



Carers NSW Australia

in partnership with



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2020 National Carer Survey

Executive Summary

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. Carers NSW is part of the National Carer Network and a member of Carers Australia. 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

<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 Australia, there are approximately 2.65 million informal carers, around 10.8% of the population; 861,600 primary carers and 1.79 million non-primary carers (ABS 2019a).

This report was prepared by the Carers NSW Policy and Research team in October 2020 in partnership with the state and territory Carer Associations.

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Executive summary

The biennial Carers NSW Carer Survey, funded by the NSW Department of Communities and Justice, collects information about carers in New South Wales (NSW) to provide an evidence base that informs the organisation's direction, support, and systemic advocacy for all carers across NSW. In 2020 the Carer Survey was conducted nationally for the first time, with the support of the state and territory Carer Associations.

The 2020 National Carer Survey builds on the successes of the previous Carer Surveys by expanding the evidence base regarding carers' experiences and support needs, with its new national scope presenting additional opportunities to better understand and support all carers.

The *2020 National Carer Survey: Summary report* provides an overview of high-level national findings from the Survey regarding caring relationships, carers' experiences accessing services, carer health and wellbeing, and carer employment. Some state and territory comparisons are highlighted throughout to indicate national variation, with further comparative analysis between the states and territories and between various cohorts of carers to be completed in future.

The 2020 National Carer Survey received a total of 7,735 valid responses from carers in every state and territory of Australia, with particularly high response rates among carers in South Australia, New South Wales, Victoria and Tasmania. More than 1,300 carers (17.7%) completed and returned a paper copy of the Survey, with the remaining majority completing the Survey online. The Survey was promoted through the state and territory Carer Associations' member and client networks, as well as key stakeholder and sector contacts, and some paid advertising was conducted to reach carers who were not currently connected to carer services.

Carers were able to complete the Survey between April and June 2020, when many Australians were in lockdown due to government Coronavirus (COVID-19) restrictions. Data collection also coincided with the commencement of in-person services under the new national Carer Gateway from April 2020. The timing of the Survey has therefore enabled Carers NSW and the state and territory Carer Associations to obtain a critical snapshot of carers' lives during an unprecedented national crisis and in the early stages of significant carer support reforms.

Of the 7,735 Survey respondents, 92.8% were current carers and 7.2% were former carers. Most respondents (93.2%) were primary carers, those individuals providing the most support to the person(s) they care for. More females (81.7%) than males (17.7%) responded to the Survey, reflecting the larger proportion of primary carers in the overall population who are female. The mean age of respondents was 58.3 years, with the eldest Survey respondent being 94 years of age.

Respondents were most likely to care for their child, including adult children (45.1%), and/or partner (37.0%) and one in four respondents (25.9%) cared for more than one person. The most common group of people being cared for by survey respondents were people with physical disability (36.1%), followed by people with a chronic condition (29.2%) and people living with a mental illness (26.4%).

In line with previous Carers NSW Carer Surveys, this sample cannot be considered representative of the broader Australian carer population of 2.65 million, which limits the generalisability of the findings presented. However, a wide range of caring experiences were evident across the sample, including relatively strong representation from diverse cohorts of carers. Among Survey respondents were 108 young carers aged 25 years and under, 142 Aboriginal and/or Torres Strait Islander carers, 196 LGBTQI+¹ carers and 340 culturally and linguistically diverse (CALD) carers..

The findings presented in this summary report raise important implications for governments, service providers, employers and the broader community at a time of considerable challenge and change for carers across Australia. They will be used to direct additional data analysis and dissemination and to inform ongoing service delivery, advocacy and research work conducted by Carers NSW, the other state and territory Carer Associations and our key partners and stakeholders.

¹ Lesbian, gay, bisexual, transgender, queer, intersex and other sexuality, sex and gender diverse

2020 National Carer Survey: Key findings

- The typical respondent was a female primary carer of working age with a high school education, not participating in paid employment.
- The typical person being cared for was an adult son with physical disability who is not able to be left alone for more than a few hours.
- Most respondents provided 40 or more hours of care per week, and more than half had been caring for 20 years or more.
- Nearly half of the carers who responded were experiencing high or very high psychological distress, and one in three felt highly socially isolated.
- One in three respondents said they never get time out from their caring responsibilities, with only around half having enough time to keep on top of other responsibilities.
- It was relatively uncommon for carers to be asked about their own needs when accessing services or on behalf of the person they care for, and services were much less likely to meet carers' needs than the needs of the people being cared for.
- The most common challenges carers experienced when accessing services were getting information about what services are available, and the time and energy it took to organise services. Waiting periods to access services were also a common challenge.
- One in four carers reported spending more money than they made in the past 12 months.
- Exiting employment and reducing working hours were common impacts of caring on carers' career trajectories.