

# Coronavirus (COVID-19) and carers

Carers NSW Position statement, 13 January 2022



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 policy and media analysis, carer case studies, and ongoing consultation with carers and other stakeholders.

## Why are carers particularly affected?

While anyone can catch COVID-19 and experience severe symptoms, 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 masks, Rapid Antigen Tests (RATs) 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 reduced carers' access to support for

themselves and increased the social isolation and financial stress that many already experience.<sup>1</sup>

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.<sup>2</sup> It is estimated that the cost of replacing the care provided by carers in NSW is \$25 billion per year.<sup>3</sup>

Carers in NSW have been under immense pressure due to COVID-19 for nearly two year now, and the Omicron outbreak has only exacerbated this by adding new challenges, such as a significantly increased risk of contracting the virus and having to manage symptoms from home, difficulty accessing scarce testing options and goods and service shortages resulting from widespread self-isolation.

## Carer health and wellbeing

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



In other cases, carers are required to self-isolate with the person they care for, replacing formal services that have withdrawn and providing additional support to manage COVID-19 systems with limited assistance from the health system. If carers themselves contract COVID-19, this can significantly compromise their capacity to care, in some cases placing the health and safety of the person they care for at risk.

Difficulties sourcing essential supplies such as specific food and hygiene items has caused significant distress at

different stages of the pandemic. Current and anticipated shortages in groceries, RATs and other essentials are likely to particularly affect carers and the people they care for, who may rely on particular items to manage a health condition, and who may face additional barriers to accessing the community or ordering goods online.

Furthermore, priority grocery delivery and RAT distribution initiatives generally exclude carers and many of the vulnerable people they care for as they do not meet strict service eligibility criteria based on, for example, receipt of National Disability Insurance Scheme (NDIS) services or income support payments.

Higher risk of transmission during the Omicron outbreak and limited access to testing have also created additional barriers to carers being able to see friends and family members, access peer support and recreational activities and look after their own health, which are already significant challenges for many carers.

A range of carer services are available nationally through the <u>Carer Gateway</u>, however not all carers are aware of how to access support, and due to social distancing requirements, in-person support has been severely limited throughout the pandemic. Many carers are also too busy attending to the needs of others to reach out for support or make time for themselves.

#### **Carer-inclusive information and support**

Rapid policy change has made media commentary confusing, and information quickly becomes out of date. Coordinated messaging regarding vulnerable groups has vastly improved since the start of the pandemic, however in many cases information and resources applying recommendations and announcements to carers and the people they care for have been lacking. Official sources of information can also lack detail and take time to incorporate new information, and rapid changes make providing timely translated resources difficult.



Initiatives to support vulnerable groups to access vaccination, RATs and essential grocery items often exclude carers, even when carers may be acting on behalf of the person they care for. Cohort-based prioritisation of vaccination, which was in place in 2021, has also not been introduced to assist with the rollout of booster vaccination or initial vaccination for 5-11 year olds living with disability or a chronic health condition in NSW.

# Safe, quality service provision

Restrictions on visitors to residential aged care facilities and hospitals have been an ongoing cause of concern throughout the pandemic for carers who provide essential emotional, social and practical support to supplement the care provided by busy staff. While visitor restrictions are required to limit transmission risk, more needs to be done to ensure that existing exemption guidelines are implemented to ensure the health and safety of vulnerable people is not unwittingly put at risk.

Reductions in the aged care and disability workforces due to COVID-19 infection and exposure, vaccine mandates and staff burnout are exacerbating existing gaps in the provision of formal care services both in residential environments and in the community. Not-for-profit organisations including peak bodies been working over-time for nearly two years to provide additional information and flexible support to help

clients navigate personal crisis, potentially affecting organisational and sector sustainability.

### **Financial support**

Carers often face financial hardship due to lower incomes and significant costs related to caring.<sup>4</sup> Many carers, along with other groups, have been impacted by loss of income, medical costs and inflated prices and price gouging. While some will benefit from additional government payments and subsidies, not all will be eligible. 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 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.

### What Carers NSW is doing

Carers NSW continues to consult with carers and service providers and draw on other evidence in order to:

- provide timely, targeted information and resources to assist carers to understand and apply public health advice
- adapt our services to meet emerging needs and address access barriers
- make recommendations to government about how to adjust information, policy and service provision to better meet carers' needs

#### What governments can do

Carers NSW is advocating for the NSW government to:

- Extend the priority distribution of RATs to include all people living with a disability or chronic health condition and their carers
- Expand the information collected and provided in the registration of positive RAT results to ensure that vulnerable groups and their carers have access to timely clinical and practical support
- Prioritise access to vaccination for children aged 5-11 years living with a disability or chronic health condition and their carers, and prioritise access to booster shots for vulnerable groups and their carers

- Improve the clarity of, and timeliness of updates to, key official information sources
- Acknowledge the role of the not-for-profit sector in providing ongoing crisis support to vulnerable groups, and the impacts on the sector and workforce

#### Carers NSW is advocating for the Australian government to:

- Extend eligibility for free RATs to vulnerable groups and their carers who do not have a Concession Card
- Encourage national retailers like Coles and Woolworths to expand eligibility for priority delivery to include carers, people living with chronic health conditions and people with disability who are not eligible for the NDIS
- Consider distribution of free RATs through Carer Gateway Service Providers

#### Information and support for carers

- For tailored information and resources to support carers during the COVID-19 pandemic, visit <a href="www.carersnsw.org.au/about-us/news">www.carersnsw.org.au/about-us/news</a> or follow Carers NSW on Facebook <a href="www.facebook.com/carersnewsouthwales">www.facebook.com/carersnewsouthwales</a>.
- To report issues affecting carers, please complete the Carers NSW Policy Advice Form at <a href="www.surveymonkey.com/r/policy\_advice\_form">www.surveymonkey.com/r/policy\_advice\_form</a>, email <a href="policy@carersnsw.org.au">policy@carersnsw.org.au</a> or phone the Policy team on 02 9280 4744.
- For **practical and emotional support**, contact your local Carer Gateway Service Provider on 1800 422 737 or visit www.carergateway.gov.au.

<sup>&</sup>lt;sup>1</sup> Carers NSW (2020), Carers NSW 2020 National Carer Survey: Summary report, Carers NSW, North Sydney.

<sup>&</sup>lt;sup>2</sup> Australian Bureau of Statistics (2019), *Survey of Ageing, Disability and Carers 2018*, Table Builder Dataset.

<sup>&</sup>lt;sup>3</sup> Deloitte Access Economics (2020), *The economic value of informal care in Australia in 2020, Carers Australia.* 

<sup>&</sup>lt;sup>4</sup> Carers NSW (2020).