Carers NSW
Australia

# 2024 National Carer Survey

## SUMMARY REPORT

In partnership with

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

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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

## 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 3.0 million informal carers, around 11.9% of the population, including 1.2 million primary carers and 1.9 million carers who were not primary carers (ABS 2024).

This report was prepared by the Carers NSW Research team March 2025 in partnership with the State and Territory Carer Organisations.

# Executive Summary

From May to June 2024, the 2024 National Carer Survey asked carers across the country about their caring roles, their experiences with services for themselves and the people they care for, their work life, health, and wellbeing. Led by Carers NSW with the support of the State and Territory Carer Organisations, and proudly funded by the NSW Department of Communities and Justice, the National Carer Survey is conducted every two years since 2020 with the aim of expanding the evidence base regarding carers' experiences and support needs.

This summary report provides an overview of national findings from the 2024 National Carer Survey regarding carers' economic and social needs, caring relationships, carers' experiences accessing services, and their health and wellbeing as well as diverse caring experiences.

Part 1 of this report presents background information about the Survey, including details about the methodology, the research process and the sample size and composition. Part 2 presents key findings, with detailed analysis regarding carers' income, employment and the cost of living; recognition and service inclusion; carer support and breaks from caring; and health, wellbeing and social connectedness outcomes. Part 3 presents insights into the diversity of carers in Australia. The 2024 National Carer Survey for the first time included specific questionnaire modules for First Nations carers and young carers, two groups of often hidden carers with highly specific support needs.

Of the 10,096 carers who responded to the 2024 National Carer Survey, the majority identified as female, they were on average 58 years old and represented a range of locations and cultural backgrounds. Most identified their cultural background as Australian and lived in metropolitan areas, and 57.2% of respondents were employed 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. One in four were caring for more than one person, most likely their child (including adult children), or their partner. The most common conditions of people being cared for were physical disabilities, followed by mental health conditions, Autism and chronic health conditions. The majority of respondents dedicated 40 or more hours per week to providing care and was in their caring role for more than 10 years.

The 2024 National Carer Survey found that far too many carers across Australia are missing out on basic necessities: 4.3% of respondents reported never having enough food, with another 6.9% only sometimes having access to enough food. A further 6.1% of respondents had a safe place to live only sometimes or not at all. These findings indicate that many carers are living in acute poverty and need urgent support.

The wellbeing, psychological distress and social connectedness reported by respondents to the National Carer Survey is showing a downward trajectory since 2020. The number of carers who experienced high to very high levels of psychological distress has risen to more than half of respondents (53.7% in 2024, up from 47.7 in 2020), and 61.2% were socially isolated or highly socially isolated, up from 56.2% in 2020. The average wellbeing score remains with 55.7% on the Personal Wellbeing Index significantly below the Australian average of 74.4%. Further, the financial situation of carers also has deteriorated since 2020, with 58.6% of respondents experiencing financial stress, up from 50.7% in 2020.

In line with previous National Carer Surveys, this sample cannot be considered representative of the broader Australian carer population of 3 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 provides significant insights into the lives of carers in Australia.

We would like to thank all participants for their contribution to this research.

**Recommended citation:**
Carers NSW (2025). 2024 National Carer Survey: Summary Report. Carers NSW, North Sydney. Online available from www.nationalcarersurvey.com.au.

# Part 1: About the Survey

## About the 2024 National Carer Survey

The National Carer Survey is an initiative of Carers NSW in partnership with the State and Territory Carer Organisations, proudly funded by the NSW Department of Communities and Justice. The 2024 National Carer Survey was conducted from June to July 2024 and received a total of 10,096 responses from all states and territories of Australia. More than half (52.3%) of the carers who responded in 2024 were members of, or otherwise connected with, the Carer Organisation in their state or territory.

## Respondent profile

Of the 10,096 carers who responded to the 2024 National Carer Survey, the majority identified as female (82.6%), and they were on average 58 years old. Respondents represented a range of locations and cultural backgrounds, but most identified as Australian (75.4%) and lived in metropolitan areas (64.5%). 45% of respondents were either employed or looking for paid work while providing care.

## Typical respondent

Most commonly, respondents were caring for their child (including adult children) (44.4%). The largest proportion were providing care to someone living with disability (38.3%), with more 2 in 3 respondents (69.6%) reporting that the person they cared for experienced two or more conditions.

The 'typical' respondent was a woman in her 50s, caring for her child (including adult children) living with a disability. She lives in a metropolitan area and provides care for more than 60 hours per week.

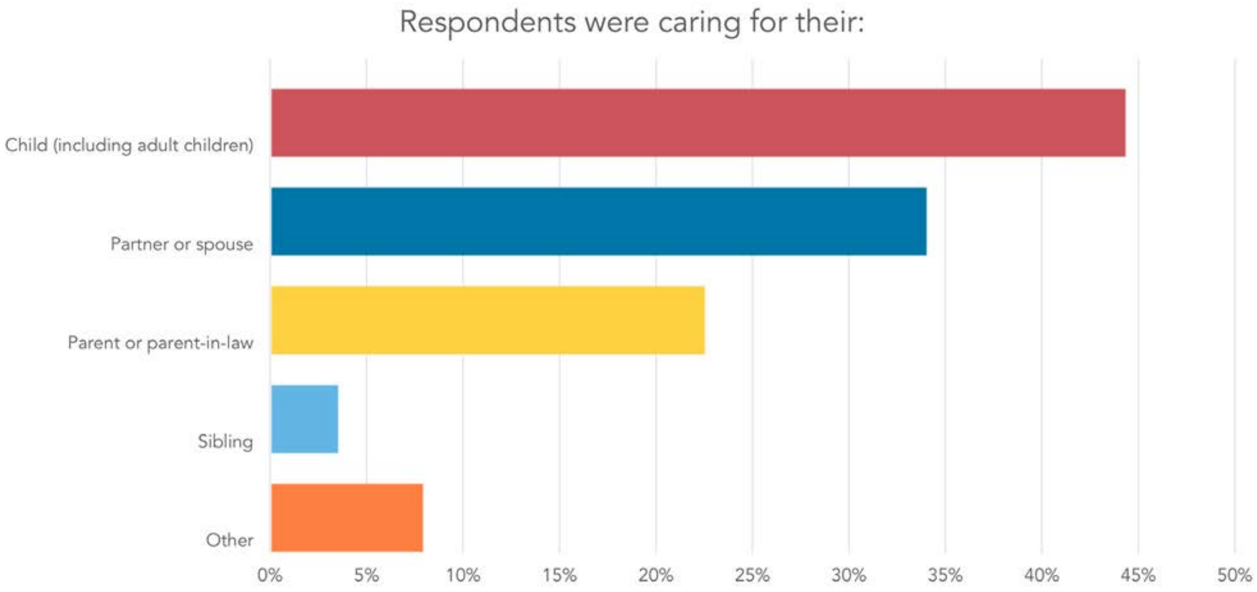


*Figure 1: Relationship of carer with person(s) being cared for*

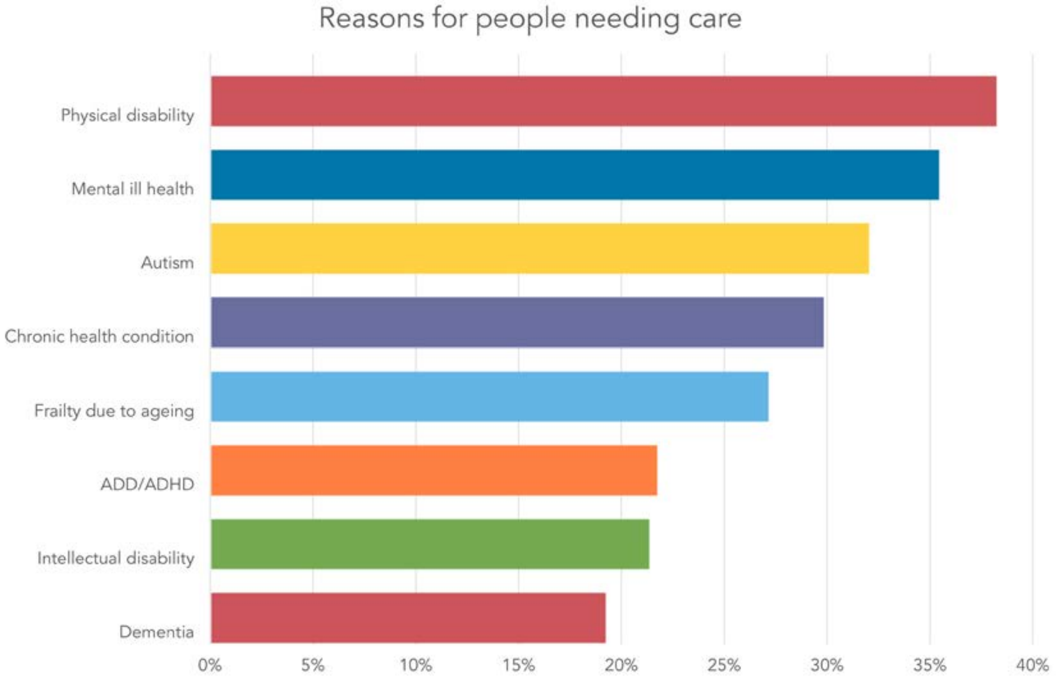


*Figure 2: Reported reasons for people needing care from respondents*

Most respondents cared for one person only (67.1%), and they were most commonly the sole carer for that person (53%). They were also most likely to live with the person they care for (83.9%). Respondents typically spent more than 60 hours per week caring (65%) and had been caring for an average of 12.1 years. The people cared for by respondents were most commonly below 20 years of age (26.9%), 80+ years old (22.0%) or aged 70 to 79,and more than half (55.8%) were male.

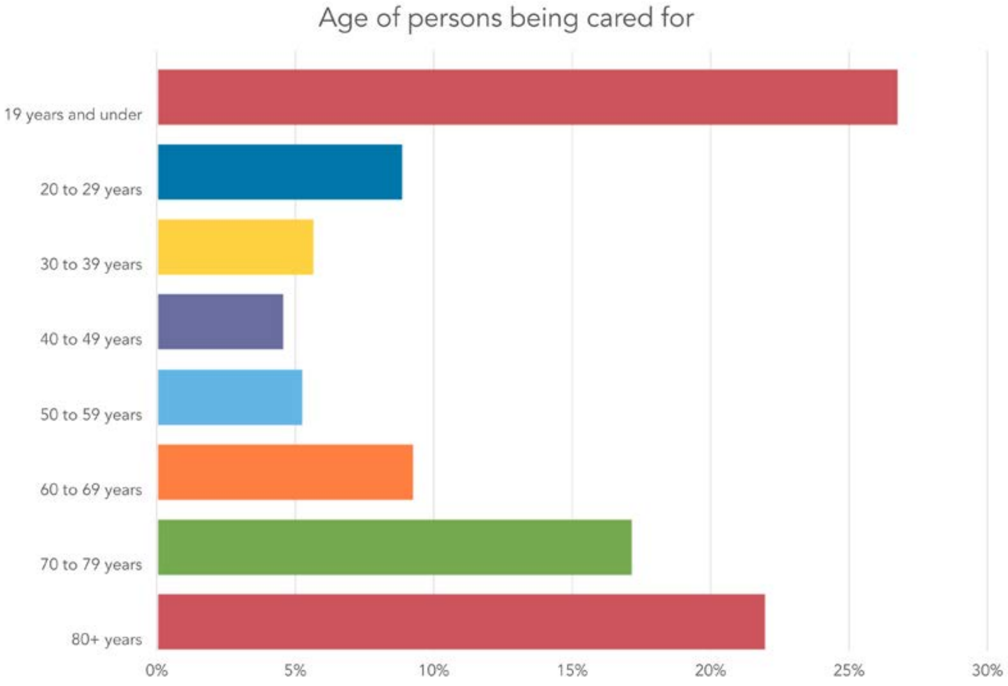
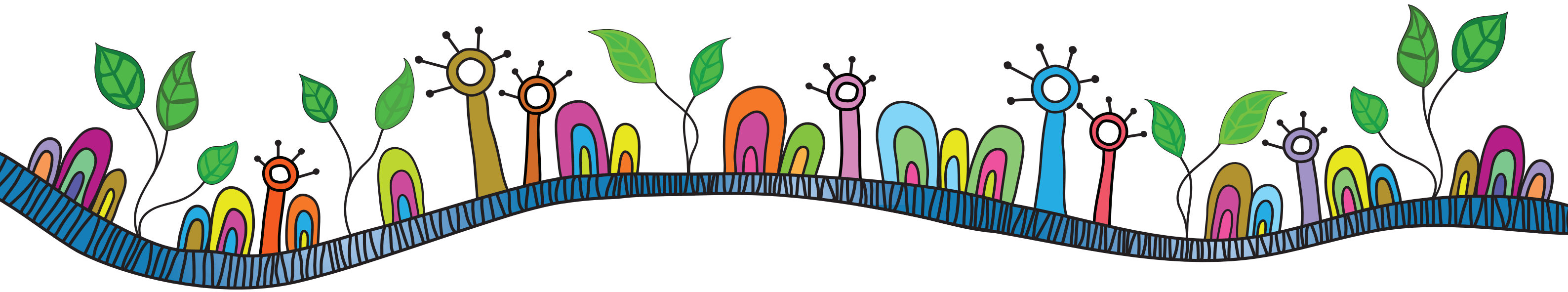


*Figure 3: Age of persons being cared for by respondents*

Not everyone who responded to the Survey was still in a caring role; 673 respondents (6.7%) identified as former carers. 2,677 respondents (30.4%) had previously cared for someone and were now caring for someone else.



## Sample composition

Compared to the average carer in Australia, respondents to the 2024 National Carer Survey were more likely to be primary carers (the person providing to most care to someone) and more likely to be female, older, and have higher educational attainment. They were also less likely to be employed and more likely to live with a disability or long-term health condition (Table 1). These key demographic differences must be considered when interpreting findings from the Survey.

Selected demographic characteristics comparing results from the 2024 and 2022 National Carer Surveys with population level estimates from the Australian Bureau of Statistics 2022 Survey of Disability, Ageing and Carers (SDAC, ABS 2024) are summarised in Table 1. The comparison with the 2022 National Carer Survey demonstrates the development of the sample over time.

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

| | | 2024 National Carer Survey | | 2022 National Carer Survey | | Population estimate (ABS 2024) |
|---|---|---|---|---|---|---|
| | | **N** | **Valid %** | **N** | **Valid %** | **%** |
| **Total respondents/carers** | | 10,096 | - | 6,825 | - | (3.04 mil.) |
| Primary carer | | 8,650 | 85.6 | 6,157 | 90.2 | 38.0 |
| Gender | Female | 8,171 | 82.6 | 5,428 | 82.0 | 53.8 |
| | Male | 1,652 | 16.7 | 1,144 | 17.3 | 46.2 |
| | Non-binary/ other | 68 | 0.7 | 31 | 0.4 | Not provided |
| Age | Mean (years) | 58.0 | - | 59.8 | - | 49.7 |
| | Up to 24 years | 167 | 1.7 | 78 | 1.2 | 12.9 |
| | 25 to 64 years | 6,259 | 62.0 | 3,876 | 58.9 | 62.2 |
| | 65+ years | 3,535 | 35.0 | 2,625 | 39.9 | 25.0 |
| Education | Bachelor degree or higher | 2,914 | 35.3 | 2,094 | 32.0 | 26.4 |
| | Certificate/diploma | 2,867 | 34.7 | 2,209 | 33.8 | 30.7 |
| | High school | 1,013 | 12.3 | 821 | 12.5 | 14.1 |
| | < High school | 1,030 | 12.5 | 1,034 | 15.8 | 23.1 |
| Employment | Employed | 3,208 | 37.4 | 2264 | 33.5 | 54.3 |
| | Unemployed* | 653 | 7.6 | 513 | 7.6 | 2.9 |
| | Not in labour force | 4,721 | 55.0 | 3979 | 58.9 | 39.2 |
| Disability or long-term health condition** | | 3,850 | 46.5 | 3117 | 47.6 | 38.6 |

*Not employed but seeking employment

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

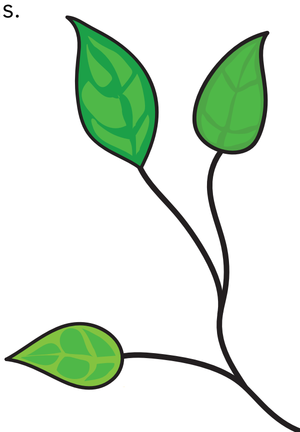


Table 2 presents the demographic diversity of respondents to the 2024 National Carer Survey. The majority of the respondents identified as culturally Australian and spoke only English at home, with 17.6% identifying as being of a culturally or linguistically diverse (CALD) background[1], and 9.7% speaking a language other than English at home. After Australian, the four most commonly identified cultural backgrounds were; English/British (6.3%), Italian (2.6%), Chinese (1.5%), and Greek (1.2%). The respondents to the 2024 National Carer Survey spoke 90 different languages. The five most common languages other than English (LOTE) spoken at home were Italian (0.9% of total respondents), Greek (0.6%), Arabic (0.5%), and Auslan (0.4%).

3.9% of respondents identified as First Nations, with 3.5% identifying as Aboriginal, 0.2% as Torres Strait Islander, and 0.2% as both. This represented a 216% numerical increase from the 2022 National Carer Survey due to a specific focus on First Nations carer engagement in 2024.

With regard to sexuality, 84.8% of carers responding to the Survey identified as heterosexual, 2.5% identified as bisexual, 2.2% as lesbian, gay, or homosexual, and 2.1% as queer or other, with 8.4% preferring no answer. Detailed statistics on carers' sexuality and gender identity are very limited in the Australian context, making this response, along with the 0.7% of respondents who identified their gender as non-binary, a significant contribution to the evidence base.

***Table 2: Sample diversity***

| | | N | Valid % |
|---|---|---|---|
| First Nations | Aboriginal | 347 | 3.5 |
| | Torres Strait Islander | 17 | 0.2 |
| | Aboriginal and Torres Strait Islander | 16 | 0.2 |
| | Prefer not to say | 206 | 2.1 |
| Culture and language | Australian | 7,429 | 75.4 |
| | Other main English speaking country | 862 | 8.7 |
| | Speaking a language other than English at home | 952 | 9.7 |
| | Identifies as culturally and/or linguistically diverse | 1,736 | 17.6 |
| Sexuality | Heterosexual/straight | 6,708 | 84.8 |
| | Lesbian, gay, or homosexual | 173 | 2.2 |
| | Bisexual | 200 | 2.5 |
| | Queer | 86 | 1.1 |
| | Other/not listed | 77 | 1.0 |
| | Prefer not to say | 663 | 8.4 |

The geographic distribution of respondents correlates well with the overall distribution of the Australian population. Following the remoteness classification of the Australian Bureau of Statistics (ABS 2022), 64.5% of survey participants providing a postcode lived in Major cities, 24.3% in Inner Regional areas, 10% in Outer Regional areas, and 1.2% lived in Remote or Very Remote areas. Slightly less representative is the distribution of respondents by state or territory. The largest number of respondents was received from South Australia, followed by carers from Victoria and New South Wales, due to the outcomes of specific promotional initiatives undertaken by the respective State and Territory Carer Organisations and the government and community partners within their jurisdictions.

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[1] Cultural background other than Australian or major anglophone countries (UK, USA, Canada), or speaking a language other than English at home

***Table 3: Geographic distribution of respondents***

| | | N | Valid % |
|---|---|---|---|
| Geographical area | Major Cities | 6,036 | 64.5 |
| | Inner Regional | 2,272 | 24.3 |
| | Outer Regional | 934 | 10.0 |
| | Remote or Very Remote | 118 | 1.2 |
| State / territory | Australian Capital Territory | 185 | 1.8 |
| | New South Wales | 1,981 | 19.6 |
| | Northern Territory | 25 | .2 |
| | Queensland | 613 | 6.1 |
| | South Australia | 2,765 | 27.4 |
| | Tasmania | 640 | 6.3 |
| | Victoria | 2,684 | 26.6 |
| | Western Australia | 1,203 | 11.9 |

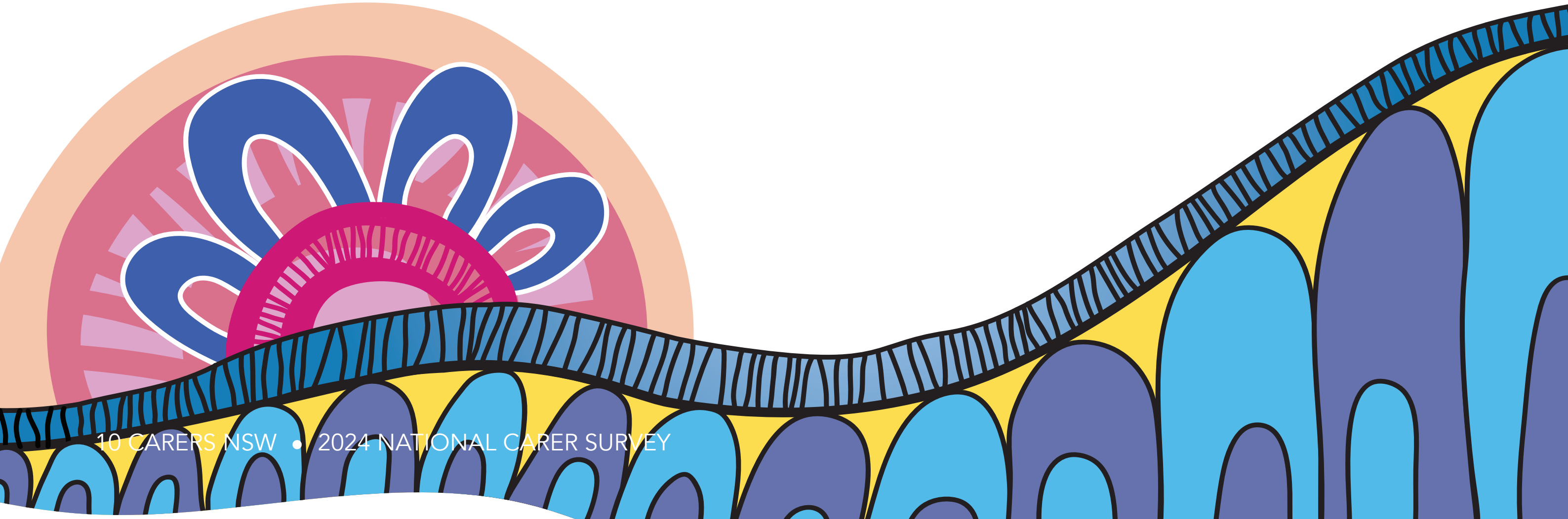
## Methodology

### Project oversight

The project was led by the Carers NSW Research team, 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. In line with the First Nations carer engagement focus of the 2024 National Carer Survey, there was an identified Aboriginal and Torres Strait Islander representative on each group, both State and Territory Carer Organisation staff.

The Academic Working Group focused on the scientific rigour of the questionnaire design and 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, with a particular focus on appropriate engagement with First Nations sector representatives, communities and networks, and continues 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 Participant Information and Consent form (see Appendix). and have access to datasets and summary tables as well as ongoing tailored data analysis and interpretation support.



### Research ethics approval

The research protocol for the 2024 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 27 February 2024). The Participant Information and Consent Form (PICF) 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 (see Appendix). The PICF was included with the paper questionnaires and had to be viewed and 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 questionnaire consisted of a total of 79 questions across 10 sections, however, not all questions were compulsory, and many could be skipped depending on prior responses. The questionnaire built on the 2020 and 2022 Surveys to allow for consistency and comparison over time. New questions included a questions on recognition and social support, legal instruments, work-care balance and the interface with formal care services. The questionnaire also included for the first time  dedicated modules for First Nations carers (6 questions) and young carers (5 questions) to encourage increased participation from these priority cohorts and to generate new, cohort-specific evidence on their experiences and support needs to inform evolving policy and practice . Records indicate that the Survey took on average 20 minutes to complete.

The Survey questionnaire was developed by the Carers NSW Research team in close collaboration with the Academic Working Group, the State and Territory Working Group and relevant Carers NSW staff, including the Policy team. Work on the First Nations module was led by a dedicated working group of identified First Nations representatives from Carers NSW and Carers WA, in accordance with the AIATSIS Code of Ethics (AIATSIS 2020), and informed by extensive consultation with Carers NSW Carer Gateway Outreach staff, including several additional identified staff members. The young carer module was informed by extensive consultation with the Carers NSW Young Carer team, the Young Carer Advisory Group and a number of other key stakeholders. The overall questionnaire was piloted with 3 carers and 5 Carers NSW staff who provided feedback to improve clarity, accessibility and data quality.

### Recruitment and data collection

The 2024 National Carer Survey questionnaire was distributed in both online (via Survey Monkey) and paper formats to maximise participation. The majority of respondents (87.9%) participated online, a significantly higher proportion than in previous years, with only 12.1% completing the paper version. Participants were recruited primarily through the client, member and stakeholder networks of Carers NSW and the State and Territory Carer Organisations, including via their websites and social media accounts, printed and email newsletters, and member and client databases. 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. However, printed questionnaires were distributed by State and Territory Carer Organisation staff at events and at face-to-face service locations, and included in member mail-outs by Carers NSW, Carers Queensland, Carers SA. Paper copies were also provided to respondents to the 2022 National Carer Survey who had registered their interest to link their responses to the 2024 National Carer Survey. Paper copies were also made available on request to individual carers, groups of carers and organisations supporting carers. More than 15,000 paper copies were distributed nationwide.

For First Nations carers, a dedicated engagement plan was developed together with identified Carers NSW staff and the State and Territory Working Group. Tailored promotional information was developed for both First Nations and young carer audiences, including stakeholder fact sheets and tailored social media tiles and reels.

Table 4 details the percentage of paper copy responses by state and territory. It shows that with 12.1% 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. In total 20.1% of the respondents living in outer regional, and 10.3% of those living in remote areas responded using paper copies, compared to 10.0% of those living in major cities.

*Table 4: Hard copy and online response*

| State / Territory | Hard copy | Online | Total responses |
|---|---|---|---|
| Australian Capital Territory | 9.2% | 90.8% | 185 |
| New South Wales | 17.3% | 82.7% | 1,981 |
| Northern Territory | 40.0% | 60.0% | 25 |
| Queensland | 17.9% | 82.1% | 613 |
| South Australia | 10.3% | 89.7% | 2,765 |
| Tasmania | 27.5% | 72.5% | 640 |
| Victoria | 8.2% | 91.8% | 2,684 |
| Western Australia | 5.2% | 94.8% | 1,203 |
| Total | 12.1% | 87.9% | 10,096 |

Respondents were provided with the option of entering a prize draw to win one of three $200 gift vouchers per state or territory when completing the Survey, intentionally enhancing the participation incentive from previous National Carer Surveys, which only offered one, larger prize per state and territory. Extensive consultation with the State and Territory Working Group and carer feedback from the Carers NSW-led Carer Knowledge Exchange project informed the careful planning of gift voucher source and delineation, in recognition of the significant cost of living crisis facing carers and communities, and the common perception from carers of gift vouchers used in research projects being too low in value and too difficult to use in rural and remote areas.

Several Prezzee gift vouchers (allowing for purchase from a wide range of providers) and relatively high value vouchers were selected in order to address these concerns, and the significantly higher response rate to the 2024 National Carer Survey compared to previous years may in part reflect the success of this approach.

## Data cleaning and analysis

The final dataset was exported from Survey Monkey and cleaned, coded, and analysed using the software package SPSS 29 in August and September 2024. Removing identifiable duplicates, out of scope responses and empty or insufficiently completed surveys reduced the final number to 10,096 valid responses.

A number of publications reporting results from the 2024 National Carer Survey were published in October 2024 and are available to download from the www.nationalcarersurvey.com.au, where other publications will be added in due course. 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 and Carer Knowledge Exchange Research Library.

The Carers NSW Research team also welcomes requests for data points, summary tables and more detailed data exports from government, academic and community stakeholders to enhance the reach and impact of the 2024 National Carer Survey.

# Part 2: Key findings

## 2022 to 2024: What has changed?

The Carers NSW National Carer Survey aims to provide an opportunity for carers in Australia to have a say about their experiences, what does and does not work for them, and which supports they need.

The first two waves of the National Carer Survey in 2020 and 2022 provided important insights into the impact of the COVID-19 pandemic on Australia's carers, while the years between the 2022 and 2024 Surveys were dominated by recovery from the pandemic, economic uncertainty, and increased financial pressure on most Australians. The last two years saw the return of high inflation, followed by an increase in interest rates. The resulting rise in housing costs due to increases in mortgage payments and rents developed into a housing crisis that especially impacted vulnerable groups in society, such as people living with a disability or with health conditions, older people, and their carers.

The National Carer Survey collects a range of outcome data from carers documenting how they are faring against key measures of their overall wellbeing. In the two years to June 2024, Survey results show that stress levels have increased, while carers' social connectedness and wellbeing continue to decline. Financial stress, measured by a range of experiences such as not being able to pay bills, or having trouble affording unexpected expenses, also increased slightly, however, to a lesser degree than between 2020 to 2022. This trend is consistent with other reports of deteriorating living standards and increasing financial stress experienced by carers (e.g. Lim et al, 2025; NCOSS, 2023). Detailed comparison of the changes to key outcome measures over time is reflected in Table 5.

***Table 5: Distress, wellbeing, and social connectedness in the National Carer Survey 2020 to 2024***

| | 2024 National Carer Survey | 2022 National Carer Survey | 2020 National Carer Survey |
|---|---|---|---|
| Carers reporting high/very high psychological distress (Kessler 5) | 53.7% | 47.5% | 47.7% |
| Average wellbeing score (PWI, % of scale maximum) | 55.7% | 57.4% | 56.5% |
| Carers reporting being socially isolated or highly socially isolated | 61.2% | 56.3% | 56.2% |
| Carers reporting at least one experience of financial stress | 58.6% | 57.4% | 50.7% |

Support to alleviate the emotional, social and financial challenges of caring can come in a variety of forms. In line with the increased need for emotional, social and financial support, participants in the 2024 National Carer Survey again reported increasing use of carer support services such as carer counselling, peer support and respite. However, after decreasing between 2020 and 2022, the reported unmet need for services jumped in 2024 to almost 3 in 4 participants reporting some form of an unmet need across service types (see Table 6). The service types reflecting the highest unmet need in 2024 were emergency and planned respite (42.7 and 42.2%), followed by skills training (40.6%). This shows that breaks from the caring role and the opportunity to increase confidence and competence in caring are at the forefront for Australia's carers.

***Table 6: Use of, and unmet need for, carer support services in the National Carer Survey, 2020 - 2024***

| | 2024 National Carer Survey | 2022 National Carer Survey | 2020 National Carer Survey |
|---|---|---|---|
| Used carer support services | 64.4% | 62.0% | 50.3% |
| Unmet need for carer support services | 73.2% | 53.4% | 66.0% |

Since the National Carer Survey is not based on a random sample and is not statistically representative, these results should be interpreted with caution. However, the large sample sizes (2020 n= 7,735; 2022 n= 6,825; 2024 n=10,096) and comparable sample composition across the three Surveys deliver a powerful snapshot of the evolving situation for carers, which is examined in more detail in the coming chapters.

As carers' needs change over time, the National Carer Survey is adapted to capture new evidence about current issues affecting carers in their lives. As outlined above, in 2024 topics of renewed interest were the cost-of-living crisis, including the challenges being experienced by many Australians to meet their basic needs; the increasing costs of housing and the insecurity resulting from rising rents, increased interest rates, and house prices; the need for more reliable and meaningful breaks from caring; and the lasting impacts of recent natural disasters. Additional questions were added to the Survey in response.

Building on extensive exploration in previous National Carer Surveys of work-care interactions and flexible working arrangements, the focus of the employment section in 2024 shifted to more closely examine the interaction between formal service provision and carers' employment patterns. Additional items were also added to better capture carers' perceived recognition by their employer and by the person they care for, and to elicit carers' perspectives on policy and service initiatives that may improve carer recognition and support.

Further, agreed focuses on increased engagement of First Nations and young carer respondents resulted in changes to the overall Survey content and format, as well as the addition of two discrete, cohort-specific modules addressing new questions regarding the distinct experiences of these groups.

A further aspect of caring roles that was newly included in the 2024 National Carer Survey was the role of legal instruments such as Powers of Attorney and Guardianship in the provision of care. In addition to the continuing refinement of previously included questions throughout the questionnaire, these aspects constitute new lines of enquiry for the Survey team.

## Income, employment and the cost of living

A defining experience for Australians in 2024 was the building cost-of-living crisis that followed the social and economic recovery from the COVID-19 pandemic. As an economically vulnerable group, carers especially felt the economic pressures of high inflation and the increasingly deteriorating affordability of housing.

### Basic needs

To capture the impact of the cost-of-living pressures on carers, the 2024 National Carer Survey included a set of questions about to what extent respondents' basic needs were met, such as reliable access to food, affordable housing, affordable health services, reliable internet and reliable transport.

While most respondents reported that all these basic needs were met at least most of the time, the results nevertheless show that far too many carers across Australia are missing out on basic necessities. In the Survey, 4.3% of respondents reported never having enough food, with another 6.9% only sometimes having access to enough food. A further 6.1% of respondents only sometimes had a safe place to live (2.8%) or not at all (3.3%). These findings indicate that many carers are living in acute poverty and need urgent support.

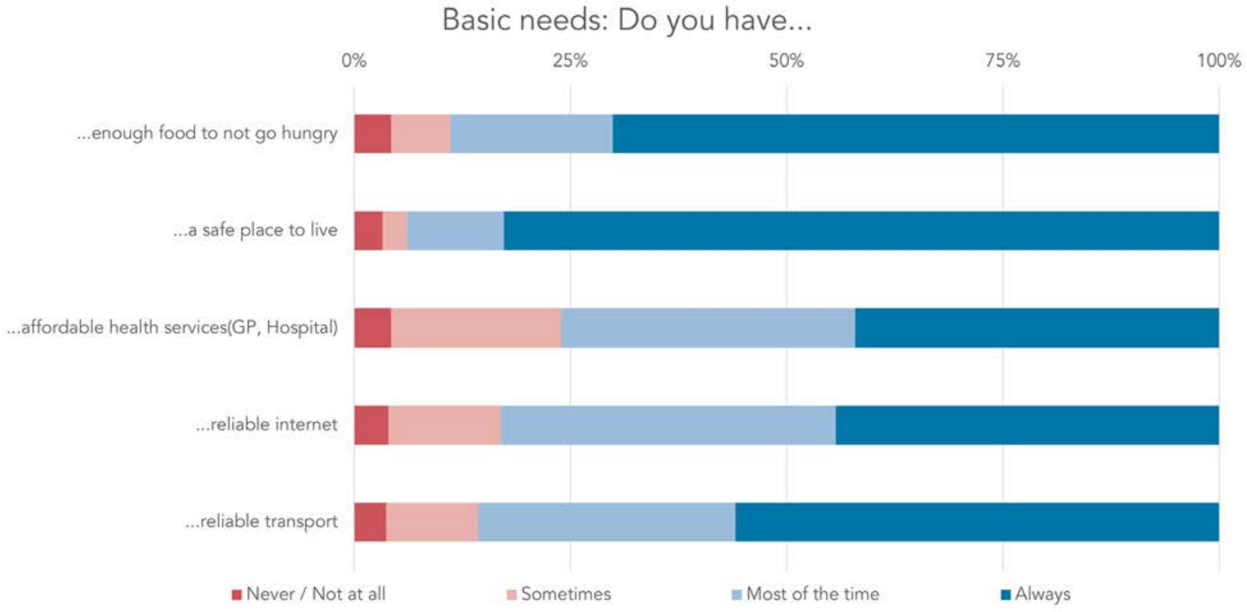


*Figure 4: Basic needs*

Concerningly, a far larger proportion of carers is missing out on critical means to participate in society: 14.3% only sometimes (10.6%) or never (3.7%) have access to reliable transport, and 17.0% have insufficient access to reliable internet (13.0% sometimes, 4.0% never). Being restricted in their mobility and having insufficient access to essential communication infrastructure contributes to the social isolation and low wellbeing of carers.

Furthermore, almost one in four carers reported only sometimes (19.7%) or never (4.3%) having access to affordable healthcare. This finding reflects the ongoing challenges carers face supporting their own health needs. The high costs of healthcare compounds issues that carers face in caring for themselves, such as scarcity of time away from caring and the prioritisation of the needs of the the person they care for.

The results of the question on basic needs demonstrate the need for better financial support and improved access to social infrastructure for carers. While these issues are systemic and affect large parts of Australian society, carers are a particularly vulnerable group that require specifically targeted support.

## Housing

A central aspect of the cost-of-living pressures experienced by carers is their housing situation. The 2024 National Carer Survey included a number of additional questions designed to generate greater understanding of this important topic, including housing tenure, whether their home was adequate for their needs, and whether their housing situation was secure.

The majority of respondents lived with the person they care for in the same household (83.9%), however one in seven (14.5%) cared for someone who was living separately, 4.7% of respondents cared for someone living in a care facility, and 3.8% cared for someone living with other family.

In line with the older respondent demographic, most Survey respondents owned their home (75.1%), with large proportions owning their home outright (44.1%) or making mortgage repayments (31.0%). Others rented from a private landlord (15.1%) or a community or public housing provider (6.1%). A small number of carers lived in the home of the person they care for and did not co-own or pay rent (3.7%). 14.5% of respondents had moved house in the two years prior to completing the Survey, and 8.5% had been impacted by a natural disaster in the prior two years, including (but not limited to) experiencing property damage, isolation or evacuation.

The Survey found a clear connection between the type of housing carers were living in and their health and wellbeing outcomes. A significantly lower proportion of carers who owned their home felt highly stressed or socially isolated, compared to carers who had to pay a mortgage or rent. Carers with secure home ownership also reported significantly higher wellbeing scores on average. Differences in how respondent groups felt about their future security were particularly pronounced, with those renting from private landlords only scoring 32.5%, compared to 62.8% average satisfaction with future security among those who own their home outright (see Table 7).

***Table 7: Housing tenure and health/wellbeing***

| Housing tenure | % who are in high/ very high psych. distress | % who are socially isolated/ highly isolated | Personal Wellbeing score (mean) | Satisfaction with future security (mean) |
|---|---|---|---|---|
| I/we rent the place I live in from a private landlord | 66.8% | 73.8% | 45.0% | 32.5% |
| I/we rent the place I live from a community/public provider | 65.1% | 70.4% | 47.9% | 42.6% |
| I live in the home of the person I care for, but do not co-own or pay rent | 61.6% | 70.5% | 48.7% | 40.3% |
| I/we own the place I live in, but we pay down a mortgage | 60.4% | 66.6% | 53.2% | 46.6% |
| I/we own the place I live in outright | 41.8% | 50.5% | 63.3% | 62.8% |

Most respondents agreed that their home met their personal needs (68.0%) and was adequate for the requirements of their caring role (66.4%), however, sizeable proportions disagreed with these statements (20.9% and 21.2% respectively). Most respondents also agreed that their housing situation was secure in the long term (71.1%), however, 16.0% disagreed with that statement. While most respondents could independently meet their housing needs (56.6% agreement), the housing security of 29.6% of respondents depended on the person they care for.

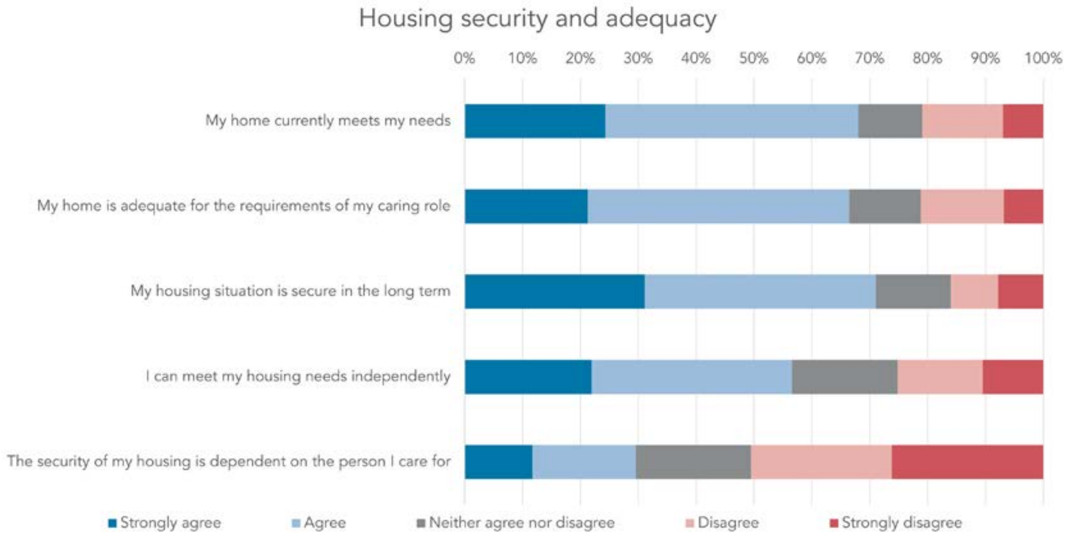


*Figure 5: Housing security and adequacy*

The insecurity of many housing situations also was apparent in relation to housing affordability. Just under one in ten respondents (8.1%) reported being unable to pay rent or mortgage repayments on time in the 12 months prior to completing the Survey. Larger proportions reported being unable to pay household bills on time (18.3%) or to cool or heat their home (11.8%), however, due to the high rate of homeowners in the sample, only 4.3% of respondents reported receiving Commonwealth Rent Assistance.

This data shows the complexity of housing situations among carers, and the high rate of insecurity carers face even if their housing needs are currently met. Housing costs are a substantial factor contributing to cost-of-living pressures for many carers, especially for those who do not own their own home. These results demonstrate the need for better protections for carers who rent.

## Employment and income

Other important contributors to the cost-of-living pressures felt by carers is their source and level of income. Many carers are not participating in the labour market, either due to the demands of their caring role or because they are of retirement age. Almost one in three respondents to the Survey (32.0%) had already retired, and almost one in four respondents (23.0%) was not in the labour force, i.e. not in paid employment and also not looking for work. Just over half of the respondents of working age (52.7% of the respondents aged 15 to 64 years), and just more than one in three of all respondents (37.4%) were in paid employment. A further 7.6% of all respondents, equalling one in ten of the respondents of working age (15 to 64), were unemployed.

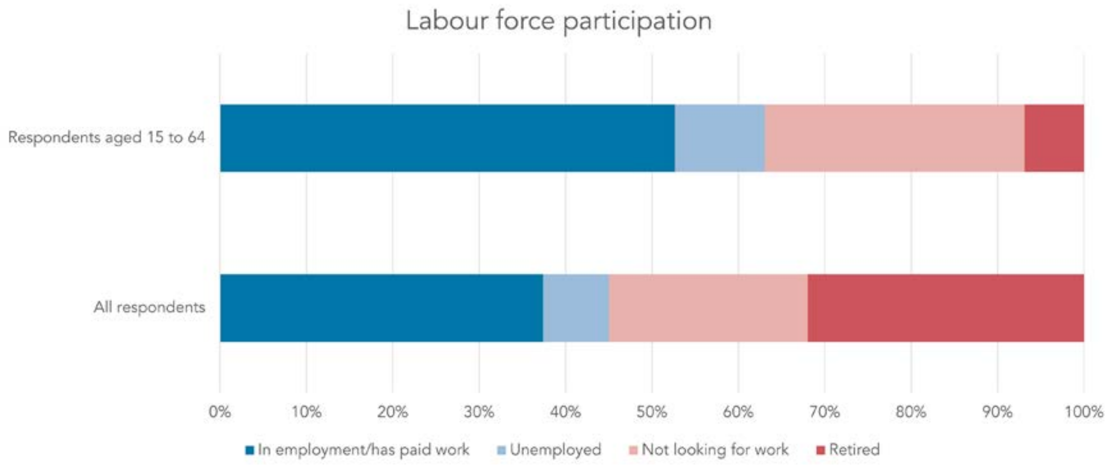
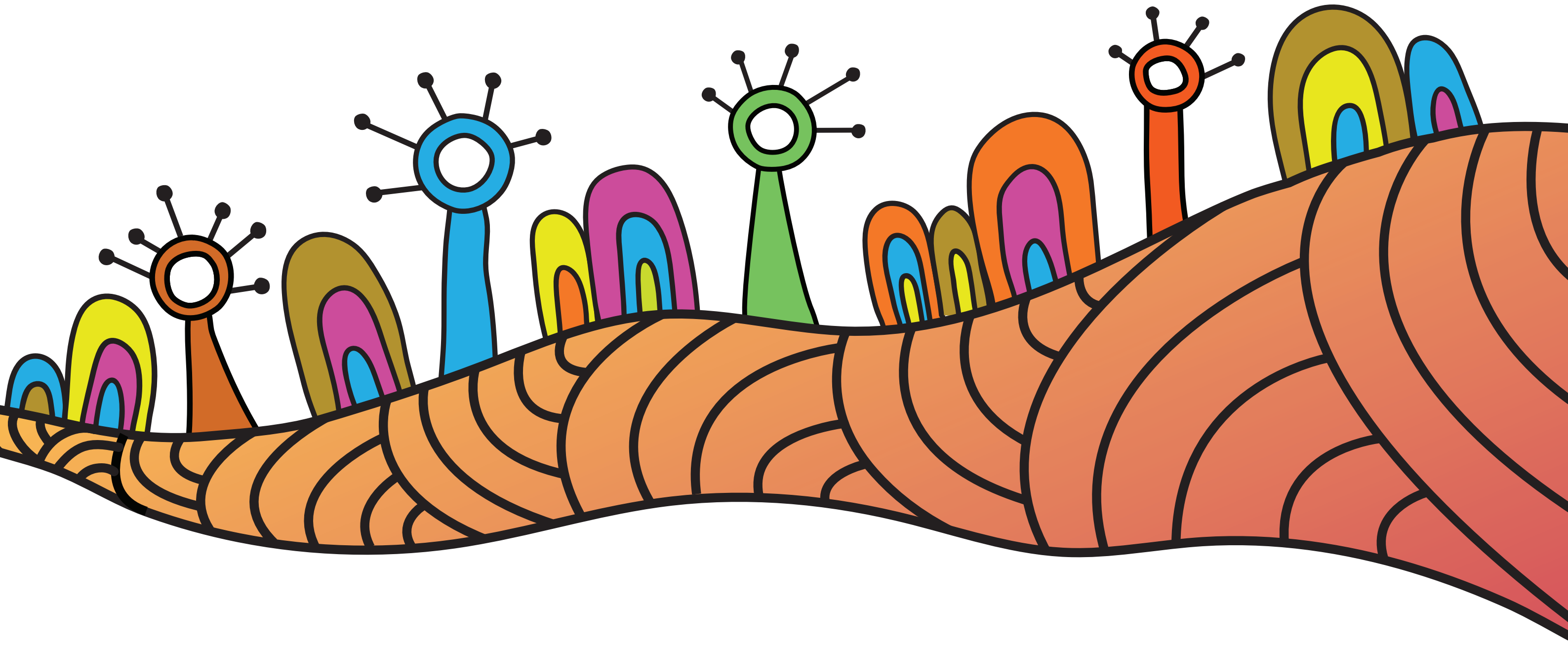


*Figure 6: Labour force participation of survey respondents*

Of those in employment, 61.9% were permanent employees, and 11.5% were self-employed. Almost one in three worked in more flexible, but often also precarious employment arrangements, either on fixed-term contracts (10.6%), in casual jobs (17.7%) or as independent contractors ("gig-work", 2.9%). One in seven respondents in paid employment (14.9%) had taken on more than one job to make ends meet.

Two in three respondents (63.9%) typically worked normal business hours, with 14.4% doing shiftwork, and 15.7% working other, self-determined hours. A relatively high rate of flexible working arrangements was also reflected, with just over half of working carers (55.0%) reporting on-site/in office jobs, 42.2% working from home either full time or as part of hybrid arrangements, and 16.7% working mobilein a mobile role or in the community.

Even for those in employment, the demand of their caring roles often significantly impacts carers' working lives. For many respondents, meeting the requirements of their caring role meant reducing their working hours, as reported by two in three respondents in paid work (65.8%) and one third of all respondents (37.8%). Many carers had also missed out on career opportunities or promotions (reported by 45.1% of those in employment and 30.5% of all respondents). More than a third of all respondents (37.7%), and more than one in five of those in the paid workforce, reported that they had stopped working either temporarily or permanently because of the demands of their caring role.



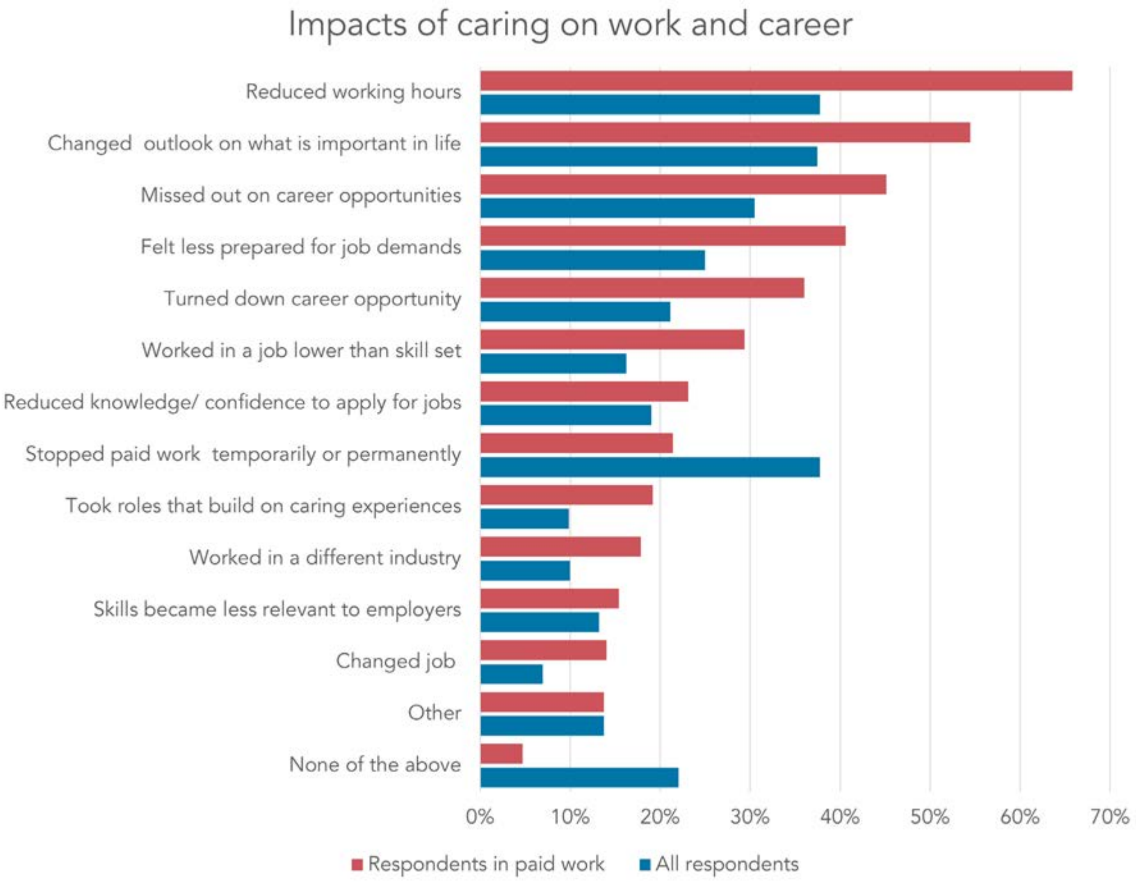


*Figure 7: Impacts of caring on work and career*

The main source of income for a quarter of respondents (24.6%) was income from paid employment, however, 43.5% of Survey respondents depended on Centrelink payments (either for themselves or the person they care for) as their main source of income (See Figure 8). Two in three carers in paid employment who participated in the Survey also received an income support payment in addition to their employment income.Only 23.2% of all Survey participants received no payments from Centrelink. Almost two in three respondents to the Survey received Carer Allowance, and almost one in four received Carer Payment. 17.3% of participants received the Age Pension.

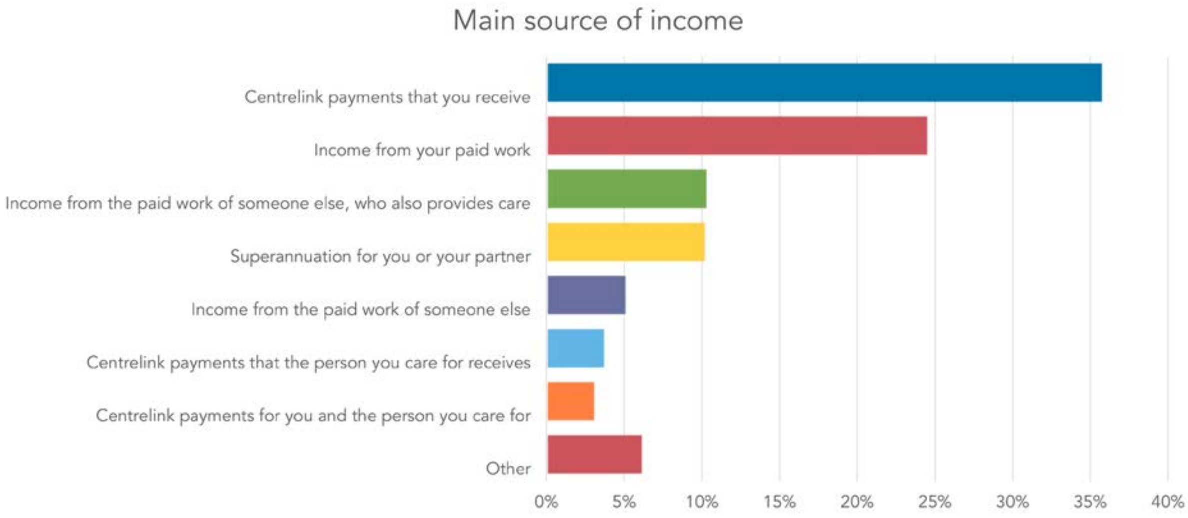


*Figure 8: Main sources of income for carer households*

## Financial stress and financial support

The combination of reduced income and increased living costs experienced by carers results in high financial stress among carers. Financial stress means difficulty meeting basic financial needs and commitments, such as housing and food. Most respondents (58.6%) to the 2024 National Carer Survey reported at least one form of financial stress. Approximately one in three (36.0%) had spent more than they received in a month, and a similar proportion (35.7%) had been unable to raise $2,000 in a week for something important (See Figure 9).

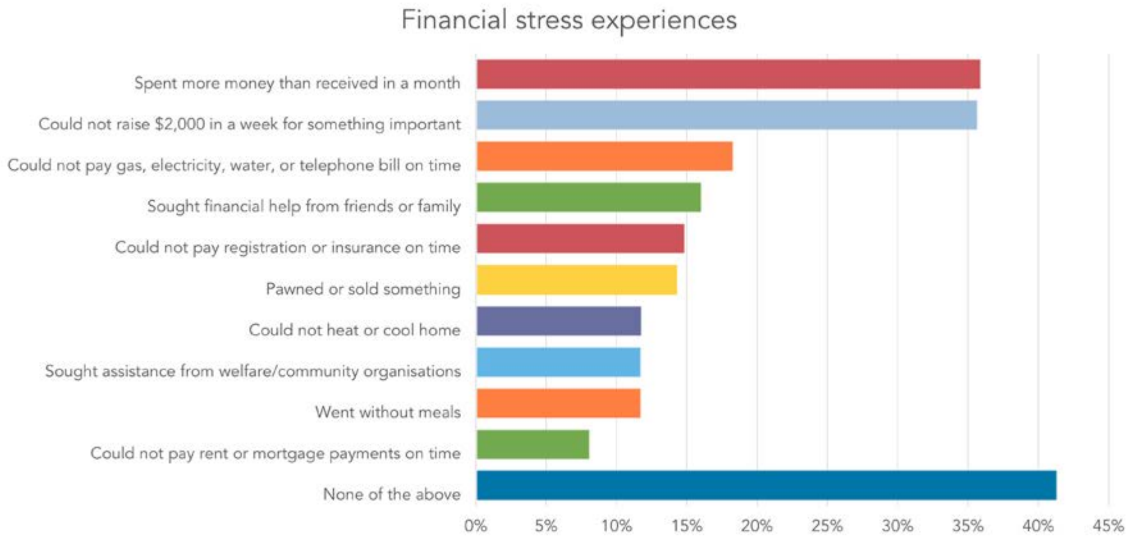


*Figure 9: Financial stress experiences*

With the exception of the Age Pension, recipients of Centrelink payments were significantly more likely to experience financial stress. However, even among carers who did not receive income support payments, 47.6% had at least one experience of financial stress in the two years leading up to the survey. The rate of financial stress is highest among recipients of the Jobseeker Payment and Commonwealth Rent Assistance, with 84.8% each reporting at least one financial stress experience. More than three quarters of carers depending on the Carer Payment (77.6%) experienced at least one form of financial stress (see Figure 10).

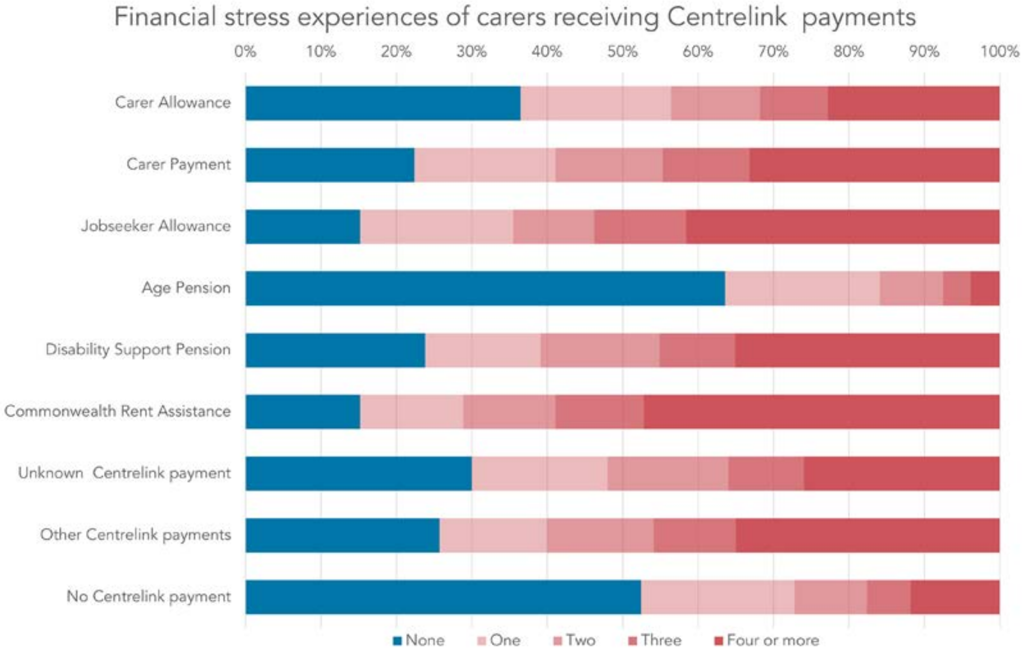


*Figure 10: Financial stress experiences of carers receiving Centrelink payments*

A comparison with data from the 2020 and 2022 National Carer Surveys shows that the overall prevalence of financial stress has increased over time. Further, the intensity of financial stress (i.e. the number of experiences) has also increased, with the proportion of those experiencing four or more aspects of financial stress increasing by more than one third from 2020 (14.4%) to 2024 (19.5% of respondents).

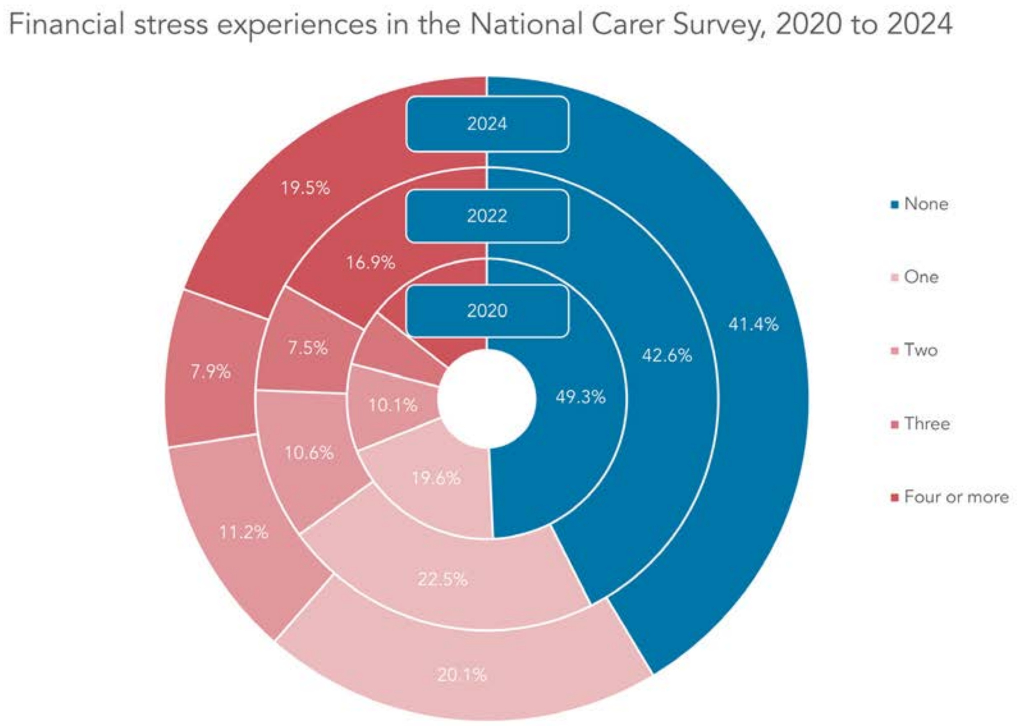


*Figure 11: Financial stress experiences in the National Carer Survey, 2020 to 2024*

This data highlights the insufficiency of formal financial supports for carers and shows that the cost of living has significantly increased over the last four years. Ever more frequently, carers are not able to meet even their most basic needs on an ongoing basis. A central aspect of the cost-of-living crisis is housing costs, which an increasing number of carers cannot sustainably meet. Many carers face a dire economic outlook, given the precarious nature of their employment and living arrangements, their high rate of reliance on social security, and the consequently increasing prevalence and intensity of financial stress. This renders many caring roles unsustainable and directly affects carers' health and wellbeing.

## Carer recognition and service inclusion

The recognition of carers is a central principle guiding the support for carers in Australia.[2] Recognition is understood to mean that carers need to be acknowledged 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 by formal service providers. These principles are enshrined in legislation such as the *Carer Recognition Act 2010* (Cwth) and corresponding state and territory legislation, which create obligations for policy makers and service providers.

Although carer recognition is such a pivotal concept for the support of carers in Australia, it is a largely unexplored area of research. The National Carer Survey is the first instrument to measure the perceived recognition on a national scale since 2020. Analysis of data from the 2020, 2022 and 2024 National Carer Surveys has shown that recognition is linked to better social connectedness, personal wellbeing, and reduced psychological distress among carers (Hamilton et al 2024, Carers NSW 2023, 2021). It is also closely tied to service experiences and the availability of carer support.

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[2] See for example *Carer Recognition Act 2010* (Cwth), *NSW Carers (Recognition) Act 2010*, National Carer Strategy 2024-2034, NSW Carers Strategy 2020-2030.

## Sources of recognition

In the 2024 National Carer Survey, carers were asked how much they feel recognised and valued for their caring role by the community, by family, friends, service providers, employers, and governments. Carers reported family members and friends as their main sources of recognition, while reporting relatively low levels of recognition by communities and governments. Service providers and carers' employers take a middle position. While 44.2% of respondents feel recognised by service providers and 40.8% feel recognised by their employers, for both categories almost one in three carers were undecided (32.8% and 31.1% respectively, see Figure 12). These results underscore the high importance of close, personal relationships as sources of recognition.

Organisations and institutions with more formal, direct interactions with carers, such as service providers and employers, were seen more positively than negatively by carers, albeit with a large part of respondents remaining unclear about their feelings. On the level of generalised social relations - with the community or government - more negative sentiments prevailed, indicating that many carers feel unvalued. This demonstrates the need to improve the general visibility of, and knowledge about caring in the Australian community, along with better inclusion of, and rights and supports for, all Australian carers.

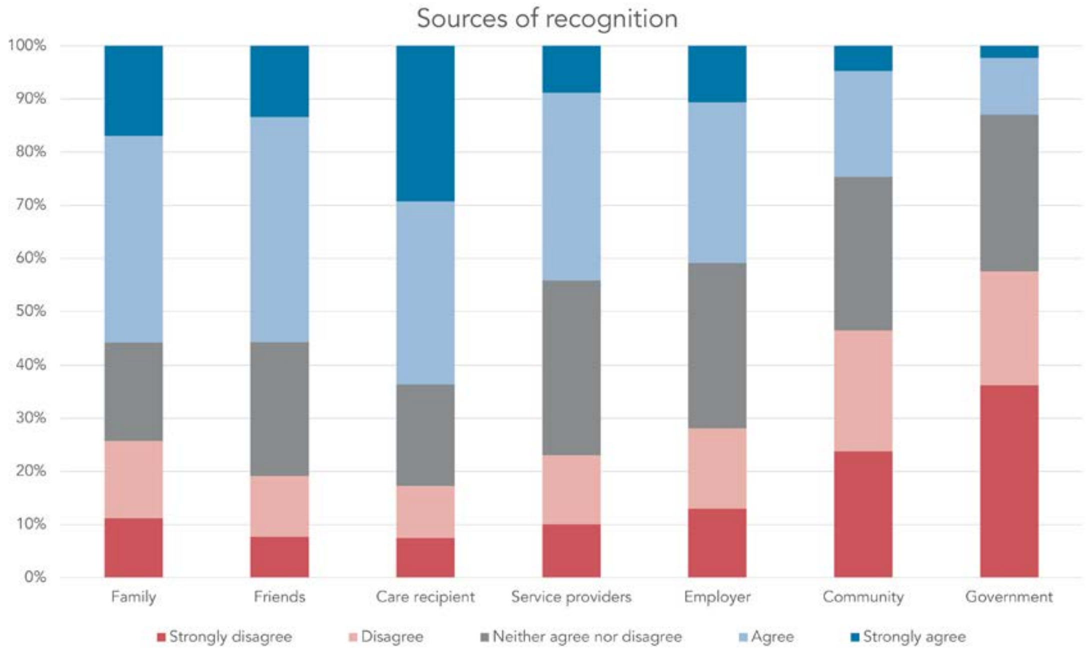
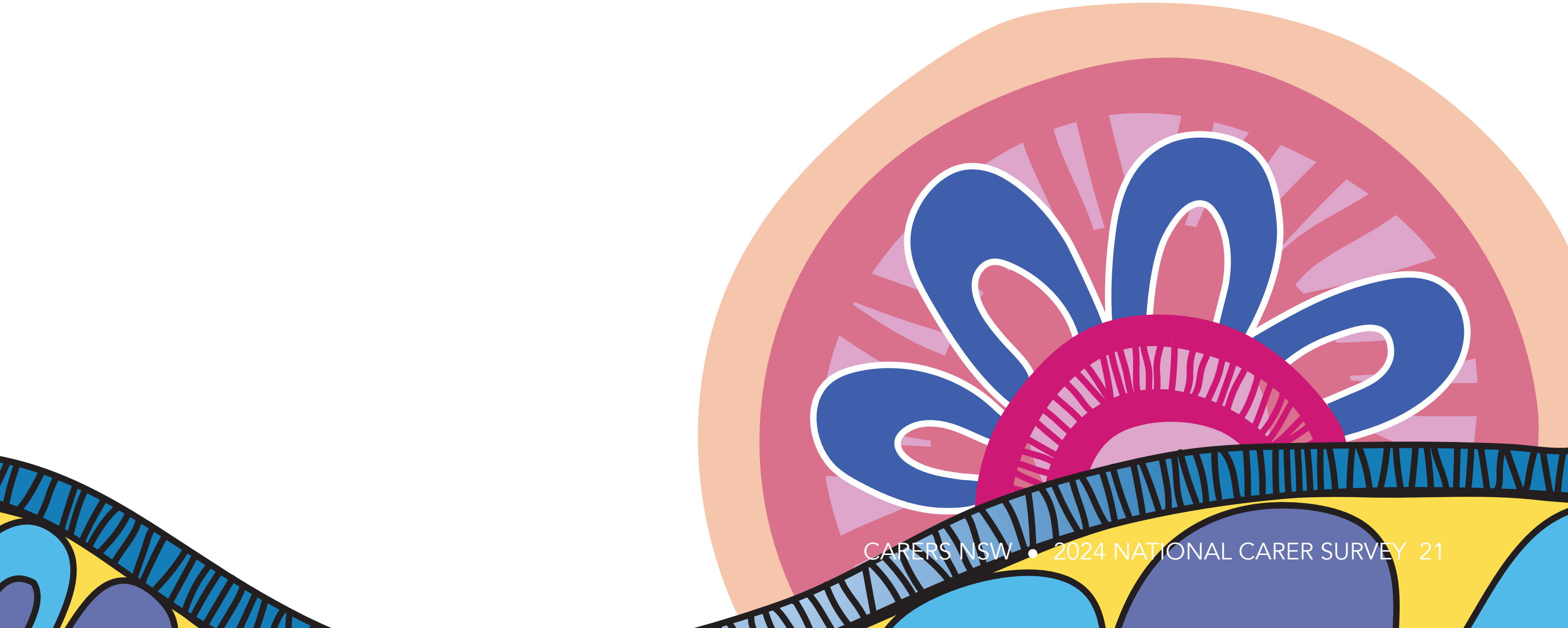


*Figure 12: Sources of recognition*

The question whether carers feel recognised by their community is particularly instructive about how valued carers feel in Australia. A detailed demographic breakdown of reported recognition by their community reveals significant differences between demographic groups (see Figure 13). While almost half of all female carers did not feel recognised for their caring role in the community, only one in three male carers responded negatively. A similar proportion of male carers answered positively (32.1%), significantly more than female carers (23.3%).



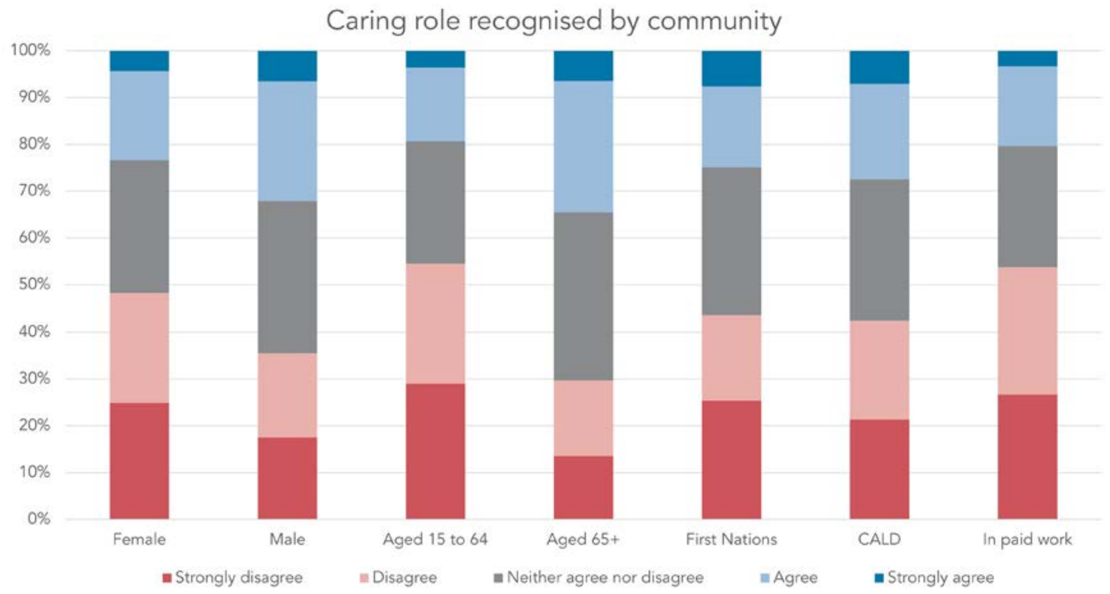


*Figure 13: Caring role recognised by community, disaggregated by demographic groups*

The strongest differences in perceived community recognition were found along lines of age, with carers aged 65 years and above being the group with the strongest feelings of recognition. Inversely, carers of working age (15 to 64 years), and carers in paid work were the groups with the largest negative response, with more than half (54.5% and 53.8% respectively) not feeling recognised by their community for their caring role, and only one in five in each group giving a positive response. The group feeling the most recognised, carers aged 65 years and above, also includes many male carers, who start their carting role only after exiting the labour force. This underlines the undervaluing of informal care relative to the value placed on paid work in the community, and the common relegation of caring roles to later life.

## Services and support

Recognition is strongly connected to formal service providers' inclusion of carers as partners in care, and to experiences carers have with these services. Interactions with services shape the health and wellbeing of carers both directly and indirectly, through feelings of recognition (see also Hamilton et al, 2024). The National Carer Survey routinely asks carers about their experiences with aged care services, NDIS/disability services, mental health services and health carer services delivered by GPs and hospitals / community health providers.

The degree to which carers feel recognised by service providers varies across the service systems the people they care for access, i.e. aged care services, NDIS/disability services, and mental health services, with aged care services receiving the most positive responses (43.9% feeling recognised in their caring role), and mental health services receiving the least number of positive ratings (37.8% feeling recognised in their caring role) (see Figure 14). For each of these service types, explicit carer inclusion and support by services were explored separately (see Part 2: Carer recognition and service inclusion).

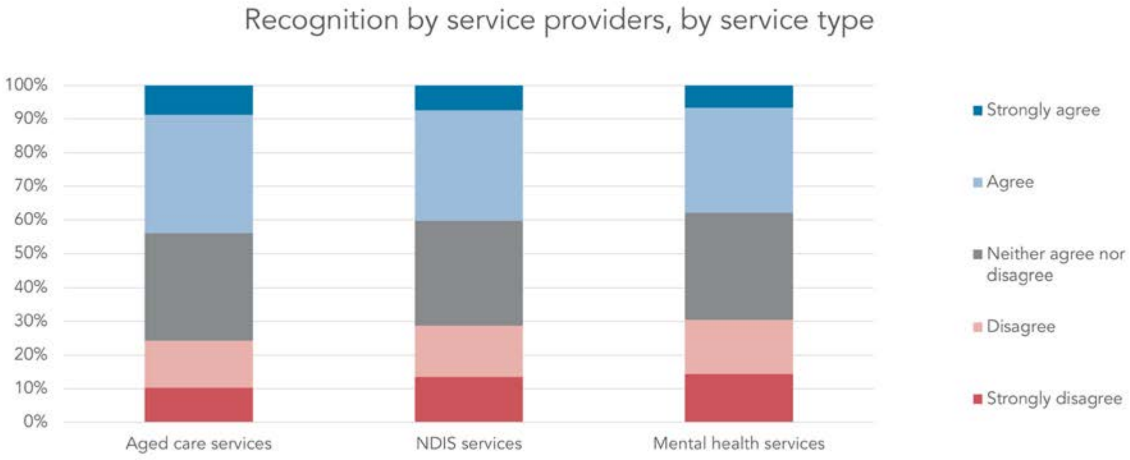


*Figure 14: Recognition by service type*

### 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 3,271 respondents (37.9%) indicated that someone they were caring for was accessing aged care services of some kind.

Of the 3,271 respondents caring for someone using aged care services, 60.7% 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 40.1% 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. One in six respondents indicated that the older people they were caring for were accessing privately funded aged care services, and 17.0% were caring for someone living in residential aged care (see Figure 15).

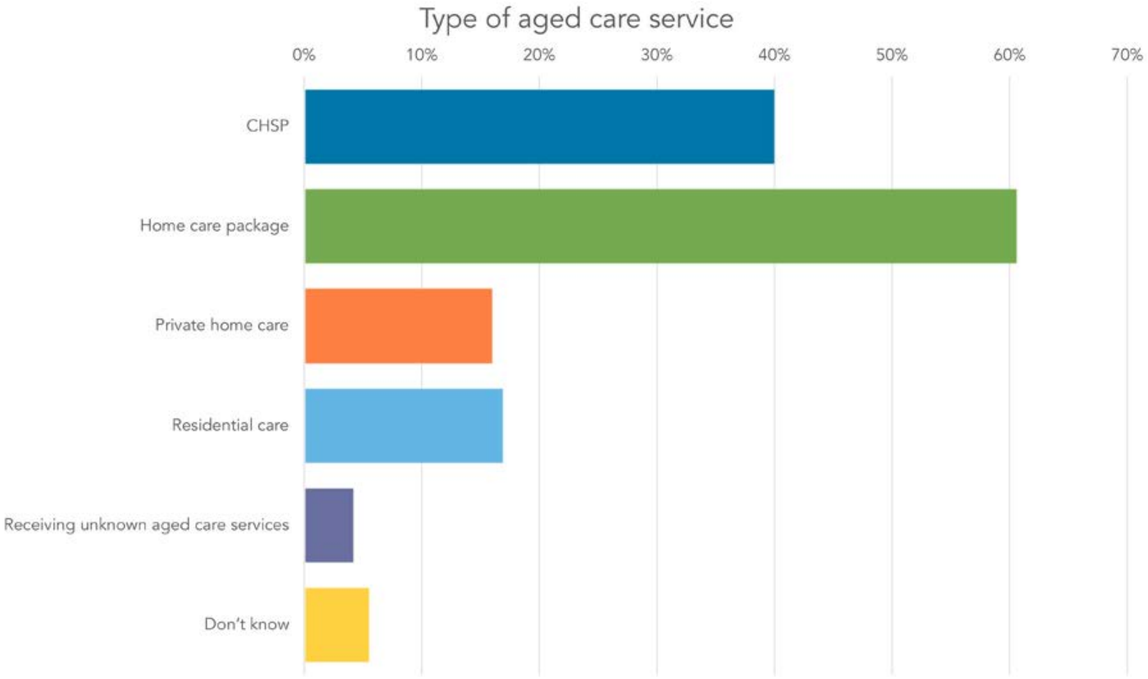


*Figure 15: Type of aged care service received*

- **Carer inclusion in aged care services**

Carers of people using aged care services were asked to respond to a range of statements about the services' inclusiveness, as well as their impacts and quality. Including the carer as a "partner in care" (terminology used in carer recognition legislation) and supporting their needs is a significant recognition of their role and contribution and strongly contributes to carer wellbeing (Hamilton et al, 2024).

When carers engaged with aged care services for the person they care for, roughly two in five (42.9%) reported that they were not asked about their own needs, however a similar proportion (39.8%) were satisfied with their services in this regard, while 31.3% were undecided. Aged care services were, however, mostly inclusive of carers in service decision making and planning, where three quarters of respondents reported that they were involved by service providers in these activities, and 59.3% reporting that their views had a real influence on the services provided. About half of respondents felt they were provided with all necessary information, while one quarter (24.5%) disagreed (see Figure 16).

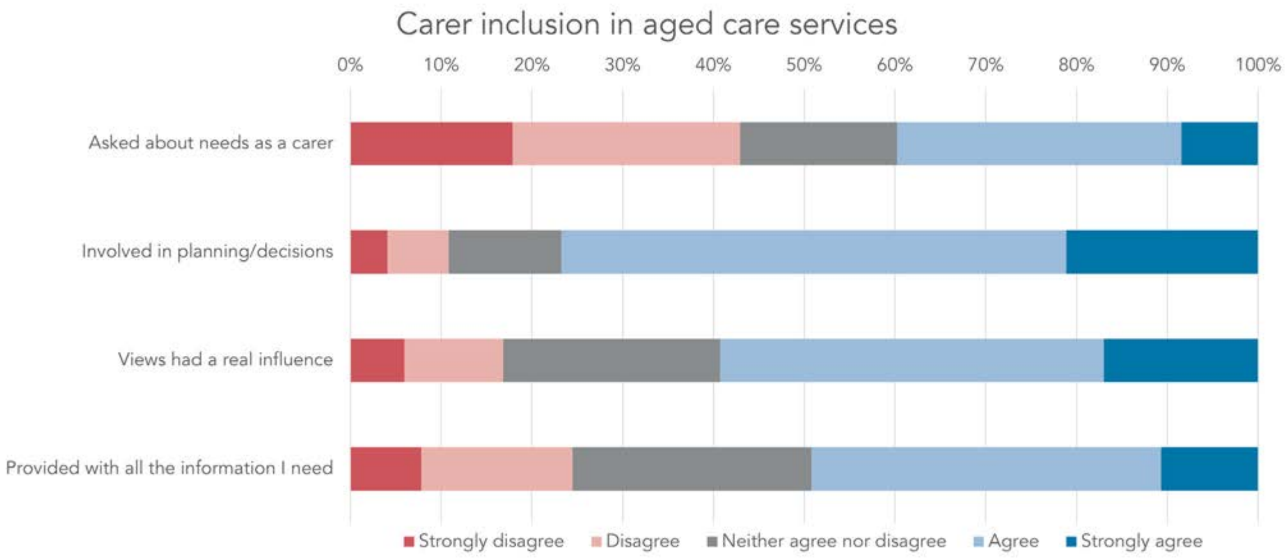


*Figure 16: Carer inclusion in aged care services*

- **Access and quality issues**

Respondents were asked whether they had encountered any of a typical set of challenges with accessing the aged care services for the people they care for (see Figure 17). Such experiences can significantly contribute to feelings of not being recognised and can negatively impact carer wellbeing.

Overall, more than three in four carers reported at least one such experience. Most frequently carers encountered long wait times to access aged care services (40.1%) and or assessments (37.4%), with almost one in three carers (31.8%) reporting challenges finding information and organising services. More than one in four respondents reported that the services the person they cared for received were at a lower level than required, and one in five reported that necessary services were not accessible locally.

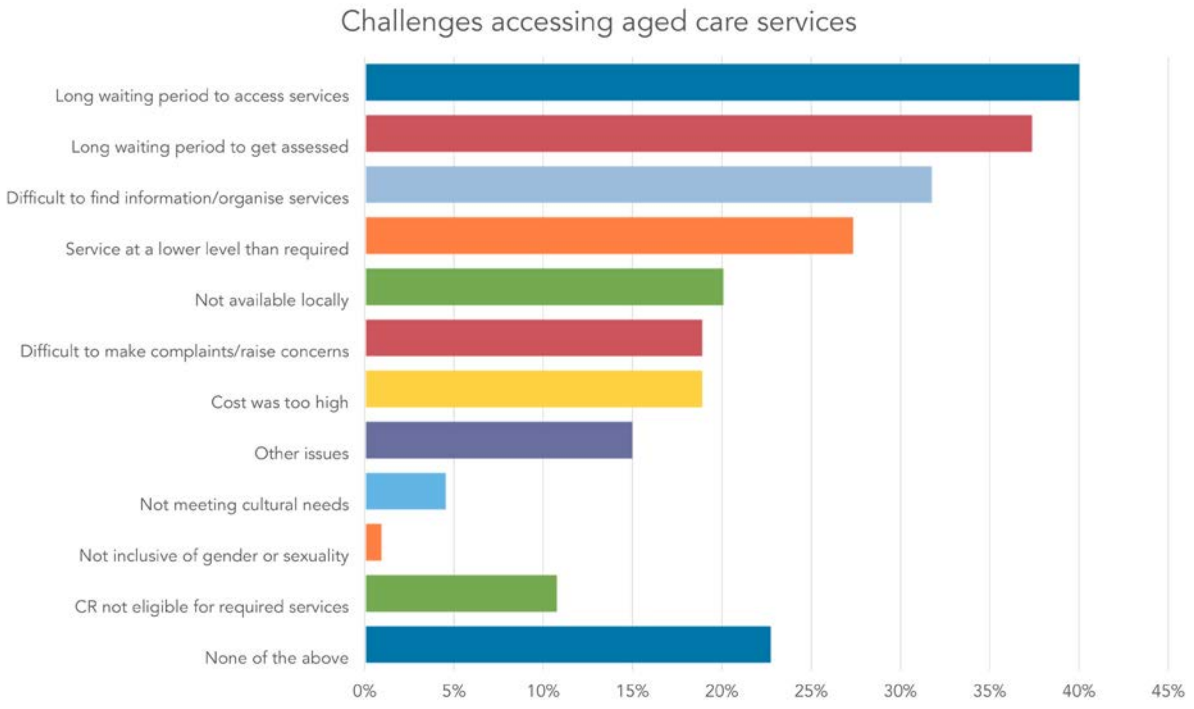


*Figure 17: Challenges accessing aged care services*

## NDIS/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 3,877 respondents (47.3%) to that question reported caring for someone who has a NDIS plan (known as an 'NDIS participant'), while another 16.9% indicated that the person they care for needs NDIS support but does not receive it.

- **Carer inclusion in NDIS services**

A large majority of respondents who cared for someone with an NDIS plan (62.9%) was not asked about their own needs as a carer by service providers, however even more (70.8%) agreed with the statement that they were involved in planning and decision making (see Figure 18). Almost half (48.3%) reported that their views had a real influence on the services provided, while 29.2% disagreed. Two in five carers (40.5%) further disagreed that they were provided with all necessary information for their caring role. This data shows that, although service providers engage with carers and involve them in the delivery of care, their needs as carers are often not taken into account, and their expertise is often disregarded by NDIS services.

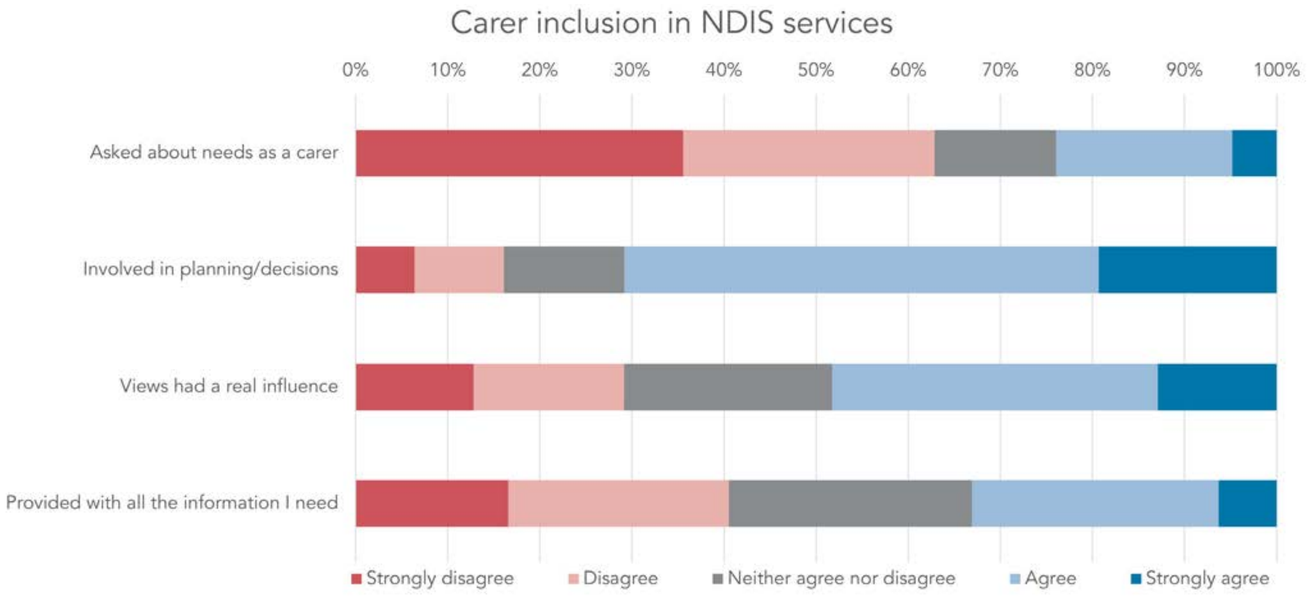


*Figure 18: Carer inclusion in NDIS services*

- **Access and quality issues**

Similarly, the majority of respondents (85.8%) reported at least one issue with accessing NDIS services (see Figure 19). The complexity of organising services (38.0%), and to adapt services when circumstances changed (34.1%) ranked high among the most commonly encountered issues. A second set of common negative experiences were long wait times to access services (37.3%) and to get assessed (31.1%). That the NDIS plan did not cover all costs associated with the required services was encountered by a third of respondents (33.7%). More than one in four respondents reported challenges with local service availability (27.0%) and with raising concerns and complaints (26.7%).

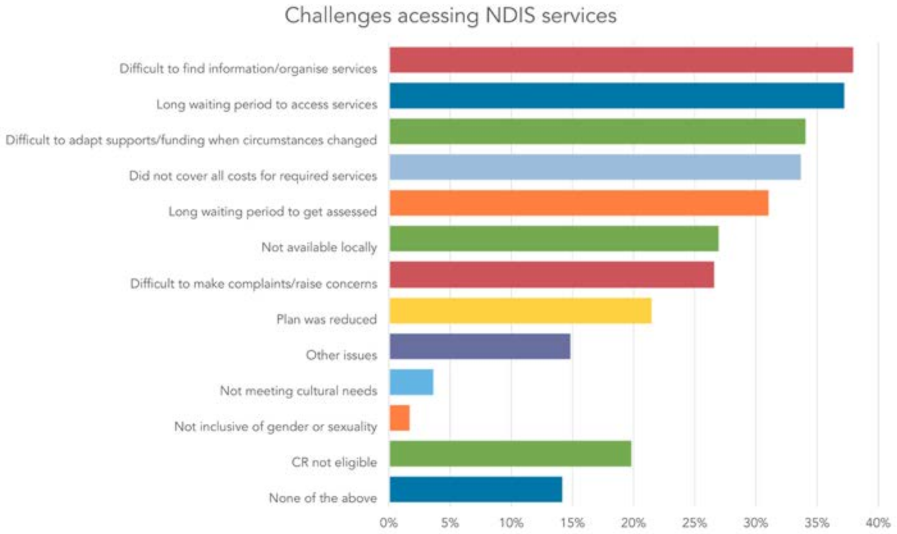


*Figure 19: Challenges accessing NDIS services*

## Mental health services

Almost two in five (39.8%) respondents (3,940 carers) were caring for someone using mental health services (see Figure 20). These services included hospital based services, either admitted as an in-patient or out-of-hospital care, seeing psychologists or psychiatrists, community mental health services such as drop-in clinics or rehabilitation programs, counselling services, or mental health services provided through a general practitioner (GP). A further 9.1% of total respondents cared for someone who needed mental health services but was unable to access them.

More than two in three carers supporting someone who received mental health care services were seeing a psychologist (67.8%), with GPs (47.0%) and psychiatrists (40.7%) being the second and third most commonly accessed mental health service providers. Slightly more than one in three respondents were caring for someone using counselling services and hospital-based services respectively.

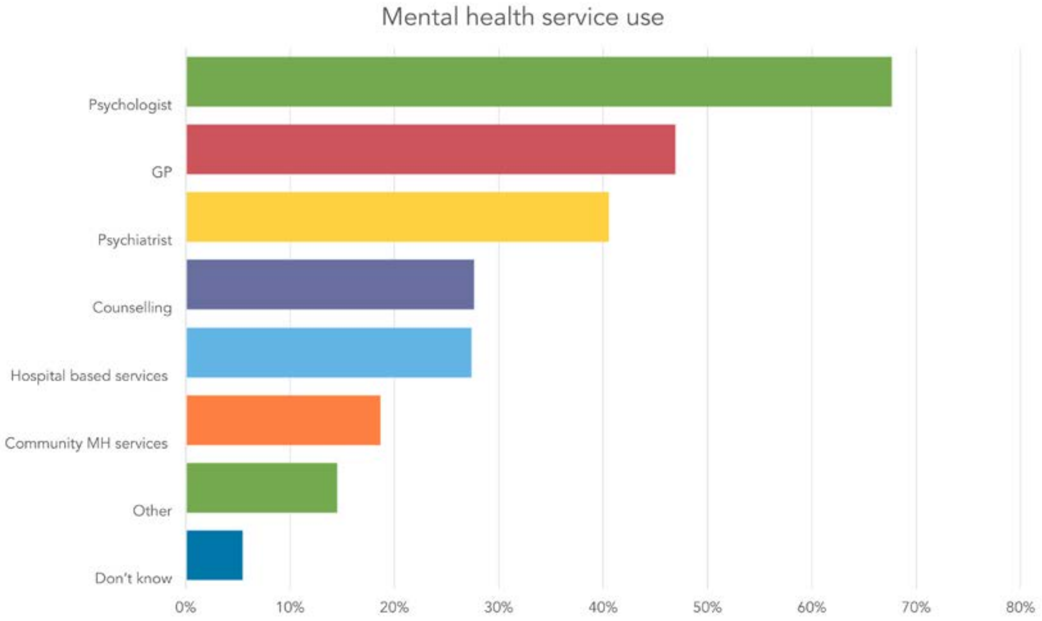


*Figure 20: Mental health services accessed*

- **Carer inclusion in mental health services**

Similar to other service types, almost two thirds of respondents who cared for someone using mental health services (61.5%) were not asked about their own needs as a carer, while the other indicators for carer inclusion were judged more positively by respondents (see Figure 21). More than half of respondents agreeing that they were involved in decision making, and 41.0% reporting that their views had a real influence on the services provided. While one third of respondents felt well informed by service providers, slightly more (38.7%) disagreed that they were provided with all the information they needed.

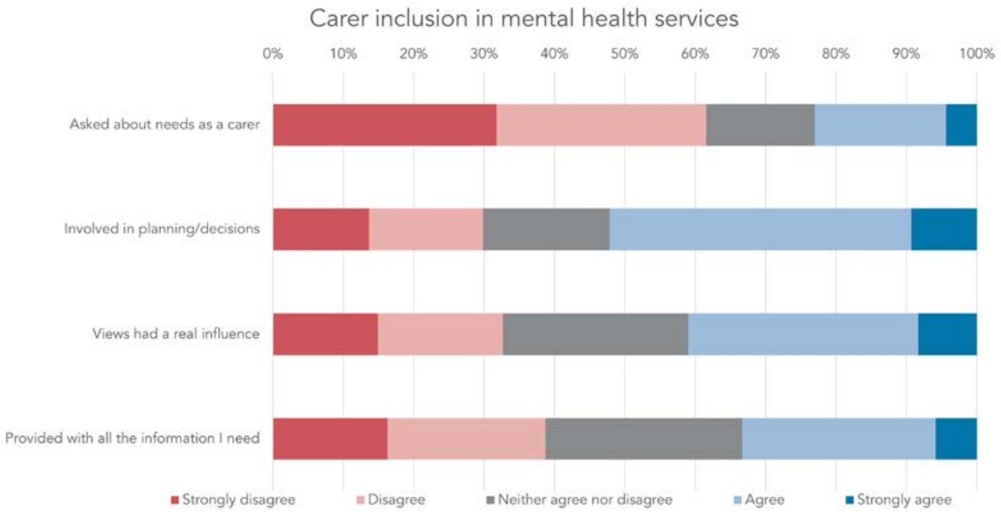


*Figure 21: Carer inclusion in mental health services*

- **Access and quality issues**

The majority of respondents (80.9%) reported at least one issue with accessing mental health services, or in regards to their quality (see Figure 22). Long wait times to access required services were the most common experience (43.1%), followed by high costs or co-payments, which were mentioned by one in three respondents (36.4%). That services could not address the complexity of needs of the person cared for (34.7%) and that it was too difficult to find information and organise services (33.2%) were similarly common experiences. About one quarter of respondents each reported issues with accessing mental health services for the person they care for in terms of frequency and/or duration (26.3%), or because they were not available locally (26.3%).

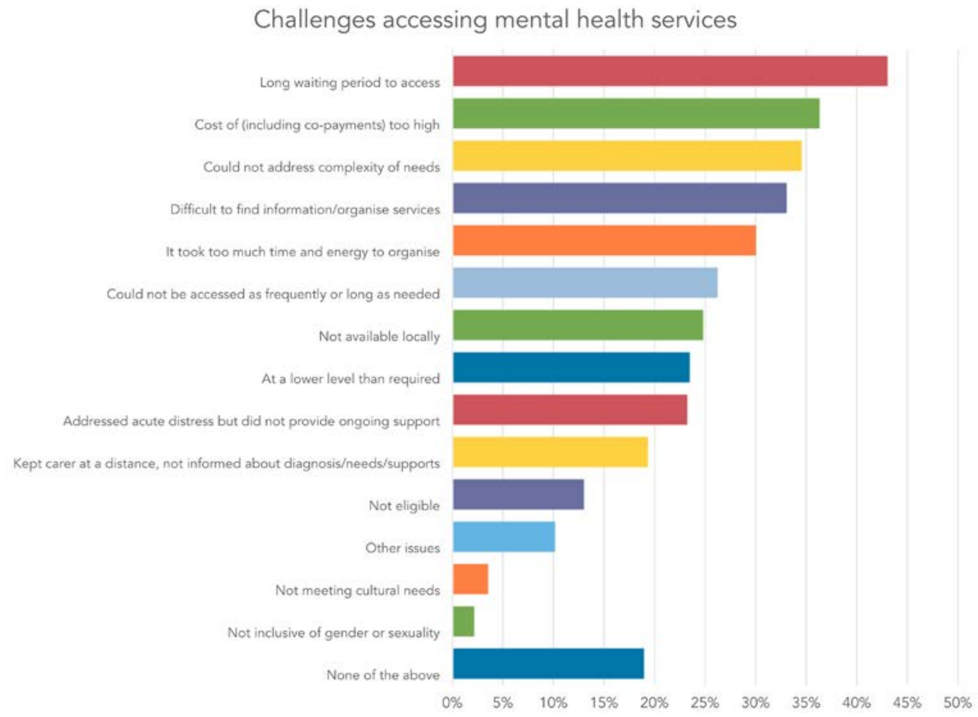
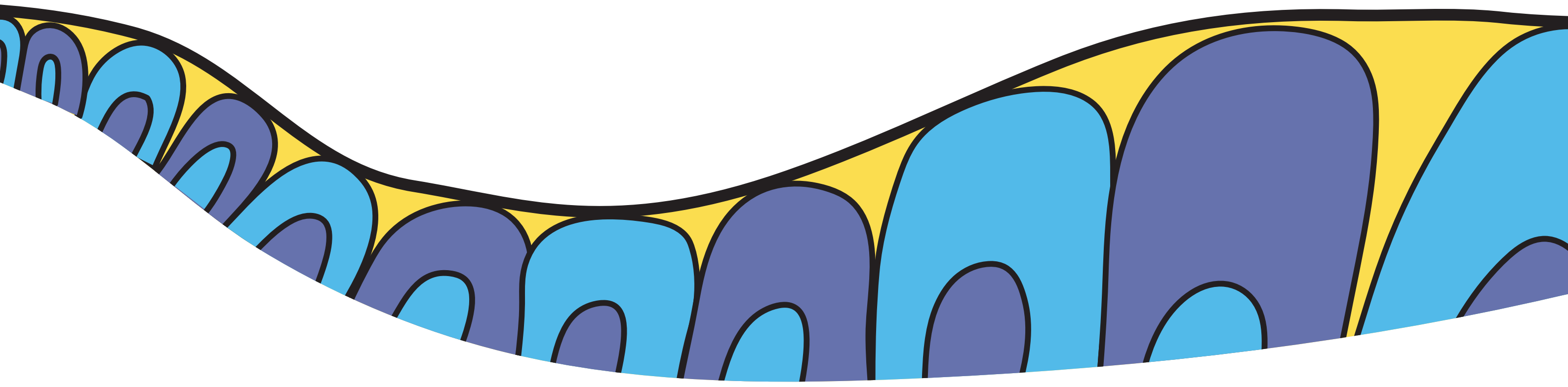


*Figure 22: Challenges accessing mental health services*



## 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 primary health care services, such as general practitioners (GPs), or public health care services, such as hospitals and community health services.

- **Primary health care services**

When accompanying the person they care for to visit a GP, only one in four respondents (25.2%) reported being asked about their own needs as a carer, with 57.9% disagreeing that this had occurred. Two in three carers (66.9%) were involved in treatment discussion and planning when visiting a GP, with slightly fewer (57.6%) reporting that their views had a real influence on the services provided. Almost half of all respondents (47.7%) reported that GPs provided them with the information they needed, however, around one in four (23.4%) disagreed (see Figure 23).

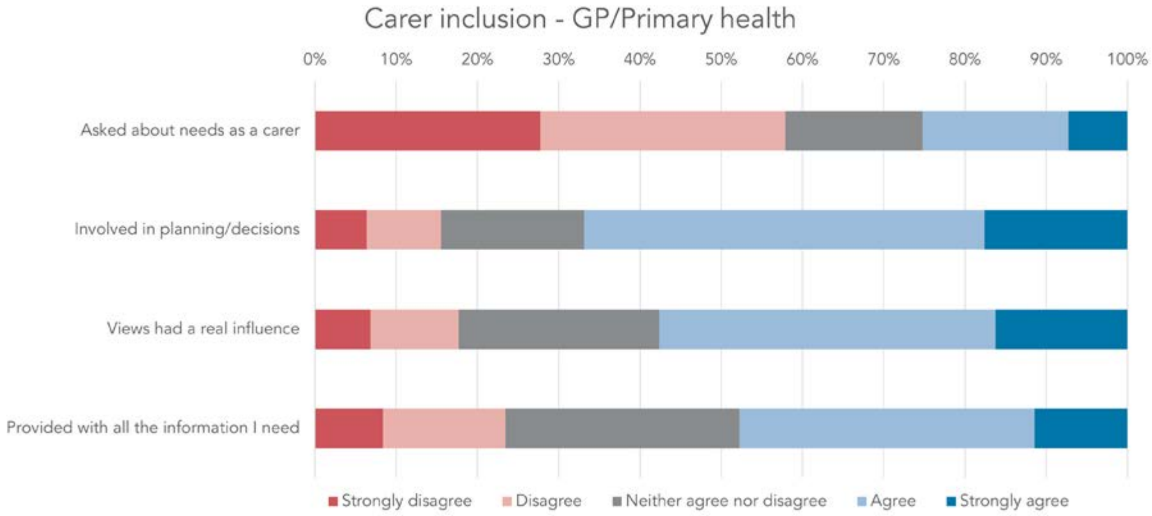


*Figure 23: Carer inclusion in primary health*

- **Public health services**

Even fewer carers felt they were asked about their own needs when presenting with the person they care for at a hospital or community health service (66.9% disagreement) (see Figure 24). The majority of carers agreed with the statement that they were involved in decision making (50.8%), with 42.0% reporting that their views had a real influence on the services provided. More carers felt they were provided with all the information they needed (38.6%) than disagreed (32.5%). Just over half of respondents (55.2%) also felt that there were insufficient facilities provided for carers during the hospital stay of their loved ones, while one in five agreed with that statement.

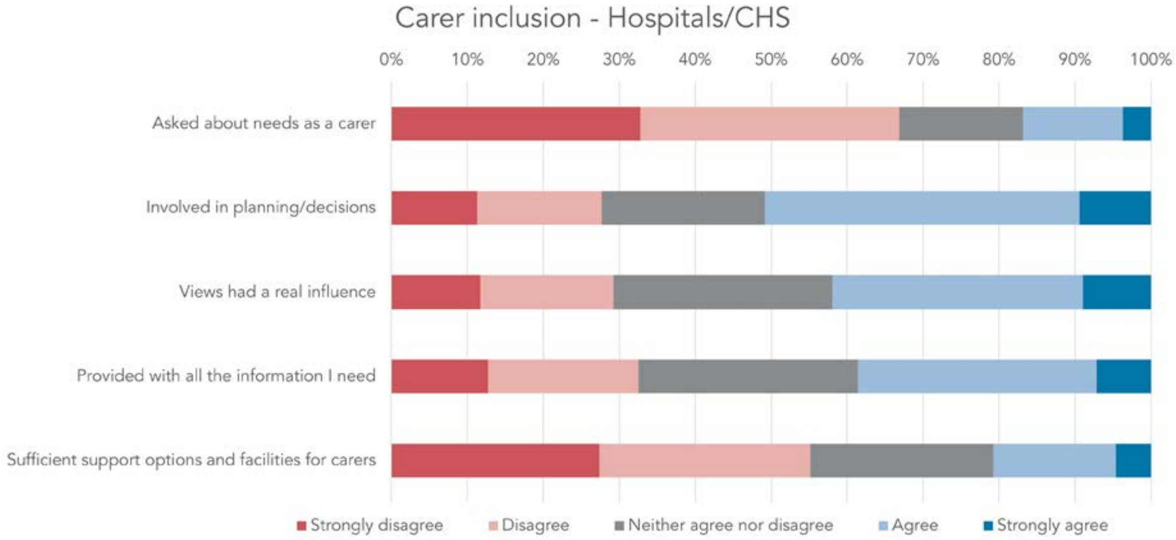


*Figure 24: Carer inclusion by hospitals and community health services*

## Key points

- Across service types, the majority of carers felt they were included in decision making, and carers largely felt that their views had a real influence on the services provided, which is an important aspect of recognising carers' experience and contributions to the provision of care.
- However, most carers were not asked by service providers about their own needs, and many did not feel adequately informed by service providers. This signifies a lack of recognition for carers as having their own and independent needs by service providers, especially in the disability and mental health sectors.

## Carer support and breaks from caring

Dedicated carer support services recognise that carers have needs in their own right and require tailored support. Since 2020, most carer support services in Australia are provided through Carer Gateway, the Australian Government's national carer support program. The National Carer Survey asks carers about their use of carer support services, and the types of carer support they need more access to.

One very important type of carer support is the ability to take breaks from caring, in order to look after oneself, rest and recharge, or attend to other responsibilities. This is often referred to as "respite" a dedicated support type providing carers with time away from the caring role and professional care for the person they look after, either planned ahead of time or provided in unexpected emergencies. Such formal breaks are, however, not always available (Carer Respite Alliance, 2021). The National Carer Survey also investigates whether aged care, disability and mental health services provide opportunities for carers to take breaks and/or offer a 'respite effect'.

### Carer support services – use and unmet need

In total, two in three (64.4%) of the 7,442 carers who responded to the question had used at least one form of carer support, however, 73.2% reported an unmet need for at least one carer support type (see Figure 25).

The most commonly used support listed was the Carer Gateway website (40.9%), followed by carer support groups, which were used by roughly one in four carers (23.9%). About one in five carers each used counselling (20.0%) and planned respite (19.5%), while all other support types were used by less than 10% of respondents. The combination of reported use and unmet need indicates that social connection, breaks, and mental health are the areas where carers require the most support.

Only very few carers who accessed a given support type still had unmet needs in that area, with counselling being the exception – 7.7% of all carers accessed counselling but nevertheless reported a need for more sessions.

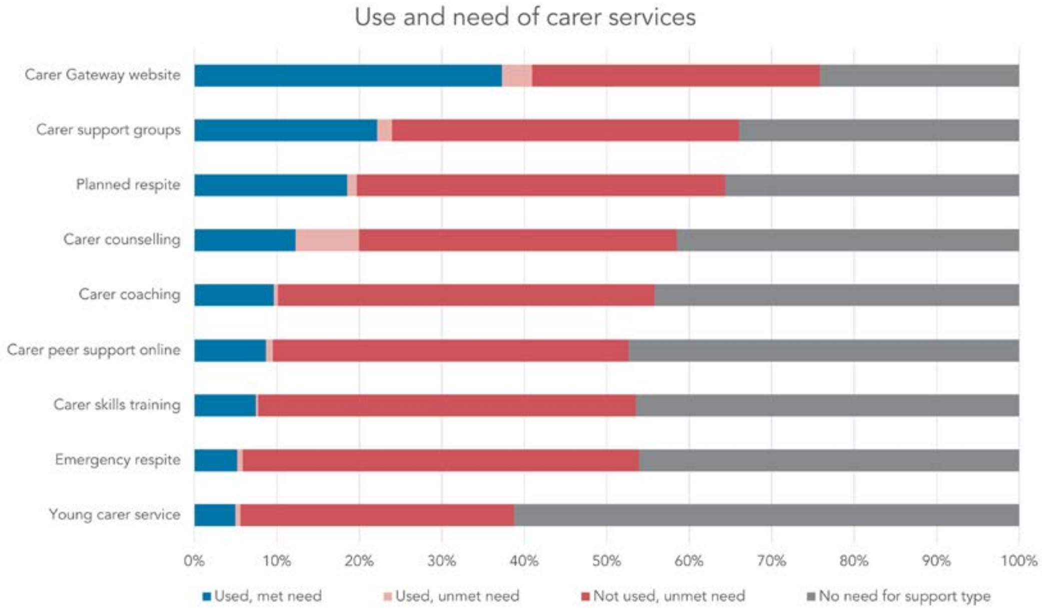


*Figure 25: Usage of, and unmet need for, carer support services*

Overall, however, the proportion of carers with an unmet need for all service types (except for the information offered by the Carer Gateway website) largely exceeded the number of carers using the support type. The service type where demand outstripped supply the most was emergency respite, with eight times more carers reporting unmet need compared to those using it, followed by dedicated young carer services and carer-specific skills training, where the number of respondents reporting an unmet need was six times the number of users. For online peer support and carer coaching, the ratio of use to unmet need was around 1:4.5, and for planned respite and carer counselling, the carers reporting unmet need numbered more than twice the carers using these supports.

The small proportion of users of each service type reporting an unmet need likely indicates that if carers access a support, their needs are usually met. Correspondingly, the high rates of unmet need among those who did not access a given support type likely results from access issues. From the 2022 National Carer Survey (Carers NSW 2023:56), we know that these may stem from limited information or knowledge about available supports and from service availability limitations, as well as from carers not being able to take enough time out of their caring role to organise and use services. An indication for the latter can be found in the replacement care and respite effects of formal services.

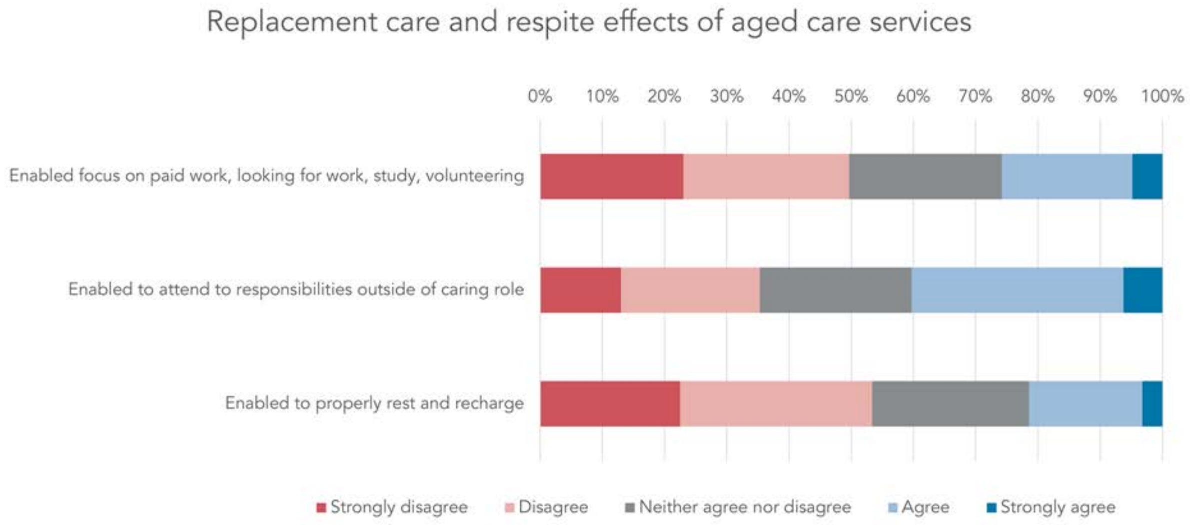
### Replacement care and respite effects

Well-functioning formal services for the person they care for are an invaluable support for carers because they reduce caring stress and make caring roles more sustainable. Inversely, when formal care services do not function well, they can make carers feel less recognised and contribute to carer stress.

The National Carer Survey asks about the impacts of aged care, disability and mental health services on carers' ability to focus on paid work, looking for work, studying, or volunteering, and whether the services replaced the care provided by carers sufficiently to enable them to attend to responsibilities outside of caring role, e.g. parenting responsibilities, their own appointments, or household chores, as an indication whether formal care services actually can replace the care provided by the carer, and whether they provide a respite effect.

- **Aged care services**

Only one in four carers reported that the aged care services for the person they cared for enabled them to focus on work or study, while almost half (49.6%) explicitly disagreed (see Figure 26). However, 40.3% agreed that these services allowed them to attend to other responsibilities outside their caring role. Only one in five carers (21.4%) agreed that services allowed them to properly rest and recharge, while more than half (53.3%) disagreed, showing the limited respite effect of aged care services.


Replacement care and respite effects of aged care services

- **NDIS/Disability services**

Overall, carers were highly critical of the notion that NDIS services for the person they care for would support them to undertake activities outside their caring role (see Figure 27). Almost two thirds (60.5%) reported NDIS services did not enable them to focus on paid work, looking for work, study, or volunteering, more than half (52.2%) reported that NDIS services did not allow them to focus on responsibilities outside their caring role, and two in three disagreed that the person they were caring for receiving NDIS services let them properly rest and recharge.

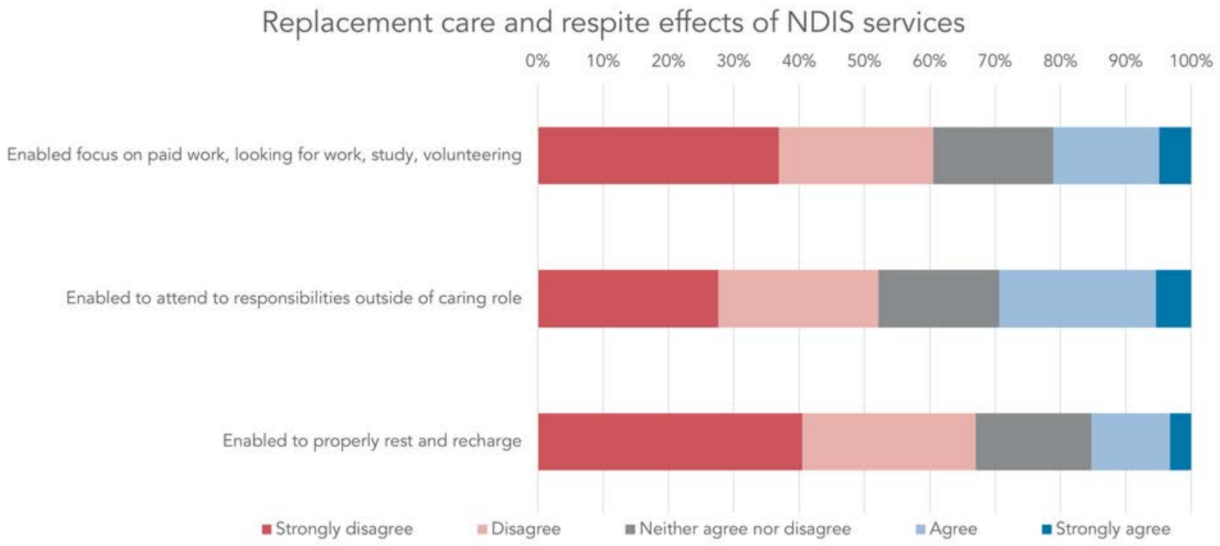


*Figure 27: Replacement care and respite effects of NDIS services*

- **Mental health services**

Respondents overwhelmingly disagreed that mental health services freed them up to focus on other activities (see Figure 28). More than two in three disagreed with the statements that mental health services enabled carers to properly rest and recharge (70.9%) or to focus on paid work, looking for work, or to study or volunteer (68.5%). A large majority also disagreed with the statement that mental health services enabled them to attend to responsibilities outside of the caring role. The significantly worse rating of mental health services in terms of replacement care and respite effects speaks to the complexity and episodic nature of mental health caring roles.

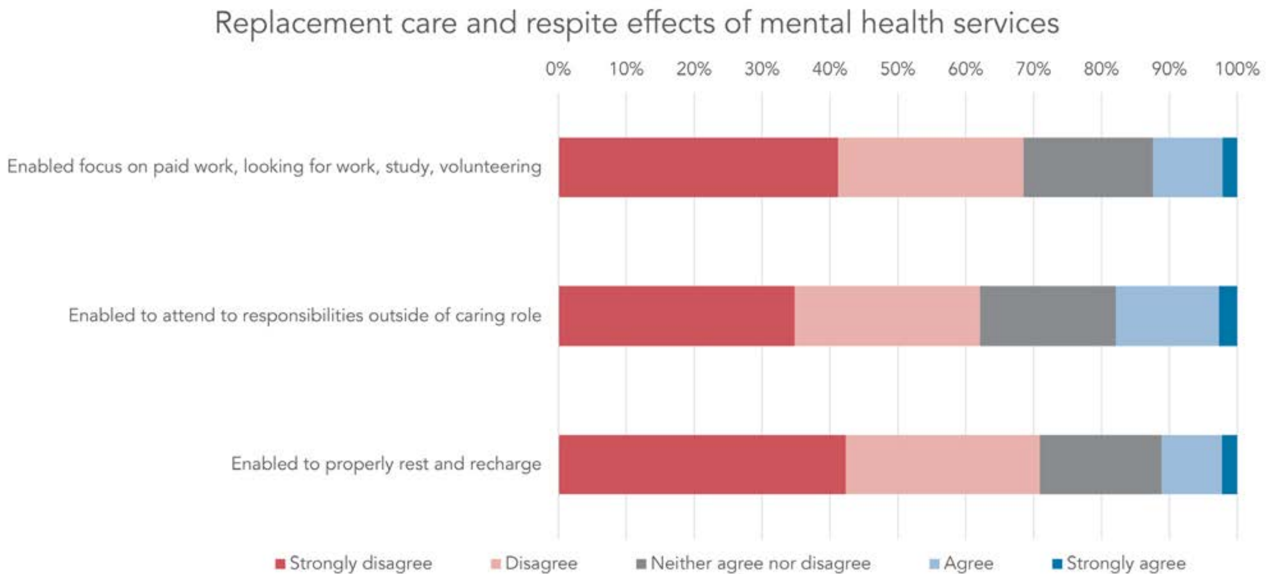


*Figure 28: Replacement care and respite effects of mental health services*

The need for replacement care and respite can also be seen from the time carers have available for themselves. Respondents were asked how many hours per week they generally have to themselves, i.e. for pursuing activities of their choice not relating to caring responsibilities, work, or household and other chores (see Figure 29). Of the 7,263 carers who responded to this question, the average hours per week carers had to themselves was 11.4 hours, or approximately 1.6 hours per day, which equates to less than half a day per week. Almost one in two carers (44.7%) reported having five hours or less to spend on themselves each week, including one in five (19.2%) having just one hour or less available.

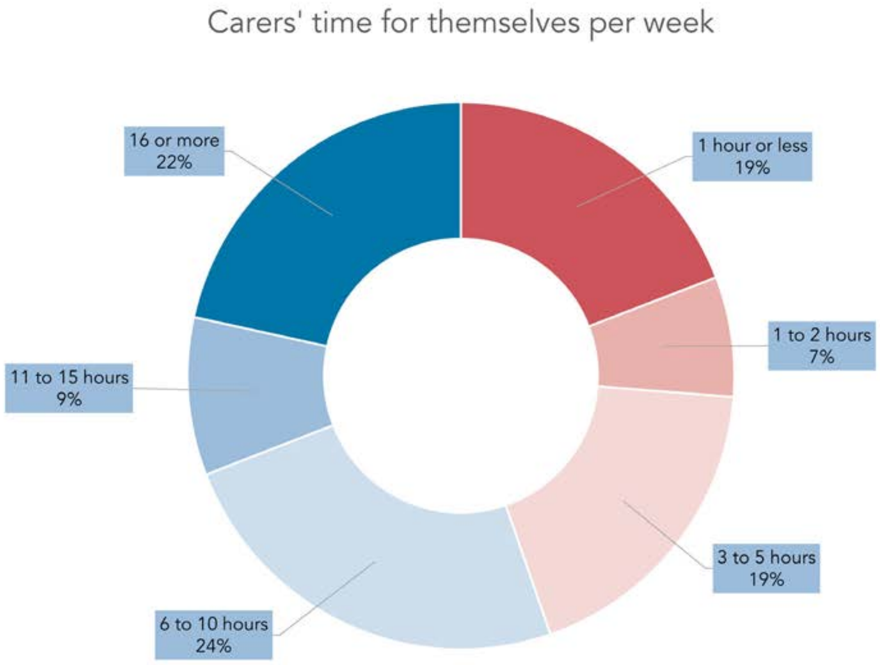


*Figure 29: Carers' time for themselves per week*

**Key points**

- Carers' highest reported support needs are for peer support, breaks from caring, and supports for their own mental health.
- Formal services do not necessarily facilitate breaks from the caring role, even when this is a stated intention. Overall, the majority of carers disagree that the services the person they care for receives provide a 'respite effect', i.e. enable them to rest and recharge, or focus on paid work or studying.
- Only among carers of people using aged care services did a relative majority agree that the services allowed them to dedicate time to focusing on responsibilities outside their caring roles. For those caring for someone accessing NDIS and mental health services, the majority disagreed.
- On average, carers only have about 1.6 hours a day for themselves, i.e. not occupied with caring or work responsibilities. One in five carers have one hour or less per week for themselves.

## The caring role

Most carers who responded to the 2024 National Carer Survey support close family members. Of the 9,423 respondents with a current caring role (93.3%), more than two in five (44.4%) were caring for a child, including adult children, one in three (34.1%) were caring for a partner or spouse, and more than one in five (22.6%) were caring for a parent or parent in law. One in three (32.9%) were caring for more than one person. More than half of the people cared for by respondents were male (55.8%), 42.8% were female, and 1.3% were non-binary or gender diverse. More than one in four respondents (26.8%) cared for someone under the age of 20 years, while almost half of all respondents (48.4%) cared for someone aged 65 years or older (see also Part 1).

The vast majority of respondents (83.9%) lived with the person they care for in the same household, with one in seven (14.5%) caring for someone who lived separately and 4.7% caring for someone in an aged care home or supported accommodation.

The caring roles of respondents to the Survey were predominantly long, ongoing and of a relatively high intensity (see Figures 30 and 31). Almost half of all respondents (48.1%) had had a caring role for ten or more years, while a further 27.9% had been caring for five to ten years. Only 12.5% had been caring for less than two years.

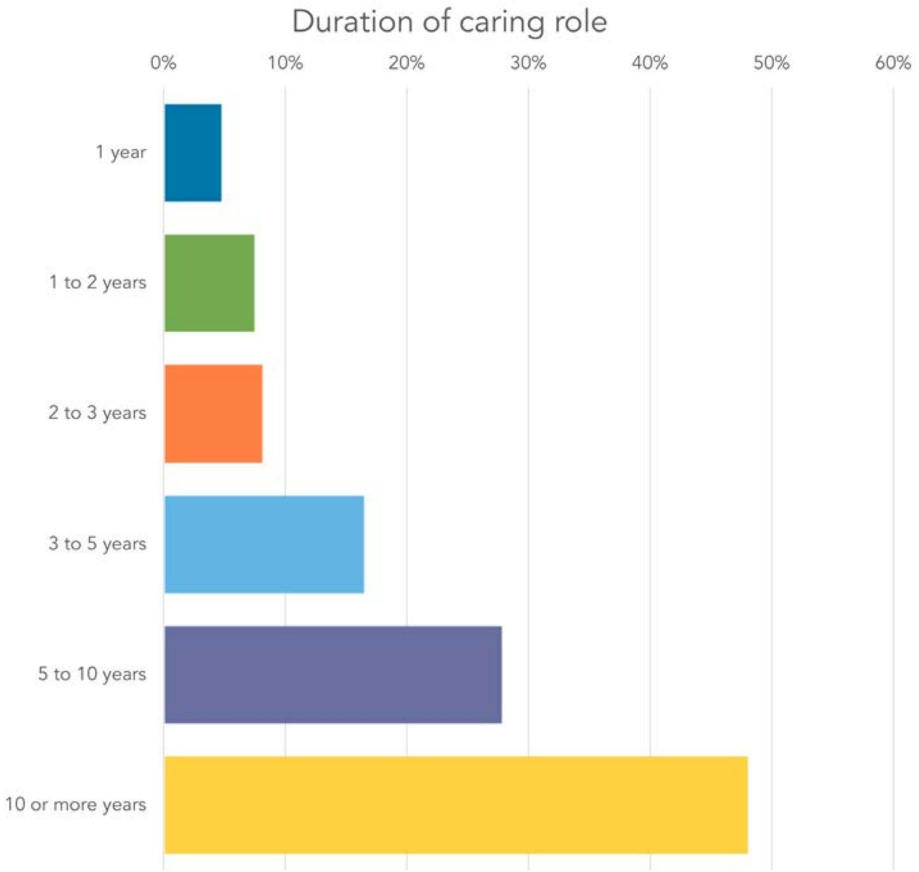


*Figure 30: Duration of caring role*

Respondents provided on average 108.4 hours of care per week, with 65% providing more than 60 hours, and half of all respondents (49.3%) providing 24/7 care. While about one third of respondents (29.9%) received support from others in their caring role, and a further 14.3% shared care equally with a partner, more than half (53.0%) provided care alone.

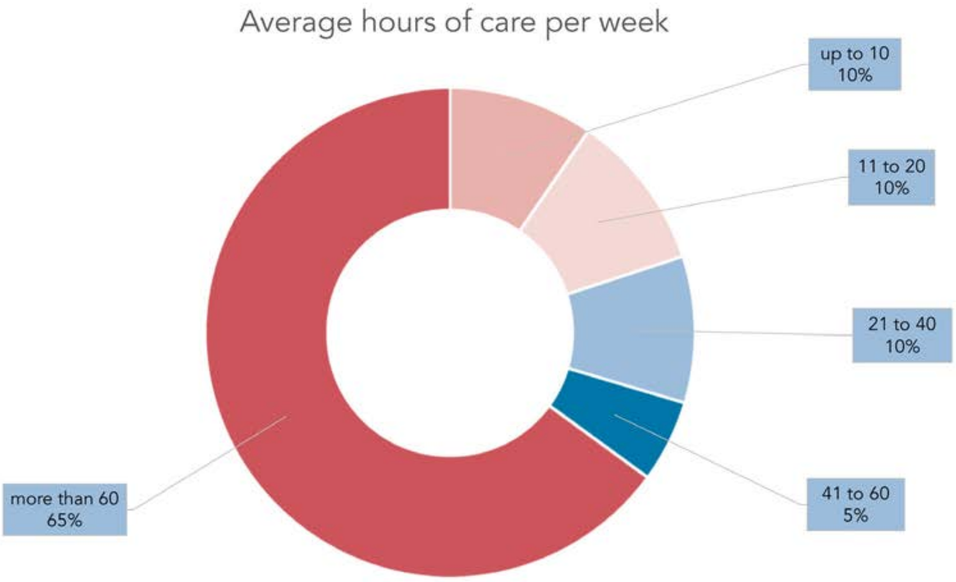


*Figure 31: Average hours of care per week*

The most frequent form of support provided by respondents was transport (87%), followed by Monitoring/supervision (86.5%) and support with administration and organising services (81.0%) (see Figure 32). Four in five carers (79.9%) provided domestic assistance and a similar proportion provided assistance with health care tasks (79.6%).

Slightly more than three in four provided cognitive and decision-making support (77.7%) and supported the person they cared for in managing their finances (77.2%). Around 70% of respondents provided support with advocacy and personal care, while three in five provided behavioural support.

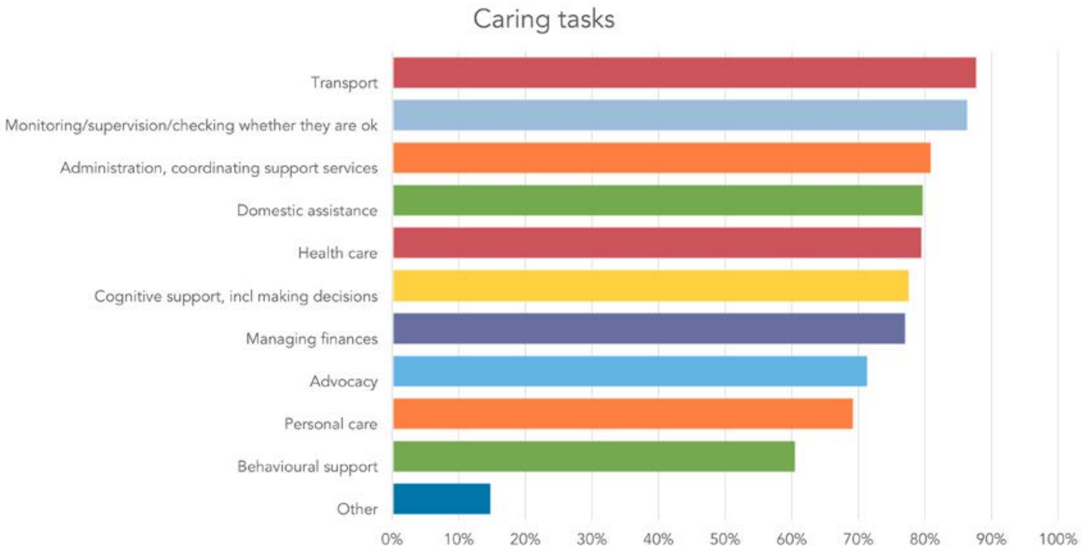


*Figure 32: Caring tasks*

## Knowledge and skills in caring roles

In their many years of caring, respondents have built up a reservoir of skills and knowledge that sustains their caring roles. Almost three in four carers (72.9%) reported that they learned new skills through their caring role, and 90% said that they draw on their experience in providing care (see Figure 33). Two in five respondents were confident that they know everything that is expected of them in their caring role, while 29.1% disagreed. Confidence was even higher when asked whether respondents knew what they are required to do in every aspect of their caring role, with half agreeing (49.7%) and a quarter disagreeing (25.1%). However, almost all respondents perceive their caring role as emotionally demanding (94.5%), and just over half of all respondents (55.3%) agreed that they feel they can continue the demands of their caring role, while one in five (20.6%) disagreed with that statement. These results show that carers are largely confident in their knowledge and skills. However, only around half (55.3%) of all respondents were confident that their caring role was sustainable.

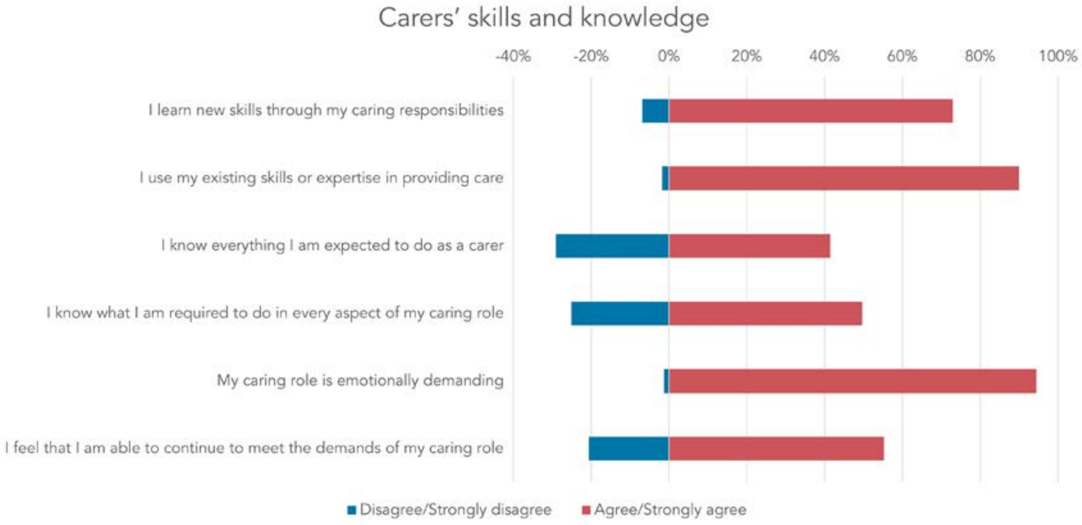


*Figure 33: Carers' skills and knowledge*

## Legal instruments in care

Many carers provide support to the person they care for with understanding, making and communicating decisions. While not all decision-making support is formalised, there are a set of legal arrangements that can be used to safeguard the rights and interests of the person, while also ensuring that the carer is included in the decision-making process.

These instruments range from an Advance Care Plan, which documents the health care preferences of a person in case of an unforeseen injury or illness, or deteriorating condition, to Powers of Attorney, giving the carer authority in a person's financial and legal decisions, and forms of Guardianship, allowing the carer to make lifestyle, health and medical decisions on a person's behalf.

While such instruments are common, no accessible prevalence data exists on their use in Australia. The 2024 National Carer Survey is the first to provide such data, and to allow for an analysis of connected outcomes. In total almost two in three respondents to the question (59.4%) had at least one of these instruments in place (see Figure 34).

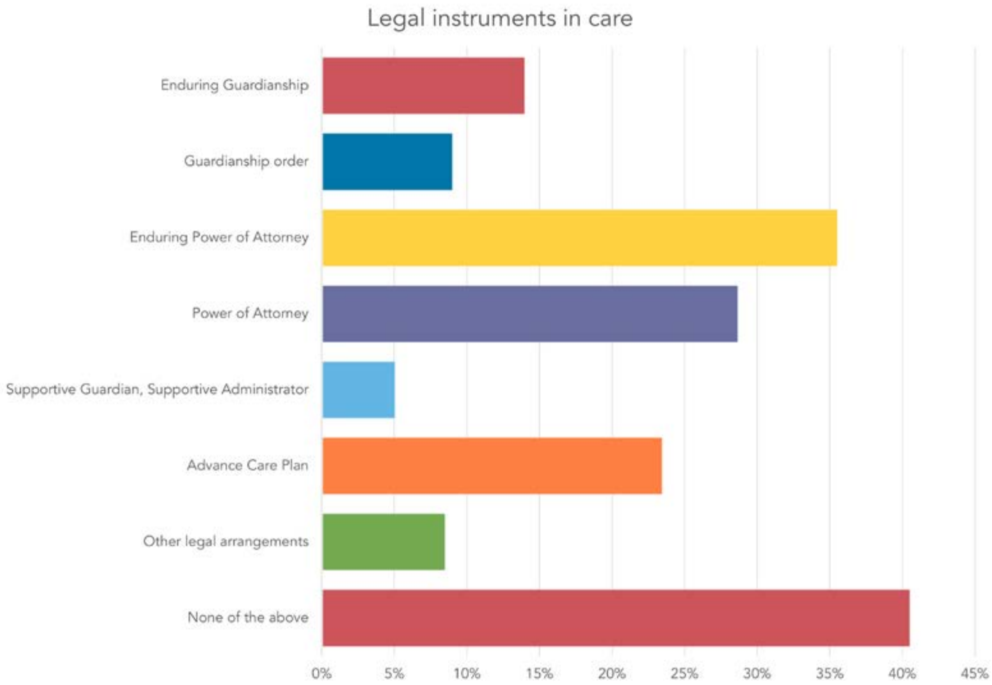


*Figure 34: Legal instruments in care*

More than one in three respondents had an Enduring Power of Attorney in place for the person they care for. This was the most common legal instrument reported in the Survey. Enduring Powers of Attorney allow carers to manage financial and legal decisions if the person they care for loses the ability to make decisions. A further 28.7% of respondents held a temporary Power of Attorney. Carers of older people were the largest group to hold Enduring Powers of Attorney (47.9%), followed by carers of people living with a physical disability (44.0%) and carers of people living with dementia (41.2%).

One in seven respondents was managing the lifestyle, health and medical decisions of the person they care for through Enduring Guardianship, and 9.1% had a Guardianship order in place. The most common groups of carers with with an Enduring Guardianship in place were those caring for an older person (45.9%) or someone living with dementia (44.8%). The most common group of carers holding a Guardianship order for the person they care for were carers of people living with a physical disability (41.6%), followed by carers of people living with an intellectual disability (36.0%) and carers of people living with mental health challenges (33.4% of Guardianship orders).

Almost one in four respondents reported that the person they care for had an Advance Care Plan in place. An Advance Care Plan is a voluntary document that outlines preferences for medical care for the case that the person needing care is unable to communicate them, and can provide the carer with a level of security around the wishes of the person they care for. Most commonly, people requiring care due to advanced age had an Advance Care Plan (49.9%), with 38.9% of Advance Care plans being for someone living with dementia.

This data is the first in Australia to show the widespread use of these various legal instruments in informal care.

### Planning for natural disasters and emergencies

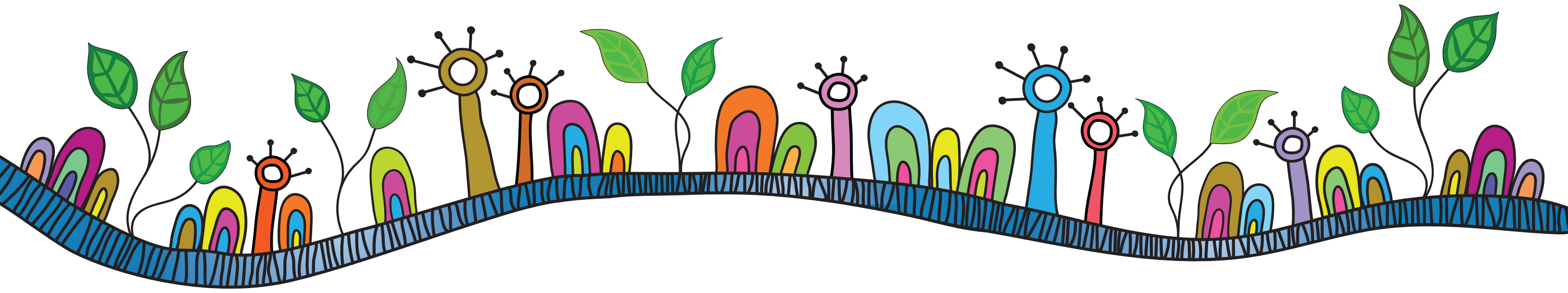
Natural disasters have been a common experience for Australians in the years since the first National Carer Survey in 2020. The 2022 National Carer Survey was the first to ask carers about these experiences. The 2024 National Carer Survey included an additional question focusing on carers' preparedness for natural disasters.

A relative minority of respondents (4.1%) to the 2024 National Carer Survey had been impacted by a natural disaster in the two years prior, however, this proportion was higher in Inner and Outer regional areas (6.7% and 6.5% respectively). Just over one third (34.4%) of all respondents had a natural disaster plan in place, while 41.3% did not. Around one in four (24.3%) responded 'Don't know or Not applicable'.

This is reflective of the uneven exposure to natural disasters across the country. Regional areas of Australia experience a higher risk of natural disaster impacts, so it is not surprising that respondents to the 2024 National Carer Survey living in regional areas were significantly more likely to have a natural disaster plan in place. Almost half of respondents living in Inner regional areas (47.6%) and of those living in Outer regional areas (47.7%) had a natural disaster plan in place, while this applied to only 26.6% of carers living in Major cities. This still leaves a large proportion of carers without plans in place for how to manage in a natural disaster; only half (51.7%) of those impacted by a natural disaster in the years 2022 to 2024 had a disaster preparedness plan in place.

**Key points**

- Caring roles are long, ongoing and of relatively high intensity.
- Almost half of respondents provided 24/7 care, most for ten years or more.
- Most carers are confident in their skills and knowledge, however, only 55% think their caring role is sustainable long-term.
- Three in five respondents had a legal instrument in place to support the person they care for with decision making.
- Only half of the respondents impacted by a natural disaster between 2022 and 2024 reported having a disaster plan in place.



## Health, wellbeing and social connectedness

To monitor the health and wellbeing of Australia's carers, the National Carer Survey includes four validated 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 frequently have poor health, in many cases as a result of the demands of their caring role. The Survey used a question developed for the ABS National Health Survey to ask carers about their subjective health estimate. Figure 35 shows the results by age and compares it with the population estimates of the 2022 National Health Survey (ABS 2024, latest available release).

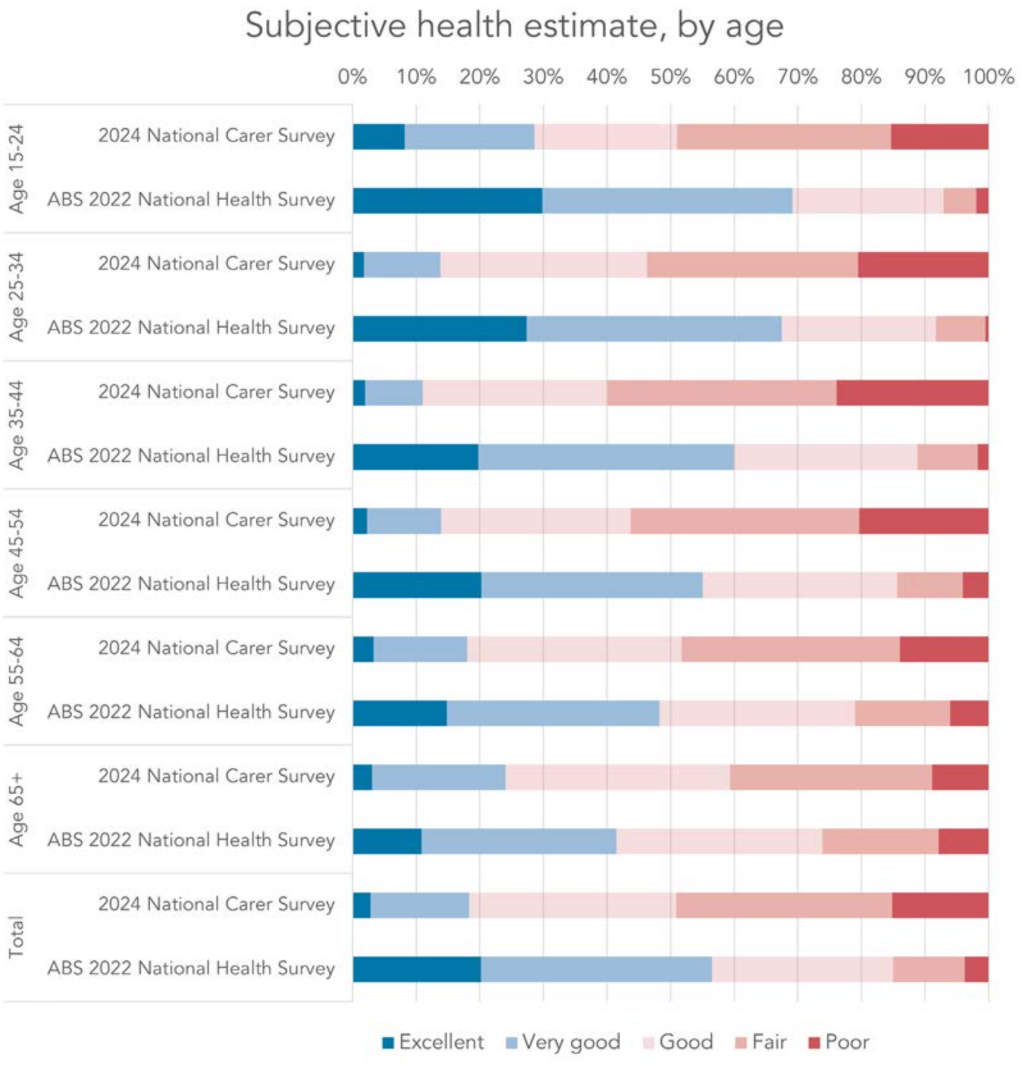


*Figure 35: Subjective health estimate, by age*

While in the general population, 46.0% of Australians estimate their health as "Very good" or "Excellent", in the National Carer Survey only 18.3% of respondents do so. Carers across all age groups estimate their personal health significantly worse than the general population. Interestingly, it is older carers who report relatively better health than those of working age, and even younger carers. Carers overall report poor/fair health at a rate of four times of the general population.

This can be in part attributed to the large proportion of carers who live with a long-term health condition or a disability themselves – almost half of the respondents to the National Carer Survey (46.5%), as shown in Table 8. However, even the carers who do not have such a condition report poor or fair health at 2.5 times the rate than the general population.

***Table 8: Subjective health estimate, by long-term health condition/disability***

| | | **Long-term health condition/disability** | |
|---|---|---|---|
| | | **No (53.5%)** | **Yes (46.5%)** |
| Subjective health estimate | **Excellent** | 4.8% | 0.5% |
| | **Very good** | 24.4% | 5.7% |
| | **Good** | 39.7% | 24.6% |
| | **Fair** | 26.2% | 42.4% |
| | **Poor** | 4.8% | 26.9% |

## Personal wellbeing index (PWI)

One of the most common indicators used to measure wellbeing in Australia 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, feelings of safety, community connectedness and future security (Cummins et al 2007).

The average PWI score amongst respondents to the 2024 National Carer Survey was 55.7%, significantly lower than the national average of 74.7% as reported in the 2024 Australian Unity Wellbeing Report (Frykberg et al 2024). Overall, the mean wellbeing score of respondents was 74.5% of the wellbeing score of the Australian population. Figure 36 shows the differences in wellbeing by age group. Noticeably, the average score of the lowest scoring groups of carers, those aged 34 to 54 years, lies below 50%, whereas the lowest scoring age group in the general population, the 25 to 34 year olds, scores 62.9%. Carers aged 34 to 54 years also report the largest difference to the general population. While older carers report significantly better wellbeing, their average scores still lie significantly below the population average for their respective age cohorts.

*Figure 36: Average Personal Wellbeing Index score, by age group*

Figure 37 shows the average score for each of the seven domains of the PWI, again in comparison to the general population. Across all domains, carers report significantly lower satisfaction compared to the general population. Carers report the lowest domain score in satisfaction with their achievements in life, whereas the general population records the lowest average score in satisfaction with their community connectedness. The largest distances between carers' satisfaction and the average Australian scores are in the domains Achieving in life and Personal relationships (23.9% points for both), which indicates the low recognition caring roles receive, and their often isolating nature. The smallest difference is recorded in satisfaction with Standard of living (13.5% points).

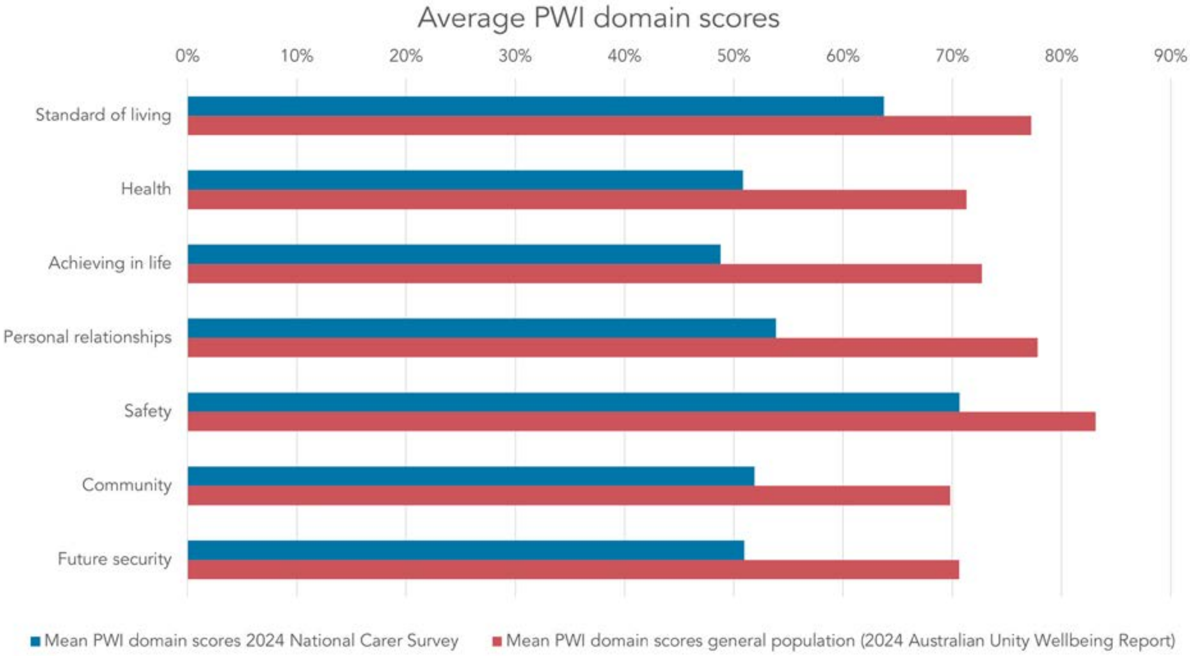


*Figure 37: Average PWI domain scores*

## Psychological distress

Psychological distress was measured using the Kessler 5-Item Scale of Psychological Distress (K5), which is categorised to indicate low, moderate, high or 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 ABS 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). High to very high distress scores indicate the likely presence of a depression or anxiety disorder.

Overall, there is a high prevalence of psychological distress among carers, with more than half (53.7%) of respondents indicating they experienced high or very high psychological distress. This compares to 14.5% in the general population, or a rate 3.7 times higher for carers. In the general population, younger people are most likely to feel distressed. More than one in five Australians aged 15 to 24 years experienced high to very high distress according to the 2022 National Health Survey (ABS 2024). However, among carers it is the age cohort of 25 to 44 years where the highest rates of high/very high distress are reported, with more than 71% reporting high/very high distress (see Figure 38). Among carers, the rate of distress then steadily declines with age, illustrating the impact caring has, especially on working age carers.

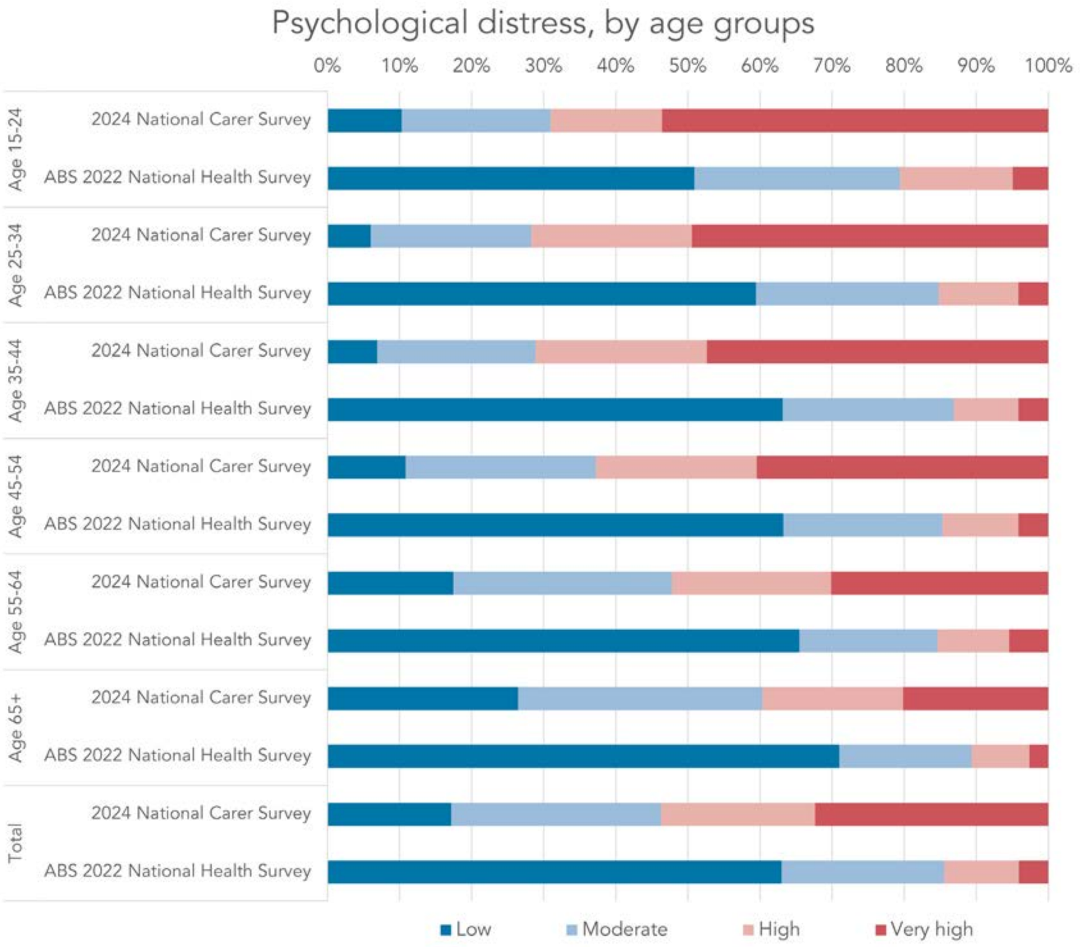
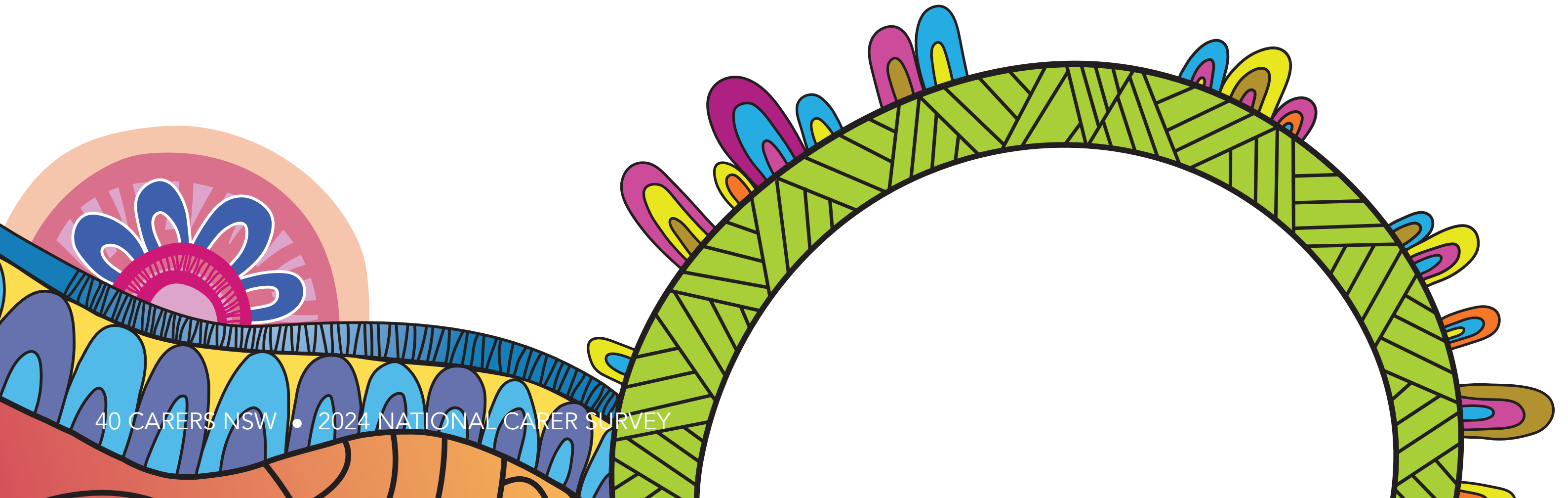


*Figure 38: Psychological distress, by age*

## Social connection, relationship satisfaction and social support

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 39 shows the scores reported by respondents in the 2024 National Carer Survey. Most respondents (61.2%) indicated they were socially isolated or highly socially isolated. Fewer than one in three (22.4%) identified that they were socially connected or highly socially connected. Particularly high rates of isolation were found among carers aged 25 to 34 years, where almost four in five (78.2%) reported being socially isolated or highly socially isolated.



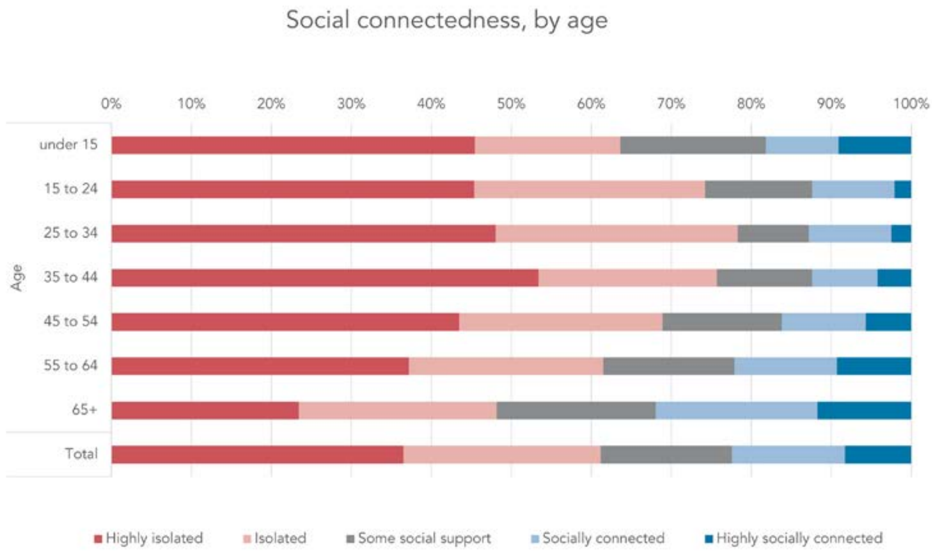


*Figure 39: Social connectedness, by age*

Carers were also asked about their satisfaction with personal relationships on a scale from 0 (completely dissatisfied, represented as %) to 10 (completely satisfied, represented as %), to identify particular sources of social and emotional support (see Figure 40). On average, respondents were most satisfied in their relationships with the person they care for, followed by their children. The average satisfaction with the relationships with partners and parents however remained below 50%, indicating the high pressure caring roles can put on close family relationships.

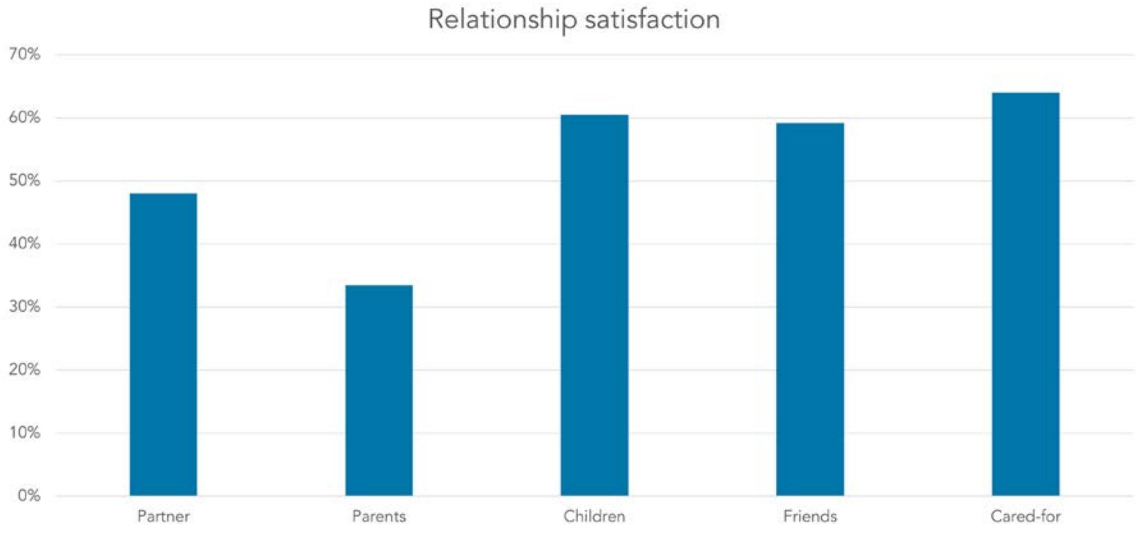


*Figure 40: Relationship satisfaction*

The 2024 National Carer Survey also asked respondents whether they receive emotional, financial or practical support from family and friends (see Figure 41). More than two in five (40.1%) agreed that their family and friends supported them emotionally, however more than one in three (36.5%) disagreed, illustrating that even in personal relationships, caring roles often are not recognised. A similar pattern emerged for practical support, where slightly fewer respondents agreed (33.9%) and slightly more disagreed (46.8%) that they were receiving support from family members and friends. Despite the often high material needs of carers described in previous chapters, less than one in four (22.6%) reported they were receiving financial support, while three in five (60.9%) disagreed or strongly disagreed about receiving financial support.

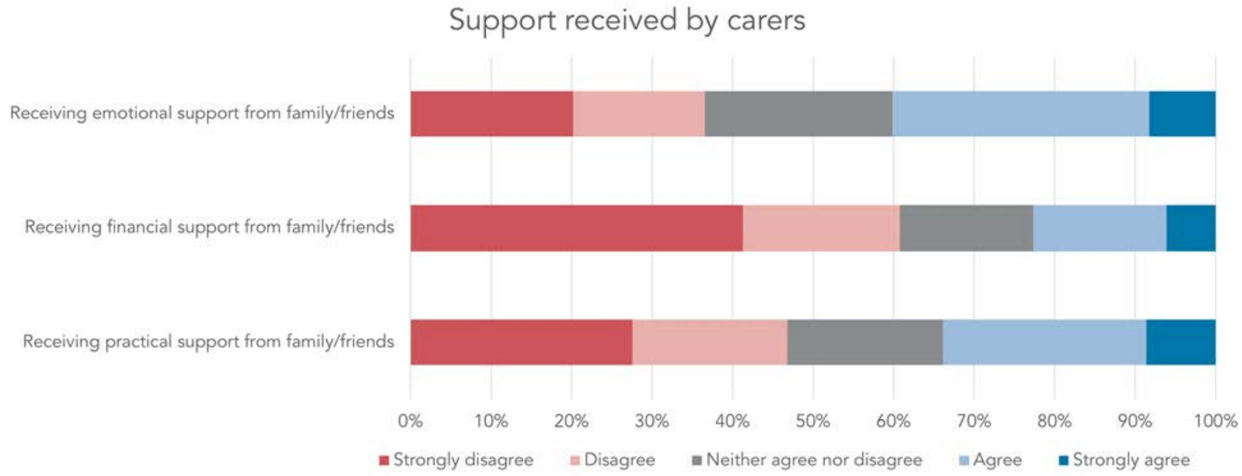


*Figure 41: Support received by carers*

**Key points**

- Carers in general experience poor physical and mental health, low wellbeing, and high rates of social isolation.
- Younger adults (aged 25-44 years) tend to report lower outcomes for all health and wellbeing measures.
- Caring roles can impact the quality of close family relationships.
- Many carers report receiving little practical and financial support from family and friends.

# Part 3: Diverse caring experiences

## First Nations carers

The 2024 National Carer Survey for the first time included a question module specifically for First Nation carers.

380 respondents to the Survey (3.8%) identified as First Nations carers, comprised of 347 respondents (3.5%) who identified as Aboriginal, 17 as Torres Strait Islander, and 16 as both Aboriginal and Torres Strait Islander.

The average age of First Nations carers in the Survey was 47 years, significantly younger than the overall average of 58 years. Similar to other respondents, 81.4% of First Nations carers were women, with 17.8% identifying as male and 0.8% identifying as non-binary. Most First Nations respondents live in Major cities (47.9%), and Inner regional areas (32.4%). 41.7% live on Country with cultural significance for them.

Many First Nations respondents reported that yarning and learning from Elders, sustaining and sharing culture, and the preservation of language, values and traditional knowledge and practices were important to them. When interacting with service providers, First Nations respondents generally felt less recognised than other carers, however, their perception of recognition by government was similarly low to that of other carers.

- **About the people they care for**

First Nations carers were more likely to have multiple caring roles than other respondents, and were significantly more likely than other carers to care for more than one person (59.0% compared to 67.8%), with 13.1% caring for four or more people, underscoring the wider networks of care in First Nations communities. Just over half (51.4%) of First Nations respondents were caring for a child (including adult children), 25.7% were caring for a parent or parent-in-law, and 17.4% were caring for a partner (see Figure 42). Around 6% each were caring for a former partner, a sibling, or other family relations, and around 5% for a friend or neighbour or foster/kinship child. Most First Nations respondents (82.1%) reported caring for someone living with disability, and 46.2% reported caring for someone with mental ill health.

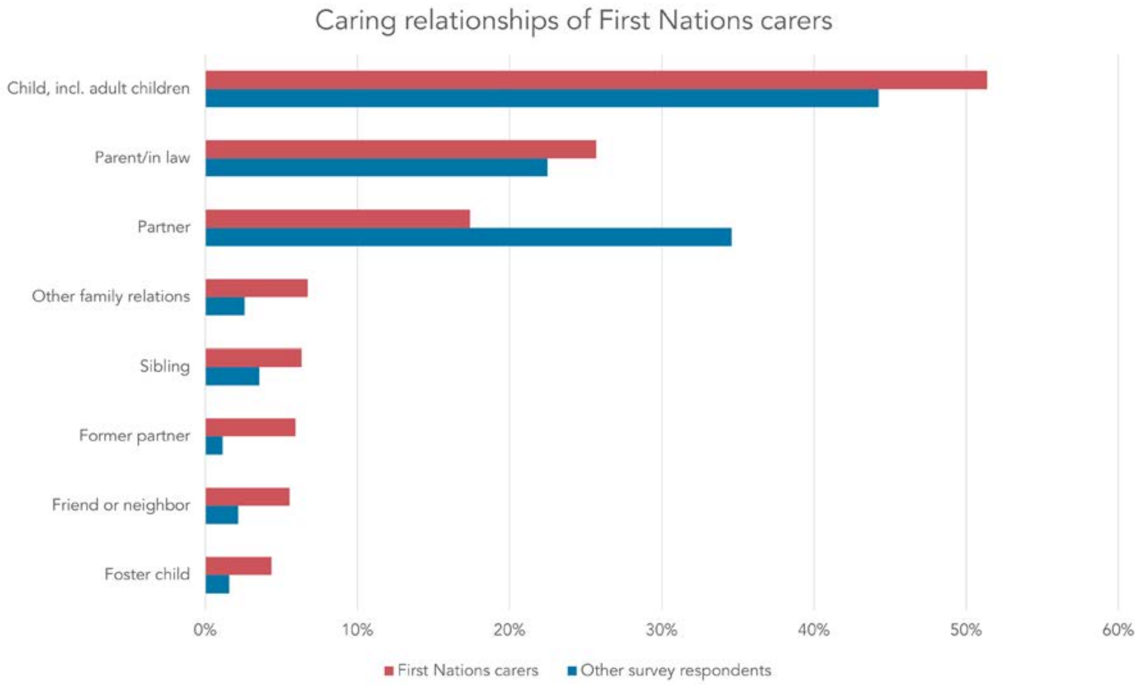


*Figure 42: Caring relationships of First Nations carers*

- **About the caring experience**

On average, First Nations carers provided 124.1 hours of care per week, with 62.6% providing 24/7 care. Most commonly, First Nations carers were the sole carer (55.3%) and the majority (84.8%) were living with the person they care for. Around half (49.7%) reported that the person they care for also identified as First Nations.

- **Experiences accessing services**

First Nations carers were more likely than other respondents to be caring for someone who was not receiving formal services (aged care, disability, or mental health services), with 46.5% caring for someone who was not receiving such services. For those who were accessing formal services, First Nations carers also reported access issues at a rate higher than the Survey average, across all service systems, with 40% to 50% reporting long wait times for necessary services, and around one in three carers reporting that necessary services were not locally available (see Figure 43). For each service type, one in four First Nations carers found that services were not meeting the cultural needs of the person they cared for. Only 10% to 15% reported no issues with formal care services.

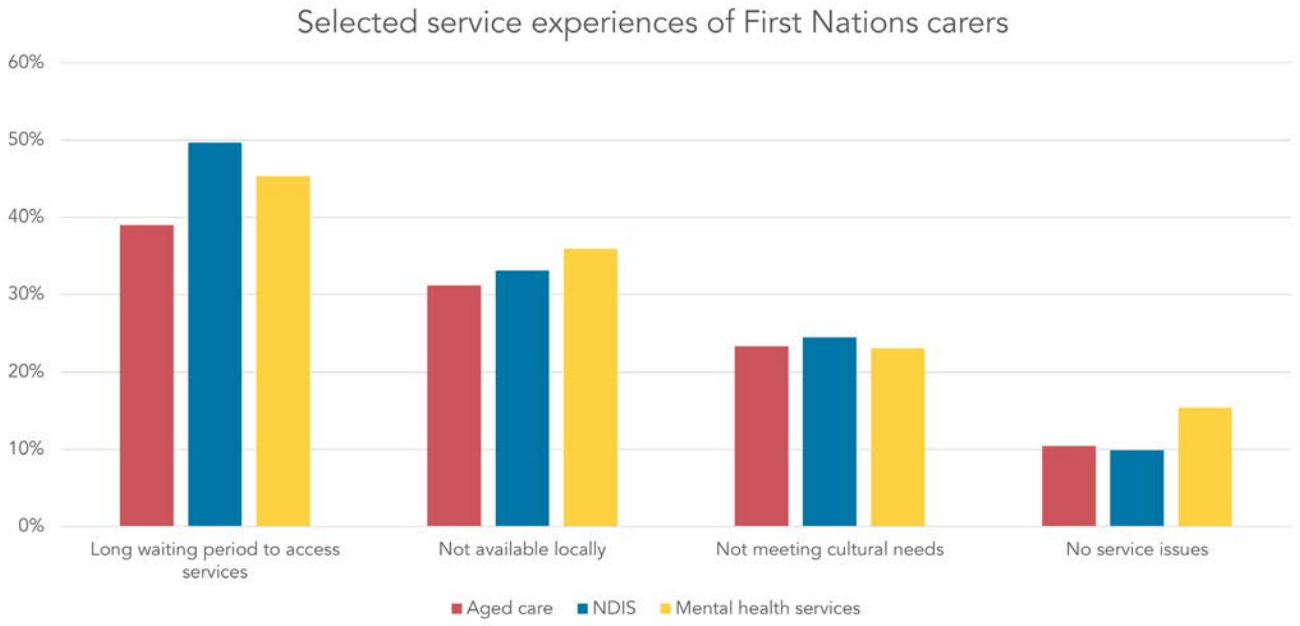
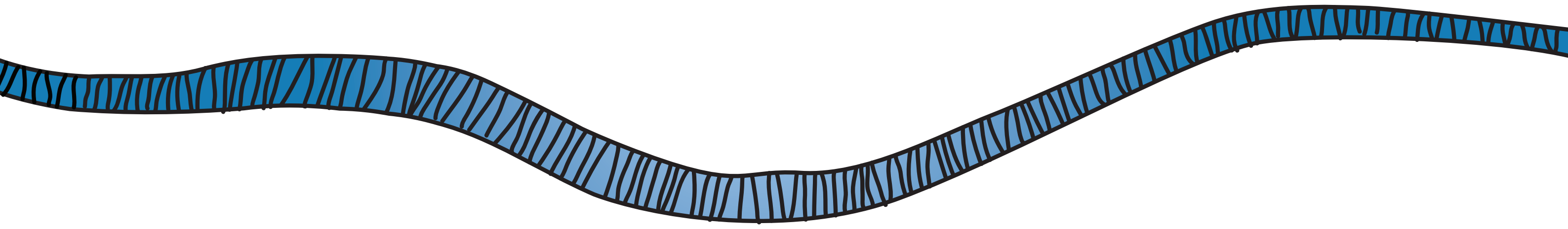


*Figure 43: Selected service experiences of First Nations carers*

Asked about the extent to which they carers feel culturally safe when engaging with mainstream services, 60% of First Nations respondents answered "mostly" or "always", while 30.2% only sometimes, and 10.2% never felt culturally safe, underscoring the need for better implementation of culturally safe and informed practices in mainstream services (see Figure 44).



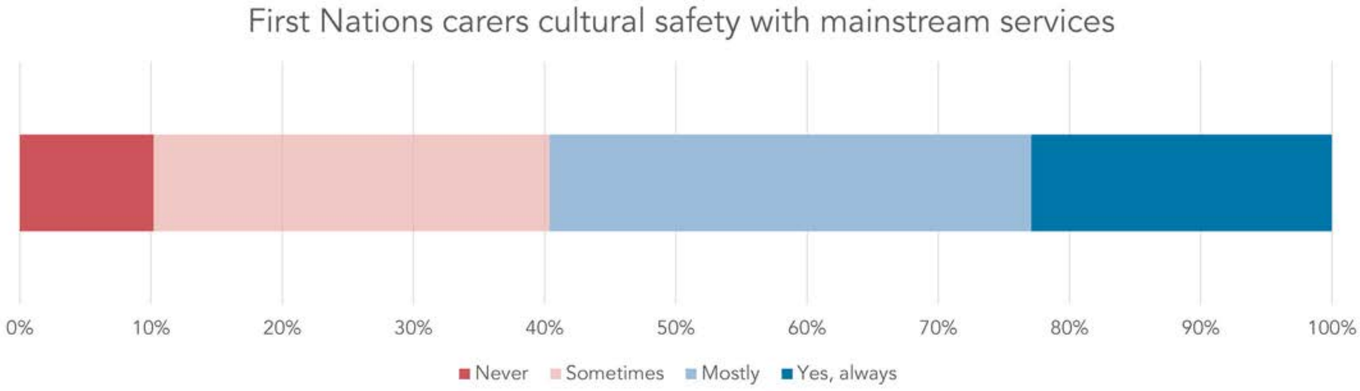


*Figure 44: Reported cultural safety of mainstream services*

- **Basic needs and finances**

As research and government reports consistently show (e.g. Commonwealth 2025, Klein et al. 2024), Australian First Nations people are a very marginalised population who still experiences the effects of colonialism, racism, and intergenerational trauma. These effects are particularly visible in economic and material aspects of life. This is also true for First Nations carers, which the 2024 National Carer Survey reported have their basic needs met at a significantly lower rate than other respondents (see Figure 45). One in three First Nations respondents reported only sometimes having enough food to not go hungry, and only one third reported always having access to enough food. Almost one in five only sometimes had a safe place to live, and around only one in four First Nations carers had always access to affordable healthcare or reliable transport.

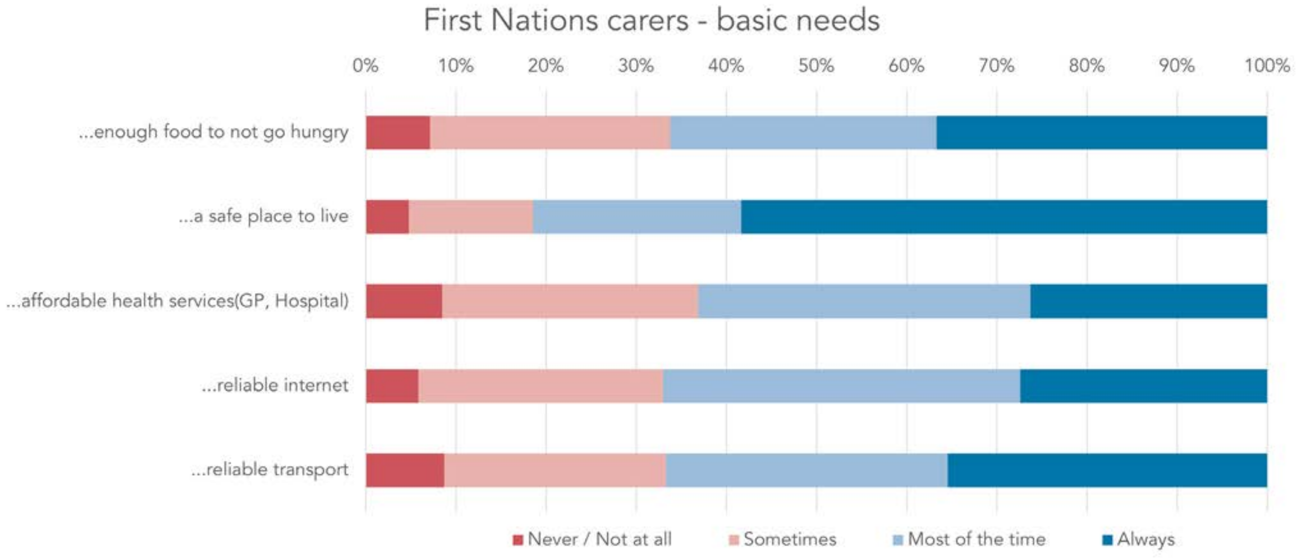


*Figure 45: First Nations carers - basic needs*

Although First Nations respondents were engaged in paid work at a slightly higher rate than other carers (39.1% compared to 37.3%), a larger proportion than other respondents were also receiving Centrelink payments (87.6% compared to 76.6%).

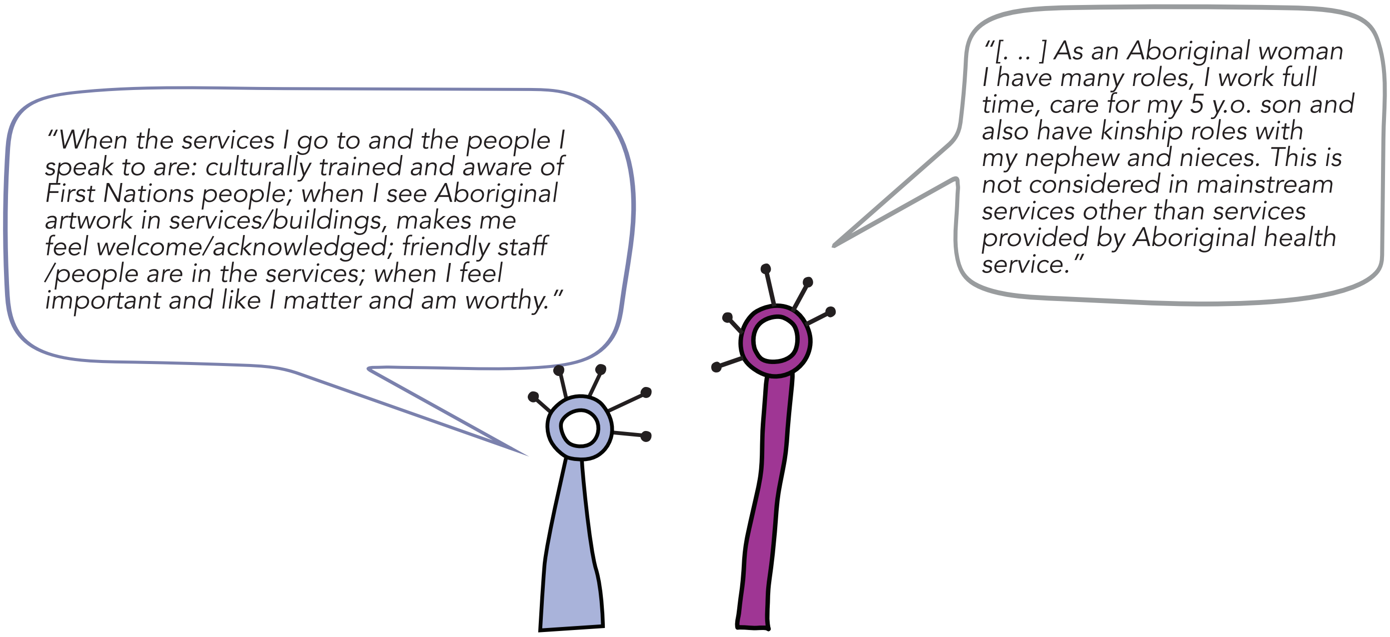
The large majority of First Nations carers (87.0%) experienced at least one form of financial stress, 1.5 times the rate of other respondents. Further, 44.0% had four or more financial stress experiences, more than double the rate of other carers.

- **Health and Wellbeing**

On average, First Nations carers had significantly lower wellbeing than other carers, with an average Personal Wellbeing Index score of 49.9%, compared to 55.9% for other carers. Almost two thirds of First Nations carers (60.2%) experienced high to very high psychological distress, and more than two in three were socially isolated.

**Key points**

- First Nations carers need culturally safe services, ensuring all staff have the cultural competency to engage with First Nations carers in a respectful and empowering way.
- First Nations carers require support in a way that recognises their history and needs while promoting their dignity and self-determination.
- Increased financial and wellbeing support should be available to First Nations carers.



*"When the services I go to and the people I speak to are: culturally trained and aware of First Nations people; when I see Aboriginal artwork in services/buildings, makes me feel welcome/acknowledged; friendly staff /people are in the services; when I feel important and like I matter and am worthy."*

*"[. .. ] As an Aboriginal woman I have many roles, I work full time, care for my 5 y.o. son and also have kinship roles with my nephew and nieces. This is not considered in mainstream services other than services provided by Aboriginal health service."*

## Young carers

Of all respondents to the 2024 National Carer Survey, 182 were young carers aged 25 years and under. The majority (70.6%) of these carers identified as female, 21.7% as male and 7.8% as non-binary or gender diverse. Just under one in four young carers in Survey (23.7%) identified as LGBTQ+. Almost a third (29.5%) had a culturally and linguistically diverse background, and one in five (20.5%) spoke a language other than English at home. Nearly one in five (17.7%) identified as Aboriginal and/or Torres Strait Islander.

- **About the people they care for**

More than half of the young carers who responded to the Survey were caring for their parent (54.1%), and nearly a third cared for a sibling (29.5%). Other caring relationships were less common, with 8.9% caring for a child and 6.2% caring for a partner. The majority of young carers (77.1%) were caring for someone living with disability, including 45.8% of all young cares for someone living with a physical disability, and 27.1% for someone with Autism. The most frequent other conditions reported were mental health challenges (43.8%) and chronic illness (31.3%). Two thirds (60%) of young carers responding to the Survey were caring for someone under the age of 50 years.

- **About the caring experience**

Most young carers (62.4%) who responded to the Survey were only caring for one person. They spent an average of 80 hours per week caring, with 37.7% providing 24/7 care. A large proportion (46.9%) had been caring for five or more years. Only 15.1% 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 (32.8%) or disability services (26.6%). Only 13.0% were caring for someone accessing aged care services.

Experiences with services differed across service systems. Overall, only one in three (36.0%) young carers felt they were recognised by service providers, significantly fewer than among other carers. As 85.1% of young respondents to the Survey were caring for someone while attending school or an apprenticeship, an aspect of particular importance for young carers is whether formal supports allow them to focus on their studies or paid work. While a majority of those caring for someone using aged care services agreed that this was the case (see Figure 46), fewer than half of those caring for someone using disability services, and only one third of those caring for someone using mental health services felt that this was true.

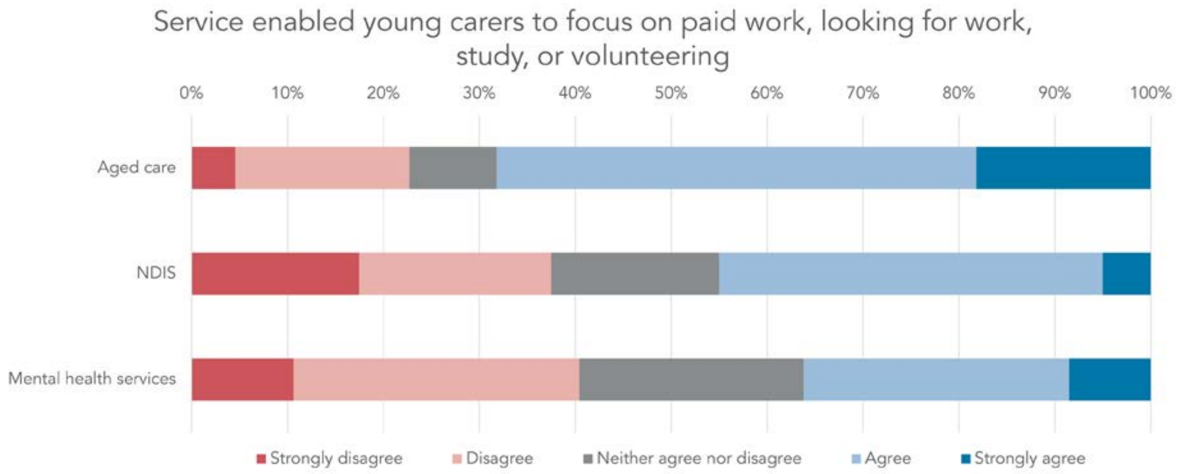


*Figure 46: Whether services enabled young carers to focus on paid work, looking for work, study, or volunteering*

- **Challenges and support needs**

Young carers often have specific support needs due to the many important life experiences and transitions that can be affected by caring. However, of the 85.1% of young carers who cared while attending school or apprenticeships, less than half (49.2%) reported that someone at their school (e.g. teachers or other staff) knew about their caring role, and of those, only 42% (21.0% of all young carers in the sample) received extra support.

Caring at a young age can have significant impacts on many aspects of young carers' lives. Around two thirds of respondents reported at least moderate impacts on their relationships, how they see themselves, and their plans for the future (see Figure 47). The majority of young carers (61.1%) also reported effects on their education, and half (49.6%) reported impacts on their physical health.

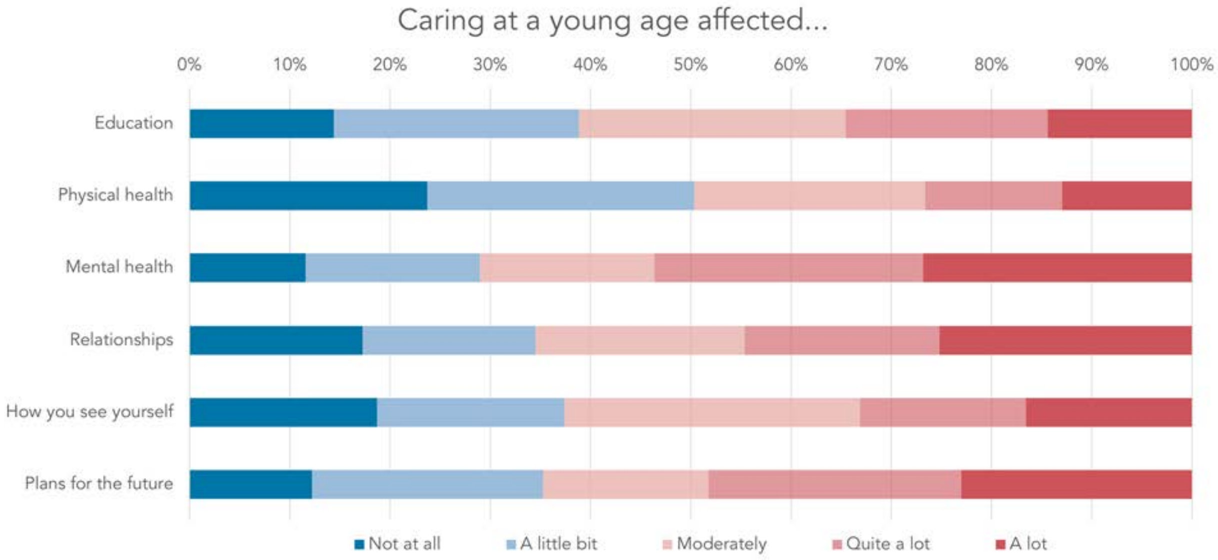
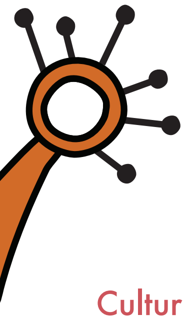


*Figure 47: Effects of caring at a young age*

Outcome measures for young carers paint a generally rather challenging picture: 70.8% of young carers reported high to very high levels of psychological distress, significantly more than older carers, and 73.3% reported being socially isolated or highly isolated. The majority (77.7%) had experienced at least one form of financial stress in the year prior to the Survey, and many reported not having their basic needs met, with one in four (25.3%) reporting that they only sometimes, or never, had enough food to not go hungry. Only 68% of young carers reported always having a safe place to live, and only 36.5% always having access to reliable internet.

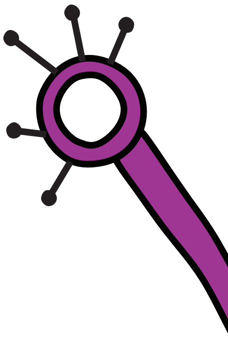
**Key points**

- Young carers need improved awareness and understanding, including supporting young carers to self-identify and access services and supports.
- Young carers need flexible supports in education that is tailored and individualised to meet their needs.
- Increased financial support needs to be made available to young carers, to meet their basic needs and support educational requirements.



> *"I did not/do not receive any support as I was not aware I am a young carer until recently. I do not know what support I need."*

> *"The role and concept [of young carers] needs to be included in schools, so perhaps our society becomes more caring and understanding."*



## Culturally and linguistically diverse carers

A total of 1,707 respondents (17.1%) to the Survey were 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 (81.2%) and the mean age was 55 years old. More than half (54.8%) of CALD respondents spoke a language other than English at home. Similar to all respondents, 5.1% of CALD carers identified as LGBTQ+ in the Survey.

- **About the people they care for**

CALD respondents were most commonly caring for their child (including adult children) (40.3%), followed by a parent (33.2%) or partner (26.7%). More than half (56.7%) were caring for someone who also has a CALD background. Respondents were most commonly caring for someone living with physical disability (35.9%), someone frail due to age (32.4%), or someone living with mental health challenges (31.7%). Taken together, 72.9% of CALD carers were providing care for someone living with disability (physical or intellectual disability, ASD, acquired brain injury, or sensory impairment). Approximately half (50.9%) of the people receiving care from Survey respondents were aged 65 years and older.

- **About the caring experience**

The majority of CALD respondents (65.4%) were caring for only one person. On average, they provided 104.9 hours of care per week, with 49.3% providing 24/7 care. Most commonly, CALD carers were the sole carer (49.4%) and the majority (82.0%) 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 27.2% caring for someone who was receiving no formal services. Some CALD respondents reported challenges accessing culturally appropriate services or having no culturally appropriate services available for the person they care for (see Figure 48).

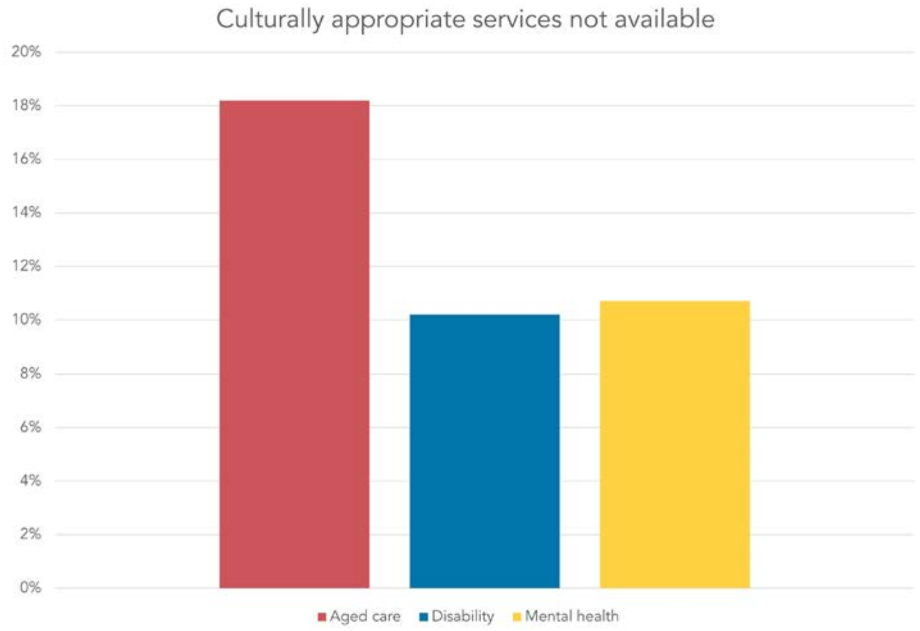


*Figure 48: Culturally appropriate services not available, by service type)*

CALD respondents were slightly more likely to have accessed carer support services than other respondents (64.9% compared to 61.8%), but were also more likely to report an unmet need for carer support services (75.1% compared to 63.4%). 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.

- **Health and wellbeing**

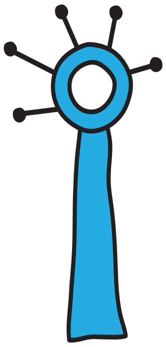
Approximately three in five CALD respondents (59.7%) reported financial stress, with 17.9% experiencing financial distress. The majority (65.6%) reported being socially isolated and three in five (61.4%) experienced high or very high psychological distress – a significant increase, compared to 53.5% of respondents who were experiencing high or very high psychological distress in 2022. CALD carers also reported lower wellbeing than other carers.

**Key points**

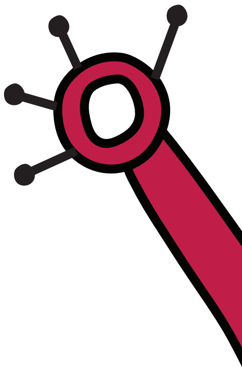
- CALD carers responding to the 2024 National Carer Survey were most commonly caring for their child, including adult children. More than half of CALD carers were caring for someone from a CALD background themselves.
- They were more likely to be accessing carer support services than other carers, but 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.

> *"It is a privilege to be entrusted with that responsibility, but it does come at a significant cost - financially and holistically/personally."*

> *"I was always stressed, was not aware about the services I could access, there was no info made known of where to go for services. Even the mental services did not inform me of where to apply."*



> *"Being a carer was for me a cultural obligation - an obligation not completely understood or acknowledged by the govt/powers that be. Losing my career, losing my identity and purpose to life has been devastating and this will not change in the future since I am almost 71 years of age. The trauma of caring for a dying loved one will be lifelong especially due to the ineffective practices of the providers/govt Aged Care Packages - and also due to the exploitation/abuse I have experienced in my role as primary carer of someone else's life - i.e. my mother. My body will hold the score forever."*



## Male carers

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 2024 National Carer Survey, 1,676 respondents (16.8%) identified as male. With an average age of 65 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 (see ABS 2022). In line with the Survey average, 18.9% of male carers identified as culturally or linguistically diverse, with 10.9% speaking a language other than English at home, and 4.0% identified as Aboriginal and/or Torres Strait Islander. A further 5.2% of male respondents identified as part of the LGBTQ+ community.

- **About the people they care for**

The majority of male carers who responded to the Survey were caring for their partner (59.2%), followed by an even distribution of male carers caring for their parent or parent-in-law (19.3%) or caring for their child, including adult children (19.8%). The most frequent reasons for providing care were due to a disability (all disability types, 68.6%), frailty due to age (31.0%) or a chronic health condition (30.2%).

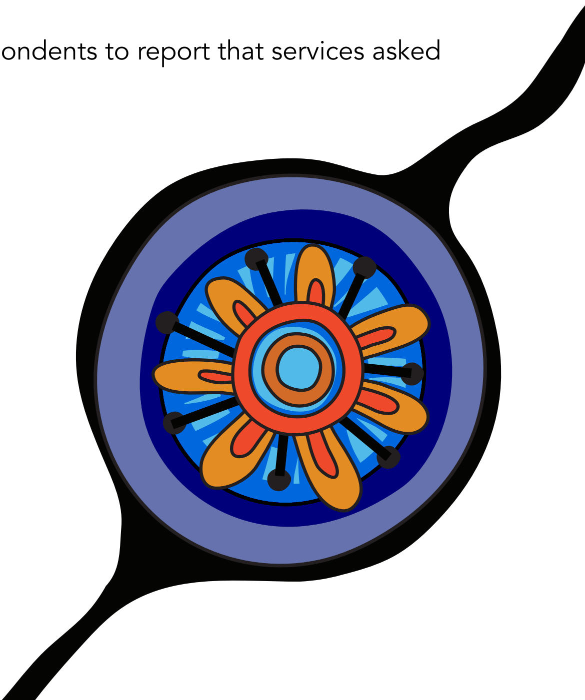
- **About the caring experience**

Most male carers cared for one person only (81.6%). They spent an average of 111.2 hours per week caring, with 55.0% providing 24/7 care. Just over one in three (36.3%) had been caring for tenyears or more. Around one in six (16.3%) were not living with the person they care for, and almost three in five (58.0%) were that person's sole carer.

- **Experiences accessing services**

Just under half of all male carers who responded to the Survey were caring for someone accessing aged care services (45.7%), with one in three (32.0%) accessing mental health services. Over one quarter of male carers (26.4%) were caring for someone who was not accessing formal services.

Interestingly, male respondents were significantly more likely than other respondents to report that services asked about their needs as a carer (see Figure 49).



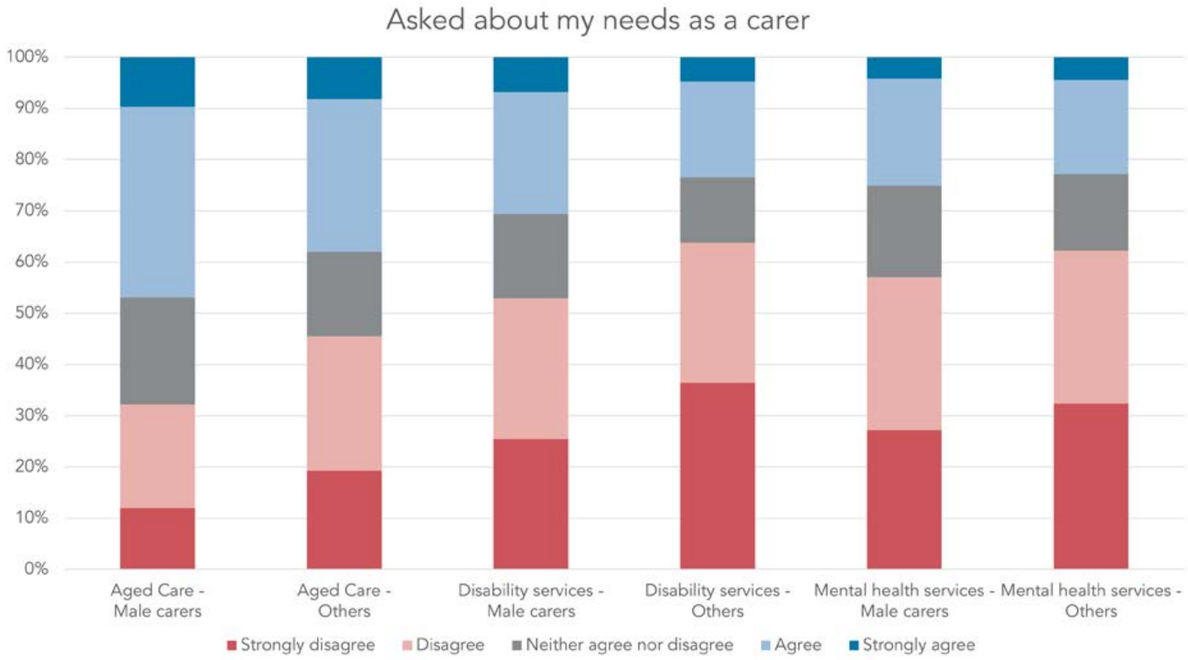


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*Figure 49: Service asked about the needs of male carers*

- **Work, income and finances**

Around one in four (24.1%) male carers were active in paid employment, which is significantly below the rate of other carers (40.0%). However, they spent on average more hours in paid work, with the majority spending between 31 and 40 hours per week at work compared to other carers who spend on average up to 20 hours per week. One in three (31.1%) male respondents receive the Age Pension, and one in five (20.7%) receive the Carer Payment. Male respondents were less likely to experience financial stress, however around one in two (48.9%) still reported at least one experience of financial stress in the year leading up to the Survey.

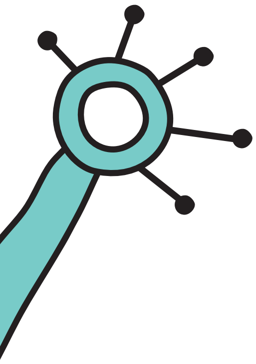
- **Health and wellbeing**

On average, male respondents reported significantly higher wellbeing than other carers, with a Personal Wellbeing Index (PWI) score of 60.85%. However, this is still significantly lower than the population average. They also reported lower rates of psychological distress than other respondents, with 40.0% reporting high to very high distress, compared to 56.5% 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. Male carers also rated their health better than other carers, with 41.5% estimating that their health was "poor" or "fair" compared with 50.5% of other carers. However, 71.8% of male respondents reported feeling socially isolated or having only low social support.

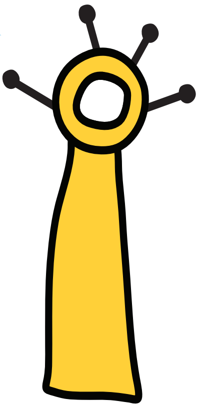
**Key points**

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

> *"Being a carer, in my situation, is rewarding because I love my wife and want her to be happy, but the only way I feel I can do that requires significant sacrifices in areas of finances and outside interpersonal relationships. I don't know if there is a better way of doing things and feel very alone."*



> *"Twelve years ago at age 52 I had to give up paid work to become full time carer for my wife. Financially this was not a sound decision, but money is not the only thing that matters."*



## LGBTQ+ carers

A total of 556 respondents to the 2024 National Carer Survey (5.6%) 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 47.8 years, they are significantly younger than other carers in the sample. One in six LGBTQ+ carers (16.0%) was identified as culturally or linguistically diverse, with 9.7% speaking a language other than English at home, and 5.8% identified as Aboriginal and/or Torres Strait Islander, significantly higher than for other cohorts.

- **About the people they care for**

Two in five LGBTQ+ carers (39.0%) were providing care for more than one person. Most commonly, LGBTQ+ carers were caring for a child, including adult children (44.6%), with 24.0% caring for a partner and 27.7% caring for a parent. The most frequent reasons for providing care were due to a mental health condition (51.9%), Autism (44.1%) or a physical disability (41.3%). Taken together, 79.5% of LGBTQ+ carers were providing care for someone living with disability (physical or intellectual disability, Autism, acquired brain injury, or sensory impairment).

- **About the caring experience**

Two in three LGBTQ+ carers provided care for more than 40 hours per week, with 44.7% providing 24/7 care. A large proportion (44.0%) had been caring for 10 years or more. One quarter (24.5%) were not living with the person they care for, and 52.4% were the sole carer for the person they cared for.

- **Experiences accessing services**

More than half of all LGBTQ+ respondents to the Survey were caring for someone accessing mental health services (59.2%) compared to 38.7% of carers not identifying as LGBTQ+. Nearly half (46.1%) were caring for someone accessing disability services and one in three (31.8%) accessing aged care services with the person they care for. A further 14.5% 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 (56.5% disagreement), disability services (72.9% disagreement) and mental health services (70.2% 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 also felt significantly less recognised for their caring role compared to other carers in the sample. More than half of the LGBTQ+ respondents felt that they are not recognised by the community, and two in three felt that their caring role is not recognised or valued by the government.

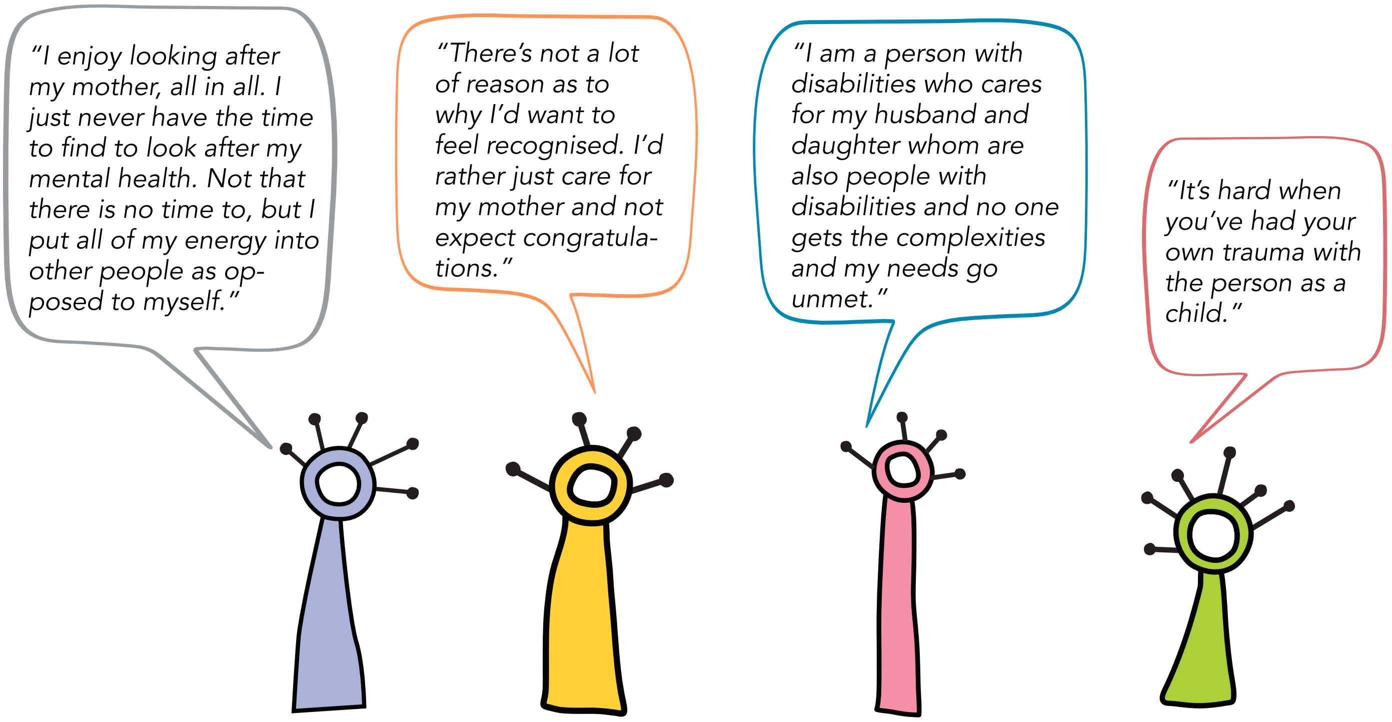
- **Health and wellbeing**

On average, LGBTQ+ carers report significantly lower wellbeing than other carers, with an average Personal Wellbeing Index (PWI) score of 49.7%, significantly below the sample average of 55.7%. They also experience psychological distress at a significantly higher rate than other carers, with 70.7% reporting high to very high distress, compared to 52.6% among other carers.

As a younger cohort, LGBTQ+ carers were more likely to be in paid work (47.5%) or to be looking for work (12.0%). However, they were also more likely to experience financial stress, with 76.4% reporting at least one experience of financial stress over the year leading up to the survey, compared to 57.4% among other carers. The rate of financial distress among LGBTQ+ carers was 33.5%, significantly more than other carers (18.5%).

**Key points**

- LGBTQ+ carers were younger than other respondents, and most commonly caring for a child (including adult children).
- 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.



## Older carers

Of all Survey respondents, 3,123 were carers aged 65 years and older with an average age of 73 years. This age group had the largest proportion of male carers, with 27.4% identifying as male and 72.5% as female. More than one in ten (12.8%) identified as culturally and linguistically diverse, but only 5.7% spoke a language other than English at home. Only 1.2% identified as Aboriginal and/or Torres Strait Islander. Only 2.4% of carers 65 years and older identified as part of the LGBTQ+ community.

- **About the people they care for**

Two in three older carers who responded to the Survey were caring for their partner (66.1%) and 78.9% of care recipients were also over the age of 65. The most frequent reasons for providing care were due to a physical disability (46.2%), frailty due to age (33.1%) or a chronic health condition (32.8%). Just under one third (30.6%) of older carers were caring for someone living with dementia.

- **About the caring experience**

Most carers over 65 cared for one person (85.4%). They spent an average of 114 hours per week caring, with 57.8% providing 24/7 care. 40.8% had been caring for ten years or more. One in five (21.6%) were not living with the person they care for.

- **Experiences accessing services**

Older carers who responded to the Survey were most commonly caring for someone accessing aged care services (54.3%), with 29.5% accessing mental health services. Nearly one in four (23.7%) were caring for someone who was not accessing any formal support services. Across aged care and disability services, carers older than 65 years felt significantly better informed than other carers. They also felt that the services better asked about their needs as a carer. More than half (52.2%) of carers over the age of 65 years felt recognised by service providers for their caring role, compared to only 39.7% of other carers.

- **Health and wellbeing**

On average, older carers reported significantly higher wellbeing than other carers, with a Personal Wellbeing Index (PWI) score of 63.86%, however this is still significantly lower than the population average (75%). They also experienced psychological distress at a significantly lower rate than other carers, with 40.6% reporting high to very high distress, compared to 61.5% among other carers. However, 68.5% of older carers feel socially isolated or have only low social support. Older carers also rate their health better than other carers, and slightly fewer have a long-term health condition or disability themselves (see Figure 50).

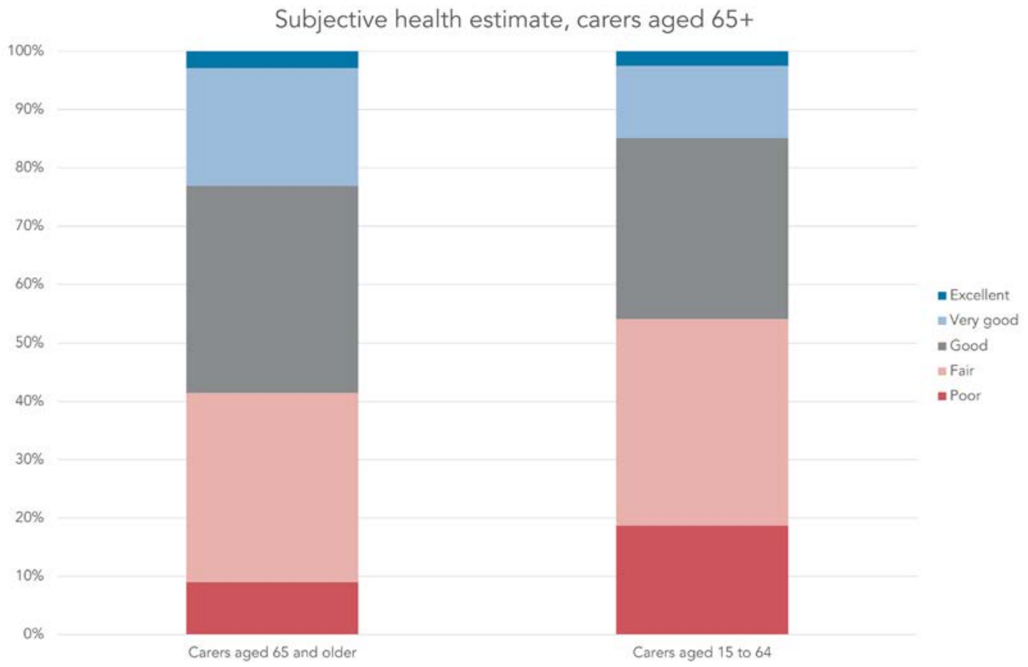


*Figure 50: Subjective health estimate, carers aged 65+ years*

Around 10.1% of carers over the age of 65 were still active in paid employment, and 2.6% were looking for work. Nearly half (46.4%) received the Age Pension and 14.4% received the Carer Payment. After their working life, older carers have better financial stability than other carers. Nevertheless, 37.5% report experiencing one or more experiences of financial stress in the year leading up to the Survey, compared to 70.7% of other carers.

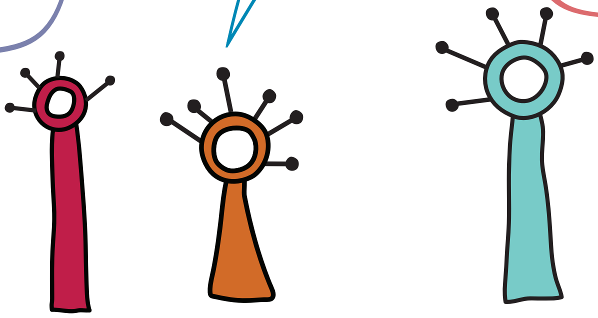
**Key points**

- Older carers are most likely to care for another person of advanced age, most commonly their partner.
- Older carers responding to the 2024 National Carer Survey were scoring better on most outcome indicators (wellbeing, psychological distress, social connectedness, financial stress, subjective health rating) than other carers.
- Two in three older carers are socially isolated, and two in five experiences high or very high psychological distress.
- They were more likely to feel informed by service providers and felt better recognised by service providers.

> *"A recognition that my efforts to maintain a caring and loving environment for my wife contributes to a sustainable society. Even though I comment about only being paid $115 a fortnight, our financial situation for which we worked and saved during both our working lives, does not require more $. We are grateful that the Aus Government provides a system that helps people grow older in their own homes. We enjoy the company too of the carers who visit our home during the week."*

> *"Caring is challenging, rewarding, a mindfield of confusion and hopelessness however when I see the smile on my grandchildrens faces and they say "love you Granz" it makes it all worth it."*

> *"I find it has changed me and made me grow as a person, and that I now look at life with a great deal of appreciation for the smaller things in life, that it is better to live simply and to look for the beauty each day, enjoy my garden and the very precious time we have left together. I am aware life is short and what I can do for family and others is often small things, not the bigger materialistic things of the past."*



## Former carers

Taking 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.

There were 673 respondents to the 2024 National Carer Survey who previously cared for someone and have not taken on another caring role (former carers). These former carers were 66 years of age on average, significantly older than the average age of carers with a current caring role. Former carers who responded to the Survey are otherwise demographically quite similar to current carers: 76.6% were female, 17.3% identified as culturally or linguistically diverse and 8.6% spoke a language other than English at home. Additionally, 4.3% identified as LGBTQ+, and 2.4% identified as Aboriginal and/or Torres Strait Islander.

- **About the people they care for**

Most former carers had cared for a partner (47.8%) or a parent (36.9%) in their most recent caring role, while 7.7% had cared for their child (including adult children). The average duration of this caring role was 8.3 years, and on average it had been 6.8 years since the caring role had ended.

- **About the end of the caring experience**

The most frequently given reason for the end of the caring role was bereavement (66.9% of respondents), followed by the person being cared for moving to residential care, which one in five former carers (20.3%) identified as ending their caring role. A smaller but significant proportion (15.8%) of former carers reported that their caring role ended because the demands of the caring role increased beyond what they could manage. When asked what kinds of supports they had needed since their caring role has ended, one in four former carers (25.9%) reported emotional support as an unmet need.

- **Health and wellbeing**

With an average Personal Wellbeing Index (PWI) score of 65.45%, the wellbeing of former carers is significantly higher than that of current carers, who have an average PWI score of 55.07%. However, this remains significantly lower than the Australian population average. This speaks to 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. On average, former carers rate their health better than current carers, and slightly fewer have a long-term health condition or disability themselves despite being older than current carers on average (see Figure 51).

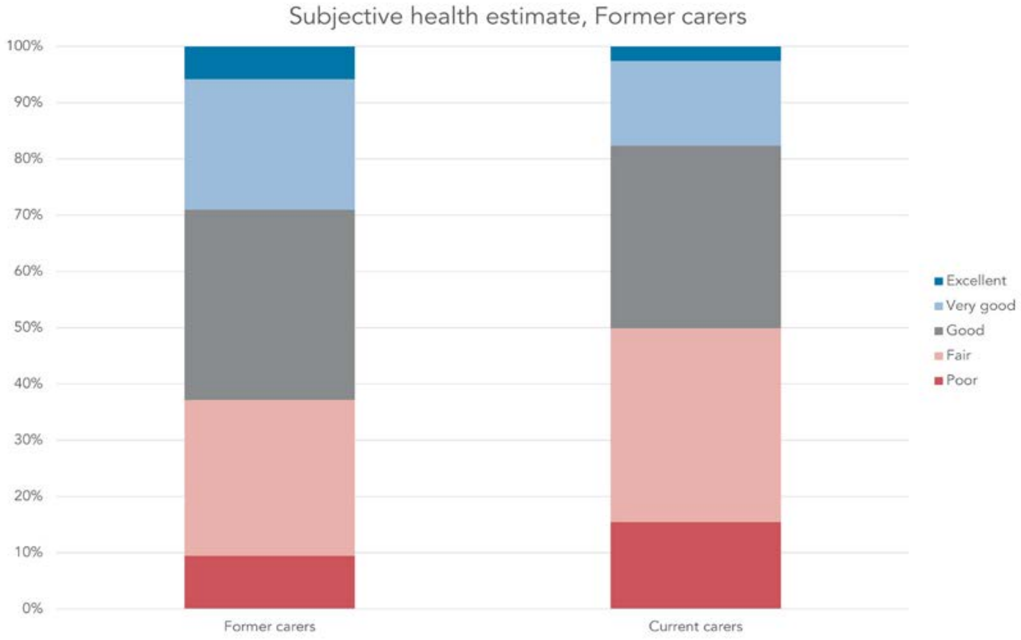


*Figure 51: Subjective health estimates, former compared to current carers*

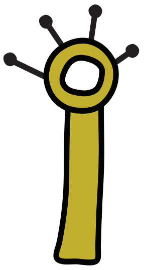
Former carers responding to the Survey reported lower psychological distress than current carers, however two in five (40.6%) still reported high to very high distress. While former carers were more socially connected than current carers, 47.5% remain in socially isolated after their caring role ends.

Although financial stress among former carers is lower than for current carers, the financial impacts of caring can be ongoing, with 43.0% of former carers reporting that they have experienced at least one form of financial stress in the 12 months prior to the survey. 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.

**Key points**

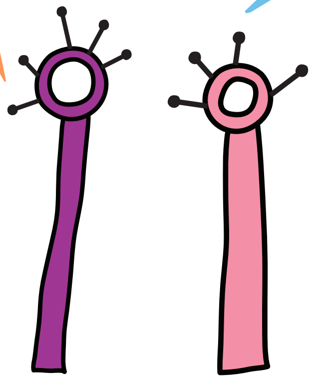
- Carers can experience ongoing impacts of caring after the caring role ends, such as reduced wellbeing and financial insecurity.
- Bereavement is the most frequent cause for the end of a caring role, however one in five former carers said their caring role ended because the demands of caring became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

> *"It is so much freer. It wasn't till it was over that I realised just how much we were both chained to [the person I care for]'s illness in terms of time and mental energy. Almost every decision we made factored in that illness, from what we'd eat to who could come to the house. I see more people, travel, am out more often, don't have to cook, leave a mess if I feel like it, exercise more and can be spontaneous again. I have a whole in my heart from the loss of my wife but I love this freedom."*



> *"I have not gone back to full-time employment (left work to provide care), my financial resources are much lower than they were. I am grieving the loss of my partner and re-establishing a very different life."*

> *"My life has changed so much since my husband of 60 years went into a nursing home. I am so sad. And my caring role has not ended I still care for him in other ways."*



## Carers living with long-term health conditions or disability

Nearly half (46.5%) of all Survey respondents reported living with their own long-term health condition or disability, including arthritis, chronic illnesses, mental health challenges, as well as metabolic, cardiovascular, respiratory or neurological conditions, and recovery from surgery. Carers in this cohort were 58 years of age on average, and most (84.7%) identified as female. Many (14.9%) of the carers living with a long-term health condition or disability identified as culturally and linguistically diverse, with 7.8% speaking a language other than English at home. A larger proportion (3.4%) than carers without a health condition or disability (1.9%) identified as Aboriginal and/or Torres Strait Islander. This cohort also had the largest proportion of LGBTQ+ carers, with 8.0% identifying as LGBTQ+.

- **About the people they care for**

One in two (49.7%) carers living with a health condition or disability were caring for their child (including adult children). The most frequent reasons for providing care to someone were their living with mental health challenges (43.7%), a physical disability (40.6%) or Autism (37.8%).

- **About the caring experience**

While most carers from this cohort cared for one person, more than one in three (37.0%) provided care to two or more people. They spent an average of 110.9 hours per week caring, with 52.0% providing 24/7 care. More than half (54.6%) had been caring for 10 years or more, and most (84.9%) with their own long-term health condition or disability were living in the same household as the person/s they care for.

- **Experiences accessing services**

Over half (51.5%) of carers living with a long-term health condition or disability were caring for someone receiving mental health services, followed by 48.1% caring for someone receiving disability services and 41.3% caring for someone receiving aged care services. Around one in ten (11.0%) were caring for someone who was not accessing any formal support services. Carers living with a long-term health condition or disability felt significantly less recognised as carers across all domains when compared to other carers (see Figure 52).

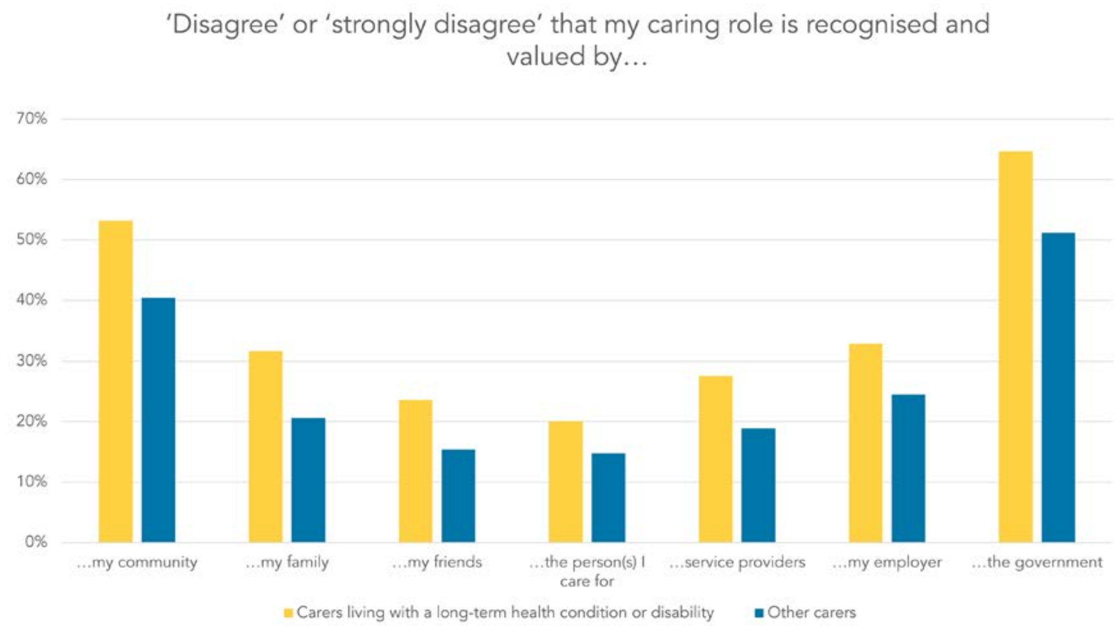


*Figure 52: Carer recognition for carers living with a long-term health condition or disability*

- **Health and wellbeing**

On average, carers living with a long-term health condition or disability reported significantly lower wellbeing than other carers and the population average broadly, with a Personal Wellbeing Index (PWI) score of 49.7%. They also experienced psychological distress at a significantly higher rate than other carers, with 62.9% reporting high to very high distress, compared to 45.7% among other carers. Additionally, 68.9% of carers with a health condition or disability completing the Survey felt socially isolated.

One in three (33.9%) carers living with a long-term health condition or disability was still active in paid employment, while one in four (26.7%) was not working or looking for work. Nearly one in three (30.0%) were retired and no longer working, and 42.2% reported wanting to work more hours than they currently do, compared to 36.0% of other carers. Only 8.4% of these carers received the Disability Support Pension, while one in four (25.4%) received the Carer Payment. While one in three (33.0%) carers reported financial stability, 67.0% of carers living with long-term health condition or disability had one or more experiences of financial stress in the year leading up to the Survey.

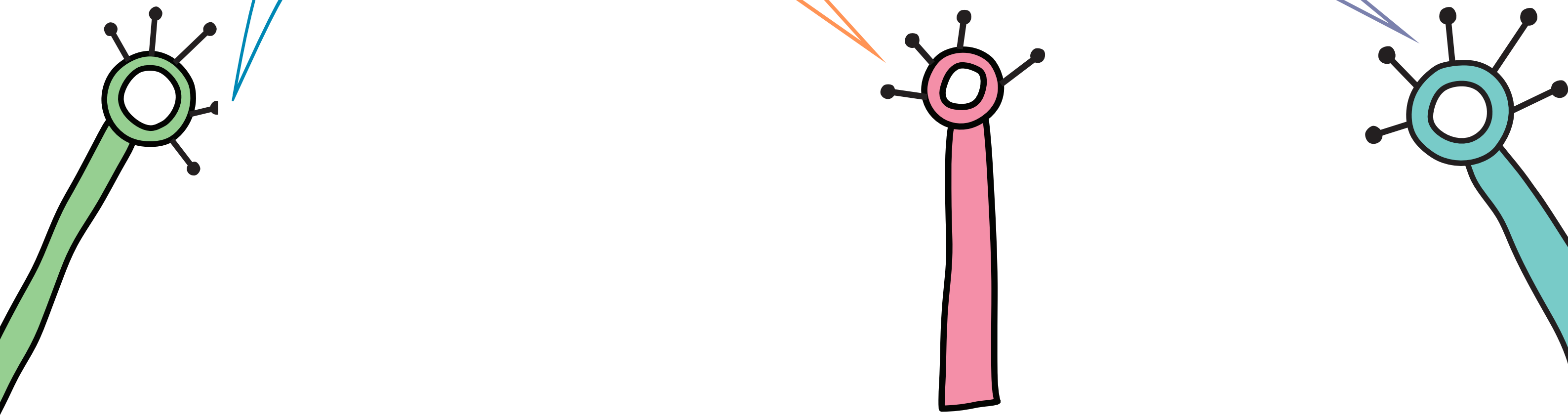
**Key points**

- Nearly half of Survey respondents reported living with their own long-term health condition or disability.
- These carers are most likely caring for their own child (including adult children), with 51.5% caring for someone receiving mental health services.
- Carers with their own health condition or disability who responded to the 2024 National Carer Survey scored worse on most outcome indicators (including wellbeing, psychological distress, social connectedness and financial stress) than other carers.

> *"A caring role is made more difficult by government bureaucracy, a lack of communication between government departments, and the constant hoops carers and people with a disability have to jump through to prove they are disabled or receive appropriate services."*

> *"Our situation is complicated by my own health / disability situation. Currently managing my own stuff and Mum's stuff means that I am virtually incapable of working. I would like this to change; getting a sustainable, proper level of support for Mum would help a lot."*

> *"Yes - given my disability and caring role - I'm unable to work full-time and need to find work with part-time/restricted hours. Currently unemployed and actively seeking such work whilst sustaining the level of care my father needs is very difficult and I can only sustain this for another 2 weeks."*



## Carers of two or more people

Of all Survey respondents, 3,030 carers were providing care for more two or more people: 67.9% cared for two people, 21.0% cared for three people and 11.2% cared for four or more people.

The average age of this group of carers was 51 years, with 90.2% identifying as female, 9.0% identifying as male, and 0.8 as non-binary/gender diverse. Almost one in five (18.5%) were from a culturally and linguistically diverse background, with one in ten (10.8%) speaking a language other than English at home. A larger proportion (4.9%) of carers who identified as Aboriginal and/or Torres Strait Islander provided care for two or more people. There were also a larger proportion (6.9%) of carers caring for two or more people who identified as LGBTQ+ compared to carers who care for one person (5.2%).

- **About the people they care for**

Two in three (68.3%) carers who reported providing care for two or more people were caring for their child (including adult children), with 42.8% caring for someone under 19 years of age. Nearly one in three carers (31.1%) were caring for a parent or parent-in-law, with 38.1% caring for someone over the age of 65. More carers providing care for two or more people cared for someone who was culturally and linguistically diverse (16.0%) than those who only care for one person (14.2%).

More than half (55.3%) of respondents were caring for someone living with Autism , followed by mental health challenges (51.2%) and ADD or ADHD (41.6%).

- **About the caring experience**

Carers of two or more people spent an average of 105.6 hours per week caring, with 47.2% providing 24/7 care. Most (63.9%) had been caring for ten years or more. Over half (55.9%) were providing care with other people, a higher proportion than that of carers supporting one person (42.7%).

- **Experiences accessing services**

Carers were most commonly caring for someone accessing disability services (57.6%) or mental health services (56.4%). One in five carers were caring for someone who was not accessing any formal support services (19.2%).

Across all service types, the majority of carers of two or more people did not agree with the statement that they were asked about their needs as a carer by aged care services (55.1% disagreement), disability services (65.8% disagreement) and mental health services (66.7% disagreement). More than one in four (28.4%) carers for two or more people disagreed or strongly disagreed that they were recognised by service providers.

- **Health and wellbeing**

On average, carers of two or more people reported significantly lower wellbeing than other carers, with a Personal Wellbeing Index (PWI) score of 49.6%. They also experienced psychological distress at a significantly higher rate than other carers, with 63.9% reporting high to very high distress, compared to 50.2% among carers supporting one person. Most carers of two or more people (84.6%) feel socially isolated or have only low social support. More than half (53.7%) were living with a long-term health condition or disability themselves.

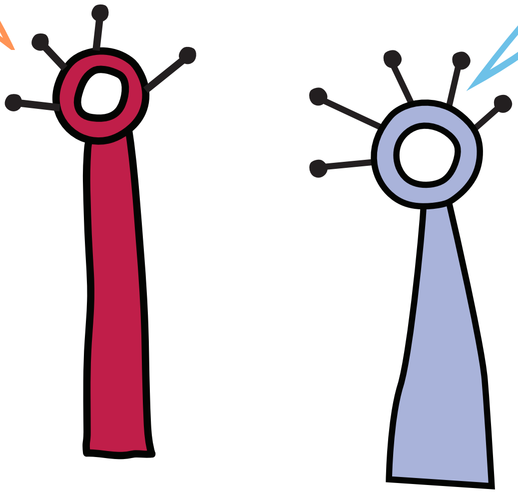
Carers of two or more people were more likely to experience financial stress, with three in four (73.6%) reporting at least one experience of financial stress in the year leading up to the Survey. Nearly half of respondents (47.0%) who cared for two or more people reported being in paid work, compared to 33.7% of carers providing care for one person reporting being in paid work at the time of completing the Survey.

**Key points**

- Carers of two or more people are most likely to care for their child under 19 and a parent over the age of 65 – known as 'sandwich carers'.
- They were most commonly caring for someone accessing disability services (57.6%) or mental health services (56.4%).
- Carers of two or more people reported significantly lower wellbeing than other carers, higher psychological distress, higher reported social isolation and higher reported experiences of having a long-term health condition or disability themselves.

> *"Caring for someone could be an enriching experience that increases our empathy, connection with and understanding of each other. Instead, because of the extreme financial and emotional pressure carers are subject to, it becomes a stressful, unfair, exhausting and at times horrific experience."*

> *"Their chronic illness is undiagnosed. It is difficult to get any support at all for them because of this. We are trying to do testing to rule out various things, but everything costs. A lot. Even the ADHD medication - they would like to trial non-stimulant meds, but it is prohibitively expensive because they are not on the PBS. In order to provide care for my children, I deny myself care, because we can't afford both."*



> *"Caring for our son is something I would not change. No one understands his needs better than a parent. I have educated myself on all aspects if his condition, I have advocated for his rights and needs, and I will do my best to set up a support network for when we pass.   Taking on guardianship, care and advocacy for my brother was not something I wanted to do especially for our family. I'm the youngest of 6 with 8 years between oldest to youngest. No one else in the family could help him and he was already living out of his car on the streets.*

> *"When people hear any of my story they say 'You're so strong' what I always think is 'Behind every strong person is a situation they never wanted to be in'."*

## Working carers

In total, 3,181 respondents (37.4%) to the Survey were balancing their caring responsibilities with paid work. The majority of these carers had either full time or part time permanent employment (62.5%). Nearly one in five (17.8%) had one or more casual jobs, 11.3% were self-employed, one in ten (10.7%) had a full time or part time fixed-term contract, and a small percentage (2.9%) reported being an independent contractor (including gig work).

The majority of working carers who responded to the Survey identified as female (88.5%), and their mean age was 50 years old. Just under one in five (18.7%) identified as culturally and linguistically diverse, with one in ten (10.6%) speaking a language other than English at home. Additionally, 2.7% identified as Aboriginal and/or Torres Strait Islander and 8.2% identified as LGBTQ+.

- **About the people they care for**

Over half (57.3%) of working carers who responded to the Survey were caring for their child (including adult children), while 28.4% were caring for their parent. Two in five (42.7%) working carers were caring for someone living with Autism, while 39.1% were caring for someone living with mental health challenges and 32.9% were caring for someone living with a physical disability.

- **About the caring experience**

Three in five (60.1%) carers from this cohort cared for one person, and they spent an average of 88.2 hours per week caring compared to non-working carers who provided 120.6 hours of care per week. Only one in three (33.8%) provide 24/7 care. Around half (51.2%) had been caring for ten years or more, and 39.0% were the sole carer. Most working carers (81.8%) were living in the same household as the person they care for.

- **Experiences accessing services**

More than half (53.7%) of working carers were caring for someone receiving disability services, followed by a similar proportion (52.2%) caring for someone receiving mental health services and 31.8% caring for someone receiving aged care services. More than one in ten (12.8%) were caring for someone who was not accessing any formal support services. When asked if the services that support the person they care for aligns well with their work patterns, 35.7% of working carers agreed or strongly agreed that services were well aligned with work. However, a large majority (89.4%) of carers felt that it was important or very important to improve reliability of services for the person they care for, and a similar proportion (89.3%) felt that more consistency in the staff of formal care services was important or very important (see Figure 53).

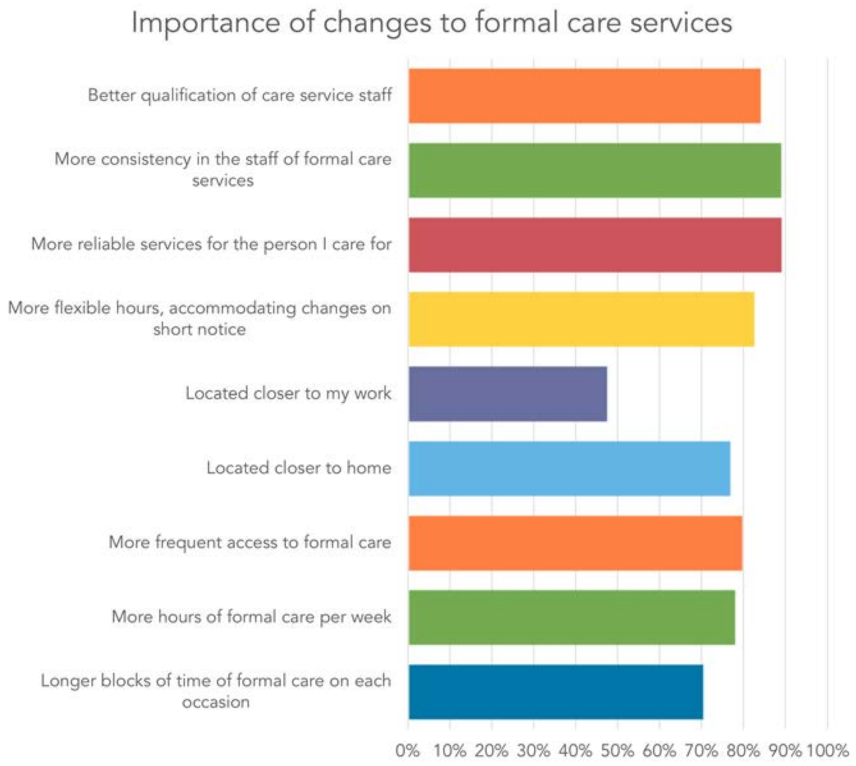


*Figure 53: Importance of changes to formal care services (% of working carers)*

When compared with carers not in paid work, working carers reported higher access to online peer support groups and carer skills training, but were overall less likely to have accessed carer support services than other respondents.

- **Health and wellbeing**

On average, working carers reported similar wellbeing scores to non-working carers, with a Personal Wellbeing Index (PWI) score of 55.28, which is lower than the population average. Most (56.3%) working carers reported high to very high psychological distress, and 62.3% reported feeling isolated or highly isolated, similar to the proportion of non-working carers.

When asked how caring had impacted their career, two in three (65.8%) carers reported that they had reduced their working hours, while one in three (36.0%) reported that they had turned down a job or promotion opportunity. More than one in ten (12.7%) working carers received the Carer Payment, 56.4% were received Carer Allowance and 35.7% were not receiving any Centrelink payments. While one in three carers (34.8%) reported financial stability, 65.2% had one or more experiences of financial stress in the year leading up to the Survey. Only two in five working carers who responded to the Survey felt that their caring role was recognised and valued by their employer (see Figure 54).

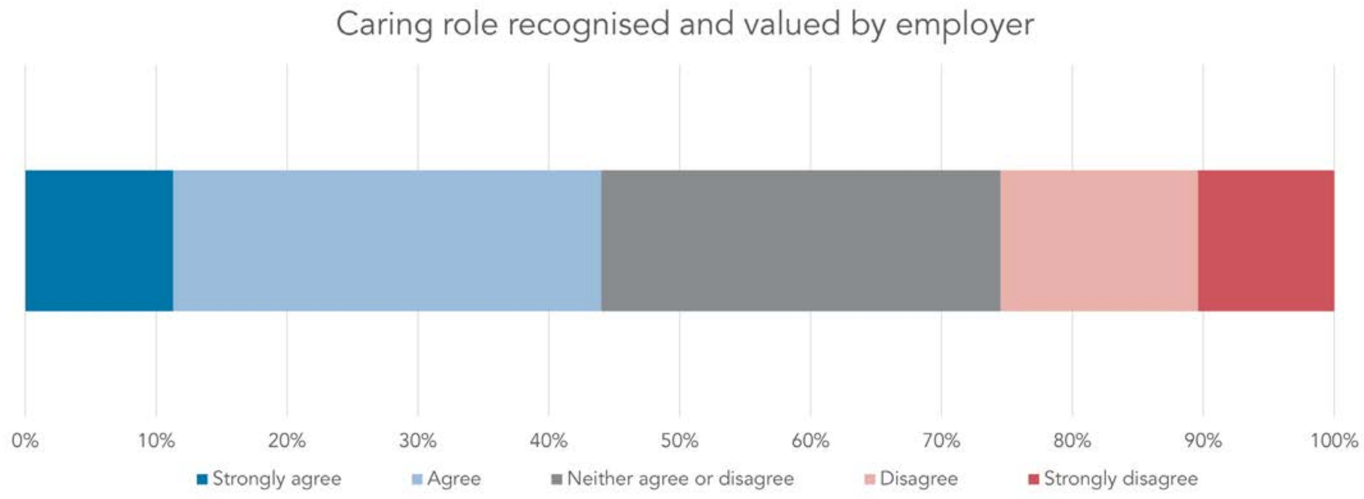
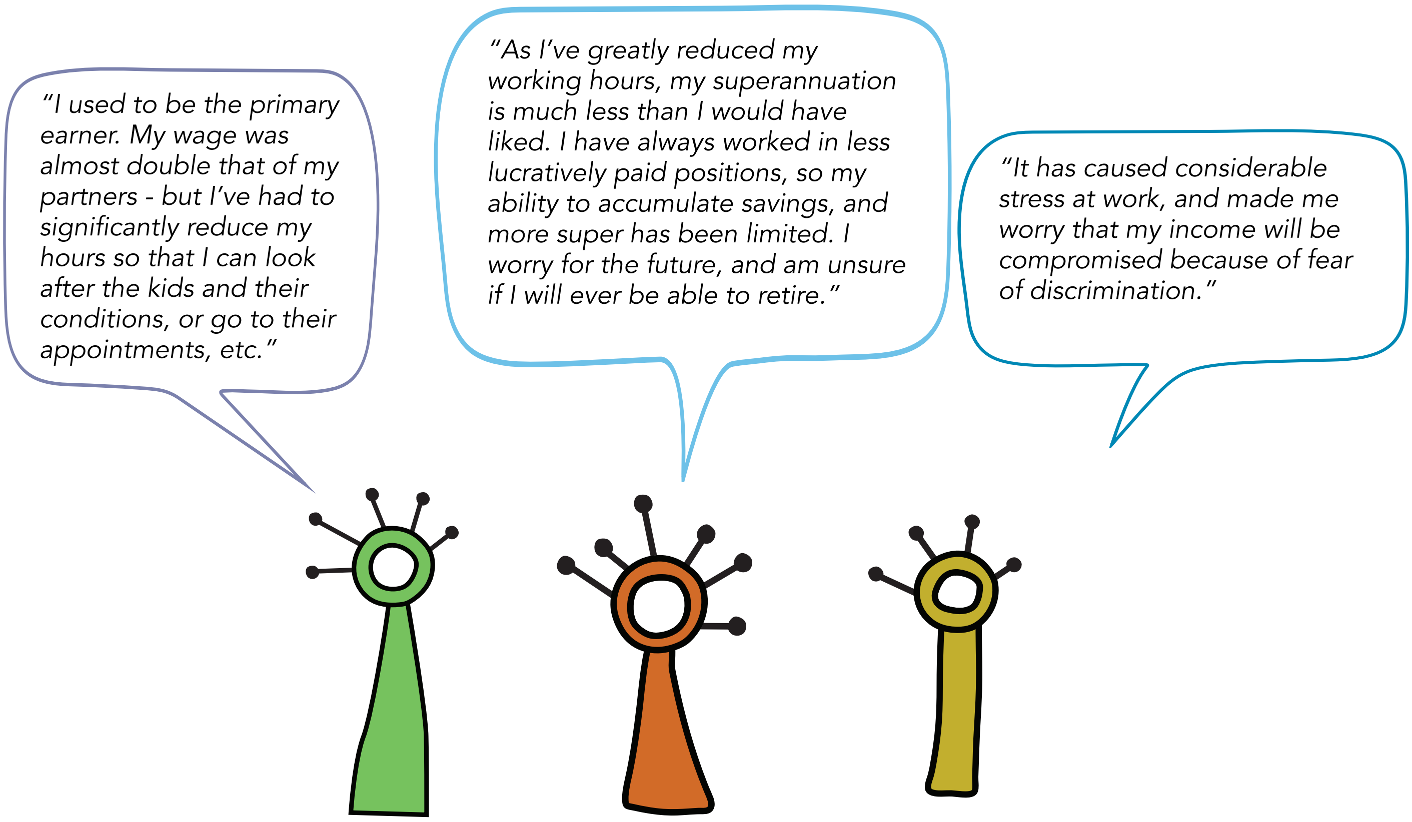


*Figure 54: Caring role recognised and valued by employer*

### Key points

- Working carers responding to the 2024 National Carer Survey were most commonly caring for their child, including adult children. Two in five working carers were caring for someone living with Autism
- Working carers reported better access to online peer support groups and carer skills training, but were less likely overall to have accessed carer support services than other respondents.
- Two in three working carers reported feeling isolated or highly isolated, similar to the proportion of non-working carers.



*"I used to be the primary earner. My wage was almost double that of my partners - but I've had to significantly reduce my hours so that I can look after the kids and their conditions, or go to their appointments, etc."*

*"As I've greatly reduced my working hours, my superannuation is much less than I would have liked. I have always worked in less lucratively paid positions, so my ability to accumulate savings, and more super has been limited. I worry for the future, and am unsure if I will ever be able to retire."*

*"It has caused considerable stress at work, and made me worry that my income will be compromised because of fear of discrimination."*

## Regional and remote carers

Respondents to the 2024 National Carer Survey came from all over Australia, with 3,324 respondents (35.5%) living in regional and remote areas. Most (68.4%) were living in an Inner regional area, while 28.1% lived in an Outer regional area and 3.5% reported living in a Remote or Very remote area. The communities where carers live can have significant impacts on their experiences.

Carers living in regional and remote areas are a similar age to other carers, at 59 years compared to 57 years for carers living in major cities. The rate of carers identifying as Aboriginal and/or Torres Strait Islander in these areas was 5.3%, twice as high as in major cities (2.7%). However, significantly fewer carers in these areas were identified as culturally and/or linguistically diverse (7.8% compared to 22.7%) or identified as speaking a language other than English at home (2.8% compared to 13.1%). A smaller proportion (4.5%) of respondents living in regional or remote areas identified as part of the LGBTQ+ community, compared to 6.1% living in major cities.

- **About the people they care for**

Around two in five (41.0%) of carers living in regional or remote areas were caring for a child (including adult children), two in five (40.3%) were caring for their partner, and one in five (19.3%) were caring for a parent; this differed significantly from caring arrangements in major cities, where only 30.2% cared for a partner and almost half (47.6%) cared for their child. The most frequent reasons for providing care among regional and remote respondents were due to a physical disability (41.6%), mental health challenges (35.6%) or a chronic health condition (31.7%).

- **About the caring experience**

Most regional and remote respondents were caring for one person (68.0%), and 85.4% were living with the person they care for. Almost three in five (57.7%) regional and remote carers were the sole carer for the person they cared for. They spent an average of 113.8 hours per week caring, higher than the average for those living in major cities, with 55.0% providing 24/7 care. Nearly half (47.9%) had been caring for ten years or more.

- **Experiences accessing services**

More than one in three (39.8%) of regional and remote carers were caring for someone accessing aged care services, with a similar proportion (39.7%) accessing mental health services and 37.8% accessing disability services. However, one in five (20.9%) were caring for someone who was not accessing any of these formal support services at the time of completing the Survey.

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, they experienced more challenges with services not being available locally compared to carers living in major cities (see Figure 55).

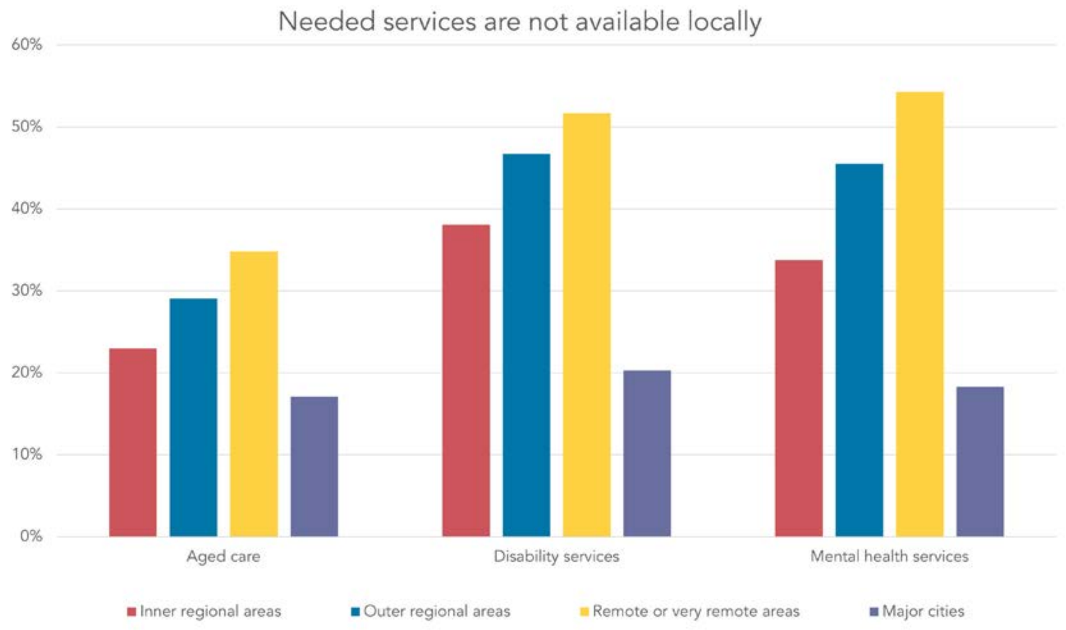


*Figure 55: Needed services not available locally, by geography*

In regional and remote areas, 39.0% of respondents caring for people requiring disability services and 46.1% of carers for people requiring mental health services reported longer waiting periods to access services than carers in major cities (37.4% and 42.1% respectively).

- **Health and wellbeing**

With an average score of 56.94% on the Personal Wellbeing Index (PWI), regional and remote carers are slightly more satisfied with their lives overall than those living in major cities (55.22%) (see Table 9).

*Table 9: Wellbeing of carers living in regional/remote areas and major cities*

| *Personal Wellbeing Index: How satisfied are you with…* | **Major Cities** | **Regional or remote** |
|---|---|---|
| …your standard of living | 63.3% | 65.1% |
| …your health | 50.3% | 51.7% |
| …what you are achieving in life | 48.1% | 50.3% |
| …your personal relationships | 53.4% | 55.3% |
| …your safety | 70.2% | 71.9% |
| …your community | 51.3% | 53.4% |
| …your future security | 50.3% | 52.2% |
| *Overall score* | *55.2%* | *56.9%* |

Carers in regional and remote areas experienced lower rates of psychological distress than other carers, however half of respondents (50.9%) still reported 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 was similar to carers in major cities, with 61.4% 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 (33.2% compared to 40.5%). Those who were in paid work spent slightly fewer hours at work on average, with carers in regional and remote areas spending 25.9 hours a week on average compared to 27.0 hours a week for carers in major cities. They reported financial stress at a slightly higher rate compared to carers living in major cities, with 60.1% experiencing at least one instance of financial stress in the year leading up to the survey, compared to 58.0% in major cities.

**Key points**

- Carers in regional and remote areas are most likely to care for someone using aged care or mental health services.
- Challenges accessing services locally and long wait periods for services were commonly reported by regional and remote carers.
- Carers in regional and remote areas were more satisfied with their lives than carers in living in major cities, even though they experienced similar rates of social isolation and financial distress.

## Variation across states and territories

The 2024 National Carer Survey received responses from all Australian states and territories (see Table 10), and there was great diversity across respondents both 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. Due to the relatively small sample size, results from the Northern Territory (NT) are not reliable.

*Table 10: State and territory sample sizes*

| State/Territory | Respondents | % of total |
|---|---|---|
| Australian Capital Territory | 185 | 1.8% |
| New South Wales | 1,981 | 19.6% |
| Northern Territory | 25 | .2% |
| Queensland | 613 | 6.1% |
| South Australia | 2,765 | 27.4% |
| Tasmania | 640 | 6.3% |
| Victoria | 2,684 | 26.6% |
| Western Australia | 1,203 | 11.9% |
| Total | 10,096 | 100.0% |

The largest response was received from South Australia (2,765 respondents) followed by Victoria (2,684) and New South Wales (1,981) (see Table 10). Table 11 shows the distribution of key demographics among states. With 54.3 years average age, the Australian Capital Territory (ACT) had the youngest sample, followed by Queensland with 55.9 years average age. Other than the NT, the ACT returned the most highly diverse sample, with 1.1% of respondents identifying as non-binary or gender diverse, 9.7% identifying as First Nations respondents and 22.2% culturally and linguistically diverse (CALD) respondents. Tasmania had the oldest respondents on average, and was also the state with the highest male participation (22.6%).

*Table 11: State and territory sample composition*

| | Mean Age | Female | Male | Non-binary/ Gender diverse/ other | First Nations | CALD |
|---|---|---|---|---|---|---|
| Australian Capital Territory | 54.3 | 84.2% | 14.8% | 1.1% | 9.7% | 22.2% |
| New South Wales | 57.2 | 86.3% | 13.0% | 0.7% | 5.9% | 15.1% |
| (Northern Territory)* | (56.5) | (72.0%) | (24.0%) | (4.0%) | (32.0%) | (20.0%) |
| Queensland | 55.9 | 86.7% | 12.8% | 0.5% | 7.0% | 11.1% |
| South Australia | 59.6 | 80.3% | 19.1% | 0.6% | 2.8% | 15.1% |
| Tasmania | 61.9 | 76.8% | 22.6% | 0.6% | 4.4% | 7.3% |
| Victoria | 55.5 | 83.0% | 16.3% | 0.8% | 2.0% | 23.8% |
| Western Australia | 60.6 | 81.8% | 17.7% | 0.5% | 3.0% | 18.1% |
| **Total** | **58.0** | **82.6%** | **16.8%** | **0.7%** | **3.8%** | **17.2%** |

*Insufficient sample size for reliable analysis

Significant variation also exists between samples in relation to the typical caring roles of respondents (see Table 12). Tasmania had the sample with the highest proportion of carers of people receiving aged care services (50.4%), and the lowest rates of carers of NDIS participants (27.3%) and carers of people using mental health services (34.5%). The highest proportion of carers of NDIS participants was found in the Queensland sample (51.2%), which also included the highest rate of mental health carers (45.7%) and one of the lowest rate of carers for people receiving aged care services (29.3%), with only the Victorian sample including fewer of this cohort (28.7%).

**Table 12: State and territory sample composition, formal care services**

| | Caring for someone receiving aged care services | Caring for someone receiving NDIS services | Caring for someone receiving mental health services | No ongoing formal care services |
|---|---|---|---|---|
| Australian Capital Territory | 40.7% | 44.0% | 42.9% | 23.9% |
| New South Wales | 37.0% | 40.4% | 41.3% | 23.3% |
| (Northern Territory)* | (45.8%) | (33.3%) | (29.2%) | (38.1%) |
| Queensland | 29.3% | 51.2% | 45.7% | 19.7% |
| South Australia | 42.8% | 33.8% | 36.6% | 23.3% |
| Tasmania | 50.4% | 27.3% | 34.5% | 20.6% |
| Victoria | 28.7% | 46.7% | 44.0% | 23.0% |
| Western Australia | 42.9% | 33.2% | 35.3% | 24.6% |

*Insufficient sample size for reliable analysis

This social, demographic, and cultural diversity across the state and territory samples and the variety of caring situations contribute to differing wellbeing outcomes in each jurisdiction (see Table 13). The average wellbeing score was highest in the Tasmanian sample (58.3%) and lowest in Queensland (51.0%). The Queensland sample also has the second highest rate of carers experiencing high or very high psychological distress (61.1%), with the ACT reporting the highest (61.9%), and the Tasmanian sample including the lowest rate of cares in high/very high distress (50.2%). This likely correlates with the trend reported in Part 2 that older carers have higher wellbeing on average.

**Table 13: State and territory wellbeing and psychological distress indicators**

| | PWI Mean | High/very high distress |
|---|---|---|
| Australian Capital Territory | 54.9% | 61.9% |
| New South Wales | 55.2% | 53.3% |
| (Northern Territory)* | (66.2%) | (55.0%) |
| Queensland | 51.0% | 61.1% |
| South Australia | 57.4% | 52.0% |
| Tasmania | 58.3% | 50.2% |
| Victoria | 54.7% | 55.5% |
| Western Australia | 55.9% | 51.3% |

*Insufficient sample size for reliable analysis

Social connectedness varied in a similar pattern, with states with a younger sample such as Queensland and Victoria reporting higher rates of social isolation, while states with older samples such as Tasmania and South Australia reporting higher rates of social connectedness (see Figure 56).

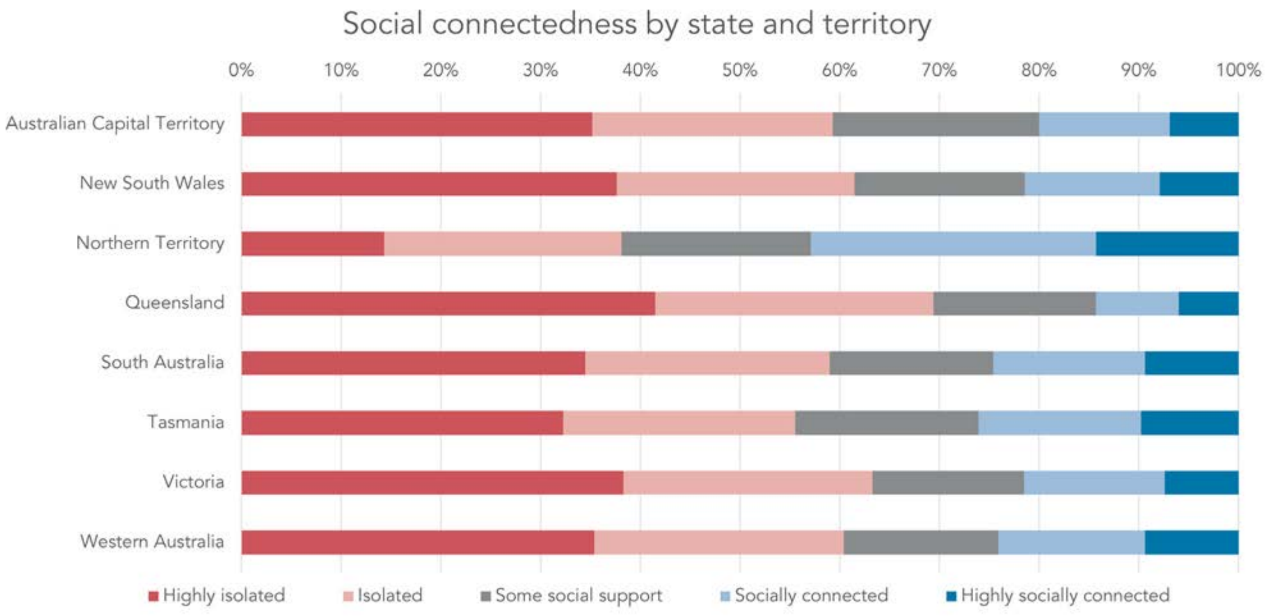


*Figure 56: Social connectedness by state and territory*

This pattern is also found with regard to experiences of financial stress, with the Tasmanian sample including the lowest rate of carers in financial stress (51.6%), and Queensland the highest (69.1%) (see Figure 57).

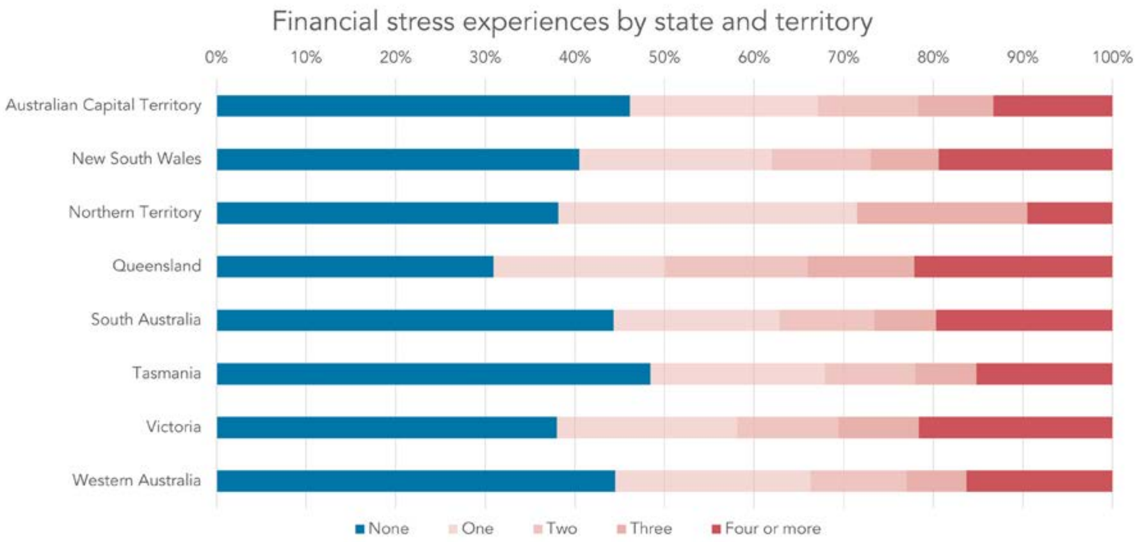
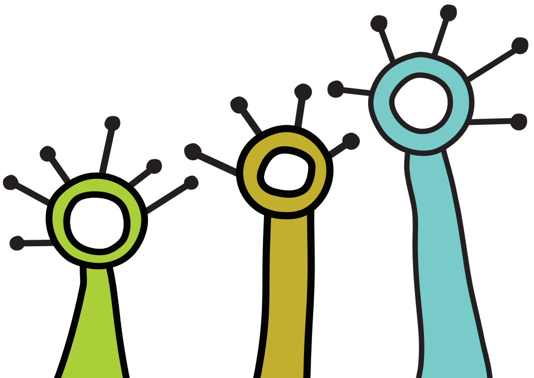


*Figure 57: Financial stress experiences by state and territory*

While there was little variation in most recognition domains, some minor variation was found between jurisdictions with regard to perceived recognition by government, with Tasmanian and South Australian respondents felt slightly more recognised in their caring role by government than those from other states and territories (see Figure 58).



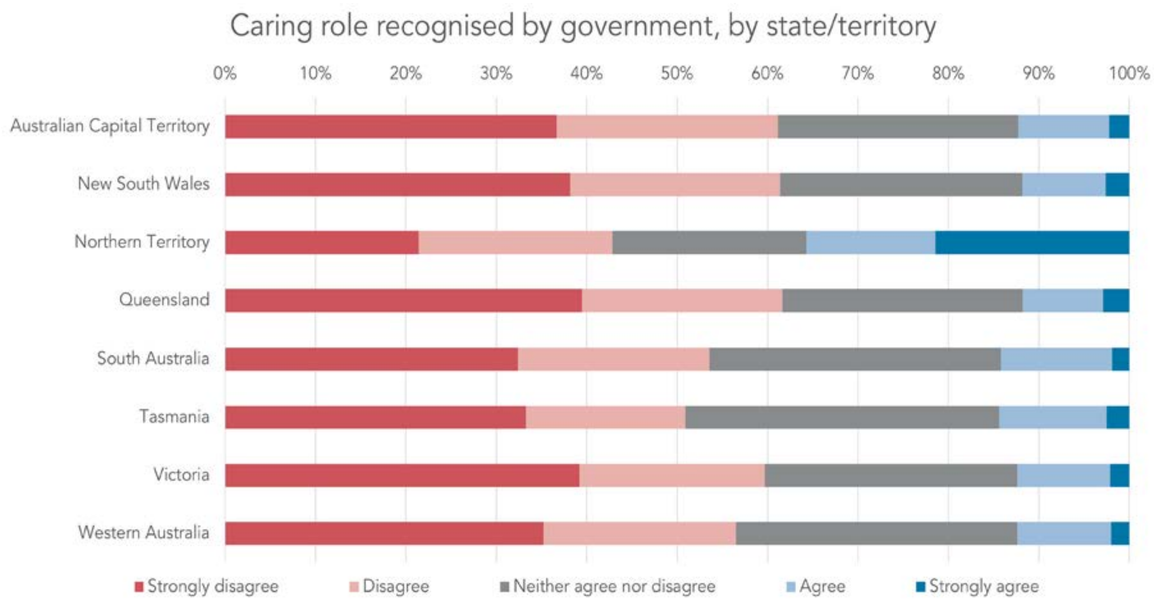


*Figure 58: Caring role recognised by government, by state/territory*

The experiences of carers captured in the 2024 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 www.nationalcarersurvey.com.au.

**Key points**

- The 2024 National Carer Survey captured diverse caring experiences from all across Australia.
- Typical caring roles vary strongly between states and territories.
- Health and wellbeing outcomes between state vary strongly with average sample age.

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# Appendix

## i - List of tables

## ii - List of figures

# Appendix - iii

# Questionnaire

# 2024 National Carer Survey

## State and Territory Carer Organisations head offices around Australia

**Carers ACT**
*Ngunnawal Country*
2/80 Beaurepaire Crescent
Holt ACT 2615
(02) 6296 9900
carers@carersact.org.au

**Carers NSW**
*Gorualgal Country*
Level 10, 213 Miller Street
North Sydney NSW 2060
(02) 9280 4744
contact@carersnsw.org.au

**Carers NT**
*Larrakia Country*
1 Willeroo Street
Tiwi NT 0810
1800 422 737
carersnt@carersnt.asn.au

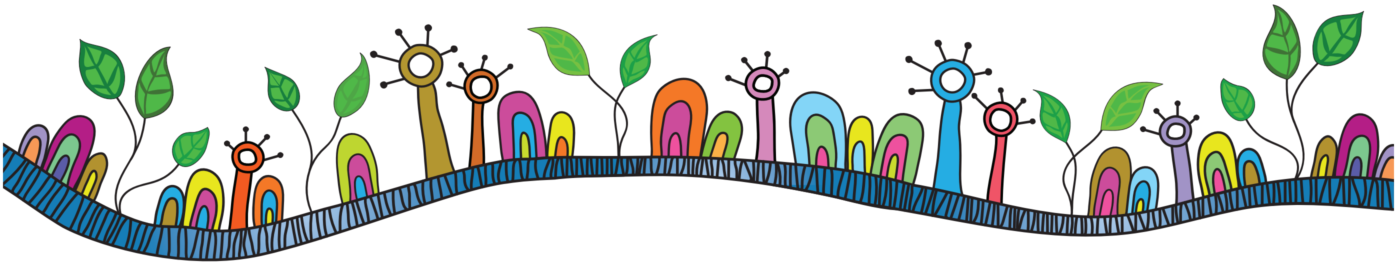
**Carers QLD**
*Turrbal Country*
Level 1
Lutwyche City Shopping Centre
120 Chalk Street
Lutwyche QLD 4030
1300 747 636
info@carersqld.com.au

**Carers SA**
*Kaurna Country*
338-340 Tapleys Hill Road
Seaton SA 5023
(08) 8291 5600
info@carerssa.com.au

**Carers TAS**
*Palawa Country*
95 Albert Road
Moonah TAS 7009
(03) 6144 3700
peak@carerstasmania.org

**Carers VIC**
*Wurundjeri Woi-wurrung and*
*Bunurong/Boon Wurrung*
*Country*
1/485 La Trobe Street
Melbourne VIC 3000
(03) 9396 9500
reception@carersvictoria.org.au

**Carers WA**
*Wadjuk Noongar*
182 Lord Street
Perth WA 6000
1300 227 377
info@carerswa.asn.au



## *Thank you for participating in the 2024 National Carer Survey!*

The experiences you share in this survey will help the Australian State and Territory Carer Organisations to better advocate for carers.

**Every caring role is different. Not all questions in this survey will be relevant to you. To make it easier to complete, the survey has several parts . Please skip the questions and parts that are not relevant to you. You don't have to answer any question you don't want to. If you feel like you don't want to answer a question, please leave it blank.**

Please complete only the parts that are relevant to you:

**1.** About you

**2.** For First Nations carers

**3.** For young carers (25 and under)

**4**. About the people you care for

**5.** About people you used to care for

**6.** About your caring role

**7.** Services and support

**8.** Paid work

**9.** Health and wellbeing

**10.** Finances, housing and other experiences

At the end of the survey, you will be asked whether you would like to be contacted for the next wave of the survey in 2026. You don't have to say yes.

Three carers from each state and territory will win a $200 gift voucher. If you would like a chance to win, please enter your contact details on page 30. This information will not be linked to your responses, which will remain anonymous.

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 2022 National Carer Survey and agreed to participate in this year's follow up study, a unique code should appear on the bottom left of the front page. If you would prefer to complete this survey online rather than on paper, you can enter the code in the online version of the survey at:
https://www.research.net/r/2024NationalCarerSurvey

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

**A1. In which state or territory do you live?**

☐ Australian Capital Territory
☐ New South Wales
☐ Northern Territory
☐ Queensland
☐ South Australia
☐ Tasmania
☐ Victoria
☐ Western Australia
☐ I do not live in Australia **(Unfortunately you do not fit our respondent profile. Thank you for your interest.)**

**A2. Do you look after someone (or help look after someone) who lives with a disability, mental illness, alcohol or other drug 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.)**

**A3. Is/was this person your family member, friend or neighbour?**

☐ Yes
☐ 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.)**

## About you

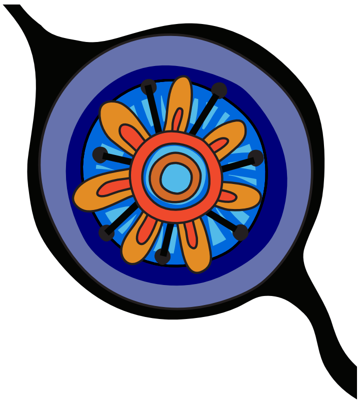
*Please tell us a bit about yourself first*:

**A4. What is the postcode where you live?** ____________

**A5. What is your gender?**

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

**A6. How old are you?** ________ years



**A7.** **Are you of Aboriginal or Torres Strait Islander origin?**

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

**A8.** **Are you currently enrolled in any formal education?**

- ☐ No
- ☐ Yes – high school
- ☐ Yes – TAFE / apprenticeship / traineeship
- ☐ Yes – university
- ☐ Other (please specify): ______________________________

**A9.** **What is your cultural background? (e.g. Australian, Italian, Chinese)**

______________________________________________

**A10.** **Do you mainly speak a language other than English at home? (e.g. Vietnamese, Auslan)**

- ☐ No, English only
- ☐ Yes, at home I mainly speak: _________________
- ☐ Prefer not to say

**A11.** **In general, do you have what you need in the following areas?**

| | Never / Not at all | Sometimes | Most of the time | Always |
|---|---|---|---|---|
| Enough food to not go hungry | ☐ | ☐ | ☐ | ☐ |
| A safe place to live | ☐ | ☐ | ☐ | ☐ |
| Affordable health services (GP, Hospital) | ☐ | ☐ | ☐ | ☐ |
| Reliable internet | ☐ | ☐ | ☐ | ☐ |
| Reliable transport | ☐ | ☐ | ☐ | ☐ |

## For First Nations carers

*The questions in this part are for anyone who identifies as First Nations / Aboriginal or Torres Strait Islander. If this is not you, please skip this part and go to page 8.*

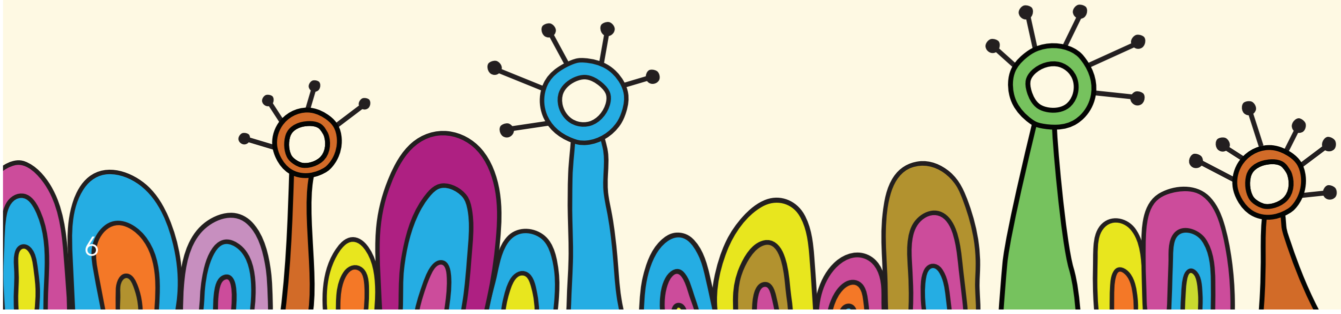
**B1. What Nation or Country do you belong to? You can mention more than one.**

**B2. Do you live on Country?**

☐ Yes
☐ No
☐ I don't know or prefer not to say

**How is a connection to Country important for the care you provide?**

**B3. What type of cultural activities are part of your caring role? For example, healing activities, cultural events, traditional practices. How could these activities be better supported?**



**B4. As a First Nations carer, what are the most important issues for you? What would help?**

**B5. When you or the person you care for use mainstream health, aged care or disability services, do you feel that they are culturally safe for First Nations people?**

☐ Yes, always
☐ Mostly
☐ Sometimes
☐ Never
☐ Don't know/Prefer not to say

**B6. What makes a service safe and welcoming for you?**

## For young carers

*The questions on this page are for people aged 25 years and under. If you are older than 25 years, please skip this page and go to the next part (About the people you care for) on page 9.*

**C1. Do you (or did you) care for someone while you are (or were) attending school or an apprenticeship?**

☐ Yes
☐ No
☐ Don't know

*If you answered 'No' here, please skip to Question C5.*

**C2. Do (or did) the teachers or other staff at your school know that you are (or were) caring for someone?**

☐ Yes
☐ No
☐ Don't know

**C3. Do (or did) you get extra support at school because you are (or were) caring for someone?**

*For example: to meet assignment deadlines, to pay for things like school trips and sports activities, to keep on top of school work?*

☐ Yes
☐ No
☐ Don't know

**C4. Please describe any extra support you need (or needed) at school, and whether you receive (or received) the support you needed.**

**C5. How much has caring for someone affected any of the following areas of your life?**

| | Not at all | A little bit | Moderately | Quite a lot | A lot |
|---|---|---|---|---|---|
| Your education | ☐ | ☐ | ☐ | ☐ | ☐ |
| Your physical health | ☐ | ☐ | ☐ | ☐ | ☐ |
| Your mental health | ☐ | ☐ | ☐ | ☐ | ☐ |
| Your relationships with people your own age | ☐ | ☐ | ☐ | ☐ | ☐ |
| How you see yourself | ☐ | ☐ | ☐ | ☐ | ☐ |
| Your plans for the future, including plans for work, education, and/or personal relationships | ☐ | ☐ | ☐ | ☐ | ☐ |

## About the people 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. If you do not currently provide care for someone, please go to the next part (About people you used to care for) on page 11.*

**D1. How many people do you care for?** ________

### PERSON 1

**D2. 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

**D3. How old is this person?** __________(in years)

**D4. 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 son or daughter)
☐ Foster or kinship child
☐ Sibling, brother or sister
☐ Grandparent
☐ Friend
☐ Neighbour
☐ Other, please specify:______________________________

**D5. Is this person Aboriginal or Torres Strait Islander?**

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

If yes, what is this person's nation or country (if you know)? ___________________________________

**D6. What is their cultural background? (e.g. Australian, Italian, Chinese)**

____________________________________________

### PERSON 2

**D2. 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

**D3. How old is this person?** __________(in years)

**D4. 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 son or daughter)
☐ Foster or kinship child
☐ Sibling, brother or sister
☐ Grandparent
☐ Friend
☐ Neighbour
☐ Other, please specify: ______________________________

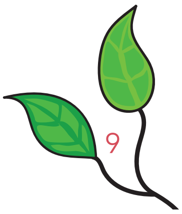
**D5. Is this person Aboriginal or Torres Strait Islander?**

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

If yes, what is this person's nation or country (if you know)? ___________________________________

**D6. What is their cultural background? (e.g. Australian, Italian, Chinese)**

____________________________________________



**PERSON 1 (continued)**

**D7. For what conditions, disabilities or 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 health challenges
☐ Alcohol or other drug dependency
☐ Dementia
☐ Chronic health condition
☐ Acquired brain injury or stroke
☐ Neurological condition (e.g. epilepsy, Parkinson's disease, multiple sclerosis)
☐ ADD/ADHD
☐ Terminal or serious illness
☐ Cancer
☐ Receiving palliative care
☐ Other health condition or disability, please specify: ________________

**D8. Do you and the person you care for live in the same household?**

☐ Yes
☐ No, they live by themselves
☐ No, they live with another family member (e.g. their partner, other parent or children) 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:___________________________

*If you answered No, how many minutes on average does it take you to travel to where they live (including there and back)?* ___________________

**D9. Do any other family members or friends help care for this person?**

☐ No - I am the only one who provides care
☐ Yes - I share the care equally with someone (e.g. a partner)
☐ Yes - I provide the most care, but others help with care sometimes
☐ Yes - Someone else provides the most care, but I help with care sometimes

**PERSON 2 (continued)**

**D7. For what conditions, disabilities or 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 health challenges
☐ Alcohol or other drug dependency
☐ Dementia
☐ Chronic health condition
☐ Acquired brain injury or stroke
☐ Neurological condition (e.g. epilepsy, Parkinson's disease, multiple sclerosis)
☐ ADD/ADHD
☐ Terminal or serious illness
☐ Cancer
☐ Receiving palliative care
☐ Other health condition or disability, please specify: ________________

**D8. Do you and the person you care for live in the same household?**

☐ Yes
☐ No, they live by themselves
☐ No, they live with another family member (e.g. their partner, other parent or children) 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: ___________________________

*If you answered No, how many minutes on average does it take you to travel to where they live (including there and back)?* ___________________

**D9. Do any other family members or friends help care for this person?**

☐ No - I am the only one who provides care
☐ Yes - I share the care equally with someone (e.g. a partner)
☐ Yes - I provide the most care, but others help with care sometimes
☐ Yes - Someone else provides the most care, but I help with care sometimes

**PERSON 1 (continued)**

**D10. 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

**D11. How long have you been caring for this person?**

_____years ____months

**PERSON 2 (continued)**

**D10. 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

**D11. How long have you been caring for this person?**

_____years ____months

**D12. How has/have your caring role(s) changed over time?**

________________________________________________

________________________________________________

________________________________________________

## About people you used to care for

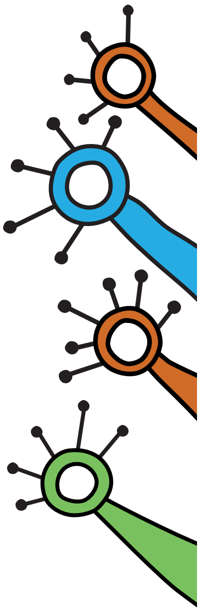
**E1. Have you previously cared for anyone who you are no longer caring for?**

☐ Yes
☐ No **(Please continue with the next part (About your caring role) on page 13)**

*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.*

**E2. 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 son or daughter)
☐ Sibling, brother or sister
☐ Grandparent
☐ Friend
☐ Neighbour
☐ Foster or kinship child
☐ Other, please specify:_______________



**E3. For how long did you care for that person?** ______years ____months

**E4. How long ago did this caring role end?** _____years _____months

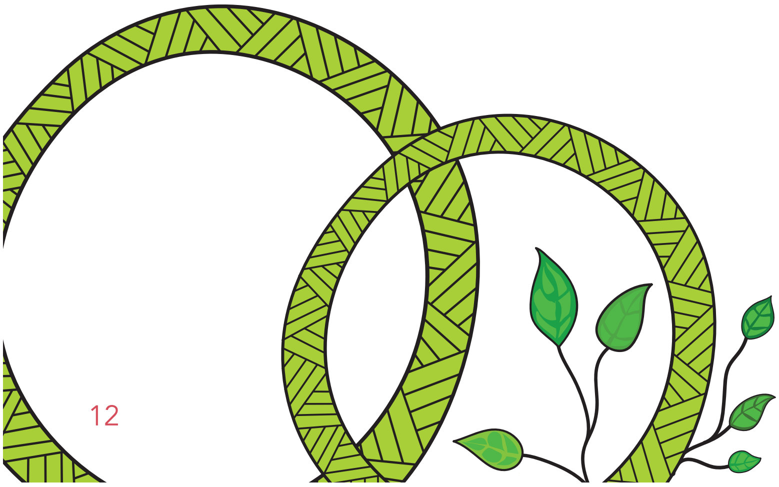
**E5. Why did this caring role end? Please tick all that apply.**

- ☐ 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 broke down or ended
- ☐ Another family member or friend took over the caring role
- ☐ The person moved into residential care (e.g. nursing home, group home, supported accommodation)
- ☐ Other, please specify:______________________________

**E6. What kinds of support have you needed and accessed since this caring role ended?**

| | Needed | Accessed |
|---|---|---|
| Financial support | ☐ | ☐ |
| Emotional support (e.g. counselling) | ☐ | ☐ |
| Support with relationships | ☐ | ☐ |
| Support with household tasks | ☐ | ☐ |
| Support with using technology | ☐ | ☐ |
| Support with transport | ☐ | ☐ |
| Support with housing | ☐ | ☐ |
| Support related to paid work (trainings, employment support) | ☐ | ☐ |
| Support navigating services/government supports | ☐ | ☐ |
| None of the above | ☐ | ☐ |

**E7. How has life changed for you since this caring role ended?**



# About your caring role

*If you are not currently providing care for someone, please answer the following questions as they were applicable for your most recent caring role.*

**F1. On average, how many hours per week do/did you provide care**

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

**F2. Please tick all the types of support that you provide to the person(s) you care for, at any time in the past six months:**

☐ Transport
☐ Administration, coordinating support services
☐ Managing finances
☐ Advocacy
☐ Cognitive support, incl making decisions
☐ Behavioural support
☐ Personal care
☐ Health care
☐ Domestic assistance
☐ Monitoring/supervision/checking whether they are ok
☐ Other ______________________________

**F3. Which, if any, of the following do you have in place for the person/s you care for?**

☐ Power of Attorney
☐ Enduring Power of Attorney
☐ Guardianship order
☐ Enduring Guardianship
☐ Advance Care Plan
☐ Supportive Guardian, Supportive Administrator
☐ Other (please specify) ____________________
☐ None of the above

**F4. Do you have a plan for how to respond to bushfires, floods, or other natural disasters?**

☐ Yes
☐ No
☐ Don't know/not applicable

**F5. Thinking about your caring role, how much do you agree with the following statements:**

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Not applicable |
|---|---|---|---|---|---|---|
| I learn new skills through my caring responsibilities | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| I use my existing skills or expertise in providing care | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| I know everything I am expected to do as a carer | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| I know what I am required to do in every aspect of my caring role | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| My caring role is emotionally demanding | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| I feel that I am able to continue to meet the demands of my caring role | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

## Services and support

*If you did not provide care to someone in the last two years, please continue with the next part (Paid Work) on page 21.*

### Aged care services

*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.*

**G1. Did someone you care/cared for use aged care services in the past two years? Please tick all that apply.**

☐ **No**, nobody I care/cared for needs aged care services **(Please go to the next section – Disability services on page 16)**

☐ **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

☐ **Yes**, someone I care/cared for 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

☐ **Yes**, someone I care/cared for paid for aged care services privately, such as cleaning, or in-home support

☐ **Yes**, someone I care/cared for lives/lived in residential aged care, for example a nursing home or care facility

☐ **Yes**, someone I care/cared for is/was receiving aged care services, but I don't know which services they are using

☐ I don't know **(Please go to the next section – Disability services on page 16)**

**G2. Please indicate how much you agree with the following statements:**

**When aged care services were being planned for the person I care for…**

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Not applicable |
|---|---|---|---|---|---|---|
| ... I was asked about my needs as a carer | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| … I was involved in planning and decisions about services | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| … My views had a real influence on the care provided | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ... I was provided with all the information I need | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**The aged care services accessed by the person I care for gave me enough time away from my caring responsibilities to:**

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Not applicable |
|---|---|---|---|---|---|---|
| ...focus on paid work, looking for paid work, study or volunteering | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| …attend to other responsibilities outside of my caring role, e.g. parenting responsibilities, my own appointments, household chores | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| …properly rest and recharge | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**G3. Have you or the person(s) you care for experienced any of the following challenges with aged care services? Please tick all that apply.**

- ☐ The person I care for was not eligible for the required services
- ☐ The service received was at a lower level than required
- ☐ 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 out of pocket cost of services (including co-payments) was too high
- ☐ It was difficult to find information about available services and to organise them
- ☐ It was difficult to make complaints or raise concerns
- ☐ Other, please describe:________________________
- ☐ None of the above

**G4. Please leave any comments you might have on your experience with aged care services:**

## Disability services/NDIS

**H1. Did someone you care/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 needs disability services **(Please go to the next section - Mental health services on page 17)**

☐ **No**, someone I care for needs disability services but is ineligible for the NDIS **(Please go to question H3)**

☐ **Yes**, someone I care/cared for has/had a National Disability Insurance Scheme (NDIS) plan

☐ I don't know **(Please go to the next section - Mental health services on page 17)**

**H2. Please indicate how much you agree with the following statements:**

**When NDIS supports were being planned for the person I care for...**

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Not applicable |
|---|---|---|---|---|---|---|
| ... I was asked about my needs as a carer | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| … I was involved in planning and decisions about services | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| … My views had a real influence on the care provided | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ... I was provided with all the information I need | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**The supports included in the NDIS plan gave me enough time away from my caring responsibilities in order to:**

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Not applicable |
|---|---|---|---|---|---|---|
| ...focus on paid work, looking for paid work, study or volunteering | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| …attend to other responsibilities outside of my caring role, e.g. parenting responsibilities, my own appointments, household chores | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| …properly rest and recharge | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**H3. Have you or the person(s) you care for experienced any of the following challenges with the NDIS or other disability services? Please tick all that apply.**

☐ The person I care for was not eligible for the NDIS
☐ The plan was reduced/cut
☐ There was a long waiting period to get assessed
☐ There was a long waiting period to access services
☐ The services 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 packages did not cover all the costs for required
☐ It was difficult to find information about what services were available and to organise them
☐ It was difficult to adapt supports or access more funding when circumstances changed
☐ It was difficult to make complaints or raise concerns
☐ Other, please describe:
☐ None of the above

**H4. Please leave any comments you might have on your experience with disability services:**

________________________________________

________________________________________

________________________________________

## Mental health services

*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 Alzheimer's or dementia.*

**I1. Did someone you care/cared for use mental health services in the past two years? Please tick all that apply.**

☐ **No**, nobody who I care/cared for needs mental health services **(Please go to the next section - Health services on page 19)**
☐ **No**, the person I care for needs mental health services, but has not been able to access these services to date **(Please go to the next section - Health services on page 19)**
☐ **Yes**, someone I care/cared for used hospital based mental health services as an admitted patient or in out-of-hospital care
☐ **Yes**, someone I care/cared for saw a psychologist
☐ **Yes**, someone I care/cared for saw a psychiatrist
☐ **Yes**, someone I care/cared for used community mental health services, such as Drop-In Clinics, or Rehabilitation programs
☐ **Yes**, someone I care/cared for used a counselling service
☐ **Yes**, someone I care/cared for received mental health treatment and support through their GP
☐ Other, please specify:____________________
☐ I don't know **(Please go to the next section - Health services on page 19)**

**I2. Please indicate how much you agree with the following statements:**

**When mental health services were being planned for the person I care for…**

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Not applicable |
|---|---|---|---|---|---|---|
| … I was asked about my needs as a carer | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| … I was involved in planning and decisions about services | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| … My views had a real influence on the care provided | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| … I was provided with all the information I need | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**The mental health services accessed by the person I care for gave me enough time away from my caring responsibilities in order to:**

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Not applicable |
|---|---|---|---|---|---|---|
| …focus on paid work, looking for paid work, study or volunteering | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| …attend to other responsibilities outside of my caring role, e.g. parenting responsibilities, my own appointments, household chores | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| …properly rest and recharge | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**I3. Have you or the person(s) you care for experienced any of the following challenges with mental health services? Please tick all that apply.**

☐ The person I care for was not eligible for the required services
☐ The service received was at a lower level than required
☐ There was a long waiting period to access services
☐ The services required 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 out of pocket 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 could not address the complexity of needs
☐ The service addressed acute mental distress but did not provide ongoing support
☐ The service kept me at a distance and did not keep me updated about the person's diagnosis, status, or supports
☐ The services could not be accessed as frequently or as long as needed
☐ Other, please describe:
☐ None of the above

**I4. Please leave any comments you might have on your experience with mental health services:**

______________________________

______________________________

______________________________

## Health services

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

**J1. Please indicate how much you agree with the following statements:**

**When I accompanied the person I care for or cared for to visit a GP…**

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Not applicable |
|---|---|---|---|---|---|---|
| ... I was asked about my needs as a carer | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| … I was involved in planning and decisions about services | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| … My views had a real influence on the care provided | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ... I was provided with all the information I need | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**When I accompanied the person I care or cared for on a visit to the hospital or community health service…**

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Not applicable |
|---|---|---|---|---|---|---|
| ... I was asked about my needs as a carer | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| … I was involved in planning and decisions about services | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| … My views had a real influence on the care provided | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ... I was provided with all the information I need | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| …I was provided with sufficient support options and facilities for carers (e.g. seating, overnight rooms, transport support) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**J2. Please leave any comments you might have on your experience with health services:**

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

## Carer support services

**K1. Did you use any of the following carer support services in the past 2 years? Would you need to use any of these supports more than you were able to?**

| | I have used this support in the past 2 years | I have not been able to use this service as much as I would like/need |
|---|---|---|
| Carer Gateway (website, phone number or local provider) | ☐ | ☐ |
| Carer support groups | ☐ | ☐ |
| Carer peer support online | ☐ | ☐ |
| Carer counselling (counselling designed specifically to address challenges relating to the caring role) | ☐ | ☐ |
| 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 skills training | ☐ | ☐ |
| Young carer service/program | ☐ | ☐ |
| Other, please specify: ______________________ | ☐ | ☐ |
| None of the above | ☐ | ☐ |

**K2. What types of support (for you or the person you care for) would be most useful for you as a carer?**

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

# Paid work

**L1. How has your caring role impacted your employment? Please tick any of the following that apply.**

☐ It changed my outlook on what is important in life
☐ It reduced my knowledge and confidence to apply for jobs
☐ It contributed to my skills and qualifications becoming less relevant to employers
☐ It made me feel less prepared to meet my job demands
☐ It meant that I worked in a job that is lower than my skill set
☐ It led to me reducing my working hours
☐ It led me to choose roles or industries that built on my caring experiences
☐ It led to me taking on a different job (but one in which I did similar types of work).
☐ It led to me working in a different industry or occupation
☐ It meant that I turned down a job or promotion opportunity
☐ It meant that I stopped doing paid work (or looking for paid work) either temporarily or permanently
☐ It led to me missing out on important career or work opportunities
☐ Other, please specify:______________________________
☐ None of the above

**L2. What is your primary occupation (or was your primary occupation if you are not currently in paid work)?**

_______________________

**L3. Do you currently have a paid job?**

☐ Yes
☐ No, but I am looking for work **(Please go the question L11 on page 23)**
☐ No, and I am not looking for work **(Please go to the next part - Health and Wellbeing on page 24)**
☐ I am retired/no longer working **(Please go to the next part - Health and Wellbeing on page 24)**

**L4. Which of the following apply to you? Please select all that apply:**

☐ 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 one or more casual jobs
☐ I am self-employed
☐ I am an independent contractor (including gig work)
☐ Other, please specify: ______________________________

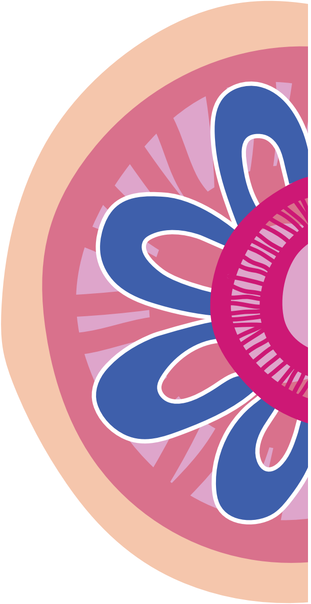
**L5. How many paid jobs do you have currently?** _________

**L6. How many hours per week do you usually spend doing paid work?**

_________ hours

**Would you like to work more hours than you currently do?**

☐ Yes
☐ No
☐ Don't know



**L7. Which of the following patterns of work are usual for you? Please select all that apply:**

☐ Business hours (e.g. 9:00am to 5:00pm or similar, Monday to Friday)
☐ Rostered shiftwork outside business hours (e.g. night shifts, weekend work)
☐ Varying hours that I determine as an independent contractor or gig worker
☐ Other (please specify): ____________________

**L8. Where do you mainly work?**

☐ On-site / in the office
☐ Mobile / in the community (e.g. visiting clients, delivery driving)
☐ From home / remote
☐ I have hybrid work arrangements (e.g. can sometimes work from home / remote)
☐ Other (please specify): ____________________

**L9. How much do you agree with the following statement:**

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Not applicable |
|---|---|---|---|---|---|---|
| The services that support the person I care for align well with my work patterns | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**L10. Is there anything you would like to change about the following to help you balance your paid work with your caring responsibilities?**

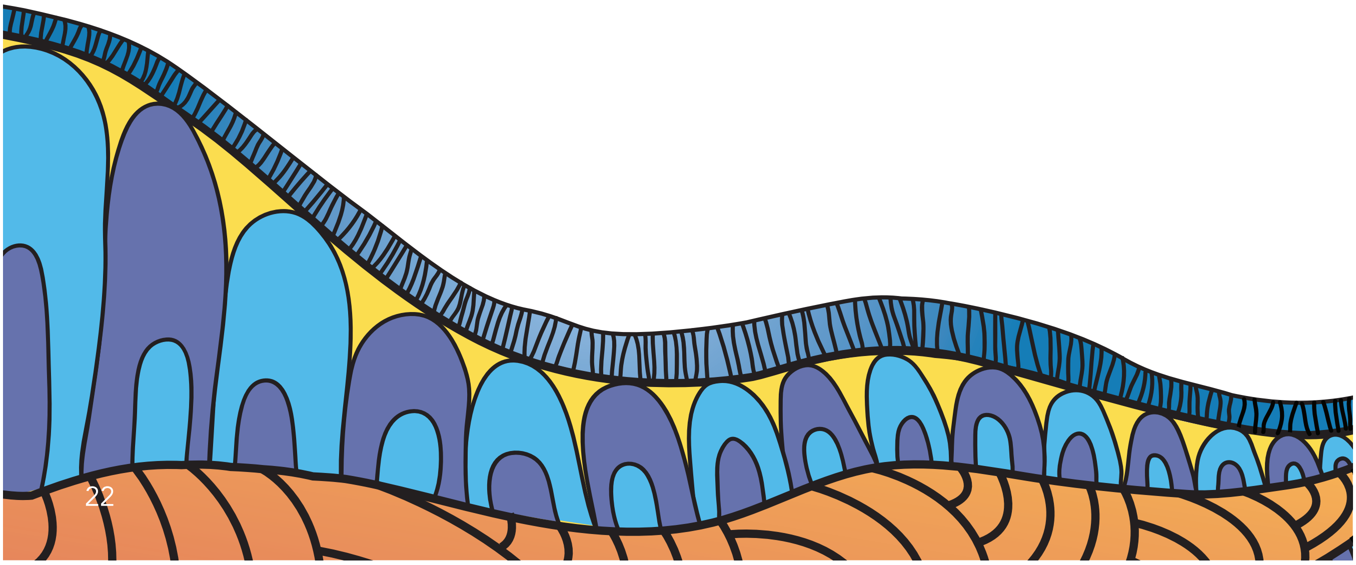
☐ Yes, my current job type or work structure
☐ Yes, the services available to support the person you care for
☐ No/not applicable

*If yes, please describe the changes you would make and why:*

______________________________________________

______________________________________________

______________________________________________



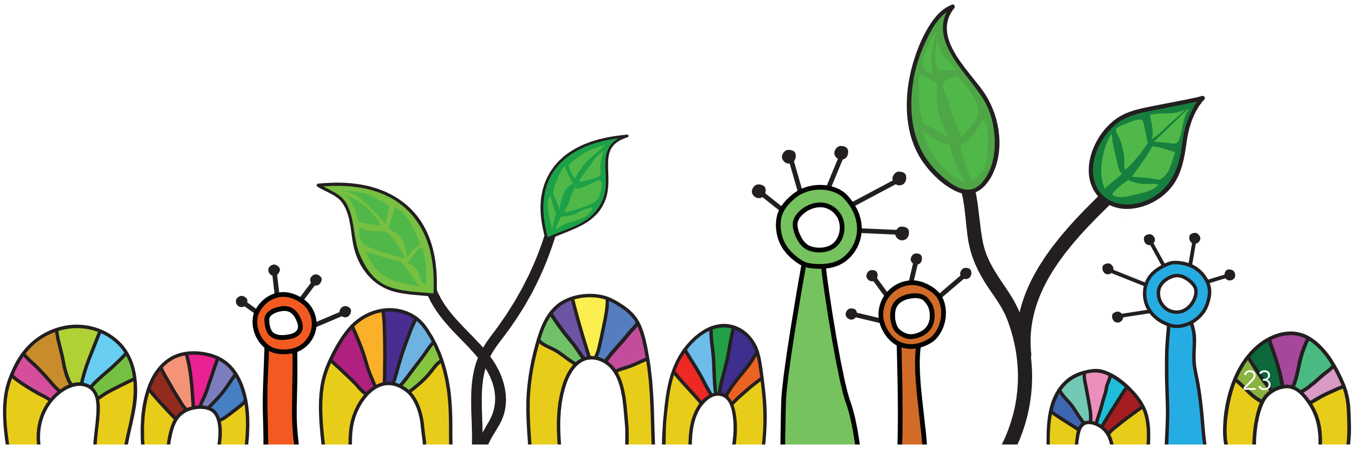
**L11. What changes to formal care services (e.g. aged care, disability, mental health or carer support services such as respite) would better support you to combine your paid work or job search with your caring responsibilities?**

| | Not important | Somewhat important | Important | Very important | Not applicable |
|---|---|---|---|---|---|
| Longer blocks of time of formal care on each occasion | ☐ | ☐ | ☐ | ☐ | ☐ |
| More hours of formal care per week | ☐ | ☐ | ☐ | ☐ | ☐ |
| More frequent access to formal care | ☐ | ☐ | ☐ | ☐ | ☐ |
| Located closer to home | ☐ | ☐ | ☐ | ☐ | ☐ |
| Located closer to my work | ☐ | ☐ | ☐ | ☐ | ☐ |
| More flexible hours, accommodating changes on short notice | ☐ | ☐ | ☐ | ☐ | ☐ |
| More reliable services for the person I care for | ☐ | ☐ | ☐ | ☐ | ☐ |
| More consistency in the staff of formal care services | ☐ | ☐ | ☐ | ☐ | ☐ |
| Better qualification of care service staff | ☐ | ☐ | ☐ | ☐ | ☐ |

**L12. Would you ever consider paid work providing care to clients, e.g. aged care worker, disability support worker?**

☐ Yes, I already do or have done this type of work
☐ Yes, I am seriously considering it
☐ Yes, I would be open to it
☐ No, I would never consider it

Please tell us why:



## Health and wellbeing

*The following questions are about your health and wellbeing. If any question causes you discomfort, you can skip it. If you need help and support, please contact one of the following numbers:*

If you need support with your caring role, including respite or counselling, please call

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

If you are in crisis, anxious or depressed and want to talk with someone, please

**Call Lifeline: 13 11 14 (24/7)** or

**Text Lifeline: 0477 13 11 14 (24/7)**

If you are Aboriginal or Torres Strait Islander and you are feeling worried or no good, please call

**13YARN: 13 92 76 (24/7)**

to talk with an Aboriginal or Torres Strait Islander Crisis Supporter.

**M1. 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 responsibilties, work, or to household and other chores.*

**M2. Please indicate how satisfied you are with each of the following (0-10):**

| | Completely dissatisfied<br>0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Completely satisfied<br>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 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**M3. 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 | ☐ | ☐ | ☐ | ☐ | ☐ |

**M4. 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 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 | ☐ | ☐ | ☐ | ☐ | ☐ |

**M5. How satisfied are you with… (Please only complete those that are relevant to you. If you do not have a relationship of that kind, please tick "Not applicable".)**

| | Completely dissatisfied | | | | | | | Completely satisfied | | | | Not applicable |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |
| …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(s) you care for? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**M6. How much do you agree with the following statement?**
**My family and friends assist or support me with my caring responsibilities when I need support…**

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Not applicable |
|---|---|---|---|---|---|---|
| ...practically (by helping with care activities, helping with the household, shopping, transport, etc) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ...financially (paying for expenses, shopping or with loans) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ...emotionally (by taking care of my emotional needs, e.g. when I need to vent, or grieve, or need distraction) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**M7. How much do you agree with the following statements? If a category does not apply to you, please tick "not applicable".**
**I feel that my caring role is recognised and valued by…**

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Not applicable |
|---|---|---|---|---|---|---|
| …my community | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| …my family | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| …my friends | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| …the person(s) I care for | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| …service providers | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| …my employer | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| …the government | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**What would make you feel more recognised as a carer?**

**M8. In general, would you say that your health is:**

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

**M9. 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

If yes, please specify: ____________

## Finances, housing and other experiences

**N1. In the last two years, has any of the following happened to you:**

☐ You experienced ongoing impacts from COVID-19 (health, financial or otherwise)
☐ 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 or injured
☐ You lost work or significant amounts of income
☐ You were impacted by a natural disaster, such as bushfires, floods, e.g. you had property damage, became isolated, had to evacuate
☐ You started a new job
☐ You retired
☐ You moved house
☐ You finished your education
☐ None of the above

**N2. What is the highest level of education you have completed?**

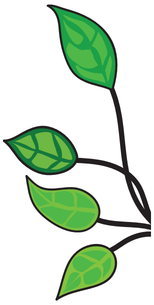
☐ Less than high school (year 12 or equivalent)
☐ High school (year 12 or equivalent)
☐ Certificate / diploma
☐ Bachelor degree or higher
☐ Other (please specify): ______________________________

**N3. Are you:**

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

**N4. *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



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**N5. What best describes your household's living situation:**

- ☐ I/we rent the place I live in from a private landlord
- ☐ I/we rent the place I live from a community/public provider
- ☐ I/we own the place I live in outright
- ☐ I/we own the place I live in, but we pay down a mortgage
- ☐ I live in the home of the person I care for, but do not co-own or pay rent
- ☐ If other, please specify: ______________________________

**N6. How much do you agree with the following statements?**

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Not applicable |
|---|---|---|---|---|---|---|
| My home currently meets my needs | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| My home is adequate for the requirements of my caring role | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| My housing situation is secure in the long term | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| I can meet my housing needs independently | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| The security of my housing is dependent on the person I care for | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**N7. Do you receive any payments from Centrelink? Please tick all that apply.**

- ☐ Carer Allowance (currently $153.50 per fortnight)
- ☐ Carer Payment (currently up to $1,020.60 per fortnight for singles and $1,538.60 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

**N8. What is the main source of income for your household?**

☐ Income from your paid work
☐ Income from the paid work of someone else, who also provides care
☐ Income from the paid work of someone else who does not provide care
☐ Centrelink payments that you receive
☐ Centrelink payments that the person you care for receives
☐ Centrelink payments that someone else in the household receives
☐ Other (please specify):

**N9. 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 spent 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

**N10. Has caring impacted your financial situation, or do you expect it to impact your financial situation in the future? If yes, please describe how.**

**N11. Are you a member / affiliate member of, or registered with, the Carers Association in your state or territory (e.g. Carers NSW, Carers WA…)?**

☐ Yes
☐ No

**N12. Optional: Is there anything else you would like to tell us about your experiences as a carer?**

## Thank you for sharing your experiences!

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, Monday to Friday, 8am to 5pm)**, which will offer support and carer specific services in your area.

If you are in crisis, anxious or depressed and want to talk with someone, please call **Lifeline: 13 11 14 (24/7) or text Lifeline: 0477 13 11 14 (24/7)**.

If you are Aboriginal or Torres Strait Islander and you are feeling worried or no good, please call **13YARN: 13 92 76 (24/7)** to talk with an Aboriginal or Torres Strait Islander Crisis Supporter.

If you would like us to get in contact with you about this survey, please don't hesitate to call the Carers NSW Research Team on (02) 9280 4744 or email research@carersnsw.org.au.

***OPTIONAL:*** *Please participate in the 2026 National Carer Survey 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 2026. Your answers will be assigned a randomly generated unique identifier, allowing a 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.

***OPTIONAL****: As a thank you for participating in the survey, you can win one of three $200 gift vouchers per state! The prizes will be drawn on 1 September 2024, the winners will be contacted via email.*

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

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:**

## The Artist - De Greer-Yindimincarlie

De Greer-Yindimincarlie is an Australian Aboriginal woman from Wiradjuri country in central western New South Wales. She is a curator, educator and multi award-winning artist. She celebrates her Aboriginal culture everyday through working within her Authentic Aboriginal businesses delivering to public and private collections worldwide, her stunning Aboriginal artworks. De works in many mediums including art, music, graphic and textile design, and film.

De was awarded the 2008 South East Queensland NAIDOC award for ‘Distinguished Services in the Visual Arts Industry; and was nominated for ‘Visual Artist of the Year’ in the 2011 and 2013 National Deadly Awards. She also won the Professional Deadly Dressed Award at the 2013 Deadly Awards, for the collaboration piece The ‘Yindi’ dress, which bore De’s textile design. In 2022, De also won the SA Woman First Nations Women in Business award.

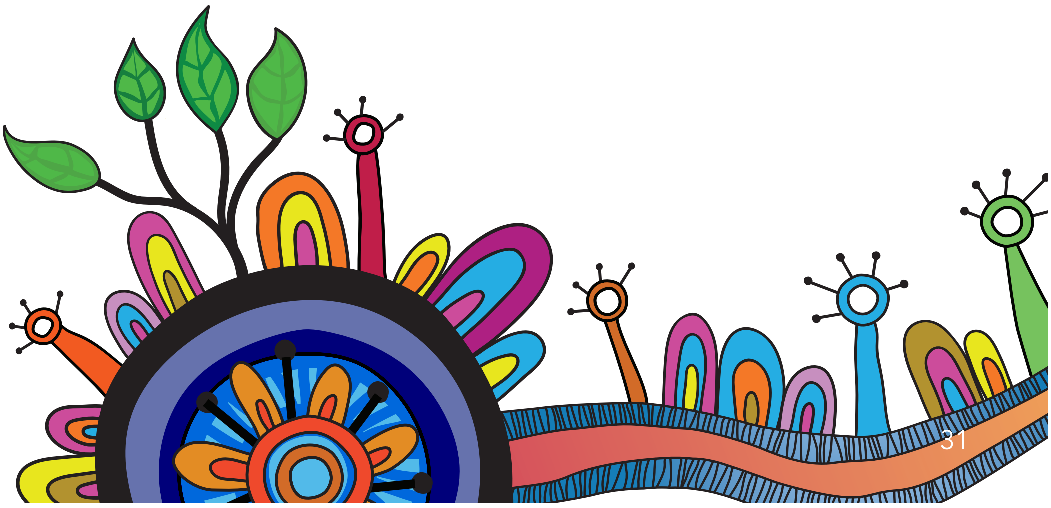
De’s Aboriginal artworks and Authentic products are held by the National Gallery of Australia, and the Toledo Museum of Art in Ohio USA, and numerous other galleries and gift shops. De’s artwork can be found on every continent of the world.

De is a respected member of the community, and she is one of Australia’s highly sought after female Aboriginal graphic designers, and she has worked and collaborated with several organisations including Department for Agriculture, Water and the Environment, QLD Health, NSW Rural Doctors Network, TAFE NSW, Australia’s First People’s Education Network, Australian Skills Quality Authority, Commonwealth Grants Commission, MSS Security, QLD Aboriginal and Islander Health Council, All Together Now, the eSafety Commissioner and many more.

De has lectured and/or tutored at Sunshine Coast University OLD, Griffith University OLD, Edith Cowan University WA, Charles Sturt University NSW, and University of Sydney on a diverse range of subjects including Aboriginal Art Practices and Protocols, Aboriginal Culture, Creativity and Innovation in Business, and Business Practices.

De has also been a professional musician, and she has composed for film, and produced albums for many musicians in her own studio. De has recorded six albums to date, and she has played with musician greats such as Dan Sultan, Wolfmother, Neil Murray, Kev Carmody, Archie Roach, and Andrew Farris.

Contact - Email: yindi@yindiartz.com.au | Web: www.yindiartz.com.au



Carers NSW Australia

### The artwork - Together we stand

Together we stand represents carers, Aboriginal and Torres Strait Islander, and non-Indigenous standing together. Caring impacts not only the people we care for, but us as people everyday in our own lives. We connect with country, the people we care for, and each other. We are separate, but we come together to stand as one.

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

# Appendix iv

# Participant information and consent form

## Participant information and consent form

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

### 2024 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 (UNSW), 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 |
| Dr Brendan Churchill | University of Melbourne | brendan.churchill@unimelb.edu.au |
| A/Prof Myra Hamilton | University of Sydney | m.hamilton@unsw.edu.au |
| Dr Lukas Hofstaetter | Carers NSW | lukash@carersnsw.org.au |
| Sarah Judd-Lam | Carers NSW | sarahj@carersnsw.org.au |
| Prof Emma Kirby | UNSW | emma.kirby@unsw.edu.au |
| Dr Abner Poon | UNSW | w.poon@unsw.edu.au |

**State and Territory Carer Organisation representatives:**

| | | |
|---|---|---|
| Dr Margaret Boulos | Carers Victoria | Margaret.Boulos@carersvictoria.org.au |
| Bronwyn Maelzer | Carers Victoria | Bronwyn.Maelzer@carersvictoria.org.au |
| Kamla Brisbane | Carers ACT | Kamla.Brisbane@carersact.org.au |
| Vanessa Corunna | Carers WA | vanessa.corunna@carerswa.asn.au |
| Carissa Gautam | Carers WA | carissa.gautam@carerswa.asn.au |
| Carers QLD Quality & Assurance Team | Carers Queensland | quality@carersqld.com.au |
| Marianne Lewis | Carers SA | marianne.lewis@carerssa.com.au |
| Steve Vitone | Carers NT | ceo@carersnt.asn.au |
| Julie Ryan | Carers Tasmania | peak@care2serve.com.au |
| Joshua Maguire | Carers NSW | joshuam@carersnsw.org.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 around 20 to 30 minutes to complete. You can do it 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 2024**.

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 your contact details to participate a follow-up study in 2026. These contact details will only be used to contact you for the follow-up study, and not for any other purpose. Your contact details will be separated from your survey response and stored in a different database. You can still take part in the survey without providing any contact details. The follow-up study is optional.

You may also provide your contact details if you choose to enter the prize draw for your state or territory. Three randomly drawn entrants from each state and territory will win a $200 Prezzee gift voucher which can be used at a range of retailers Australia-wide. Prize draws will take place on **30 August 2024** and winners will be contacted via email or post. Your contact details will be stored separately to your survey response and only used for the purpose of the prize draw.

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 unlikely that you will experience discomfort while filling out the survey. However, sharing your story may bring up complex emotions or memories. If your participation raises any concerns or discomfort, you are encouraged to call either of these services:

If you need support with your caring role, including respite or counselling, please call

**Carer Gateway: 1800 422 737**

(8am – 5pm Monday-Friday)

If you are in crisis, anxious or depressed and want to talk with someone, please

**Call Lifeline: 13 11 14** (24/7) or

**Text Lifeline: 0477 13 11 14** (24/7)

If you are Aboriginal or Torres Strait Islander and you are feeling worried or no good, please call

**13YARN: 13 92 76** (24/7)

to talk with an Aboriginal or Torres Strait Islander Crisis Supporter.

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. Choosing not 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 inform the systemic advocacy and service delivery of the State and Territory Carer Organisations. Findings will be used to identify the needs of carers across Australia and the way that characteristics such as age, gender, cultural background and location impact these needs. Results will be published in infographics, fact sheets and reports that will be made publicly available online. Results will also be published in peer reviewed journal articles and presented at conferences. The research team will have ongoing access to the de-identified information. Third party requests for use of the deidentified information will go through a formal approval process.

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 confidentially investigated and you will be informed of the outcome.

## State and Territory Carer Organisations head offices around Australia

**Carers ACT**
*Ngunnawal Country*
2/80 Beaurepaire Crescent
Holt ACT 2615
(02) 6296 9900
carers@carersact.org.au

**Carers NSW**
*Gorualgal Country*
Level 10, 213 Miller Street
North Sydney NSW 2060
(02) 9280 4744
contact@carersnsw.org.au

**Carers NT**
*Larrakia Country*
1 Willeroo Street
Tiwi NT 0810
1800 422 737
carersnt@carersnt.asn.au

**Carers QLD**
*Turrbal Country*
Level 1
Lutwyche City Shopping Centre
120 Chalk Street
Lutwyche QLD 4030
1300 747 636
info@carersqld.com.au

**Carers SA**
*Kaurna Country*
338-340 Tapleys Hill Road
Seaton SA 5023
(08) 8291 5600
info@carerssa.com.au

**Carers TAS**
*Palawa Country*
95 Albert Road
Moonah TAS 7009
(03) 6144 3700
peak@carerstasmania.org

**Carers VIC**
*Wurundjeri Woi-wurrung and Bunurong/Boon Wurrung Country*
1/485 La Trobe Street
Melbourne VIC 3000
(03) 9396 9500
reception@carersvictoria.org.au

**Carers WA**
*Wadjuk Noongar*
182 Lord Street
Perth WA 6000
1300 227 377
info@carerswa.asn.au

Carers NSW (2025). 2024 National Carer Survey: Full report. Available online at:

http://www.carersnsw.org.au/research/survey