

# CARING FOR OTHERS AND YOURSELF

## The 2021 Carer Wellbeing Survey

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AUGUST 2021



# EXECUTIVE SUMMARY

## 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).

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.

### 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.

## 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.

### How likely are you to be a carer at different ages?

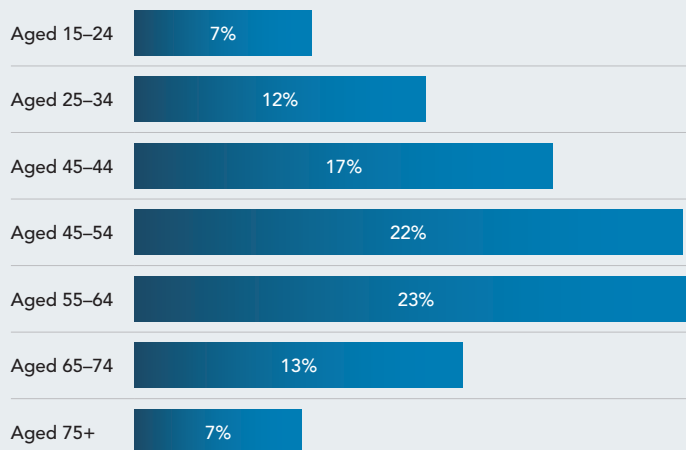


Figure E1: % Australians who are carers, by age group (data source: ABS 2016 Census of Population and Housing)

## 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.

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.

### Those caring for people with high assistance needs commonly have lower wellbeing

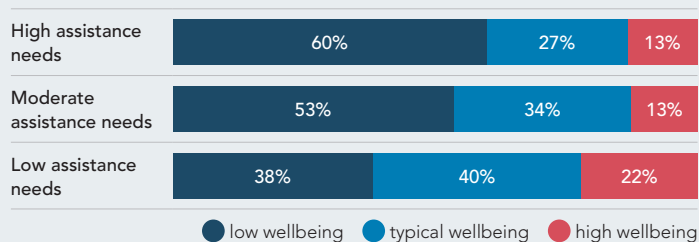


Figure E3: Difference in wellbeing of those caring for people with different levels of daily assistance needs

### Carers are 2.5 times more likely to have low wellbeing than the average Australian

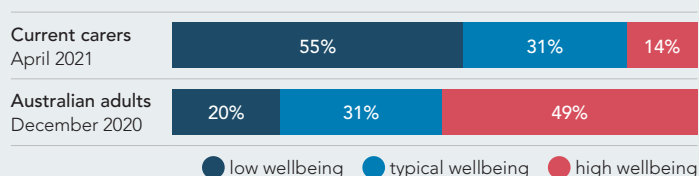


Figure E2: The wellbeing gap between carers and the typical Australian

## 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



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 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.

### Overall health status

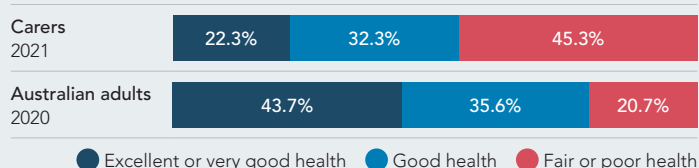


Figure E4: Self-rated health of carers compared to the Australian population

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

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### % who experienced 1 or more financial stress events in the previous 12 months

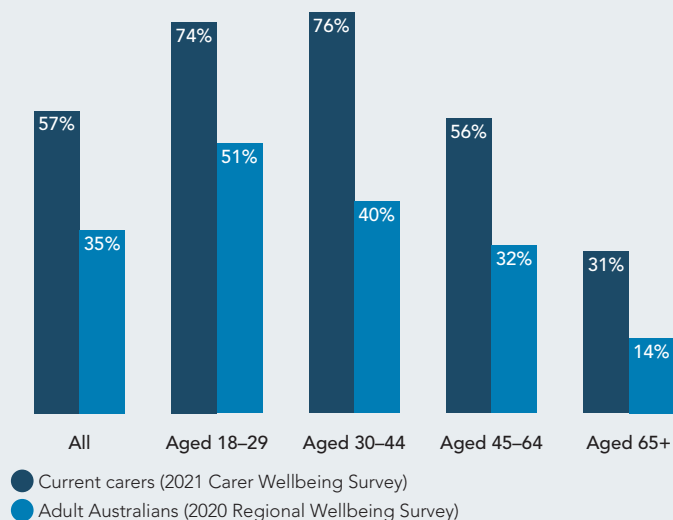


Figure E5: % carers experiencing one or more financial stress events

## 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. 57 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.

## 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.

Participation in the labour force declines the longer a person is a carer

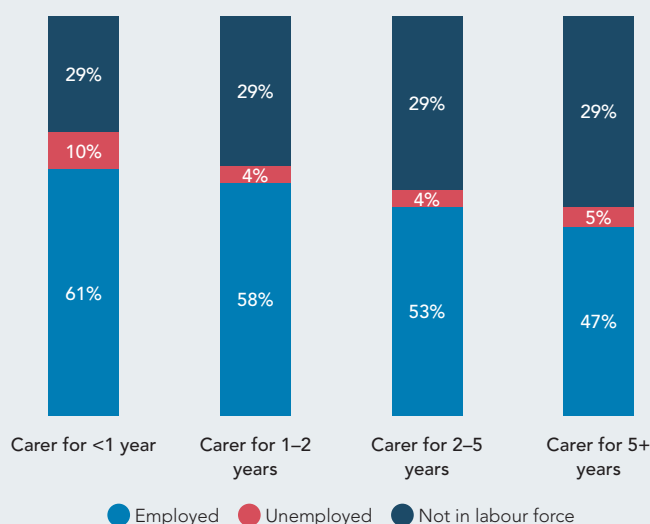


Figure E6: Proportion of carers in the labour force, by number of years they had been a carer

## 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.

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

### % current carers who regularly/always

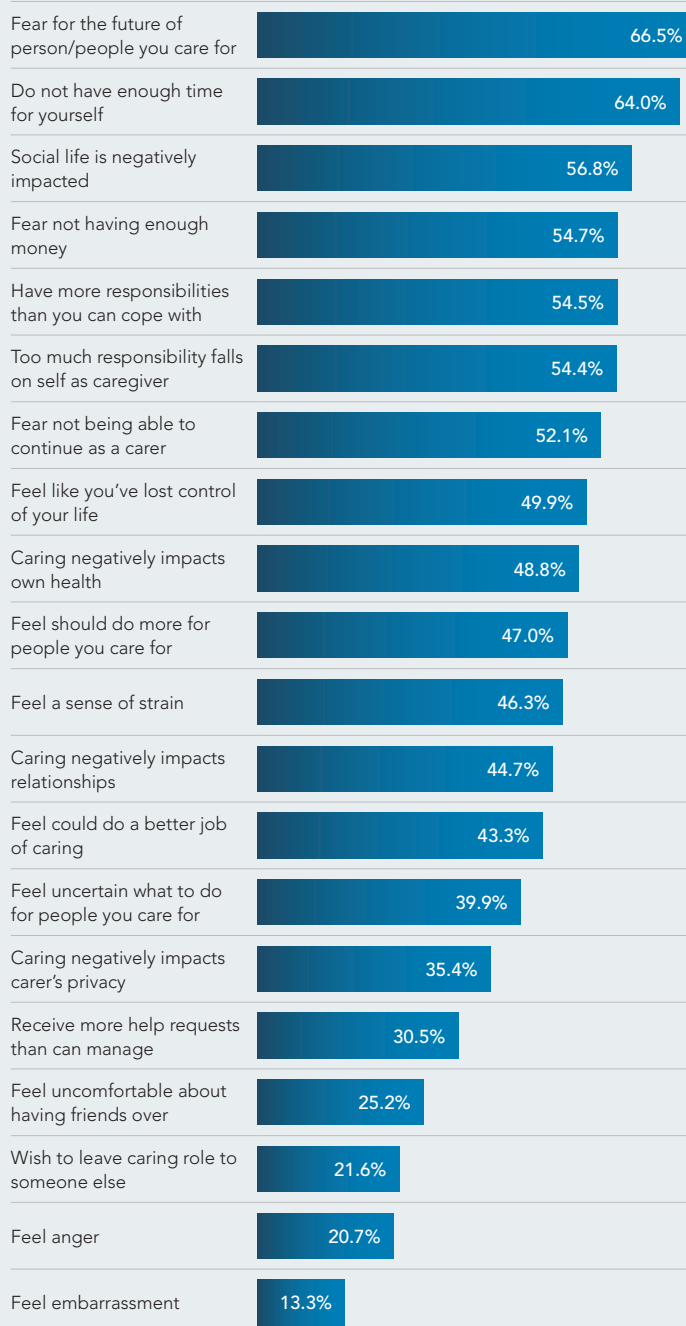


Figure E7: Common challenges experienced by carers

### 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.

### 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.

Carer's access to support from friends and family

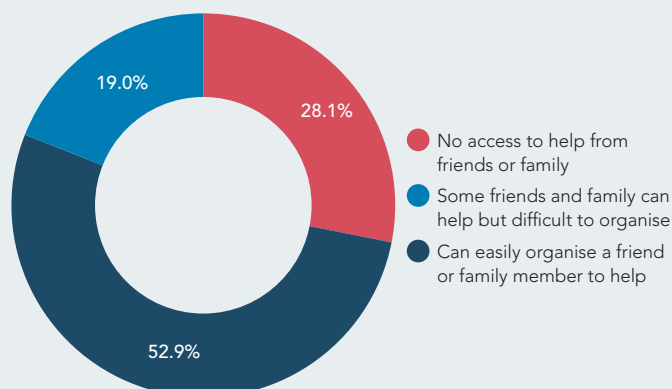


Figure E8: Access to support from friends and family

### 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 – their 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 compared 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.









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