

Coronavirus (COVID-19) and carers

Carers NSW Position statement, 7 May 2020



People providing ongoing care and support to a family member or friend living with a disability, mental illness or health condition have experienced many of the same impacts on health, wellbeing, work and finances that other groups have faced, while also navigating the added challenges of supporting a vulnerable loved one at a time when formal services, essential supplies and opportunities for social support are reduced.

As the peak non-government organisation for carers in NSW, Carers NSW has been closely monitoring related policy developments that may directly impact carers and the people they care for, and has been in continual contact with carers across the state to understand and respond to their changing support needs. This position statement draws on ongoing policy and media analysis, more than 50 carer case studies, and 5 consultations held with 30 carers and other stakeholders.

Why are carers particularly affected?

Coronavirus (COVID-19) poses a significant threat to all members of the Australian community. Vulnerable persons such as people who are ageing or frail and people living with chronic illness or disability are at a heightened risk from illness related complications. Many also rely on the support of family members and friends to manage their condition and effectively participate in the community.

Assisting a vulnerable family member or friend may expose that person to an increased risk of contracting the virus, especially where access to personal protective equipment (PPE) and clear information about how to care safely at home are limited. In many cases, physical contact with the care recipient – and others such as paid workers – is unavoidable in order to meet a person's needs.



Carers are often the safety net for a person when formal services are reduced or no longer available, so in the current environment, many carers have taken on additional caring responsibilities to replace formal services and to assist the person they care for to self-isolate. This has made working from home or supervising school children more challenging for many carers, and in many cases has resulted in additional financial and emotional costs at a time when few face to face carer support services are available.

Carers play a significant role in the community. Approximately 854,300 people in NSW provide unpaid care and support to a family members or friend who needs help because of illness, disability, frailty or ageing.ⁱ It is estimated that the cost of replacing the care provided by all carers in Australia is over \$60 billion per year.ⁱⁱ

Carers NSW believes that without adequate consideration and support, the health and wellbeing of carers and their care recipients will deteriorate, making care arrangements unsustainable and placing additional strain on the already stretched health and care service systems.

Carer health and wellbeing

For many carers, the risk of the person they care for contracting COVID-19 and experiencing complications or inadequate support is very anxiety provoking. Constantly changing and conflicting information about the level of risk and government requirements has compounded this distress. In some cases, carers have chosen or been forced to remain separate from the person they care for due to self-isolation or the lockdown of residential facilities. This has often affected the health and wellbeing of both parties.

Many carers and care recipients have decided to withdraw temporarily from receiving formal services, or seen those services cease for other reasons beyond their control, and are currently providing unsustainable levels of care in the home, often while supervising school



children or attempting to work from home. Difficulties sourcing essential supplies such as specific food and hygiene items during the COVID-19 period has also caused significant distress. Carers are a very socially isolated population in general, and the peer support activities many rely on for a break from the caring role, emotional support and practical advice have struggled to transition to an online environment.

A range of carer services are available nationally through the [Carer Gateway](#), however not all carers are aware of how to access support, and due to social distancing requirements, in-person support is currently limited. Many carers are also too busy attending to the needs of others to reach out for support.

Carers NSW has been advocating for flexible, responsive carer support, inclusive and affordable telehealth options, practical assistance with online engagement, and carer-aware policy making and service delivery to address these issues. Carers NSW is pleased to see both NSW and Australian governments improve their inclusion and support of carers over the duration of this crisis, but believe there remains room for improvement.

Carer-inclusive messaging

Rapid policy change has made media commentary confusing, and information quickly becomes out of date. Coordinated messaging regarding older people and people with disability has vastly improved since the start of this crisis, however in many cases information and resources applying recommendations and announcements to carers and the people they care for have been lacking.

Carers supporting a person at home have been confused about whether it is safe to continue to receive in-home aged care and disability services, whether they will be fined if they are seen in public with the person they care for, or whether they have to wear PPE at home. Carers supporting people living in residential facilities have received limited information and support from service providers about whether they can visit, what rules are in place, and how to stay in touch with their loved ones remotely.

Initiatives to support vulnerable groups to access essential grocery items have been well-meaning, but have often unintentionally excluded carers from their eligibility criteria, placing additional barriers in the way of vulnerable groups accessing what they need.

Carers NSW has been advocating for clear, tailored messaging from governments, practical advice and regular communication from service providers, and inclusive messaging from retailers to address these issues. We are pleased to have seen more announcements recognising the needs of families and heard of improved communication from service providers.



Safe, quality service provision

Restrictions on visitors to residential aged care facilities have caused concern for many carers who provide regular emotional, social and practical support to supplement the care provided by busy staff. Residents of many facilities have struggled to maintain contact with family members and friends due to visitor restrictions, and increased demands on staff may have further implications for care safety and quality.

Reductions in the aged care and disability workforces due to COVID-19 infections and transmission risk are already creating gaps in the provision of formal care services both in residential environments and in the community. Many residential facilities have been refusing or limiting respite admissions to mitigate risk, limiting the options available to carers in need of a break, or unable to care due to contracting the virus themselves.

The severe national shortage of personal protective equipment (PPE) for even frontline workers has caused much concern among workers and families, contributing to service withdrawal and leaving vulnerable people, their carers and workers all at higher risk of contracting the virus.

Carers NSW has been advocating for more balanced visitor policies, improved testing and protection for workers, and improved access to PPE to address these issues. We have been pleased to see eligibility for testing expanded and PPE supplies improving, and welcome recent statements from the Australian Government supporting the importance of visitors and respite provision in the residential care setting, however barriers to access still remain.

Financial support

Carers often face financial hardship due to lower incomes and significant costs related to caring. Many carers, along with other groups, have been impacted by loss of income, medical costs and inflated prices due to panic buying. While some will benefit from the JobSeeker Payment and Coronavirus Supplement, and those receiving Carer Payment and other pensions are eligible for the two stimulus payments available, many are nonetheless reporting financial distress. For those who have been able to retain paid work, their capacity to access appropriate leave or to work sustainably from home have also been of concern.

The possibility of accessing superannuation to mitigate financial hardship during COVID-19 also threatens to disadvantage carers, whose superannuation is often significantly depleted by reduced working hours and career breaks in order to care. This is particularly the case for women.



The sudden move to digital service delivery and communication has also been a challenge for many carers, especially those being required to continue to engage with study or paid work online. Caring households often experience significant financial disadvantage, and in many cases do not have access to the devices, other equipment and internet connections required to participate effectively from home.

Carers NSW has been advocating for financial support for carers, in particular to assist with access to digital technology, and has been pleased to see a range of funding opportunities presented at State and Federal levels.

Inclusive education

Parents of children with disability required to learn from home are often finding that the modes of remote delivery are not inclusive or accessible, and learning support needs are higher. This is keeping many parents from attention to other responsibilities including paid work. Carers working from home have in many cases embraced the flexibility, but have also noted that being at home with care recipients all day can make it difficult to focus on work. Some young carers have also reported requiring special consideration for their university assignments due to increased caring responsibilities while studying from home.

Carers NSW has been advocating for greater support for school students with disability and their families, and for workers and students with caring responsibilities to address these issues. With restrictions starting to relax, students and workers may start returning to face to face learning environments, however inclusion and support are still important.

Recommendations

Carers NSW continues to recommend that:

1. Carers' needs and interests be taken into account in all COVID-19 related policy making and service delivery adjustments, in line with State and Commonwealth carer recognition legislation.
2. Information and resources regarding in-home care services be inclusive of carers, including advice on hygiene practices at home and how and when to access to PPE.
3. Priority shopping and delivery programs be inclusive of carers accessing supplies on behalf of vulnerable groups.
4. Residential care facilities be supported to safely allow visitors and respite placements.
5. Support workers be resourced and supported to maintain quality and safety and assist residents to stay connected to families.
6. Employers and educational institutions be flexible in accommodating the impacts of increased caring responsibilities and limited access to digital technology.

ⁱ ABS (2019a).

ⁱⁱ Deloitte Access Economics (2015) *The economic value of informal care in Australia in 2015, Carers Australia*.