

A review of the evidence

July 2020

The widespread social and economic impacts of the COVID-19 pandemic have prompted many organisations to rapidly conduct research and consultation in order to better understand people's experiences and support needs. Carers have been the focus of a number of these studies, and several other studies have produced findings that are highly relevant to carers. This briefing summarises the key consistent themes identified across published COVID-19 data relating to carers from Australia and the comparable jurisdictions of the UK, Ireland and the USA.

Key findings

The main challenges experienced by carers during COVID-19 have been described fairly consistently across the Australian and international sources examined. These challenges can be divided into six main categories: health and wellbeing, service access, caring role, education and employment, finances, and technology. The most commonly raised issues under each of these categories are summarised below.

Health and wellbeing

The main health and wellbeing issues identified across both Australian and international sources of evidence related to adverse impacts of the pandemic on the mental health and stress levels of carers and the people they cared for, and the increased isolation carers experienced in lockdown. A lack of clear, accessible, carer-inclusive information on social distancing rules and hygiene advice was also highlighted in Australian and international sources as a key issue, as was the challenge of caring for someone who was in a high-risk health or age category. Some carers were also in high-risk categories themselves. Where either party was at high risk, self-isolation looked like a longer-term prospect than for the



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. Carers come from all walks of life, cultural backgrounds and age groups.

general community, prompting concerns about longer-term associated impacts on finances, health and service access for carers and the people they care for.

Many carers expressed anxiety about contracting COVID-19 and what would happen if they could no longer care due to becoming very ill or passing away, as well as what may happen if the person they care for were to contract the virus. Stress and confusion about ongoing changes and unclear messaging from official sources was also a prominent issue.

Carers across Australian and international sources referred to physical health challenges that they experienced due to COVID-19, including changed sleep patterns, reduced access to health and fitness activities, and delayed access to health interventions such as surgery and face to face medical treatment.

“Caring for someone can often be a demanding and socially isolating experience. COVID-19 certainly added another level of complexity for carers as they were required to isolate with the person(s) they care for in addition to many social support activities and respite options ceasing or being postponed.”

(Carers Queensland, 2020)

A number of studies highlighted carers' sense of a lack of recognition and acknowledgement from governments and service providers about the level of care they were providing and their need for support, guidance and protection. Limited access

to personal protective equipment (PPE) and no opportunity for prioritised testing were raised among carers, as well as the paid care workers with whom they came into contact. Some carers felt they were at higher risk of contracting the virus due to having to move around the community to purchase supplies for, and visit, the people they care for.

Carers also mentioned an increased risk of violence and abuse in the home and community due to the stress associated with household changes and uncertainties regarding the health and financial impacts of the virus. Challenging behaviours among the people they cared for, resulting from or exacerbated by these circumstances, were also raised, along with the risk of restrictive practices being misused in this environment.

Service access

Reduced access to respite opportunities – including use of formal services and informal opportunities to take a break from the caring role – was the most commonly raised challenge relating to services. General reductions in services and social support were also key challenges, as were changes in the delivery of services, especially the prioritising of digital delivery, which was not always considered to be an effective or adequate replacement for face to face services.



Where services were reduced, this was often initiated by service providers themselves, but it was sometimes the result of carers cancelling services due to concerns about the safety of allowing workers into the home environment. A number of studies also reported confusion and lack of knowledge among carers about the services and supports that were available to them during COVID-19.

Findings regarding the challenges experienced by aged care and disability support workers were also significant, as the additional requirements imposed on workers, limited protections available and resulting reductions in their wellbeing affected service quality and availability.

Caring role

The leading challenge identified in both the Australian and international sources in relation to the caring role itself was the nearly universally reported increase in the amount and intensity of care provided. The second most highlighted issue surrounded the inability of many carers to visit those they were caring for due to restrictions in place at aged care facilities and hospitals, travel restrictions preventing visits to particular geographies, and self-isolation protocols recommended to protect high-risk individuals. These restrictions also meant that for many carers, alternative informal supports such as grandparents and relatives were no longer able to be called upon. A key related challenge reported widely was the lack of contingency plan in place for if the primary carer became ill.



“Even before the outbreak of Coronavirus, young carers and young adult carers were all too often spending significant amounts of time caring for a relative in addition to the time they needed to spend on education, work and time for themselves. Coronavirus has significantly increased those pressures.”

(Carers Trust, 2020)

At the same time, many other carers reported increasingly crowded households, with existing household members being at home instead of at work or school, and other family members including people being cared for often living with the carer. The challenges of balancing caring roles, employment and schooling in crowded households caused significant stress for many carers and relationship quality was impacted.

Education and employment

Many carers, like other members of their communities, experienced reduced employment and income, with some being stood down or losing work, especially young people and women in lower paid, casualised sectors. Others were able to work from home, but while flexibility was valued by some, there were also considerable challenges or the many carers maintaining their employment responsibilities while caring for someone at home, especially with children unable to attend school. The added stress of home-schooling children placed additional pressure on many caring families, especially when the student had additional needs that were not well catered for in a digital environment, or health risks that meant returning to school would not be safe for the medium term.



“People across Australia have experienced work and income disruption, supply shortages and educational difficulties. However, all of these disruptions are exacerbated for children and young people with disability and their families.”

(Dickinson and Yates, 2020)

Continuing with school or higher education in the home environment also proved a challenge for many carers, especially young carers. With limited quiet environments to study in, and lost opportunities to take a break from the family environment, as well as difficulties accessing and using technology, students who were already disadvantaged were found to experience additional ‘learning losses’, falling further behind.

Finances

The considerable impacts of COVID-19 on employment have had obvious flow on effects to carers’ finances. In both Australia and overseas, the evidence reflected



difficulty accessing essential items, including groceries and medication, and an overall increase in basic living expenses. Carers also reported difficulty accessing adequate income support, which did not assist the many carers experiencing financial hardship, and was also viewed as evidence of a lack of recognition by government.

The main additional costs mentioned other than increased daily living expenses were the costs associated with acquiring and setting up IT equipment and an adequate internet connection to successfully access services, maintain social contacts and undertake work and study commitments. Due to the lack of recreational activities outside of the home that were accessible during this period, some sources also pointed to additional costs for remote or digital activities to keep those receiving care occupied and maintain carer health and wellbeing.

Technology

In addition to the costs associated with technology, digital literacy and training needs were commonly raised, as were other barriers to equitable technology usage, such as poor internet access and cultural barriers. The difficulty of finding quiet, private environments in crowded households to access services, connect with friends and family and participate in work and study meetings was also raised. Telehealth and online learning were also flagged as particularly inaccessible for some people with disability.



“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.”

(Carers NSW, 2020)

Implications

Early evidence regarding the impacts of COVID-19 of carers across Australia and overseas indicates critical levels of carer stress that are unlikely to abate even as immediate public health risks decrease. The additional pressure on carers of uncertain information, unstable finances and changing service landscapes, coupled with the loss of social and recreational supports, places carers in a very vulnerable position.

In order to reduce the stress on carers, governments and communities need to:

- Recognise and include carers in official messaging
- Provide information, training and protective equipment to assist carers to care safely in the home and community
- Train and equip care workers to work safely in people's homes, relieving carers of extra responsibility while reducing transmission risk
- Provide flexible financial assistance to carers with increased expenses and reduced income
- Improve access to affordable, quality mental health care
- Enable ongoing connection with friends and family, and with safe recreational activities that support health and wellbeing
- Help carers to adjust to a digital service environment
- Offer flexibility and support to students, parents of school children with disability, and workers juggling multiple responsibilities

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