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# The COVID-19 Pandemic: Challenges and opportunities for carers in NSW

Consultation report, May 2020

## ABOUT CARERS NSW

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

[www.carersnsw.org.au](http://www.carersnsw.org.au)

<https://twitter.com/CarersNSW>

<https://www.facebook.com/carersnewsouthwales/>

## ABOUT CARERS

A carer is any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail.

Across NSW, there are approximately 854,300 carers<sup>1</sup> and to replace the care they provide the NSW Government would have to spend more than \$17 billion each year.<sup>2</sup> Carers come from all walks of life, cultural backgrounds and age groups. For many, caring is a 24 hour-a-day job with emotional, physical and financial impacts that can also affect their participation in employment, education and community activities.

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Carers NSW Policy and Research Team

April 2020

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<sup>1</sup> Australian Bureau of Statistics 2018 Survey of Disability, Ageing and Carers.

<sup>2</sup> Carers NSW estimate based on Deloitte Access Economics (2015) *The economic value of informal care in Australia in 2015*.

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## INTRODUCTION

COVID-19 is a respiratory disease caused by a new form of coronavirus. It was first reported in December 2019 in Wuhan City in China, but fast paced international transmission of the virus led the World Health Organization (WHO) to announce COVID-19 as a global pandemic on 11 March 2020. Symptoms of COVID-19 have ranged from mild illness to severe pneumonia, and while many people have recovered easily, others have become critically ill, with some dying from the effects of the virus.<sup>3</sup>

Confirmed cases and deaths in Australia remain relatively low when compared internationally, however significant precautions have been taken within Australia and NSW to reduce transmission of the virus and slow pressure on intensive care units. Groups identified as being particularly vulnerable to serious illness if they contract the virus have been the focus of preventative measures. These groups include people with compromised immune systems, people 65 years and older with chronic medical conditions (or 50 years and older in Aboriginal and Torres Strait Islander communities) and all people 70 years and older.<sup>4</sup> ABS data indicates that many people in these cohorts rely on the regular support of family members and friend.<sup>5</sup>

Carers NSW has been closely monitoring COVID-19 developments in NSW, the ongoing government response and the wide ranging impacts the virus and associated social distancing requirements have had on carers. Carers have experienced a variety of impacts, both in relation to the people they care for and in relation to their own health and overall wellbeing. Many carers provide care and support to people who are in higher risk categories, and many are in higher risk categories themselves due to age or an existing health condition. These factors have resulted in complexities surrounding provision of care, particularly in maintaining social distancing.

Carers engaged in employment or education are in many cases required to carry out these activities from their home, with the support of digital technologies. Balancing paid work and caring is always a challenge, but particularly when both roles are conducted in the same location. Limited access to digital devices, connections and capabilities has also disadvantaged many carers, especially those who are culturally and linguistically diverse and live in regional and remote areas. The financial costs of caring have also increased at a time when many people are experiencing diminished employment security.

With some services ceasing or reducing in-person offerings, many carers have increased seen their caring responsibilities increase while their own support networks have decreased. In other cases, particularly where recipients of care live in residential settings, carers have been disconnected from their loved one at the request of providers who continue to adjust to infection control measures. The long term impacts of COVID-19 are yet to be fully understood, but it is likely that the mental and physical health and financial impacts of this period will be acutely felt into the future.

Carers NSW determined that it was crucial to hear directly from carers and other key stakeholders in order to gain a clear and accurate picture of the key issues, challenges and opportunities for carers during the pandemic. This report identifies the key findings of consultation conducted to inform Carers NSW service adjustments and systemic advocacy.

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<sup>3</sup> Department of Health (2020). *Coronavirus (COVID-19) health alert*. Canberra, Australia. Accessed online at: [https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert?qclid=EAJaiQobChMiuLTN4uGM6QIV2BSPCh2rPQUQEAAAYASAAEgJLpPD\\_BwE](https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert?qclid=EAJaiQobChMiuLTN4uGM6QIV2BSPCh2rPQUQEAAAYASAAEgJLpPD_BwE); World Health Organisation (2020). *Coronavirus*. Geneva. Accessed online at: [https://www.who.int/health-topics/coronavirus#tab=tab\\_1](https://www.who.int/health-topics/coronavirus#tab=tab_1)

<sup>4</sup> Department of Health (2020). *What you need to know about coronavirus (COVID-19)*. Canberra, Australia. Accessed online at: <https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/what-you-need-to-know-about-coronavirus-covid-19>

<sup>5</sup> Australian Bureau of Statistics (2019) Survey of Ageing, Disability and Carers 2018, TableBuilder Dataset. Australian Government, Canberra. Available online at: [www.abs.gov.au](http://www.abs.gov.au)

## APPROACH

### COVID-19 stakeholder consultations

In order to gain a holistic, state-wide perspective on what additional support carers need during the COVID-19 pandemic, Carers NSW scheduled a series of one-hour Zoom videoconference consultations over a one week period in early April 2020 with key stakeholder networks. Members of Carers NSW working groups<sup>6</sup>, key research contacts and trained Carers NSW Carer Representatives<sup>7</sup> were contacted via email and offered the opportunity to participate. Respondents could express their interest, after which time they were contacted to arrange an appropriate date and time. Those who were unfamiliar with Zoom software were also offered assistance to set up and utilise the program.

In addition, those who were unable to prioritise participating in a consultation were welcomed to raise concerns and suggestions with Carers NSW via email, by phone or through Carers NSW Policy Advice Form.

A total of 35 expressions of interest were received, and five Zoom consultations were arranged; one focusing on Carer Representatives, one on carer-focused researchers and three to accommodate a range of non-government organisation and government agency representatives participating in various Carers NSW working groups. As a number of participants are in multiple roles, they were invited to attend the most relevant and convenient group, with discussion questions slightly adjusted to suit the audience. Other participants were included in the invitations following the expression of interest stage, resulting in a total of 30 participants. An overview of the consultations and number of participants is included below.

| Consultation date and time          | Stream  | Number of participants        |
|-------------------------------------|---|-------------------------------|
| Monday 6 April 2020, 2-3pm          | Carer Representatives   | 6 participants (1 apology)    |
| Tuesday 7 April 2020, 12-1pm        | Working group members (non-government organisation and government agency representatives) | 1 participant (1 apology)     |
| Thursday 9 April 2020, 9-10am       | Carer-focused researchers   | 8 participants (2 apologies)  |
| Thursday 9 April 2020, 11am-12pm    | Working group members (non-government organisation and government agency representatives) | 7 participants (2 apologies)  |
| Thursday 9 April 2020, 2-3pm        | Working group members (non-government organisation and government agency representatives) | 8 participants (1 apology)    |
| <b>Total number of participants</b> |   | 30 participants (7 apologies) |

All sessions were facilitated by the Carers NSW Manager, Policy and Research and assisted by a member of the Policy and Research team, who also took detailed notes. The consultations were semi-structured but directed by the issues raised by the group. Key focus areas included the effect of COVID-19 on carers generally, and specific impacts on employment, income, living situation and mental wellbeing, as well as the impact of COVID-19 on provision of care, such as a change in the caring role, navigating social distancing and access to services. The consultations also focused on the impact of COVID-19 on the person receiving care, including on emotional needs, healthcare,

<sup>6</sup> Carers NSW hosts the following sector working groups: Carer Respite Alliance, Carer Rights and Complaints Network, Strategic Carers Action Network. The following time-limited project advisory groups were also invited: the Carers NSW 2020 Carer Survey Reference Committee and the Young Carer Research Project Project Advisory Group.

<sup>7</sup> Carers NSW Carer Representatives are specially trained volunteers that play an important role in representing carers and Carers NSW across a variety of settings by sharing their caring experiences with service providers, government, the media and broader community. They are provided with a sitting fee for these kinds of opportunities in recognition of their time.

communication, service availability and accessibility, transport and access to essential items. Carers NSW also wanted to know how carers are accessing information. Feedback was specifically requested around what Carers NSW could implement and/or advocate for to enable better support for carers.

Notes taken by the manager and team member were then collated and summarised in the results section of this report. Key themes have been identified and drawn out further in the discussion section. Participants were aware that the information shared would be used in this report and to inform ongoing systemic advocacy work by Carers NSW. No major technical or other difficulties were encountered during each of the meetings.

## Carer case studies

In addition to the Zoom consultations, Carers NSW has continued to actively promote the opportunity to provide feedback via our Policy Advice Form (PAF) survey, available [online](#) and used by Carers NSW staff, carers and service providers to succinctly capture systemic policy issues to inform Carers NSW advocacy. The form, as well as options for providing feedback to the Carers NSW Policy Team via phone or email, was promoted on Carers NSW social media channels, in e-newsletters and through direct emails to staff and stakeholders.

At the time of writing, more than 50 case studies have been collected regarding COVID-19 impacts on carers. Issues continue to be reported to, and analysed by, Carers NSW through these means. The information collated through these surveys is anonymous and assists Carers NSW to continue adjusting our service delivery, including through the Carer Gateway<sup>8</sup> and continue advocating for carers' evolving needs during the pandemic.

## FINDINGS

The Carers NSW Policy and Research Team held 5 consultations with a variety of key stakeholders using Zoom videoconferencing software between 6 and 9 April 2020. This included 1 consultation with Carers NSW Carer Representatives, 3 separate consultations with professional stakeholders, including policy makers and service providers; and 1 consultation with carer-focused researchers. Feedback received in these consultations will be summarised below, along with the key themes identified in case studies collected through the Carers NSW Policy Advice Form. Carers NSW would like to thank each stakeholder who contributed their feedback, and particularly acknowledge the carers who took part in the consultations with such openness and transparency.

### Carer Representative consultation, 6 April 2020

*“Carers are the proactive, unrecognised health care workforce”*

- Carer Representative

Six Carers NSW Carer Representatives participated in the Zoom consultation on the afternoon of 6 April 2020. These carers reflected demographic diversity, representing different cultural and linguistic

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<sup>8</sup> Carers NSW is the Carer Gateway Service Provider in the NSW 4 service area, which includes the Hunter New England and Central Coast and North Coast PHN regions. A range of in-person services were launched under the Carer Gateway on 6 April 2020, with some service delivery impacted by COVID-19 social distancing restrictions. Locally based support from the Carer Gateway is available everywhere in Australia by phoning 1800 422 737 (Monday to Friday, 8am to 5pm).

backgrounds, genders, geographic locations, including regional locations, and age ranges. The key concerns identified by participants are summarised overleaf.

### **Separation from the care recipient**

Carer Representatives caring for someone located in a residential facility, group home or hospital where visitor access was restricted, or self-isolating at home due to COVID-19, reported significant distress as a result of this separation. Difficulty maintaining contact with care recipients and facilities had caused concern about the level of risk and quality of care.

Several participants reported being actively prevented from visiting care recipients in facilities for public health reasons, and noted that there were not clear channels for regularly making contact by phone or digital means or for delivering supplies, as both would generally require staff assistance and staff were understandably preoccupied.<sup>9</sup> Visits and other regular contact with care recipients were identified by Carer Representatives as essential in providing practical and emotional support and in maintaining the health and wellbeing of both parties.

Participants expressed that they understood the need for facilities to be cautious about allowing access to non-residents, and some mentioned that facility restrictions and business shutdowns had provided them with an unexpected and helpful break from the caring role. However, the most common feeling was concern for the ongoing welfare of their care recipient. Participants highlighted the unpredictability of how long social distancing measures will persist, and emphasised that the adverse impacts on carers and the people they care for will be compounded over time.

### **Increased caring responsibilities**

For carers living with the person they care for, spending additional time in the home had been a challenge. Constantly remaining indoors and the cancellation of some formal supports and social groups had impacted carers who were no longer able to access incidental respite from the caring role. Those working or studying at home described particular challenges balancing caring and other responsibilities in a crowded home environment. Increased caring responsibilities at home was also reported to make it more difficult for some carers to go out and purchase medication, groceries and other essentials.

### **Employment**

Some carers in employment had found working from home to be a positive experience, enabling them to monitor the person they care for whilst maintaining employment. Some felt able to advise their employer of interruptions to work resulting from caring responsibilities in the home, while others reported that caring complexities were an unhelpful distraction that affected their privacy and productivity while completing work.

### **Access to services**

Participants explained that there simply isn't enough formal support for carers and the people they care for. At baseline there is insufficient respite or replacement care, both informal and formal, but this would be exacerbated if a carer or support worker were to become unwell with the virus. Some reported local disability services reducing their administration staffing, making it difficult to access rosters, find out what is happening with the service or make an enquiry. Those consulted anticipated that fewer support workers might be available within NDIS services due to staffing reductions or illness.

Concerns were also expressed about telehealth, in that many care recipients still require face to face treatment and check-ups, exposing them and carers to a higher risk of contracting the virus,

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<sup>9</sup> Since the consultations took place, some visitor restrictions have been lifted.



especially when private transport was not available to them. A lack of technological skill was also cited as a challenge.

### **Mental health**

Participants reflected that people who were already isolated, including carers, were becoming increasingly isolated during the pandemic. Some expressed concern about the likely increase in domestic and family violence, especially where serious mental illness is present in the family home. Mental health and isolation of care recipients and carers, especially those with existing mental health conditions or propensity, remains a serious concern for those consulted.

The added stresses associated with ever-changing social distancing rules and observing the varied compliance of others in the community were also identified as potentially aggravating mental health conditions. The ability to share these challenges with peers was seen to be an important coping strategy, and carer advocates were mentioned as having been useful sources of self-care and peer support information during COVID-19.

### **Physical health and wellbeing**

Carers were identified at particular risk of exposure to the virus due to the difficulties many would have in maintaining a social distance from care recipients and support workers. Carer Representatives were concerned that should carers contract the virus, they may be unavailable to care, and were not sure what would happen to the person they care for in that scenario.

### **Shopping for essentials**

This group described visiting the supermarket as a “traumatic experience” for most carers. They reported that carers were sometimes being prevented from accessing the priority shopping hour at major supermarkets because they were not with their care recipient. Online groceries, even with priority service, had been difficult for them to access. Carers also report that essential medications had been difficult to get as the result of panic buying.<sup>10</sup>

### **Financial impacts**

Participants described contact with Centrelink as “traumatic”, noting that queuing at Centrelink is not an option for many carers given the time pressures of their caring role, and in these circumstances, the potential health risks. However, calling Centrelink was also reported to be largely ineffectual due to long waiting times. Participants argued for carers to be considered as distinct from job seekers and treated differently in the context of income support. Some expressed that the timing of the JobKeeper policy announcement was counterproductive, and that many may have kept their jobs had it been implemented earlier.

## **Working group member consultations, 7 and 9 April 2020**

Sixteen non-government organisation and government agency representatives involved in Carers NSW working groups were consulted over three consultation sessions. This included representatives from a range of service providers and peak organisations across a range of service sectors, including aged care, disability, multicultural, mental health and legal sectors. A number of stakeholders were also in caring roles themselves. Participants were offered 3 meeting times to accommodate variable availability and allow for more in-depth consultation in a smaller group setting.

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<sup>10</sup> Since the consultations took place, panic buying and related supply chain issues have reduced significantly in prevalence.

### **Separation from the care recipient**

Participants reported that many carers are isolated from the people they care for who are living in residential care facilities and other non-community based settings. Some people living in community settings, it was also reported, continue to request visits from family and carers despite social distancing restrictions. Carers are concerned about the physical and mental health of their care recipient if they reduce or cease visits to their loved one, particularly in cases where the person they care for usually enjoys an active social life. For many, their social supports have been cancelled or reduced.

### **Shopping for essentials**

Some essential items have become more expensive as they have become less readily available.<sup>11</sup> Participants reported that carers have been having to 'make do' with what is available in store, even as the rates of panic buying and hoarding have decreased over time. Carers have had mixed experiences in both accessing supermarket concession hours and in registering for online delivery of groceries.

Reductions in home and community care services were reported to have made it difficult for some people with disability and older people to visit the supermarket, and information about alternative options and funding streams for online delivery, such as use of NDIS funds, had not been clear.<sup>12</sup>

### **Information and messaging**

Stakeholders raised the lack of consistent and clear information available to carers and the people they care for, especially those living with mental illness, resulting in anxiety and confusion. Carers need detailed and specific information about what to do at this time to protect the rights, needs and safety of themselves and the people they care for. Carers were also reported to have also experienced information overload due to the constant changes in advice soon after the pandemic was announced, and many carers have disconnected from the news to maintain wellbeing, which may adversely affect their ability to stay up to date and access emerging support options.

### **Increased caring responsibilities**

Participants described carers juggling working from home, home schooling and additional supports for care recipients. Some carers are also reported to be required to assist in delivering therapies in the home with direction from professionals via telehealth, but a lack of prior training and specialist equipment, and the challenges of working with a digital medium, have resulted in concerns for the health and safety of the carer and care recipient.

### **Physical health and wellbeing**

It was discussed that carers often have to balance concerns about the health impacts of allowing formal supports into the home with concerns for their own health and wellbeing if they have to take over the provision of care when suspending formal supports. Limited availability of Personal Protective Equipment (PPE) for services coming into the home was also highlighted as exacerbating health risks, as some people with conditions requiring care, despite being immunocompromised, are dependent on daily, face to face external support. At the time of the consultations, disability support workers also had limited access to testing.<sup>13</sup>

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<sup>11</sup> Since the consultations took place, panic buying and related supply chain issues have reduced significantly in prevalence.

<sup>12</sup> NDIS policy and messaging on this has changed significantly since the consultations took place.

<sup>13</sup> Since this time, testing eligibility has been broadened.

Carers are also reporting instances of abuse as the result of increased challenging behaviours in the home. Support services continue to work with carers experiencing abuse, including by the person they care for.

Carers are concerned about the treatment of their care recipient should they contract the virus and require hospitalisation. This extends to a genuine fear that their loved one may be considered “unworthy” of ongoing treatment.

### **Access to services**

For some carers, access to formal care services, carer support and respite has diminished considerably. With family members and care recipients at home, participants reported that carers are often without the incidental respite they may have received when the person they care for accessed a support away from the home. Some older people have been reducing or cancelling in-home services placing additional pressures on carers.

There was general concern that some NDIS providers have misinterpreted guidelines, reducing services where this is not consistent with recommendations or in the interests of client safety. Participants also expressed concern that COVID-19 price increases within the NDIS had not been matched by increases to participant budgets. In addition, the requirement to provide 10 days’ notice in order to avoid payment for cancellation of a service was framed as unreasonable, given that contracting the virus or displaying symptoms is both unpredictable and sudden. An overall shortage of PPE has reportedly seen some service providers putting pressure on carers to independently provide this.

Stakeholders reported that people requiring respite or permanent placement on discharge from hospital are in some cases being rejected by aged care facilities unless they agree to isolate for 14 days. Carers who previously provided practical support, such as feeding, are often unable to visit their loved one. For residents living with dementia, who may require over an hour of support with feeding, the resultant swallowing and choking risks are high. Carers are conflicted, wanting to receive an update about their loved one, but realising this takes away from the provision of care. Carers have found it difficult to advocate on behalf of themselves or the person they care for. There is a general lack of consistency across facilities and participants were concerned that limited resources was part of the issue.

### **Financial impacts**

The ineligibility of Carer Payment and Disability Support Pension recipients for the COVID-19 Supplement was raised, as well as the significant delays being experienced by carers attempting to access Centrelink.

### **Digital access and literacy**

Sudden reliance on technology, including for social connection, medical appointments, therapies, and caring, has presented considerable challenges for carers, according to participants, as carers vary widely in their access to technology and capacity to use it effectively. Some may require additional resources, training and support to increase their confidence. Without these interventions, those carers are at risk of becoming increasingly socially isolated. It was also acknowledged that carers are often enablers and connectors where supports are provided digitally, and this is often associated with additional costs for equipment and internet.

Participants highlighted that the pandemic presents an opportunity to pool resources which enable all carers to access the technologies that people have been adapting to, making access and usage intuitive. They further recommended a decision making matrix be developed to understand how a person learns technology, then further resources be developed specific to the style of learning identified.

### Aboriginal and Torres Strait Islander carers

Stakeholders reported significant concern about the social and emotional wellbeing of Aboriginal and Torres Strait Islander communities, where many carers rely on the stability and connection of their family and kinship systems, currently hampered by social distancing requirements. Some carers are reportedly misinterpreting social distancing as “no one cares about me anymore”, and this is exacerbated in cases where services are reduced. Culturally specific services are trialling various techniques to improve the social and emotional wellbeing of communities.

Aboriginal carers are also seeing “money go out the door everyday”. Using increasing amounts of water and electricity and paying increased amounts for essential items, people are conscious of the costs of their activities and daily lives. Word-of-mouth information exchange is important within these communities, therefore services are focusing on strategies to mobilise these channels.

### Culturally and linguistically diverse (CALD) carers

It was raised that CALD communities differ in their experience of access to information, engagement in supports and use of technology. Some communities limit their use of certain applications due to concerns around privacy, and some experience low internet access rates. Typically these communities prefer methods which enable them to communicate verbally, and see each other face to face. Written messaging applications are required in a variety of languages.

Some communities had reportedly experienced significant racism, particularly when accessing a public space. It was reported that the misinformed perception that Chinese people are carrying the virus has led to acts of discrimination such as being shouted at in the supermarket.

### Regional and remote carers

Regional and remote carers face additional challenges during the pandemic. Participants reported that formal services have in some cases been cancelled, and home delivery of groceries in rural and regional areas is limited. Where regional carers may have relied on friends or family, this informal network of support has reduced as a result of social distancing requirements.

### Employment

It was noted that some carers are finding it difficult to balance their employment and caring responsibilities but are anxious about the financial implications of reducing their working hours to care. Some workplaces have been unable to provide adequate leave entitlements or other flexible arrangements. Carers are in some cases working extended hours to accommodate their caring responsibilities. There was suggestion that following the pandemic, we would see a lot of carers “completely burn out”.

## Researcher consultation, 9 April 2020

*“[We] are noticing fault lines in structures that are in place for carers. These are shockingly inadequate”*

- Researcher

Eight carer-focused researchers participated in a dedicated consultation, many of them also being carers themselves. Researchers represented a range of NSW based universities in both metropolitan and regional areas and a variety of disciplines.

## **Mental health and wellbeing**

The mental health consequences of isolation were raised as significant, especially given that COVID-19 requires long-term hospital admissions without visits from carers or families. A variety of mental health consequences have also resulted from fear of hospitalisation, isolation, insufficient supply of essential items and the unavailability of PPE. A lack of space within households has resulted from school closures and multiple competing demands for attention within the home, putting pressure on families. This has included e-learning, which for some carers has not been feasible due to the complexity of their care recipient's diagnosis i.e. autism, intellectual disability or mental ill-health. This is compounded by the impacts of COVID-19 on employment and income. Researchers reported an increased demand in carers accessing helplines, where it is not simply the caring role that has changed, but many factors external to their caring as well.

There is ongoing fear amongst carers about how to keep their care recipient safe at home, particularly where the person they care for has multiple chronic health conditions or other vulnerabilities, or where the care recipient's condition reduces their capacity to understand social distancing requirements.

## **Access to services**

Issues surrounding system navigation were highlighted as a significant barrier to carers accessing services. Systems such as My Aged Care which were already challenging to navigate were reported to have become more complicated, placing additional stress on carers. Complex system navigation can negatively impact carer and care recipient mental health.

In clinical settings the demand for social work services had reportedly increased, in order to replace the informal support of carers who have had to self-isolate. Where carers have contracted COVID-19, care recipients have sometimes needed intensive and at times complex support in isolation. This is not dissimilar to the replacement care needs during a general hospitalisation of a carer, however the speed and complexity is different when immediate isolation is a factor and emergency respite is needed.

Researchers reported that the pandemic has exposed 'fault-lines' in support services; carers are overburdened by increasing demand on them to perform multiple roles. Formal support is often being withdrawn due to infection risk, but carers are not adequately trained to replace this care. Suspension and closure of services, including day-care centres and some home visiting services, has placed more pressure on carers to supplement these roles and navigate complex systems with added anxiety. Previously available informal supports, such as grandparents, are no longer able to be engaged and some carers have become dependent on the immediate family within their household for support.

## **Employment and education**

According to participants, many carers are required to use their leave, including carers' leave, and other entitlements, in order to provide the increased level of care at home. It is expected that this will result in flow-on and potential crisis effects once the pandemic has ended. Normalising working from home has offered opportunities but also challenges, especially for carers. Interruptions for carers as the result of their caring role have been less recognised than for parents.

It was also reported that students who are young carers have been putting in leave of absences because they are unable to cope with study at home in conjunction with their caring role, even when they have had the infrastructure required. The closure of universities has disadvantaged young carers who previously used this space as a place of respite from the caring role.

## Digital access and literacy

Carers are playing a critical role in enabling access for themselves and their care recipient to essential services that have transitioned to telehealth. The use of telehealth systems requires multiple forms of literacy and resources for consumers, carers and providers. Training and support for telehealth services often does not extend to carers in the home environment, therefore problems are harder to detect and address. Carers are taking on the role as technological enablers where possible, however this requires carers to have technological literacy.

It was reported that transition to telehealth is also not always possible due to the barriers associated with poor mental health or cultural and linguistic diversity. COVID-19 has exacerbated access inequalities for groups of all ages.

## Increased caring responsibilities

According to participants, policies and procedures have been rapidly developed to enable non-COVID-19 patients to be discharged earlier, leading to higher rehab-needs at home. Carers are under pressure to care for people who would be better discharged to rehabilitation services rather than to home. Some care recipients are being sent home in much more challenging situations, but depending on their condition at discharge, may not have access to funding for formal support.

## COVID-19 Policy Advice Form feedback

The following summarises the key issues drawn out of individual case studies as reported to Carers NSW via the Policy Advice Form.

### Shopping for essentials

Panic buying within the community significantly disadvantaged carers who have reported being unable to access essential items which support hygiene and nutrition. Incontinence pads, medication, hand sanitiser, toilet paper and paper towel have been in short supply. Carers who are required to self-isolate due to the vulnerabilities of their care recipient have been unable to do so due to the limited supplies available and the constant need to visit the shops in the hope that products will have been restocked.

Restrictions placed on certain store items have also negatively impacted carers who often use large quantities of these products to meet the needs of their care recipient i.e. for hygiene purposes or to minimise the risk of transmitting the infection between the carer and care recipient. Carers also report that product shortages have resulted in extended shopping trips and subsequently, extended periods away from their care recipient. Many carers are unable to visit supermarkets during the allocated concession hours as the result of employment and/or caring, and therefore are further disadvantaged in their attempt to purchase the items they need.

Carers are concerned at the cost of food and online delivery. The increased price of 'free from' foods, for those with food intolerances has increased the financial strain on some carers. The cost of online grocery delivery has been unaffordable for some carers, who suggest delivery costs should be covered for vulnerable groups. Some carers feel they are excluded from online shopping due to poor digital literacy, and many carers propose that increased support is required for vulnerable groups who are unable to do their shopping online.

### Access to services

Many care recipients are no longer attending care services, education or employment in person, and are therefore at home most, if not all of the time. Carers have also reported cancelling in-home

services in order to protect the health of their care recipient, particularly where they are immunocompromised. As a result, many carers are now filling service gaps and providing an increased amount of informal support, often without formal training.

Carers have expressed concern that if they were to become unwell, or were required to self-isolate, there would be no one available to care for their care recipient. Carers report an overall lack of planned and emergency respite for carers during the COVID-19 pandemic. Carers of people with a disability state that NDIS funding is insufficient to cover the additional supports required in the home, and carers are reducing work hours in order to assist. Carers of people accessing education, who are now accessing their learning online, report there is insufficient funding from the state government to support their online learning needs.

In relation to disability supports, the 10% increase to the price limit of core supports and capacity building within NDIS has seen a significant reduction in participant plans. In addition, carers have expressed that the 10 day notification period required to cancel NDIS services free of charge is not feasible given the unpredictability of the virus.

Carers who are employed in essential service roles i.e. emergency services, who have a care recipient in the 'high risk' category for COVID-19, are having to take leave from their 'essential' roles in order to care at home. These carers are concerned they will be forced to take leave without pay or resign from their employment as the pandemic continues.

### Physical health and wellbeing

Carers have reported being unable to look after their own health and wellbeing. Some carers have expressed feeling increasingly isolated, while others report they are unable to self-isolate due to their caring role, and this is increasing the risk to their health. Carers living with chronic ill-health or disability are at increased risk. Many have highlighted the direct correlation between the health and wellbeing of carers and care recipients. Some carers have proposed that more monitoring and support, both in person and online, is required to ensure carer health and wellbeing.

Care recipient health outcomes are deteriorating as the direct result of limited access to their usual health supports. Doctors and nurses are still needed to attend to 'business as usual' health care and increased health care at home, but are busy managing COVID-19. Some health services have been unable to deliver support via telehealth or conduct home visits. The delay of some surgeries has also left some care recipients without crucial health support.

Carers face ongoing challenges managing hygiene and social distancing, particularly when caring involves close contact, such as when carrying out personal care. Carers report needing safety equipment, including PPE, and consistently report that some generic medications that they need are out of stock.

Carers are deeply concerned that if their care recipient was to contract COVID-19 and was hospitalised, they would be unable to visit them or maintain other contact. This is particularly concerning for carers of people with a diagnosis impacting cognition, capacity or communication, as carers have expressed that clinicians may not effectively communicate during assessment and decision making without the carer's communication support.

*"If my son got COVID-19 and was hospitalised, we [carer and husband] could not support him in hospital... health clinicians could not communicate due to [my] son's speech impairment and he would be traumatised"*

- Carer of son with a disability

Finally, carers are concerned that vulnerable people with pre-existing health conditions will not receive equal health care in the event they are diagnosed with COVID-19 and required urgent treatment.

### Mental health

Increased service support is needed for people living with mental illness. Carers have reported that social distancing has meant that individuals, families and carers have needed to confront many issues which have not been addressed in therapy contexts.

Where residential aged care facilities have limited contact between carers and their care recipients, carers also report that this has an impact on the mental health of carers and the person they care for. Some carers have reported being denied access to their care recipient in an aged care facility, in cases where the care recipient is in the end stages of their life.

*“Staff need more time to facilitate communication between residents, families and carers at this time”*

- Carer of young person in residential aged care

Carers are experiencing increased distress at having to make important decisions with or on behalf of the person they care for, such as when and how to self-isolate. One carer described that carers are spending “more time locked away in their caring roles” and suggested that the risk of mental ill-health and violence increases as carers have no relief or respite. Many carers have expressed feeling overwhelmed and exhausted as the result of being with their care recipient all of the time.

A carer highlighted the recognition within the media of health staff as ‘carers’, expressing that informal carers are still not seen as ‘essential workers’, and feel they receive no recognition for the contribution they make every day.

*“The media constantly uses ‘carer’ for health workers in Australia and the UK during COVID-19... Family and friend lived experience carers are being completely overlooked, and not seen as essential workers”*

- Carer of someone living with disability, mental illness and frailty

Care recipients have reportedly experienced ongoing challenges as their routine is disrupted. This has particularly been the case for those living with an intellectual disability, autism, or another diagnoses where change can cause distress for both the care recipient and carer.

### Information and messaging

Carers continue to report that there is insufficient information about COVID-19 for vulnerable cohorts and their carers. This has particularly been the case for people with disability and their carers, particularly specialist and additional education, group homes, day programs and employment.

*“I feel emotional and exhausted trying to explain to my 44 year old son that he is not able to keep his usual routine. Daily outings that [he] enjoys are no longer possible, and it is challenging to be at home with [him] and my husband all of the time”*

- Older parent carer



## Financial impacts

Carers have expressed distress at being excluded from the \$550 Coronavirus supplement from Centrelink, despite the increased costs experienced as the direct result of COVID-19, particularly costs related to essential items and health and medical costs. Some carers have reported increased financial hardship as a result of lost employment coinciding with increased living costs.

## Employment and education

Carers have reported ongoing barriers in relation to employment and education. Many carers have experienced reductions in employment hours and difficulty sustaining employment. This is sometimes the direct result of the COVID-19 impacts on businesses, but is exacerbated by an increase in caring responsibilities during the pandemic. Some carers have encountered reduced flexibility in the workplace at a time when they need it most. Others report exhausting flexible working options, including utilising all available leave to provide care and support to their loved one.

Some young carers report having insufficient equipment and resources to study from home, including no access to a laptop or other device, and poor or no internet connection. For a variety of reasons, including education, language and age, carers continue to struggle with the increasing digitalisation of services, particularly when accessing groceries, government support and employment.

## Housing

Carers are finding it increasingly difficult to source suitable accommodation to meet the specific needs of their care recipient during the pandemic. Carers have also expressed concern that despite the difficulties in securing accommodation, their loved one will be discharged to homelessness to alleviate pressure on the hospital system and to free beds for those diagnosed with Coronavirus. Carers' own housing stability is at risk as the result of ongoing employment and financial instability.

# SUMMARY

Consultation participants and subjects of Policy Advice Form case studies identified very similar themes, despite their differing roles and backgrounds. Carers, professional and researchers discussed additional challenges facing carers on top of community-wide concerns such as lost employment, supervising e-learning at home, and supply shortages due to panic buying. Five core themes are explored in more detail below.

## Digital literacy and technology access

The existing inequalities for carers in relation to digital access, affordability and literacy have been further exposed and exacerbated during the COVID-19 pandemic. Increased and sudden reliance on technology for social connection, medical appointments, therapies, and caring has further disadvantaged some carers and the person(s) they care for in cases where barriers to access exist. Carers are playing a critical role in enabling access for themselves and their care recipient to essential services during the pandemic, many of which have transitioned to telehealth. Information and guidelines on improving literacy are limited in availability and scope and urgent resources, training and support to increase confidence and build digital capacity are required.

## Access to services

COVID-19 has seen many carers and care recipients experience a significant reduction in their access to supports, services and both informal replacement care or formal respite. Formal support is often being withdrawn due to infection risk, but carers are not adequately trained or equipped to replace this care sustainably. Suspension and closure of services has placed more pressure on carers to supplement these roles and navigate complex systems with added anxiety. These changes

have meant that many carers are over-burdened by increasing demand on them to perform multiple roles, including adapting to a new working or learning environment whilst managing the increased care needs of their care recipient.

### **Physical and mental health**

Various physical and mental health impacts were identified, some directly related to the virus and others related to the impacts of the virus. Deterioration in mental health was directly linked to disconnection between carers and the people they care for, increased isolation, decreased socialisation, and changes in carers' circumstances, including in employment, income, education and caring demands.

Physical and health risk is significantly increased for carers and care recipients living with illness or disability, and those who are immunocompromised. Carers are having to balance the health impacts of allowing formal supports into the home with concerns for their own health and wellbeing when replacing services. A vast majority of supports have transitioned to telehealth, which has disadvantaged carers who lack the equipment and resources to access this form of support.

Carers are also fearful of what might happen if they or the person they care for contracts the virus and requires hospitalisation and subsequent separation from both informal and formal support networks. Finally, carers are providing increased care with limited health resources. This includes intimate personal care without sufficient PPE to minimise infection risk.

### **Social isolation**

Carers are increasingly disconnected from the people they care for. This is particularly the case when a care recipient is living in a residential aged care facility, disability group home or hospital setting. In these residential settings, carers are prevented from providing care and support provided prior to the pandemic. Some of these supports are integral to maintain the wellbeing of the care recipient, such as feeding and nutritional support for care recipients living with dementia.

### **Information**

A lack of consistent, clear and applied information has created confusion for carers and the people they care for. This has also resulted in increased fear and anxiety, particularly for people living with mental illness. Carers need detailed and specific information from trusted sources about what to do at this time to protect the rights, needs and safety of themselves and the people they care for. Carers also reported needing information directly from the services they and the person they care for are accessing. This includes information on the crisis, current risks to the service and its users, and mitigation management strategies in place.

*Carers and service providers are welcome to provide ongoing feedback and suggestions relating to COVID-19 and other policy issues affecting carers by contacting the Carers NSW Policy Team at [policy@carersnsw.org.au](mailto:policy@carersnsw.org.au) or on 02 9280 4744, or by completing our online [Policy Advice Form](#) survey.*