4%	51.4%	65.5%	53.6%	47.9%	21.5%
	High assistance needs	**37.6%**	**65.9%**	65.8%	**62.4%**	56.0%	24.5%
	Very high assistance needs	**35.9%**	**65.7%**	**77.6%**	**63.2%**	**63.2%**	**24.8%**
Labour force status	Employed	**34.3%**	54.8%	65.8%	52.7%	49.6%	**30.1%**
	Unemployed	38.4%	**66.5%**	74.2%	**68.4%**	48.2%	15.3%
	Not in labour force	**25.8%**	53.2%	66.9%	55.7%	54.9%	20.2%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

5.8.6 Accessing supports and services needed by care recipients

For many carers, a core part of their role involves organising access to the supports and services needed by the people they care for.

Carers were asked 'what challenges have you experienced accessing the services needed by the person or people you care for?' This was asked as an open-ended question, with carers able to write as much or as little as they wished. In total, 3,200 carers provided responses. These were categories by theme; as some carers identified more than one challenge, a total of 3,654 themes were coded into categories after excluding the small number of carers (approx. 400) who commented that they had sufficient support and/or experienced no difficulties or challenges.

Table 32 summarises the themes identified in responses. The most common theme – almost twice as common as any other – was that carers often found it difficult to identify where they could access support, with 623 carers reporting this. This was followed by often long waiting times to access services and support (352), overall lack of availability of services (281), experiencing a reduction in services available to the care recipient when they shifted to NDIS (260), and lack of suitably skilled or experienced staff providing support services (237). A further 215 carers reported difficulty accessing funding needed to be able to access services.

Other common themes included lack of services in rural areas, the difficulty involved in reaching out and applying for support as carers often had to engage in complex application and administrative processes, lack of responsiveness from service providers, and unwillingness of care recipients to access services.

Table 32 Challenges carers reported experiencing when accessing services needed by the people they cared for

What challenges have you experienced accessing the services needed by the person or people you care for?	No. of carers
Difficulty identifying where it is possible to access support	623
Long waiting times	352
Lack of availability of services and supports	281
NDIS reduced availability of support	260
Lack of skilled experienced staff at support providers	237
Difficulty accessing funding to cover cost	215
Generally hard	160
Lack of services in rural areas	157
Carers have to actively seek support - requires a lot of time & effort	154
Care recipient unwilling to accept support	147
Complex, too much information & confusion	144
Lack of response from service providers	143
Lack of services specific to care recipient’s needs	141
Service provider/s unhelpful	102
Government services, bureaucracy, red tape	83
Fatigue, workload, stress or frustration	78
COVID-related difficulties	68
Poor quality of services	64
Have to travel to access specialists or services; inadequate support for accommodation and transport	64
Difficulty scheduling appointment times/support scheduling	62
Additional procedure/ paperwork	60
Centrelink reduced availability of support	46
Services don't talk to each other	45
High cost	44
Ineligible for services	38
Lack of family support	37
Complex dealing with multiple organisations	35
Worry	34
Require technical knowledge/ technology	32
Mental health issues	31
Rapid staff turnover	29
Services don't talk to carer	28
Hard to make appointments/get support due to caree travel limits	26
High caring responsibilities even with access to services	26
Support unavailable in general (not specified why)	26
Circular referrals	24
Conflicting advice about availability of services	24
Support stopped	23
Difficulties with health professionals	22
Lack of social group, community/ support groups	22
Language, cultural, ethnic issues	18
Carers have to fight to get access to support	15
Constant change in names, service providers, government support	15
Feeling afraid or overwhelmed	14
Feeling criticised or judged	13
Conflicting advice on caree needs and status	13
Privacy concerns	12

5.9 Confidence in carer role

Carer’s confidence in their ability to manage different aspects of their caring role, including being able to maintain their own wellbeing, was examined. A set of specific questions in the CWS asked carers about their confidence in their ability to take care of the physical and emotional needs of the people they cared for, to find out about and access services, to cope with the stresses associated with caregiving, make caregiving activities pleasant, and to manage unexpected events or emergencies (Tables 33 to 36).

While 67.5% of carers had high confidence they could take care of the physical needs of the people they cared for, fewer – 48.1% - had high confidence in their ability to take care of the emotional needs of the people they cared for. Only just over half (52.3%) were highly confident in their ability to find out about and organise access to services for the people they cared for. Only one in three (33.1%) were highly confident they could cope with the stress of caring and caregiving activities, and 41.0% highly confident they could make caregiving activities pleasant for the care recipient and themselves. Just over half – 52.5% - were highly confident that they could manage unexpected events or emergencies related to their caring duties.

Those with higher caring obligations tended to have higher confidence in their ability to meet physical and emotional needs and access services needed by the people they cared for. However, the same group were slightly less confident they could cope with the stress of caregiving, as were those caring for a person with ASD, mental illness, or drug/alcohol dependency.

Table 33 Confidence in ability to take care of physical and emotional needs of care recipients and organise access to services (a)

Group	At the moment, how confident do you feel that you are able to do the following well?	Take care of the physical needs of the person/people you care for		Take care of the emotional needs of the person/people you care for		Find out about and organise access to services for the person/people you care for	
		Low confidence	High confidence	Low con-fidence	High confidence	Low conf-idence	High conf-idence
All current	Current carers	12.3%	67.5%	22.9%	48.1%	23.0%	52.3%
Gender	Female	12.0%	68.1%	24.1%	46.8%	23.5%	50.9%
	Male	12.1%	67.0%	21.3%	50.0%	22.4%	55.0%
Age	Aged 15-24	14.9%	**53.4%**	26.3%	**36.9%**	**33.7%**	**40.5%**
	Aged 25-34	12.1%	62.7%	23.7%	48.8%	19.1%	50.6%
	Aged 35-44	**6.1%**	**73.2%**	**14.9%**	**55.5%**	23.8%	52.3%
	Aged 45-54	12.2%	71.4%	23.3%	48.2%	23.1%	50.8%
	Aged 55-64	14.5%	67.0%	24.4%	46.0%	23.6%	52.9%
	Aged 65-74	13.6%	67.3%	25.7%	49.0%	22.5%	**58.2%**
	Aged 75+	15.2%	62.3%	25.4%	42.4%	17.8%	57.9%
Typical caring hours per week	<20 hours/week	14.2%	**63.4%**	24.2%	45.6%	23.8%	51.4%
	20-39 hours/week	10.9%	67.7%	23.7%	45.6%	21.8%	53.0%
	40+ hours/week	10.5%	**72.6%**	20.7%	**52.7%**	22.7%	52.9%
Cultural and language diversity	Aboriginal/Torres Strait Islander	17.4%	58.7%	21.5%	52.1%	25.7%	52.7%
	Not Aboriginal/Torres Strait Islander	11.9%	67.8%	23.0%	47.9%	22.8%	52.6%
	Usually speak language other than English at home	9.8%	68.6%	21.0%	51.8%	23.8%	55.5%
	Usually speak English at home	12.8%	67.3%	23.7%	46.9%	23.1%	51.7%
State/ Territory of residence	NSW	13.1%	65.1%	21.7%	48.8%	25.4%	50.2%
	Vic	13.0%	66.9%	23.8%	47.3%	21.7%	53.8%
	Qld	**8.6%**	**73.2%**	24.6%	46.7%	21.4%	55.4%
	SA	11.2%	68.1%	20.4%	51.1%	21.2%	54.4%
	WA	12.2%	68.9%	23.7%	48.7%	23.7%	51.8%
	Tas	12.3%	69.9%	26.3%	49.0%	23.6%	53.4%
	NT	5.3%	64.9%	12.4%	54.5%	19.3%	54.8%
	ACT	18.7%	61.2%	30.0%	36.6%	26.1%	44.5%
Primary carer	Primary carer	10.8%	**71.2%**	23.4%	46.8%	25.2%	50.6%
	Not a primary carer	16.0%	**56.4%**	26.4%	**41.1%**	26.8%	46.8%
Sole or assisted carer	Sole carer	**9.4%**	**74.7%**	22.4%	47.4%	**26.9%**	49.7%
	Assisted in caring role	13.1%	64.7%	25.0%	45.0%	24.1%	50.5%
No. people currently caring for	Currently care for 1 person	10.7%	68.8%	23.2%	47.1%	22.7%	52.5%
	Currently care for 2 people	15.0%	63.3%	23.2%	48.3%	24.3%	51.9%
	Currently care for 3 or more people	13.2%	72.3%	**17.1%**	51.3%	22.6%	52.0%
Caree residence	Caree lives elsewhere	**21.9%**	**52.4%**	25.7%	**41.0%**	22.6%	53.2%
	Caree lives in home	**9.6%**	72.2%	23.5%	46.9%	25.9%	49.6%
Length of time being a carer	Carer for 5+ years	11.9%	68.5%	23.5%	48.4%	23.9%	51.3%
	Carer for 2-5 years	13.2%	68.0%	20.8%	48.4%	20.5%	54.2%
	Carer for 1-2 years	11.2%	69.7%	19.6%	51.2%	21.6%	**59.4%**
	Carer for <1 year	13.5%	**54.9%**	**29.1%**	**41.0%**	25.9%	**44.5%**

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 34 Confidence in ability to take care of physical and emotional needs of care recipients and organise access to services (b)

		Take care of the physical needs of the person/people you care for		Take care of the emotional needs of the person/people you care for		Find out about and organise access to services for the person/people you care for	
Group	**At the moment, how confident do you feel that you are able to do the following well?**	**Low confidence**	**High confidence**	**Low confidence**	**High confidence**	**Low confidence**	**High confidence**
Care recipient disability, illness or injury type	Dementia	14.7%	64.9%	24.2%	45.3%	22.0%	54.0%
	Old-age related frailty	13.7%	66.1%	**19.3%**	48.2%	20.6%	**56.5%**
	Terminal illness	14.0%	62.9%	22.1%	48.5%	20.8%	55.4%
	Autism spectrum disorder	10.6%	71.5%	22.5%	49.0%	25.4%	**46.7%**
	Other development disorder	10.7%	72.0%	**17.6%**	51.0%	24.7%	49.2%
	Mental illness/psychosocial disability	13.8%	65.0%	**28.5%**	**43.1%**	25.2%	48.8%
	Drug/alcohol dependency	**20.6%**	**55.8%**	**34.2%**	**37.8%**	18.8%	**43.4%**
	Physical disability	11.7%	68.6%	21.6%	48.4%	22.8%	54.3%
	Intellectual disability	11.7%	70.8%	**17.6%**	53.0%	22.8%	47.8%
	Chronic non-terminal illness or injury, 6 months+	11.7%	67.7%	23.3%	44.5%	25.1%	51.0%
	Short term non-terminal illness	**2.0%**	**50.1%**	19.9%	44.2%	**33.8%**	42.1%
Type of care recipient	Care for child/grandchild	9.6%	70.6%	23.0%	48.8%	22.4%	49.9%
	Care for partner	13.4%	68.4%	25.0%	47.4%	22.4%	55.5%
	Care for parent/grandparent	12.2%	65.3%	20.3%	46.7%	24.1%	53.8%
	Care for sibling	17.4%	**58.4%**	20.7%	**38.5%**	28.3%	**42.4%**
	Care for friend or other type of relative	17.1%	66.6%	17.1%	**59.8%**	16.9%	57.0%
Level of assistance needed by care recipient	Low assistance needs	15.6%	65.6%	20.6%	49.9%	27.9%	53.6%
	Low-moderate assistance needs	14.6%	**60.5%**	**31.7%**	**39.3%**	26.0%	50.3%
	Moderate assistance needs	11.0%	68.3%	21.8%	44.3%	23.8%	48.5%
	High assistance needs	9.3%	69.6%	21.4%	52.5%	21.2%	52.3%
	Very high assistance needs	12.5%	70.9%	20.0%	52.3%	20.6%	**57.1%**
Labour force status	Employed	12.7%	66.0%	23.0%	46.3%	22.6%	52.2%
	Unemployed	13.9%	60.2%	27.2%	47.1%	**31.3%**	**41.8%**
	Not in labour force	10.8%	70.4%	22.4%	50.2%	22.9%	54.0%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 35 Confidence in ability to cope with caregiving activities, make activities pleasant, and manage unexpected caring events (a)

Group	At the moment, how confident do you feel that you are able to do the following well?	Cope with the stress of caring/ caregiving activities		Make caregiving activities pleasant for both you and the person/people you care for		Manage unexpected events or emergencies involving the person/people you care for	
		Low confidence	High confidence	Low confidence	High confidence	Low confidence	High confidence
All current	Current carers	33.0%	33.1%	24.3%	41.0%	21.4%	52.5%
Gender	Female	**38.0%**	**27.0%**	26.9%	**36.9%**	23.8%	50.9%
	Male	**23.9%**	**43.3%**	**19.7%**	**47.8%**	**17.2%**	**56.8%**
Age	Aged 15-24	29.2%	37.6%	24.8%	35.5%	**28.7%**	**38.0%**
	Aged 25-34	33.4%	36.1%	21.3%	47.0%	22.2%	**44.4%**
	Aged 35-44	30.8%	**39.3%**	22.0%	42.2%	21.2%	52.4%
	Aged 45-54	37.0%	26.0%	24.5%	39.5%	21.0%	51.7%
	Aged 55-64	33.6%	29.3%	26.7%	38.8%	22.7%	54.8%
	Aged 65-74	30.9%	37.2%	25.3%	43.4%	19.5%	**59.2%**
	Aged 75+	28.6%	**40.7%**	24.5%	40.9%	16.1%	58.9%
Typical caring hours per week	<20 hours/week	**29.2%**	35.5%	24.0%	40.6%	21.5%	51.3%
	20-39 hours/week	31.3%	33.0%	23.4%	41.3%	21.8%	50.5%
	40+ hours/week	**39.0%**	30.1%	25.1%	41.4%	21.2%	55.1%
Cultural and language diversity	Aboriginal/Torres Strait Islander	32.0%	42.8%	23.4%	48.9%	19.7%	54.3%
	Not Aboriginal/Torres Strait Islander	32.9%	32.7%	24.4%	40.3%	21.5%	52.8%
	Usually speak language other than English at home	28.7%	36.3%	21.1%	42.0%	22.1%	52.3%
	Usually speak English at home	34.4%	31.6%	25.5%	40.1%	21.5%	52.9%
State/ Territory of residence	NSW	32.8%	35.3%	24.7%	43.0%	22.3%	49.8%
	Vic	31.7%	31.1%	25.5%	40.7%	23.9%	54.1%
	Qld	35.2%	31.1%	24.2%	37.0%	19.3%	53.2%
	SA	30.3%	30.9%	20.0%	42.2%	21.1%	55.3%
	WA	35.0%	30.6%	25.1%	35.5%	16.6%	56.8%
	Tas	30.9%	37.9%	21.2%	45.4%	23.4%	56.0%
	NT	40.8%	29.8%	14.5%	53.2%	9.6%	54.7%
	ACT	39.2%	31.5%	33.5%	38.5%	24.4%	52.9%
Primary carer	Primary carer	**36.9%**	**29.8%**	26.3%	40.0%	22.2%	53.2%
	Not a primary carer	30.6%	**24.7%**	25.1%	**30.5%**	**28.7%**	**44.7%**
Sole or assisted carer	Sole carer	**37.1%**	29.7%	26.1%	39.7%	21.1%	56.1%
	Assisted in caring role	35.2%	**28.8%**	26.3%	38.1%	24.6%	48.9%
No. people currently caring for	Currently care for 1 person	31.3%	33.6%	24.6%	40.2%	21.6%	52.4%
	Currently care for 2 people	**38.1%**	32.2%	25.8%	41.3%	23.2%	53.5%
	Currently care for 3 or more people	37.0%	**26.0%**	23.4%	42.3%	18.5%	47.8%
Caree residence	Caree lives elsewhere	32.0%	29.0%	23.2%	36.8%	24.8%	51.5%
	Caree lives in home	**36.8%**	**29.2%**	26.7%	39.2%	22.7%	52.3%
Length of time being a carer	Carer for 5+ years	**36.4%**	**29.6%**	26.2%	38.9%	22.5%	52.0%
	Carer for 2-5 years	30.7%	36.6%	23.3%	41.8%	18.4%	54.5%
	Carer for 1-2 years	**24.7%**	**39.6%**	21.2%	44.9%	22.0%	51.0%
	Carer for <1 year	**24.7%**	**41.4%**	**16.3%**	**50.1%**	21.9%	51.0%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 36 Confidence in ability to cope with caregiving activities, make activities pleasant, and manage unexpected caring events (b)

Group	At the moment, how confident do you feel that you are able to do the following well?	Cope with the stress of caring/ caregiving activities		Make caregiving activities pleasant for both you and the person/people you care for		Manage unexpected events or emergencies involving the person/people you care for	
		Low confi-dence	High confi-dence	Low confi-dence	High confi-dence	Low confi-dence	High confi-dence
Care recipient disability, illness or injury type	Dementia	**37.8%**	31.1%	26.7%	40.0%	22.0%	53.5%
	Old-age related frailty	**28.3%**	36.7%	21.0%	43.5%	**18.1%**	53.3%
	Terminal illness	31.9%	39.1%	24.4%	**48.7%**	19.6%	48.2%
	Autism spectrum disorder	**39.6%**	**27.3%**	28.1%	**36.4%**	25.2%	**46.8%**
	Other development disorder	**40.9%**	28.2%	27.5%	40.2%	20.9%	51.5%
	Mental illness/psychosocial disability	**40.1%**	**24.4%**	**32.0%**	**33.6%**	**27.1%**	**48.1%**
	Drug/alcohol dependency	**41.8%**	**24.1%**	**36.1%**	**32.9%**	**27.9%**	**43.2%**
	Physical disability	33.0%	33.3%	23.6%	42.5%	19.9%	55.3%
	Intellectual disability	36.9%	28.9%	24.9%	39.2%	24.4%	52.9%
	Chronic non-terminal illness or injury, 6 months+	35.0%	30.6%	25.8%	39.7%	19.2%	55.0%
	Short term non-terminal illness	40.1%	27.2%	21.9%	38.5%	**35.3%**	**38.3%**
Type of care recipient	Care for child/grandchild	35.7%	**28.6%**	26.0%	39.0%	21.9%	**47.8%**
	Care for partner	35.2%	33.7%	27.0%	40.0%	20.1%	**58.6%**
	Care for parent/grandparent	32.7%	32.8%	22.0%	42.4%	20.7%	51.6%
	Care for sibling	33.6%	29.4%	27.1%	35.0%	**30.3%**	**40.4%**
	Care for friend or other type of relative	27.5%	39.3%	20.5%	**52.4%**	21.7%	54.7%
Level of assistance needed by care recipient	Low assistance needs	**23.2%**	**42.6%**	**18.2%**	45.8%	19.0%	52.5%
	Low-moderate assistance needs	28.8%	34.7%	26.1%	40.7%	19.5%	52.4%
	Moderate assistance needs	31.9%	31.2%	24.7%	37.1%	22.6%	49.9%
	High assistance needs	**39.1%**	29.3%	25.5%	41.9%	22.7%	50.8%
	Very high assistance needs	36.0%	32.4%	25.4%	41.8%	21.9%	55.5%
Labour force status	Employed	31.4%	33.5%	24.7%	40.8%	20.9%	51.7%
	Unemployed	39.4%	27.7%	24.7%	33.0%	**30.7%**	48.0%
	Not in labour force	33.8%	32.7%	24.2%	41.2%	21.5%	54.4%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

5.10 Access to formal and informal support

5.10.1 Overall access to support

Carers were asked about their access to both informal and formal sources of support. When asked ‘are you able to call on friends or family to help you in your caring responsibilities if you are ill or need a break’, only 19.0% of carers could easily organise this type of support, while 52.9% could organise it with difficulty, and 28.1% had no access to this type of support (Figure 17).

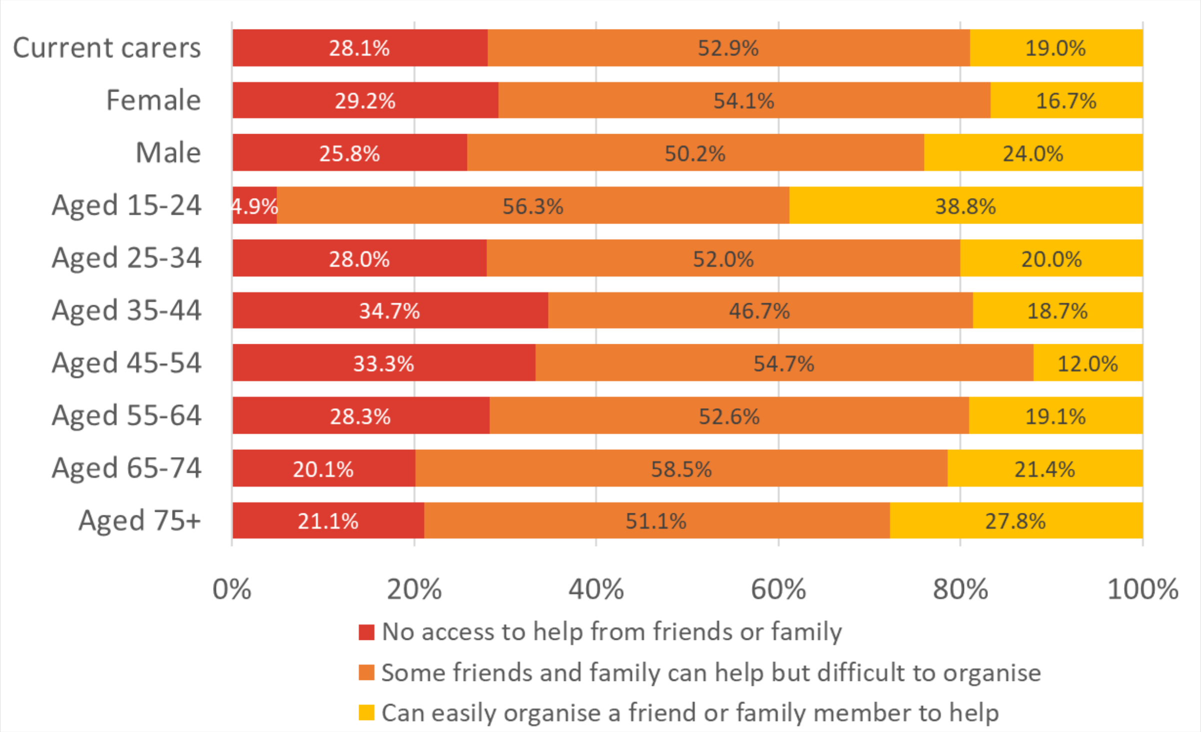


Figure 17 Carer access to informal support, by gender and age group

Access to support varied a little between male and female carers (Figure 17, Tables 37 and 38): male carers were more likely than female carers to report being able to easily organise a friend or family member to help (24.0% compared to 16.7% of female carers). There was also some variation by age, with carers aged 15-24 (38.8%) more likely to have access to informal support, and those aged 35-44 and 45-54 less likely to (34.7% and 33.7% respectively having no access to help in these age groups.

Other carers reporting better than typical access to informal support were those identifying as Aboriginal or Torres Strait Islander (38.4%), and those who cared for a person with low levels of assistance needs (43.2%). In addition to those aged 35-54, the following groups of carers were less likely than other carers to have access to informal support from family or friends: those who spent 40 or more hours caring in a typical week (36.3%); those caring for two people (33.9%) or three or more people (39.9%); those caring for a person with ASD (37.9%), development disorders (34.6%), mental illness (33.5%), or drug/alcohol dependency (37.6%); and those caring for a child or grandchild (34.0%).

Table 37 Access to informal support from friends and family (a)

Group	Category	No access to help from friends or family	Some friends and family can help but difficult to organise	Can easily organise a friend or family member to help
All current	Current carers	28.1%	52.9%	19.0%
Gender	Female	29.2%	54.1%	16.7%
	Male	25.8%	50.2%	**24.0%**
Age	Aged 15-24	**4.9%**	56.3%	**38.8%**
	Aged 25-34	28.0%	52.0%	20.0%
	Aged 35-44	**34.7%**	46.7%	18.7%
	Aged 45-54	33.3%	54.7%	**12.0%**
	Aged 55-64	28.3%	52.6%	19.1%
	Aged 65-74	**20.1%**	58.5%	21.4%
	Aged 75+	21.1%	51.1%	**27.8%**
Typical caring hours per week	<20 hours/week	23.9%	53.7%	22.3%
	20-39 hours/week	**21.3%**	55.9%	22.8%
	40+ hours/week	**36.3%**	50.4%	**13.3%**
Cultural and language diversity	Aboriginal/Torres Strait Islander	26.9%	**34.7%**	**38.4%**
	Not Aboriginal/Torres Strait Islander	28.1%	53.5%	18.4%
	Usually speak language other than English at home	32.9%	**45.8%**	21.4%
	Usually speak English at home	26.7%	54.9%	18.3%
State/ Territory of residence	NSW	27.0%	54.4%	18.6%
	Vic	26.9%	51.6%	21.5%
	Qld	32.4%	53.1%	14.5%
	SA	28.7%	52.0%	19.3%
	WA	27.8%	55.0%	17.2%
	Tas	27.9%	48.3%	23.8%
	NT	37.4%	32.2%	30.4%
	ACT	21.2%	57.2%	21.7%
Primary carer	Primary carer	28.7%	54.4%	16.9%
	Not a primary carer	22.5%	**45.8%**	**31.8%**
Sole or assisted carer	Sole carer	**33.1%**	52.1%	**14.8%**
	Assisted in caring role	**23.4%**	54.3%	22.3%
No. people currently caring for	Currently care for 1 person	**24.3%**	56.2%	19.5%
	Currently care for 2 people	**33.9%**	47.1%	19.1%
	Currently care for 3 or more people	**39.9%**	49.0%	**11.1%**
Caree residence	Caree lives elsewhere	22.3%	53.5%	24.3%
	Caree lives in home	28.9%	53.3%	17.9%
Length of time being a carer	Carer for 5+ years	31.0%	53.6%	**15.3%**
	Carer for 2-5 years	23.4%	54.5%	22.2%
	Carer for 1-2 years	25.4%	47.7%	**26.9%**
	Carer for <1 year	21.0%	51.4%	**27.6%**

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 38 Access to informal support from friends and family (b)

Group	Category	No access to help from friends or family	Some friends and family can help but difficult to organise	Can easily organise a friend or family member to help
Care recipient disability, illness or injury type	Dementia	28.8%	52.6%	18.6%
	Old-age related frailty	26.7%	55.3%	18.0%
	Terminal illness	28.2%	60.1%	**11.7%**
	Autism spectrum disorder	**37.9%**	**45.2%**	16.9%
	Other development disorder	**34.6%**	53.1%	**12.3%**
	Mental illness/psychosocial disability	**33.5%**	53.7%	**12.8%**
	Drug/alcohol dependency	**37.6%**	53.0%	**9.3%**
	Physical disability	27.2%	54.5%	18.3%
	Intellectual disability	33.6%	48.8%	17.6%
	Chronic non-terminal illness or injury, 6 months+	28.3%	56.7%	15.0%
	Short term non-terminal illness	28.7%	43.5%	27.8%
Type of care recipient	Care for child/grandchild	**34.0%**	50.7%	**15.3%**
	Care for partner	24.2%	56.4%	19.4%
	Care for parent/grandparent	27.0%	53.1%	19.9%
	Care for sibling	21.1%	57.1%	21.7%
	Care for friend or other type of relative	29.0%	55.5%	15.5%
Level of assistance needed by care recipient	Low assistance needs	**18.6%**	**38.2%**	**43.2%**
	Low-moderate assistance needs	**21.6%**	52.3%	**26.1%**
	Moderate assistance needs	23.4%	**58.7%**	17.9%
	High assistance needs	33.6%	54.7%	**11.6%**
	Very high assistance needs	**33.7%**	50.7%	15.6%
Labour force status	Employed	**23.5%**	54.0%	22.5%
	Unemployed	36.1%	49.5%	14.4%
	Not in labour force	31.8%	52.4%	15.8%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

5.10.2 Types of support accessed in the last 12 months

Carers were asked about the types of formal and informal support they had been able to draw on in the previous 12 months to help them in their role as a carer (Figure 18). Carers most commonly reported relying on informal support from friends and/or family members, with just under 60% doing this. However, 40.2% did not have any access to informal support in the last 12 months. It is not known to what extent this was impacted by restrictions related to COVID-19, which may have reduced access of many carers to support: comparing access to informal support in 2021 with access in future years in which the CWS is repeated will enable better understanding of whether the 2021 findings represent typical levels of access carers have to informal support.

In terms of formal supports:

- 32.6% of carers had connected to other carers in the last 12 months, for example through support groups or online forums
- 31.4% had accessed psychological support for their role as a carer
- 30.6% had accessed respite care services
- 29.0% had received some form of financial support, such as the Carer Payment or Carer Allowance, or a financial grant to assist in buying items that could reduce burden of caring duties, and
- 22.0% had accessed carer training and skills courses of some type.

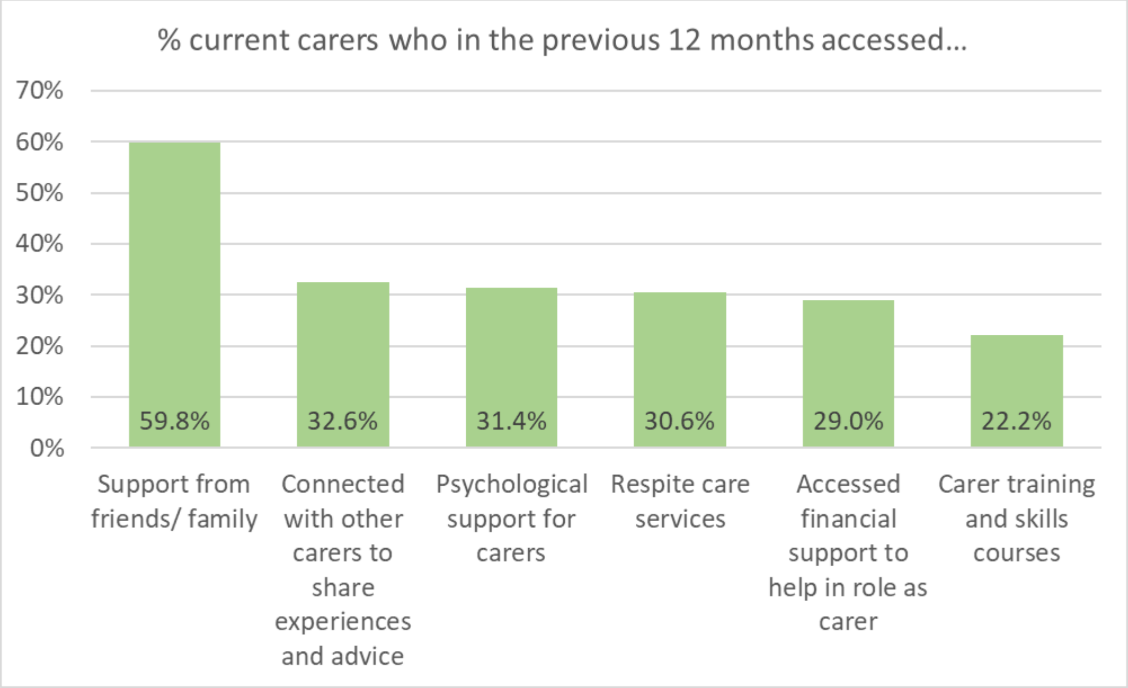


Figure 18 Formal and informal supports drawn on by carers in the last 12 months

When asked about the types of formal and informal support accessed in the last 12 months to help them in their caring role (Tables 39 and 40):

- Support from friends and family:
    - More likely to have accessed this in the past 12 months: Carers aged 15-24 (67.1%), 25-34 (67.0%), Aboriginal/Torres Strait Islander carers (70.9%),

    - employed carers (65.6%), and those caring for a person with drug/alcohol dependency (70.0%) or dementia (68.9%)
    - Less likely to have accessed this in the past 12 months: Male carers (54.8%), careered aged 45-54 (54.6%), carers with 40 or more hours a week caring obligations (54.9%), sole carers (52.9%) and unemployed carers (51.5%)
- Respite care:
    - More likely to have accessed this in the past 12 months: Carers aged 15-24 (39.6%), Aboriginal/Torres Strait Islander carers (41.3%), those who had been a carer for less than two years (38.1%), and those caring for a person with dementia (44.1%), terminal illness (39.9%), old age related frailty (34.6%) or more generally with high support needs (39.7%)
    - Less likely to have accessed this in the past 12 months: Carers aged 45-54 (26.0%), sole carers (19.8%), and those caring for a person with mental illness/psychosocial disability (23.6%).
- Training courses or coaching:
    - More likely to have accessed this in the past 12 months: Carers aged 15-24 (37.1%) and 25-34 (32.5%), and those caring for a person with drug/alcohol dependency (35.4%), dementia (30.3%), terminal illness (29.9%) or ASD (28.0%).
    - Less likely to have accessed this in the past 12 months: Those with 40 hours or more a week of caring obligations (15.6%), sole carers (15.0%), and who had been carers for 5 or more years (18.1%); more generally, older carers were less likely to access this than younger carers.
- Psychological counselling:
    - More likely to have accessed this in the past 12 months: Carers aged 15-24 (52.7%), or 25-34 (39.6%), those caring for three or more people (40.7%), and those caring for a person with drug or alcohol dependency (48.7%), mental illness/ psychosocial disability (38.5%) or ASD (36.0%).
    - Less likely to have accessed this in the past 12 months: Carers aged 65 and older (22.2% or less).
- Connecting with other carers:
    - More likely to have accessed this in the past 12 months: Carers aged 15-24 (52.1%), Aboriginal/Torres Strait Islander carers (56.5%), those caring for a child/grandchild (37.5%), and those caring for a person with drug or alcohol dependency (47.4%) or ASD (38.9%).
    - Less likely to have accessed this in the past 12 months: Male carers (29.0%) and those caring for a person with old-age related frailty (28.7%) or a physical disability (28.7%).
- Financial support for carer role:
    - More likely to have accessed this in the past 12 months: Carers aged 15-24 (44.5%) and 25-34 (38.9%), and Aboriginal/Torres Strait Islander carers (47.7%).
    - Less likely to have accessed this in the past 12 months: Carers aged 55 and older (23.6% or fewer), sole carers (23.5%), those who had been a carer less than a year (22.2%), and those caring for a person with low assistance needs (20.6%).

Table 39 Types of informal and formal support accessed in last 12 months (a)

		% carers who had accessed different types of support in the previous 12 months					
Group	**Category**	**Support from friends/ family**	**Respite care**	**Carer training and skills courses**	**Accessed psychological support**	**Connected with other carers to share experiences and advice**	**Accessed financial support to help in role as carer**
All current	Current carers	59.8%	30.6%	22.2%	31.4%	32.6%	29.0%
Gender	Female	62.1%	28.6%	**19.3%**	30.3%	33.7%	27.4%
	Male	**54.8%**	32.4%	25.5%	30.1%	**29.0%**	31.3%
Age	Aged 15-24	**67.1%**	**39.6%**	**37.1%**	**52.7%**	**52.1%**	**44.5%**
	Aged 25-34	**67.0%**	34.4%	**32.5%**	**39.6%**	37.4%	**38.9%**
	Aged 35-44	64.4%	30.3%	**29.2%**	**36.4%**	**38.5%**	32.5%
	Aged 45-54	**54.6%**	**26.0%**	19.8%	34.4%	29.4%	27.7%
	Aged 55-64	55.9%	29.9%	**14.6%**	**23.4%**	**27.6%**	**23.6%**
	Aged 65-74	59.4%	29.0%	17.8%	**22.2%**	28.5%	**21.5%**
	Aged 75+	63.9%	37.2%	**16.0%**	**18.7%**	30.1%	30.1%
Typical caring hours per week	<20 hours/week	60.9%	28.3%	23.9%	32.0%	34.0%	27.6%
	20-39 hours/week	**65.5%**	32.4%	**29.3%**	**36.6%**	34.9%	32.1%
	40+ hours/week	**54.9%**	32.6%	**15.6%**	**27.6%**	29.5%	28.8%
Cultural and language diversity	Aboriginal/Torres Strait Islander	**70.9%**	**41.3%**	**48.8%**	**55.1%**	**56.5%**	**47.7%**
	Not Aboriginal/Torres Strait Islander	59.0%	29.6%	20.8%	29.9%	31.2%	28.3%
	Usually speak language other than English at home	58.1%	32.5%	25.9%	34.9%	34.6%	28.7%
	Usually speak English at home	59.7%	29.2%	20.5%	29.2%	31.0%	28.6%
State/ Territory of residence	NSW	63.0%	32.7%	25.2%	33.9%	36.1%	29.3%
	Vic	59.6%	29.8%	19.5%	30.0%	29.5%	28.8%
	Qld	**51.1%**	28.1%	19.2%	**26.7%**	**27.5%**	25.4%
	SA	61.4%	26.0%	20.1%	30.3%	33.3%	29.5%
	WA	57.7%	28.6%	20.9%	26.2%	31.6%	32.0%
	Tas	57.3%	27.6%	20.3%	22.7%	27.4%	21.4%
	NT	71.7%	**54.5%**	30.0%	**50.6%**	33.7%	35.5%
	ACT	63.8%	**16.7%**	25.8%	30.1%	38.9%	35.5%
Primary carer	Primary carer	59.3%	**27.1%**	19.8%	31.6%	31.4%	28.1%
	Not a primary carer	**70.6%**	31.9%	21.3%	29.4%	35.3%	24.4%
Sole or assisted carer	Sole carer	**52.9%**	**19.8%**	**15.0%**	**26.5%**	**26.0%**	**23.5%**
	Assisted in caring role	**67.2%**	34.3%	24.2%	**35.3%**	**36.7%**	31.2%
No. people currently caring for	Currently care for 1 person	59.8%	30.5%	20.9%	29.1%	30.9%	29.9%
	Currently care for 2 people	62.5%	30.3%	25.7%	35.2%	37.1%	29.0%
	Currently care for 3 or more people	56.6%	28.7%	24.9%	**40.7%**	33.3%	29.1%
Caree residence	Caree lives elsewhere	**69.7%**	27.1%	22.2%	33.7%	32.5%	**20.5%**
	Caree lives in home	59.1%	28.8%	21.3%	32.2%	32.8%	30.2%
Length of time being a carer	Carer for 5+ years	**55.6%**	27.8%	**18.1%**	28.9%	30.6%	26.6%
	Carer for 2-5 years	63.3%	29.6%	23.2%	30.7%	32.3%	29.4%
	Carer for 1-2 years	**69.8%**	**38.1%**	**30.8%**	**42.7%**	**41.0%**	**39.9%**
	Carer for <1 year	65.6%	**38.0%**	23.7%	25.9%	30.1%	**22.2%**

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 40 Types of informal and formal support accessed in last 12 months (b)

		% carers who had accessed different types of support in the previous 12 months					
Group	**Category**	**Support from friends/ family**	**Respite care services**	**Carer training and skills courses**	**Psychological support for carers**	**Connected with other carers to share experiences and advice**	**Accessed financial support to help in role as carer**
Care recipient disability, illness or injury type	Dementia	**68.9%**	**44.1%**	**30.3%**	34.8%	34.4%	32.8%
	Old-age related frailty	61.5%	**34.6%**	21.7%	31.5%	**28.7%**	29.5%
	Terminal illness	65.5%	**39.9%**	**29.9%**	**41.1%**	32.2%	**36.9%**
	Autism spectrum disorder	58.5%	29.9%	**28.0%**	**36.0%**	**38.9%**	**34.3%**
	Other development disorder	59.9%	28.5%	26.0%	33.9%	36.4%	33.1%
	Mental illness/ psychosocial disability	59.0%	**23.6%**	23.2%	**38.5%**	34.8%	26.5%
	Drug/alcohol dependency	**70.0%**	32.8%	**35.4%**	**48.7%**	**47.4%**	30.5%
	Physical disability	58.9%	29.7%	**16.4%**	**27.1%**	**28.7%**	27.8%
	Intellectual disability	58.0%	32.4%	20.5%	30.0%	34.8%	28.3%
	Chronic non-terminal illness or injury, 6 months+	56.5%	**21.4%**	**15.7%**	30.1%	30.2%	25.9%
	Short term non-terminal illness	67.8%	39.0%	**36.3%**	**51.7%**	41.2%	**40.8%**
Type of care recipient	Care for child/grandchild	59.1%	27.6%	24.5%	34.2%	**37.5%**	32.5%
	Care for partner	59.4%	27.3%	19.6%	28.1%	29.0%	27.0%
	Care for parent/grandparent	63.0%	**34.8%**	23.8%	34.2%	31.3%	28.4%
	Care for sibling	67.5%	30.9%	26.6%	37.4%	35.9%	28.6%
	Care for friend or other type of relative	53.6%	29.8%	26.2%	33.8%	39.1%	30.3%
Level of assistance needed by care recipient	Low assistance needs	63.3%	**21.3%**	21.7%	25.2%	34.4%	**20.6%**
	Low-moderate assistance needs	59.2%	**25.2%**	24.0%	33.1%	35.7%	25.3%
	Moderate assistance needs	61.4%	**24.7%**	23.7%	33.1%	33.8%	31.8%
	High assistance needs	59.1%	34.2%	21.8%	35.2%	29.2%	30.1%
	Very high assistance needs	59.2%	**39.7%**	20.5%	28.5%	31.7%	31.1%
Labour force status	Employed	**65.6%**	31.3%	**26.5%**	33.7%	34.8%	31.3%
	Unemployed	**51.5%**	28.5%	24.9%	27.8%	34.2%	22.8%
	Not in labour force	**53.1%**	28.1%	**15.8%**	**26.6%**	**28.1%**	26.4%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

5.10.3 Satisfaction with supports accessed in the last 12 months

Just over half of carers who had used different types of formal and informal support in the last 12 months reported being highly satisfied with that support, and between 10% and 18% reported low satisfaction, for all types of support except financial support (Figure 19). Fewer were highly satisfied with the financial support they received as a carer (44.1%) and more reported low satisfaction with financial support (22.9%) compared to all other forms of carer support accessed.

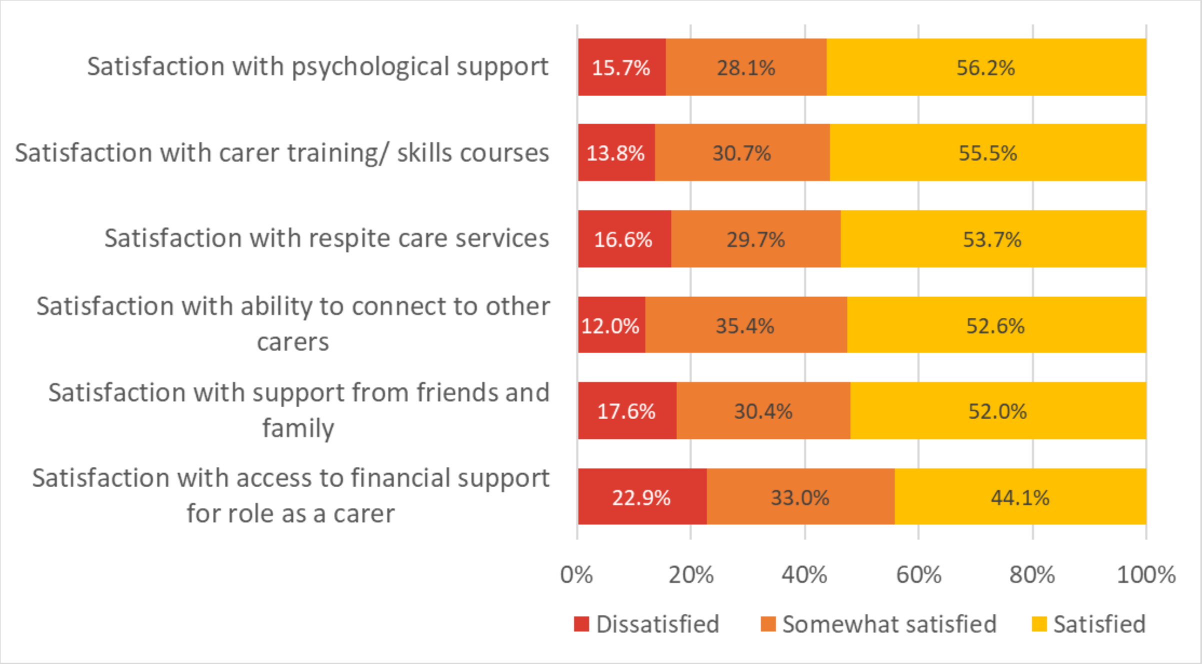


Figure 19 Satisfaction with carer supports accessed in last 12 months

When groups of carers were compared (Tables 41 to 44), there were mostly relatively small differences in levels of satisfaction. Key exceptions were the following:

- Support from family and friends: Those least satisfied were carers aged 45-54 (28.8% reporting dissatisfaction), caring for three or more people (27.4%) and caring for a person experiencing mental illness/psychosocial disability. Carers were more likely to report high satisfaction if they were aged 75 or over (64.2%), had been a carer less than two years (60% or more depending on length of time), or cared for a person with low assistance needs (65.6%).
- Respite care: Somewhat higher satisfaction was reported by male carers (64.3%) and those aged 35-44 (63.3%). Dissatisfaction was more common amongst those caring for a person with a terminal illness (26.8%) or development disorder (25.1%).
- Financial support: Higher levels of dissatisfaction were reported amongst carers with 40 or more hours of caring obligations a week (31.1%), who cared for a person not living with them (35.9%), had been a carer for less than one year (36.7%), or cared for a person with mental illness/psychosocial disability (32.8%). Higher satisfaction was reported by male carers (51.5%), those with fewer than 20 hours a week caring obligations (51.5%) and those aged 75 and older (60.6%).

Table 41 Satisfaction with different types of support accessed in the last 12 months (a)

		Satisfaction with support from friends and family		Satisfaction with respite care services		Satisfaction with carer training/ skills courses	
Group	**Category**	**Low**	**High**	**Low**	**High**	**Low**	**High**
All current	Current carers	17.6%	52.0%	16.6%	53.7%	13.8%	55.5%
Gender	Female	18.3%	48.0%	19.0%	47.7%	16.5%	50.7%
	Male	16.2%	**59.5%**	11.8%	**64.3%**	9.2%	**63.6%**
Age	Aged 15-24	15.1%	55.5%	15.0%	50.7%	14.5%	**41.9%**
	Aged 25-34	16.9%	49.7%	17.3%	56.0%	16.1%	55.7%
	Aged 35-44	**10.7%**	57.8%	**9.7%**	**63.3%**	15.3%	63.7%
	Aged 45-54	**28.8%**	**39.7%**	17.9%	**40.3%**	13.4%	56.0%
	Aged 55-64	14.8%	55.1%	16.4%	57.3%	9.8%	53.0%
	Aged 65-74	17.2%	53.3%	21.7%	53.4%	13.1%	53.1%
	Aged 75+	**10.8%**	**64.2%**	15.5%	61.6%	9.2%	62.5%
Typical caring hours per week	<20 hours/week	**12.8%**	55.4%	15.5%	56.7%	13.2%	57.0%
	20-39 hours/week	**23.2%**	53.0%	11.7%	58.5%	**5.1%**	62.7%
	40+ hours/week	20.7%	**46.3%**	20.7%	47.7%	24.5%	**44.4%**
Cultural and language diversity	Aboriginal/Torres Strait Islander	12.9%	61.8%	21.2%	60.1%	9.3%	61.2%
	Not Aboriginal/Torres Strait Islander	17.7%	51.6%	16.4%	53.3%	14.1%	55.6%
	Usually speak language other than English at home	17.0%	57.1%	**10.3%**	50.5%	14.4%	59.8%
	Usually speak English at home	17.9%	50.4%	18.4%	54.8%	13.1%	54.8%
State/ Territory of residence	NSW	17.3%	55.4%	14.9%	55.9%	13.5%	62.1%
	Vic	16.1%	49.9%	15.9%	54.2%	11.8%	47.6%
	Qld	22.9%	48.2%	19.2%	46.2%	20.7%	55.5%
	SA	14.3%	49.2%	20.3%	48.8%	10.8%	47.7%
	WA	20.9%	50.1%	16.1%	62.5%	15.1%	56.1%
	Tas	15.9%	53.4%	19.4%	55.9%	14.3%	55.8%
	NT	19.7%	50.7%	9.9%	63.9%	4.4%	53.1%
	ACT	9.0%	62.7%	30.4%	35.2%	**0.0%**	62.9%
Primary carer	Primary carer	20.1%	**46.0%**	18.7%	47.3%	16.3%	50.4%
	Not a primary carer	13.5%	**64.7%**	15.3%	53.5%	5.4%	57.4%
Sole or assisted carer	Sole carer	20.9%	46.8%	21.2%	**41.7%**	15.1%	50.1%
	Assisted in caring role	18.1%	50.1%	16.8%	51.3%	14.7%	52.2%
No. people currently caring for	Currently care for 1 person	16.3%	53.1%	14.6%	56.2%	13.9%	56.7%
	Currently care for 2 people	17.4%	51.7%	19.4%	48.8%	12.1%	58.6%
	Currently care for 3 or more people	**27.4%**	**39.2%**	21.5%	**40.4%**	15.6%	**40.5%**
Caree residence	Caree lives elsewhere	18.1%	50.7%	12.4%	61.7%	12.5%	51.4%
	Caree lives in home	19.2%	48.5%	18.5%	**47.3%**	14.8%	51.7%
Length of time being a carer	Carer for 5+ years	20.2%	**46.8%**	21.4%	48.1%	18.5%	49.6%
	Carer for 2-5 years	13.6%	55.3%	12.7%	**62.9%**	8.2%	64.4%
	Carer for 1-2 years	15.2%	**59.7%**	10.0%	55.4%	**5.0%**	57.0%
	Carer for <1 year	16.0%	**64.7%**	10.0%	55.9%	21.3%	56.3%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 42 Satisfaction with different types of support accessed in the last 12 months (b)

		Satisfaction with support from friends and family		Satisfaction with respite care services		Satisfaction with carer training/ skills courses	
Group	**Category**	**Low**	**High**	**Low**	**High**	**Low**	**High**
Care recipient disability, illness or injury type	Dementia	18.4%	52.4%	15.1%	56.7%	9.6%	54.3%
	Old-age related frailty	18.5%	52.1%	15.0%	55.8%	11.2%	60.5%
	Terminal illness	18.7%	50.2%	**26.8%**	49.5%	19.7%	60.4%
	Autism spectrum disorder	18.8%	**45.8%**	19.3%	47.4%	16.5%	52.1%
	Other development disorder	20.4%	**42.5%**	**25.1%**	**38.2%**	19.1%	52.1%
	Mental illness/psychosocial disability	**25.3%**	**42.2%**	20.2%	**40.9%**	19.0%	**44.9%**
	Drug/alcohol dependency	21.6%	47.8%	23.1%	43.2%	16.2%	**37.6%**
	Physical disability	17.4%	53.5%	19.2%	48.4%	13.6%	47.4%
	Intellectual disability	20.8%	**45.1%**	18.0%	**39.1%**	15.3%	54.1%
	Chronic non-terminal illness or injury, 6 months+	19.5%	50.3%	19.3%	50.2%	13.5%	44.4%
	Short term non-terminal illness	15.8%	45.3%	13.5%	66.8%	**40.1%**	**33.5%**
Type of care recipient	Care for child/grandchild	19.6%	**46.4%**	17.4%	47.8%	17.7%	52.7%
	Care for partner	16.2%	56.2%	20.4%	55.6%	15.8%	52.1%
	Care for parent/grandparent	18.9%	49.9%	13.0%	56.6%	9.0%	58.3%
	Care for sibling	18.1%	51.1%	13.0%	**37.5%**	8.6%	57.0%
	Care for friend or other type of relative	18.3%	**62.0%**	14.5%	56.8%	7.8%	53.7%
Level of assistance needed by care recipient	Low assistance needs	**6.9%**	**65.6%**	**1.2%**	63.8%	7.9%	57.1%
	Low-moderate assistance needs	**8.9%**	56.3%	17.4%	60.3%	11.0%	63.8%
	Moderate assistance needs	19.2%	50.7%	12.7%	52.7%	14.9%	55.0%
	High assistance needs	21.7%	45.9%	16.8%	59.5%	14.4%	52.0%
	Very high assistance needs	20.3%	51.1%	20.4%	**46.0%**	14.5%	53.9%
Labour force status	Employed	15.6%	53.0%	13.5%	53.8%	12.7%	57.6%
	Unemployed	22.6%	57.2%	12.6%	64.4%	7.7%	**74.3%**
	Not in labour force	20.1%	50.1%	20.6%	52.9%	16.1%	49.8%
Past carers	Past carers - all	14.4%	55.8%	13.9%	58.3%	15.9%	51.3%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 43 Satisfaction with different types of support accessed in the last 12 months (c)

		Satisfaction with psychological support		Satisfaction with ability to connect to other carers		Satisfaction with access to financial support for role as a carer	
Group	**Category**	**Low**	**High**	**Low**	**High**	**Low**	**High**
All current	Current carers	15.7%	56.2%	12.0%	52.6%	22.9%	44.1%
Gender	Female	14.4%	55.4%	13.2%	48.9%	26.0%	39.1%
	Male	16.6%	60.0%	8.1%	**61.8%**	19.3%	**51.5%**
Age	Aged 15-24	13.4%	54.9%	5.9%	56.5%	13.9%	51.5%
	Aged 25-34	19.0%	57.0%	12.0%	49.8%	15.2%	51.6%
	Aged 35-44	15.2%	58.1%	11.8%	56.5%	27.4%	38.5%
	Aged 45-54	18.5%	55.2%	13.7%	45.9%	29.1%	**34.3%**
	Aged 55-64	11.9%	56.1%	12.5%	54.1%	24.5%	46.4%
	Aged 65-74	13.2%	55.9%	9.5%	59.5%	20.6%	44.3%
	Aged 75+	15.7%	58.9%	15.4%	52.5%	16.6%	**60.6%**
Typical caring hours per week	<20 hours/week	14.3%	57.1%	9.7%	55.9%	18.8%	**51.5%**
	20-39 hours/week	12.8%	63.6%	12.3%	51.1%	18.1%	44.1%
	40+ hours/week	19.9%	49.6%	15.3%	48.5%	**31.1%**	**34.6%**
Cultural and language diversity	Aboriginal/Torres Strait Islander	11.2%	57.2%	9.0%	47.0%	**8.0%**	45.0%
	Not Aboriginal/Torres Strait Islander	15.8%	56.9%	11.5%	53.3%	24.1%	44.3%
	Usually speak language other than English at home	16.6%	58.8%	8.6%	53.0%	17.4%	44.3%
	Usually speak English at home	15.1%	56.5%	12.1%	53.2%	24.8%	44.3%
State/ Territory of residence	NSW	13.3%	62.1%	8.9%	55.0%	21.0%	40.8%
	Vic	15.2%	54.0%	13.3%	52.8%	25.2%	49.3%
	Qld	23.4%	50.5%	11.5%	50.7%	29.3%	39.8%
	SA	8.5%	67.7%	9.2%	54.4%	20.2%	44.2%
	WA	20.9%	45.1%	17.1%	50.1%	19.8%	50.4%
	Tas	16.1%	55.3%	9.7%	48.5%	20.7%	40.5%
	NT	8.9%	44.0%	14.2%	48.1%	27.7%	39.8%
	ACT	13.3%	60.3%	11.3%	45.7%	22.7%	40.9%
Primary carer	Primary carer	19.7%	52.0%	14.0%	48.7%	26.6%	**37.0%**
	Not a primary carer	9.5%	**71.9%**	10.2%	61.3%	17.6%	51.8%
Sole or assisted carer	Sole carer	18.6%	51.5%	15.0%	47.4%	26.6%	36.3%
	Assisted in caring role	18.5%	56.2%	12.6%	52.4%	25.1%	40.1%
No. people currently caring for	Currently care for 1 person	16.0%	54.5%	11.8%	52.9%	22.3%	43.1%
	Currently care for 2 people	14.4%	61.3%	11.6%	52.7%	22.8%	46.7%
	Currently care for 3 or more people	19.8%	54.4%	18.6%	46.8%	29.1%	41.7%
Caree residence	Caree lives elsewhere	15.8%	55.3%	13.7%	53.3%	**35.9%**	**30.7%**
	Caree lives in home	19.1%	53.7%	13.3%	50.8%	23.3%	40.5%
Length of time being a carer	Carer for 5+ years	18.6%	52.2%	15.0%	48.0%	27.5%	39.9%
	Carer for 2-5 years	13.0%	60.7%	9.0%	58.1%	18.3%	**53.4%**
	Carer for 1-2 years	9.3%	66.0%	6.1%	57.2%	**12.1%**	44.9%
	Carer for <1 year	14.1%	54.3%	10.6%	49.2%	**36.7%**	38.8%

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

Table 44 Satisfaction with different types of support accessed in the last 12 months (d)

		Satisfaction with psychological support		Satisfaction with ability to connect to other carers		Satisfaction with access to financial support for role as a carer	
Group	**Category**	**Low**	**High**	**Low**	**High**	**Low**	**High**
Care recipient disability, illness or injury type	Dementia	13.5%	58.6%	10.2%	55.5%	19.9%	47.6%
	Old-age related frailty	14.9%	61.5%	10.5%	54.4%	18.8%	48.5%
	Terminal illness	22.0%	54.8%	16.6%	**41.3%**	20.5%	47.8%
	Autism spectrum disorder	16.4%	53.5%	15.3%	49.0%	23.7%	42.1%
	Other development disorder	19.4%	51.5%	17.3%	47.7%	29.8%	**33.0%**
	Mental illness/psychosocial disability	17.2%	52.0%	15.3%	47.0%	**32.8%**	**35.4%**
	Drug/alcohol dependency	12.4%	55.1%	9.0%	56.6%	20.8%	35.4%
	Physical disability	19.3%	53.5%	11.0%	55.2%	25.9%	44.7%
	Intellectual disability	19.5%	50.5%	14.2%	50.3%	30.0%	37.8%
	Chronic non-terminal illness or injury, 6 months+	17.9%	55.0%	14.0%	50.8%	26.8%	41.6%
	Short term non-terminal illness	**46.9%**	**37.4%**	16.6%	51.9%	15.3%	32.7%
Type of care recipient	Care for child/grandchild	19.6%	50.4%	15.7%	47.8%	27.0%	38.5%
	Care for partner	18.4%	54.9%	12.8%	49.6%	20.7%	47.9%
	Care for parent/grandparent	13.3%	60.1%	9.7%	56.6%	18.9%	46.1%
	Care for sibling	**1.8%**	68.3%	4.9%	**38.6%**	32.4%	39.8%
	Care for friend or other type of relative	11.6%	65.5%	13.8%	62.1%	27.5%	45.8%
Level of assistance needed by care recipient	Low assistance needs	13.8%	44.3%	10.1%	62.2%	17.6%	42.8%
	Low-moderate assistance needs	21.7%	55.4%	10.7%	61.2%	14.6%	43.9%
	Moderate assistance needs	13.6%	56.8%	9.9%	50.3%	21.1%	45.3%
	High assistance needs	15.2%	59.2%	15.8%	50.0%	26.2%	44.3%
	Very high assistance needs	17.5%	57.0%	14.6%	49.5%	28.2%	41.9%
Labour force status	Employed	15.2%	56.6%	10.5%	53.4%	21.0%	43.9%
	Unemployed	12.6%	58.8%	12.7%	49.7%	32.2%	37.7%
	Not in labour force	16.0%	58.2%	12.3%	53.8%	26.0%	45.6%
Past carers	Past carers - all	**8.7%**	51.1%	9.9%	52.8%	21.5%	50.6%
	Ceased caring in last 6 months	14.1%	55.9%	13.4%	49.9%	30.8%	45.2%
	Ceased caring 7-12 months previously	15.7%	**23.6%**	21.8%	31.3%	**53.3%**	**12.6%**

Interpreting findings in this table: Findings highlighted in **bold** indicate that this group of carers differed significantly to the average for current carers in Australia based on 95% confidence intervals.

5.10.4 Is having support associated with higher carer wellbeing?

Having access to support can make an important difference to the wellbeing of carers. This section examines whether those carers who were able to access different types of support in the previous 12 months had higher levels of wellbeing and/or lower levels of psychological distress compared to carers who did not have access to support.

Different types of carers will vary in their level of need for support. When wellbeing was examined earlier in this report, some of the greater variance in wellbeing of carers was amongst those caring for people with differing levels of assistance needs. Those who cared for someone with low assistance needs reported much higher wellbeing compared to those who cared for people with very high assistance needs: there was a 13 point difference in global life satisfaction, and almost 16 point difference in the Personal Wellbeing Index measure. The proportion of carers reporting low wellbeing rose from 31.1% amongst those caring for a person with low assistance needs, to 63.6% amongst those caring for one or more people with very high assistance needs.

Given this, when examining whether access to supports made a different to wellbeing, carers were compared based on the level of assistance needs they were providing to care recipients.

Having access to support is associated with higher wellbeing, particularly for carers who are caring for one or more people with high assistance needs. As shown in Figure 20 and Table 45:

- Carers with access to support from family and friends had significantly higher wellbeing – amongst those caring for people with moderate assistance needs, wellbeing was 10 points higher if they had access to this type of support, and 11 points higher amongst those caring for someone with high assistance needs
- Accessing respite care was associated with higher wellbeing, with an increase of five points amongst those caring for a person with low assistance needs, and 8 to 11 point increase amongst those caring for people with moderate and high assistance needs
- Access to financial support was associated with significantly higher wellbeing for those caring for a person with moderate or high assistance needs, but not those caring for a person with low assistance needs
- Accessing skills and training, and connecting with other carers, were both associated with significantly higher wellbeing, particularly for those caring for a person with high assistance needs
- Accessing psychological counselling was not typically associated with higher wellbeing: this may reflect that those accessing counselling may have lower wellbeing to begin with compared to those who do not need to seek this type of counselling.

Overall, access to support is associated with significantly higher levels of wellbeing. Providing carers with access to support – particularly from friends and family, respite care, financial support, skills/training, and peer support networks – is likely to be key to supporting wellbeing. However, access to support was associated with fewer differences in levels of psychological distress (Table 44), suggesting a need to better understand whether and how higher levels of wellbeing made help to moderate negative impacts of psychological distress, and different impacts of support on wellbeing versus distress. This should be examined further in future waves of this survey.

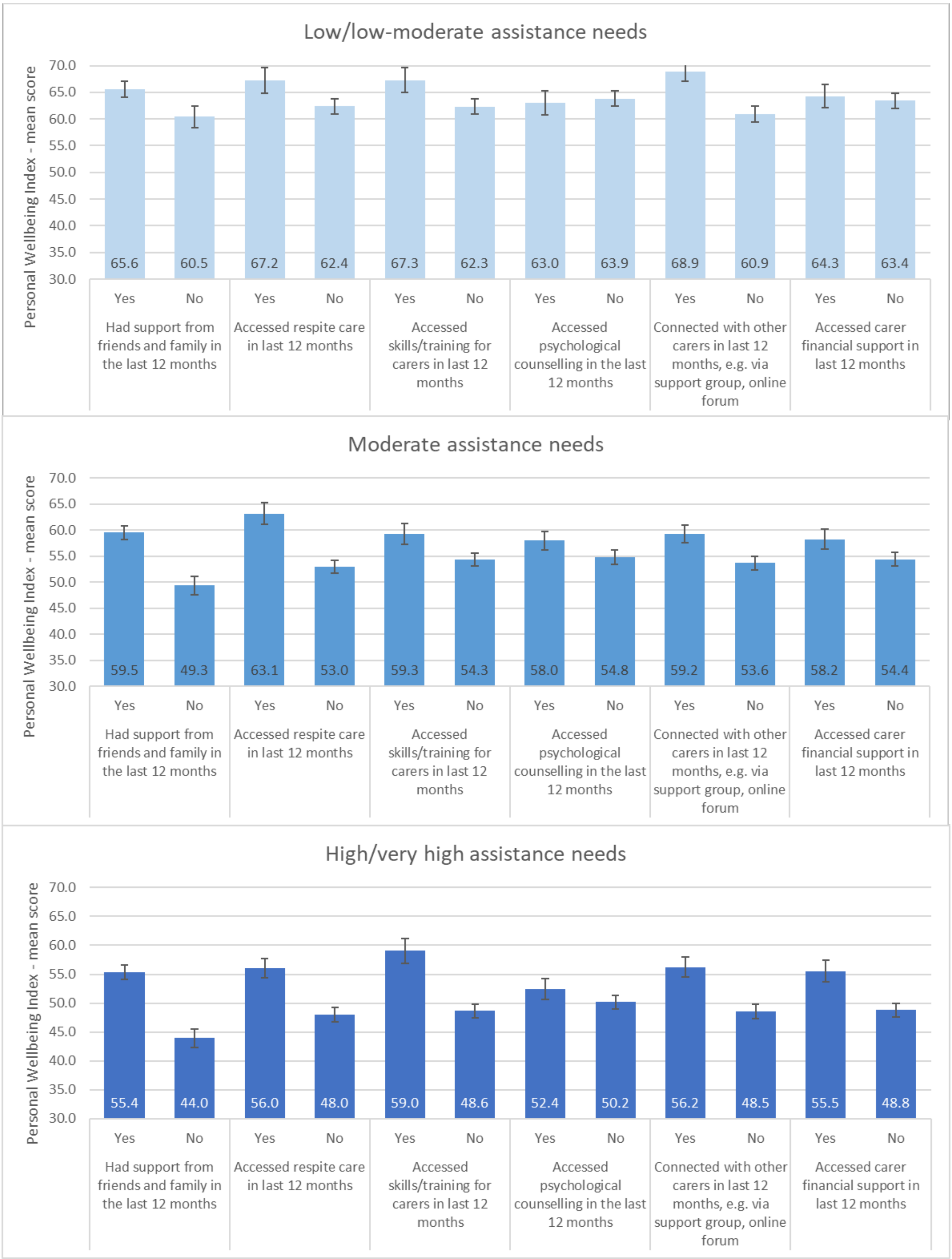


Figure 20 Wellbeing levels of carers who were and were not able to access different supports in the last 12 months

Table 45 Wellbeing and psychological distress levels of carers who were and were not able to access different forms of support in the last 12 months

	Assistance needs of care recipient	Had support from friends and family in the last 12 months			Accessed respite care in last 12 months			Accessed skills/training for carers in last 12 months			Accessed psychological counselling in the last 12 months			Connected with other carers in last 12 months, e.g. via support group, online forum			Accessed carer financial support in last 12 months		
		Yes	No	Diff.	Yes	No	Diff.	Yes	No	Diff.	Yes	No	Diff.	Yes	No	Diff.	Yes	No	Diff.
Global Life Satisfaction - mean score (0-100)	Low/low-moderate	61.5	58.6	2.9	**64.7**	**59.3**	**5.4**	**64.4**	**58.8**	**5.6**	58.2	61.2	-3.0	**64.3**	**58.1**	**6.1**	59.9	60.4	-0.5
	Moderate	**57.6**	**50.7**	**7.0**	**60.6**	**53.0**	**7.7**	57.6	54.0	3.6	56.1	54.0	2.0	**58.6**	**53.0**	**5.6**	56.4	54.3	2.0
	High/very high	**54.8**	**44.5**	**10.3**	**55.3**	**48.3**	**7.1**	**58.7**	**48.5**	**10.3**	51.4	50.4	1.1	**57.2**	**47.8**	**9.4**	**55.6**	**48.5**	**7.0**
Personal Wellbeing Index - mean score (0-100)	Low/low-moderate	**65.6**	**60.5**	**5.2**	**67.2**	**62.4**	**4.9**	**67.3**	**62.3**	**5.0**	63.0	63.9	-0.8	**68.9**	**60.9**	**8.0**	64.3	63.4	0.9
	Moderate	**59.5**	**49.3**	**10.2**	**63.1**	**53.0**	**10.1**	**59.3**	**54.3**	**5.0**	**58.0**	**54.8**	**3.2**	**59.2**	**53.6**	**5.6**	**58.2**	**54.4**	**3.8**
	High/very high	**55.4**	**44.0**	**11.4**	**56.0**	**48.0**	**8.0**	**59.0**	**48.6**	**10.4**	52.4	50.2	2.2	**56.2**	**48.5**	**7.7**	**55.5**	**48.8**	**6.7**
Psychological distress - mean score (measured 10-50)	Low/low-moderate	**23.6**	**22.0**	**1.6**	**24.8**	**22.4**	**2.4**	**24.6**	**22.4**	**2.2**	**25.1**	**22.0**	**3.1**	23.7	22.5	1.2	24.1	22.5	1.6
	Moderate	23.9	25.2	-1.4	23.4	24.7	-1.3	**25.6**	**24.0**	**1.6**	**26.0**	**23.7**	**2.3**	24.5	24.3	0.2	**25.3**	**23.9**	**1.4**
	High/very high	25.3	27.9	-2.6	25.4	26.8	-1.4	26.5	26.3	0.2	27.1	26.0	1.1	25.5	26.7	-1.3	25.4	26.8	-1.4

Interpreting findings in this table: Findings highlighted in **bold** indicate that this there was a significant difference in the wellbeing or distress of carers who did and didn't have this type of support, based on 95% confidence intervals.

6. Discussion and conclusions

The findings of this study confirm that carers have much greater risk of poor wellbeing, high psychological distress, and poor health, compared to the average Australian. Multiple factors are likely to be contributing to this higher risk. In particular, carers experience much higher levels of social isolation and financial stress than other Australians, as well as often experiencing lack of time for self-care, and a range of complex challenges fulfilling their role as a carer.

Some carers are at higher risk of poor outcomes than others. Table 46 synthesises key findings from the study to summarise the extent to which different types of carers were at higher or lower risk of poor wellbeing, high distress, poor health, loneliness, financial stress, loss of time for themselves, low confidence in being able to be a successful carer, negative impacts on social life, and lack of access to support.

It is important when examining Table 46 to interpret it correctly. Table 46 compares different types of carers to the ‘average’ Australian carer. In many cases, the average Australian carer typically has poorer wellbeing outcomes than Australians more broadly. For example, those carers identified as having higher wellbeing still typically have lower wellbeing levels than the average Australian. This means that even those carers identified as having somewhat better outcomes are still likely to be experiencing significant stress on their wellbeing.

While it is important to recognise that all carers are at higher than typical risk of experiencing poor wellbeing, different groups of carers have specific risks:

- Female carers: Female carers are more likely than male carers to be lonely, have little time to themselves, and have poorer health and wellbeing
- Carers aged under 35: While these carers typically had better health and were less likely to experience social isolation or lack time for themselves, they had higher levels of psychological distress, higher financial stress, more negative emotions and lower confidence in their ability to be a good carer.
- Carers aged 35-44: This group had higher psychological distress, high loneliness, less time, lower confidence, and more negative emotions associated with their caring role.
- Carers aged 45-54: This group was at particularly high risk of low wellbeing, poor health, social isolation, financial stress, lack of time, and poor access to support from family and friends.
- Carers aged 55 and older: Older carers in general had fewer wellbeing risks compared to other carers, although their wellbeing was still significantly poorer than other Australians of similar age.
- Caring hours: As caring hours increased, risk of poor outcomes also typically increased.
- Aboriginal and Torres Strait Islander carers: These carers are at higher risk of psychological distress, financial stress, negative emotions associated with their carer role, and low confidence in being able to deliver on their caring role. However, they have better access to support than some other groups of carers.
- Number of people cared for: As the number of people cared for increased, risk of negative outcomes increases

- Time spent as a carer: As time spent as a carer increases, risk of negative outcomes increases
- Caring for a person with ASD, development disorder, mental illness/psychosocial disability, intellectual disability, or drug/alcohol dependency: These carers were at higher risk of negative wellbeing outcomes compared to those caring for people with other types of needs.
- Caring for a child or grandchild: Those caring for children or grandchildren were at higher risk of negative outcomes compared to those caring for a parent, partner, sibling, other relative, or friend.
- Caring for a person with higher assistance needs: As the level of daily assistance needs of care recipients increases, so does risk of poor wellbeing outcomes
- Unemployment: Carers who were unemployed were at great risk of negative wellbeing outcomes.

The findings show clearly that carers who have better access to support have higher levels of wellbeing and fewer negative outcomes for their own health and relationships. However, access to informal support from family and friends tends to be lower amongst those caring for people with high assistance needs, those aged 45-54, those who have been carers for longer, and those caring for people with mental illness, drug/alcohol dependencies, or development disorders. These groups in particular can benefit from access to formal supports.

Overall, there is an ongoing need to tailor supports available to meet the unique needs of different types of carers. A person who is caring for someone experiencing mental illness is likely to have different support needs compared to someone caring for a person with old-age related frailty. Those who are carers at different stages of life also experience different types of care-related stress, and are likely to benefit from support tailored to the needs common to that stage of life.

Table 46 Wellbeing drivers and outcomes: which carers are at higher than average risk of low wellbeing?

Group	Category	Wellbeing	Psycho-logical distress	Health	Lonel-iness	Finances	Benefits	Time	Confi-dence in carer role	Negative emotions	Negative impacts on social life, relation-nships	Access to informal support	Access to formal supports
Gender	Female	Lower		Poorer	Higher		Fewer	Less					
	Male	Higher		Better	Lower		Higher	More		More		Better	
Age	Aged 15-24		Higher	Better	Lower	Poorer		More	Lower	More	Fewer	Better	Higher
	Aged 25-34		Higher	Better		Poorer		More			Fewer		Higher
	Aged 35-44		Higher		Higher	Poorer	Higher	Less	Lower	More	More		
	Aged 45-54	Lower		Poorer	Higher	Poorer	Fewer	Less			More	Poorer	
	Aged 55-64		Lower			Better							Lower
	Aged 65-74		Lower		Lower	Better		More	Higher	Fewer	Fewer		
	Aged 75+	Higher	Lower		Lower	Better		More	Higher	Fewer	Fewer	Better	
Typical caring hours	<20 hours/week			Better	Lower			More			Fewer		
	20-39 hours/week	Higher		Better									
	40+ hours/week	Lower	Higher	Poorer	Higher			Less			More	Poorer	
Cultural, language diversity	Aboriginal/Torres Strait Islander		Higher	Better		Poorer			Lower	More		Better	Higher
	Usually speak language other than English at home												
Sole or assisted carer	Sole carer	Lower		Poorer	Higher						More	Poorer	Lower
	Assisted in caring role												
No. people	Currently care for 1 person		Lower										
	Currently care for 2 people	Lower	Higher			Poorer							
	Currently care for 3 or more people	Lower	Higher	Poorer	Higher	Poorer		Less				Poorer	
Caree resid-ence	Caree lives elsewhere	Higher	Lower	Better	Lower						Fewer		
	Caree lives in home			Poorer	Higher			Less			More		
Length of time being a carer	Carer for 5+ years	Lower		Poorer	Higher							Poorer	
	Carer for 2-5 years			Better	Lower								
	Carer for 1-2 years	Higher	Lower	Better	Lower							Better	Higher
	Carer for <1 year	Higher			Lower			More		More	Fewer	Better	
Care recipient disability illness or	Dementia					Better	Fewer			More	More		Higher
	Old-age related frailty						Higher	More					
	Terminal illness		Higher	Better		Poorer				More	More	Poorer	Higher
	Autism spectrum disorder	Lower	Higher	Poorer	Higher	Poorer		Less	Lower		More		Higher

Group	Category	Wellbeing	Psychological distress	Health	Loneliness	Finances	Benefits	Time	Confidence in carer role	Negative emotions	Negative impacts on social life, relationnships	Access to informal support	Access to formal supports
injury type	Other development disorder	Lower	Higher	Poorer	Higher	Poorer		Less	Lower		More	Poorer	
	Mental illness/ psychosocial	Lower	Higher	Poorer	Higher	Poorer	Fewer		Lower		More	Poorer	Varied
	Drug/alcohol dependency	Lower	Higher			Poorer	Fewer		Lower	More		Poorer	Higher
	Physical disability												Lower
	Intellectual disability	Lower	Higher	Poorer	Higher			Less	Lower		More		
	Chronic illness or injury												
	Short term non-terminal illness			Poorer	Lower			More					
Type of care recipient	Care for child/grandchild	Lower	Higher	Poorer	Higher	Poorer		Less	Lower		More	Poorer	
	Care for partner								Higher				
	Care for parent/ grandparent			Better									
Care recipient needs	Lower assistance needs	Higher	Lower	Better	Lower	Better		More			Fewer	Better	
	Moderate assistance needs			Better	Lower								
	High/ assistance needs	Lower	Higher	Poorer	Higher			Less	Lower		More	Poorer	
Labour force status	Employed			Better					Lower				
	Unemployed	Lower	Higher	Poorer	Higher	Poorer	Fewer			More			
	Not in labour force	Lower		Poorer					Higher				

7. References

ABS (Australian Bureau of Statistics). 2016. Census Household Form. URL: https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2901.0Main%20Features802016/$FILE/2016%20Census%20Sample%20Household%20Form.pdf Accessed June 2021.

ABS (Australian Bureau of Statistics). (2018). Census of Population and Housing, TableBuilder Pro. ABS Canberra, data accessed during April to June 2021.

ABS (Australian Bureau of Statistics). (2018). National health survey: first results. ABS, Canberra. URL: https://www.abs.gov.au/statistics/health/health-conditions-and-risks/national-health-survey-first-results/latest-release#about-the-national-health-survey

ABS (Australian Bureau of Statistics). (2019). Disability, ageing and carers, Australia. URL: https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release Accessed June 2021.

Andrews, G., & Slade, T. (2001). Interpreting scores on the Kessler psychological distress scale (K10). *Australian and New Zealand journal of public health*, *25*(6), 494-497.

Blanchflower, D. G., & Graham, C. L. (2021). The U-shape of happiness: A response. *Perspectives on Psychological Science*, 1745691620984393.

Cacioppo, J. T., & Cacioppo, S. (2018). The growing problem of loneliness. *The Lancet*, *391*(10119), 426.

Carers NSW. (2020). 2020 National Carer Survey. URL: https://www.carersnsw.org.au/about-us/our-research/carer-survey Accessed June 2021.

Christensen, A. I., Ekholm, O., Glümer, C., & Juel, K. (2014). Effect of survey mode on response patterns: comparison of face-to-face and self-administered modes in health surveys. *The European Journal of Public Health*, *24*(2), 327-332.

Deloitte (2020). The value of informal care in 2020. Report produced for Carers Australia. Deloitte Access Economics. URL: https://www2.deloitte.com/au/en/pages/economics/articles/value-of-informal-care-2020.html Accessed June 2021.

Dolan, P., & Kavetsos, G. (2016). Happy talk: Mode of administration effects on subjective well-being. *Journal of Happiness Studies*, *17*(3), 1273-1291.

Hughes, M. E., Waite, L. J., Hawkley, L. C., & Cacioppo, J. T. (2004). A short scale for measuring loneliness in large surveys: Results from two population-based studies. *Research on aging*, *26*(6), 655-672.

International Wellbeing Group (2013). Personal Wellbeing Index: 5th Edition. Melbourne: Australian Centre on Quality of Life, Deakin University

Matthews-Ewald, M. R., & Zullig, K. J. (2013). Evaluating the performance of a short loneliness scale among college students. *Journal of College Student Development*, *54*(1), 105-109.

Mushtaq, R., Shoib, S., Shah, T., & Mushtaq, S. (2014). Relationship between loneliness, psychiatric disorders and physical health? A review on the psychological aspects of loneliness. *Journal of clinical and diagnostic research: JCDR*, *8*(9), WE01.

Schirmer, J., Yabsley, B., Mylek, M. & Peel, D. (2016). *Wellbeing, Resilience and Liveability in Regional Australia: the 2015 Regional Wellbeing Survey*. University of Canberra. http://www.regionalwellbeing.org.au

Schirmer, J. and Miranti, R. (2021). Carer Wellbeing Survey – methods and sampling. 2021 edition. University of Canberra.

Schirmer, J., Mylek, M. and Peel, D. (2021). 2020 Regional Wellbeing survey data tables. August 2021, version 1.0. University of Canberra, Canberra. Available at www.regionalwellbeing.org.au

Singer, E., & Ye, C. (2013). The use and effects of incentives in surveys. *The ANNALS of the American Academy of Political and Social Science*, *645*(1), 112-141.

Snape, D. and Martin, G. (2018). Measuring loneliness: guidance for use of the national indicators on surveys. Office for National Statistics, United Kingdom. URL: https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/methodologies/measuringlonelinessguidanceforuseofthenationalindicatorsonsurveys

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The gerontologist*, *20*(6), 649-655.