Carers NSW
Australia

2022 National Carer Survey

FULL REPORT

In partnership with

Carers Australia ACT
Carers NT Australia
Carers QLD Australia
Carers SA Australia
Carers TAS Australia
Carers VIC Australia
Carers WA

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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 October 2023 in partnership with the State and Territory Carer Organisations.

For more information please contact:

Carers Australia ACT	02 6296 9900	carers@carersact.org.au
Carers NSW Australia	02 9280 4744	contact@carersnsw.org.au
Carers NT Australia	1800 422 737	carersnt@carersnt.asn.au
Carers QLD Australia	07 3900 8100	info@carersqld.com.au
Carers SA Australia	1800 422 737	info@carerssa.com.au
Carers TAS Australia	1800 422 737	intake@carerstasmania.org
Carers VIC Australia	1800 514 845	reception@carersvictoria.org.au
Carers WA	1300 227 377	info@carerswa.asn.au

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EXECUTIVE SUMMARY

The 2022 National Carer Survey was the second time the State and Territory Carer Organisations asked carers across Australia about their caring roles, their experiences with services for themselves and the people they care for, their experiences with paid work, and their health, and wellbeing. Led by Carers NSW and proudly funded by the NSW Government the 2022 National Carer Survey has expanded the evidence base regarding carers' experiences and support needs.

This report provides an overview of national findings from the Survey regarding caring relationships, carers' experiences with services, paid work and health and wellbeing, as well as a deeper exploration of selected topics and diverse caring experiences.

Part 1 of this report presents background information about the Survey, including details about the methodology, the research process and sample size and composition. In part 2, selected topics are explored in depth, with detailed analysis regarding the experiences of carers during the COVID-19 pandemic, care and paid work, caring and the cost of living, and carer health and wellbeing. Part 3 presents the detailed findings of the Survey regarding caring relationships, experiences with services for the carer and the people they care for, carer's health and wellbeing, finances and housing.

Carers were able to complete the Survey between June and July 2022. Of the 6,825 carers who responded to the 2022 National Carer Survey, the majority identified as female, they were on average 59.8 years old, and represented a range of locations and cultural backgrounds. Most identified their cultural background as Australian and lived in metropolitan areas. 41.1% of respondents were working or looking for paid work while providing care. Most frequently, respondents were caring for one person with no assistance from other family members or friends. 1 in 4 were caring for more than one person, most were caring for a child (including adult children), or their partner. The most common conditions of people being cared for were identified as physical disabilities, followed by chronic conditions and mental illnesses. The majority of respondents dedicated 40 or more hours per week to providing care, and the typical duration was between 5-9 years.

The wellbeing, psychological distress and social connectedness reported by respondents to the 2022 National Carer Survey remains at concerning levels, similar to the 2020 Survey. Almost half of all respondents (47.5%) experience high to very high levels of psychological distress, and 56.3% are socially isolated or highly socially isolated. The average wellbeing score remains with 57.4% on the Personal Wellbeing Index significantly below the Australian average of 74.4%. Further, the financial situation of carers has deteriorated relative to 2020, with 57% of respondents experiencing financial stress.

In line with previous Carers NSW biennial 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, and the depth of data collected provides significant insights into the lives of carers of all kinds across Australia.

Carers NSW and the research team would like to sincerely thank all participants for contributing their valuable time and insights to support this important research.

PART 1: ABOUT THE SURVEY

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ABOUT THE 2022 NATIONAL CARER SURVEY

The biennial National Carer Survey is an initiative of Carers NSW in partnership with the State and Territory Carer Organisations. The Survey is proudly funded by the NSW Department of Communities and Justice. The 2022 National Carer Survey was conducted from June to July 2022. A total of 6,825 carers from all 6 states and 2 territories of Australia participated in the 2022 National Carer Survey. More than half (55.9%) of the carers who responded in 2022 were members of, affiliated with, or registered with, the Carer Organisation in their state or territory.

RESPONDENT PROFILE

Of the 6,825 carers who responded to the 2022 National Carer Survey, the majority (82%) identified as female, and they were on average 59.8 years old. They represented a range of locations and cultural backgrounds, but most identified as Australian and lived in metropolitan areas. 41.1% of respondents were working or looking for paid work while providing care.

The 'typical' respondent was a woman in her late 50s, caring for her child (including adult children) living with a disability. She lives in a metropolitan area and provides care for 104 hours per week.

The caring role

Most commonly (45.1%), respondents were caring for their child (including adult children). A majority were providing care to someone living with disability (70.3%), with 2 out of 3 respondents (66.3%) reporting that the person they cared for required care for two or more conditions.

Most carers who responded cared for one person (72.1%), and they were most commonly the sole carer (56.4%). They were also most likely to live with the person they care for (82.3%). Respondents typically spent 104 hours per week caring[1] and had been caring for an average of 12.6 years. The people cared for by respondents were on average 52.3 years of age, and more than half (56.5%) were male.

Not everyone who responded to the Survey was still in a caring role; 450 respondents (6.6%) identified as former carers. 1,859 respondents (29.2%) had previously cared for someone and were now caring for another person.

Figure 1: Carer relationship to person cared for

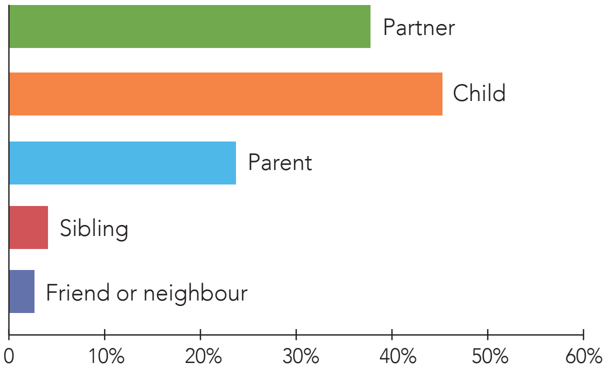
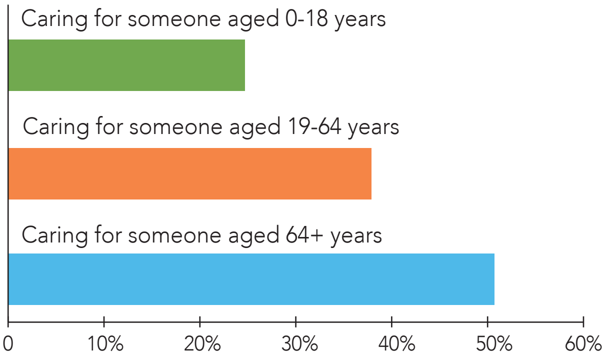


Figure 2: Age of person cared for



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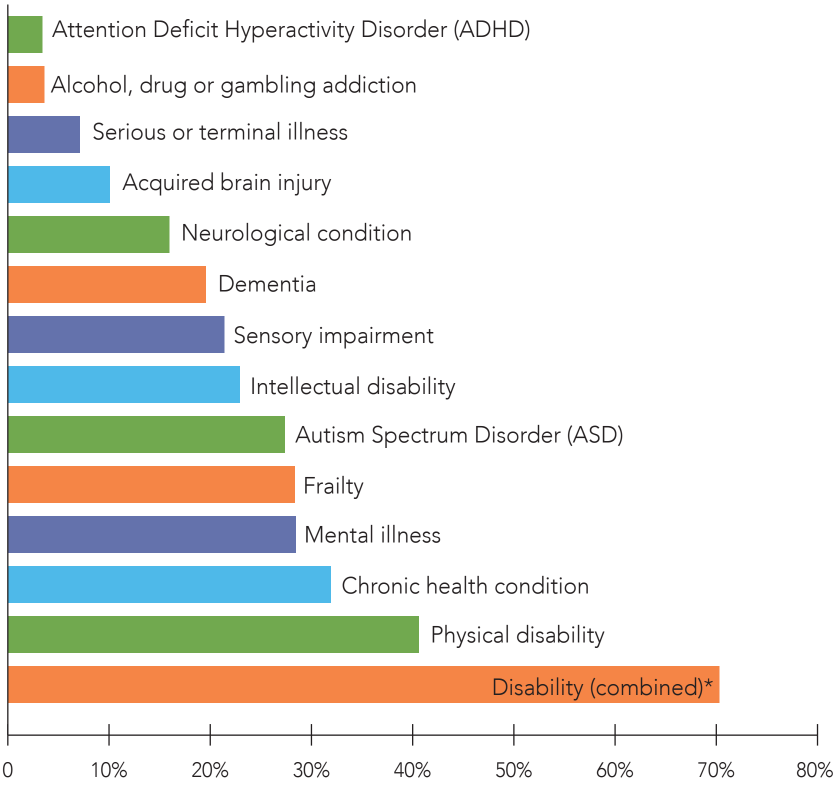
[1] For the calculation of the average hours of care provided per week, the provision of 24/7 care is treated as 168 hours of care per week

Demographic characteristics

Compared to the averaged carer in Australia, respondents to the 2022 National Carer Survey were more likely to be primary carers and more likely to be female, older, and have higher educational attainment. They were also less likely to be employed and more likely to be living with a disability or long term health condition. These key demographic differences must be considered when interpreting findings from other sections of the Survey.

Selected demographic characteristics comparing results from the Carers NSW 2020 National Carer Survey with population level estimates from the Australian Bureau of Statistics (ABS) 2018 Survey of Disability, Ageing and Carers are summarised in Table 1.

Figure 3: Conditions of the person cared for



** Includes physical disability, intellectual disability, autism spectrum disorder, acquired brain injury, and sensory impairment*

Table 1: Demographic characteristics of sample, compared to ABS population estimates

		2022 National Carer Survey		Population estimate (ABS 2019a)
		N	Valid %	%
Total respondents/carers		6,825	100	(2.65 mil.)
Primary carer		6,157	90.2	32.5
Gender	Female	5,428	82.0	57.3
	Male	1,144	17.3	42.7
	Non-binary/other	31	0.4	Not provided
Age	Mean (years)	59.8	-	51.2
	Up to 24 years	78	1.2	7.0
	25 to 64 years	3,876	58.9	56.0
	65+ years	2,625	39.9	34.0
Education	Bachelor or higher	2,094	32.0	25.6
	Certificate/diploma	2,209	33.8	34.3
	High school	821	12.5	11.9
	< High school	1,034	15.8	28.0
Employment	Employed	2264	33.5	53.7
	Unemployed	513	7.6	3.3
	Not in labour force	3979	58.9	42.9
Disability or long-term health condition*		3117	47.6	32.1

**Carers who had experienced any long-term illness or disability themselves during the last 12 months.*

Table 2 presents demographic characteristics showing the diversity of respondents in the 2022 National Carer Survey. While the majority of the respondents are identified as Australian, and spoke only English, 18.0% of respondents were identified as being of a culturally or linguistically diverse (CALD) background[2]. After Australian, the four most commonly identified cultural backgrounds were: English/British (7.5%), Italian (2.8%), New Zealand (1.2%), and Greek (1.2%).

The respondents to the 2022 National Carer Survey spoke 86 different languages. The five most common languages other than English (LOTE) spoken at home were Italian (1.4%), Greek (0.9%), German (0.7%), and Auslan (0.6%).

With regard to sexuality, 86.3% of carers identified as heterosexual, 5.1% identified as bisexual, lesbian, gay, homosexual, or queer, with 8.2% preferring not to answer.

Table 2: Sample diversity

		N	Valid %
Aboriginality	Aboriginal	160	2.4
	Torres Strait Islander	5	0.1
	Aboriginal and Torres Strait Islander	11	0.2
	Prefer not to say	133	2.0
Culture and language	Australian/Australian and other	4,444	70.7
	Speaking a language other than English at home	721	11.1
	Identifies as culturally and/or linguistically diverse	1,227	18.0
Sexuality	Heterosexual/straight	5,351	86.3
	Lesbian, gay, or homosexual	129	2.1
	Bisexual	134	2.2
	Queer	48	0.8
	Prefer not to say	506	8.2
Geographical area	Major Cities	3,798	58.7
	Inner Regional	1,794	27.7
	Outer Regional	789	12.2
	Remote or Very Remote	90	1.4
State or territory	Australian Capital Territory	113	1.7
	New South Wales	1,352	19.8
	Northern Territory	75	1.1
	Queensland	623	9.1
	South Australia	2,248	32.9
	Tasmania	691	10.1
	Victoria	1,356	19.9
	Western Australia	368	5.4

The geographic distribution of respondents correlates well with the overall distribution of the Australian population (see Table 2). Following the remoteness classification of the Australian Bureau of Statistics (ABS 2016), 58.7% of survey participants providing a postcode lived in Major cities, 27.7% in Inner Regional areas, 12.2% in Outer Regional areas, and 1.4% lived in Remote or Very Remote areas. Slightly less representative is the distribution of respondents by state or territory. Most responses were received from South Australia, followed by carers from Victoria and New South Wales. While the number of responses is sufficient for all jurisdictions to present relevant results, data for the Northern Territory and the ACT are based on small samples and should be interpreted with caution. For an overview on the differences please see the chapter Variation across states and territories.

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[2] Reported cultural background other than Australian, American, English/British, Canadian, New Zealand or another English speaking country, or reported speaking a language other than English at home.

METHODOLOGY

PROJECT OVERSIGHT

The 2022 National Carer Survey was led by the Carers NSW Research team, with input from an Academic Working Group, made up of researchers, stakeholders and Carer Representatives, and a State and Territory Working Group, comprising representatives from the State and Territory Carer Organisations. The Academic Working Group focused on the scientific rigour of the questionnaire design and panel data analysis, as well as pursuing joint academic publishing opportunities in relation to the national data. The State and Territory Working Group focused on planning and logistics to ensure effective, nationally-inclusive design, distribution, analysis and reporting. It guided the implementation and participant recruitment in the states and territories and has continued to work closely with the Carers NSW Research team to analyse, report on and disseminate Survey findings.

Members of both working groups were named as investigators on the University Ethics application and have access to datasets and overview tables as well as tailored data analysis and interpretation support.

RESEARCH ETHICS APPROVAL

The research protocol for the 2022 National Carer Survey was approved by the Macquarie University Faculty of Arts Human Research Ethics Committee as follow-up to the 2020 National Carer Survey (Reference No: 52020623314360, approval 27 February 2020, amendment approved 26 April 2022). The Participant Information and Consent Form (PICF, see Appendix II.I) contained all relevant information for participants, including intent and purpose of the research, the involved researchers and organisations, data usage, and information in case of participants experiencing distress. The PICF was included with the paper questionnaires and had to be acknowledged before filling out the online survey. A completed and submitted questionnaire was taken as acknowledgement of the information provided in the PICF.

SURVEY INSTRUMENT

The Survey questionnaire was developed by the Carers NSW Research team in close collaboration with the Academic Working Group and the State and Territory Working Group. The questionnaire was piloted with five carers and five Carers NSW staff who provided feedback to improve clarity, accessibility and data quality.

The questionnaire consisted of a total of 77 questions across six sections, however, not all questions were compulsory, and many could be skipped depending on prior responses. The questionnaire built on the 2020 Survey to allow for consistency and comparison over time. New questions included a substantially revised section on paid work, an added question on carers' own use of health and community services, and specific questions on the impacts of COVID-19 and recent natural disasters. Records indicate that the Survey took on average 20 minutes to complete.

RECRUITMENT AND DATA COLLECTION

The 2022 National Carer Survey questionnaire was distributed in both online (via Survey Monkey) and paper formats to maximise participation. The majority of respondents (76.6%) participated online, with 23.3% completing a paper copy. Participants were recruited through the websites and social media accounts of Carers NSW and the State and Territory Carer Organisations and through their printed and email newsletters, as well as member and client databases and broader stakeholder networks. Media releases and paid social media promotion were also utilised to broaden the reach of the Survey beyond carers already in contact with the State and Territory Carer Organisations.

Promotion centred on the online version of the Survey. Printed questionnaires were included in mail-outs by Carers NSW, Carers Queensland, Carers SA, and to the 3,029 participants in the 2020 Survey who had registered their interest to link their responses to the 2022 Survey. Paper copies were also made available on request to individual carers, groups of carers and organisations supporting carers. More than 10,000 paper copies were distributed nationwide.

Table 3 details the percentage of paper copy responses by state and territory. It shows that with 23.3% of total responses, the paper copy response remains a sizeable proportion of the overall dataset. Notably, paper copies were an important medium in states with older respondents, and where more respondents are living remotely, especially the Northern Territory and Tasmania. In total 31.9% of the respondents living in regional or remote areas responded using paper copies, compared to 18.1% of those living in major cities.

Table 3: Hardcopy and online response

	2022		
State / Territory	Paper	Online	Total responses
Australian Capital Territory	15.0%	85.0%	113
New South Wales	39.1%	60.9%	1,352
Northern Territory	74.7%	25.3%	75
Queensland	23.6%	76.4%	623
South Australia	13.4%	86.6%	2,248
Tasmania	38.2%	61.8%	691
Victoria	17.7%	82.3%	1,355
Western Australia	9.5%	90.5%	368
Total	**23.3%**	**76.7%**	**6,825**

Respondents were provided with the option of entering a prize draw to win 1 of 8 iPads (one drawn for each state and territory) when completing the Survey.

DATA CLEANING AND ANALYSIS

The final dataset was exported from Survey Monkey and cleaned, coded, and analysed using the software package SPSS 22. Removing identifiable duplicates, out of scope responses and empty or insufficiently completed surveys reduced the final sample to 6,825 valid responses.

A number of factsheets and briefings reporting results from the 2022 National Carer Survey are already available to download from the Carers NSW website. The Carers NSW Policy and Research teams, the State and Territory Carer Organisations and researchers participating in the Academic Working Group will continue to analyse and report on the findings of the Survey and share these publications via the Carers NSW website (www.carersnsw.org.au/research/survey) and Carer Knowledge Exchange Research Library (www.carerknowledgeexchange.com.au).

LIMITATIONS

Because participation in the Survey was open to all carers, and the recruitment strategy was one of convenience rather than random sampling, the Survey sample cannot be considered representative of the broader Australian carer population of 2.65 million. Given the complexities involved, the Research team decided not to correct for representativity by weighting the data. Therefore, the generalisability of the findings is limited, especially for the jurisdictions with small sample sizes (the Northern Territory and the ACT).

However, a wide range of caring experiences were evident across the sample, including relatively strong representation from diverse cohorts of carers, and the depth of data collected provides significant insights into the lives of carers of all kinds across Australia.

PART 2: KEY FINDINGS

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2020 TO 2022: WHAT HAS CHANGED?

The *2022 National Carer Survey* was the second time the State and Territory Carer Organisations asked carers across the country about their caring roles, their experiences with services and their work life, health and wellbeing.

The two years between the 2020 National Carer Survey (conducted between April and June 2020) and the 2022 National Carer Survey (conducted between June and July 2022) were dominated by the experience of the COVID-19 pandemic, especially in the eastern states of Australia that registered higher numbers of cases and greater government restrictions on movement and gathering. The 2022 Survey provides unique evidence of the particular impacts of this period on carers. As many hospitals and care facilities limited visitation opportunities, and border closures limited the movement of families between the states and territories and from overseas, many carers were separated from their loved ones and could not provide their usual level of care and support. For many others, their level of their caring responsibilities increased significantly because formal services were often interrupted or in some cases ceased completely. Because carers were especially anxious to protect their vulnerable loved ones, carers often limited their social contact even more than required by government mandated lockdowns. Many carers also belong to vulnerable groups themselves due to their age or because they are living with health conditions or disabilities, and for many, restricted social contact and increased precautions are still an ongoing experience. The next section of this report examines what the 2022 National Carer Survey found regarding the experience of caring through COVID-19 in more detail.

COVID-19 was not, however, the only crisis event with large-scale impact on Australian carers. Between 2020 and 2022, a number of significant natural disasters occurred in parts of Australia, with particular impacts for carers. In 2022, 524 respondents (8.1%) reported that they were impacted by natural disasters, either by having to evacuate (1.7%) or experiencing property damage (7.2%).

In the wake of these events, financial pressure on Australian households also grew due to loss of income, inflation and increased costs of living. Carers are particularly vulnerable to economic pressures, because of their limited ability to participate in paid work, their comparatively high reliance on social support payments and the additional living costs associated with care.

A comparison of 2020 and 2022 Survey data shows that, while the economic pressure on respondents increased during that period, with 57.4% reporting at least one experience of financial stress in 2022 compared to just over half (50.7%) in 2020, the wellbeing, psychological distress, and social connectedness of carers remained remarkably stable. Although there was no marked increase (see Table 4), the persistence of high levels of stress, low wellbeing, and high social isolation is very concerning.

Table 4: Distress, wellbeing, and social connectedness in the 2020 and 2022 National Carer Surveys

	2022 National Carer Survey	2020 National Carer Survey
Carers reporting high/very high psychological distress (Kessler 5)	47.5%	47.7%
Average wellbeing score (PWI, % of scale maximum)	57.4%	56.5%
Carers reporting being socially isolated or highly socially isolated	56.3%	56.2%
Carers reporting at least one experience of financial stress	57.4%	50.7%

Headline numbers, means and percentages however hide the individual stories in the data, which are highly diverse. Caring journeys are shaped by many personal events with significant impact on carers lives, positive and negative. Table 5 shows a selection of such events that respondents told us had occurred in their lives. While COVID-19-related events were most common, others were less frequent, however all may have had significant impacts on individual carers lives.

Table 5: Selected life events of survey respondents, 2020-2022

Event	N	%
You were separated from family/loved ones for a long time due to COVID-19 restrictions	2911	44.8
You or the person you care for caught COVID-19	2382	36.7
You worked from home due to COVID-19 restrictions	1480	22.8
You experienced the loss of a partner or close family member	1238	19.0
You lost work or significant amounts of income	1189	18.3
You became seriously ill (not including COVID-19) or injured	981	15.1
You had property damaged due to a natural disaster (e.g. fires, floods)	471	7.2
You got divorced or experienced the breakdown of a long-term relationship	317	4.9
You had to evacuate your home due to a natural disaster (e.g. fires, floods)	108	1.7
You got married, or started a common household with a partner	104	1.6
You became a parent	85	1.3
None of the above	1324	20.4

Between 2020 and 2022 the service landscape for carers also changed significantly, as carer support services were reorganised with the introduction of Carer Gateway, which launched in April 2020. In the 2020 Survey, which was conducted one month later in May and June, only 13.2% of respondents had used Carer Gateway, and another 42.7% had heard of it, but not used any services, and 44.1% of respondents had not heard of it at all. In 2022, 62.0% of carers who responded to the National Carer Survey had used services through Carer Gateway, with 35.2% of respondents using the Carer Gateway website and 28.0% using the Carer Gateway phone line. Overall, 2 in 3 carers participating in the 2022 Survey had used carer services, up from half of all participants in 2020. While more than half of all respondents still reported an unmet need for services in 2022, this also decreased from two thirds who reported unmet needs in 2020 (see Table 6).

Table 6: Use and unmet need for carer services, 2020-2022

	2022	2020
Used carer support services	62.0%	50.3%
Unmet need for carer support services	53.4%	66.0%

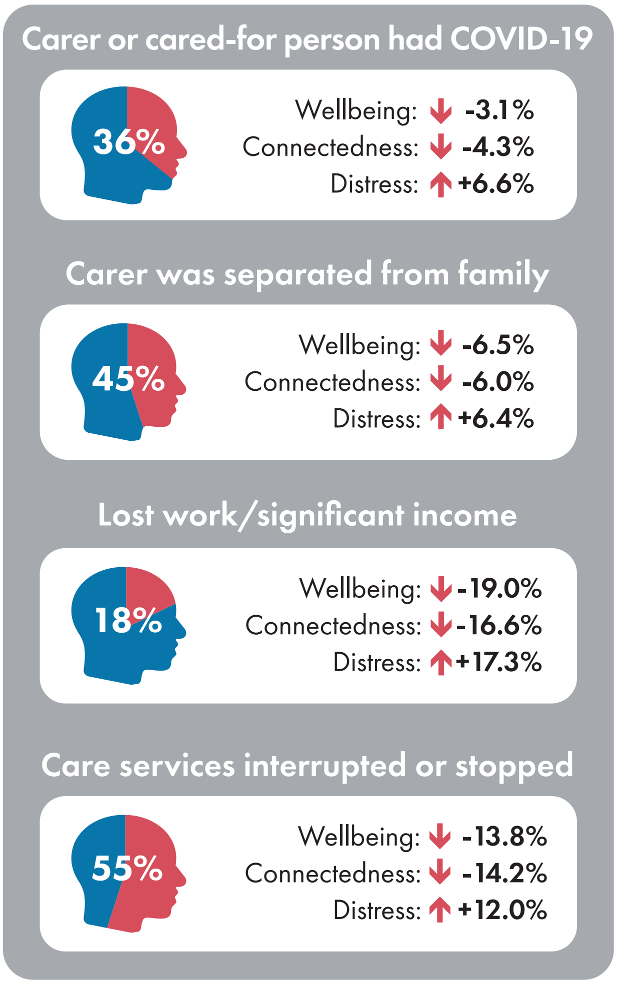
Since the National Carer Survey is not based on a random sample, and is not statistically representative, these figures are to be interpreted with caution. However, the large sample sizes of the 2020 and 2022 Surveys deliver a powerful snapshot of the situation for carers which is examined in more detail in the coming chapters.

CARING DURING COVID-19

When the 2020 National Carer Survey was conducted from May to June 2020, the majority of Australia had just experienced the first wave of COVID-19 lockdowns. At the time of the 2022 National Carer Survey, the pandemic was still ongoing, however government mandated restrictions had been significantly pared back. The impact of COVID-19 on carers remained a central topic for the 2022 Survey. The pandemic impacted carers both directly, through experiences of contracting COVID-19, as well as indirectly, through the impacts of restrictions on movement and gatherings. The effects of both aspects of the pandemic significantly impacted carers' lives in terms of their wellbeing, psychological distress, and how connected they felt to other people.

In 2022, 1 in 3 respondents to the National Carer Survey reported that either the person they care for or they themselves had contracted COVID-19 over the past two years. Movement restrictions, border closures, and access restrictions to facilities such as hospitals or residential aged care also meant that 44.8% of respondents were separated from their loved ones for a long time. More than half of all respondents also reported that services for the people they care for were reduced or stopped completely. This experience was most frequent for carers of someone using disability services (65.7% affected), but was also common for carers of someone using mental health services (42.0% affected) and aged care services (40.4% affected).

Figure 4: Impacts of COVID-19 on carers



These experiences significantly reduced the wellbeing of carers and increased their stress and social isolation (see Figure 4).[3] Carers were also particularly vulnerable to the economic impacts of COVID-19; almost 1 in 5 respondents (18.3%) reported that they had lost significant amounts of work or other income between 2020 and 2022. Of all consequences of the pandemic, the increased economic vulnerability had the largest impact on social outcomes, with wellbeing falling by 19% on average for affected carers, distress increasing by 17.3% on average, and social connectedness falling by 16.6% on average.

From 2020 to 2022 a wave of surveys by the Australian Bureau of Statistics (ABS 2022) utilised the same indicator as the Carers NSW biennial Carer Surveys to investigate psychological distress, the Kessler 5-Item Scale (Kessler et al., 2002). These surveys showed that the perceived stress of Australians - measured by answering at least "some of the time" to questions about feeling nervous, hopeless, exhausted or sad - increased significantly at the beginning of the COVID-19 pandemic.

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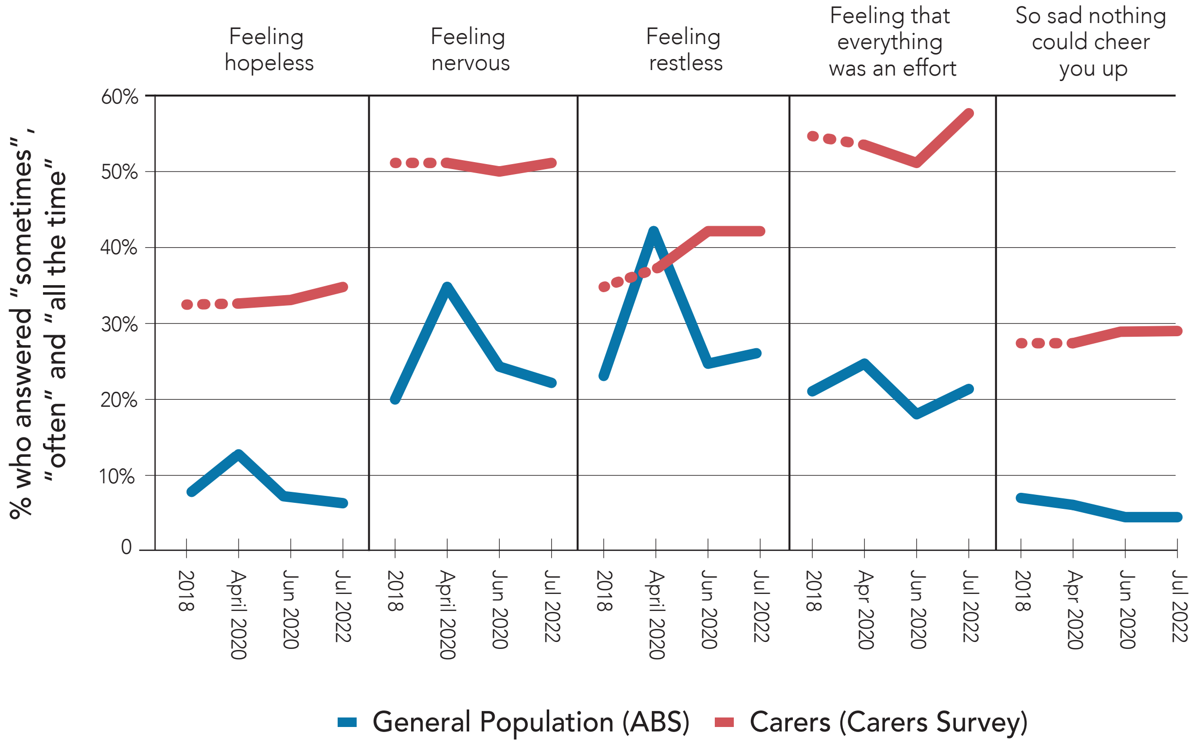
[3] All impacts statistically significant (p<.05), see appendix for detailed analysis

Figure 5: Psychological stress indicators during the COVID-19 pandemic



Note: 2018 data for NSW only, April 2020 data for General Population (ABS) only

A comparison of the ABS data with data from the 2020 and 2022 National Carer Surveys shows however that carers were 2-3 times more likely to answer negatively to the items of this scale. A further comparison with data from the *Carers NSW 2018 Carer Survey* (conducted in NSW only) and the *2018 ABS National Health Survey* shows that the distress experienced by carers was already very high before the pandemic.

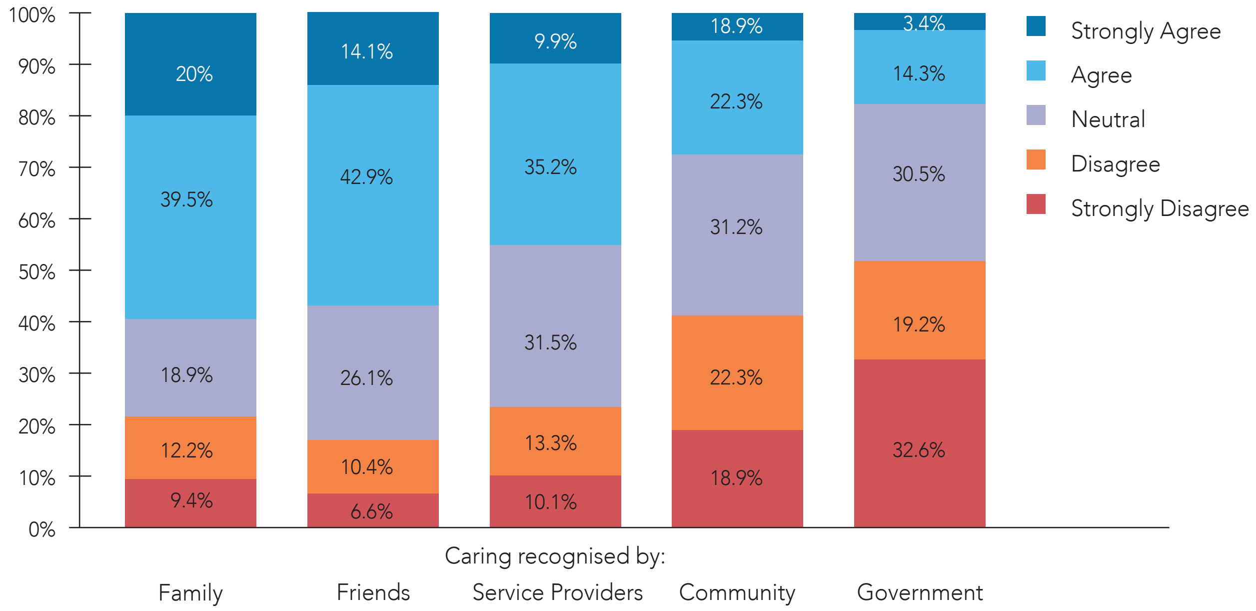
It is likely that the impacts of the pandemic on health, mental health and finances will be acutely felt into the future. However, even before COVID-19, the general wellbeing of carers was so low that the heightened psychological distress of the COVID-19 pandemic had only limited negative impact on reported wellbeing. The additional pressure on carers of uncertain information, financial instability and changing service landscapes, coupled with the loss of social and recreational supports, placed carers in a very vulnerable position. It is the responsibility of a caring society to establish safeguards in the form of increased, flexible, and responsive social and financial supports, to allow carers not only to recover from the immediate stresses of the COVID-19 pandemic, but to create more sustainable circumstances for carers.

CARER RECOGNITION

Improving the recognition of carers is a key way in which governments across Australia have sought to improve outcomes for carers. Recognition is understood to mean that carers need to be recognised and valued for their contribution to the care of their loved ones, that their own needs as a carer should be considered separately from the needs of the person they care for, and that they should be treated as partners in the provision of care together with formal service providers. This understanding of recognition is enshrined in the *Commonwealth Carer Recognition Act 2010* and similar state and territory legislation. Carer recognition is rarely measured. The 2020 and 2022 National Carer Surveys were the first instruments to measure the perceived recognition of carers nationally.

In the Survey, carers were asked how much they feel recognised and valued by the community, by family, friends, service providers and governments. Statistical analysis shows that these five dimensions can be understood as forming aspects of one overarching concept (see Appendix I.I). While carer recognition legislation at both, state and territory and Commonwealth levels, has aimed to improve awareness and recognition of carers within their communities and by governments, carers continue to report family members and friends as their main source of recognition, and relatively low levels of recognition by communities, service providers and governments. As Figure 6 indicates, perceived recognition from government is especially low, with 1 in 2 respondents disagreeing that their caring role is recognised and valued by the government.

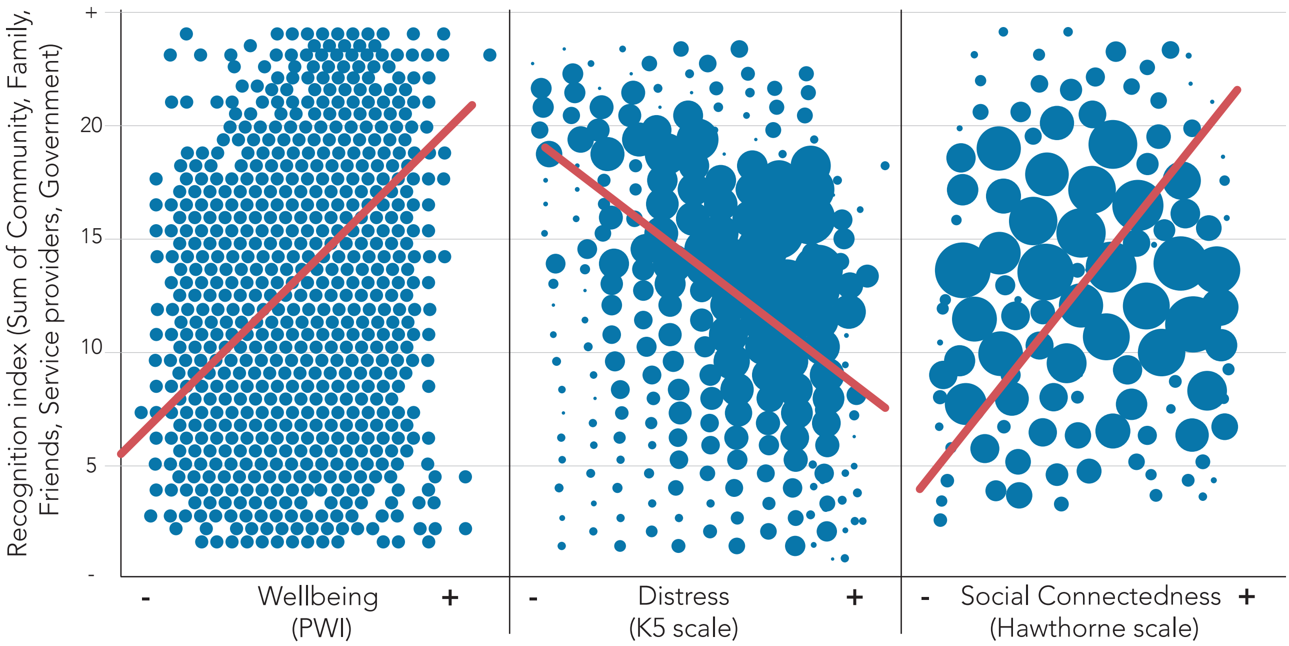
Figure 6: Carer recognition by source



RECOGNITION IMPACTS CARER WELLBEING

Recognition matters, because, as the 2022 National Carer Survey shows, there is a significant relationship between feeling recognised in one's caring role and carers' reported wellbeing, psychological distress and social connectedness. Figure 7 demonstrates that respondents who perceived that their caring role was recognised by others experienced higher wellbeing, lower psychological distress and greater social connectedness than those who felt less recognised (see Appendix I.I for details).

Figure 7: Relationships between recognition and wellbeing, psychological distress, and social connectedness



DETERMINANTS OF RECOGNITION

To explore what influences whether a carer feels recognised, an exploratory regression model (R2=.253, p<.001, for details see Appendix I.I) was used to analyse the relationship between socio-demographic variables and characteristics of the caring role and the recognition perceived by carers. This analysis shows that recognition was significantly impacted by:

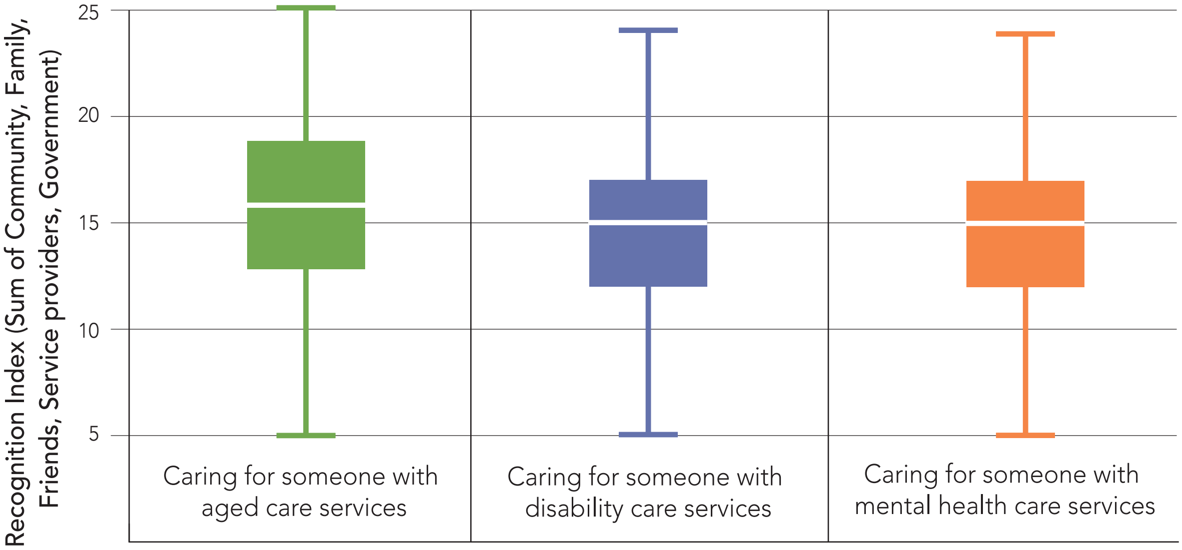
- Caring situation and the type of care provided: Caring for someone using aged care services was associated with feeling more recognised, and caring for someone using disability services was associated with decreased feelings of recognition.
- The carer's gender, with male carers feeling more recognised than female or non-binary/gender diverse carers.
- Whether the carer identified as culturally or linguistically diverse (CALD), with CALD carers feeling more recognised relative to other carers.
- Overall satisfaction with personal relationships was found to positively impact perceived recognition of the caring role.
- Whether the carer was in paid work, with working carers feeling less recognised for their caring role than carers not engaged in paid work.
- Financial stress: the more financial stress carers experience, the less they feel recognised.
- Access to income support: the receipt of carer payment also had a positive effect on the perceived recognition.
- Care intensity (measured as hours of care per week) was not found to be significant for carer recognition.

While this analysis is by no means exhaustive, it shows that it is not only the relationship with the person they care for that impacts carers' sense of recognition. Rather, the different role expectations towards carers, their embeddedness in communities, their financial situation, and their relationships with service providers all impact how recognised carers feel in their caring role. Service providers, workplaces, and the financial support provided by Australian governments have an important role to play, and all of them have room for improvement in making carers feel recognised and valued.

SERVICES NEED TO RECOGNISE CARERS AS PARTNERS IN CARE

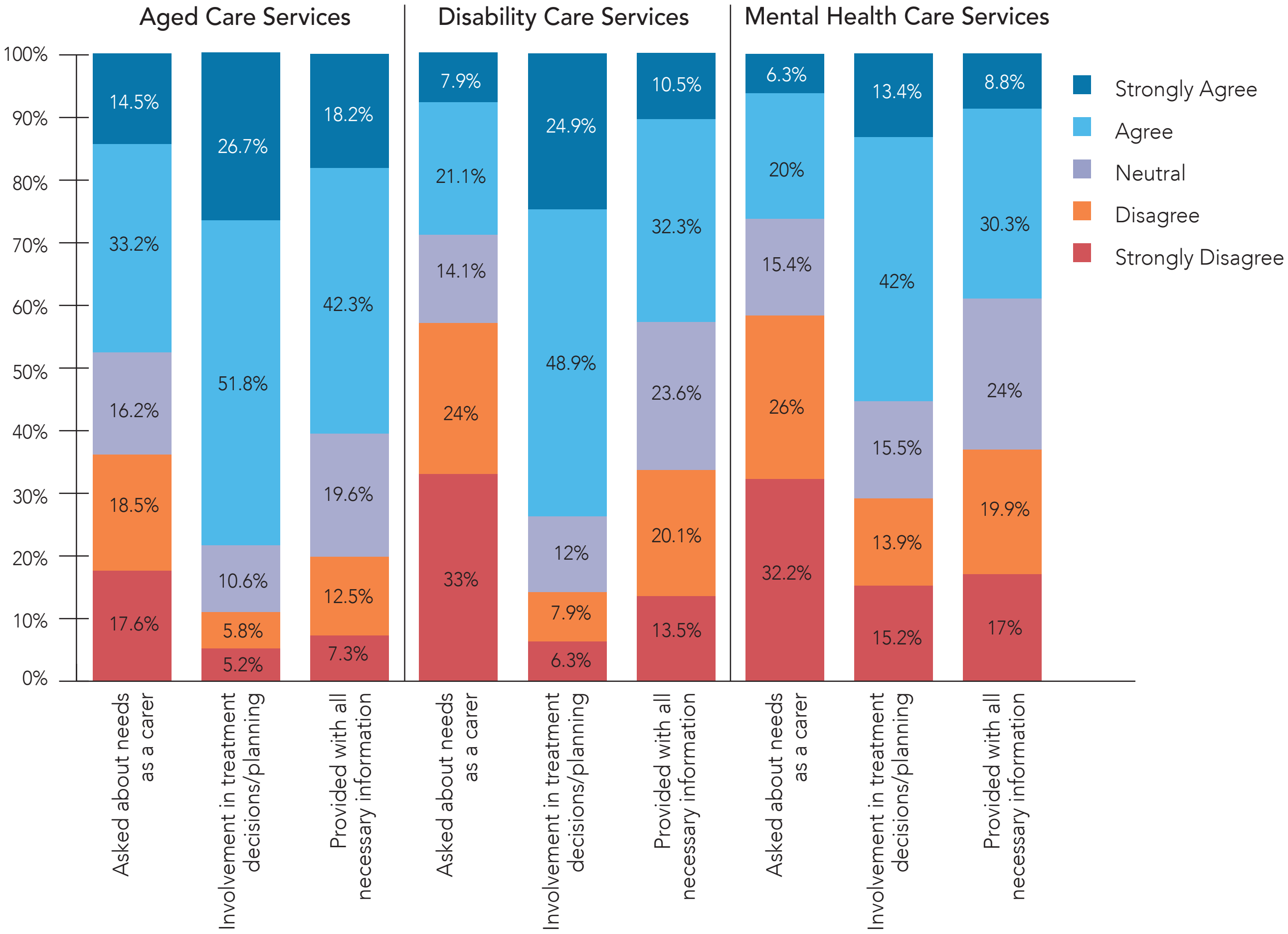
Respondents' perceived recognition also varied depending on the service systems they accessed with or on behalf of the person they care for. Overall, carers of people using aged care services reported feeling more recognised than carers of people using disability and mental health services.

Figure 8: Overall recognition by service system



Across all service systems, inclusion of carers in service planning and delivery was found to be highly related to whether a carer feels recognised and valued by service providers. The Survey asked respondents whether they were asked about their needs as a carer, involved in decision making and planning, and whether they were provided with all the information they needed. Figure 9 shows the results for carers who accessed aged care services, disability and mental health care services with or on behalf of the person they care for.

Figure 9: Carer inclusion by service type



These results show that the recognition and inclusion of carers as partners in care varies strongly between service systems. While almost 1 in 2 carers are asked about their needs in aged care service settings, only slightly more than a quarter reported the same way about mental health and disability services. It is also noticeable that involvement in treatment decisions and planning is high across all services, despite many carers not feeling sufficiently informed.

Carer recognition has many different aspects and comes in different forms. The Survey results show that through better recognising the contributions and the needs of carers, governments, service providers and the community can significantly support carers' wellbeing.

CARE AND PAID WORK

Carers who balance care with paid work can face significant challenges. Without suitable flexible working arrangements, carers often reduce their engagement with the paid workforce, limiting their income and their opportunities for career advancement. This can significantly affect carers' long-term financial security as well as their health and wellbeing. Supporting carers in the paid workforce to maintain employment benefits carers, the people they care for, employers and the economy.

3 in 4 carers enjoy social connections of paid work outside caring role.

82% of carers feel a sense of purpose from paid work.

In the Survey, 33.4% of respondents were balancing care with paid work and 7.5% were unemployed.
The majority (59.0%) were not in the labour force, mostly due to retirement.

Table 7: Respondents by employment status and gender

Employment status	Female (n=5428)	Male (n=1143)	Non-binary/other (n=31)	Total (N=6602)
Employed/in paid work	35.9%	22.0%	29.0%	33.4%
Unemployed	7.8%	5.9%	22.6%	7.5%
Not in labour force	56.3%	72.1%	48.4%	59.0%
Total	100%	100%	100%	100%

BENEFITS OF PAID WORK

Paid work is important for carers not only to achieve financial security, but also for social connection and as a meaningful activity. Of the 2,264 carers in paid work who responded to the 2022 National Carer Survey, 3 in 4 (74.7%) reported that paid work provides important social connections outside of their caring role, and 82% reported that it gives them a sense of purpose.

FACTORS INFLUENCING WORKFORCE PARTICIPATION

Despite the importance of paid work for carers, not all can participate to the extent they want to. A range of factors can influence a carer's ability to participate in paid work:

Care intensity

Respondents to the 2022 National Carer Survey cared for an average of 103.8 hours per week, with almost half (48.5%) providing 24/7 care. As a result, carers are more likely to be in part time work (ABS 2019), and some carers are not able to engage in paid work at all.

Access to care services

Many carers do not have others to help them care – 56.2% of respondents were the sole carer for a person they cared for – and therefore rely on aged care or disability services to support the person they care for while they are at work. However, accessing suitable, timely and reliable services can be difficult. Fewer than 1 in 3 (30.9%) respondents to the Survey reported that aged care services enabled them to stay in or return to work, and only 1 in 4 (24.6%) said the same about disability services.

Workplace flexibility

In addition to seeking part time work, many carers choose more flexible jobs and industries and take advantage of flexible working arrangements. Many respondents varied their work start and finish times (51%) or worked from home (33%) to accommodate their caring role. A majority of respondents (57.7%) reported having access to sufficient flexible working arrangements. However, nearly 1 in 2 (48.5%) were not satisfied with their work-life balance and nearly 1 in 2 (49.7%) did not have access to enough paid leave to meet their caring requirements.

1 in 2 carers are not satisfied with work/life balance and do not have enough paid leave for their caring needs.

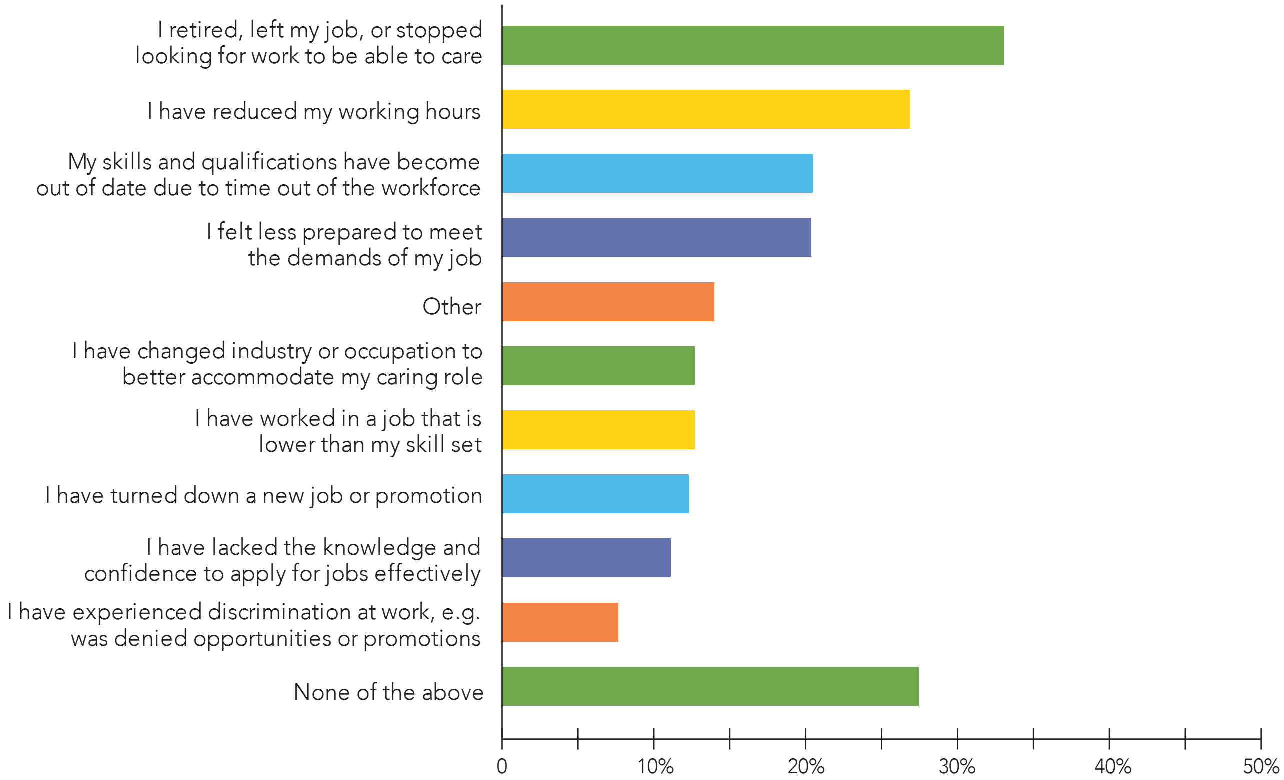
57% of carers have flexible working arrangements.

CARE IMPACTS ON CAREER PROGRESSION

Where there is inadequate support in place, carers tend to either reduce their engagement with the paid workforce or limit their career development, thereby reducing their income potential and their superannuation reserves. These impacts can particularly disadvantage women, who are most likely to be primary carers and may experience additional career breaks due to parental leave.

Of the 6,825 respondents to the 2022 National Carer Survey, 1 in 3 (33.6%) had retired or at some point left their paid job or stopped looking for work to care, and more than 1 in 4 (27.3%) had reduced their working hours at some stage. Many had made other trade-offs to focus on caring, such as changing industry or occupation (12.9%), taking a job below their skillset (12.9%) or turning down a new job or promotion (12.5%).

Figure 10: Career impacts of providing care



A SUPPORTIVE WORKPLACE

For carers who are in paid work, recognition, understanding and support from their manager can positively impact job satisfaction and retention. Most carers in paid work (64.8%) who responded to the 2022 National Carer Survey were comfortable discussing their caring role with their manager and most (60.3%) found their manager to be supportive. Carers who disclosed their caring role were more likely to feel supported and report access to sufficient flexible working arrangements.

A supportive work environment and an employer with a track record of supporting employees with caring responsibilities are also important to carers seeking paid work. More than half (54.9%) of those currently in paid work reported choosing their employer because they offered flexible working arrangements, and the majority (57.0%) were open about their caring role during the recruitment process.

Paid work offers carers social connection and a sense of purpose outside of their caring role. Carers in paid work have better health and wellbeing than their peers outside of the paid workforce. Time spent caring, inadequate replacement care services and a lack of workplace flexibility can make it difficult to balance paid work and care. Carers often make career trade-offs to stay in paid work, or leave the workforce altogether. Flexible working conditions, adequate leave and supportive managers can help carers to sustainably balance paid work and care.

CARING AND THE COST OF LIVING

The rising cost of living is a concern for many Australians, especially those living on lower incomes. Research suggests that carers have been disproportionately affected because of their reduced incomes and increased living costs (ABS 2022, NCOSS 2022). This chapter draws on findings from the 2022 National Carer Survey to explore carers' experiences of financial stress across Australia between 2020 to 2022.

CARING AND INCOME

Because caring can place high demands on their time and attention, carers frequently reduce their working hours or withdraw from of the workforce altogether. To accommodate their caring responsibilities, more than 1 in 3 respondents (37.3%) to the 2022 National Carer Survey who were balancing care with paid work had reduced their working hours, and just over 1 in 3 (34.6%) had left their job or stopped looking for paid work.

37% of carers in paid work have reduced their working hours.

1 in 3 carers have left their job or stopped looking for paid work.

Reduced engagement with paid work means that carers earn less on average than non-carers, and are more likely to depend on income support payments (ABS 2019). Lower incomes mean that carers can struggle to meet their basic needs, to save for emergencies and to accumulate superannuation to support their retirement (Carers NSW 2022, Furnival & Cullen 2022).

In addition to diminished income, many carers also have increased living costs. In this Survey, 29.6% of respondents reported that they incurred extra expenses related to their caring role. Research indicates that price increases across essential goods and services (ABS 2022) have disproportionately affected carers, with a recent report by the NSW Council of Social Service finding that carers were, for example, more likely than other disadvantaged groups to go without prescribed medication and be unable to afford essential travel (NCOSS 2022).

CARING AND FINANCIAL STRESS

The combination of reduced income and increased living costs results in high financial stress among carers, and in turn, reduced wellbeing. Financial stress means difficulty meeting basic financial needs and commitments, such as housing and food. Most respondents (57.1%) to the 2022 National Carer Survey reported at least one form of financial stress. Approximately 1 in 3 (34.4%) had been unable to raise $2,000 in a week for something important and a similar proportion (33.7%) had spent more money than they received in a month.

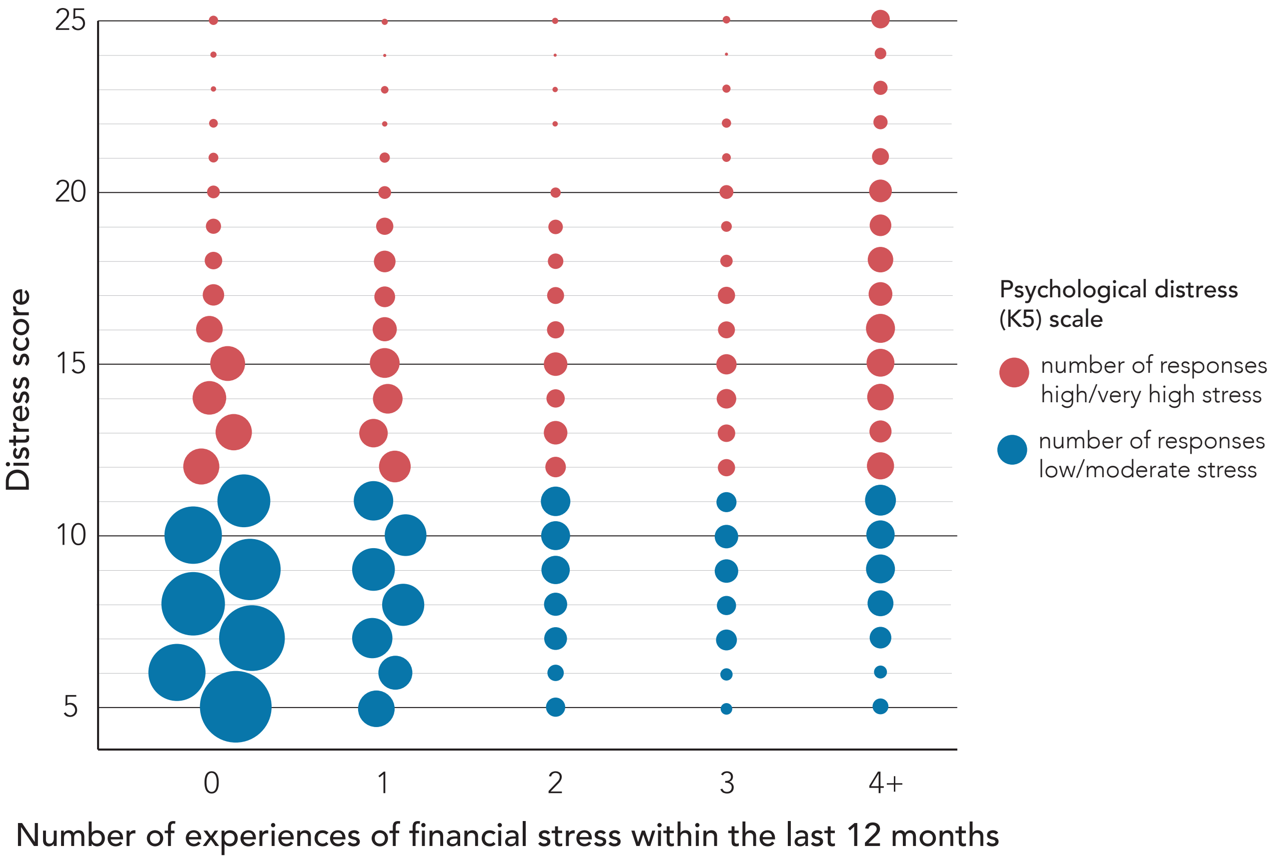
Nearly 1 in 5 respondents (16.9%) reported being in financial distress, defined as four or more experiences of financial stress in the last 12 months. Financial distress was higher overall for carers receiving income support payments. For example, 29.4% of respondents receiving the Carer Payment reported financial distress compared to 8.4% of those who did not receive income support.

The financial stress experienced by carers is significantly associated with reduced overall wellbeing, reduced social connectedness, and increased psychological distress. Respondents to the 2022 National Carer Survey who reported financial distress scored 30 points lower on the Personal Wellbeing Index (38.1%) than carers who did not experience any financial stress (68.1%). For comparison, the average wellbeing of the Australian population is 75%.

Financial stress also affects carers' social connectedness. There are often costs associated with participating in social engagement, for example costs associated with transport or food and beverages. Therefore, the more carers experience financial stress, the less able they are to participate in social activities and the less socially connected they are. The majority (62.2%) of Survey respondents who reported financial distress were also highly socially isolated.

General wellbeing and social connections are important protective factors against psychological distress. Carers reporting financial distress were therefore significantly more likely to experience high or very high psychological distress, which is associated with poor mental health outcomes such as anxiety and depression.

Figure 11: Experiences of financial stress and psychological distress



Due to their already precarious financial situation, increased costs of living are exacerbating the financial pressure on carers, resulting in poorer health and wellbeing. For carers, the rising costs of living for carers are not just a short term problem, but are likely to contribute to accumulated disadvantage in the longer term.

Financially stable and mentally well carers enable safe and sustainable care in the community, reducing costs to the health and welfare systems. It is therefore critical that governments act to address the increasing costs of living overall, and in particular find ways to mitigate the immediate and longer term impacts on carers.

CARER HEALTH AND WELLBEING

The 2022 National Carer Survey and other research (e.g. Cummins et al 2007, Mohanty & Niyonsenga 2022) show that providing care to a family member or friend can have a significant impact on the overall wellbeing of the carer. Generally, the literature tends to discuss carer health and wellbeing in a negative way, focusing on factors reducing the wellbeing of carers. This chapter aims to change this slightly, and instead focus on protective factors and the resilience many carers demonstrate in sustaining their caring roles.

When investigating specific groups and how their experiences differ from the overall population, a common approach is to compare the mean score of groups on a scale. One of the most common indicators used is the Personal Wellbeing Index (PWI). It measures wellbeing as a combination of satisfaction with seven dimensions: standard of living; health; achieving in life; personal relationships; feeling safe; community connectedness; future security. On this scale, Australians on average had a score of 74.4% in 2022 (Crowe et al 2023). In the 2022 National Carer Survey, the average for carers was significantly lower with 57%.

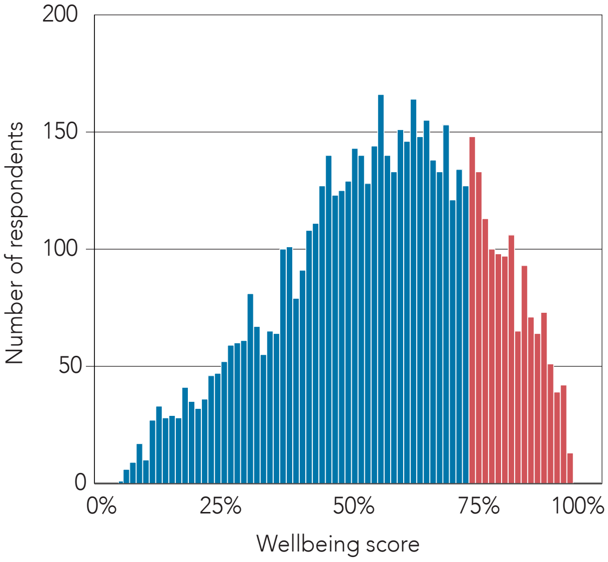
The average, however, is not the full story. Although caring is inherently stressful, outcomes are widely distributed. Some carers actually report that they are quite satisfied with their lives. Figure 12 shows that the top 25% of Survey respondents (shaded in red) report higher wellbeing scores than the Australian population average. So what is different for carers who are doing relatively well? Can lessons be drawn from their experiences to improve the lives for all carers?

Personal Wellbeing Index measure

74%
Average PWI of general population

57%
Average PWI of carers

Figure 12: Histogram of PWI scores



WHAT SETS CARERS WITH HIGHER WELLBEING APART?

In our analysis most demographic factors, such as the gender of the carer, their cultural background, or whether or they are in paid work, did not make a significant difference to reported wellbeing. Age, however, is connected with wellbeing. Carers with higher wellbeing are older than the Survey average (64 years, compared to 57 years among other carers). Other significant factors are:

A manageable caring load

Carers with higher wellbeing tend to have a more manageable caring load – on average, they provide care for 70 hours per week, compared to 107 hours for those with lower wellbeing. While 70 hours per week still equates to almost two full-time jobs, carers with higher wellbeing also felt better supported by formal services than other carers.

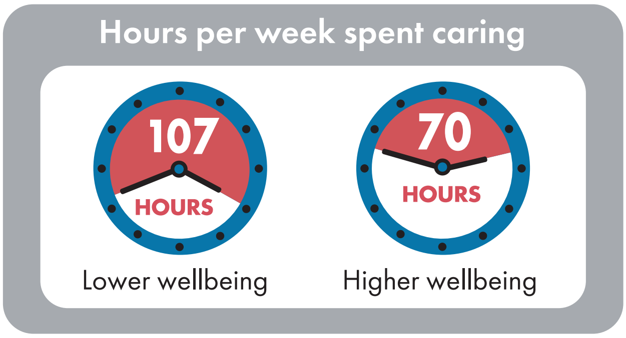
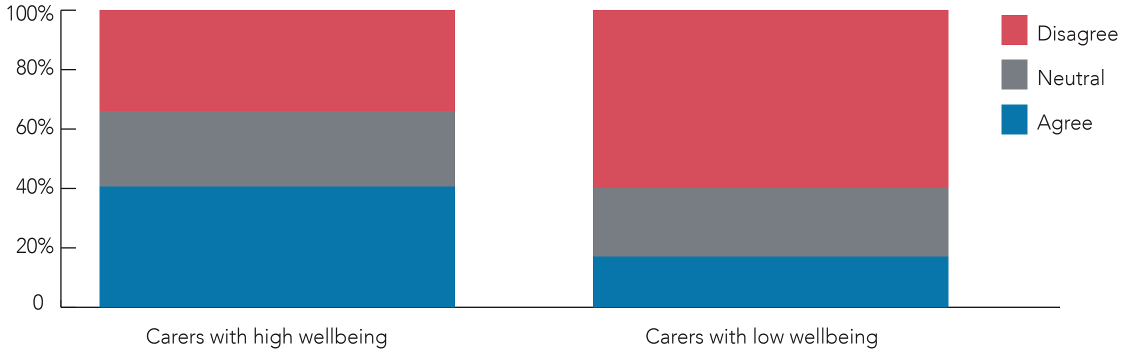


Figure 13: Services meeting needs of carers impacts wellbeing



Supportive formal services

About 2 in 5 carers with higher wellbeing scores said that the formal services accessed by the person they care for meet their own needs as a carer. Only 1 in 3 carers with higher wellbeing said that services did not meet their needs, compared to 2 in 3 carers with lower wellbeing.

Feeling recognised and valued

An important influence on carer wellbeing was whether carers felt recognised and valued in their caring role by the community, service providers, government, friends and family. The more carers feel recognised the higher their wellbeing.

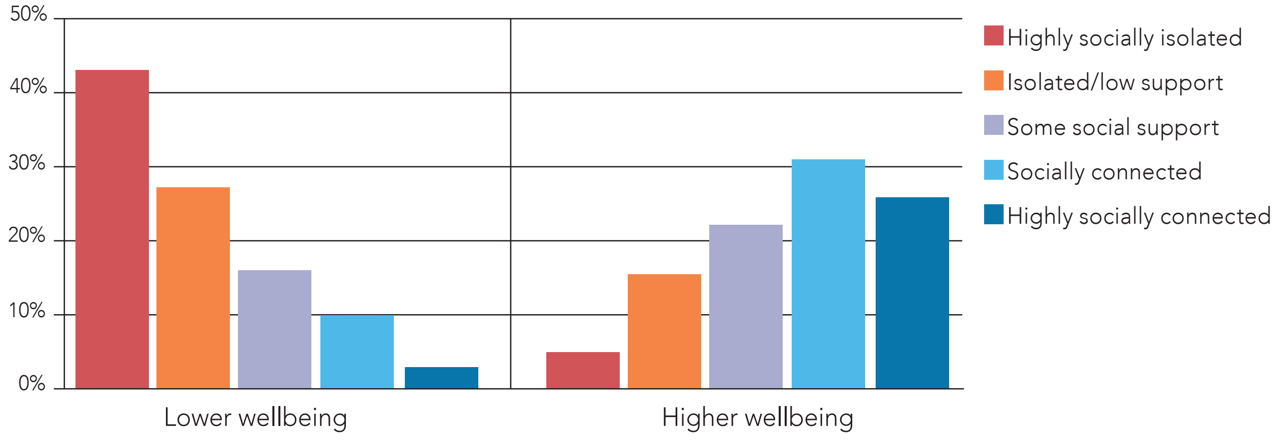
Access to carer support services

In terms of services for the carer themselves, 2 in 3 carers with higher wellbeing said that their needs for respite, counselling, or peer support, are met. Among carers with lower wellbeing, more than 60% reported an unmet need for carer support services.

Social connection

A very important factor supporting wellbeing is being socially connected. Among those with higher wellbeing, almost 3 in 5 report that they are socially connected, and 1 in 5 report to have at least some social support. This is markedly different to the carers with lower wellbeing, where 70.9% report that they are socially isolated.

Figure 14: Wellbeing and social connectedness



Financial security

As reported in the previous section on the costs of living, experiences of financial stress are very common among carers, because they have reduced opportunities for paid work due to the demands of their caring role, and are therefore often dependent on social security payments. Financial stress significantly impacts wellbeing, as the difference between carers with high and lower wellbeing illustrates: 70% of those with high wellbeing had not experienced any form of financial stress in the 12 months leading up to the survey, whereas 70% of those with lower wellbeing had experienced at least one form of financial stress during that period.

IMPLICATIONS FOR SUPPORTS AND SERVICES

This analysis shows that carers need support services that create social connection in and beyond the caring role, and formal services for the person they care for that also meet the carer's needs. This means services that are available when the carer is not, that allow the carer to take time away from the caring role, and that make the carer feel supported. Care services that recognise the contribution of the carer and work with them as a partner in care significantly improve carer wellbeing.

Another fundamental building block for positive wellbeing is financial stability, which is often eroded by reduced participation in paid work and by the constraints of financial support payments. For caring roles to be sustainable, services are needed that support them to avoid financial hardship. This includes not just support payments, but also tailored financial advice and well-functioning services for the person requiring care that enable carers to return to, or stay in work.

DIVERSE CARING EXPERIENCES

ABORIGINAL AND TORRES STRAIT ISLANDER CARERS

Key demographics: majority of Aboriginal and/or Torres Strait Islander respondents

84%
female

53 yrs
average age

56.5% live in
regional areas

6.6% speak a
language other than English

Of all respondents to the Survey, 176 (2.5%) identified as Aboriginal and Torres Strait Islander. Among them, the majority (84.1%) identified as female. With an average age of 53 years, they were significantly younger than the Survey average of 59 years. The majority (56.5%) lived in regional areas, with 41.8% living in major cities, and 1.8% in remote areas. Respondents came from traditional lands all over the continent and 6.6% reported speaking a language other than English at home.

The clans and language groups most frequently represented among identified respondents were Wiradjuri, Kaurna, Darug/Burramattagal, Bundjalung and Kamilaroi. However more than half of respondents (50.5%) did not specify, or did not know about their ancestral connection because they or their parents belonged to the Stolen Generations.

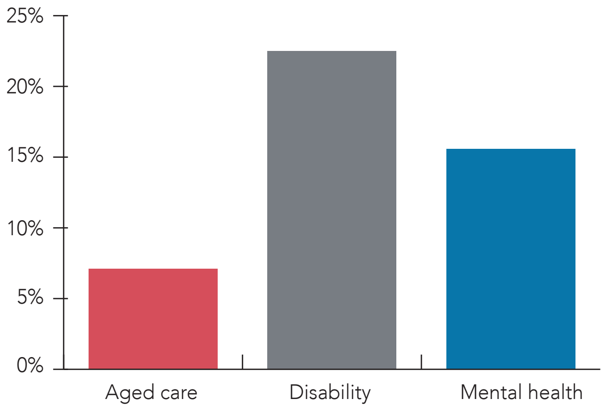
About the people they care for

With 43.1% of identified respondents caring for more than one person, and 17.4% caring for three or more people, they were much more likely than other carers to be caring for multiple people. Most (85.4%) of those receiving care were aged under 65 years. Two thirds of Aboriginal and Torres Strait Islander respondents were caring for their child (including adult children), 1 in 4 for their partner, and 1 in 5 for a parent. The majority (80.9%) were caring for someone living with a disability, with 42.6% caring for someone with a chronic health condition and 39.5% caring for someone living with a mental illness. Aboriginal and Torres Strait Islander respondents spent an average of 112 hours per week caring, with more than half (55.1%) providing 24/7 care, and the

KEY POINTS

- Aboriginal and Torres Strait Islander carers responding to the 2022 National Carer Survey were most often caring for their child (including adult children) living with disability.
- Nearly 1 in 5 did not have access to culturally appropriate services.
- Aboriginal and Torres Strait Islander respondents reported low wellbeing, and high levels of social isolation and psychological and financial stress.

Figure 15: Culturally appropriate services not available (% of indigenous carers using service type)



majority (81.5%) caring for five years or more. While 90.8% of were living with a person they care for, almost 1 in 4 were also caring for someone living separately.

Experiences accessing services

Aboriginal and Torres Strait Islander carers were most commonly caring for someone accessing mental health services (50.9%) or disability services (50.3%). Across all service types, around half of respondents were involved in planning and decision-making, however, they were significantly less likely to be asked about their needs as a carer than the survey average. The most frequently reported service issues were long wait times to access services (reported by 62.9%), interruptions due to COVID-19 (60.9%), and required services not being available locally (32.6%). Overall, 17.4% of Aboriginal and Torres Strait Islander carers reported that no culturally appropriate services were available for the person they care for. This was reported most frequently by carers for someone using disability services (22.5%) and carers of someone using mental health services (15.6%).

Challenges

Aboriginal and Torres Strait Islander carers reported significantly lower wellbeing (50.2%) than the survey average (57.5%). The majority reported being socially isolated (69.4%) and experiencing high to very high psychological distress (61.2%). Most respondents (84.3%) had experienced some form of financial stress, with 38.4% being in financial distress. In the past two years, 1 in 5 identified carers had accessed emergency support and 1 in 3 said their home is not adequate for their caring role.

CULTURALLY AND LINGUISTICALLY DIVERSE CARERS

Key demographics: majority of CALD respondents

80.9%
female

56.9 yrs
average age

%
born overseas

1,159 respondents (17%) to the Survey identified as culturally and linguistically diverse (CALD). This means they did not speak English as their first language and/or identified with a non-English speaking cultural background. Cultural and linguistic diversity can influence a person's caring experiences, access to services and other outcomes. The majority of CALD respondents identified as female (80.9%) and the mean age was 56.9 years old. Only 54.2% of CALD respondents were born overseas themselves.

About the people they care for

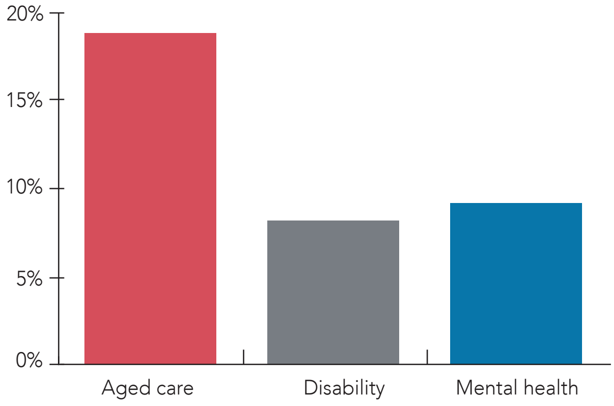
Culturally and linguistically diverse respondents were most commonly caring for their child (44.8%), followed by a parent (34.5%) or partner (28.3%). Most (67.4%) were caring for someone from a

KEY POINTS

- CALD carers responding to the 2022 National Carer Survey were more likely than other carers to be caring for someone from a CALD background.
- They were more likely to be accessing carer support services than other carers, but also more likely to need more carer support.
- CALD respondents experienced greater impacts of caring than other respondents, with poorer wellbeing and higher levels of psychological distress, social isolation and financial stress.

CALD background themselves. The majority of respondents were caring for someone living with disability (69.2%), someone frail due to age (32.5%), or someone living with a chronic health condition (31.2%). Approximately half (51.3%) of those receiving care from respondents were aged 65 years or older.

Figure 16: Culturally appropriate services not available (% of CALD carers using service type)



About the caring experience

The majority of CALD respondents (70.6%) cared for only one person. On average, they provided 98.6 hours of care per week, with 44% providing 24/7 care. Most commonly, CALD carers were the sole carer (52.4%) and the majority (82%) were living with the person they care for.

Experiences accessing services

CALD carers were more likely than other respondents to be caring for someone who was not receiving formal services of any kind, with 18.8% receiving no formal services. Some CALD respondents reported challenges accessing culturally appropriate services, with 14% having no culturally appropriate services available for the person they care for.

CALD respondents were more likely to have accessed carer support services than other respondents, but were also more likely to report an unmet need for carer support services. CALD respondents caring for people accessing disability, mental health and aged care services were less likely than other carers to be asked by service providers about their own needs.

Challenges

Approximately 3 in 5 CALD respondents (58.9%) reported financial stress, with 15.9% experiencing financial distress. The majority (58.1%) reported being socially isolated and more than half (53.5%) experienced high or very high psychological distress. CALD carers also reported lower wellbeing than other carers.

YOUNG CARERS

Key demographics: majority of young respondents

69.6% female

29% identified as LGBTQ+

20.7% born overseas

20.5% speak a language other than English

Of all Survey respondents, 92 were carers aged 25 years and under, classifying them as young carers. The majority (69.6%) of these carers identified as female, 21.7% as male and 5.4% as non-binary or gender diverse. Just under 1 in 3 young carers in Survey (29%) identified as LGBTQ+. Almost 1 in 5 (20.7%) were born overseas and a similar proportion (20.5%) spoke a language other than English at home. Nearly 1 in 10 (8.7%) identified as Aboriginal and/or Torres Strait Islander.

About the people they care for

Most young carers who responded to the Survey were caring for their parent (65.1%) or sibling (34.9%), and the majority (80.9%) were caring for someone living with a disability, however almost half (46.1%) were caring for someone living with a mental illness and 41.6% for someone living with chronic illness. More than 2 in 3 (70%) people being cared for by young carers responding to the Survey were under the age of 65 years.

KEY POINTS

- Young carers responding to the 2022 National Carer Survey were more likely than other carers to be caring for a parent.
- They were more likely to be included in discussions with service providers than asked about their needs.
- Young carer respondents reported higher levels of psychological distress, social isolation and financial stress than other carers.

About the caring experience

Most young carers (65.6%) cared for one person, however they were more likely to be caring for more than one person than carers in other age groups. They spent an average of 63 hours per week caring, with 21.8% providing 24/7 care, and the majority (69.3%) had been caring for at least 5 years. Only 1 in 10 were not living with the person they care for.

Experiences accessing services

The Survey asked carers about their experiences accessing services with or on behalf of the person they care for. Young carers who responded to the Survey were most commonly caring for someone accessing mental health services (56.7%) or disability services (52.2%). Just under 1 in 5 (18.9%) were caring for someone accessing aged care services.

Overall, more than half of the young carers who responded felt that they were involved in planning and decision making in service settings. However, they were less likely than other carers to be asked about their own needs. Despite this, young carers were slightly more likely to report that services for the person they care for met their own needs as a carer, gave them a break and enabled them to work. The most frequently reported service issues were interruptions as a result of COVID-19, long wait times for assessments or to access services, service costs, difficulty finding information about services, and that it required too much time and energy to access support.

Challenges

Approximately 4 in 5 young carers who responded to the Survey (82.1%) reported financial stress, with 1 in 4 (26.2%) experiencing financial distress. Almost 2 in 3 (63%) reported being socially isolated and more than half (55.1%) had high/very high psychological distress. While young carers reported higher wellbeing than other carers, they still reported lower wellbeing than the population average.

OLDER CARERS

Key demographics: majority of older respondents

72.6% female

73.6 yrs average age

21.1% born overseas

6.9% speak a language other than English

Of all Survey respondents, 2,625 were carers aged 65 years and older. The average age in this group was 73.6 years. This age group had the largest proportion of male carers, with 27.3% identifying as male and 72.6% as female. Almost 1 in 4 (21.1%) were born overseas, but only 6.9% spoke a language other than English at home. Only 1.7% identified as Aboriginal and/or Torres Strait Islander.

About the people they care for

2 in 3 older carers who responded to the Survey were caring for their partner (67.8%), and 76.4% of persons cared for were also over the age of 65. The most frequent reasons for providing care were due to a physical disability (44.4%), a chronic health condition (33.0%) or due to frailty (31.2%).

About the caring experience

Most carers over 65 cared for one person (86.7%). They spent an average of 113 hours per week caring, with 57.2% providing 24/7 care. 44.4% had been caring for ten years or more. Only 1 in 10 were not living with the person they care for.

KEY POINTS

- Older carers are most likely to care for another person of advanced age, most commonly their partner.
- Older carers responding to the 2022 National Carer Survey were scoring better on most outcome indicators (wellbeing, psychological distress, social connectedness, financial stress, subjective health rating) than younger carers. Nevertheless, 2 in 5 older carers are socially isolated, and 1 in 3 suffers high or very high psychological distress.
- They were more likely to feel informed by service providers and a third of older carers reported that the services for the person they care for also met their needs as a carer.

Experiences accessing services

Older carers who responded to the Survey were most commonly caring for someone accessing aged care services (58.1%), with 1 in 3 (33.3%) also accessing mental health services. More than 1 in 6 (17.4%) were caring for someone without accessing formal support services. Across all service types, carers older than 65 felt significantly better informed than other carers - 51.4% felt that the respective services provided them with all necessary information. They also felt that the services better met their needs as a carer, with 1 in 3 rating their respective services positively. This group's service experiences were also affected to a relatively lesser degree by COVID-19, with 39.1% reporting related service interruptions, compared to 69.7% of other carers reporting such instances.

Health and Wellbeing

On average, older carers report significantly higher wellbeing than other carers, with a PWI score of 63.6%, however this is still significantly lower than the population average. They also suffer from psychological distress at a significantly lower rate than other carers, with 36.0% reporting high to very high distress, compared to 54.6% among other carers. However, 44.4% of older carers feel socially isolated or have only low social support. Older carers also rate their health better than younger carers, and slightly fewer have a long term illness or disability themselves.

Table 8: Older carers' health and wellbeing

Subjective health estimate	Carers aged 65 and older	Younger carers
Poor	9.2%	17.4%
Fair	33.7%	35.2%
Good	35.9%	30.6%
Very good	18.6%	14.4%
Excellent	2.6%	2.4%
Has long term illness/disability	46.5%	48.2%

Around 8.2% of carers over the age of 65 are still active in paid employment, and 2.7% are looking for work, while 49.9% receive the Age Pension, and 14.4% the Carer Payment. After their working life, older carers have better financial stability than younger carers. Nevertheless, 38.5% report experiencing one or more experiences of financial distress in the year leading up to the survey, compared to 69.5% of younger carers.

MALE CARERS

Key demographics: majority of male respondents

66.2 yrs average age

26.1% born overseas

11.3% speak a language other than English

Carers come from all walks of life, however because of gendered social and cultural norms, caring is often still considered the domain of women. Male carers are therefore less likely to be primary carers and are often not as recognised as female carers by communities and service providers.

In the Survey 1,144 respondents (16.8%) identified as male. With an average age of 66.2 years, they were significantly older than the other carers in the sample, which is reflective of many men becoming carers later in life, typically for a spouse after retirement. In line with the Survey average, 19.9% male carers identified as culturally or linguistically diverse, with 26.1% being born overseas and 11.3% speaking a language other than English at home, and 2.1% identified as Aboriginal and/or Torres Strait Islander.

KEY POINTS

- Male carers are likely older, and most commonly care for their partner.
- They tend to be more financially secure than other carers, however 49.8% report at least one experience of financial stress in the year leading up to the survey.
- Male respondents were more satisfied with services meeting their needs as a carer.

About the people they care for

2 out of 3 male carers who responded to the Survey were caring for their partner (63.5%), and 19.2% were caring for a child (including adult children). The most frequent reasons for providing care were due to a disability (physical and/or intellectual, 64.3%), a chronic health condition (30.1%) or due to frailty (26.8%).

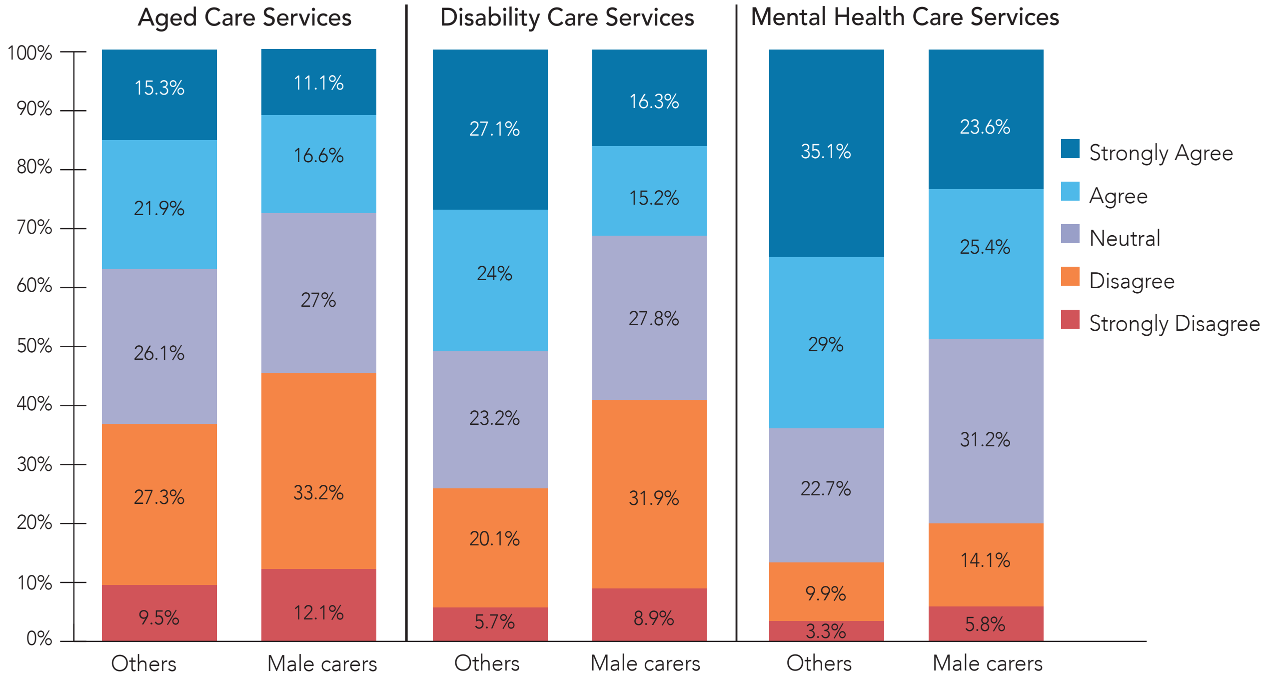
About the caring experience

Most male carers cared for one person only (86.4%). They spent an average of 100.2 hours per week caring, with 47.3% providing 24/7 care. More than 1 in 3 (38.1%) had been caring for 10 years or more. Only 13.1% were not living with the person they care for, and almost 3 in 5 (59.4%) were that person's sole carer.

Experiences accessing services

Half of all male carers who responded to the Survey were caring for someone accessing aged care services (49.5%), with 1 in 3 (35.5%) accessing mental health services. 18.0% were caring for someone without accessing formal support services. Interestingly, male respondents were significantly more likely to report that services met their needs as a carer than other respondents.

Figure 17: Services met my needs as a carer (by gender)



Health and Wellbeing

On average, male respondents report significantly higher wellbeing than other carers, with a PWI score of 62.1%, however this is still significantly lower than the population average. They also report lower rates of psychological distress than other respondents, with 34.0% reporting high to very high distress, compared to 50.1% among other carers. These results are in line with male carers in the sample also being older, which is associated with better outcome measures for carers. However, 48.8% of male respondents report feeling socially isolated or having only low social support. Male carers also rated their health better than other carers, with 42.3% estimating that their health was "poor" or "fair" compared with 50.1% of other carers.

Around 22.0% of male carers are active in paid employment, which is significantly below the rate of other carers (35.9%). However, they spent on average more hours at work, with 32.7 hours compared to 26.4 hours among other carers. 1 in 3 male carers draw their income from the Age Pension, and 1 in 5 (20.2%) receive the Carer Payment. Male carers are less likely to experience financial stress, however with 1 in 2 (49.8%) reporting at least one experience of financial stress in the year leading up to the survey, the rate is still very high.

LGBTQ+ CARERS

Key demographics: majority of LGBTQ+ respondents

47.3 yrs
average age

13%
born overseas

6.5%
Aboriginal and/or Torres Strait Islander

8.8%
speak a language other than English

In the survey 322 respondents (4.7%) identified as lesbian, gay, bisexual, transgender, queer, sexuality or gender diverse. LGBTQ+ carers are often hidden carers, they may be hesitant due to disclose their caring role due to fear of stigma or discrimination, or their caring relationships may not be recognised by their service providers, employers or communities.

With an average age of 47.3 years, they are significantly younger than other carers in the sample. 1 in 6 LGBTQ+ carers (17.1%) identified as culturally or linguistically diverse, with 13.0% being born overseas and 8.8% speaking a language other than English at home. 6.5% identified as Aboriginal and/or Torres Strait Islander, significantly more than in other cohorts.

KEY POINTS

- LGBTQ+ carers are likely younger, and most commonly care for a child (including adult children).
- 2 in 5 LGBTQ+ carers provide care for more than one person.
- They feel significantly less recognised for their caring role than other carers, especially by community and government.
- They are significantly less likely to be included by formal care services than other carers.

About the people they care for

2 in 5 LGBTQ+ carers (39.3%) were providing care for more than one person. Most commonly, LGBTQ+ carers were caring for a child (45.1%), with 1 in 3 caring for a partner or for a parent. The most frequent reasons for providing care were due to a mental health condition (43.2%), a physical disability (41.5%) or Autism Spectrum Disorder (ASD) (37.2%). Taken together, 74.1% of LGBTQ+ carers were providing care for someone living with a form of disability (physical or intellectual disability, ASD, acquired brain injury, or sensory impairment).

About the caring experience

2 in 3 LGBTQ+ carers provided care for more than 40 hours per week, with 41.4% providing 24/7 care. 43.7% had been caring for 10 years or more. 14.7% were not living with the person they care for, and 57.2% were the sole carer for the person they cared for.

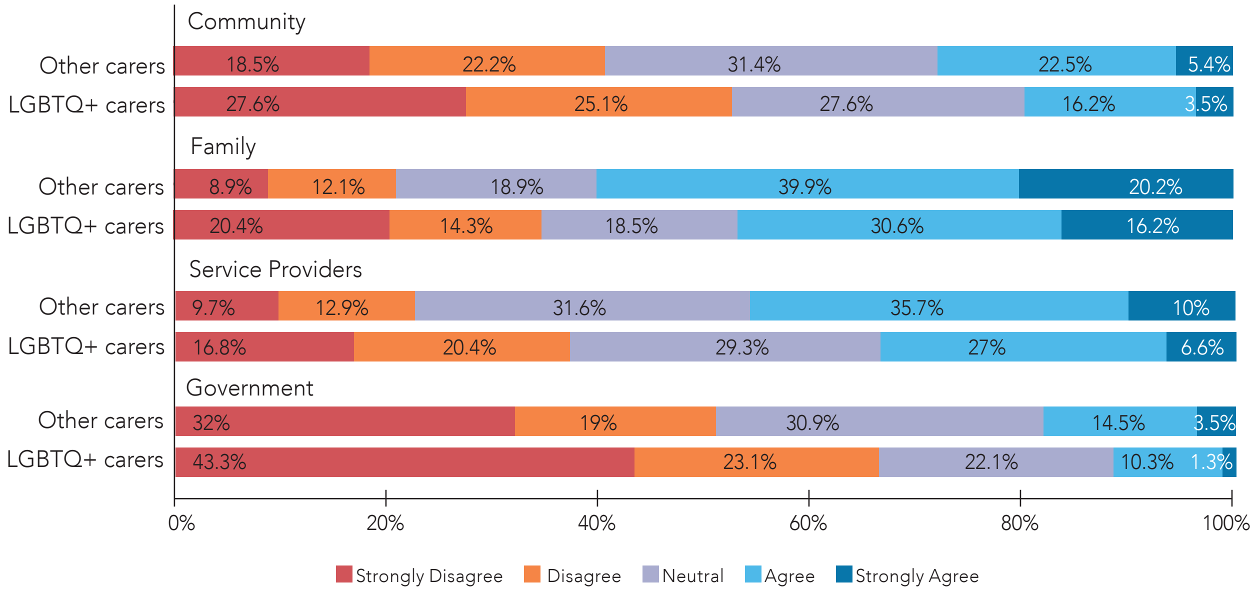
Experiences accessing services

More than half of all LGBTQ+ respondents who responded to the Survey were caring for someone accessing mental health services (54.6%), with 44.1% accessing disability services and 1 in 3 (31.4%) accessing aged care services with the person they care for. 18.1% were caring for someone who was not accessing formal support services.

Across all service types, LGBTQ+ carers were significantly more likely to report negative experiences in terms of carer inclusion. They were significantly less likely than other carers to agree with the statement that they were asked about their needs as a carer by aged care services (61.2% disagreement)[4], disability services (64.0% disagreement) and mental health services (63.2% disagreement) when they were accessing services with the person they cared for. Consequently, LGBTQ+ carers were also less involved in treatment discussions and planning.

Overall, LGBTQ+ carers feel significantly less recognised for their caring role compared to other carers in the sample. More than half of the LGBTQ+ respondents feel that they are not recognised by the community, and 2 in 3 feel that their caring role is not recognised or valued by the government.

Figure 18: Agreement with the statement: "My caring role is recognised and valued by…", by LGBTQ+ identification



Health and Wellbeing

On average, LGBTQ+ carers report significantly lower wellbeing than other carers, with an average PWI score of 50.7%, significantly below the sample average of 57.7%. They also experience psychological distress at a significantly higher rate than other carers, with 61.9% reporting high to very high distress, compared to 46.8% among other carers.

As a younger cohort, LGBTQ+ carers are more likely to be in paid work (46.0%) or to be looking for work (10.2%). However, they are also more likely to experience financial stress, with 79.6% reporting at least one experience of financial stress over the year leading up to the survey, compared to 56.2% among other carers. The rate of financial distress among LGBTQ+ carers is 37.8%, more than double compared to other carers (15.8%).

[4] Percent of respondents who identified as LGBTQ+ who disagreed or strongly disagreed with the statement "When aged care/disability/mental health services were planned for the person I care for, I was asked about my needs as a carer".

FORMER CARERS

Key demographics: majority of former respondents

79.6%
female

66.7 yrs
average age

21.8%
born overseas

30.5% have
a university degree

KEY POINTS

- Carers can experience ongoing impacts of caring after the caring role ends, such as reduced wellbeing and financial insecurity.
- Bereavement is the most frequent cause for the end of a caring role, however 1 in 5 former carers said their caring role ended because the demands of caring became too high.

Talking on a caring role results in significant change for many carers, who often completely re-orient their lives around providing care for a loved one. The end of a caring role can also be a period of significant change. The transition out of a caring role is a part of almost every caring journey, and can have significant impacts on carers' lives, however these transitions are rarely investigated in depth.

The 450 respondents to the 2022 National Carer Survey who previously cared for someone and have not taken on another caring role (former carers) were on average 66.7 years of age, significantly older than the average of 59.3 years for carers with a current caring role. Former carers who responded to the Survey are otherwise demographically very similar to current carers: 79.6% were female, 2.1% identify as Aboriginal or Torres Strait Islander, 21.8% were born overseas and 15.1% identify as culturally or linguistically diverse.

Most former carers had cared for a partner (41.8%) or a parent (34.7%) in their most recent caring role, 10.9% had cared for a child. The average duration of this caring role was 9.2 years, and on average it had been 2.7 years since the caring role had ended.

The most frequently given reason for the end of the caring role was bereavement (59.8% of respondents), followed by the person being cared for moving to residential care, which 22.8% of respondents identified as ending their caring role. 1 in 5 (19.2%) respondents report that their caring role ended because the demands of the caring role increased beyond what they could manage.

With an average Personal Wellbeing Index score of 65.7%, the wellbeing of former carers is significantly higher than that of current carers, who score on average 56.8% on the PWI. However, this remains significantly lower than the Australian population average of 74.4% in 2022 (Crowe et al 2023). This speaks for the ongoing diminishing effects of caring roles on wellbeing especially since former carers are usually older, and older Australians report higher wellbeing on average. The duration of the caring role and the time that has passed since it ended were not found to have a significant relationship with a carer's level of wellbeing, indicating that having had a caring role has long term impacts.

Former carers responding to the Survey reported lower psychological distress than current carers, however 1 in 3 (32.5%) still reported high to very high distress.

Effects of the caring role also linger in terms of social connections. While former carers are more socially connected than current carers, 48.1% remain socially isolated after their caring role ends.

Material effects also may be ongoing, with 44.7% of former carers reporting that they have experienced at least one form of financial stress (such as not having enough savings to cope with an emergency, not being able to pay their bills on time, or having to seek financial assistance) in the 12 months prior to the survey. This is less than the 58.4% of current carers, who report experiencing financial stress, but still concerning. Other research (e.g. Furnival and Cullen 2022) has detailed that the impacts of having a caring role on long-term income, lifetime savings and the superannuation balance at retirement age is substantial.

REGIONAL AND REMOTE CARERS

Key demographics: majority of regional/remote respondents

80.4%
female

62 yrs
average age

3.4%
Aboriginal and/or
Torres Strait Islander

4.9%
speak a language
other than English

Respondents to the 2022 National Carer Survey came from all across Australia, with 2,673 respondents (41.3%) living in regional and remote areas. The communities where carers live can have significant impacts on their experiences.

Carers living in regional and remote areas are slightly older than other respondents, with an average age of 62 years compared to 58 years for carers living in major cities. The proportion of male carers is slightly higher in remote areas (19.6% compared to 15.7%). The rate of carers identifying as Aboriginal and/or Torres Strait Islander is 3.4%, twice as high as in major cities (1.7%). Significantly fewer carers in these areas identified as as culturally or linguistically diverse (9.8% compared to 24.4%), or speak a language other than English at home (4.9% compared to 15.3%).

KEY POINTS

- Carers in regional areas are most likely to care for someone using aged care services, with 1 in 3 caring for someone accessing disability services.
- Service access, especially to disability services, is a major issue for regional carers.
- Carers in regional areas are more satisfied with their lives than carers in living in major cities, however they report similar rates of social isolation and financial distress.

About the people they care for

Almost half of all respondents living in regional areas were caring for their partner (46.9%), 39.1% were caring for a child (including adult children), and 18.6% were caring for a parent; this differed significantly from caring arrangements in major cities, where almost 1 in 3 (27.1%) cared for a parent. The most frequent reasons for providing care among regional and remote respondents were due to a physical disability (43.2%), a chronic health condition (32.0%) or due to frailty (28.7%). 1 in 4 cared for someone living with Autism.

About the caring experience

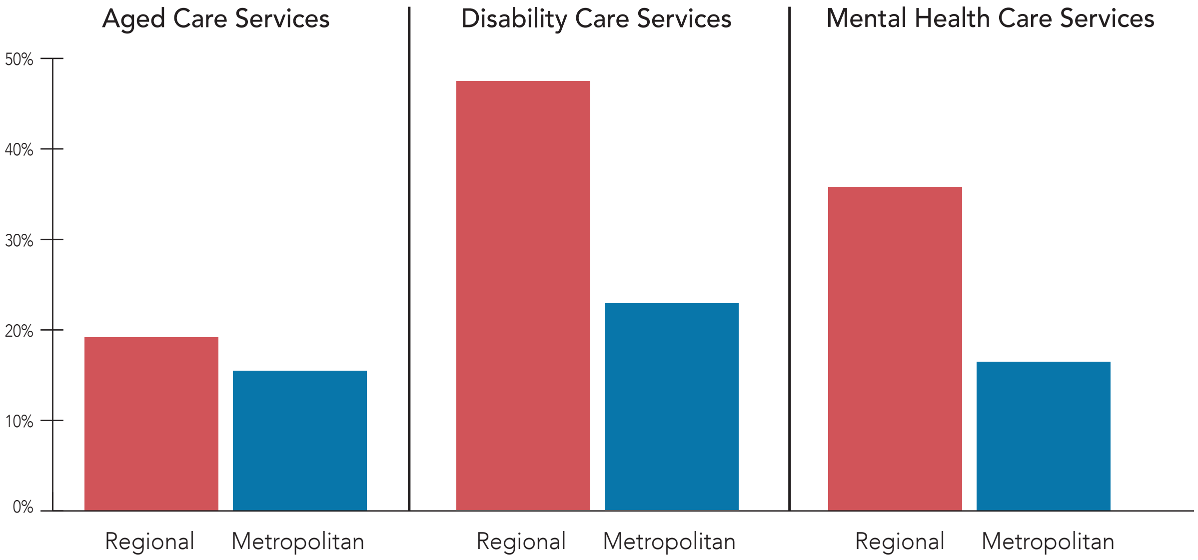
Most regional and remote respondents were caring for one person (75.9%), and 85.7% were living with the person they care for. 3 in 5 regional and remote carers were the sole carer for the person they cared for (59.7%). They spent an average of 109.2 hours per week caring, with 52.0% providing 24/7 care. Nearly 1 in 2 (48.1%) had been caring for 10 years or more.

Experiences accessing services

Almost half of regional and remote carers were caring for someone accessing aged care services (44.5%), with 1 in 3 (36.5%) accessing disability services and 2 in 5 accessing mental health services. However, 17.1% were caring for someone without accessing any of these formal support services.

For most questions about service experiences, regional and remote carers responded similarly to those living in major cities. While regional and remote carers reported fewer service issues overall, services being unavailable locally was affecting almost half of regional carers for people requiring disability services.

Figure 19: Required services are not available locally (% of carers using service type)



Health and Wellbeing

With an average score of 59.9% on the Personal Wellbeing Index, regional and remote carers are slightly more satisfied with their lives overall than those living in major cities (55.8%) (see Table 9). They also experience lower rates of psychological distress than other carers, however 44.2% still report high to very high distress. Despite regional and remote carers being more satisfied with their community connections and personal relationships than other respondents, their rate of social isolation is similar to carers in major cities, with 54.1% feeling socially isolated or highly socially isolated.

Carers in regional and remote areas are less likely to be in paid work than those in major cities (28.3% compared to 37.2%) and those who were spent slightly fewer hours in paid work, at 25.7 hours a week on average compared to 27.8 hours/week for carers in major cities. They also report financial stress at a similar rate to carers living in major cities, with 56.1% experiencing at least one instance of financial stress in the year leading up to the survey, compared to 58.6% in major cities.

Table 9: Regional and remote carers' health and wellbeing

How satisfied are you with your:	Metropolitan	Regional or remote
Standard of living	62.9%	66.4%
Health	50.2%	58.2%
What you are achieving in life	49.7%	58.9%
Personal relationships	55.4%	59.9%
Safety	69.1%	72.6%
Community	52%	57.4%
Future security	51.6%	56.1%
Overall score	**55.8%**	**59.9%**

VARIATION ACROSS STATES AND TERRITORIES

The 2022 National Carer Survey had respondents from all Australian states and territories, and there was a great diversity across respondents within and between jurisdictions. Because the Survey is not statistically representative, all comparisons between states and territories should be viewed in the context of state and territory sample size and composition.

Table 10: Survey respondents by state and average age

State	Respondents	%	Average Age
Australian Capital Territory	113	1.7	57.1
New South Wales	1,352	19.8	60.2
Northern Territory	75	1.1	62.3
Queensland	623	9.1	54.8
South Australia	2,248	32.9	59.9
Tasmania	691	10.1	65.6
Victoria	1,355	19.9	58.6
Western Australia	368	5.4	59.6
Total	**6,825**	**100**	**59.8**

With 2,248 respondents, the largest subsample is that of carers from South Australia, followed by Victoria and New South Wales. The demographic characteristics of respondents vary considerably across states and territories (see Table 11). Average age ranges from 54.8 years in Queensland to 62.3 years in the Northern Territory; in terms of gender, the rate of male carers ranges from 9.1% in the ACT sample to 24.9% in Tasmania. The largest proportion of Aboriginal and Torres Strait Islander respondents is found in the sample from the Northern Territory, which also had the highest rate of carers identified as culturally and linguistically diverse. The ACT and Victoria had the next highest rate of respondents identified as CALD (21.2% and 26.8% respectively).

Table 11: Core demographics of respondents by State/Territory

State/Territory	Average age	Gender			Aboriginal and/or Torres Strait Islander	CALD
		Female	Male	Non-binary/gender-diverse/other gender		
Australian Capital Territory	57.1	86.4%	9.1%	3.8%	0.9%	21.2%
New South Wales	60.2	84.9%	14.4%	0.4%	3.9%	17.4%
Northern Territory	62.3	78.4%	21.6%	0.0%	9.4%	33.3%
Queensland	54.8	85.6%	13.6%	0.3%	4.3%	14.8%
South Australia	59.9	79.8%	19.3%	0.6%	2.0%	15.7%
Tasmania	65.6	74.5%	24.9%	0.2%	2.7%	10.4%
Victoria	58.6	84.5%	14.9%	0.4%	1.4%	26.8%
Western Australia	59.6	81.7%	18.1%	0.3%	1.7%	17.4%
Total	**59.8**	**82.0%**	**17.3%**	**0.3%**	**2.8%**	**18.0%**

Significant variation also exists in terms of the type of care provided by respondents from different states and territories (see Table 12). Tasmania (52.8%), Western Australia (52.8%) and South Australia (45.8%) have the highest representation of carers of people using aged care services, whereas Queensland and Victoria have the highest representation of carers of people accessing disability and mental health services. The highest rate of carers for people without formal services is found in the sample from the Northern Territory.

Table 12: Services for the cared-for person by State/Territory

State/Territory	Caring for someone with:			
	Aged care services	Disability services	Mental health services	No formal services
Australian Capital Territory	28.3%	42.5%	57.5%	15.0%
New South Wales	37.9%	39.3%	42.0%	14.2%
Northern Territory	34.7%	24.0%	40.0%	26.7%
Queensland	26.2%	58.7%	51.5%	12.5%
South Australia	45.8%	32.4%	38.5%	17.6%
Tasmania	52.8%	25.2%	32.9%	17.4%
Victoria	32.5%	52.3%	47.6%	14.2%
Western Australia	46.5%	38.9%	38.6%	14.9%
Total	**40.1%**	**39.8%**	**41.9%**	**15.7%**

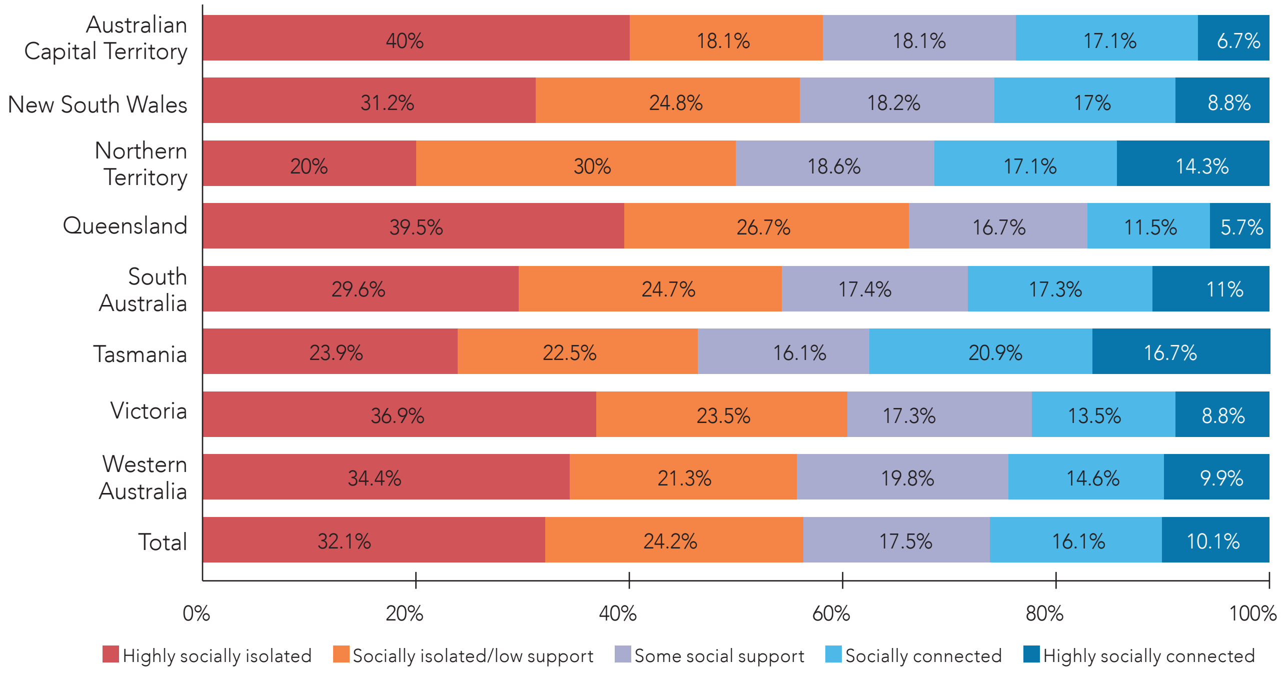
This social, demographic, and cultural diversity in the samples, and the variety of caring situations all contribute to different outcomes in terms of wellbeing measures per state/territory. The average wellbeing score is highest in the Tasmanian sample, with 63.9%, and lowest in Queensland, at 51.9%. The Queensland sample also has the second-highest rate of carers experiencing high or very high psychological distress, with Tasmania reporting the lowest.

The reported social connectedness varies in a similar way, with states and territories with an older sample (Tasmania, NT) reporting higher social connectedness, and samples with on average younger carers reporting higher rates of social isolation.

Table 13: Wellbeing and distress by State/Territory

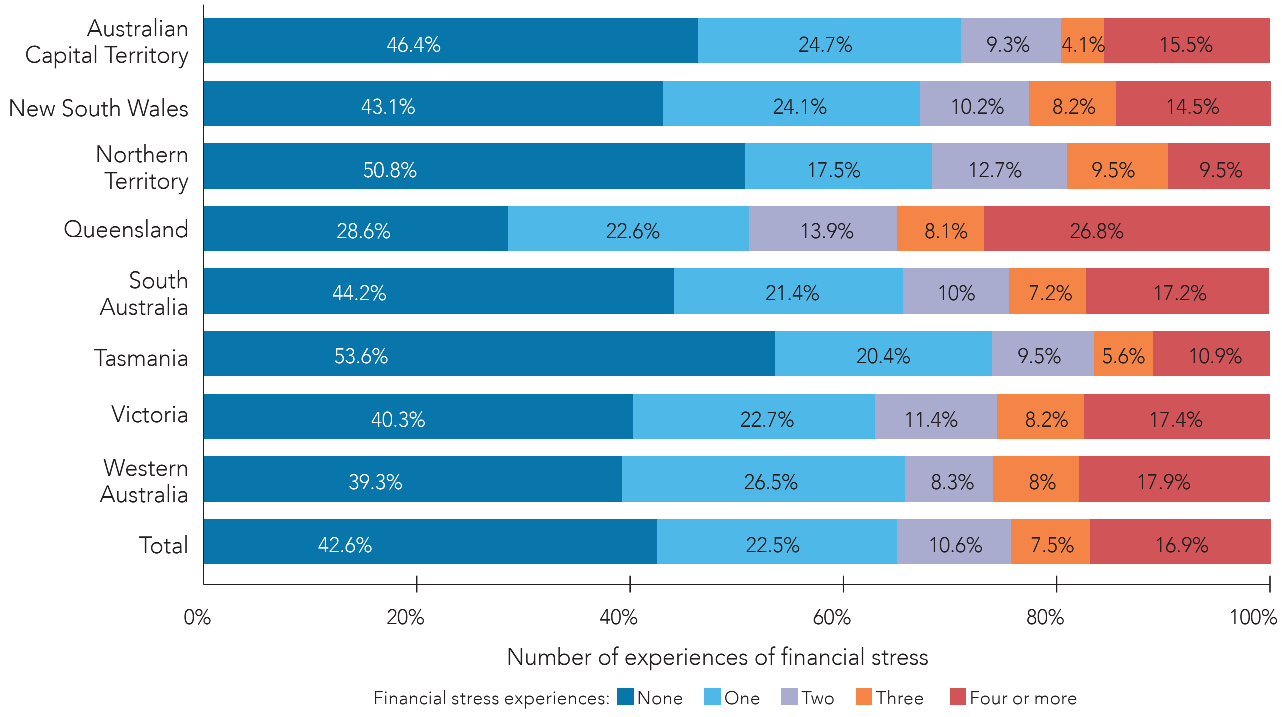
State/Territory	PWI (% of scale max)	% reporting high/very high psychological distress
Australian Capital Territory	52.4%	56.5%
New South Wales	57.5%	47.4%
Northern Territory	62.0%	42.0%
Queensland	51.9%	53.9%
South Australia	58.5%	47.4%
Tasmania	63.9%	35.2%
Victoria	55.3%	51.1%
Western Australia	55.5%	44.6%
Total	**57.3%**	**47.5%**

Figure 20: Social connectedness by State/Territory



Experiences of financial stress are reported in a similar pattern across the Survey sample, with Queensland recording the highest rate of financial stress, and the respondents from Tasmania and the NT the lowest.

Figure 21: Experiences of financial stress by State/Territory



The experiences of carers captured in the 2022 National Carer Survey are diverse and varied, within and across States and Territories. Further information about the results for each State and Territory is included in the State and Territory factsheets available from the Carers NSW website.

PART THREE: DETAILED RESULTS

3

THE CARING RELATIONSHIP

A total of 6.6% of respondents indicated they were not currently caring, but had in the past. The 6,375 (93.4%) of respondents who identified as a current carer reported caring for a combined total of 8,837 people – an average of 1.39 per carer. More than half of all carers were the sole carer and did not receive any assistance from other family members or friends (56.5%).

Table 14: Characteristics of the caring relationship

Carer status (N=6,825)	Current	93.4%
	Former	6.6%
Care arrangements (N=6,336)	I am the only one who provides care	56.5%
	I provide the most care, but others help with care sometimes	33.0%
	Someone else provides the most care, but I help with care sometimes	6.9%
Number of persons being cared for (N=6,378)	One	72.1%
	Two	20.3%
	Three or more	7.5%

The ages of people being cared for by Survey respondents was on average 50.3 years, and ranged from less than 1 year old to over 100 years old, but were most likely to be aged 65 years or older. Most respondents cared for someone male (56.5%), 42.6% cared for someone female, and 1.3% cared for someone identifying as non-binary/gender diverse or another gender. Respondents were most commonly caring for their child (including adult children) (45.1%), spouses/partners (37.6%), and parents/parents in law (23.6%). Key demographic characteristics of the persons cared for are summarised in Table 15.

Table 15: Demographic characteristics of persons being cared for (multiple responses possible)

Gender of person cared for (N=6,336)	Caring for someone female	42.6%
	Caring for someone male	56.5%
	Caring for someone non-binary/gender diverse	1.3%
Age of person cared for (N=6,293)	Caring for someone 0-18 years	24.7%
	Caring for someone 19-64 years	37.9%
	Caring for someone 65+ years	50.7%
Relationship to person cared for (N=6,178)	Caring for a parent/parent in law	23.6%
	Caring for a partner	37.6%
	Caring for a child	45.1%
	Caring for a sibling	4.0%

Respondents were asked to identify the conditions, disabilities, or illnesses for which the people they were caring for needed their care. Respondents were most likely to provide care for someone living with a physical disability (40.6%), a chronic health condition (31.9%), or a mental illness (28.3%) (Table 16).

Table 16: Conditions of persons being cared for (multiple responses possible)

Condition (N=6,262)	%
Caring for someone living with a disability*	70.3
Caring for someone living with a physical disability	40.6
Caring for someone living with a chronic health condition	31.9
Caring for someone living with a mental illness	28.4
Caring for someone frail due to age	28.3
Caring for someone living with Autism Spectrum Disorder	27.4
Caring for someone living with an intellectual disability	22.9
Caring for someone living with a sensory impairment	21.4
Caring for someone living with dementia	19.6
Caring for someone living with a neurological condition	15.9
Caring for someone living with acquired brain injury or stroke	10.1
Caring for someone living with a terminal or serious illness	7.1
Caring for someone living with a drug or alcohol dependency	3.6
Caring for someone living with ADHD/ADD#	3.4

* Including physical disability, intellectual disability, Autistm Spectrum Disorder, Acquired Brain Injury/stroke, sensory impairment

Estimated from open text responses

Most respondents cared for someone who could not be left alone for more than a few hours, and 1 in 3 cared for someone who could not be left alone at all (Table 17).

Table 17: Length of time the person being cared for can be left alone (multiple responses possible)

How long can the person being cared for left alone? (N=6,330)	%
Not at all	30.1
Less than 1 hour	16.2
Few hours	43.4
One day	15.9
Few days	14.1
More than a few days	10.5

On average, respondents to the Survey provided 103.7 hours of care per week, with 48.5% of respondents providing 24/7 care and a large majority of carers (69.1%) providing 40 or more hours per week. Table 18 compares the 2020 and 2022 National Carer Survey with the ABS Survey of Disability, Ageing and Carers (SDAC), showing that the carers responding to the 2022 National Carer Survey were more likely to be providing a higher amount of care than respondents to the 2020 Survey and the primary carers captured by 2018 SDAC.

Table 18: Average hours of care provided per week, 2022 and 2020 National Carer Surveys and SDAC 2018

Average hours of care provided	Carer Survey 2022 (n= 6,074)	Carer Survey 2020 (n= 6,343)	SDAC 2018 (ABS 2019a)
Less than 20 hours	18.7%	22.0%	43.7%
20–39 hours	12.3%	18.9%	18.4%
40 hours or more	69.1%	59.1%	33.2%

The duration of caring roles ranged from 8 months to 68 years. The current caring roles of respondents had lasted on average 12.7 years, with a 53.1% providing care for more than 10 years.

Table 19: Duration of care provided, 2022 and 2020 National Carer Surveys and SDAC 2018 (multiple responses possible)

Years of care provided	Carer Survey 2022 (n=6,034)	Carer Survey 2020 (n=6585)	SDAC 2018 (ABS 2019a)
Less than 2	11.2%	10.2%	13.0%
2–4	12.7%	12.7%	25.1%
5–9	23.1%	22.7%	23.7%
10–24	39.1%	40.6%	29.0%
25 or more	14.0%	13.8%	6.7%

KEY POINTS

- Most respondents were caring for one person with no assistance from other family members or friends. 1 in 4 were caring for more than one person.
- Survey respondents were most likely to be caring for their child (including adult children), or caring for their partner.
- The most common conditions of people being cared for were physical disabilities, followed by chronic conditions and mental illnesses.
- 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.
- The majority of respondents dedicated 40 or more hours per week to providing care.
- More than half of all respondents provided care for more than 10 years.

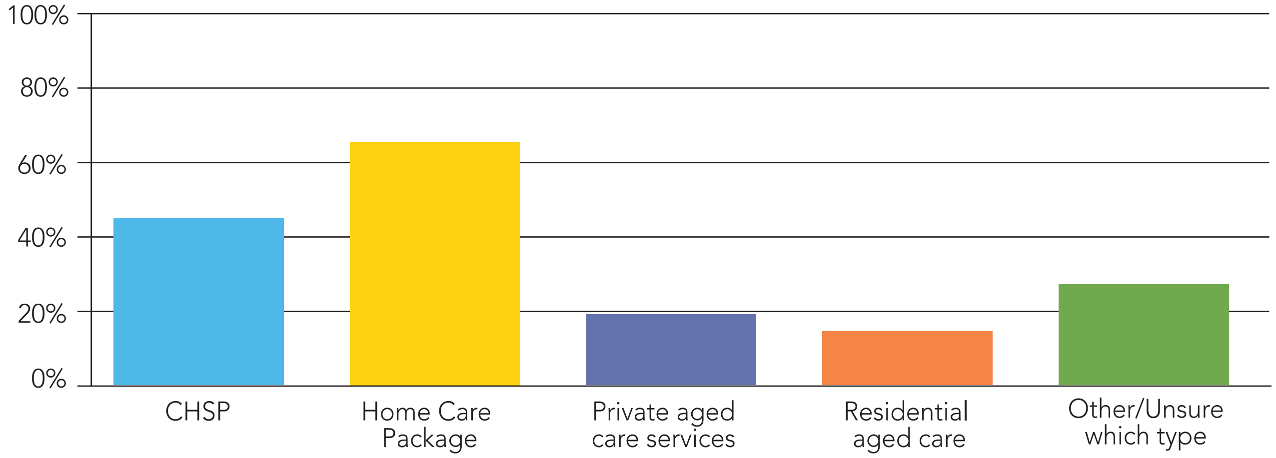
SERVICES AND SUPPORT

AGED CARE SERVICES

Respondents were asked whether anyone they currently care for uses aged care services, which are services designed for people over the age of 65 years (or over the age of 50 years for Aboriginal and Torres Strait Islander Australians), funded by government or purchased privately. A total of 2740 respondents (41.3%) indicated that someone they were caring for was accessing aged care services of some kind.

Of the 2740 respondents caring for someone using aged care services, 65.7% reported that the person had a Home Care Package, a government funded package of support that enables the purchase of aged care services such as personal care or respite. An additional 45% were accessing entry-level aged care services subsidised by the Commonwealth Home Support Program (CHSP), such as cleaning, community transport, or basic in-home support. 1 in 5 respondents indicated that the older people they were caring for were accessing privately funded aged care services, and 14.5% were caring for someone living in residential aged care.

Figure 22: Aged care services, by type (N=2,740)



Information and service coordination

Carers of people using aged care services were asked to respond to a range of statements about the quality and impacts of those services. The majority (60.5%) of the carers engaging with aged care services had been provided with all the information they needed, while less than 1 in 5 (19.8%) disagreed with the statement.

These findings indicate that a reasonably large proportion of carers are resourced and supported to access the aged care services they need; however, a significant minority require more information and support with accessing services.

Service quality and appropriateness

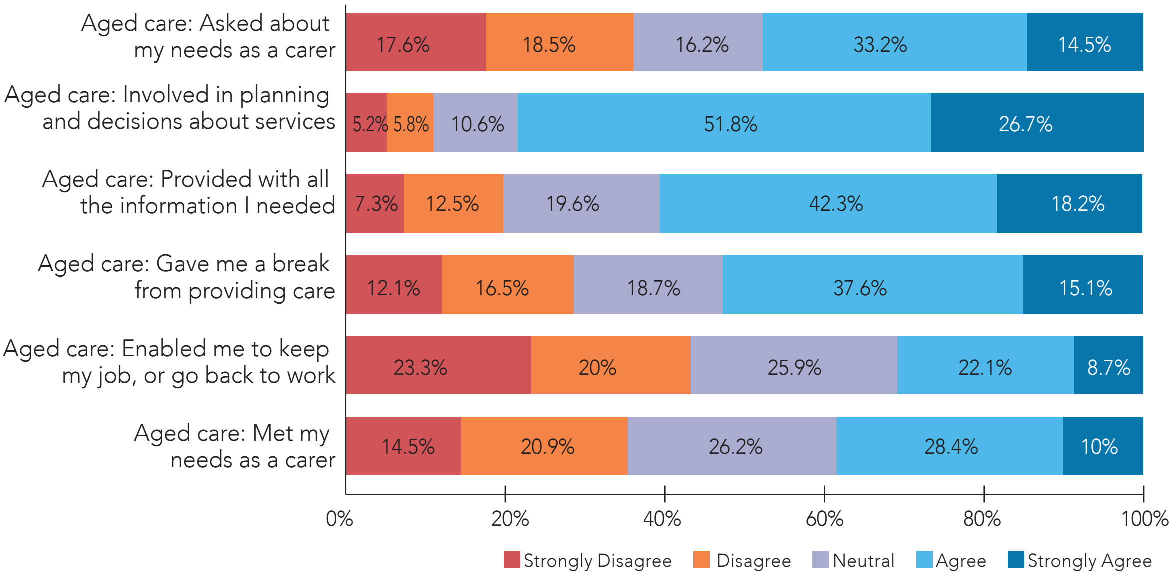
Carers of people accessing aged care services were asked whether the aged care services have met their own needs as a carer, e.g. services were available when they were not able to care. One third of the carers agreed (38.4%) that services met their needs, while another one third disagreed (36.1%) with the statement. The similar proportions of agreement and disagreement with this statement suggest an inconsistency in the quality and appropriateness of services.

Carer inclusion and support

Meeting carers' needs requires eliciting and understanding those needs. Nearly 1 in 2 (47.7%) had been asked about their own needs when the person they care for was accessing aged care services, while 36.1% disagreed that this had occurred (see Figure 3). Despite a considerable number of respondents not being asked about their own needs, the large majority (78.5%) of carers were still involved in the planning and decision-making process of the aged care services for the person they care for. Only 11.0% of the carers disagree with the statement.

Just over half of respondents (52.7%) indicated that aged care services enabled them to take a break from their caring role. However, 1 in 4 (28.6%) did not find this to be the case. Furthermore, while a large proportion (43.3%) believed that the aged care services provided to the person they care for were insufficient to allow them to keep their job or return to paid work, a further 30.8% were supported by services to maintain their employment or go back to work.

Figure 23: Carer inclusion in aged care services (N=2,740)

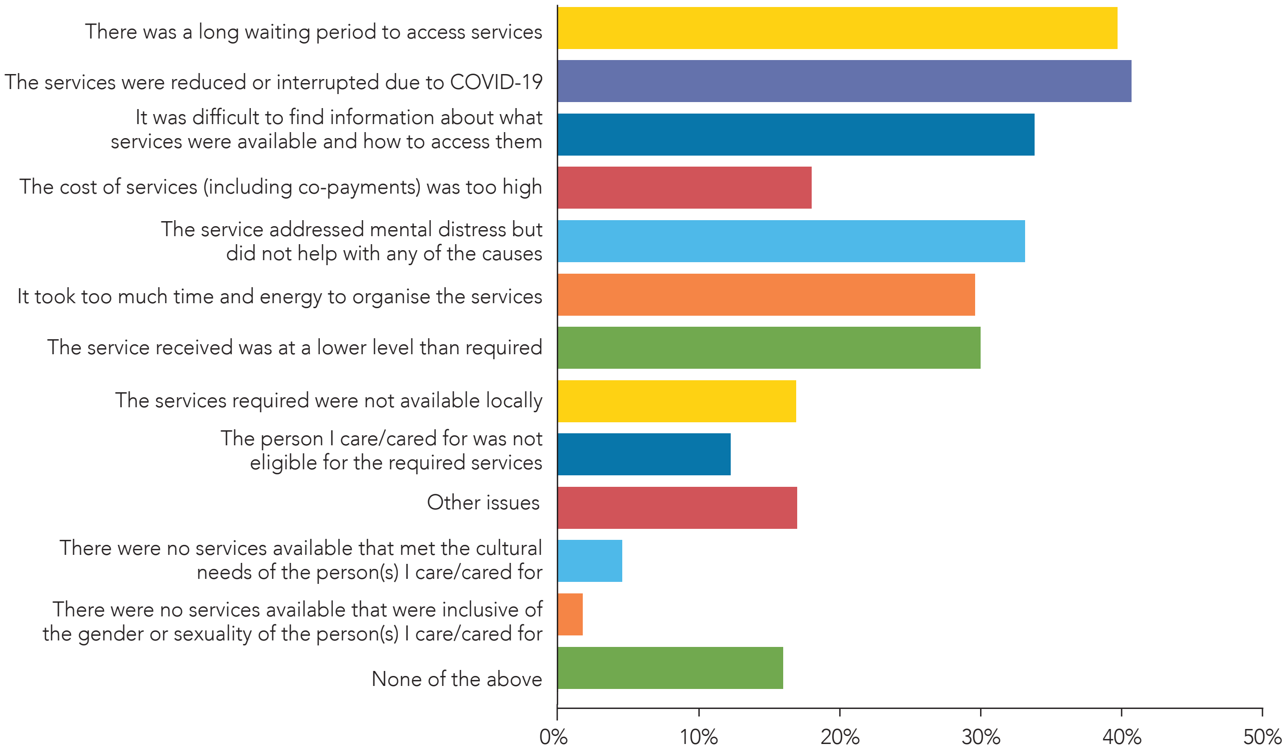


Challenges accessing aged care services

All respondents caring for someone who was accessing, or who needed to access, aged care services were asked whether they, or the person they cared for, had experienced any of a range of commonly identified challenges when seeking to access aged care services. In addition to service interruptions due to COVID-19, long waiting periods and difficulty access information were common. Nationally the five most common issues reported were:

- The services were reduced or interrupted due to COVID-19 (40.4%)
- There was a long waiting period to access services (39.4%)
- It was difficult to find information about what services were available and how to access them (33.6%)
- There was a long waiting period to get assessed (32.9%)
- The service received was at a lower level than required (29.8%).

Figure 24: Challenges accessing aged care services (N=2,580)



DISABILITY SERVICES

Respondents were asked whether they were caring for someone who received support through the National Disability Insurance Scheme (NDIS), which provides government funded services to people under the age of 65 years who have a significant and permanent disability. A total of 2,717 respondents (44.1%) to that question reported caring for someone who has an NDIS plan (known as an 'NDIS participant'), while another 6.2% indicated that the person they care for needs NDIS support but does not receive it. A further 5.0% reported accessing disability services outside the NDIS.

Information and service coordination

Carers of NDIS participants were asked to respond to a range of statements about the nature, quality and impacts of those services on themselves. A relatively large proportion (42.8%) of respondents had been provided with all the information they needed, while 33.6% disagreed that this had been the case.

Service quality and appropriateness

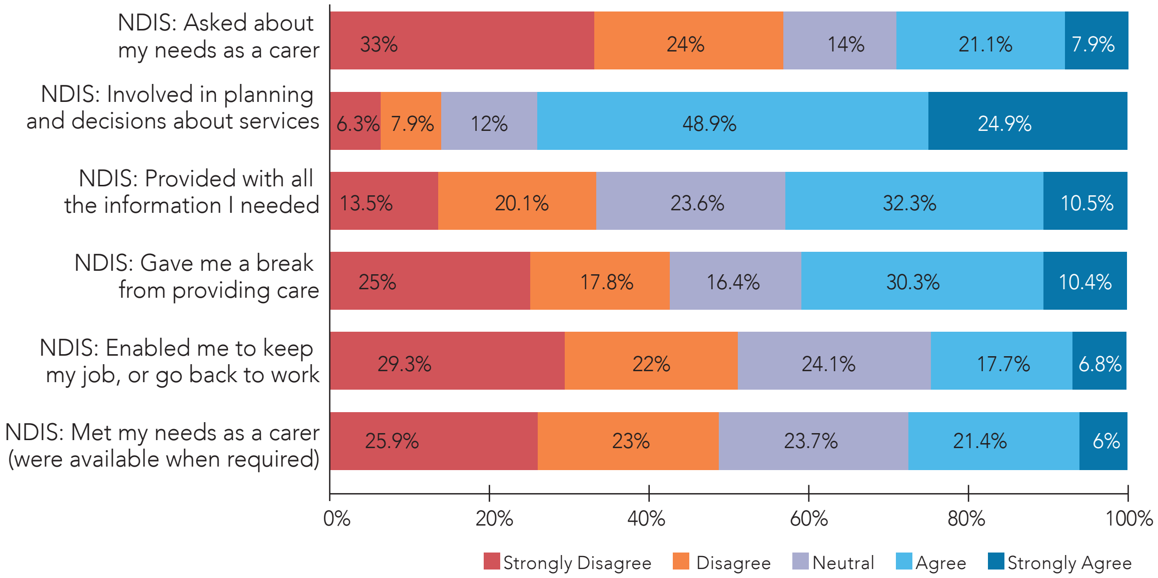
Carers of people accessing disability services were asked whether the services provided by NDIS have met their own needs as a carer, e.g., were available when they were not able to care. Nearly 1 in 2 carers (48.9%) disagreed that the services provided has met their needs, while 1 in 4 carers (27.4%) report that their needs have been met.

Carer inclusion and support

The majority of respondents (57.0%) had not been asked about their own needs when the person they care for accessed NDIS services. Only 29.0% of carers report being asked about their needs. However, the majority of carers (73.8%) were involved in the planning and decision-making process for NDIS supports. Only 14.2% of carers disagreed with this.

A total of 40.7% of carers indicate that NDIS support enabled them to take a break from the caring role; 42.8% disagreed with that statement. Only 1 in 4 carers (24.5%) report that NDIS support enabled them to keep their job or go back to paid work, while more than 1 in 2 (51.3%) disagreed this was the case.

Figure 25: Carer inclusion in disability services (N=2,717)



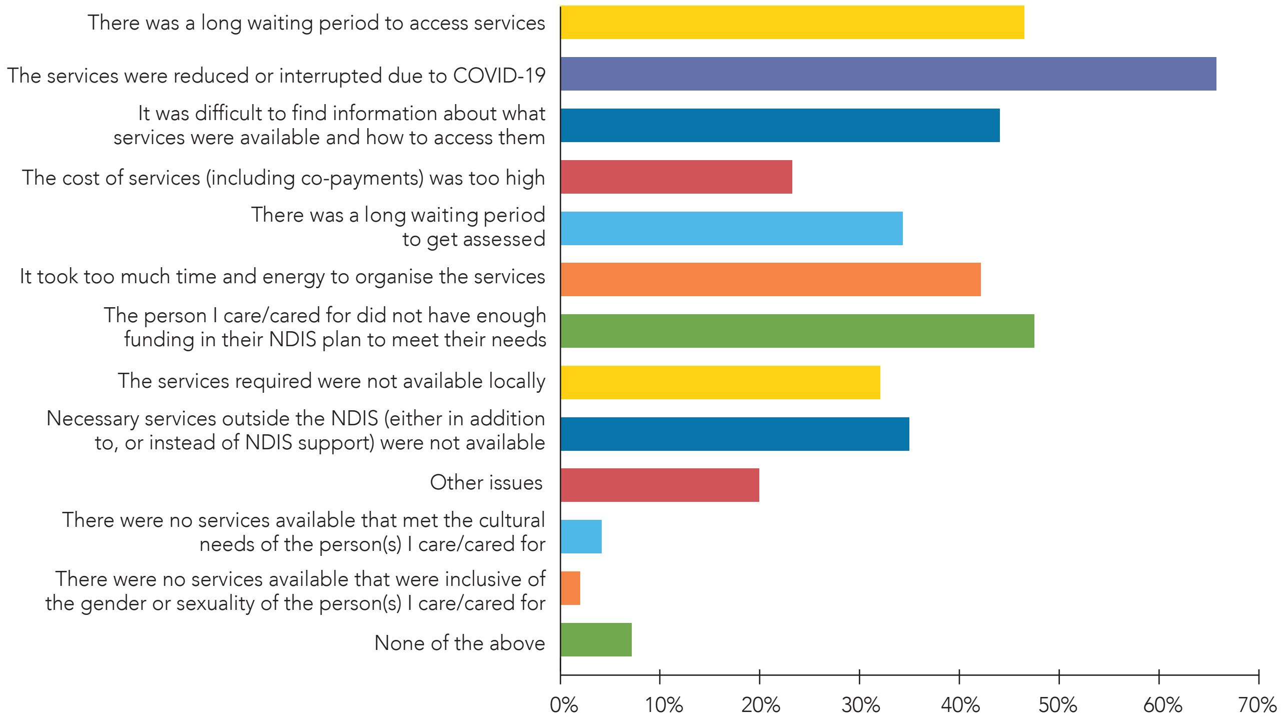
Challenges accessing disability services

Carers of NDIS participants were asked whether they or the person they care for had experienced any of a range of common challenges in attempting to access NDIS services. Beside services being interrupted due to COVID-19, insufficient funding of individual NDIS plans was identified by almost half of all carers for people accessing the NDIS as a significant challenge.

The five most commonly reported challenges were as follows:

- The services were reduced or interrupted due to COVID-19 (65.7%)
- The person I care/cared for did not have enough funding in their NDIS plan to meet their needs (47.4%)
- There was a long waiting period to access services (46.5%)
- It was difficult to find information about what services were available and how to access them (44.0%)
- It took too much time and energy to organise the services (42.1%)

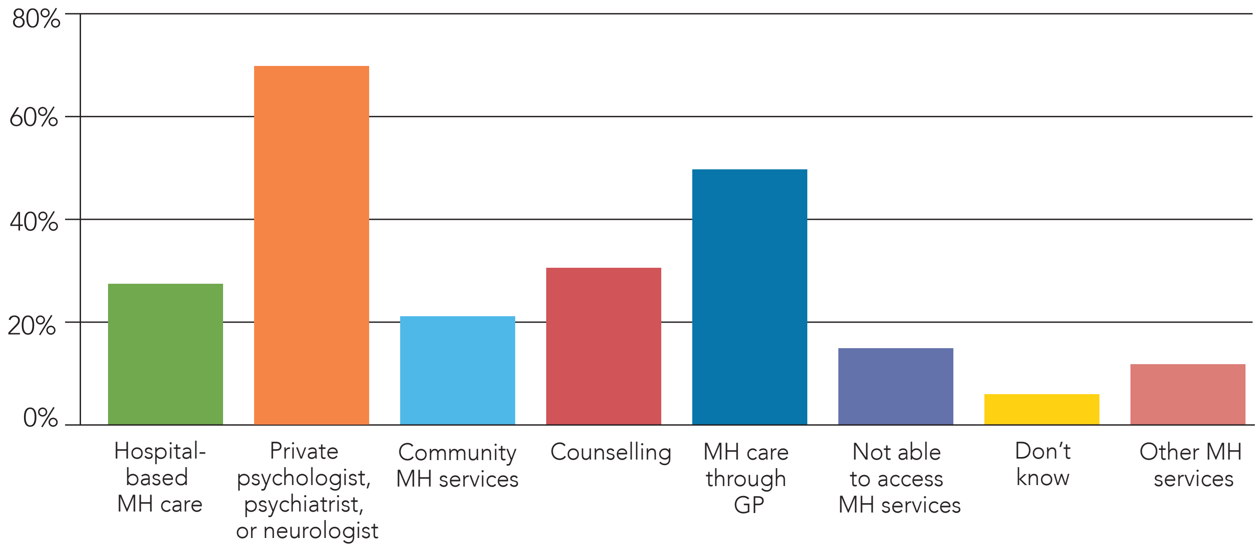
Figure 26: Challenges accessing disability services



MENTAL HEALTH SERVICES

Respondents were asked whether they cared for someone who uses mental health services, including government funded community services, hospital services and Medicare subsidised clinical support (e.g. psychology appointments) that assist people experiencing mental ill health or living with a mental illness. A total of 2,863 respondents (41.9%) were caring for people accessing mental health services. More than 2 in 3 of those respondents (69.8%) were caring for someone who was accessing a private psychologist or psychiatrist, nearly half were caring for someone who received mental health care through their GP, 30.6% were caring for someone receiving counselling and 27.4% for someone receiving hospital-based mental health services. A further 14.9% of respondents indicated that the person they care for needed mental health services but was not able to access them (Figure 27).

Figure 27: Mental health service types (N=2,863)



Information and service coordination

Carers of people accessing mental health services were asked to respond to a range of statements about the quality and impacts of those services on themselves and the person they care for. Similar proportions agreed (39.1%) and disagreed (36.9%) that they had been provided with all the information they needed when the person they cared for was accessing mental health services (see Figure 28), suggesting significant inconsistency between the services available.

Service quality and appropriateness

The majority of carers (62.2%) disagreed that the services provided had met their needs; only 14.0% reported that their needs were met.

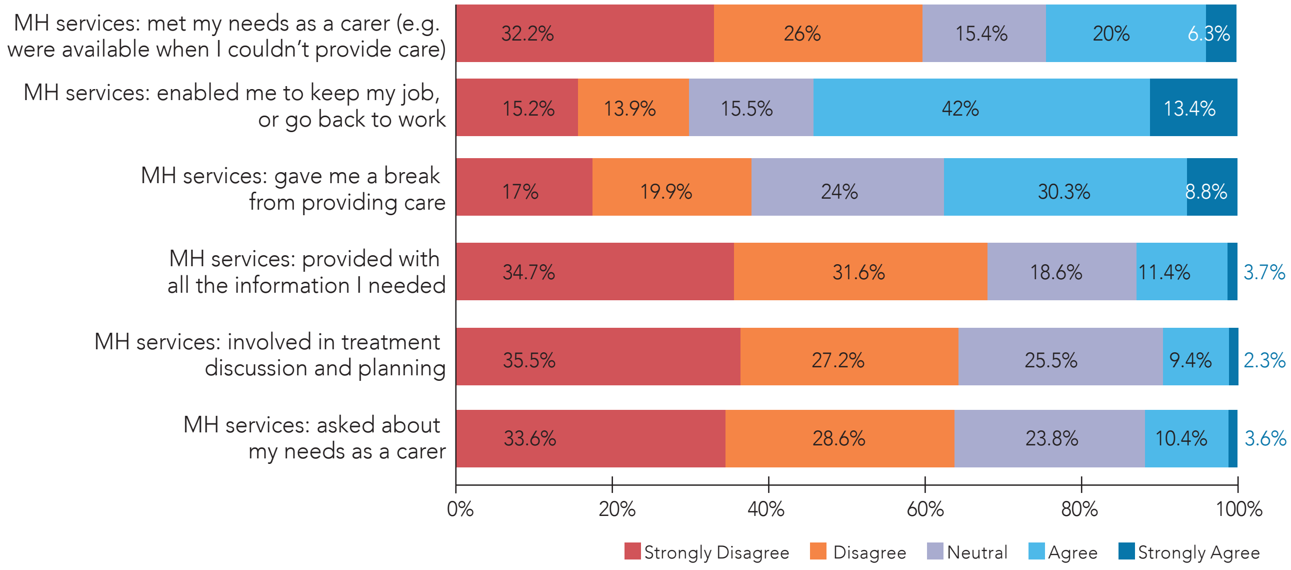
This may relate in part to the high proportion of respondents supporting someone who was accessing private psychology or psychiatry services which are generally delivered confidentially and one-on-one with the individual requiring support.

Carer inclusion and support

Carers were unlikely to have been asked about their needs when mental health services were being provided. 1 in 4 carers (26.3%) said they had been asked about their needs, while the majority (58.2%) had not (see Figure 6). More than half (55.4%) were involved in treatment discussion and planning, however, 29.1% reported not being involved.

The majority of carers (66.3%) disagreed that mental health services enabled them to have a break from providing care. This is not surprising, given that mental health services are more clinically focused, dealing with the individual in need of support. However, 15.1% of carers reported that mental health services allowed them to have a break from providing care. Similarly, the majority of respondents (62.7%) indicated that mental health services do not support carers to maintain or return to paid work; only 11.7% agreed that this was the case.

Figure 28: Carer inclusion in mental health services (N=2,863)

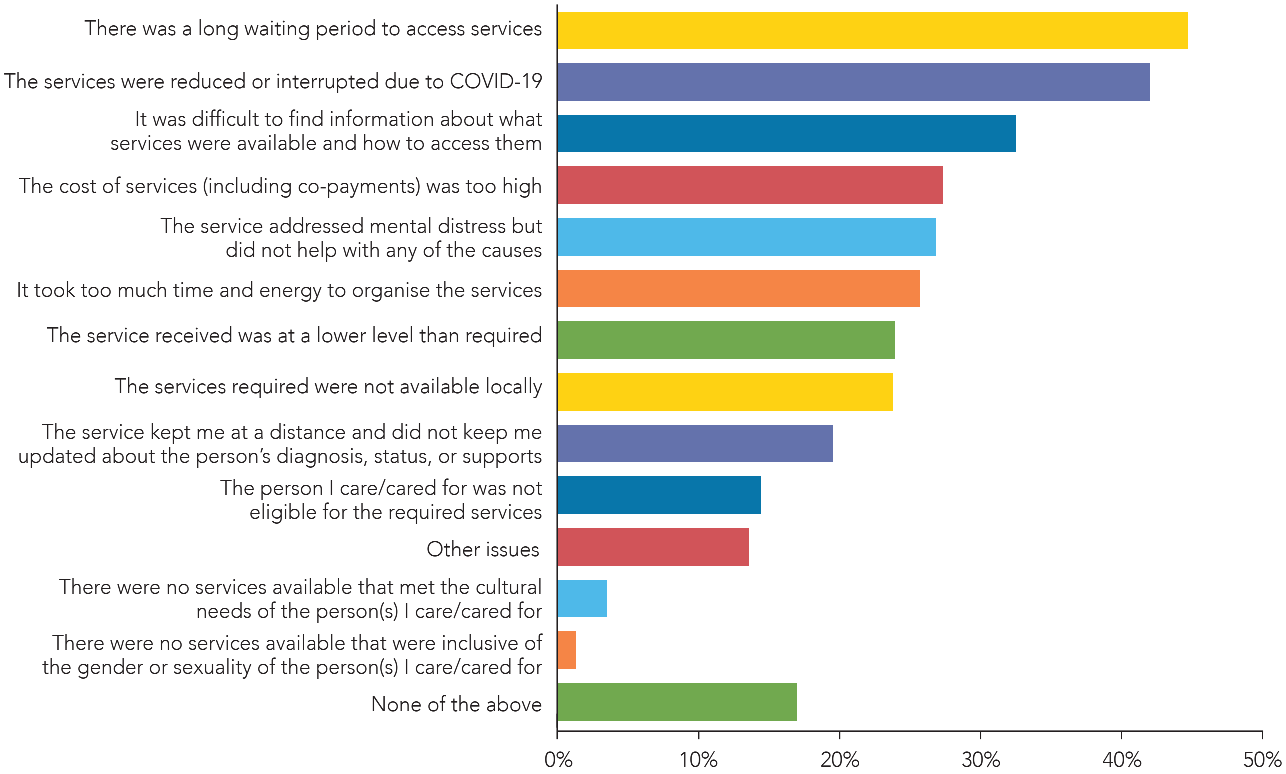


Challenges accessing mental health services

Carers of people accessing mental health services were asked whether they or the person they care for had experienced any of a range of commonly reported challenges when accessing mental health services. The most commonly reported challenges in response to this question were related to long waiting periods, however the complexity of accessing mental health services and high costs associated with them were also frequently mentioned. The five most commonly reported challenges were as follows:

- There was a long waiting period to access services (43.1%)
- The services were reduced or interrupted due to COVID-19 (42.0%)
- It was difficult to find information about what services were available and how to access them (32.5%)
- The cost of services (including co-payments) was too high (27.3%)
- The service addressed mental distress but did not help with any of the causes (26.8%).

Figure 29: Challenges accessing mental health services (N=2,809)



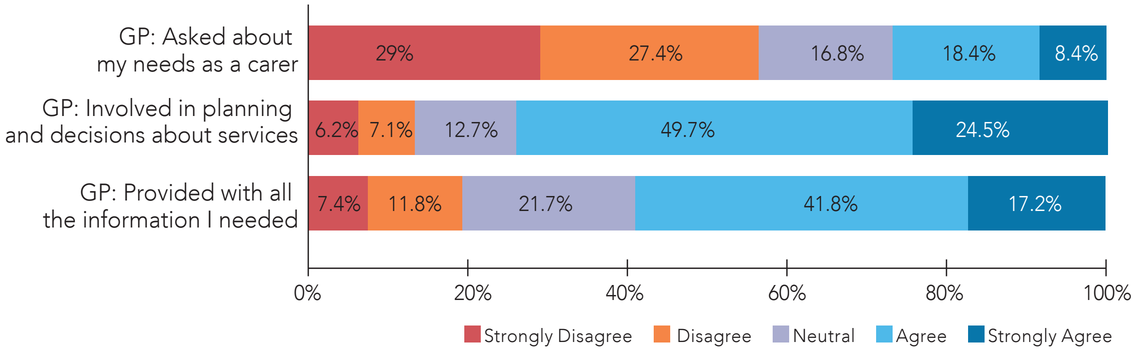
HEALTH CARE SERVICES

All respondents were asked about the ways in which they are engaged and supported when the person they care for is accessing health care services, including a general practitioner (GP) or family doctor, community health service and services within a hospital.

Primary health care services

When accompanying the person they cared for to visit a GP, only 1 in 4 respondents (26.8%) reported being asked about their own needs as a carer, with 56.4% disagreeing that this had occurred. Most carers (74.2%) were involved in treatment discussion and planning when visiting a GP, while 13.3% disagreed that was the case. The majority of carers (59.0%) report that GPs have provided them with the information they needed, however, around 1 in 5 (19.2%) disagreed (see Figure 30).

Figure 30: Carer inclusion in primary health services (N=5,642)

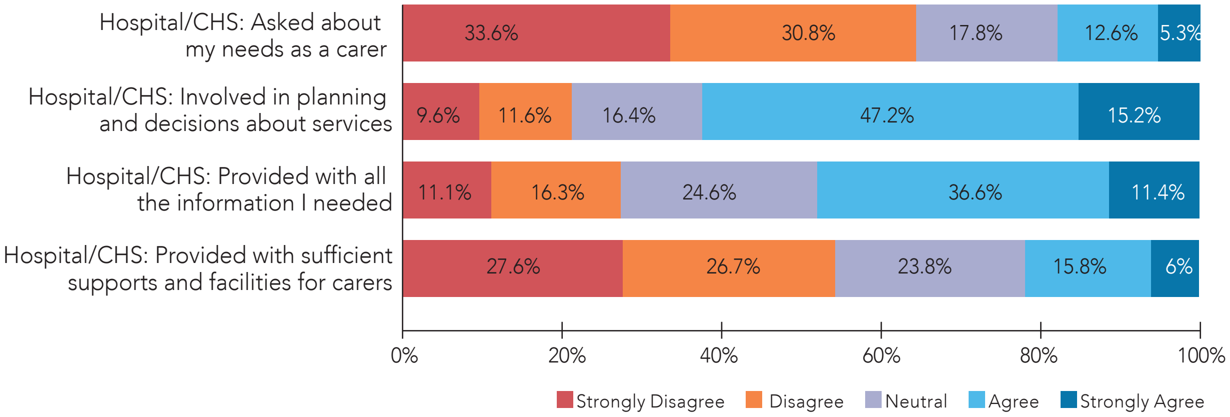


Public health care services

Carers were even less likely to report being asked about their needs in hospital or community health care service settings (17.9%), where the majority (64.4%) disagreed that this occurred. Carers were also less likely to be involved in treatment discussions and planning in this context than in primary health care settings. While 62.4% agreed that they were involved in treatment discussion and planning, and 21.2% disagreed. Nearly half (48.0%) reported that they had received all the information they needed, however 27.4% disagreed.

Carers were also asked about the support options and facilities available to them in-hospital and community health care settings, such as seating, overnight rooms and transport support. 1 in 5 respondents (21.8%) indicated that the availability of these supports was sufficient, while more than half (54.3%) did not agree.

Figure 31: Carer inclusion in public health services (N=5148)



KEY POINTS

- 2,740 respondents were caring for someone using aged care services, 2,717 respondents were caring for a NDIS participant, and 2,863 respondents were caring for someone accessing mental health services.
- 1,070 cared for someone who did not receive formal services other than GP or hospital care.
- Carers were generally provided with all the information they needed and involved in the planning for people accessing aged care, disability, and mental health services.
- The support provided by aged care, disability, and mental health services were generally not sufficient to allow carers to stay in work.
- COVID-19 interruptions and long waiting periods to access services were common challenges faced by respondents across all service types.

CARER SUPPORT SERVICES

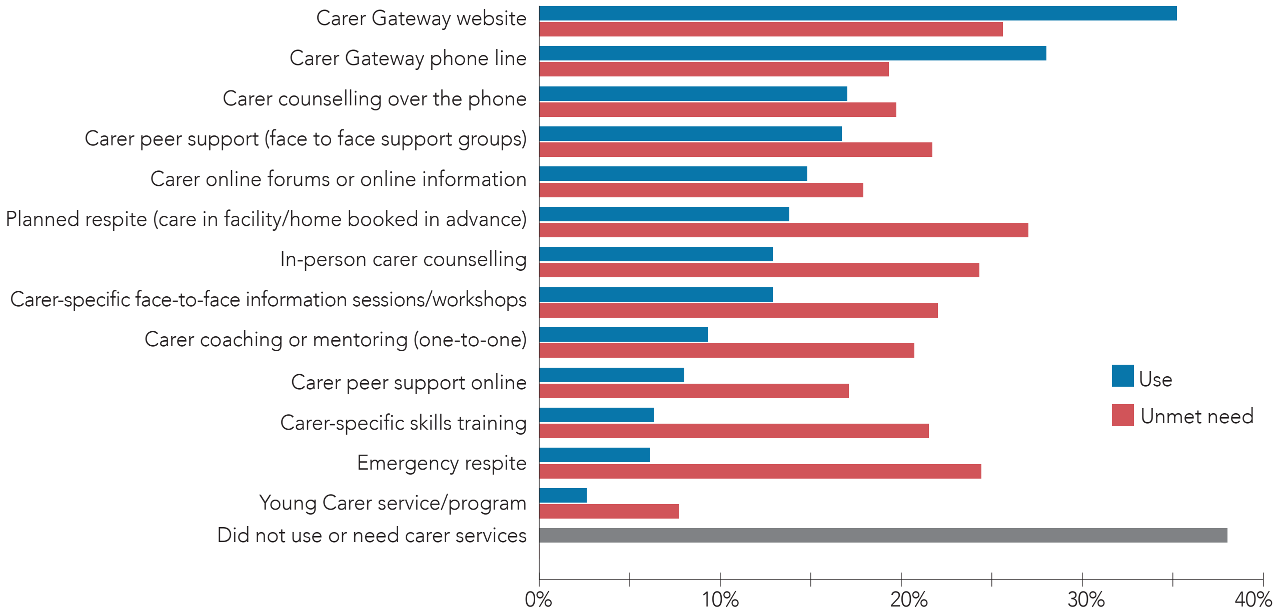
Respondents were asked which of a range of common carer-specific support services they have used in the past two years, and for which they had an unmet need. Overall, 3,496 respondents had used at least one type of service aimed at carers (62% of valid responses).

SERVICE UPTAKE

The most commonly used types of carer support in the past two years were the Carer Gateway website (35.2%) and phone line (28.0%), followed by phone-based carer counselling (17.0%), and face-to-face carer peer support groups (16.7%).

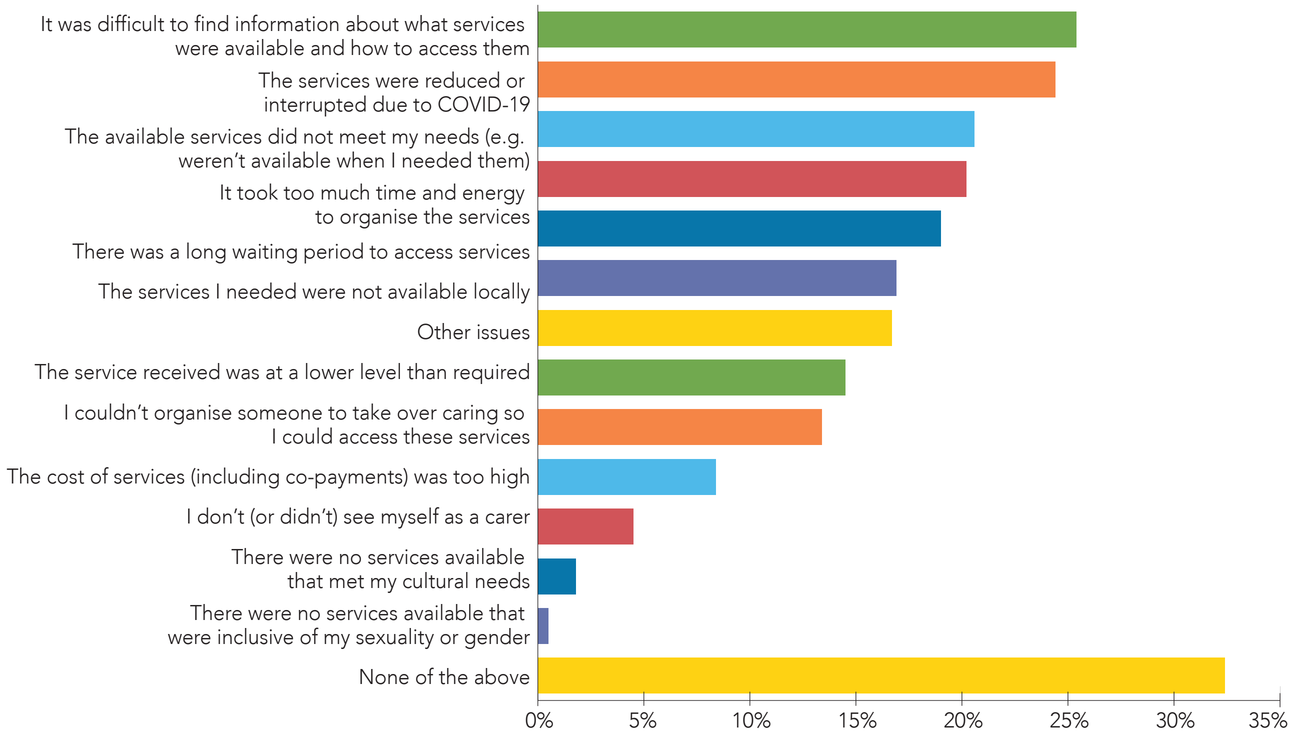
As in previous Surveys, the largest unmet need was for planned and emergency respite services (Figure 32). For planned respite services, the unmet need (27.0%) is twice as high as the rate of use among respondents (13.8%); for emergency respite, unmet need (24.4%) is four times the rate of use (6.1%). About 1 in 4 carers reported an unmet need for in-person counselling, twice the rate of carers using this service type (12.9%). High unmet need also was reported for carer specific information sessions (22.0%), skills training (21.5%), and face-to-face peer support (21.7%). The largest group of respondents (38.0%), however, reported not using or needing carer support services at all.

Figure 32: Carer support services, use and unmet need (N=5,640)



Despite the Carer Gateway website and phone line being the most frequently used carer support services, the most common issue reported regarding carer support services was difficulty finding information about available services. 1 in 4 respondents (24.4%) reported that carer support services were interrupted or cancelled due to COVID-19, and around 1 in 5 respondents found that services did not meet their needs, were too difficult to organise, or had a long waiting period.

Figure 33: Impacts of carer services (N=5,640)

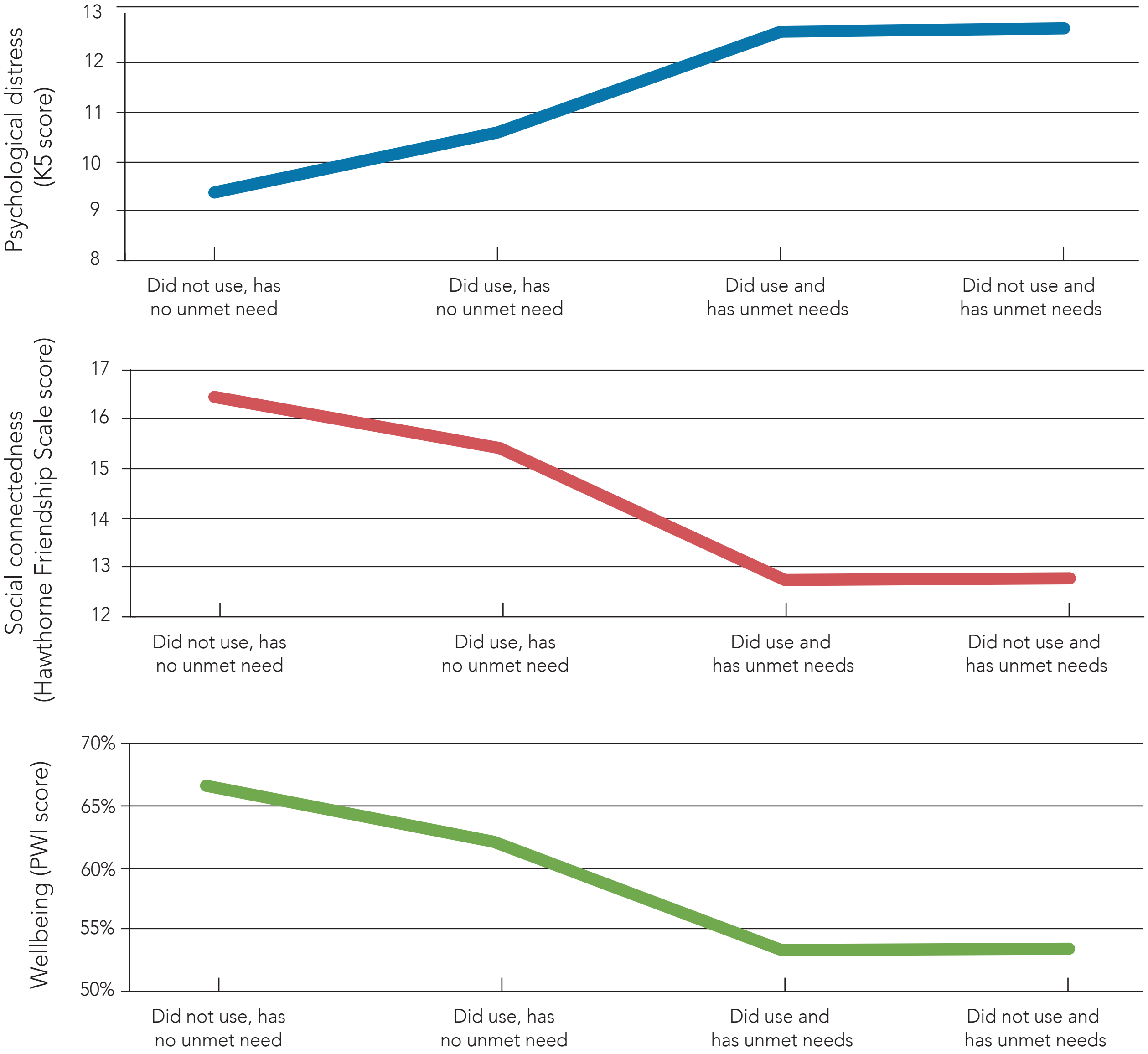


IMPACTS OF CARER SERVICES

Because the Survey sample is not statistically representative, 2022 National Carer Survey data is not suitable for a detailed evaluation of specific service types or for measuring their effectiveness in detail. Nevertheless, the results show that measures for wellbeing, distress and social connectedness interact with reported use and need for carer services, demonstrating that carer services are playing an important role in supporting carers' health and wellbeing.

Another important insight stemming from this analysis is that many carers only access services once the caring situation deteriorates. Many carers who do not access services also report no unmet need, while also reporting the highest levels of wellbeing and social connectedness of all respondents, and the least psychological distress. A second group of carers accesses services at a level that meets their needs, and while they report lower wellbeing, lower social connectedness and higher psychological distress than the first group, our analysis shows that they fare significantly better than those carers who have an unmet need for services (see Appendix I.III for details). Figure 34 visualises these relationships.

Figure 34: Distress and social connectedness by Carer Service Use And Unmet Need



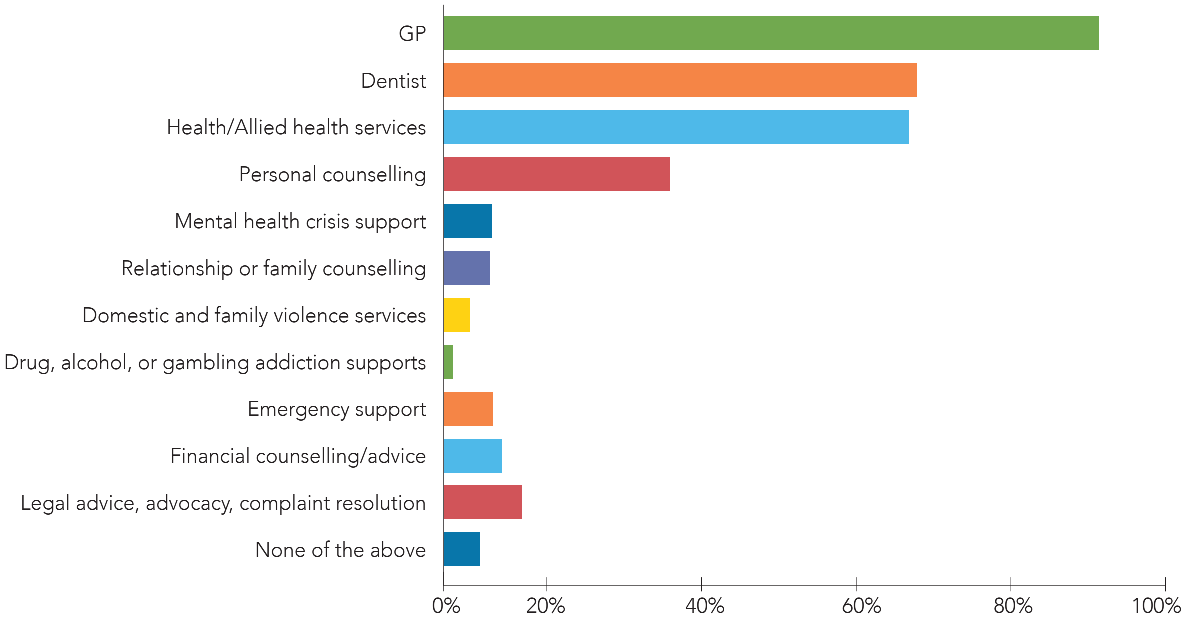
These results demonstrate that services for carers function in a way that stabilises carers' wellbeing, if they meet the carer's needs. A central insight is that services should be accessible to carers before their situation deteriorates. The responses and analyses show that there is a need for improvements in carer services, especially respite, to make them easier to access and available when carers need them. While the information and service access points (Carer Gateway website and phone line) are well established two years after launch, demand outstrips supply for all other service types, especially face-to-face services and respite.

USE OF OTHER SERVICES

Carer support services are not, however, the only means of accessing support. Carers, too, need support with their own physical and mental health, and have unique service needs on other domains because of their caring role. Often, carers neglect their own needs to focus on the needs of the people they care for. The 2022 National Carer Survey also asked about the use of non-carer specific services by carers in the two years leading up to the Survey. The use of these services also helps ascertain the prevalence of health and social issues among carers that otherwise would not be captured.

Most respondents had seen a GP (90.2%), had visited a dentist (65.2%) and had seen an allied health professional (64.1%) such as a physiotherapist for their own health in the past two years.

Figure 35: Personal service use (N=6,684)



The demands of the caring role on mental health and relationships can be seen in the reported uptake of non-carer specific personal counselling services (31.1%), relationship and family counselling (6.4%) and mental health crisis support (6.6%). A small but significant group of 240 respondents (3.6%) had used domestic or family violence services. Another area where respondents demonstrated support needs is in relation to their finances, with 8.0% of respondents using financial counselling and advice services. More than 1 in 10 carers (10.8%) also made use of legal advice, advocacy or complaint resolution services.

KEY POINTS

- Almost 2 in 3 carers (62.0%) used at least one form of carer-specific support services in the two years prior to the survey.
- 1 in 3 respondents had used the Carer Gateway website to access services, and 28.0% had used the Carer Gateway phone line
- There remains a high unmet need for planned and emergency respite services and face-to-face supports
- Carer support services predominantly conserve carer wellbeing, and unmet needs for carer services are associated with significantly worse outcomes for carers.

PAID WORK

As outlined in Table 20, 33.5% of current carers reported being in paid employment, while 7.6% are unemployed and 58.9% of carers are not participating in the labour force. The majority (60.0%) of those not in the labour force were aged 65 years and over, and therefore may have retired. Women are more likely to combine work and care, while most male carers are not participating in the labour force.

Working carers, unsurprisingly, have a lower mean age, and participation in the labour market is higher among those with higher education. Only a third of carers living with a disability or long-term health condition are in paid employment.

Table 20: Selected demographic categories by labour force status

		Employed (%)	Unemployed (%)	Not in labour force (%)
Total (N=6,756)		33.5	7.6	58.9
Age (Mean)		51.3 years	52.6 years	65.4 years
Gender	Female (N=5,428)	35.9	8.0	56.3
	Male (N=1,143)	22.0	5.9	72.1
	Non-binary (N=22)	27.3	18.2	54.5
Education	Bachelor or higher (N=2,094)	50.1	7.0	42.9
	Certificate/diploma (N=2,208)	33.4	8.9	57.7
	High school (N=821)	19.5	8.0	72.5
	Less than high school (N=1,034)	14.6	5.1	80.3
Disability or long-term health condition (N=3,117)		28.2	8.4	63.4

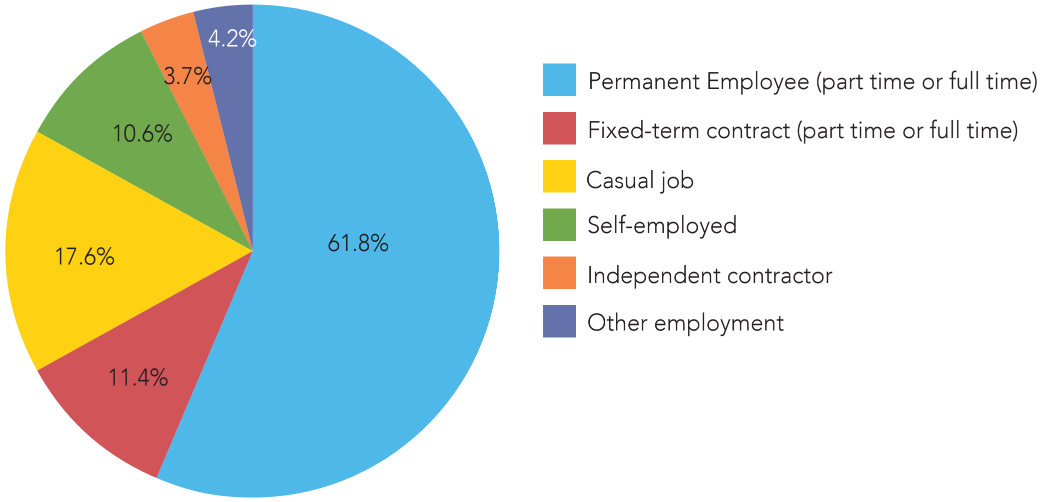
While most carers had left the labour market at 65, 8.2% of carers at retirement age were still in employment or looking for jobs. However, 39.4% of carers aged 26 to 64 were not participating in the labour market (Table 21).

Table 21: Age (broad groupings) by labour force status

	Employed (%)	Unemployed (%)	Not in labour force (%)
Up to 25 years old (N=108)	47.8	14.1	38.0
26 to 64 years old (N=3,550)	50.1	10.5	39.4
65+ years old (N=2,086)	8.2	2.7	89.1

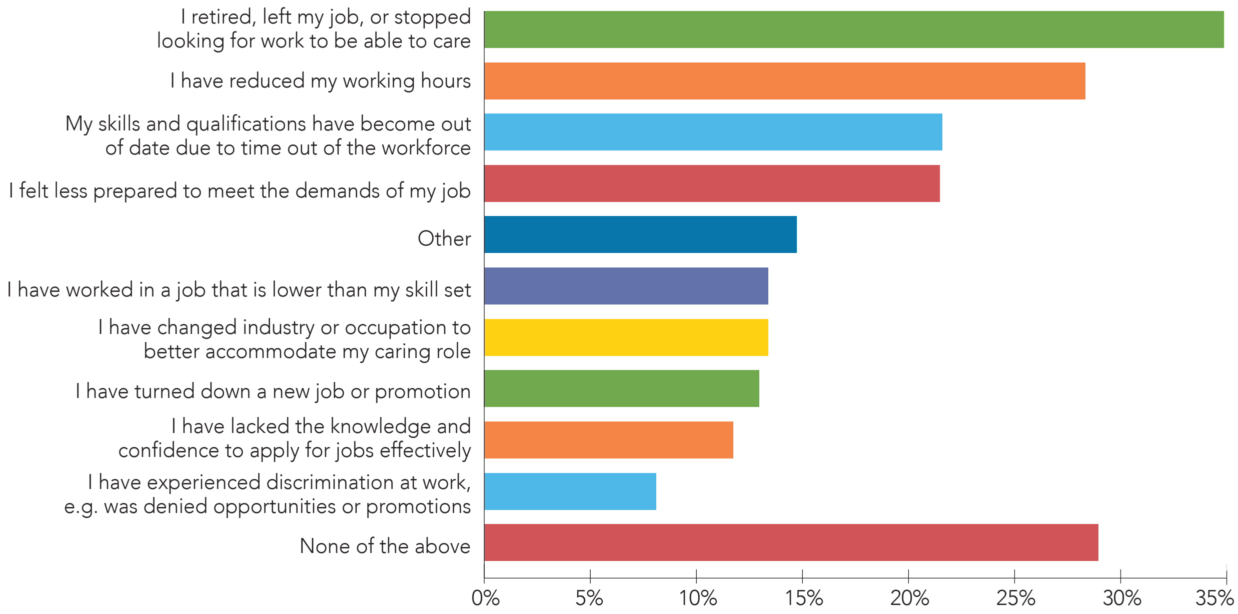
Working carers spent on average 27.2 hours per week undertaking paid work. Of the 2,444 carers in paid employment who responded to the question, most were in permanent positions (61.8%) (see Figure 36).

Figure 36: Carers' employment types (N=2,444)



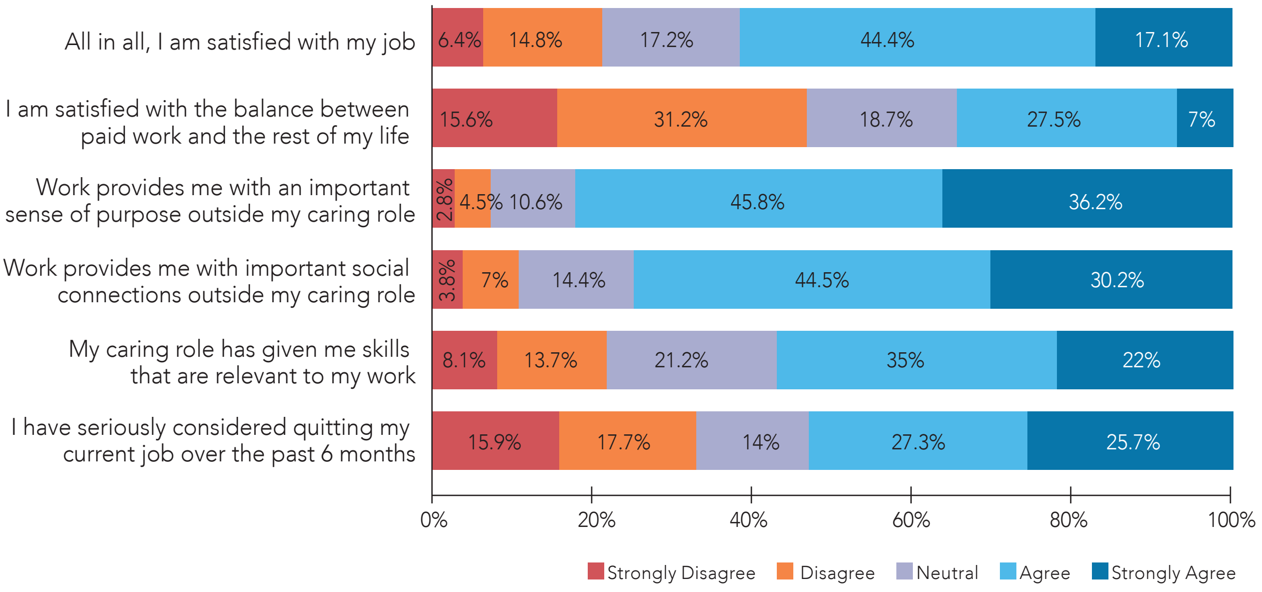
Impacts of caring responsibilities on career progression were widely felt by respondents. Of all respondents (regardless whether they were participating in paid work or not) only 27.9% reported that caring had not impacted their career. Combined with having to retire early to be able to care, 33.6% of carers reported having left the workforce due to their caring responsibilities. The second most common impact (27.3% of respondents) was reducing working hours, followed by not being able to keep skills/qualifications up to date, which was reported by 20.8% of working carers (see Figure 37).

Figure 37: Career impacts of caring (N=6,386)



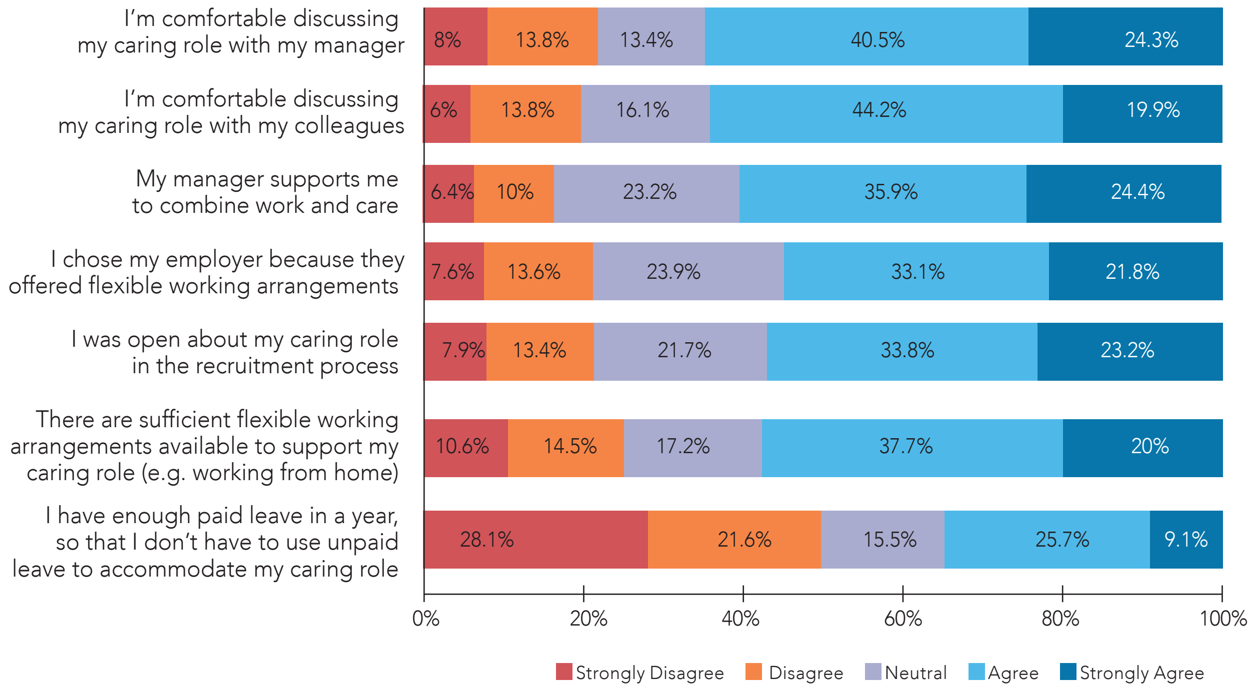
Carers were asked about balancing paid work with their caring role. Overall, carers are satisfied with their jobs. Carers believe their paid work provides them with a sense of purpose and social connection beyond the caring role. The caring role has also allowed them to acquire relevant skills for their job. Yet, many carers (46.5%) are not satisfied with their balance between paid work and their own time, and more than half (53.7%) have considered quitting their job in the past six months in order to provide care.

Figure 38: Balance of paid work and caring role (N=2,444)



Respondents were also asked about the workplace's supportiveness towards their caring role. Overall, carers are comfortable to discuss their caring role in the workplace and during the recruitment process. In most cases, managers show support towards carers in balancing their work and caregiving responsibilities. 1 in 4 carers were however dissatisfied with the available flexible working arrangements (e.g. flexible start/ finish times, work from home) that were provided to accommodate their caring role. However, the majority of carers (49.7%) did not have enough paid leave available, and had to use unpaid leave for their caring responsibilities.

Figure 39: Workplace support for carers (N=2,444)



These results show that while the majority of workplaces are culturally supportive of carers, the time demands of most carers' caring role outstrip the available workplace flexibility and available leave arrangements. This leads many carers to drop out of the labour force, despite work playing an important part for their personal development and sense of purpose.

KEY POINTS

- The typical working carer worked 27.2 hours per week in a permanent position.
- The most common impacts of caring on respondents' paid work were exiting employment and reduced working hours.
- Respondents find it challenging to balance their caring role with paid work, despite the sense of purpose and social connection it provides.
- Workplaces are generally supportive towards carers' caring role, but the majority of respondents did not have enough paid leave available to accommodate the caring role.

HEALTH, WELLBEING AND CARER RECOGNITION

The 2022 National Carer Survey included four scales designed to measure health and wellbeing. The domains measured were the self-assessed health status, subjective wellbeing (the Personal Wellbeing Index), psychological distress (Kessler 5-Item Scale of Psychological Distress) and social connectedness (Hawthorne Friendship Scale).

SELF-ASSESSED HEALTH STATUS

Carers are frequently in poor health themselves, due to the demands on the caring role. The Survey used a question developed for the ABS National Health Survey to ask carers about their subjective health estimate. Table 22 shows the results by age and gender and compares it with the results of the National Health Survey (ABS 2018, latest available release).

Table 22: Subjective health estimate

		Subjective health estimate				
		Poor	Fair	Good	Very Good	Excellent
All respondents (N=6,523)		14.1%	34.6%	32.7%	16%	2.5%
National Health Survey (ABS 2018)		3.5%	10.7%	28.7%	35.8%	21.3%
Age	up to 25 (N=90)	17.8%	25.6%	32.2%	20%	4.4%
	26 to 64 (N=3,837)	17.4%	35.5%	30.6%	14.2%	2.3%
	65 and older (N=2,593)	9.2%	33.7%	35.9%	18.6%	2.6%
Gender	Female (N=5,371)	14.8%	35.4%	32.5%	15%	2.3%
	Male (N=1,123)	10.9%	31.4%	33.4%	20.8%	3.5%
	Non-binary/ Other (N=29)	31%	20.7%	31%	13.8%	3.4%
Long term health condition	No (N=3,417)	4.1%	23.4%	41.4%	26.5%	4.5%
	Yes (N=3,101)	25.4%	47%	22.8%	4.5%	0.3%

These results show that carers estimate their personal health significantly worse than the general population, with carers reporting poor/fair health at a rate of 3.5 times of the general population. While this can be in part attributed to the large proportion of carers who live with a long-term health condition or a disability themselves, even the carers who do not have such a condition report poor or fair health at twice the rate than the general population. Among carers, it is older carers who report relatively better health than working age, and even younger carers. The worst subjective health estimate is reported by carers who do not identify their gender as male or female.

SUBJECTIVE WELLBEING

The Personal Wellbeing Index (PWI, Cummins et al. 2003, IWB 2013) measures satisfaction with life across seven domains, which can either be assessed individually, or collectively as an overall indication of personal wellbeing. Values are calculated to be expressed in the range from 0 to 100% for each domain and the overall index. Table 12 shows the mean scores for the overall index and for each of its domains, as well as a comparison to the scores calculated for the general population of Australia (the 'normative mean', obtained from Crowe et al 2023 and Kohr et al 2021).

The overall respondents' satisfaction with life was 17.0 percent points lower than that of the general population. Survey respondents are found to have the lowest satisfaction on the measures of their achieving in life, health, and future security. The greatest difference to the general population was found in the domain of satisfaction with health. In comparison to the 2022 National Carer Survey, there is a slight increase in PWI. However, respondents experienced a decrease in their standard of living, health and achieving in life. The dimension that showed the greatest increase of 2 percent points was personal relationships.

Table 23: Carers PWI scores in comparison to the general population

Dimension	2022 National Carer Survey mean (%SM) (N=5,921)	2022 normative mean (%SM)*	2020 National Carer Survey mean (%SM) (N=5,569)	2020 normative mean# (%SM)
PWI	57.4	74.4	57.2	75.4
Standard of living	64.2	77.9	65.7	78.1
Health	51.3	72.0	52.7	74.5
Achieving in life	51.3	71.8	51.6	73.4
Personal relationships	57.1	77.4	55.1	79.6
Personal safety	70.4	83.6	69.3	79.6
Community connectedness	54.0	68.2	53.4	71.2
Future security	53.3	69.8	52.4	71.2

* (Crowe et al 2023) # (Kohr et al 2021)

Table 13 compares mean overall wellbeing scores by selected carer demographics. The lowest average wellbeing score was recorded by respondents identifying as non-binary/gender diverse. Overall subjective wellbeing was significantly higher in older carers compared to carers younger than 65 years, with a difference of 11.4 percentage points. Similarly, the wellbeing of carers living remotely was reported to be better than that of the majority living in major urban areas.

Table 24: Wellbeing by selected carer demographics

	Carer Demographic	PWI (mean %SM)
Gender	Female (N=4,959)	56.4
	Male (N=1,016)	62.1
	Non-binary (N=19)	45.7
Age (broad groupings)	Up to 25 (N=84)	58.9
	26 to 64 (N=3,609)	53.0
	65+ (N=2,290)	64.4
Remoteness area	Major Cities (N=3,498)	55.9
	Inner Regional (N=1,608)	59.5
	Outer Regional (N=703)	60.4
	Remote or Very Remote (N=80)	64.0

PSYCHOLOGICAL DISTRESS

Psychological distress was measured using the Kessler 5-Item Scale of Psychological Distress (K5), which is categorised to indicate low to moderate, or high to very high levels of psychological distress. The K5 scale is an adaption of the Kessler 10-item Scale of Psychological Distress (Kessler et al 2003), developed by the Australian Bureau of Statistics to provide a population-level screening tool for psychological wellbeing that is culturally safe for surveys including Aboriginal and Torres Strait Islander respondents (see ABS 2012). Previous versions of the Carers NSW Carer Survey and many general surveys use the K10 scale, which yields comparable data, however the analytical categorisation is necessarily less detailed than in the K10.

Overall, there is a relatively high prevalence of psychological distress among carers, with nearly half of the respondents (47.5%) reporting high or very high psychological distress. Compared to the 2020 Survey, there has been a decrease in the percentage of carers experiencing high/very high distress. The average level of well-being and overall life satisfaction among carers has also increased. However, the average level of distress experienced by carers have increased (See Table 25).

Table 25: K10/K5 and PWI scores, 2020 and 2018

	2022 National Carer Survey	2020 National Carer Survey	2018 Carer Survey (NSW)
K5/K10 score indicating high/very high distress, % of carers	47.5%	47.7%	45.7%
Mean K5/K10 (% of scale maximum)	33.8%	33.0%	30.7%
Mean PWI (% of scale maximum)	57.4%	56.5%	54.3%

SOCIAL CONNECTEDNESS

The social connectedness experienced by carers was measured using the "Friendship Scale" (Hawthorne 2000). This scale provides a measure of overall social connectedness and social isolation. Its six questions explore the degree to which a person has found it easy to relate to others over the past four weeks; if they have felt isolated from other people; if they had someone to share their feelings with; the ease with which the person has been able to get in touch with others if they needed to; whether the person felt separated from others in the past four weeks; and, if they felt alone and friendless. Scores on the friendship scale can be categorised into five levels, ranging from "Highly socially isolated" to "Highly socially connected" (for details see Hawthorne 2006).

Figure 40 shows the scores reported by respondents in the 2022 National Carer Survey. Almost one third of carers reported being highly socially isolated, with another 24.2% reporting social isolation with only low levels of social support. These findings confirm the results obtained from the PWI dimension on satisfaction with personal relationships, and demonstrate that social isolation is a central issue affecting the wellbeing of carers, especially during the COVID-19 pandemic.

Table 26 shows a comparison of Friendship Scale scores by selected demographic groups in the 2022 and 2020 National Carer Surveys. The highest rates of social isolation are reported by non-binary/gender diverse carers. The highest rates of social connectedness were reported by older carers, male carers and carers living in remote or very remote areas. Compared to the 2020 National Carer Survey, there is a notable increase in social isolation endured by non-binary/gender diverse carers. While young carers are more socially connected, the social isolation felt by other age groups have increased.

Figure 40: Social isolation/connectedness among carers (N=6,385)

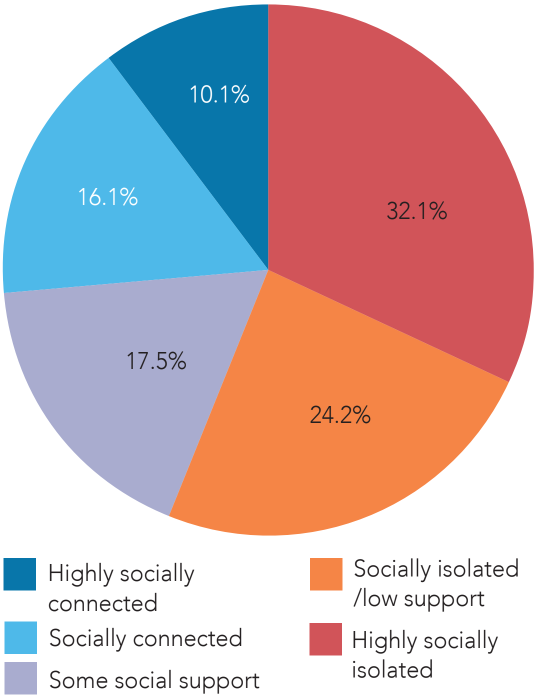


Table 26: Social isolation/connectedness among selected demographics

Friendship Scale – Category		Highly socially isolated		Socially isolated/ low support		Some social support		Socially connected		Highly socially connected	
		2022	2020	2022	2020	2022	2020	2022	2020	2022	2020
Gender	Female (N=4,506)	33%	33%	24%	25%	18%	18%	15%	15%	9%	9%
	Male (N=954)	26%	25%	23%	26%	17%	18%	21%	18%	13%	13%
	Non-binary (N=15)	62%	47%	24%	20%	0%	20%	10%	7%	5%	7%
Age	Up to 25 (N=102)	36%	43%	27%	30%	20%	17%	14%	6%	3%	4%
	26 to 64 (N=3,432)	39%	37%	25%	24%	15%	17%	13%	14%	7%	8%
	65+ (N=1,923)	21%	20%	23%	26%	21%	20%	21%	20%	15%	14%
Remoteness Area	Major Cities (N=2,818)	33%	33%	24%	26%	17%	17%	16%	15%	9%	9%
	Inner Regional (N=1,721)	30%	30%	23%	23%	19%	19%	17%	17%	11%	11%
	Outer Regional (N=761)	31%	31%	27%	26%	16%	19%	16%	15%	10%	9%
	Remote or Very Remote (N=114)	24%	22%	18%	22%	24%	16%	18%	25%	15%	15%

Carers were also asked about their satisfaction with personal relationships (see Table 27), to identify particular sources of social and emotional support. On average, the most satisfactory relationships exist with persons being cared for and friends. The average satisfaction with the relationships to partners and parents is reported as rather low (below 50% for all demographics except male carers with their partner). These results show that caring roles impact the wider family dynamic significantly, and that it is not only the relationship with the cared for that changes because of a caring role. Carers rather face significant challenges in maintaining relationships with other family members and friends.

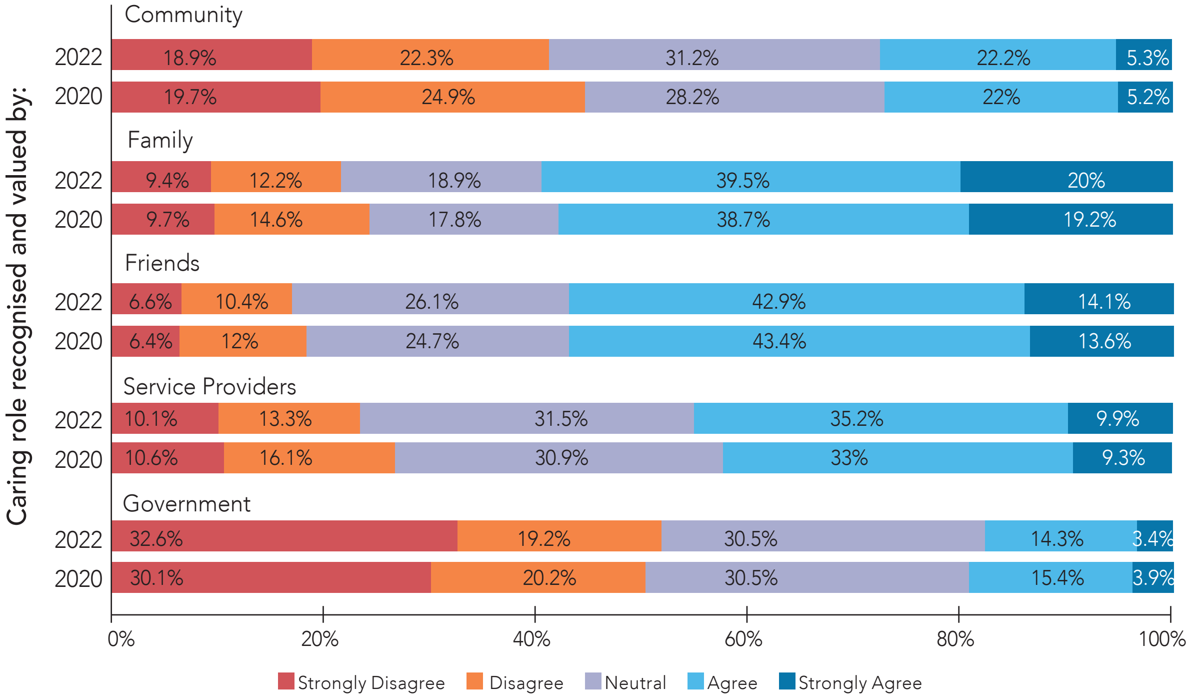
Table 27: Relationship satisfaction, mean %

		Relationship satisfaction with:				
		Partner (N=6,494)	Parents (N=6,347)	Children (N=6,494)	Friends (N=6,524)	Person cared for (N=6,524)
All carers		50.2	33.1	61.8	62.4	65.7
Gender	Female	47.7	34.7	62.8	62.0	64.7
	Male	62.3	25.2	58.0	64.6	71.1
	Non-binary	37.1	27.1	34.7	41.0	50.0
Age group	up to 25	36.8	63.8	11.1	64.2	69.7
	26 to 64	47.1	46.8	60.2	56.8	66.1
	65+	55.5	10.4	66.0	70.8	65.4

CARER RECOGNITION

All respondents to the Survey were asked to what extent they agreed that their caring role was recognised and valued by their community, family, friends, service providers, and governments. Most carers agreed that their caring role was recognised by their family and friends, and a majority feels recognised by service providers. Respondents however felt in their majority that the community and governments did not recognise carers, and for all sources of recognition, one third was undecided.

Figure 41: Carer recognition (N=6,494)



These results were remarkably stable compared to the 2020 Survey, which underscores the need for improved carer recognition, especially from government and community sources.

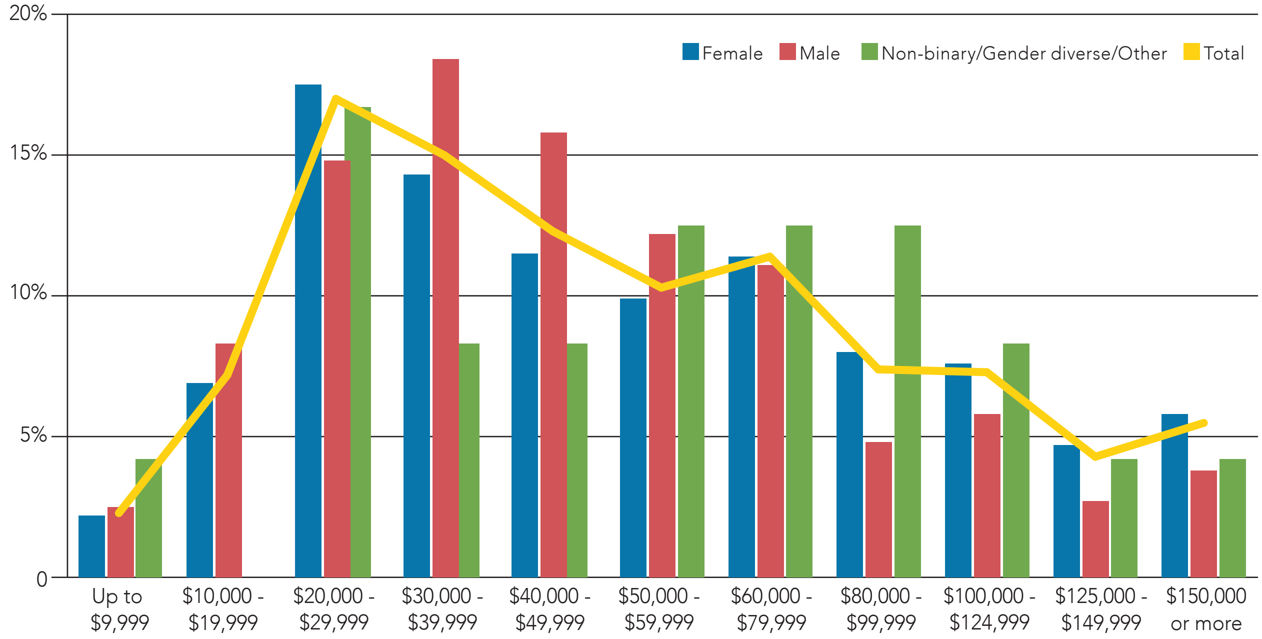
FINANCES, FINANCIAL WELLBEING, AND HOUSING

As detailed earlier in this report, caring can have a significantly negative impact on some carers' employment and income opportunities. The employment situation of many carers, and subsequently their income, may have been further affected by the economic impacts of COVID-19.

RESPONDENT INCOME

Figure 42 shows the gross household income among respondents. Carers responding to the 2022 National Carer Survey were more likely to live in lower income households than the general population. Indeed, the majority (57.1%) were living in households with an income of less than $60,000 before tax (gross income). For comparison, the median annual gross household income in Australia in 2022 was $92,040 (ABS 2023). Male carers (59.7%) were slightly more likely than female carers (52.5%) to live in households with a gross income of less than $50,000 per year.

Figure 42: Pre-tax household income (N=5,119)



Due to their relatively low incomes, many carers are eligible for income support payments. Figure 43 shows that only 1 in 4 carers (23.2%) was not receiving any income support payments, while the majority of respondents (57.8%) were receiving the Carer Allowance (currently up to $136.50 per fortnight), and 1 in 4 carers (23.8%) was receiving the Carer Payment (up to $987.60 per fortnight for singles, or $1,488.80 combined for couples, including the Pension and Energy supplements)[5].

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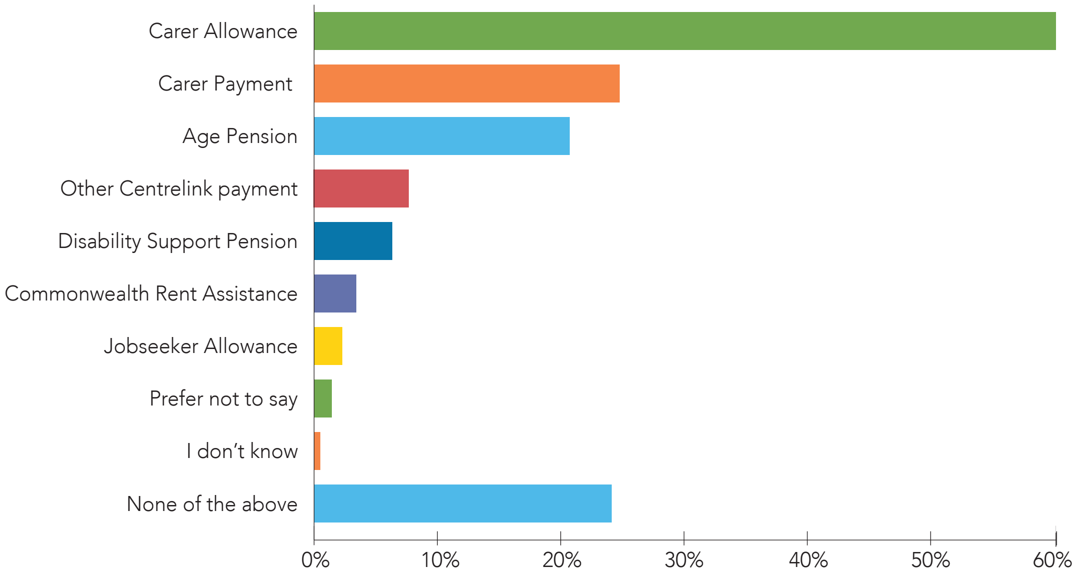
[5] Carer Allowance can be received on its own or in addition to another Centrelink payment. All Carer Payment recipients also receive Carer Allowance as a supplement.

Figure 43: Receipt of Centrelink payments (N=6,488)



Receiving an income support payment was more common in inner and outer regional areas than major cities and remote areas. Among carers of working age, 2 in 3 received the Carer Allowance, and 1 in 3 received the Carer Payment. Young carers were least likely to receive any income support, but were also more likely than other age groups of carers to receive a non-carer specific income support payment (e.g. Austudy). Among carers aged 65+, half (49.9%) received the full or part age pension, and only 15.9% received no support payments.

Table 28: Centrelink payments, by age and location

	Age (broad groupings)			Remoteness area			
	up to 25 (n=87)	26 to 64 (n=3,786)	65+ (n=2.537)	Major Cities (n=3,705)	Inner Regional (n=1,750)	Outer Regional (n=766)	Remote or Very Remote (n=88)
Carer Allowance	19.5%	60.8%	54.7%	56.7%	59.8%	60.1%	51.1%
Carer Payment	11.5%	30.3%	14.4%	22.0%	26.5%	26.6%	19.3%
Newstart/ Jobseeker	8.0%	3.4%	0.4%	2.0%	2.6%	3.3%	0.0%
Age Pension	-	0.5%	49.9%	15.6%	25.9%	27.4%	28.4%
Disability Support Pension	4.6%	7.8%	3.5%	5.8%	6.5%	6.4%	2.3%
Commonwealth Rent Assistance	2.3%	4.0%	2.4%	3.3%	3.7%	3.3%	1.1%
Other Centrelink payment(s)	20.7%	8.4%	5.5%	7.2%	7.3%	9.3%	4.5%
None of the above	50.6%	27.5%	15.9%	26.7%	19.0%	16.4%	29.5%

FINANCIAL STRESS AND DISTRESS

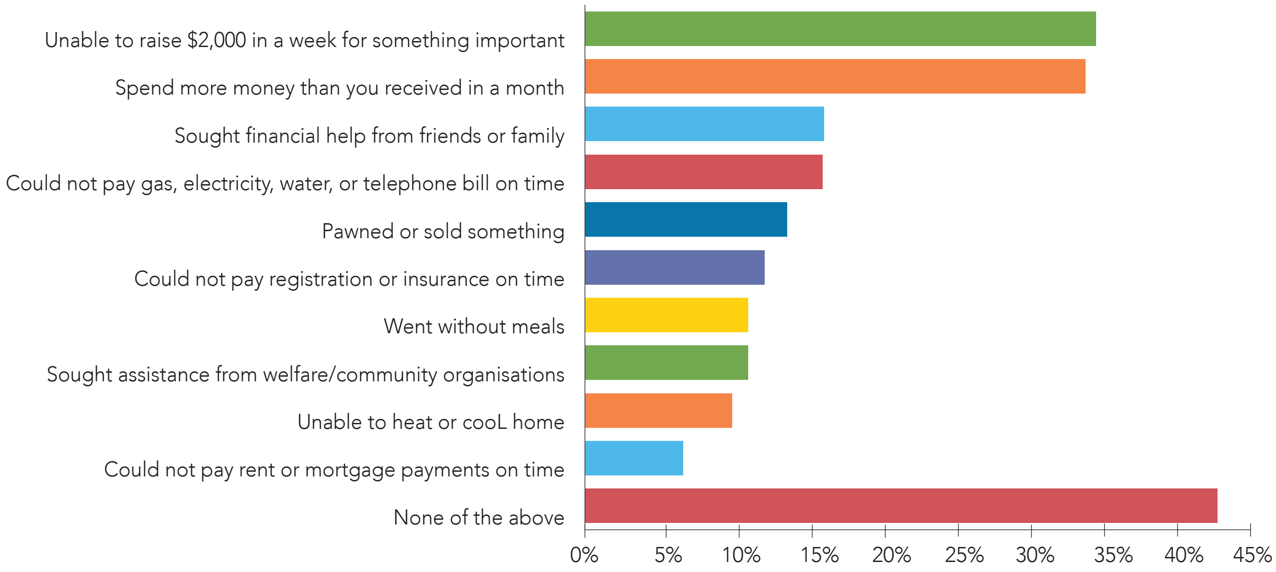
To measure the extent of financial security among carers, the 2022 National Carer Survey included a set of questions on financial stress used by the ABS in its Household Expenditure survey (ABS 2017), and, more recently and with slight modifications, in the General Social Survey (ABS 2020). The indicators of financial stress are:

- Being unable to raise $2,000 in a week for something important
- Spending more money than received
- Not being able to pay a gas, electricity or telephone bill on time
- Not being able to pay car registration or insurance on time
- Having pawned or sold something
- Going without meals
- Being unable to heat one's home
- Seeking assistance from welfare/community organisations
- Seeking financial help from friends or family.

A household is considered to be in financial distress if they experience four or more of the above indicators of financial stress within a 12-month period.

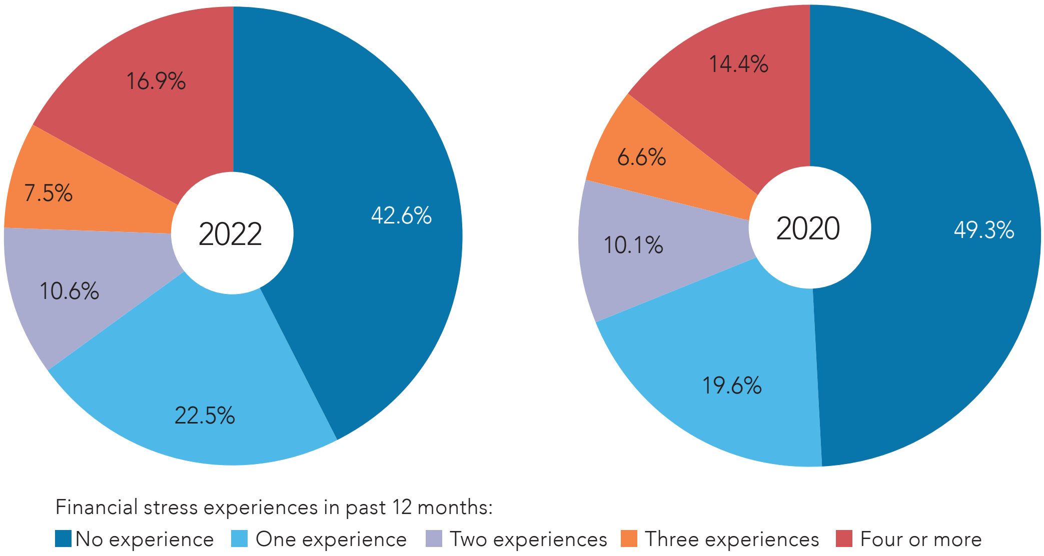
Figure 44 shows that the most common indicator of financial stress experienced by Survey respondents was being unable to raise $2,000 in a week if needed (34.4%) and spend more money than received in a month (33.7%). This applies to 1 in 3 carer households, compared to 1 in 4 of all Australian households (ABS 2020). This suggests both a lack of personal savings reserves and a lack of personal connections that can provide financial assistance.

Figure 44: Experiences of financial stress (N=5,825)



Compared with the 2020 Survey, there is a significant overall increase in carers' experiences of financial stress, reflective of the increased cost of living pressures since the end of COVID-19 restrictions (See Figure 45).

Figure 45: Number of financial stress experiences, 2022 and 2020 (N=5,825)



As detailed in Table 29, financial distress was more prevalent in larger households, with 2 in 3 households with five or more members reporting at least one instance of financial stress, and more than a quarter of these respondents reporting four or more financial stress experiences. Unemployed carers reported the highest rate of financial distress when compared to their working peers and those voluntarily outside the labour force. Carers not in the labour force (who are most commonly retired) were less likely overall to experience any financial stress than employed carers.

Table 29: Financial stress and distress by household size and labour force status

Number of experiences of financial stress in past 12 months	Household size					Labour force participation		
	1 Person (n=552)	2 Persons (n=2,581)	3 Persons (n=1,113)	4 Persons (n=784)	5 or more Persons (n=147)	Employed (n=1,919)	Unemployed (n=454)	Not in labour force (n=3,4532)
None	49.8%	48.9%	38.5%	31.9%	23.4%	38.6%	18.7%	47.9%
One	23.4%	22.7%	21.2%	21.7%	23.0%	25.1%	20.5%	21.2%
Two	8.9%	9.4%	11.9%	10.5%	15.8%	11.9%	13.7%	9.4%
Three	5.8%	6.0%	7.5%	12.9%	10.4%	8.3%	12.1%	6.5%
Four or more	12.1%	13.1%	20.9%	23.1%	27.3%	16.1%	35.0%	15.0%

HOUSING

Housing is an issue closely related to income and cost-of-living pressure. Caring roles can also change the satisfaction with the housing of carers and the people they care for, e.g. when modifications are needed for a wheelchair or guard rails, or when a carer needs to live with the person they care for in a house not accommodating additional occupants. In the Survey, we therefore asked carers whether their housing situation currently meets their needs and the needs of their caring role.

Overall, 2 in 3 carers are satisfied with their housing situation, while 1 in 5 is dissatisfied (19.9%). The satisfaction with one's home varies with age, and with household size. Older people and smaller households are more satisfied with their housing condition, while younger carers and larger households tend to be less satisfied. The dissatisfaction with housing conditions drops from 28.9% for carers younger than 25 years viewing their housing situation negatively, to 11.3% among respondents aged 65 and older. Inversely, only 1 in 10 one-person households are not satisfied with their housing conditions, where as almost 1 in 3 carers from households of 5 or more people answered negatively.

Table 30: Housing satisfaction

My home currently meets my needs	Total (N=6472)	Age (3 groups)			Household size				
		Up to 25 years	26 to 64 years	65 and older	One person	Two persons	Three persons	Four persons	Five or more
Strongly disagree	6.7%	8.9%	8.7%	3.3%	3.5%	5.4%	8.1%	6.6%	13.3%
Disagree	13.2%	20.0%	16.2%	8.0%	6.8%	11.9%	14.4%	18.4%	15.9%
Neither agree nor disagree	12.9%	17.8%	14.6%	10.1%	11.0%	12.3%	13.9%	14.9%	12.8%
Agree	42.3%	36.7%	40.3%	45.9%	45.0%	43.1%	40.4%	41.5%	40.8%
Strongly agree	24.9%	16.7%	20.2%	32.6%	33.7%	27.2%	23.3%	18.6%	17.2%

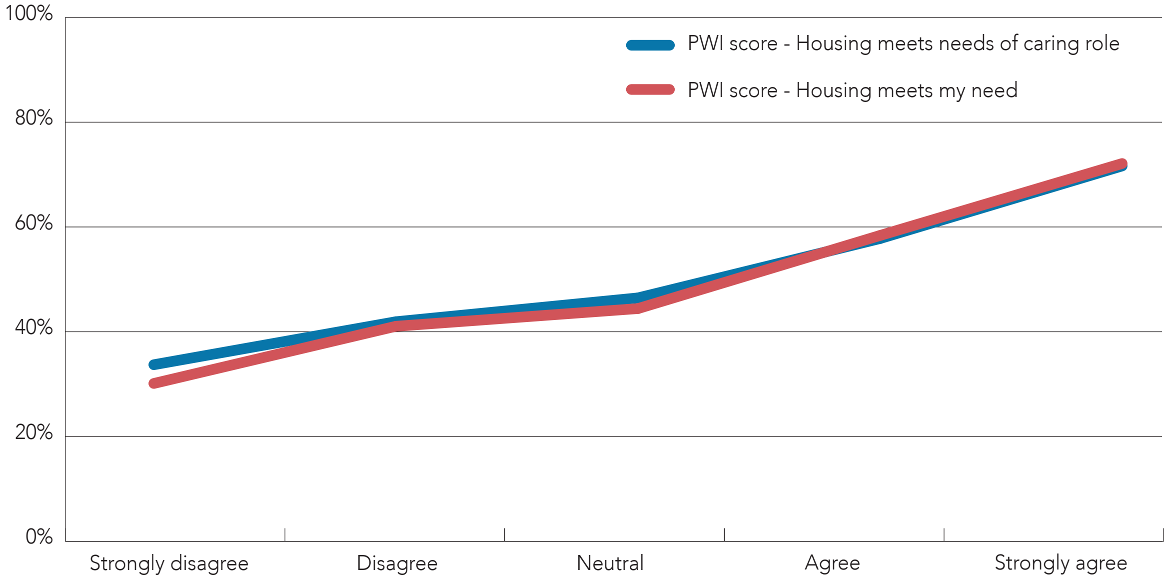
The responses to the question whether housing meets the needs of the caring role are similar, with slightly fewer respondents being satisfied, especially among the older cohort and larger households. Again, 1 in 5 carers report that overall, their housing situation is not adequate for their caring role, with younger carers and larger households being the most dissatisfied.

Table 31: Housing meets needs of caring role

My home currently meets my needs	Total (N=6472)	Age (3 groups)			Household size				
		Up to 25 years	26 to 64 years	65 and older	One person	Two persons	Three persons	Four persons	Five or more
Strongly disagree	6.7%	12.9%	8.4%	3.7%	3.9%	5.6%	7.5%	6.9%	11.9%
Disagree	13.0%	17.6%	15.7%	8.2%	10.0%	11.7%	13.5%	15.7%	16.4%
Neither agree nor disagree	14.2%	14.1%	16.0%	11.5%	14.4%	14.0%	14.2%	15.5%	13.3%
Agree	45.1%	41.2%	42.5%	49.9%	47.8%	45.6%	44.6%	44.4%	42.7%
Strongly agree	21.0%	14.1%	17.4%	26.7%	23.9%	23.0%	20.2%	17.5%	15.7%

The housing situation significantly impacts the wellbeing of carers. Figure 46 shows the relationship between how carers rate the adequacy of their housing for themselves and for their caring role, and the average score of the Personal Wellbeing Index. For both relationships a statistically significant positive relationship was found, with a neutral rating on either scale corresponding to an average PWI score below the survey mean.

Figure 46: Housing indicators and wellbeing



Like many aspects of life, housing needs and the ability to afford one's home change over the life course. These results show that caring roles also impact housing situations, and that tailored supports to support carers in inadequate housing are needed. Like many young people, young carers are especially challenged by the Australian housing market and the ill affordability it provides, and may require specialised supports.

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APPENDIX

4

I. STATISTICAL ANALYSES

I.1 CARER RECOGNITION

Factor analysis (PCA)

A principal component analysis confirms that the 5 Likert-scale items measure one underlying factor (Exploratory factor analysis using PCA extracted a single component based on eigenvalue >1), explaining 58.8% of the variance. The Cronbach's Alpha of .823 for a scale of these 5 items shows high reliability (internal consistency). This allows the summary index of all 5 items to be used in analysis.

Table 32: Carer Recognition PCA results

Factor Matrix*	Factor loading	Commonalities	
		Initial	Extraction
Recognised by family	0.639	0.368	0.467
Recognised by friends	0.720	0.447	0.583
Recognised by community	0.800	0.511	0.649
Recognised by service providers	0.695	0.408	0.506
Recognised by government	0.662	0.398	0.522

* One factors extracted. Four iterations required. Extraction Method: Generalized Least Squares.

Recognition as determinant of wellbeing, distress, and social connectedness

To demonstrate the relationship of recognition to wellbeing, distress and social connectedness, a series of linear regression analyses was performed using the summary recognition index to predict wellbeing (Personal Wellbeing Index score), psychological distress (Kessler 5 score), and social connectedness (Hawthorne Friendship Scale score). Recognition was a significant predictor for all three outcomes, as per the below table.

Table 33: Recognition as predictor for wellbeing, distress and social connectedness

Dependent variable	R	R^2	dF/F	Sig.
Personal Wellbeing Index	0.507	0.257	F(1, 5235)=1813.157	<0.001
Kessler 5	0.387	0.150	F(1,5490)=966.807	<0.001
Hawthorne Friendship Scale	0.517	0.267	F(1,5517)=2013,619	<0.001

Determinants of recognition

A standard linear regression model was used to explore the determinants of perceived recognition. Variables on demography (age, gender, indigenous identification, CALD identification), the caring situation (caring for someone using aged care services, disability services or mental health services, hours of care per week, and the average score of relationship satisfaction with family and friends) and economic situation (whether the carer was in paid work, whether they received care-related Centrelink payments, and the number of experiences of financial stress in the previous 12 months), were used to estimate the summary score on the 5 Likert-scale recognition items.

The overall model was found to be significant (F(14,4059)=106.209, p<0.001), with an adjusted R2 of 0.266. Significant predictors (p<0.05, see table below in in bold) that had a positive relationship to recognition were male gender, identifying as culturally or linguistically diverse, age, and receipt of the Carer Payment. Predictors with a significant negative relationship were caring for someone using disability services, being in paid work, and experiencing increased financial stress.

Table 34: Determinants of recognition, exploratory regression results

Coefficients[a]					
Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
1 (Constant)	8.452	.446		18.969	<.001
Caring for someone with aged care services	.170	.138	.019	1.232	.218
Caring for someone with disability services	-.332	.139	-.038	-2.393	.017
Caring for someone with mental health services	-.225	.126	-.026	-1.795	.073
Male Carer	.869	.166	.072	5.231	<.001
Aboriginal and/or Torres Strait Islander	.296	.356	.011	.831	.406
Carer identifies as LGBTQ+	-.015	.261	-.001	-.057	.954
CALD carer	.598	.152	.053	3.934	<.001
Carer in paid work	-.310	.142	-.034	-2.189	.029
Age	.046	.005	.147	8.468	<.001
Hours spent caring (all respondents)	.001	.001	.008	.534	.593
Mean relationship satisfaction	.754	.030	.350	24.770	<.001
Centrelink: Carer Allowance (currently $136.50 per fortnight)	.267	.139	.029	1.915	.056
Centrelink: Carer Payment (currently up to $987.60 per fortnight for singles and $1,488.80 for couples)	.365	.150	.037	2.431	.015
Number of financial stress experiences	-.370	.030	-.193	-12.262	<.001

a. Dependent Variable: Recognition index (Sum of Community, Family, Friends, Service providers, Government)

I.II CARER WELLBEING

Logistic regression was used to identify relationships between demographic- and experience-related variables, and whether the respondent scored in the top 25% on the PWI among survey respondents. Variables were included due to theoretical reasoning and examined for linear or quadratic relationships. Table 35 shows the results of the model. The model N was 2,215 of complete surveys. Variables with significant influence (p<0.05) are indicated with *. The model was found to be of moderate explanatory strength.

Table 35: What works for carer wellbeing - Logistic regression results

Logistic regression - results			95% CI		
Variable	B	S.E.	Lower	Exp(B)	Upper
Recognition score*	0.10	0.020	1.060	1.10	1.145
Carer in paid work	0.09	0.155	0.810	1.10	1.485
Social connectedness (Hawthorne Friendship Scale)*	0.24	0.017	1.232	1.27	1.319
Agreement: formal services meet needs for carer*	0.23	0.080	1.076	1.26	1.475
No unmet need of carer services*	0.27	0.129	1.014	1.31	1.684
Number of financial stress experiences*	-0.37	0.051	0.625	0.69	0.764
Hours spent caring*	0.00	0.001	0.996	0.997	0.999
Time for yourself	0.00	0.004	0.995	1.00	1.011
Age*	-0.08	0.028	0.877	0.93	0.977
Age squared*	0.00	0.000	1.000	1.00	1.001
CALD carer	-0.08	0.168	0.661	0.92	1.278
Male carer	-0.10	0.184	0.633	0.91	1.304
Constant	-4.35	0.822		0.01	

R2=.304 (Cox & Snell), 0.464 (Nagelkerke); Model Chi2=801.35(12), p<.001

I.III CARER SERVICES

One-way ANOVA was performed to compare the effect of reported use and unmet need of carer services on wellbeing, measured through the Personal Wellbeing Index (PWI), psychological distress, measured through the Kessler 5-Item scale (K5), and social connectedness, measured through the Hawthorne Friendship scale (FS). The comparison The analyses revealed that there was a statistically significant difference in wellbeing (F(3, 5124)=130.213, p<0.001), psychological distress (F(3, 5381)=154.970, p<0.001) and social connectedness (F(3, 5347)=136.220, p<0.001).

The tables below show the results for Tukey's HSD Test for multiple comparisons. The tests found that the mean value of PWI, K5 and FS was significantly different between carers who did not use services and had no unmet service needs, carers who used carer services and had their needs met, and carers who had unmet needs for services, regardless of their use.

Table 36: Tukey HSD, Carer Service Use/Wellbeing

Wellbeing (PWI) - Tukey HSD[a,b]				
Carer Services: Use and Need	N	Subset for alpha = .050		
		1	2	3
Did use carer services, has unmet needs	1759	52.2261		
Did not use carer services, and has unmet needs	1034	52.3349		
Did use carer services, has no unmet need	1454		61.5809	
Did not use carer services, has no unmet need	881			66.4245
Sig.		.999	1.000	1.000

Means for groups in homogeneous subsets are displayed.
a. Uses Harmonic Mean Sample Size = 1191.024. b. The group sizes are unequal.
The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 37: Tukey HSD, Carer Service Use/Psychological distress

Psychological distress (K5) - Tukey HSD[a,b]				
Carer Services: Use and Need	N	Subset for alpha = .050		
		1	2	3
Did use carer services, has unmet needs	964	9.6266		
Did not use carer services, and has unmet needs	1523		10.7938	
Did use carer services, has no unmet need	1810			12.7530
Did not use carer services, has no unmet need	1088			12.8171
Sig.		1.000	1.000	.983

Means for groups in homogeneous subsets are displayed.
a. Uses Harmonic Mean Sample Size = 1263.605.
b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

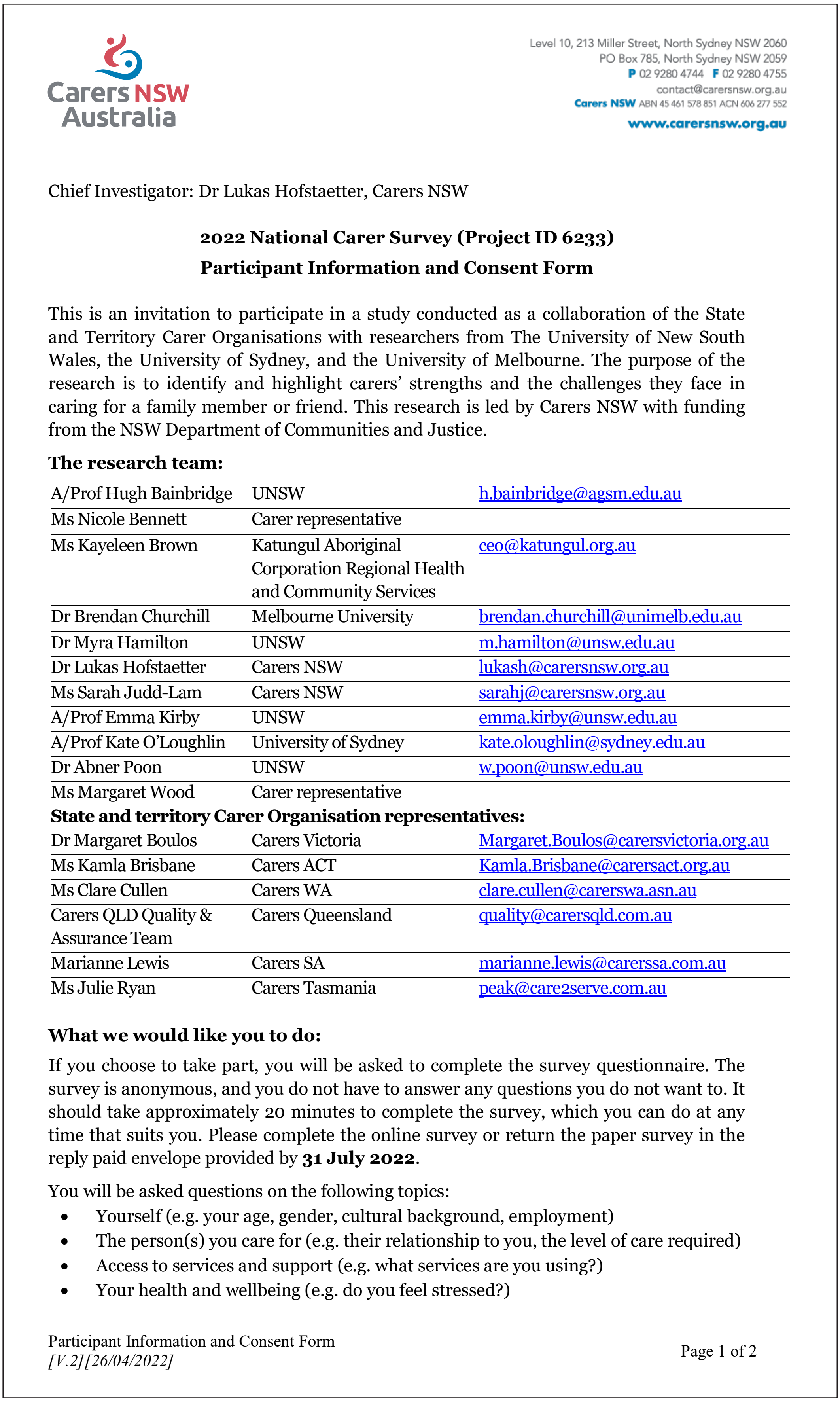
Table 38: Tukey HSD, Carer Service Use/Social connectedness

Social connectedness (Hawthorne Friendship scale) - Tukey HSD[a,b]				
Carer Services: Use and Need	N	Subset for alpha = .050		
		1	2	3
Did use carer services, has unmet needs	1790	12.7508		
Did not use carer services, and has unmet needs	1081	12.7826		
Did use carer services, has no unmet need	1528		15.3743	
Did not use carer services, has no unmet need	952			16.3918
Sig.		.999	1.000	1.000

Means for groups in homogeneous subsets are displayed.
a. Uses Harmonic Mean Sample Size = 1263.605.
b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

II. SURVEY MATERIALS

II.I PARTICIPANT INFORMATION AND CONSENT FORM



Carers NSW Australia
Level 10, 213 Miller Street, North Sydney NSW 2060
PO Box 785, North Sydney NSW 2059
P 02 9280 4744 **F** 02 9280 4755
contact@carersnsw.org.au
Carers NSW ABN 45 461 578 851 ACN 606 277 552
www.carersnsw.org.au

Chief Investigator: Dr Lukas Hofstaetter, Carers NSW

2022 National Carer Survey (Project ID 6233)
Participant Information and Consent Form

This is an invitation to participate in a study conducted as a collaboration of the State and Territory Carer Organisations with researchers from The University of New South Wales, the University of Sydney, and the University of Melbourne. The purpose of the research is to identify and highlight carers' strengths and the challenges they face in caring for a family member or friend. This research is led by Carers NSW with funding from the NSW Department of Communities and Justice.

The research team:

A/Prof Hugh Bainbridge	UNSW	h.bainbridge@agsm.edu.au
Ms Nicole Bennett	Carer representative	
Ms Kayeleen Brown	Katungul Aboriginal Corporation Regional Health and Community Services	ceo@katungul.org.au
Dr Brendan Churchill	Melbourne University	brendan.churchill@unimelb.edu.au
Dr Myra Hamilton	UNSW	m.hamilton@unsw.edu.au
Dr Lukas Hofstaetter	Carers NSW	lukash@carersnsw.org.au
Ms Sarah Judd-Lam	Carers NSW	sarahj@carersnsw.org.au
A/Prof Emma Kirby	UNSW	emma.kirby@unsw.edu.au
A/Prof Kate O'Loughlin	University of Sydney	kate.oloughlin@sydney.edu.au
Dr Abner Poon	UNSW	w.poon@unsw.edu.au
Ms Margaret Wood	Carer representative	
State and territory Carer Organisation representatives:		
Dr Margaret Boulos	Carers Victoria	Margaret.Boulos@carersvictoria.org.au
Ms Kamla Brisbane	Carers ACT	Kamla.Brisbane@carersact.org.au
Ms Clare Cullen	Carers WA	clare.cullen@carerswa.asn.au
Carers QLD Quality & Assurance Team	Carers Queensland	quality@carersqld.com.au
Marianne Lewis	Carers SA	marianne.lewis@carerssa.com.au
Ms Julie Ryan	Carers Tasmania	peak@care2serve.com.au

What we would like you to do:

If you choose to take part, you will be asked to complete the survey questionnaire. The survey is anonymous, and you do not have to answer any questions you do not want to. It should take approximately 20 minutes to complete the survey, which you can do at any time that suits you. Please complete the online survey or return the paper survey in the reply paid envelope provided by **31 July 2022**.

You will be asked questions on the following topics:

- Yourself (e.g. your age, gender, cultural background, employment)
- The person(s) you care for (e.g. their relationship to you, the level of care required)
- Access to services and support (e.g. what services are you using?)
- Your health and wellbeing (e.g. do you feel stressed?)

By submitting a completed survey, you are indicating your consent to participate.

At the end of this survey, you will have the option to register for participation in a follow-up study in 2024 by providing Carers NSW with contact details. These details will only be used to contact you for the follow-up study, and not for any other purpose. Your contact details will be stored in a separate database and will not be part of any analysis. If you do not wish to participate in the follow-up study you still can take part in the survey.

You can also choose to enter a prize draw. One participant from each state or territory can win an Apple iPad 64 GB WiFi. The prize draw will be conducted on **31 August 2022**, the winner will be contacted via email or post.

If you have any questions or would like assistance to complete the survey, please contact Carers NSW Research Team on (02) 9280 4744 or research@carersnsw.org.au.

Possible risks, inconveniences and discomforts

It is not envisaged that you will experience any discomfort as a result of participating in this survey. However, if your participation raises any issues of concern or discomfort, you are encouraged to call either of these services:

In an emergency, call **Triple Zero 000**

Carer Gateway: 1800 422 737
(8am – 5pm Monday-Friday)

Lifeline Australia: 13 11 14
(24 hours)

Lifeline Text: 0477 13 11 14
(6pm – Midnight, 7 days a week)

If you wish to contact an Aboriginal or Torres Strait Islander Health Service, please contact the service nearest to you. A list of services is available under https://healthinfonet.ecu.edu.au/key-resources/health-professionals/health-workers/map-of-aboriginal-and-islander-healthmedical-services/.

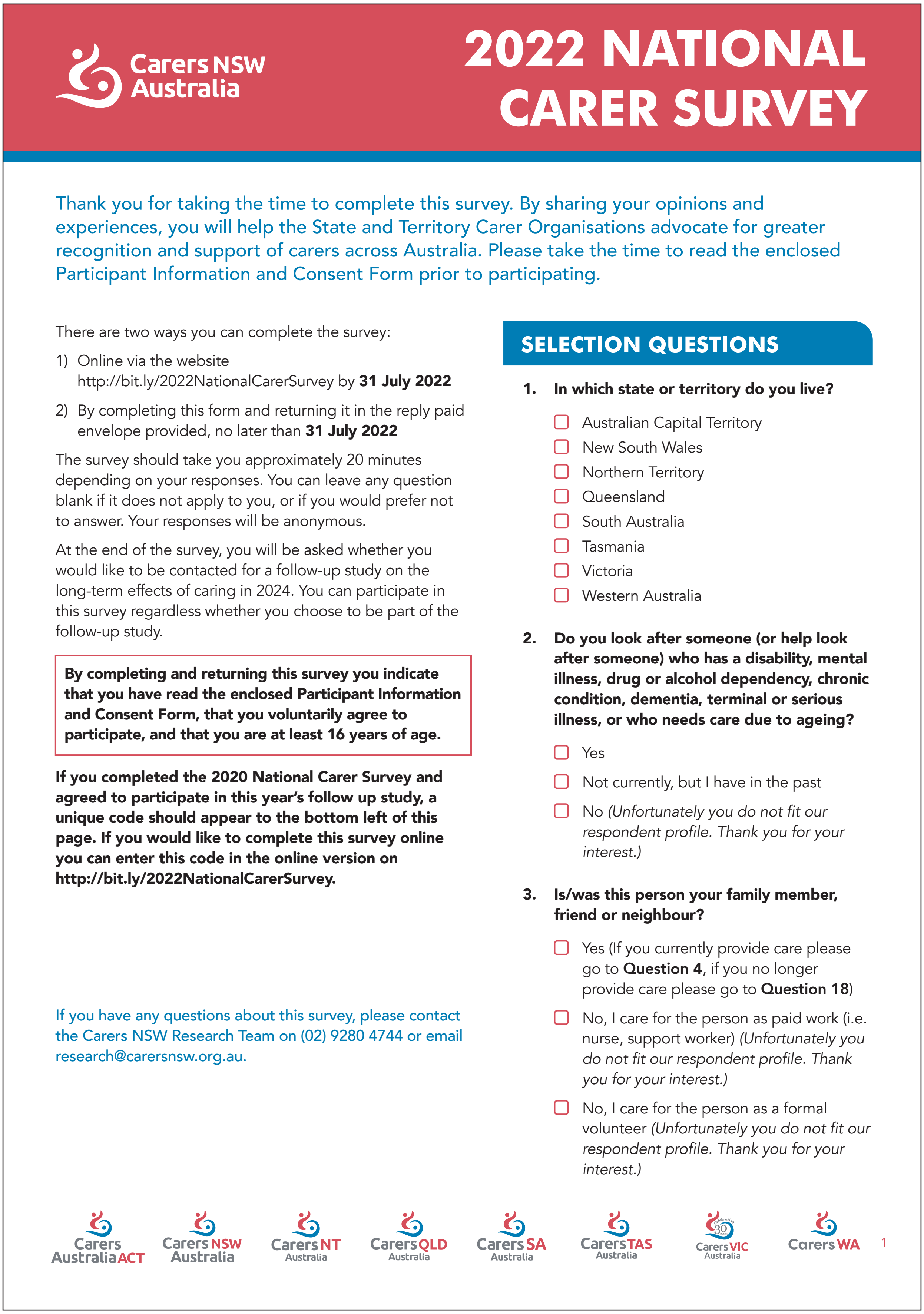
Completing the survey is completely voluntary and you may withdraw your participation at any time. Any partially completed surveys will be excluded from the final analysis. Refusal to participate will not affect your relationship with Carers NSW or any of the collaborating universities or Carer Organisations.

Benefits of the research

This research will help to direct the advocacy and support work of the state and territory Carer Organisations. Findings will be used to identify areas of greatest need amongst carers across Australia, and the particular needs of different carer groups (e.g., different geographic locations, different care recipient conditions, etc.). Survey results will be published in a report that will be made publicly available online, along with factsheets. Results will also be published in peer reviewed journal articles and presented at relevant conferences. The research team will have access to the de-identified information collected, however, as survey responses are anonymous, you will not be personally identified in any part of the research.

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee (Project ID 6233). If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics & Integrity (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

II.II SURVEY QUESTIONNAIRE



Carers NSW Australia

2022 NATIONAL CARER SURVEY

Thank you for taking the time to complete this survey. By sharing your opinions and experiences, you will help the State and Territory Carer Organisations advocate for greater recognition and support of carers across Australia. Please take the time to read the enclosed Participant Information and Consent Form prior to participating.

There are two ways you can complete the survey:

1) Online via the website http://bit.ly/2022NationalCarerSurvey by **31 July 2022**
2) By completing this form and returning it in the reply paid envelope provided, no later than **31 July 2022**

The survey should take you approximately 20 minutes depending on your responses. You can leave any question blank if it does not apply to you, or if you would prefer not to answer. Your responses will be anonymous.

At the end of the survey, you will be asked whether you would like to be contacted for a follow-up study on the long-term effects of caring in 2024. You can participate in this survey regardless whether you choose to be part of the follow-up study.

By completing and returning this survey you indicate that you have read the enclosed Participant Information and Consent Form, that you voluntarily agree to participate, and that you are at least 16 years of age.

If you completed the 2020 National Carer Survey and agreed to participate in this year's follow up study, a unique code should appear to the bottom left of this page. If you would like to complete this survey online you can enter this code in the online version on http://bit.ly/2022NationalCarerSurvey.

If you have any questions about this survey, please contact the Carers NSW Research Team on (02) 9280 4744 or email research@carersnsw.org.au.

SELECTION QUESTIONS

1. In which state or territory do you live?

- ☐ Australian Capital Territory
- ☐ New South Wales
- ☐ Northern Territory
- ☐ Queensland
- ☐ South Australia
- ☐ Tasmania
- ☐ Victoria
- ☐ Western Australia

2. Do you look after someone (or help look after someone) who has a disability, mental illness, drug or alcohol dependency, chronic condition, dementia, terminal or serious illness, or who needs care due to ageing?

- ☐ Yes
- ☐ Not currently, but I have in the past
- ☐ No *(Unfortunately you do not fit our respondent profile. Thank you for your interest.)*

3. Is/was this person your family member, friend or neighbour?

- ☐ Yes (If you currently provide care please go to **Question 4**, if you no longer provide care please go to **Question 18**)
- ☐ No, I care for the person as paid work (i.e. nurse, support worker) *(Unfortunately you do not fit our respondent profile. Thank you for your interest.)*
- ☐ No, I care for the person as a formal volunteer *(Unfortunately you do not fit our respondent profile. Thank you for your interest.)*

Carers Australia ACT · Carers NSW Australia · Carers NT Australia · Carers QLD Australia · Carers SA Australia · Carers TAS Australia · Carers VIC Australia · Carers WA

SECTION 1: THE CARING RELATIONSHIP

4. How many people do you care for? _____

The following questions are about the person/people you care for because of their needs arising from a disability, chronic condition, mental ill health or advanced age. If you care for more than one person, please complete both columns, thinking about the **two** people you provide the **most** care for.

PERSON 1

5. What is this person's gender?

☐ Female
☐ Male
☐ Non-binary / Gender diverse
☐ Their gender isn't listed.
This person's gender is: ____________________
☐ Prefer not to say

6. How old is this person?

___________ years

7. What is this person's relationship to you?

This person is my:
☐ Parent or parent in law
☐ Partner or spouse
☐ Former partner or spouse
☐ Child (incl. adult children)
☐ Sibling, e.g. brother or sister
☐ Grandparent
☐ Friend
☐ Neighbour
☐ Other, please specify:

____

8. Is this person of Aboriginal or Torres Strait Islander origin?

☐ No
☐ Yes, Aboriginal
☐ Yes, Torres Strait Islander
☐ Yes, both
☐ Prefer not to say

If yes, what is this person's clan or language group?

____

PERSON 2

5. What is this person's gender?

☐ Female
☐ Male
☐ Non-binary / Gender diverse
☐ Their gender isn't listed.
This person's gender is: ____________________
☐ Prefer not to say

6. How old is this person?

___________ years

7. What is this person's relationship to you?

This person is my:
☐ Parent or parent in law
☐ Partner or spouse
☐ Former partner or spouse
☐ Child (incl. adult children)
☐ Sibling, e.g. brother or sister
☐ Grandparent
☐ Friend
☐ Neighbour
☐ Other, please specify:

____

8. Is this person of Aboriginal or Torres Strait Islander origin?

☐ No
☐ Yes, Aboriginal
☐ Yes, Torres Strait Islander
☐ Yes, both
☐ Prefer not to say

If yes, what is this person's clan or language group?

____

PERSON 1 (continued)

9. Was this person born overseas?

☐ Yes
☐ No
☐ Don't know / Prefer not to say

If yes, how many years has this person been living in Australia?

__________ years

10. What is this person's cultural background? (e.g. Italian, Chinese, Australian, etc.)

____

11. Does this person speak a language other than English at home? (e.g. Vietnamese, Auslan)

☐ They speak English only
☐ Yes, they speak:

____

12. For what conditions / disabilities / illnesses does this person need your care?
Please tick all that apply.

☐ Physical disability
☐ Sensory impairment (e.g. loss of hearing or loss of vision)
☐ Frailty due to ageing
☐ Intellectual disability
☐ Autism Spectrum Disorder
☐ Mental illness
☐ Drug or alcohol dependency
☐ Dementia
☐ Chronic health condition
☐ Terminal or serious illness
☐ Acquired brain injury, stroke
☐ Neurological condition (e.g. epilepsy, Parkinson's disease, multiple sclerosis)
☐ Other, please specify:

____

13. Do you and the person you care for live in the same household?

☐ Yes
☐ No, they live separately
☐ No, they live with another family member or friend
☐ No, they live in a care facility (e.g. nursing home)
☐ No, they live in supported accommodation / a group home
☐ Other, please specify:

____

PERSON 2 (continued)

9. Was this person born overseas?

☐ Yes
☐ No
☐ Don't know / Prefer not to say

If yes, how many years has this person been living in Australia?

__________ years

10. What is this person's cultural background? (e.g. Italian, Chinese, Australian, etc.)

____

11. Does this person speak a language other than English at home? (e.g. Vietnamese, Auslan)

☐ They speak English only
☐ Yes, they speak:

____

12. For what conditions / disabilities / illnesses does this person need your care?
Please tick all that apply.

☐ Physical disability
☐ Sensory impairment (e.g. loss of hearing or loss of vision)
☐ Frailty due to ageing
☐ Intellectual disability
☐ Autism Spectrum Disorder
☐ Mental illness
☐ Drug or alcohol dependency
☐ Dementia
☐ Chronic health condition
☐ Terminal or serious illness
☐ Acquired brain injury, stroke
☐ Neurological condition (e.g. epilepsy, Parkinson's disease, multiple sclerosis)
☐ Other, please specify:

____

13. Do you and the person you care for live in the same household?

☐ Yes
☐ No, they live separately
☐ No, they live with another family member or friend
☐ No, they live in a care facility (e.g. nursing home)
☐ No, they live in supported accommodation / a group home
☐ Other, please specify:

____

PERSON 1 (continued)

14. Do any other family members or friends help care for this person?

- ☐ I am the only one who provides care
- ☐ I share the care equally with someone (e.g. a partner)
- ☐ I provide the most care, but others help with care sometimes
- ☐ Someone else provides the most care, but I help with care sometimes

15. How long can this person be left alone?

- ☐ Not at all
- ☐ Less than an hour
- ☐ A few hours
- ☐ One day
- ☐ A few days
- ☐ More than a few days

16. How long have you been caring for this person?

__________ years __________ months

PERSON 2 (continued)

14. Do any other family members or friends help care for this person?

- ☐ I am the only one who provides care
- ☐ I share the care equally with someone (e.g. a partner)
- ☐ I provide the most care, but others help with care sometimes
- ☐ Someone else provides the most care, but I help with care sometimes

15. How long can this person be left alone?

- ☐ Not at all
- ☐ Less than an hour
- ☐ A few hours
- ☐ One day
- ☐ A few days
- ☐ More than a few days

16. How long have you been caring for this person?

__________ years __________ months

17. Have you previously cared for anyone who you are no longer caring for?

- ☐ Yes
- ☐ No (Please go to **Question 22**)

If you cared for more than one person in the past, please think of the person you cared for most recently when responding to the next four questions.

18. What is/was this person's relationship to you?

This person is/was my:

- ☐ Parent or parent in law
- ☐ At the time partner or spouse
- ☐ At the time former partner or spouse
- ☐ Child (incl. adult children)
- ☐ Sibling, e.g. brother or sister
- ☐ Grandparent
- ☐ Friend
- ☐ Neighbour
- ☐ Other, please specify: ____

19. For how long did you care for this person?

__________ years __________ months

20. How long ago did this caring role end?

__________ years __________ months

21. **Why did this caring role end?**

Please tick all that apply.

☐ The person I cared for no longer required care
☐ The person I cared for passed away
☐ I couldn't continue to provide care because my circumstances changed
☐ Their care needs increased beyond what I could manage
☐ The relationship with this person ended
☐ Another family member or friend took over the caring role
☐ The person moved to residential care
☐ Other, please specify: ______________________________

SECTION 2: YOUR CARING ROLE

If you are not currently providing care for someone, please answer the following questions in relation to your most recent caring role.

22. **On average, how many hours per week do or did you spend caring?**

☐ __________ hours OR
☐ 24 hours a day due to care or monitoring requirements

If you did not provide care to someone in the last two years please go to Question 40.

23. **Please tick all the types of support that you provided to the person(s) you care or cared for at any time in the past two years. Please also indicate whether this task was part of a typical week.**

Please tick all that apply.

	Provided in the past two years	Is/was part of a typical week
Personal care (e.g. prompting, or helping with eating, showering, dressing)	☐	☐
Mobility (e.g. walking, getting out of bed)	☐	☐
Communication (e.g. reading, writing, helping them articulate themselves in conversations)	☐	☐
Interpreting or translating for them from or into another language	☐	☐
Advocacy (e.g. helping them dispute a treatment or a decision)	☐	☐
Emotional support (e.g. providing companionship, managing difficult feelings)	☐	☐
Cognitive support (e.g. planning, remembering appointments, staying focused)	☐	☐
Support with making decisions (e.g. choosing where to live, choosing services)	☐	☐
Help with organising finances (e.g. helping them budgeting, assisting with online banking)	☐	☐
Handling their finances (e.g. making financial decisions for them, managing their accounts)	☐	☐

Continued on next page

Continued: **Please tick all the types of support that you provided to the person(s) you care or cared for at any time in the past two years. Please also indicate whether this task was part of a typical week.**

	Provided in the past two years	**Is/was part of a typical week**
Administrative support (e.g. filling out forms, applying for and managing My Aged Care or NDIS supports, sending emails or making phone calls on their behalf)	☐	☐
Coordinating support services or care workers (e.g. finding and booking services, dealing with service providers)	☐	☐
Health care (e.g. assisting with taking medication, injections, or wound care)	☐	☐
Help with using technology (e.g. for telehealth, making calls, or operating equipment such as hoists)	☐	☐
Help with therapeutic activities (e.g. physiotherapy, mental health exercises)	☐	☐
Transport (e.g. driving them to appointments, taking public transport with them)	☐	☐
Household tasks (e.g. cleaning, cooking, shopping)	☐	☐
Property maintenance (e.g. mowing lawns, cleaning gutters)	☐	☐
Social support (e.g. helping them to engage in relationships and in the community)	☐	☐
Checking on them, seeing whether they are okay	☐	☐
Behavioural support (e.g. dealing with behaviours such as aggression or social withdrawal)	☐	☐
Other, please specify: ______	☐	☐

SECTION 3: SERVICES AND SUPPORT

If you did not provide care to someone in the last two years please go to Question 40.

24. Did someone you care or cared for use aged care services in the past two years?
Please tick all that apply.

Aged care services are services designed for people over the age of 65 years (or over the age of 50 years for Aboriginal and Torres Strait Islander Australians). They may be government funded or purchased privately.

☐ No, nobody I care/cared for needs aged care services (Please go to **Question 28**)

Yes, someone I care/cared for…

☐ …used low-level, aged care services subsidised by the Commonwealth Home Support Program (CHSP), such as cleaning, community transport, or basic in-home support
☐ …received a Home Care Package (Level 1, 2, 3 or 4), a government funded package of support that enables them to purchase aged care services, such as personal care, or respite
☐ …paid for aged care services privately, such as cleaning, or in-home support
☐ …lives/lived in residential aged care, for example a nursing home or care facility
☐ …is/was receiving aged care services, but I don't know which services they are using
☐ I don't know (Please go to **Question 28**)
☐ Other, please specify:____ (Please go to **Question 28**)

25. Please indicate how much you agree with the following statements:

	Strongly agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**	**N/A**
When aged care services were planned for the person I care or cared for, I was…						
…asked about my needs as a carer	☐	☐	☐	☐	☐	☐
…involved in planning and decisions about services	☐	☐	☐	☐	☐	☐
…provided with all the information I need	☐	☐	☐	☐	☐	☐
The aged care services that the person I care or cared for received…						
…gave me a break from providing care	☐	☐	☐	☐	☐	☐
…enabled me to keep my job, or go back to work	☐	☐	☐	☐	☐	☐
…met my needs as a carer (e.g. were available when I couldn't provide care)	☐	☐	☐	☐	☐	☐

26. **Have you or the person(s) you care or cared for experienced any of the following challenges with aged care services?** Please tick all that apply.

- ☐ The person I care/cared for was not eligible for the required services
- ☐ The service received was at a lower level than required
- ☐ The services were reduced or interrupted due to COVID-19
- ☐ There was a long waiting period to get assessed
- ☐ There was a long waiting period to access services
- ☐ The services they needed were not available locally
- ☐ There were no services available that met their cultural needs
- ☐ There were no services available that were inclusive of their gender or sexuality
- ☐ The cost of services (including co-payments) was too high
- ☐ It was difficult to find information about what services were available and how to access them
- ☐ It took too much time and energy to organise the services
- ☐ Other, please describe:__________________________________
- ☐ None of the above

27. **Please leave any comments you might have on your experience with aged care services:**

____

____

____

28. **Did someone you care or cared for receive support through the National Disability Insurance Scheme (NDIS) in the past two years?** Please tick all that apply.

- ☐ No, nobody I care/cared for required disability services (Please go to **Question 32**)
- ☐ No, someone I care/cared for needed disability services but is ineligible for the NDIS (Please go to **Question 32**)
- ☐ Yes, someone I care/cared for has/had a National Disability Insurance Scheme plan (NDIS plan)
- ☐ I don't know (Please go to **Question 32**)
- ☐ Other, please specify: ___________________________________ (Please go to **Question 32**)

29. **Please indicate how much you agree with the following statements:**

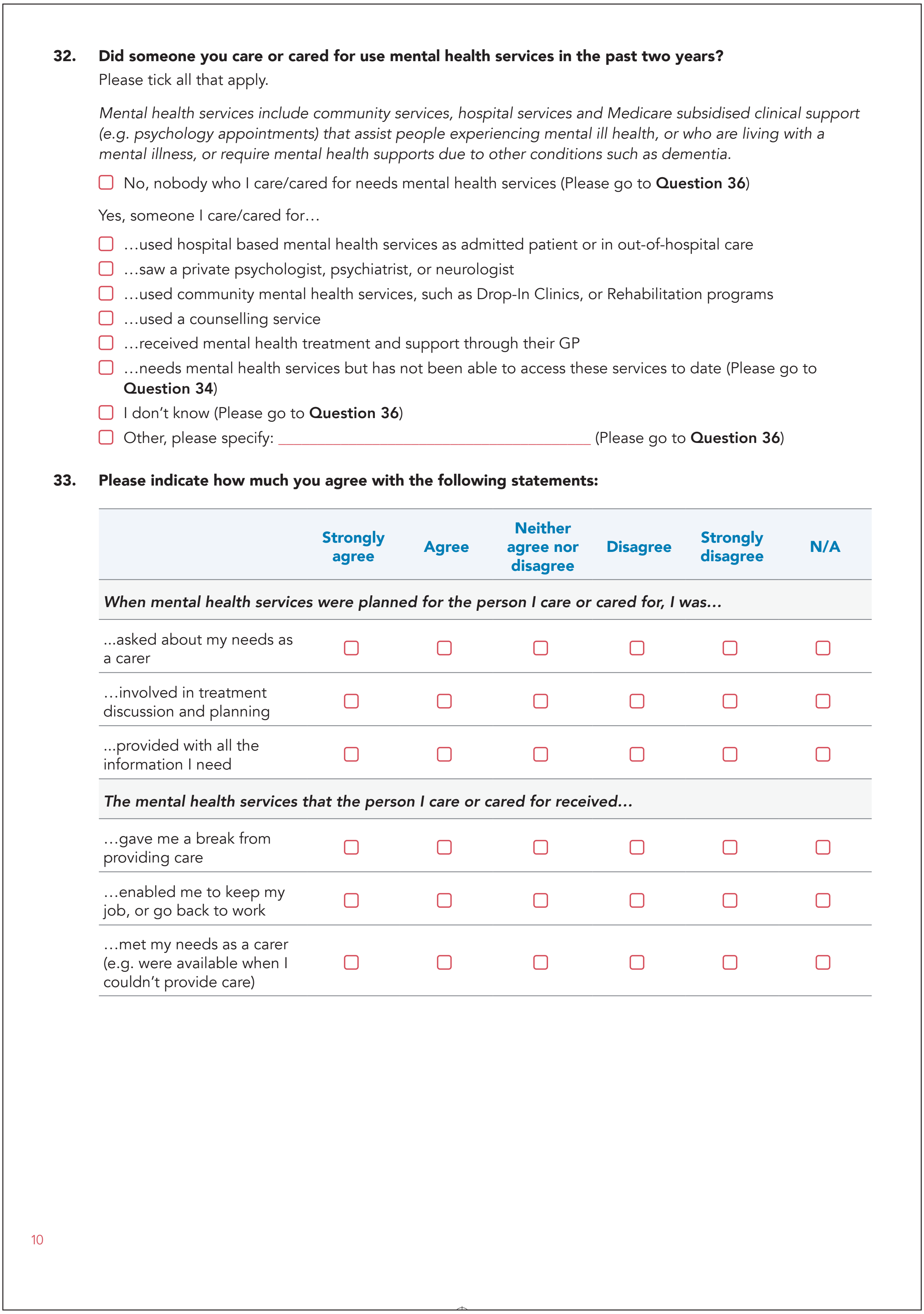
	Strongly agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**	**N/A**
When NDIS supports were planned for the person I care or cared for, I was…						
...asked about my needs as a carer	☐	☐	☐	☐	☐	☐
…involved in planning and decisions about services	☐	☐	☐	☐	☐	☐
...provided with all the information I needed	☐	☐	☐	☐	☐	☐

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
The supports included in the NDIS plan of the person I care or cared for…						
…gave me a break from providing care	☐	☐	☐	☐	☐	☐
…enabled me to keep my job, or go back to work	☐	☐	☐	☐	☐	☐
…met my needs as a carer (e.g. were available when I couldn't provide care)	☐	☐	☐	☐	☐	☐

30. **Have you or the person(s) you care or cared for experienced any of the following challenges with the NDIS or other disability services?** Please tick all that apply.

☐ The person I care/cared for did not have enough funding in their NDIS plan to meet their needs
☐ The services were reduced or interrupted due to COVID-19
☐ Necessary services outside the NDIS (either in addition to, or instead of NDIS support) were not available
☐ There was a long waiting period to get assessed
☐ There was a long waiting period to access services
☐ The required services were not available locally
☐ There were no services available that met the cultural needs of the person(s) I care/cared for
☐ There were no services available that were inclusive of the gender or sexuality of the person(s) I care/cared for
☐ The cost of services (including co-payments) was too high
☐ It was difficult to find information about what services were available and how to access them
☐ It took too much time and energy to organise the services
☐ Other, please describe:______________________________
☐ None of the above

31. **Please leave any comments you might have on your experience with disability services:**



32. Did someone you care or cared for use mental health services in the past two years?
Please tick all that apply.

Mental health services include community services, hospital services and Medicare subsidised clinical support (e.g. psychology appointments) that assist people experiencing mental ill health, or who are living with a mental illness, or require mental health supports due to other conditions such as dementia.

☐ No, nobody who I care/cared for needs mental health services (Please go to **Question 36**)

Yes, someone I care/cared for…

☐ …used hospital based mental health services as admitted patient or in out-of-hospital care
☐ …saw a private psychologist, psychiatrist, or neurologist
☐ …used community mental health services, such as Drop-In Clinics, or Rehabilitation programs
☐ …used a counselling service
☐ …received mental health treatment and support through their GP
☐ …needs mental health services but has not been able to access these services to date (Please go to **Question 34**)
☐ I don't know (Please go to **Question 36**)
☐ Other, please specify: ______________________________ (Please go to **Question 36**)

33. Please indicate how much you agree with the following statements:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
When mental health services were planned for the person I care or cared for, I was…						
…asked about my needs as a carer	☐	☐	☐	☐	☐	☐
…involved in treatment discussion and planning	☐	☐	☐	☐	☐	☐
…provided with all the information I need	☐	☐	☐	☐	☐	☐
The mental health services that the person I care or cared for received…						
…gave me a break from providing care	☐	☐	☐	☐	☐	☐
…enabled me to keep my job, or go back to work	☐	☐	☐	☐	☐	☐
…met my needs as a carer (e.g. were available when I couldn't provide care)	☐	☐	☐	☐	☐	☐

10

34. **Have you or the person(s) you care or cared for experienced any of the following challenges with mental health services?** Please tick all that apply.

☐ The person I care/cared for was not eligible for the required services
☐ The service received was at a lower level than required
☐ The services were reduced or interrupted due to COVID-19
☐ There was a long waiting period to access services
☐ The services required were not available locally
☐ There were no services available that met the cultural needs of the person(s) I care/cared for
☐ There were no services available that were inclusive of the gender or sexuality of the person(s) I care/cared for
☐ The cost of services (including co-payments) was too high
☐ It was difficult to find information about what services were available and how to access them
☐ It took too much time and energy to organise the services
☐ The service addressed mental distress but did not help with any of the causes
☐ The service kept me at a distance and did not keep me updated about the person's diagnosis, status, or supports
☐ Other, please describe:____
☐ None of the above

35. **Please leave any comments you might have on your experience with mental health services:**

____

____

____

The following questions are about when the person you care or cared for accesses health services, including a general practitioner (GP) or family doctor, community health services, and services within a hospital.

36. **Please indicate how much you agree with the following statements:**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
When I accompanied the person I care or cared for to visit a GP, I was…						
...asked about my needs as a carer	☐	☐	☐	☐	☐	☐
…involved in treatment discussion and planning	☐	☐	☐	☐	☐	☐
...provided with all the information I needed	☐	☐	☐	☐	☐	☐
When I accompanied the person I care or cared for on a visit to the hospital or community health service, I was…						
...asked about my needs as a carer	☐	☐	☐	☐	☐	☐
…involved in treatment discussion and planning	☐	☐	☐	☐	☐	☐
...provided with all the information I need	☐	☐	☐	☐	☐	☐
…provided with sufficient support options and facilities for carers (e.g. seating, overnight rooms, transport support)	☐	☐	☐	☐	☐	☐

37. **Please leave any comments you might have on your experience with health services:**

The next four questions are about the services you have accessed for yourself as a carer in the past 2 years.

38. **Did you use any of the following carer support services in the past 2 years?**
Which would you like to use more? Please tick all that apply.

	I have used this support in the past 2 years	I would like/ need to use this support, or use it more
Carer Gateway website (www.carergateway.gov.au)	☐	☐
Carer Gateway phone line (1800 422 737)	☐	☐
Carer peer support (face to face carer support groups)	☐	☐
Carer peer support online	☐	☐
Carer online forums or online information	☐	☐
In-person carer counselling (counselling designed specifically to address challenges relating to the caring role)	☐	☐
Carer counselling over the phone	☐	☐
Carer coaching or mentoring (working on personal goals and resilience relating to the caring role, one-to-one)	☐	☐
Emergency respite (care in a facility or in the home provided when you are suddenly unable to provide care for a period of time)	☐	☐
Planned respite (care in a facility or in the home booked in advance so that you are able to participate in other activities, or take a longer break from caring)	☐	☐
Carer-specific face-to-face information sessions or workshops	☐	☐
Carer-specific skills training	☐	☐
Young Carer service/program	☐	☐
☐ I did not need or want carer support services in the past two years		

39. **Have you experienced any of the following challenges with the carer services listed in the previous question?** Please tick all that apply.

☐ The service received was at a lower level than required
☐ There was a long waiting period to access services
☐ The services I needed were not available locally
☐ The available services did not meet my needs (e.g. weren't available when I needed them)
☐ The services were reduced or interrupted due to COVID-19
☐ There were no services available that met my cultural needs
☐ There were no services available that were inclusive of my sexuality or gender
☐ The cost of services (including co-payments) was too high
☐ It was difficult to find information about what services were available and how to access them
☐ It took too much time and energy to organise the services
☐ I don't (or didn't) see myself as a carer
☐ I couldn't organise someone to take over caring so I could access these services
☐ Other, please tell us:______________________________
☐ None of the above

40. **Did you use any of the following other services for yourself in the past 2 years?**

☐ A GP about my own health
☐ A dentist or getting dental work done
☐ Health or allied health services (e.g. podiatrist, optometrist, specialist doctor) for treatment of a chronic health condition
☐ Personal counselling or mental health services (not carer specific)
☐ Mental health crisis support (e.g. Lifeline)
☐ Relationship or family counselling
☐ Domestic and family violence services
☐ Drug and alcohol or gambling addiction supports
☐ Emergency support (goods and services, food supply, emergency housing)
☐ Financial counselling services or financial advice
☐ Legal advice, advocacy services, or complaint resolution support (e.g. LegalAid, Ombudsman)
☐ None of the above

41. **Please leave any comments you might have on services you used in the past 2 years, or needed and weren't able to access:**

____

____

____

SECTION 4: PAID WORK

42. Has your caring role impacted your career in any of the following ways? Please tick all that apply.

☐ I have lacked the knowledge and confidence to apply for jobs effectively
☐ My skills and qualifications have become out of date due to time out of the workforce
☐ I felt less prepared to meet the demands of my job
☐ I have worked in a job that is lower than my skill set
☐ I have reduced my working hours
☐ I have changed industry or occupation to better accommodate my caring role
☐ I have turned down a new job or promotion
☐ I retired, left my job, or stopped looking for work to be able to care
☐ I have experienced discrimination at work, e.g. was denied opportunities or promotions
☐ Other, please specify: ______________________________
☐ None of the above

43. What is or was your occupation? ______________________________

☐ I am retired/no longer working

44. Do you currently have a paid job?

☐ Yes
☐ No, but I am looking for work (Please go to **Question 49**)
☐ No, and I am not looking for work (Please go to **Question 50**)

45. How many hours per week do you usually spend doing paid work?

________ hours

46. Which of the following apply to you?

☐ I am a permanent employee (either part time or full time)
☐ I have a fixed-term contract (either part time or full time)
☐ I have a casual job
☐ I am self-employed
☐ I am an independent contractor
☐ Other, please specify: ______________________________

47. **How much do you agree with the following statements about balancing paid work with your caring role?**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
All in all, I am satisfied with my job	☐	☐	☐	☐	☐	☐
I am satisfied with the balance between paid work and the rest of my life	☐	☐	☐	☐	☐	☐
Work provides me with an important sense of purpose outside my caring role	☐	☐	☐	☐	☐	☐
Work provides me with important social connections outside my caring role	☐	☐	☐	☐	☐	☐
My caring role has given me skills that are relevant to my work	☐	☐	☐	☐	☐	☐
I have seriously considered quitting my current job over the past 6 months	☐	☐	☐	☐	☐	☐

48. **How much do you agree with the following statements about your current workplace?**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
I'm comfortable discussing my caring role with my manager	☐	☐	☐	☐	☐	☐
I'm comfortable discussing my caring role with my colleagues	☐	☐	☐	☐	☐	☐
My manager supports me to combine work and care	☐	☐	☐	☐	☐	☐
I chose my employer because they offered flexible working arrangements	☐	☐	☐	☐	☐	☐
I was open about my caring role in the recruitment process	☐	☐	☐	☐	☐	☐
There are sufficient flexible working arrangements available to support my caring role (e.g. flexible start/finish times, working from home)	☐	☐	☐	☐	☐	☐
I have enough paid leave in a year, so that I don't have to use unpaid leave to accommodate my caring role	☐	☐	☐	☐	☐	☐

49. **Please tell us how caring has affected your work life or job search:**

SECTION 5: YOUR HEALTH AND WELLBEING

50. **Please indicate how much you agree with the following statements:**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
I will be able to achieve most of the goals that I have set for myself	☐	☐	☐	☐	☐	☐
When facing difficult tasks, I am certain that I will accomplish them	☐	☐	☐	☐	☐	☐
In general, I think that I can obtain outcomes that are important to me	☐	☐	☐	☐	☐	☐
I believe I can succeed at most things to which I set my mind	☐	☐	☐	☐	☐	☐
I will be able to successfully overcome many challenges	☐	☐	☐	☐	☐	☐
I am confident that I can perform effectively on many different tasks	☐	☐	☐	☐	☐	☐
Compared to other people, I can do most tasks very well	☐	☐	☐	☐	☐	☐
Even when things are tough, I can perform quite well	☐	☐	☐	☐	☐	☐

51. **Please indicate how satisfied you are with each of the following:**

	Completely dissatisfied 0	1	2	3	4	Neutral 5	6	7	8	9	Completely satisfied 10
Your standard of living	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Your health	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
What you are achieving in life	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Your personal relationships	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How safe you feel	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Feeling part of your community	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Your future security	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Your life overall	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

52. **In the past 4 weeks, about how often did you feel:**

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Nervous	☐	☐	☐	☐	☐
Without hope	☐	☐	☐	☐	☐
Restless or jumpy	☐	☐	☐	☐	☐
That everything was an effort	☐	☐	☐	☐	☐
So sad that nothing could cheer you up	☐	☐	☐	☐	☐

53. **How many hours per week do you have for yourself?**

________ hours

"Time for yourself" is time where you can pursue activities of your choice, that are not related to caring responsibilities, work, or to household and other chores.

54. **During the past four weeks, how often have you experienced the following?**

	Almost always	Most of the time	About half the time	Occasionally	Not at all
It has been easy to relate to others	☐	☐	☐	☐	☐
I felt isolated from other people	☐	☐	☐	☐	☐
I had someone to share my feelings with	☐	☐	☐	☐	☐
I found it easy to get in touch with others when I needed to	☐	☐	☐	☐	☐
When with other people, I felt separate from them	☐	☐	☐	☐	☐
I felt alone and friendless	☐	☐	☐	☐	☐

55. **How satisfied are you with…**

	Completely dissatisfied 0	1	2	3	4	Neutral 5	6	7	8	9	Completely satisfied 10	N/A
…your relationship with your partner?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
…your relationship with your parents?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
…your relationship with your children?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
…your relationship with your friends?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
…your relationship with the person you care for?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

56. **Please tell us how your caring role has affected your relationships with the person you care for, your family or friends?**

57. How much do you agree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
My caring role is recognised and valued by my community	☐	☐	☐	☐	☐	☐
My caring role is recognised and valued by my family	☐	☐	☐	☐	☐	☐
My caring role is recognised and valued by my friends	☐	☐	☐	☐	☐	☐
My caring role is recognised and valued by service providers	☐	☐	☐	☐	☐	☐
My caring role is recognised and valued by the government	☐	☐	☐	☐	☐	☐

58. In general, would you say that your health is:

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

59. During the last 12 months, have you had any long-term illness or disability that has lasted, or is likely to last, at least 6 months?

☐ Yes ☐ No

SECTION 6: ABOUT YOU

60. In the last two years, has any of the following happened to you? Please tick all that apply.

☐ You or the person you care for caught COVID-19
☐ You were separated from family/loved ones for a long time due to COVID-19 restrictions
☐ You worked from home due to COVID-19 restrictions
☐ You got married, or started a common household with a partner
☐ You became a parent
☐ You got divorced or experienced the breakdown of a long-term relationship
☐ You experienced the loss of a partner or close family member
☐ You became seriously ill (not including COVID-19) or injured
☐ You lost work or significant amounts of income
☐ You had property damaged due to a natural disaster (e.g. fires, floods)
☐ You had to evacuate your home due to a natural disaster (e.g. fires, floods)
☐ None of the above

61. How old are you? ________ years

62. What is the postcode where you live? ________

63. What is your gender?

☐ Female
☐ Male
☐ Non-binary / Gender diverse
☐ Prefer not to say
☐ My gender isn't listed. I identify as: ______________________________

64. Are you of Aboriginal or Torres Strait Islander origin?

☐ No
☐ Yes, Aboriginal
☐ Yes, Torres Strait Islander
☐ Yes, both
☐ Prefer not to say

If yes, what is your clan or language group? ______________________________

65. Were you born overseas?

☐ Yes
☐ No
☐ Don't know / Prefer not to say

If yes, how long have you lived in Australia? ________ years

66. What is your cultural background? (e.g., Italian, Chinese, Australian, etc.) ______________________

67. Do you speak a language other than English at home? (e.g. Vietnamese, Auslan)

☐ No, English only
☐ Yes, I speak ______________________________
☐ Prefer not to say

68. What is the highest level of education you have completed?

☐ Less than high school (year 12 or equivalent)
☐ High school (year 12 or equivalent)
☐ Certificate / diploma
☐ Bachelor degree or higher
☐ Other, please specify: ______________________________

69. Are you currently enrolled in any formal education?

☐ No
☐ Yes – High school
☐ Yes – TAFE / apprenticeship
☐ Yes – University
☐ Other, please specify: ______________________________

70. Do you consider yourself to be:

☐ Lesbian, gay, or homosexual
☐ Straight or heterosexual
☐ Bisexual
☐ Queer
☐ Prefer not to say
☐ Not listed, my sexual orientation is: ______________________________

71. **How much do you agree with the following statements?**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
My home currently meets my needs	☐	☐	☐	☐	☐	☐
My home is adequate for the requirements of my caring role	☐	☐	☐	☐	☐	☐

72. **What is your household's yearly income (before tax)?**

Please include your partner's and / or family members' typical income from all sources (e.g. wages, pensions, investment income). Please tick your best estimate:

☐ Up to $9,999 per year ($1 - $189 per week)
☐ $10,000 - $19,999 per year ($190 - $379 per week)
☐ $20,000 - $29,999 per year ($380 - $579 per week)
☐ $30,000 - $39,999 per year ($580 - $769 per week)
☐ $40,000 - $49,999 per year ($770 - $959 per week)
☐ $50,000 - $59,999 per year ($960 - $1,149 per week)
☐ $60,000 - $79,999 per year ($1,150 - $1,529 per week)
☐ $80,000 - $99,999 per year ($1,530 - $1,919 per week)
☐ $100,000 - $124,999 per year ($1,920 - $2,399 per week)
☐ $125,000 - $149,999 per year ($2,400 - $2,879 per week)
☐ $150,000 or more ($2,880 per week or more)
☐ Prefer not to say

73. **Including yourself, how many people are living in your household?**

________ Children under the age of 15

________ Children aged 15 to 18

________ Adults aged 18 to 64

________ Adults aged 65 and older

74. **Do you receive any payments from Centrelink?** Please tick all that apply.

☐ Carer Allowance (currently $136.50 per fortnight)
☐ Carer Payment (currently up to $987.60 per fortnight for singles and $1,488.80 for couples)
☐ Jobseeker Allowance
☐ Age Pension
☐ Disability Support Pension
☐ Commonwealth Rent Assistance
☐ I don't know
☐ Other Centrelink payment(s), please specify: ________________________________
☐ None of the above

75. In the last 12 months, did any of the following apply to you?

☐ You would have been unable to raise $2,000 in a week for something important
☐ You could not pay rent or mortgage payments on time
☐ You spend more money than you received in a month
☐ You could not pay gas, electricity, water, or telephone bill on time
☐ You could not pay registration or insurance on time
☐ You pawned or sold something
☐ You went without meals
☐ You were unable to heat or cool your home
☐ You sought assistance from welfare/community organisations
☐ You sought financial help from friends or family
☐ You had to pay extra expenses related to providing care (e.g. services for the person you care for, equipment, housing modifications)
☐ None of the above

76. Are you a member / affiliate member of, or registered with, the Carer Organisation in your state or territory (e.g. Carers NSW, Carers WA…)?

☐ Yes
☐ No
☐ Don't know

77. Optional: Is there anything else you would like to tell us about your experiences as a carer?

You have finished the survey – thank you for your input!

Remember, if you feel upset or have any concerns about anything from this survey, we strongly encourage you to call the **Carer Gateway (1800 422 737, open Monday to Friday, 8am to 5pm)**, which will offer support and carer specific services in your area. If you are in distress, please

- **call Lifeline (13 11 14, open 24 hours, 7 days)**, or
- **contact your local GP** (https://www.healthdirect.gov.au/australian-health-services).
- **In an emergency, please call 000**.

If you wish to contact an **Aboriginal or Torres Strait Islander Health Service**, please contact the service nearest to you. A list of services is available under https://healthinfonet.ecu.edu.au/key-resources/health-professionals/health-workers/map-of-aboriginal-and-islander-healthmedical-services/.

If you would like us to get in contact with you about this survey, please call the Carers NSW Research Team on (02) 9280 4744 or email research@carersnsw.org.au.

78. OPTIONAL: Please participate in the follow-up study in 2024 and help us track the impact of caring over time!

If you agree to participate, we will contact you for the next National Carer Survey in 2024. Your answers will be assigned a randomly generated unique identifier, allowing for comparison over time. No information identifying you personally will be stored in the dataset. Please refer to the accompanying Participant Information and Consent Form for details.

☐ Yes, I would like to participate in the follow-up study! Please provide your contact information below.

79. OPTIONAL: As a thank you for participating in the survey, you can win an Apple iPad 64GB Wi-Fi!

The prizes will be drawn on 31 August 2022, the winners will be contacted via email.

☐ Yes, I would like to participate in the prize draw! Please provide your contact information below.

80. To participate, please provide your contact details. If you don't want to participate, please leave this field empty.

Name:

Street Address:

Suburb:

State/Territory:

Postal Code:

Email Address:

Carers Australia ACT · Carers NSW Australia · Carers NT Australia · Carers QLD Australia · Carers SA Australia · Carers TAS Australia · Carers VIC Australia · Carers WA

SUPPORTS ALL CARERS · AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS · AN AUSTRALIA

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

Carers NSW
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www.carersnsw.org.au/research/survey