

# Caring during Coronavirus

## *Results of the COVID-19 Carer Survey*

*“I am now cleaner, nurse, teacher, cook, driver, entertainer, problem solver, bill payer, shopper for food and any household things needed and most of all the person who hands out love.”*

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## Background

The Caring Fairly coalition conducted a survey to capture unpaid carers' experiences of the COVID-19 pandemic. The aim of the survey was to assess the self-reported impact of the pandemic on carers' work and income, expenses, health and wellbeing and access to services and supports. The survey was open to anyone who identified as being a 'carer.'

The survey was advertised using social media by Caring Fairly and partners. The survey was open from 21 April - 5 May 2020, and was hosted online using LimeSurvey. The findings draw on 471 responses, collected from carers across Australia.

At the time the survey was conducted, all States and Territories were experiencing restrictions in activity and individuals were directed to stay at home to limit the spread of COVID-19. This meant that many service providers were not able to offer the full range of face-to-face services, leading to a reduction in disability and mental health supports, as well as carer respite services.

Before the survey period, the Federal Government had implemented a raft of economic stimulus payments, including a Coronavirus Supplement, which effectively doubled the amount of a range of social security payments, including JobSeeker, Youth Allowance and the Parenting Payment. However, people receiving the Carer Payment and Disability Support Pension did not receive this supplement.

Caring Fairly sought to understand whether the changes brought about by COVID-19 were having an impact on carers.

## About Caring Fairly

Caring Fairly is a national campaigning coalition seeking recognition, reform, and a greater respect for the rights of Australia's unpaid carers. We are led by a coalition of 29 carer support organisations, NGOs, peak bodies, and carers themselves, spanning all states and territories of Australia. Caring Fairly is coordinated by Mind Australia, one of the country's leading and largest community managed mental health organisations.

## Definition of carer

This survey was for people who provide regular unpaid care and support for a family member or friend ('unpaid carers'). Carers are people who provide care to others in need of assistance or support. An informal carer provides this service free of charge and does so outside of the formal care sector. An informal carer will typically be a family member or friend of the person receiving the care, and usually lives in the same household as the recipient of care. As such, many people receive informal care from more than one person. The person who provides the majority of informal care is known as the primary carer.<sup>1</sup>

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<sup>1</sup>Deloitte Access Economics (2015) *The Economic Value of Informal Care in Australia 2015*. Available at: <https://www.carersaustralia.com.au/storage/access-economics-report-2015.pdf> (Accessed 11 June 2020).

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# Findings

## Demographics

Almost 90% of carers surveyed identified as female and 9% identified as male. Most carers were aged between 36-65 years (74%) and born in Australia (85%). Around 5% of carers identified as Aboriginal or Torres Strait Islander Australian.

Around 40% of carers were not employed and not seeking employment. One-quarter of carers were employed part-time, 15% were employed full-time and 7% were self-employed. Over half of the respondents were receiving the Carer Allowance (55%) and a third of carers were receiving the Carer Payment (33%). A smaller number were receiving the Disability Support Pension (6%), JobKeeper Payment (2%) or JobSeeker Payment (4%).

Whilst 60% of the sample cared for one person, 26% cared for two people and 14% cared for more than two people. Carers were caring for people who had a range of disabilities/ impairments and often experienced co-morbidities, including mental health issue/psychosocial disability (N=242), medical condition (N=205), physical disability (N=162), autism spectrum disorder (N=132), learning disability (N=117), neurological condition (N=116) and intellectual disability (N=104). Almost a third of the people being cared for were under 18 years of age (30%), whilst another third were aged 18-45 years (36%). Just under a third of carers reported having a mental health issue themselves (32%), 8% reported having a disability and 7% as having both a mental health issue and a disability.

## Impact on Support Services

The findings show that COVID-19 had an impact on support services that carers received for themselves and the person they cared for. Since COVID-19, 60% of carers surveyed lost some or all of the support services for the person they care for and 47% lost some or all of the support services for themselves. Fewer than 10% of carers received any extra help for the person they care for.

Not surprisingly, many carers reported needing to spend more time on care tasks during COVID-19. Before COVID-19, 27% of carers were spending more than 45 hours per week on care tasks. Since COVID-19, 50% reported that they spent more than 45 hours on care tasks. Almost one in five carers reported that the time they spent on care tasks increased from 25-45 hours to more than 45 hours (19%). For just over half of the carers, the time they spent on care tasks did not change (53%).

Many carers cited a reduction of services for the person they care for as a reason for their increasing care responsibilities. They were also experiencing a reduction in respite services, which had previously provided a break from their caring responsibilities.

*“So alone with everything because nothing is open or they have extremely limited services. And no-one cares.”*

*“Some of his supports are now happening online, which is a better situation than it was in the early days of the pandemic. But I still feel an added responsibility and requirement of care from me every day. I find I have little time to myself.”*

*“This is 24/7 and it’s hell.”*

Many carers who care for a person experiencing mental ill-health also said the person they care for has experienced increased mental distress and/or symptoms, leading to them requiring more support from their carer.

*“Anxiety around COVID-19 has led to an increase in anxiety for the person I care for, so much of the increase in time relates to giving them time to talk.”*

*"(The) person I care for requires much more care due to severe anxiety about COVID-19. I now barely sleep as their anxiety has severely affected their sleep (they now struggle to sleep without significant supports). This is affecting every part of our lives- getting groceries is significantly more difficult as the person I care for is worried to leave the house but there is no one else to care for them and they can't be left alone, we can't access supports as the risk is deadly for us, and we can't access any funding for items that may help in the home."*

*"Mum's getting more depressed cause she's too scared to go anywhere in case she catches the virus, so I've got to get the food while mum stays home, she won't even go for a walk, she just sits in her chair. So I study, shop, cook, clean, give mum food, try to encourage her to eat, shower, shop or exercise but she just wants to stay home, which is very hard for me to keep thinking of ways to motivate her to move around."*

*"I support two teenagers with mental health issues. Their needs have increased during this time as their depression and anxiety have worsened. I have had to spend much more time trying to get them to attend to their schoolwork and other matters."*

In addition to an increase in the number of hours of care provided, carers also said they have had to take on different types of support than before.

*"I used to get a couple of hours of respite two days per week when my son was at school, and my mother would also care for my son for a few hours every couple of weeks to allow my husband and I to have an outing together. This has all stopped due to COVID-19. I have also taken on the role of not only parent and Carer, but teacher, speech pathologist, [occupational therapist] etc."*

*"I am now cleaner, nurse, teacher, cook, driver, entertainer, problem solver, bill payer, shopper for food and any household things needed and most of all the person who hands out love."*

*"I am not a nurse and yet... it's exactly what I've been doing."*

*"Gyms have closed so I am responsible to maintain his exercise with continuous resistance."*

Just over a third of carers (35%) reported that they knew about supports that are available to them as part of the Australian Government's COVID-19 support packages. Fewer than 6% of carers reported that the Australian Government is currently providing enough support for carers in the COVID-19 crisis.

Many carers felt abandoned and unappreciated.

*"Feeling very alone and very much like my government has abandoned me and my child, restricted to home to ride out the storm alone... my only connection a screen when all I need is a hug."*

*"There has been a neglect in the duty of care towards carers for a long time, even before the pandemic. This pandemic has just highlighted the lack of financial, physical and emotional support we have for unpaid carers in this country."*

*"The Government needs to recognise that the disabled and carer community needs help too."*

*"My caring role is now 24/7 and the cost of living has sky rocketed and the government doesn't seem to care about carers."*

*"This is the first time I have felt the government and myself are not a team. Rather, I am on my own."*

*"The government provides no support for carers of people with disability."*

## Impact on health and wellbeing

COVID-19 generally had a negative effect on carers' physical and mental health and stress. The majority of carers said their mental health had deteriorated since the COVID-19 pandemic (81%). Fewer than 1% of carers reported that their mental health had improved (0.7%). Just over one third of carers reported that their mental health changed a lot or by an extreme amount (36%), by a moderate amount (38%), and 26% reported that their mental health had changed a little amount. Almost all carers (88%) had experienced increased stress in their role as a carer. For these carers, stress increased by a lot or extreme amount (52%) or a moderate amount (34%).

Many carers attributed a decline in their wellbeing to their increased caring responsibilities, and to not being able to have a break.

*“Increased stress for me and the person I care for, less breaks from the person I care for, more pressure on me to do more housework tasks and errands such as groceries.”*

*“Having someone clinging to me 24/7 for everything is stressful and still trying to study, look after the rest of the family, my own health and cook and shop.”*

*“I have had not one second child free in 7 weeks. I have no family, friends, or support workers. I can only shower at 11pm when the children finally go to sleep because they can't be left unsupervised but the shower often wakes them so I'm going days without showering. I used to go to the gym for respite but also to keep strong enough to carry my children and protect myself. I also usually see a psychologist for support and strategies; this is no longer possible. I am in every sense of the word alone.”*

Others felt isolated and disconnected from their informal supports.

*“Minimal social interaction, no hugs from friends and family to show me I'm loved and supported. I didn't realise how much I rely on social moments of connection away from the person I care for to pretend that my life is in some way normal. My life is always focussed on my husband's needs, but when I'm with my friends and family without him, then life can be about me for an hour or two.”*

The financial impacts of the pandemic have also taken a toll on carers' wellbeing.

*“I cannot sleep because I am concerned about money, going over and over numbers to make sure I can cover everything and hold it all together. I also feel stressed because I now have no help or support at home and feel like I am pulled in many directions.”*

*“I'm exhausted and worried about increased costs. I'm not able to go back to work part time as planned”*

*“Expenses have gone up, [I'm] unable to go to shops with my immunocompromised kid, so having to pay extra charges on delivery at home. So a lot of financial stress.”*

Some carers attributed their change in wellbeing to increased concern for themselves or people they care for contracting COVID-19.

*“Fear. Fear that someone will bring COVID-19 into the house or that I will bring it home after my brief times out.”*

*“I feel more anxious and stressed than before. I worry my daughter will get sick, I worry I will get sick and won't be able to care for her.”*

For many carers, it is the combined nature of all these factors that have negatively impacted their mental health.

*“Lack of support. Can't go anywhere. Can't provide for my child. I feel like a failure.”*

In addition to impacting on carers' mental health, almost 60% of carers reported that their physical health had deteriorated (58%). Fewer than 4% reported that their physical health had improved. For those who had experienced a change in their physical health, it tended to be a little or moderate amount (69%), and less reported that it had changed a lot (23%) or an extreme amount (8%).

Over a third of carers have been more concerned about their personal safety (38%). For 42% of those concerned about their safety, their safety concerns increased a lot or by an extreme amount.

## Impact on work, income and costs of living

For some carers, caring is a full time occupation which does not allow them to undertake paid work.

However, for those carers who do undertake paid employment, many had experienced a reduction in pay and work hours. Since COVID-19, over a third of carers reported that they lost some/all of their regular income (37%). Since COVID-19, 10% of carers reported that they lost their job.

Over a third of carers reported that they had worked fewer hours because they needed to provide more care for the person they care for (37%). This was due to a reduction in services being available, limiting contact with others to reduce the risk of infection to themselves and the person they care for, or the person they care for requiring greater support.

*“I have reduced my hours of work to meet the caring needs. I used to work 4 days and now work 3 days per week.”*

*"Since the COVID-19 outbreak I had further responsibility to care for my son because he was isolated and needed more support."*

*"I have voluntarily stopped working because of the risk to my husband if he contracts the coronavirus. I worked in retail, so impossible not to have contact with customers. I have worked for the same company for 3 years, but as I was made casual last year, I have no sick pay or holiday pay. Because I get Carer Payment, I am not eligible for JobSeeker payment, and because my employer is still quite busy, they have not claimed the JobKeeper payment, so I have no way of replacing my lost income."*

*"I have had to take some days/hours off work as the person I care for is suffering more anxiety than usual and I am supporting her through this."*

Fewer carers reported having to work less because their employer did not have as much work for them (22%).

*"[My] hours have been reduced due to current changes."*

*"My job was in tourism so no longer exists since COVID-19."*

Whilst some carers have not experienced a reduction in work hours or pay, changed conditions have had an impact on their working environment. Some carers reported that they were now working from home, which was difficult while juggling caring responsibilities.

*"Since the pandemic, all my work has been from home. This means the person I care for has become more dependent on me being home and has a meltdown when I leave the house."*

*"[I have] shifted to a working from home environment which is difficult as I usually work while my son is at preschool, but due to him being high risk I've had to pull him out of preschool and keep him at home."*

*"Working from home caring for my son with a disability, plus two kids. I still need to work my hours whilst caring for them. Very challenging!"*

However, other carers reported positive consequences from now working at home.

*"I am now working full-time from home and this has not had any bearing on my income as I recently started full-time work. It has actually made it easier for me."*

*"My work hours are the same, but I am working remotely from home. I have enjoyed the flexibility in being able to respond sooner to the needs of my family member who needs support. They are living alone and are quite isolated at the moment so we have been speaking more on the phone."*

Reductions in income has also coincided with an increase in living expenses. The majority of carers reported spending more on living costs (71%) and supporting the person they care for (58%). Common increases came from grocery shopping (94%), cleaning (48%), medication (37%) and health care (32%).

*"We barely had enough money to scrape by before this happened. I understand we haven't technically lost employment or income as others have. However, we are disadvantaged in that everything is more expensive, we are struggling to meet our most basic survival needs, having to go without essential items."*

## Discussion

The findings clearly show that carers have been significantly impacted by COVID-19.

The COVID-19 pandemic has impacted unpaid carers' work and income, expenses, health and wellbeing and access to services and supports.

While many people have been significantly impacted by COVID-19, carers have experienced adverse experiences related to their caring relationship and the support they provide. When services closed or reduced during COVID-19, it was unpaid carers who were left to provide replacement and/or additional support, often at significant cost to their own health and wellbeing. Carers experience the stress of having to navigate their own circumstances through a global pandemic, while taking care of someone else.

It is clear that carers are experiencing a profound amount of stress and isolation due to having to take on round-the-clock care, with many stating that they now feel as though all the responsibility for care now falls solely upon themselves.

*"I have no life now. It is all about mum and keeping her safe. My caring role has changed to 24 hour care which is exhausting. I don't have any time or physical space to just switch off and be "me".*

*I am 100% in "carer mode" role now and I don't know how long I can keep this up."*

The unemployment rate in Australia has risen since COVID-19 so it is no surprise that carers have been forced to either work fewer hours or have experienced job losses since COVID-19. However, the findings show that, in addition to these labour market impacts, carers have also had to decrease their work hours due to increased caring responsibilities that have come about because of changes to service and support systems for the people they care for. As such, carers are being disproportionately affected by COVID-19 as they are experiencing both the anticipated economic impacts, as well as unique challenges associated with their caring responsibilities.

The research shows that carers feel left out of Government policies and economic stimulus packages, with only 22 respondents stating that they felt the Australian Government was providing enough support for carers in the COVID-19 crisis. Being excluded from the Coronavirus Supplement was a significant reason for this sentiment.

*"I feel discriminated against by the government by their exclusion of carers."*

## Conclusion

The experiences of carers during COVID-19 serve as a snapshot of the impacts reduced mental health and disability services have on carers. The findings demonstrate that when there is a reduced service offering, carers have little choice but to subsume all caring responsibilities, at significant detriment to their health and wellbeing.

The findings show that carers have been severely financially impacted by COVID-19, with detrimental impacts on their health and wellbeing. The social security measures introduced by the Federal Government have not ameliorated this impact on people with significant caring responsibilities. The Federal Government could provide greater financial support to carers through extending the Coronavirus Supplement to carers receiving the Carer Payment, or increasing carer subsidies more broadly.

The evidence also suggests that carers feel as though they are not a priority for Government and are not considered as critical to Australia's ongoing sustainability. A whole-of-government approach to provide a coordinated strategy for carers would assist in addressing these needs.

## Limitations

There are limitations of this study that need to be considered, as only carers who had access to technology and could complete an online survey in English were able to be involved. Furthermore, with the goal of keeping this survey short, it was not possible to explore all answers in detail.

## Carers of people experiencing mental ill-health

In addition to broader results Caring Fairly sought to understand the impact of COVID-19 on carers of people with mental ill-health specifically, to inform government policy, as this group of carers often have unique needs.

The results of the 242 people who said they cared for someone with mental health issue/psychosocial disability were analysed to provide an understanding of the impact of COVID-19 on this cohort of carers.

### COVID-19 impact on support services and time spent on unpaid care tasks

Most survey participants who care for someone with mental ill health reported that since the COVID-19 outbreak they have lost some or all of the support services for the person they care for (61%) and for themselves (47%).

Less than 10% of mental health carers reported receiving any extra help for the person they care for or themselves.

Since COVID-19, 46% of mental health carers say they have increased the time they spend on caring tasks and 46% say they are now spending more than 45 hours per week on caring tasks.

Many mental health carers said that their increasing care responsibilities have occurred due to a reduction in support services.

*"It has changed as I have lost support workers who took some of the load. Having the person at home 24/7 without them being able to socialise means they want more attention of me as their carer when I'm already doing more to look after them."*

*"Increase in day to day supports, keeping person occupied, supporting them to manage their anxiety. More shopping and household work. Increase time in engaging person in activities and expenses associated with this. The person is with me all day every day as all their outside engagement has dropped off."*

In many instances mental health carers have described the COVID-19 outbreak as having a detrimental impact on the person they are caring for.

*"Her mental health has deteriorated as well due to not getting time in the community, sleeping has become less and accessing food has been a nightmare."*

Detrimental impacts experienced by the person being cared for often have flow-on impacts to their carer.

*"I feel defeated. I need to be there for my child, but it comes at a great cost that is unsustainable as this isolation continues..."*

The impact of the pandemic on the wellbeing of the people being cared for had also led to an increase in care responsibilities.

*"I mostly spend more time doing things for and with the person. Because of the isolation, the person feels depressed and lonely. I also spend more time going to and from the person's residence."*

In addition to an increase in the number of hours of care provided, mental health carers also said they were needing to take on different types of support than before.

*"The person I care for has a mental health condition and is not coping with the changes due to COVID-19. He is immunocompromised due to medications and co-morbidities and is considered vulnerable, or high risk for complications from COVID-19. Routines have changed, outings cancelled, telehealth introduced, sessions moved to online activities, cleaners cancelled services, grocery shopping (supply chains) limited and altered. I have had to provide more constant prompting and reassurance at this difficult time. I have had to do all the cooking and cleaning, planning and organising."*

### Impact of COVID-19 on Mental Health Carers' Health and Wellbeing

For the majority of mental health carers who responded to the survey, the pandemic has had a considerable negative impact on their health and wellbeing.

The vast majority (79%) said their mental health had deteriorated since the COVID-19 pandemic. Almost all mental health carers (88%) had experienced increased stress in their role as a carer, with 57% responding that their stress had increased by 'a lot' or 'an extreme amount.'

An increase in caring responsibilities since the outbreak and a lack of respite and supports was a common reason that survey participants gave for the decline in their wellbeing.

*"Being the only support, and the only person my husband sees, has put immense pressure on me. I am also worried about the financial aspects, as groceries have increased in price. I worry a lot about my husband's state of mind, also his pain and stress levels."*

*"Support services closed, more Telehealth appointments but no home support or respite."*

Another common reason people provided for their deteriorating mental health and increased stress was concern for the people they care for.

*"I am an unpaid carer for my partner of 18 years, whom has not been able to work for nearly two years due to diagnosed mental health disorders. My partner was battling issues with anxiety and agoraphobia prior to COVID-19, but now is so fearful of leaving the home that panic attacks occur with the thought of having to. The impacts have had a very negative impact on my work and mental health too."*

*"My caring role has put a lot of responsibility on me, it has given me more pressure to look after myself first and stay strong so that I can be a positive person for my son. I do get nervous when I leave the house in the event that I may catch this virus (I am being as careful as I can), it stresses me to think that if I got sick there would be nobody to care for my son."*

*"My son is coping poorly with the drastic changes/isolation. He has suicidal thoughts and is very anxious. He sleeps poorly and has become more unwell. I find that this is constantly stressful."*

The financial impacts of the pandemic have also had a toll on personal wellbeing.

*"I am not sleeping. I am stressed about finances. I am still paying last year's gas bill and am very aware that with us home all the time the next one will be huge."*

*"We save the government half a million dollars in supported living costs per year, work 110 hour weeks, killing ourselves to do so, are going without because prices have risen and we have to pay for home visit doctors and expensive chemists that have our medications in stock, all so we can be the only ones ignored in the huge amounts of cash given out."*

## **COVID-19 impacts on unpaid mental health carers' work, income and costs of living.**

Over one-third of mental health carers had lost some or all of their regular income as a result of the COVID-19 outbreak. Furthermore, over one-third have worked fewer hours because they have had to provide extra support to the person/people they care for. Additionally, 22% of mental health carers reported that they have worked fewer hours because their employer didn't have enough work for them. A further 10 per cent of mental health carers had lost their jobs entirely.

*"I've had to cut my shifts due to my 23yo son's day services closing and him being home 24/7. I have no one to look after him and I don't get Carer Payment or Carer allowance because we both work."*

*"I am a self-employed child care worker. Our industry has changed a lot since COVID, and the government now covers our income which is not at the same level that it used to be. Financially helping someone with a mental health illness on a reduced income is challenging!"*

*"I was let go then reinstated. This caused problems with my caring duties."*

In addition to losing income, almost three quarters of mental health carers reported that they have experienced increased living costs. Two-thirds of mental health carers reported that they have had to spend more money on support for the person they care for. Groceries, cleaning, healthcare and medications were the top categories where mental health carers reported increased costs.

*"Partner who I care for lost his job, so I am now covering 100% of his expenses also."*

*"Have lost my 22.5 hr a week job because of virus and no longer required. Therefore, back to below poverty line income with no extras ever. Depression seeping back as no break from caring role. Work provides outlet. Have had to order online necessities such as toilet paper etc at much higher cost as unable to get from supermarkets."*

## Carers receiving the Carer Payment

Caring Fairly wanted to understand the impact of COVID-19 on carers who receive the Carer Payment.

In March 2020, the Government introduced a Coronavirus Supplement to effectively double the amount of a range of social security payments, including JobSeeker, Youth Allowance and the Parenting Payment.<sup>2</sup> The stated reasoning for the increased rate is in recognition that the economic impact of the coronavirus pandemic will directly impede people's chances of finding and retaining paid employment over coming months.<sup>3</sup>

However, people receiving the Carer Payment and Disability Support Pension were excluded from these extra payments.

Caring Fairly sought to understand whether people receiving the Carer Payment were being financially impacted by COVID-19 through increased costs and/or decreased income and segmented the results accordingly.

A number of respondents receiving the Carer Payment work part-time or are self-employed to supplement income from the Carer Payment, with many in insecure work.

The results show that many had experienced a significant reduction in work hours due to COVID-19:

- 42% have lost some/all of their regular income since the COVID-19 outbreak.
- 40% of people say that they've had to work fewer hours because they have needed to provide extra support to the person they care for, whereas just over half that percent (24.7%) had to work fewer hours because their employers initiated a reduction in work hours
- 12% reported losing their job since COVID-19

*"Due to coronavirus my respite carers could not care for the children as they had to isolate. I have had to resign from my job as I had no care for the children who are both disabled. It's very isolating. I am unable to sleep as I worry about how I'm going to provide for the children. Due to being on carer payments, I am not eligible for the \$550 supplement payment. This leaves my single parent family \$400 worse off per week compared to other single parent families with children without disabilities. I have had to delay assessments recommended for my son as I can't afford them. It's very stressful and isolating."*

People on the Carer Payment have also reported a significant increase in costs since COVID-19:

- 86% of carers are now spending more money on livings costs. The most common increases in living costs are grocery shopping (96%), cleaning (49.5%) and medication (40.5%).
- 65% report now having to spend more money on support for the person they care for. Again, grocery shopping (80%), cleaning (63%) and medication (44%) account for the majority of these increases.

Many stated that needing to pay for essentials to get delivered was a large contributor to these increased costs.

89% of people on the Carer Payment said that their mental health has deteriorated since COVID-19, with 95% stating that they have experienced increased stress in their role as a carer since the pandemic began.

Many carers attributed the impact on their mental health to increased caring demands during COVID-19 and financial concerns.

<sup>2</sup> Prime Minister of Australia (2020) *Supporting Australian Workers and Business*, accessed 11 June 2020, <https://www.pm.gov.au/media/supporting-australian-workers-and-business>

<sup>3</sup> Hermant, N. (2020) 'People with disability say COVID-19 is pushing up costs, but they can't get Coronavirus Supplement', *ABC News*, 19 April, <https://www.abc.net.au/news/2020-04-19/coronavirus-supplement-people-with-disability/12158526>

## Appendix 1: Survey questions

### Caring Fairly COVID-19 carer survey

This survey is for people who provide regular unpaid care and support for a family member or friend ('unpaid carers'). We want to understand how the COVID-19 (Coronavirus) pandemic is impacting on unpaid carers. When we know more about the impact of COVID-19 on unpaid carers we can advocate on your behalf and make sure your voice is heard.

There are 20 questions about your experiences and what may have happened to you during the COVID-19 pandemic. There are also 14 questions about you. Only answer the questions that you are comfortable answering. If you feel concerned by any questions during this survey, please feel free to take a break or exit the survey. Please note: if you exit the survey before the end your answers will not be saved.

When answering these questions, please think about how you and the person that you care for have been affected by COVID-19. The survey will take you about 15 minutes to do. All the information you provide will be confidential and we will not record any names or contact details.

Your work and income: since the COVID-19 (Coronavirus) outbreak, have you –				
a) lost your job?	Y	N	DK	NA
b) worked fewer hours because your employer didn't have enough work for you?	Y	N	DK	NA
c) worked fewer hours because you need to provide extra support to the person that you care for?	Y	N	DK	NA
d) lost some/all of your regular income?	Y	N	DK	NA
Can you tell us more about any changes to your work or income since the COVID-19 outbreak? (free text box)				
Your expenses: since the COVID-19 (Coronavirus) outbreak, have you –				
a) had to spend more money on living costs?  If yes, please specify what you had to spend more on: (drop down list) <ul style="list-style-type: none"> <li>• Medication</li> <li>• Health care</li> <li>• Disability support</li> <li>• Grocery shopping</li> <li>• Cleaning</li> <li>• Transport</li> </ul> Other: _____	Y	N	DK	NA
b) had to spend more money on support for the person that your care for?  If yes, please specify what you had to spend more on: (drop down list) <ul style="list-style-type: none"> <li>• Medication</li> <li>• Health care</li> <li>• Disability support</li> <li>• Grocery shopping</li> <li>• Cleaning</li> <li>• Transport</li> </ul> Other: _____	Y	N	DK	NA

Your work and income: since the COVID-19 (Coronavirus) outbreak, have you –				
a) lost some/all support services for the person you care for?	Y	N	DK	NA
b) lost some/all support services for yourself?	Y	N	DK	NA
c) received any extra help for you or the person you support?  If yes, please specify what extra support you received (select all that apply): <ul style="list-style-type: none"> <li>• extra support for self</li> <li>• extra financial assistance for self</li> <li>• extra support for the person you care for</li> <li>• extra financial assistance for the person you care for</li> </ul> Other: _____	Y	N	DK	NA
d) Before COVID-19, in a normal week, how much time did you spend on care tasks (select one option): <ul style="list-style-type: none"> <li>• 0-10 hours</li> <li>• 11-25 hours</li> <li>• 25-45 hours</li> <li>• More than 45 hours</li> </ul> Since the outbreak of COVID-19, how much time do you spend on care tasks (select one option): <ul style="list-style-type: none"> <li>• 0-10 hours</li> <li>• 11-25 hours</li> <li>• 26- 45 hours</li> <li>• More than 45 hours</li> </ul>				
Can you tell us more about how the support you provide has changed (type and amount of care)? (free text box)				
Your health and wellbeing:				
a) Since COVID-19, have you experienced a change in your mental health (for example, have you felt more nervous, had difficulty sleeping, felt restless, felt depressed, or felt more positive or relaxed?)  If yes, how has your mental health changed? (drop down list) <ul style="list-style-type: none"> <li>• My mental health has deteriorated</li> <li>• My mental health has improved</li> </ul> If yes, how much has your mental health changed? (drop down list) <ul style="list-style-type: none"> <li>• A little</li> <li>• A moderate amount</li> <li>• A lot</li> <li>• An extreme amount</li> </ul> If yes, would you like to share what you think has been the main reason for the change? (free text box)	Y	N	DK	NA
b) Since COVID-19, have you experienced a change in your physical health?  If yes, how has it changed? (drop down list) <ul style="list-style-type: none"> <li>• My physical health has deteriorated</li> <li>• My physical health has improved</li> </ul> If yes, how much has your physical health changed? (drop down list) <ul style="list-style-type: none"> <li>• A little</li> <li>• A moderate amount</li> <li>• A lot</li> <li>• An extreme amount</li> </ul>	Y	N	DK	NA

<p>c) Since COVID-19, have you experienced increased stress in your role as a carer?</p> <p>If yes, how much has your stress increased? <b>(drop down list)</b></p> <ul style="list-style-type: none"> <li>• A little</li> <li>• A moderate amount</li> <li>• A lot</li> <li>• An extreme amount</li> </ul>	Y	N	DK	NA
<p>d) Since COVID-19, have you been more concerned about your personal safety?</p> <p>If yes, how much have your safety concerns increased? <b>(drop down list)</b></p> <ul style="list-style-type: none"> <li>• A little</li> <li>• A moderate amount</li> <li>• A lot</li> <li>• An extreme amount</li> </ul> <p>If yes:</p> <p>If you are in danger or have immediate concerns about your safety please dial triple zero 000</p> <p>You can also seek support from 1800RESPECT who are open 24 hours to support people impacted by sexual assault, domestic or family violence and abuse. Tel: 1800 737 732</p>	Y	N	DK	NA
<p>e) Do you know about supports that are available to you as part of the Australian Government's COVID-19 support packages?</p>	Y	N	DK	NA
<p>f) Do you feel that the Australian Government is currently providing enough support for carers in the COVID-19 crisis?</p>	Y	N	DK	NA
<p>g) Any other comments about the impact of COVID-19 on your life, and the life of the person you care for, including how your caring role has changed? <b>(free text box)</b></p>				
<p><b>The next section asks some questions about you:</b></p>				
<p>a) Your age: <b>(select one option)</b></p> <ul style="list-style-type: none"> <li>• 18-25 years</li> <li>• 26-35 years</li> <li>• 36-45 years</li> <li>• 46-55 years</li> <li>• 56-65 years</li> <li>• 66 and above</li> </ul>				
<p>b) Are you:</p> <ul style="list-style-type: none"> <li>• Aboriginal Australian</li> <li>• Torres Strait Islander Australian</li> <li>• Neither</li> </ul>				
<p>c) Postcode: _____</p>				
<p>d) Gender: <b>(select one option)</b></p> <ul style="list-style-type: none"> <li>• Female</li> <li>• Male</li> <li>• Trans*female/woman</li> <li>• Trans*male/man</li> <li>• Gender Diverse</li> <li>• Sistergirl</li> <li>• Brotherboy</li> <li>• Non-Binary/Gender-Non Conforming</li> <li>• Prefer not to say</li> <li>• Other</li> </ul>				

e) Your current employment status is (select one option):

- Full-Time employee
- Part-Time employee
- Self-employed
- Employed (unpaid worker in family business)
- Unemployed (seeking full-time work)
- Unemployed (seeking part-time work)
- Not employed (not seeking employment)

f) Your current income source is (select all that apply):

- Wage or salary
- JobKeeper Payment
- Carer Payment
- Disability Support Pension
- Aged Pension
- JobSeeker Payment
- Other government pension or benefit
- Other: \_\_\_\_\_

g) Have you applied for any of the following Government payments since March 1? (select all that apply):

- JobKeeper Payment
- Carer Payment
- Carer Allowance
- Disability Support Pension
- Aged Pension
- JobSeeker Payment

h) Do you receive the Carer Allowance?

Y

N

DK

NA

i) How many people do you normally care for?

- One
- Two
- More than two

j) The person/people you care for has/have: (tick all that apply)

- physical disability
- blind/vision impaired
- deaf/hearing impaired
- intellectual disability
- mental health issue/psychosocial disability
- neurological condition
- autism spectrum disorder
- learning disability
- medical condition
- terminal illness
- palliative care
- frail aged
- dementia

k) The person/people you care for is/are aged: (select one option)

- 18-25 years
- 26-35 years
- 36-45 years
- 46-55 years
- 56-65 years
- 66 and above

l) Do you identify as having a disability or mental health issue?

- Yes, disability
- Yes, mental health issue
- Yes, both
- No

m) Were you born in Australia?	Y	N	DK	NA
n) Do you speak a language other than English at home?	Y	N	DK	NA

## Thanks for your time!

In recognition for your time, we would like to offer you entry into a draw to win 1 of ten \$50 Coles/Myer vouchers.

The winners will be drawn after the survey closes. Please include your email below if you would like to enter. Please note that the information you provide throughout the survey will be kept separate from your email address.

Your email address will not be used for anything other than entry into the draw. We will not pass your contact details on to a third party.

We are also interested in collecting your stories about being an unpaid carer. If you would like to share your experiences with us, please let us know by email at [campaigns@mindaustralia.org.au](mailto:campaigns@mindaustralia.org.au).

## Resources

If participating in this survey has caused any distress the following resources may be able to offer support. If you are in an emergency, in danger or you or someone close to you requires immediate help, call triple zero (000) for emergency services.

## Mental Health Helplines:

### Lifeline

Tel: 13 11 14

Anyone can call Lifeline. Lifeline continues to support Australians via telephone, text and webchat services. Call 13 11 14, 24 hours/7 days and text 0477 13 11 14 from 6pm to midnight AEDT, 7 nights a week or chat online from 7pm to midnight, 7 nights a week.

### Kids Help Line

Tel: 1800 55 1800

Kids Help Line is a free, confidential and anonymous, telephone and online counselling service specifically for young people aged between 5 and 25. It's available 24 hours a day, 7 days a week.

### SANE Helpline

Tel: 1800 18 7263

SANE runs a national, out-of-hours helpline offering specialist emotional support and information to anyone affected by mental illness, including family, friends and carers. They are open every day of the year from 6pm to 11pm. The SANE helpline can also provide practical information about services in your local area through their information database.

## Suicide Helpline Call-Back Service

Tel: 1300 659 467

The Suicide Call Back Service provides crisis counselling to people at risk of suicide, carers for someone who is suicidal and those bereaved by suicide, 24 hours per day 7 days a week across Australia. People who are not linked in with current professional support can also access up to six sessions of ongoing counselling with the same counsellor at times scheduled to suit you.

## Support for carers:

### Mind Australia Carer Support Services:

The Mind Carer Helpline is a free service for families and carers of individuals living with mental health issues. You can call the helpline on 1300 554 660 9am to 5pm Monday to Friday or email [carers@mindaustralia.org.au](mailto:carers@mindaustralia.org.au). Mind also has an online carer forum where mental health carers can share information, experiences and offer each other support. [www.mindaustralia.org.au/forums](http://www.mindaustralia.org.au/forums)

### Carer Gateway Counselling Service

The Carer Gateway Counselling Service is a free service for carers. Each weekday, from 8am to 6pm, professional counsellors are available to talk through the concerns you have and how you feel about your carer role. To use the service, simply select 'Request a Callback' on this web page: <https://counselling.carergateway.gov.au/s/> fill in your details and we will call you back within one business day. You can also call 1800 422 737 and Select Option 2 to speak to the Carer Gateway team.

### Tandem

Tel: 1800 314 325

Email: [info@tandemcarers.org.au](mailto:info@tandemcarers.org.au)

Tandem is the Victorian peak body representing friends and family of those living with mental illness. They can provide information about supports that may be available for those who support someone living with a mental illness.

## Services relating to relationships and domestic and family violence:

### 1800RESPECT

Tel: 1800 737 732

1800RESPECT are open 24 hours to support people impacted by sexual assault, domestic or family violence and abuse.

### Mensline Australia

Call 1300 78 99 78 for telephone support, information and referrals for men dealing with relationship issues.

## Appendix 2: Caring Fairly COVID-19 carer survey results

Dates survey open: 21/04/2020 - 5/05/2020 (15 days)

Total number of surveys received: 674

Total number of completed surveys: 387 (page 5 reached, 'Submitted')

Total number of surveys analysed: 471

Total number of carers receiving Carer Payment: 132

Total number of carers of people with mental ill-health: 242

## 1. Work and income

Your work and income: since the COVID-19 (Coronavirus) outbreak, have you –

	Y	N	Uncertain	Total number completing this question
a) lost your job				
All carers	39 (10.3%)	311 (82.5%)	27 (7.2%)	377
Carers receiving Carer Payment	12 (12.1%)	76 (76.8%)	11 (11.1%)	99
Carers of people with mental ill-health	20 (9.9%)	168 (82.8%)	15 (7.4%)	203
b) worked fewer hours because your employer didn't have enough work for you?				
All carers	77 (22.1%)	260 (74.7%)	11 (3.2%)	348
Carers receiving Carer Payment	22 (24.7%)	64 (71.9%)	3 (3.4%)	89
Carers of people with mental ill-health	42 (22.3%)	139 (73.9%)	7 (3.7%)	188
c) worked fewer hours because you need to provide extra support to the person that you care for?				
All carers	131 (36.6%)	216 (60.3%)	11 (3.1%)	358
Carers receiving Carer Payment	39 (40.2%)	56 (57.7%)	2 (2.1%)	97
Carers of people with mental ill-health	67 (35.1%)	120 (62.8%)	4 (2.1%)	191
d) lost some/all of your regular income?				
All carers	142 (37.0%)	235 (61.2%)	7 (1.8%)	384
Carers receiving Carer Payment	44 (42.3%)	59 (56.7%)	1 (1.0%)	104
Carers of people with mental ill-health	78 (37.5%)	128 (61.5%)	2 (1.0%)	208

## 2. Expenses

Your expenses: since the COVID-19 (Coronavirus) outbreak, have you

	Y	N	Uncertain	Total number completing this question
<b>a) had to spend more money on living costs?</b>				
All carers	316 (71.3%)	104 (23.5%)	23 (5.2%)	443
Carers receiving Carer Payment	111 (86.0%)	16 (12.4%)	2 (1.6%)	129
Carers of people with mental ill-health	173 (73.6%)	52 (22.1%)	10 (4.3%)	235
<b>b) had to spend more money on support for the person that your care for?</b>				
All carers	253 (58.2%)	152 (34.9%)	30 (6.9%)	435
Carers receiving Carer Payment	81 (65.3%)	35 (28.2%)	8 (6.5%)	124
Carers of people with mental ill-health	145 (62.8%)	72 (31.2%)	14 (6.1%)	231

If you have spent more money on living costs (2a.), please specify what you had to spend more on:

[Options: Yes, No and N/A – Yes reported in table, % = total responses for item excluding N/A]

	All carers (n=316)	Carers receiving Carer Payment (n=111)	Carers of people with mental ill-health (n=173)
Medication	117 (37.0%)	45 (40.5%)	64 (37.0%)
Health care	100 (31.6%)	38 (34.2%)	62 (35.8%)
Disability support	59 (18.7%)	29 (26.1%)	31 (17.9%)
Grocery shopping	296 (93.7%)	107 (96.4%)	164 (94.8%)
Cleaning	150 (47.5%)	55 (49.5%)	77 (44.5%)
Transport	75 (23.7%)	31 (27.9%)	48 (27.7%)
Other	2 (0.6%)	0 (0.0%)	0 (0.0%)

If you have spent more money supporting the person that you care for (2b.), please specify what you had to spend more on:

[Options: Yes, No and N/A – Yes reported in table, % = total responses for item excluding N/A]

	All carers (n=253)	Carers receiving Carer Payment (n=81)	Carers of people with mental ill-health (n=145)
Medication	91 (36.0%)	36 (44.4%)	41 (28.3%)
Health care	101 (39.9%)	34 (42.0%)	58 (40.0%)
Disability support	68 (26.9%)	31 (38.3%)	36 (24.8%)
Grocery shopping	198 (78.3%)	65 (80.2%)	114 (78.6%)
Cleaning	121 (47.8%)	51 (63.0%)	64 (44.1%)
Transport	75 (29.6%)	23 (28.4%)	44 (30.3%)
Other	5 (2.0%)	1 (1.2%)	1 (0.7%)

### 3. Changes to supports

Since COVID-19, have you –

	Y	N	Uncertain	Total number completing this question
<b>a) lost some/all support services for the person you care for?</b>				
All carers	225 (60.3%)	122 (32.7%)	26 (7.0%)	373
Carers receiving Carer Payment	84 (69.4%)	29 (24.0%)	8 (6.6%)	121
Carers of people with mental ill-health	130 (60.7%)	69 (32.2%)	15 (7.0%)	214
<b>b) lost some/all support services for yourself?</b>				
All carers	169 (47.3%)	157 (44.0%)	31 (8.7%)	357
Carers receiving Carer Payment	67 (56.8%)	44 (37.3%)	7 (5.9%)	118
Carers of people with mental ill-health	96 (46.8%)	88 (42.9%)	21 (10.2%)	205
<b>c) received any extra help for you or the person you support?</b>				
All carers	37 (9.9%)	326 (86.9%)	12 (3.2%)	375
Carers receiving Carer Payment	10 (8.3%)	109 (90.1%)	2 (1.7%)	121
Carers of people with mental ill-health	21 (9.5%)	195 (87.8%)	6 (2.7%)	222

If yes (3c.), please specify what extra support you received: (select all that apply)

[Options: Yes, No and N/A – Yes reported in table, % = total responses for item excluding N/A]

	All carers (n=37)	Carers receiving Carer Payment (n=10)	Carers of people with mental ill-health (n=21)
extra support for self	7 (18.9%)	4 (40.0%)	7 (33.3%)
extra financial assistance for self	4 (10.8%)	10 (100%)	2 (9.5%)
extra support for the person you care for	25 (67.6%)	6 (60.0%)	12 (57.1%)
extra financial assistance for the person you care for	6 (16.2%)	2 (20.0%)	4 (19.0%)
Other	7 (19%)	1 (10.0%)	5 (23.8%)

d) Before COVID, in a normal week, how much time did you spend on care tasks?			
Time group	All carers (n=412)	Carers receiving Carer Payment (n=132)	Carers of people with mental ill-health (n=240)
0-10 hours	111 (26.9%)	7 (5.3%)	70 (29.2%)
11-25 hours	81 (19.7%)	14 (10.6%)	57 (23.8%)
25-45 hours	109 (26.5%)	44 (33.3%)	56 (23.3%)
More than 45 hours	111 (26.9%)	67 (50.8%)	57 (23.8%)

Since the outbreak of COVID, how much time do you spend now on care tasks?

Time group	All carers (n=412)	Carers receiving Carer Payment (n=132)	Carers of people with mental ill-health (n=241)
0-10 hours	65 (15.8%)	4 (3.0%)	42 (17.4%)
11-25 hours	74 (18.0%)	4 (3.0%)	48 (19.9%)
25-45 hours	69 (16.7%)	19 (14.4%)	41 (17.0%)
More than 45 hours	204 (49.5%)	105 (79.5%)	110 (45.6%)

Change in time spent on caring tasks since COVID-19

		All carers (n=411)	Carers receiving Carer Payment (n=132)	Carers of people with mental ill-health (n=240)
Increase in time spent on care tasks - Total:	No. of Time group changes	179 (43.5%)	49 (37.2%)	111 (46.3%)
'0-10 hours' to 'More than 45 hours'	3	3 (0.7%)		
'0-10 hours' to '25-45 hours'	2	10 (2.4%)		
'11-25 hours' to 'More than 45 hours'	2	14 (3.4%)		
'0-10 hours' to '11-25 hours'	1	44 (10.7%)		
'11-25 hours' to '25-45 hours'	1	30 (7.3%)		
'25-45 hours' to 'More than 45 hours'	1	78 (19.0%)		
Decrease in time spent on care tasks - Total:				
'11-25 hours' to '0-10 hours'	-1	10 (2.4%)	326 (86.9%)	12 (3.2%)
'25-45 hours' to '11-25 hours'	-1	3 (0.7%)	109 (90.1%)	2 (1.7%)
'More than 45 hours' to '25-45 hours'	-1	1 (0.2%)	195 (87.8%)	6 (2.7%)
'25-45 hours' to '0-10 hours'	-2	1 (0.2%)		
'More than 45 hours' to '0-10 hours'	-3	1 (0.2%)		
No change in time spent on care tasks - Total:		216 (52.7%)	81 (61.4%)	117 (48.8%)

#### 4. Health and wellbeing

Your health and wellbeing: since COVID-19, have you –

	Y	N	Uncertain	Total number completing this question
a) experienced a <b>change in your mental health</b> (for example, have you felt more nervous, had difficulty sleeping, felt restless, felt depressed, or felt more positive or relaxed?)				
All carers	327 (84.5%)	37 (9.6%)	23 (5.9%)	387
Carers receiving Carer Payment	119 (90.8%)	7 (5.3%)	5 (3.8%)	131
Carers of people with mental ill-health	202 (84.5%)	24 (10.0%)	13 (5.4%)	239

If yes, how has it changed?

	All carers (n=324)	Carers receiving Carer Payment (n=118)	Carers of people with mental ill-health (n=199)
My mental health has deteriorated	313 (96.6%)	117 (99.2%)	190 (95.5%)
My mental health has improved	11 (3.4%)	1 (0.8%)	9 (4.5%)

If yes, how much has your mental health changed?

	All carers (n=326)	Carers receiving Carer Payment (n=118)	Carers of people with mental ill-health (n=201)
A little	83 (25.5%)	24 (20.3%)	53 (26.4%)
A moderate amount	125 (38.3%)	33 (28.0%)	69 (34.3%)
A lot	82 (25.2%)	43 (36.4%)	55 (27.4%)
An extreme amount	36 (11.0%)	18 (15.3%)	24 (11.9%)

Since COVID-19, have you –

	Y	N	Uncertain	Total number completing this question
b) experienced a change in your physical health?				
All carers	239 (62.4%)	90 (23.5%)	54 (14.1%)	383
Carers receiving Carer Payment	86 (67.7%)	19 (15.0%)	22 (17.3%)	127
Carers of people with mental ill-health	155 (65.4%)	57 (24.1%)	25 (10.5%)	237

If yes, how has it changed?

	All carers (n=238)	Carers receiving Carer Payment (n=85)	Carers of people with mental ill-health (n=154)
My physical health has deteriorated	224 (94.1%)	82 (96.5%)	144 (93.5%)
My physical health has improved	14 (5.9%)	3 (3.5%)	10 (6.5%)

If yes, how much has your physical health changed?

	All carers (n=238)	Carers receiving Carer Payment (n=86)	Carers of people with mental ill-health (n=155)
A little	65 (27.3%)	14 (16.3%)	43 (27.7%)
A moderate amount	100 (42.0%)	36 (41.9%)	63 (40.6%)
A lot	55 (23.1%)	24 (27.9%)	35 (22.6%)
An extreme amount	18 (7.6%)	12 (14.0%)	14 (9.0%)

Since COVID-19, have you –

	Y	N	Uncertain	Total number completing this question
c) experienced increased stress in your role as a carer?				
All carers	340 (88.1%)	29 (7.5%)	17 (4.4%)	386
Carers receiving Carer Payment	123 (94.6%)	1 (0.8%)	6 (4.6%)	130
Carers of people with mental ill-health	210 (88.2%)	19 (8.0%)	9 (3.8%)	238

If yes, how much has your stress increased?

	All carers (n=339)	Carers receiving Carer Payment (n=122)	Carers of people with mental ill-health (n=210)
A little	48 (14.2%)	9 (7.4%)	23 (11.0%)
A moderate amount	116 (34.2%)	33 (27.0%)	68 (32.4%)
A lot	118 (34.8%)	49 (40.2%)	78 (37.1%)
An extreme amount	57 (16.8%)	31 (25.4%)	41 (19.5%)

Since COVID-19, have you –

	Y	N	Uncertain	Total number completing this question
d) been more concerned about your personal safety?				
All carers	147 (38.3%)	191 (49.7%)	46 (12.0%)	384
Carers receiving Carer Payment	61 (47.3%)	55 (42.6%)	13 (10.1%)	129
Carers of people with mental ill-health	89 (37.4%)	120 (50.4%)	29 (12.2%)	238

If yes, how much have your safety concerns increased?

	All carers (n=147)	Carers receiving Carer Payment (n=61)	Carers of people with mental ill-health (n=89)
A little	34 (23.1%)	10 (16.4%)	20 (22.5%)
A moderate amount	51 (34.7%)	15 (24.6%)	31 (34.8%)
A lot	39 (26.5%)	22 (36.1%)	24 (27.0%)
An extreme amount	23 (15.6%)	14 (23.0%)	14 (15.7%)

	Y	N	Uncertain	Total number completing this question
e) Do you know about supports that are available to you as part of the Australian Government's COVID-19 support packages?				
All carers	135 (35.4%)	155 (40.7%)	91 (23.9%)	381
Carers receiving Carer Payment	41 (32.5%)	51 (40.5%)	34 (27.0%)	126
Carers of people with mental ill-health	83 (35.0%)	103 (43.5%)	51 (21.5%)	237

	Y	N	Uncertain	Total number completing this question
f) Do you feel that the Australian Government is currently providing enough support for carers in the COVID-19 crisis?				
All carers	22 (5.7%)	260 (67.7%)	102 (26.6%)	384
Carers receiving Carer Payment	3 (2.3%)	115 (87.8%)	13 (9.9%)	131
Carers of people with mental ill-health	13 (5.5%)	161 (68.5%)	61 (26.0%)	235

## 5. Demographics

a) Your age:

	All carers (n=386)	Carers receiving Carer Payment (n=131)	Carers of people with mental ill-health (n=242)
18-25 years	6 (1.6%)	1 (0.8%)	5 (2.1%)
26-35 years	35 (9.1%)	18 (13.7%)	22 (9.1%)
36-45 years	87 (22.5%)	29 (22.1%)	57 (23.6%)
46-55 years	113 (29.3%)	43 (32.8%)	77 (31.8%)
56-65 years	86 (22.3%)	30 (22.9%)	40 (16.5%)
66 and above	59 (15.3%)	10 (7.6%)	41 (16.9%)

b) Are you:

	All carers (n=374)	Carers receiving Carer Payment (n=130)	Carers of people with mental ill-health (n=237)
Aboriginal Australian	16 (4.3%)	9 (6.9%)	14 (5.9%)
Torres Strait Islander Australian	2 (0.5%)	0 (0.0%)	2 (0.8%)
Neither	356 (95.2%)	121 (93.1%)	221 (93.2%)

c) Postcode – most responses came from Victoria and then NSW. Further analysis needed for percentages across all postcodes to determine other states.

d) Gender:

	All carers (n=379)	Carers receiving Carer Payment (n=131)	Carers of people with mental ill-health (n=239)
Female	338 (89.2%)	116 (88.5%)	217 (90.8%)
Male	35 (9.2%)	14 (10.7%)	20 (8.4%)
Trans*female/woman	0 (0.0%)	0 (0.0%)	0 (0.0%)
Trans*male/man	0 (0.0%)	0 (0.0%)	0 (0.0%)
Gender Diverse	2 (0.5%)	0 (0.0%)	0 (0.0%)
Sistergirl	0 (0.0%)	0 (0.0%)	0 (0.0%)
Brotherboy	0 (0.0%)	0 (0.0%)	0 (0.0%)
Non-Binary/Gender-Non Conforming	0 (0.0%)	0 (0.0%)	0 (0.0%)
Prefer not to say	2 (0.5%)	0 (0.0%)	1 (0.4%)
Other	2 (0.5%) (1 = lesbian; 1 = this shouldn't matter)	1 (0.8%)	1 (0.4%)

e) Your current employment status is:

	All carers (n=363)	Carers receiving Carer Payment (n=127)	Carers of people with mental ill-health (n=231)
Full-Time employee	56 (15.4%)	3 (2.4%)	37 (16.0%)
Part-Time employee	88 (24.2%)	20 (15.7%)	59 (25.5%)
Self-employed	24 (6.6%)	8 (6.3%)	13 (5.6%)
Employed (unpaid worker in family business)	8 (2.2%)	2 (1.6%)	1 (0.4%)
Unemployed (seeking full-time work)	5 (1.4%)	1 (0.8%)	4 (1.7%)
Unemployed (seeking part-time work)	32 (8.8%)	17 (13.4%)	16 (6.9%)
Not employed (not seeking employment)	150 (41.3%)	76 (59.8%)	101 (43.7%)

f) Your current income source is:

[Options: Yes, No or N/A – Yes reported, % is based on Yes response from total]

	All carers (n=402)	Carers receiving Carer Payment (n=132)	Carers of people with mental ill-health (n=242)
Wage or salary	154 (38.3%)	22 (16.7%)	101 (41.7%)
JobKeeper Payment	9 (2.2%)	2 (1.5%)	5 (2.1%)
Carer Payment	132 (32.8%)	132 (100%)	79 (32.6%)
Disability Support Pension	22 (5.5%)	5 (3.8%)	10 (4.1%)
Aged Pension	19 (4.7%)	2 (1.5%)	13 (5.4%)
JobSeeker Payment	15 (3.7%)	0 (0.0%)	11 (4.5%)
Other government pension or benefit	31 (7.7%)	13 (9.8%)	16 (6.6%)

g) Have you applied for any of the following Government payments since March yes?:

[Options: Yes, No or N/A – Yes reported, % is based on Yes response from total]

	All carers (n=402)	Carers receiving Carer Payment (n=132)	Carers of people with mental ill-health (n=242)
JobKeeper Payment	21 (5.2%)	3 (2.3%)	13 (5.4%)
Carer Payment	13 (3.2%)	7 (5.3%)	6 (2.5%)
Carer Allowance	23 (5.7%)	8 (6.1%)	13 (5.4%)
Disability Support Pension	3 (0.7%)	1 (0.8%)	2 (0.8%)
Aged Pension	4 (1.0%)	0 (0.0%)	3 (1.2%)
JobSeeker Payment	10 (2.5%)	1 (0.8%)	8 (3.3%)

j) The person/people you care for has/have:

Responses as 'Yes'	All carers	Carers receiving Carer Payment	Carers of people with mental ill-health
physical disability	162	79	94
blind/vision impaired	35	16	22
deaf/hearing impaired	48	21	23
intellectual disability	104	54	61
mental health issue/ psychosocial disability	242	79	242
neurological condition	116	58	75
Autism spectrum disorder	132	64	91
Learning disability	117	60	75
Medical condition	205	88	125
Terminal illness	20	6	11
Palliative care	9	6	5
Frail aged	64	22	32
Dementia	35	10	15

k) The person/people you care for is/are aged:

	All carers (n=371)	Carers receiving Carer Payment (n=130)	Carers of people with mental ill-health (n=239)
0-18 years	112 (30.2%)	53 (40.8%)	65 (27.2%)
18-25 years	44 (11.9%)	14 (10.8%)	36 (15.1%)
26-35 years	43 (11.6%)	11 (8.5%)	35 (14.6%)
36-45 years	46 (12.4%)	13 (10.0%)	38 (15.9%)
46-55 years	25 (6.7%)	8 (6.2%)	17 (7.1%)
56-65 years	34 (9.2%)	12 (9.2%)	22 (9.2%)
66 and above	67 (18.1%)	19 (14.6%)	26 (10.9%)

l) Do you identify as having a disability or mental health issue?

	All carers (n=372)	Carers receiving Carer Payment (n=128)	Carers of people with mental ill-health (n=240)
No	198 (53.2%)	65 (50.8%)	119 (49.6%)
Yes, mental health	118 (31.7%)	40 (31.3%)	87 (36.3%)
Yes, disability	30 (8.1%)	13 (10.2%)	15 (6.3%)
Yes, both	26 (7.0%)	10 (7.8%)	19 (7.9%)

m) Were you born in Australia?

	All carers (n=374)	Carers receiving Carer Payment (n=130)	Carers of people with mental ill-health (n=239)
Yes	316 (84.5%)	118 (90.8%)	208 (87.0%)
No	58 (15.5%)	12 (9.2%)	31 (13.0%)

n) Do you speak a language other than English at home?

	All carers (n=371)	Carers receiving Carer Payment (n=128)	Carers of people with mental ill-health (n=238)
Yes	32 (8.6%)	12 (9.4%)	19 (8.0%)
No	339 (91.4%)	116 (90.6%)	219 (92.0%)



## About Caring Fairly

Caring Fairly is a national campaigning coalition seeking recognition, reform, and a greater respect for the rights of Australia's unpaid carers. We are led by a coalition of over 29 carer support organisations, NGOs, peak bodies, and carers themselves, spanning all states and territories of Australia. Caring Fairly is coordinated by Mind Australia, one of the country's leading and largest community managed mental health organisations.

### For more information:

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**caringfairly**

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