

Carers NSW 2014

Carer Survey



Main Report



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October 2014



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Acknowledgments

Carers NSW would like to extend a special thanks to our Carer Survey Reference Committee. We greatly appreciate your support, advice, and willingness to donate your time and expertise to assist us in improving the quality of our survey and the data we collect.

Reference Committee members:

- Professor Sandra Jones
- Professor Michael Fine
- Dr Trish Hill
- Dr Rebecca Olson
- Dr Christina Aggar
- Ms Cathy Thomson
- Ms Alexandra Heron

Thanks is also extended to Thomasin Powell for her valuable assistance with data entry, coding and analysis.

Carers NSW acknowledges the work of Timothy Broady as the Principal Investigator on this project and particularly in the preparation of this report.

Finally, and most importantly, we would like to acknowledge every carer who participated in this survey. We appreciate the value of your time and are extremely grateful for your willingness to share your views and experiences with us.

List of Abbreviations

ABS	Australian Bureau of Statistics
CALD	Culturally and linguistically diverse
COPE	Carers of Older People in Europe Index
DSSI	Duke Social Support Index
K10	Kessler Psychological Distress Scale
NSW	New South Wales
PWI	Personal Wellbeing Index
SDAC	Survey of Disability, Ageing and Carers
SPSS	Statistical Package for the Social Sciences



Foreword

I am pleased to present the Main Report of the Carers NSW 2014 Carer Survey.

It is a core part of our work at Carers NSW that we listen to carers to continually enhance and grow our understanding of who carers are, and what issues, challenges and triumphs they face. Carers NSW strives at all times to contribute to the public discourse, to strategically advocate, to support, understand and ultimately to improve the lives of carers in NSW. This substantial piece of research will underpin our planning, policy and advocacy work as we move forward in this time of enormous change for carers, and for the sector as a whole.

I would like to extend my thanks to the carers who completed this survey. We appreciate that this was the longest survey we have undertaken, but through your combined efforts we have an incredibly rich and detailed story and understanding of carers in NSW.

I would like also to personally extend my thanks to the Carer Survey Reference Committee, who have worked hard to ensure that we have a robust and rigorous survey that can be replicated in years to come. Lastly I would like to thank the Carers NSW Senior Research Officer, Tim Broady, for his extensive work and commitment to this project.

This report makes a significant contribution to the knowledge base and understanding of carers in NSW. I strongly encourage you to not only read it, but to use it to advocate for better outcomes for all carers.



Elena Katrakis
CEO
Carers NSW

October 2014

Executive Summary

The biennial Carers NSW Carer Survey collects information about carers in NSW to inform the organisation's direction, support and systemic advocacy for all carers across NSW. The 2014 survey collected more extensive and detailed data than any previous Carer Survey and has established a framework to guide future surveys. This report provides an overview of the main findings from the survey data, with future publications to investigate specific issues in greater depth.

The survey was completed by 1,684 carers – 84% of whom were female, and over half were aged between 45 and 64 years. A significant majority were the main provider of care for those they supported. Approximately one in three had experienced a long-term illness or disability themselves within the previous year. While the demographic profile of survey respondents indicated a wide range of caring relationships and experiences, comparisons with population-based statistics highlight that this sample is not representative of the broader NSW carer population. This limits the generalisability of survey findings, however, it also allows for more detailed data analysis to be conducted within the more highly represented sub-groups of carers, and also suggests areas for improved data collection in future surveys.

Carers generally framed their reasons for caring in a positive way, with more than twice as many wanting to take on their caring roles than felt they had no choice. Nevertheless, a significant proportion indicated that no one else assisted them or that they would not be able to find help if they needed a break. Significantly, over one quarter of respondents reported providing more than 70 hours of care per week. This finding is particularly important, since associations were found between the hours of care provided per week, the length of caring roles, and the prevalence of carers' long-term illness or disability.

In line with a great deal of previous literature, the wellbeing of carers in this survey was low compared to the general Australian population. Despite this, carers consistently emphasised the positive value of caring as being greater than the negative impacts. This report highlights those carers who are at greater risk of experiencing low wellbeing, including those with more intensive caring demands and those with long-term illnesses or disabilities. At the same time, male carers and older carers tended to report higher levels of wellbeing.

Amongst carers who were not in paid employment, more than one in two had stopped working because of their caring responsibilities. Notably, these carers reported poorer wellbeing than those who had stopped working for other reasons. A large majority of working carers indicated that their employers knew about their caring responsibilities, but one in four did not feel supported to balance work and care. Survey responses also indicated that many carers experience some degree of conflict in balancing their caring responsibilities, finances and career progression.

Carers reported using local doctors and family/friends for support more than any other source, as well as being restricted from accessing services by the cost, not knowing what was available, and their caring responsibilities taking priority. A majority of carers were not currently accessing supportive services for themselves and interestingly, most did not want to. When carers were



satisfied with the services received by the person(s) they cared for and felt more included by service providers, they were more likely to report better wellbeing outcomes.

Carers of people with a disability were invited to share their expectations of the impact of person centred approaches and individualised funding to the disability service sector. Awareness of these concepts had increased since the Carers NSW 2012 Carer Survey, with expectations being more positive than negative. Notably, carers who had practical experience of individualised funding packages were much more positive about their introduction than those yet to experience them.

Former carers were also invited to complete the survey, with 146 responses being received. Their previous caring roles had usually ended through the death of the person they cared for or the care recipient's admission into residential care facilities. Very few indicated that they had stopped caring because they could no longer cope, highlighting carers' resilience and dedication to their caring roles.

The data collected in this survey will inform a range of advocacy and research work. Importantly, the Carers NSW 2014 Carer Survey makes a significant contribution to the evidence base regarding carers in NSW, with the main findings indicating implications for the recognition and support of carers by service providers, governments, and the wider community.

Aims and Objectives

The biennial Carers NSW Carer Survey aims to collect information about carers in NSW to inform the organisation's direction, support and systemic advocacy for all carers across NSW. The 2014 survey aimed to build on the success of previous surveys and improve the quality of data collected. Many of the major issues investigated in previous Carer Surveys were incorporated and a framework for future surveys was established in order to allow continued comparisons over time.

In developing the survey, an expert reference committee was established. Reference committee members were invited based on their professional experience in conducting research on carer related issues, with several also having caring experience themselves. As a result, the methodological rigour of the survey was strengthened, which will allow for improved comparisons of data over time with future surveys.

Focus topics for the survey were selected based on their significance in current research literature, their importance in informing Carers NSW advocacy and support work, and consultation with the reference committee. The following sections were included:

- Carer demographics
- The person cared for
- Employment
- Service access and social support
- Health and wellbeing
- Former carers
- Person centred approaches (optional section)

While some data can be directly compared with results of previous Carers NSW Carer Surveys, this is the most extensive survey Carers NSW has conducted. The level of detail is therefore much greater than previously available and will form a baseline for ongoing data collection and comparison into the future.

The findings of this survey will be used to inform a range of Carers NSW policy submissions, conference presentations, funding applications, research publications and fact sheets. Importantly, the Carers NSW Carer Survey makes a significant contribution to the growing body of knowledge and evidence regarding carers in NSW.



Methodology

Survey instrument

The survey included three screening questions to ensure that respondents belonged to the target population, followed by seven separate sections. The content of these sections is outlined here and provided in full in the Appendix.

1. The person you care for

Participants were asked to provide basic demographic characteristics of the person(s) they cared for, including: age, gender, relationship to the carer, country of birth, and the conditions, disabilities or illnesses for which they required care. They were also asked to indicate their reasons for caring, the amount of help they received, how long they had been caring and how much care they provided per week.

2. Your employment

Participants were asked to indicate whether or not they were in paid employment. Working carers were asked further details regarding their employment, such as weekly hours of employment and industry. They were asked to indicate the extent to which their employers knew about and supported their caring responsibilities, including the availability of specific workplace practices.

3. Service access and social support

Carers were asked to indicate sources of support they had accessed in their caring role, and which of those they had found useful. They were also asked to indicate any barriers they had experienced to accessing services or support and whether or not they would like to access more services. Their satisfaction with the quality of services for the person(s) they cared for was investigated, including any benefits they perceived for themselves as carers. Participants also completed the Duke Social Support Index (DSSI) (Koenig et al., 1993) – a widely used scale measuring perceived social support.

4. Your health and wellbeing

Carers' health and wellbeing was measured using the following scales, each of which has been widely used and validated in Australian and international research projects:

- Carers of Older People in Europe (COPE) Index (McKee et al., 2003)
- Positive Aspects of Caregiving (Tarlow et al., 2004)
- Personal Wellbeing Index (International Wellbeing Group, 2006)
- Kessler Psychological Distress Scale (K10) (Kessler et al., 2003)

In this section, participants also indicated the extent to which they agreed with a series of statements regarding the recognition of carers.

5. About you

This section collected a range of demographic data about the respondent, including: age, gender, cultural background, geographic region, education, income, and housing.

6. Former carers

This section was completed by participants who were no longer carers. It included questions regarding when and why their caring roles had ended, the types of support they needed and received in that time, and the supports they currently needed and received.

7. Optional section on person centred approaches

Participants were given the option of completing an additional section on person centred approaches and individualised funding. Only those who were caring for a person with a disability were included in this section, since person centred approaches have initially been implemented in the disability sector. They were asked how they thought these systemic changes would impact on the choice and control experienced by carers and those they cared for, as well as the degree to which their needs would be met.

Procedure

The survey was available online through Survey Monkey and as a paper questionnaire. Paper questionnaires were distributed with the Carers NSW bimonthly newsletter, *Carers News*, to over 4,000 members of Carers NSW. The online survey was promoted on the Carers NSW website and social media, and through the Carers NSW monthly *eBulletin*. The survey was also advertised through a range of stakeholder networks and other organisations with which Carers NSW staff have regular contact. Paper questionnaires were distributed to a number of organisations, support groups and individuals who requested them. The advertised closing date for the survey was 30th June, 2014. Survey responses were accepted until one month past this date.

Completed paper questionnaires were entered into Survey Monkey, and the data were exported in SPSS format. The final dataset was cleaned, coded and analysed using SPSS 22.

Participants

The survey was commenced by 2,228 participants. Of those, 99 were screened out before completion – 28 did not live in NSW, 44 indicated they were not carers, 20 were paid care workers, and 7 were formal volunteers. The Participant Information Sheet informed carers that not submitting a completed survey would be considered a withdrawal of their consent to participate – 296 responses were excluded from analysis for this reason. For ethical reasons, only carers aged 16 years and over were invited to participate, with 3 responses being screened out for being under this age limit. This resulted in a final sample of 1,797 – 1,684 of whom were current carers and 146 were former carers (33 participants completed the survey as both a current and former carer). 1,072 completed the online version, 723 completed the paper version, and 2 completed the survey over the telephone with Carers NSW staff. A demographic profile of participants is provided in the Results section of this report.

Ethics

Ethics approval was granted by the University of Wollongong Human Research Ethics Committee (HE14/062).



Survey Results

This section provides an overview of results from the Carers NSW 2014 Carer Survey. The focus of this report is the generalised findings across all carers, though some more detailed areas of investigation are also highlighted. These specific avenues of inquiry will provide the basis for additional in-depth analysis in future reports and publications.

All results presented in this report are statistically significant, though statistical figures have been omitted in order to enhance readability. Details regarding statistical analyses will be made available in future, more detailed reports and publications.

Profile of carers

Selected demographic characteristics of the sample of carers in this survey are shown in Table 1. These results are provided alongside demographic characteristics of the broader population of carers in NSW as estimated by the Australian Bureau of Statistics 2012 Survey of Disability, Ageing and Carers (SDAC) (ABS, 2012a).

Table 1. Demographic characteristics of Carers NSW 2014 Carer Survey respondents compared to ABS estimates of the total NSW carer population

	Carer Survey 2014	SDAC 2012
Total population	1,684	857,200
Gender: Female	84.0%	55.9%
Male	14.9%	44.0%
Age: <45 years	19.9%	37.0%
45-64 years	51.7%	41.3%
65+ years	27.4%	21.2%
Employed*	42.8%	52.5%
Education: Bachelor or higher	30.8%	17.0%
Diploma	17.3%	11.8%
Certificate	18.5%	18.8%
Year 12	7.3%	13.7%
Year 10 or below	23.5%	37.8%
Disability [†]	32.1%	31.1%
Primary carer	91.8%	29.4%

* See the Carers' employment section for more detail

[†] Percentage of carers who had experienced any long-term illness or disability themselves during the last 12 months

The data presented in Table 1 demonstrate several key areas in which the current sample is not representative of the wider NSW carer population. Most notably, the current sample has a significantly higher proportion of female carers than the wider population, and is highly dominated by primary carers. The current sample also has a substantially lower proportion of carers aged under 45 years. Compared to SDAC estimates, carers in the current sample had achieved higher levels of formal education, but were less likely to be in paid employment. Interestingly, almost identical proportions of carers reported experiencing a long-term illness or disability themselves over the previous 12 months. These demographic differences must be considered when interpreting findings from other sections of this survey.

74.1% of carers reported caring for one person and 21.6% were caring for two people. The remaining 4.3% were caring for three or more people. Compared to those caring for one person, carers with multiple caring roles were:

- Even more likely to be female (89.7% vs. 82.1%)
- More likely to report having others help them in providing care, with 38.5% reporting that someone else provided a significant amount of care (vs. 18.6% of those caring for one person) and 22.7% indicating that nobody else provided assistance (vs. 49.4%)
- More likely to identify as Aboriginal or Torres Strait Islander (4.8% vs. 1.5%)
- More likely to have been caring for over 10 years, as illustrated by Figure 1

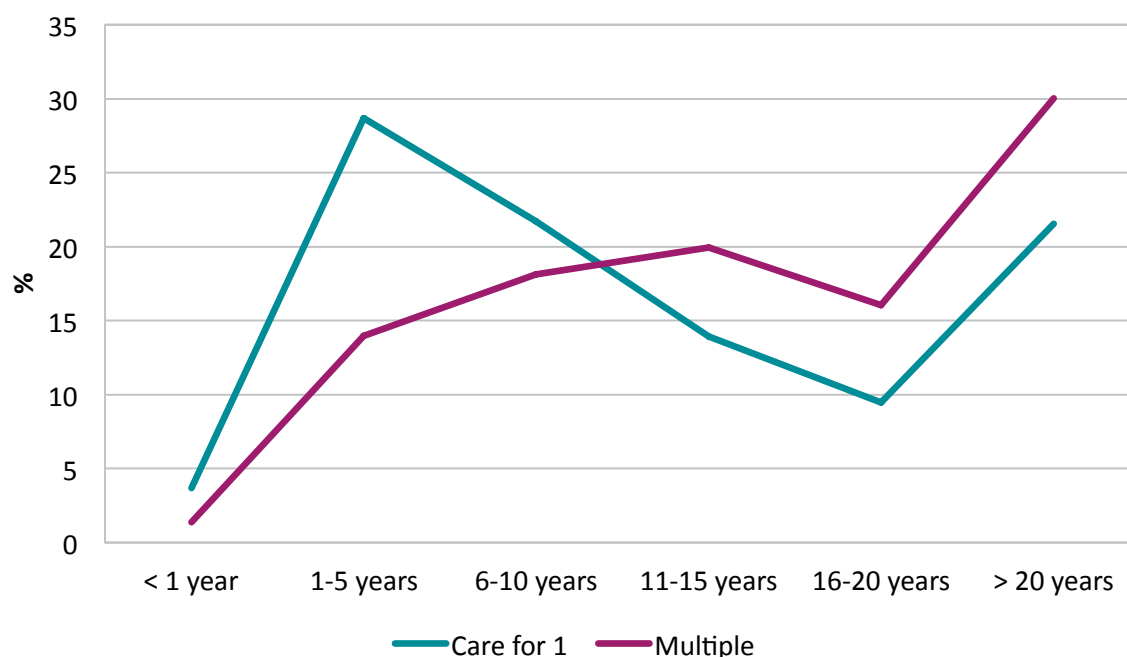


Figure 1. Length of time caring by number of caring roles

Cultural background

The vast majority of participants were born in Australia (78.2%), followed by the United Kingdom (6.5%), New Zealand (2.0%), the Philippines (1.0%), the Netherlands (1.0%) and Italy (0.8%).

A majority of carers identified as Australian (64.0%), with 20.3% identifying as being from a culturally and linguistically diverse (CALD) background. The most commonly identified cultural backgrounds (after Australian) were:

- English (15.0%)
- Italian (3.3%)
- Irish (2.0%)
- German (1.8%)
- Scottish (1.8%)
- Chinese (1.7%)
- Dutch (1.5%)
- Greek (1.5%)
- Maltese (1.1%)
- New Zealand (1.0%)

In addition, 2.4% of respondents identified as Aboriginal and/or Torres Strait Islander.

12.5% of respondents reported speaking a language other than English at home. The most commonly spoken languages were: Italian (1.7%), Greek (1.1%), Spanish (1.0%), Arabic (0.8%) and Cantonese (0.7%).

Region

More than half (54.3%) of respondents lived in Sydney and surrounding areas. The percentage of carers living in various regions of NSW is depicted in Figure 2.

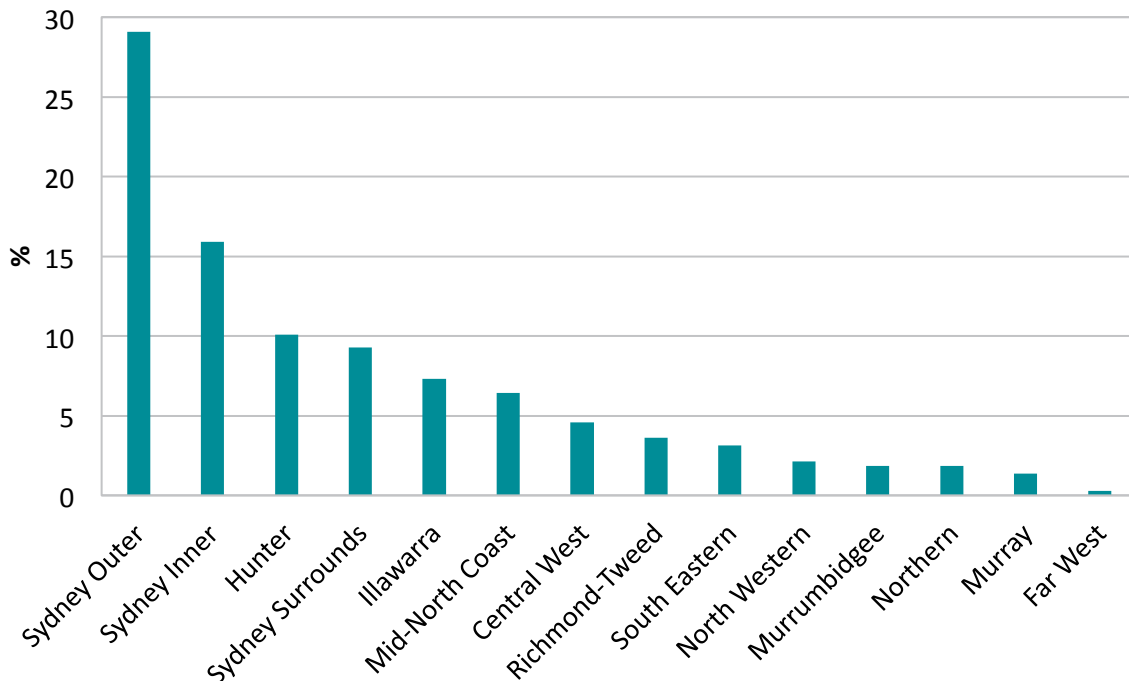


Figure 2. Percentage of carers living in geographical regions of NSW

Finances and housing

A significant proportion of survey respondents declined to disclose their personal or household income (20.4% and 24.5% respectively). The weekly personal incomes of those who did respond are shown in Figure 3, alongside comparative Census data reflecting the personal incomes of the general NSW population (ABS, 2011).

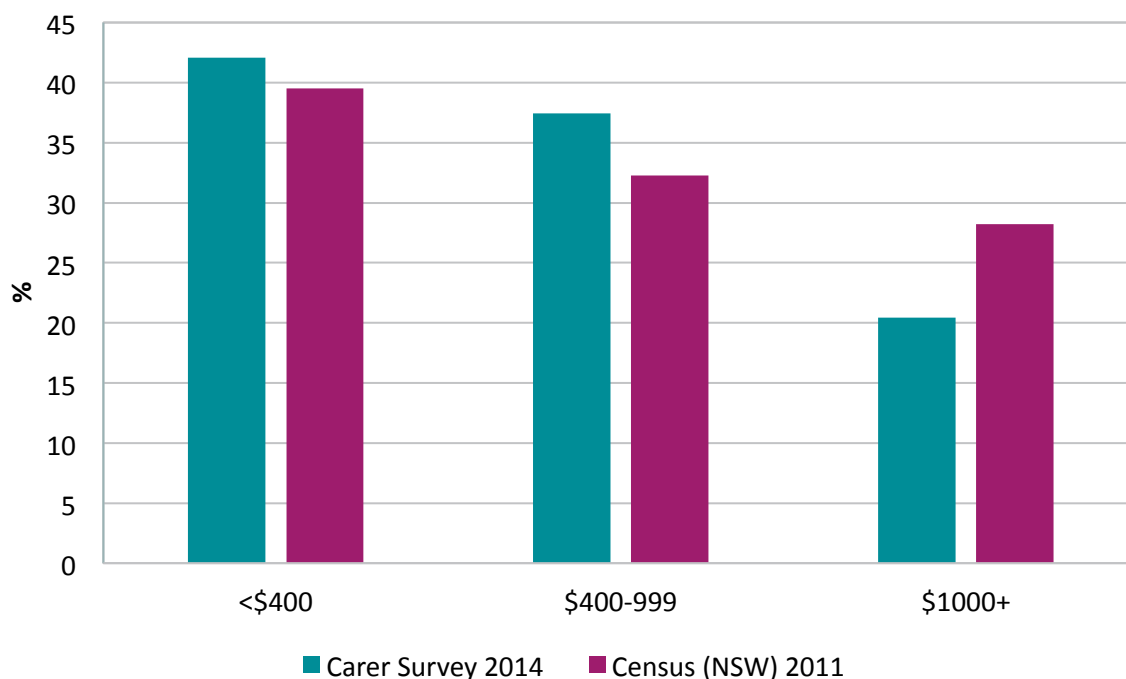


Figure 3. Weekly personal incomes of carers compared to general NSW population

Over 70% of respondents reported owning their own home, either with a mortgage (30.5%) or without (41.1%). An additional 10.8% were renting their homes, 7.2% were living in a home that belonged to a family member, and 4.5% lived in Public Housing.

Carers NSW membership

Approximately half of the total sample (49.2%) reported being members of Carers NSW. The demographic differences between members and non-members are shown in Table 2.

Table 2. Demographic differences between Carers NSW members and non-members

	Members (n=829)	Non-members (n=811)
Average age	58.7 years	53.0 years
Care for:		
Parent	17.1%	24.9%
Spouse/partner	34.4%	28.7%
Son/daughter	50.4%	46.0%
Living with care recipient	83.2%	74.5%
Completed bachelor degree or higher	25.2%	37.1%
Employed:		
Full time	20.8%	48.9%



Members were more likely than non-members to report that nobody else helped care for care recipients (47.7% vs. 37.6%) and were more likely to say there was nobody who could help if they needed a break or were ill (35.6% vs. 25.7%). This comparative lack of informal support networks may be a significant contributor to carers becoming members, as it could represent a known source of personal support.

A larger proportion of members than non-members had been caring for longer than 10 years, and this discrepancy was accentuated amongst those caring for more than 20 years, as shown by Figure 4.

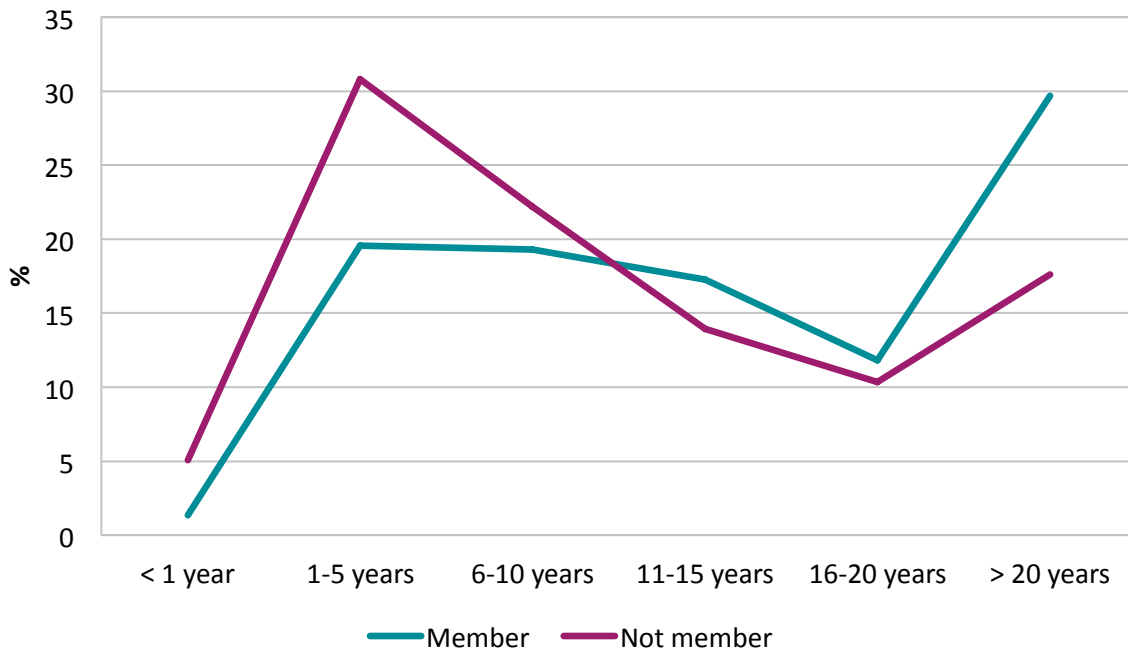


Figure 4. Length of time as a carer by membership status

Summary and implications

- The present sample is not representative of all carers in New South Wales – particularly in terms of gender, age, employment, education, and primary carer status. All survey results should be interpreted cautiously in light of this limitation.
- Future surveys and research should increase efforts to target male carers, non-primary carers, and young carers.
- More than one in four carers reported caring for multiple people, indicating the potential complexities that may exist across individual caring situations.
- Significant demographic differences existed between Carers NSW members and non-members. Membership promotion could target underrepresented groups – namely, younger carers, non-spousal carers, working carers, and those who have been caring for less than five years.

The person you care for

The 1,684 carers who completed the survey indicated that they were caring for a combined total of 2,203 people. 55.2% of care recipients were male and 42.4% were female. Care recipients' ages ranged from 1 to 101 years old (M=46.6 years). The distribution of care recipient age is shown in Figure 5.

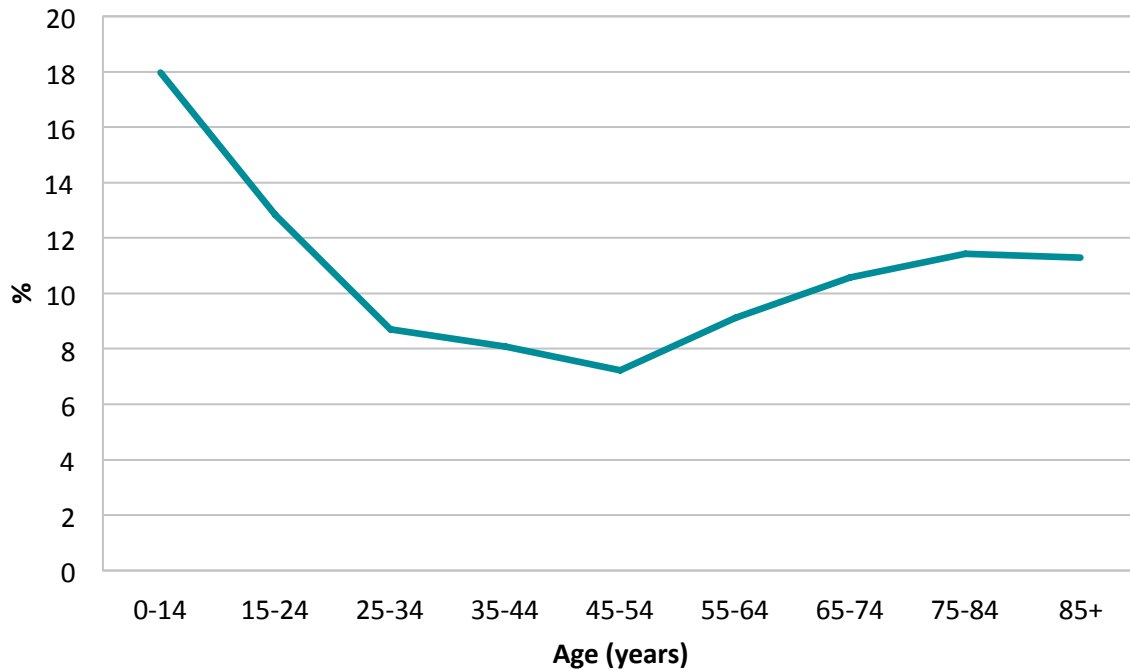


Figure 5. Care recipient age distribution

Care recipients were most commonly the carers' sons/daughters (44.1%), followed by spouses/partners (24.0%) and parents (17.6%), as illustrated by Figure 6.



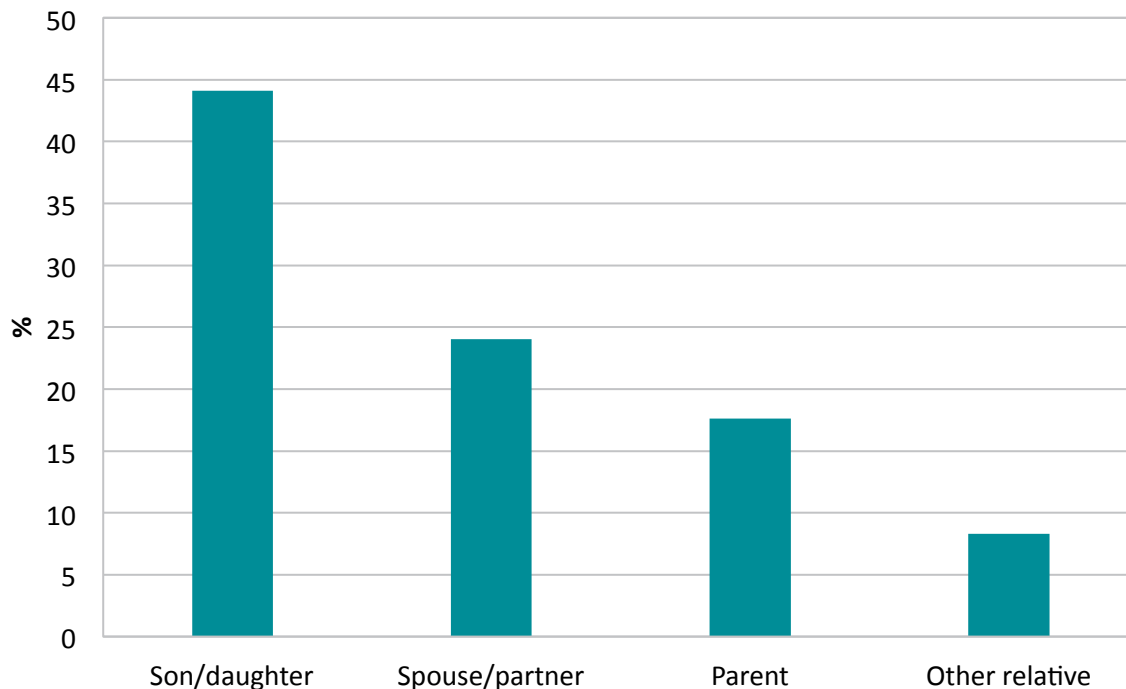


Figure 6. Relationship of care recipient to carer

Carers were asked to identify the conditions/disabilities/illnesses for which care recipients needed their care. The extensive range of responses was broadly categorised into the following:

- Disability (44.0% of care recipients)
- Health/medical/chronic condition (36.5%)
- Mental health (27.1%)
- Aged/frail (13.8%)
- Dementia (12.4%)

A substantial number of care recipients fit into more than one category, due to carers reporting multiple conditions for which they required care. An additional 5.7% could not be categorised, due to missing data or insufficient information being provided.

A significant majority of care recipients (71.3%) were reported to be living with their carers. An additional 16.9% were living in their own homes.

While carers reported that 71.1% of care recipients could care for themselves if left alone for less than one hour, only 19.6% could be left alone for a few days (Figure 7).

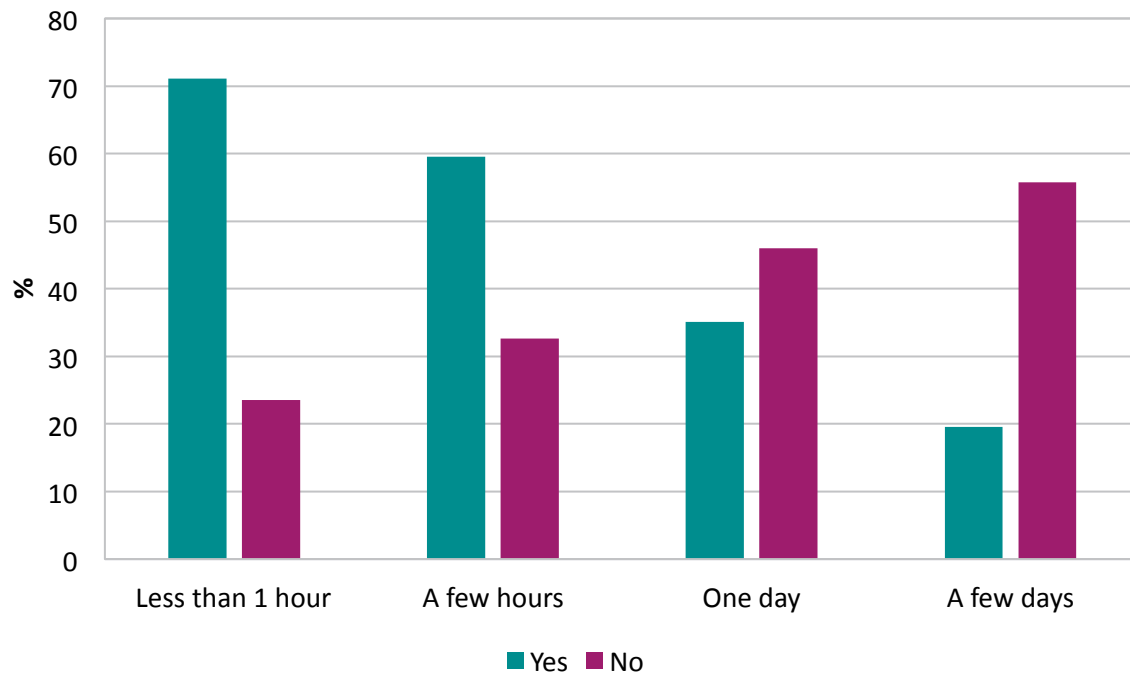


Figure 7. Length of time care recipients could take care of themselves if left alone

N.B. Categories do not add up to 100% due to missing data

Summary and implications

- Children were the most highly represented care recipients, followed by the elderly. Accordingly, there was an overrepresentation of carers who were caring for their son/daughter. Future surveys should look to increase response rates amongst spousal carers.
- Disability was the most common reason for needing care, while ageing and dementia were the least commonly reported. Further analysis is warranted in categorising and comparing different conditions/diagnoses.
- A majority of care recipients could be left alone for a few hours, but not for one day. Further analysis is warranted to investigate caring experiences as the level of required care varies.
- This is the most comprehensive picture of caring situations that the Carers NSW Carer Survey has collected to date, which will enable future analysis to investigate needs and concerns across specific caring contexts.



Caring situations

Reasons for caring

Carers were asked to indicate reasons why they started caring for each care recipient. The most commonly selected response was “I wanted to”, selected in 55.2% of caring relationships. Other common answers included:

- “I felt that caring was the responsibility of a family member” (50.0%)
- “I felt an emotional obligation” (40.8%)
- “I felt I could provide better care than someone else” (26.8%)
- “I had no other choice” (26.6%)

Help in caring

In relation to 43.1% of care recipients, carers indicated that nobody else helped care for them. In addition, carers were asked if there was anyone else who could help if they were ill or needed a break. In 32.2% of cases, carers reported that there was no one, with a further 42.6% believing they would have difficulty finding someone and 20.9% indicating they could find someone easily.

Length of caring roles

Carers were asked how long they had been caring for each person. Respondents reported a wide range of caring experience, with 20.0% of caring relationships lasting over 20 years (Figure 8).

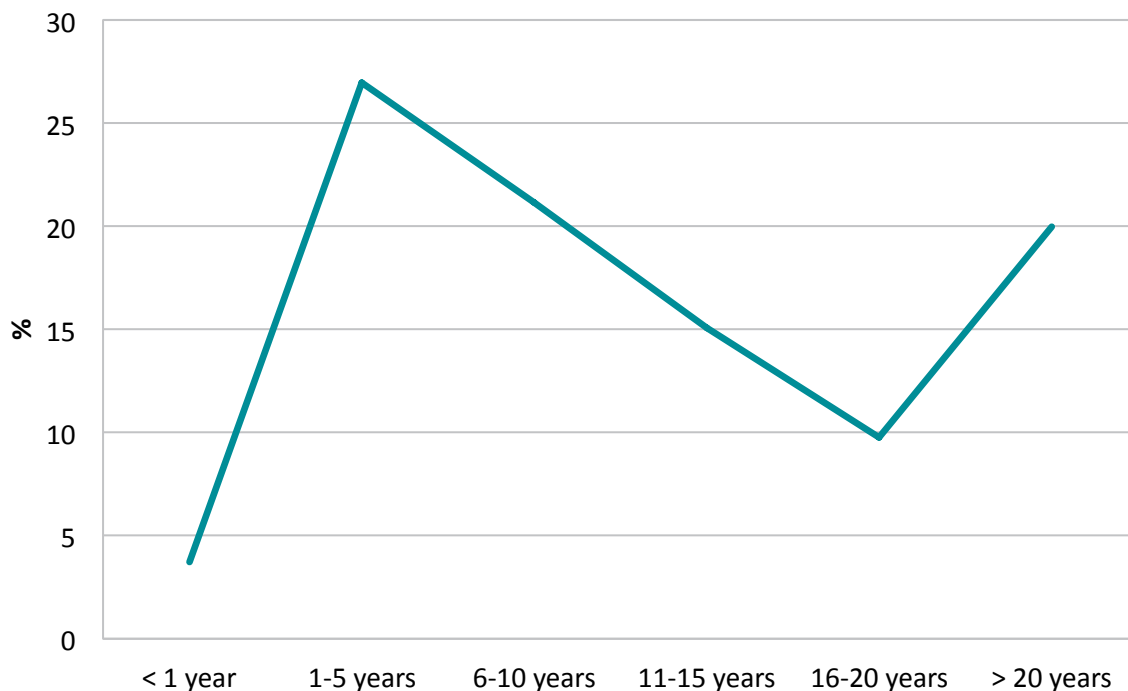


Figure 8. Length of caring roles

Those who were caring for a parent were more likely to have been caring for shorter periods of time, whereas those caring for a son/daughter were most likely to have been doing so for over 15 years, as shown by Figure 9.

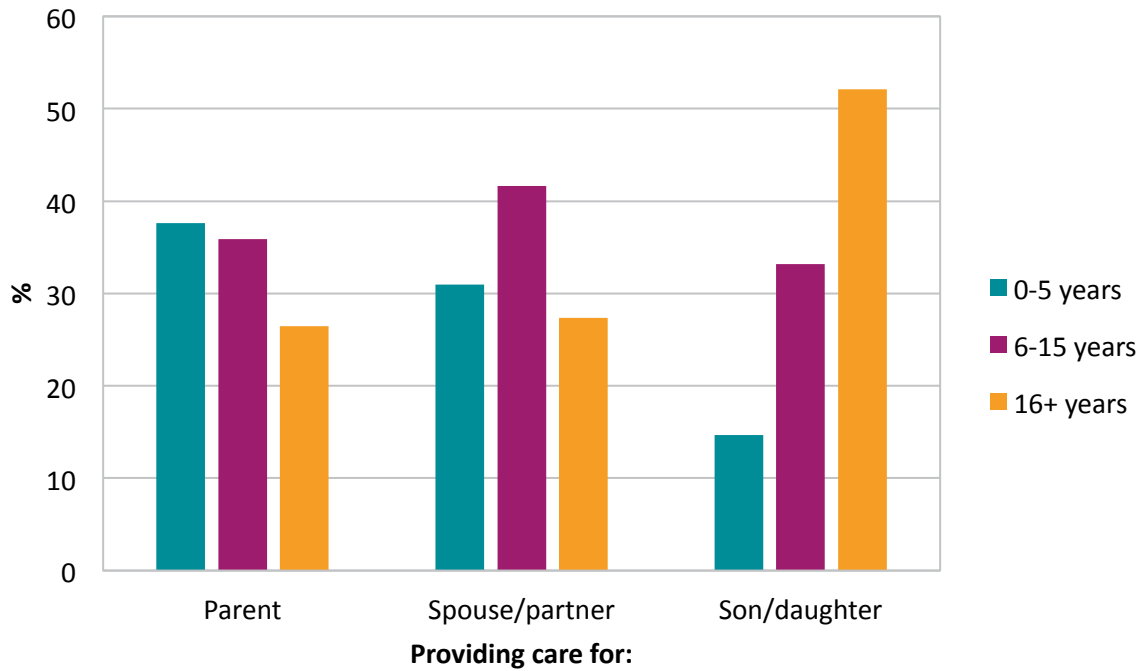


Figure 9. Length of caring role by relationship

The proportion of carers who indicated they had experienced a long-term illness or disability themselves within the past 12 months increased with time in a caring role, as illustrated by Figure 10.

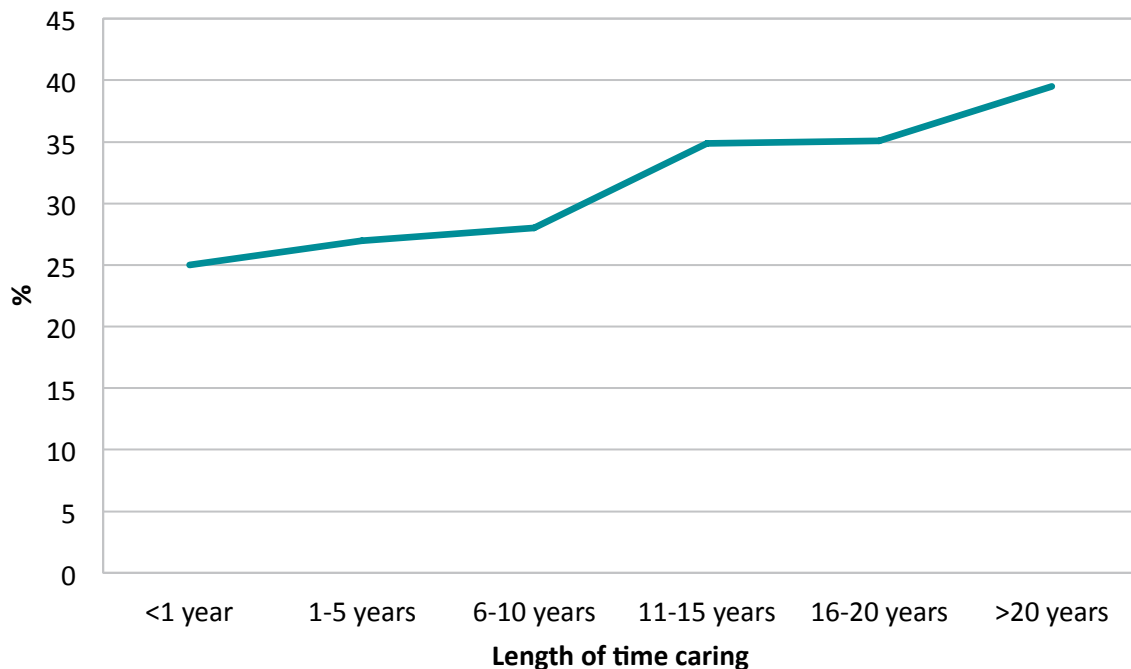


Figure 10. Prevalence of carer long-term illness/disability



Carers who have been in their role for longer are generally older than those who have not been caring for as long. It may therefore be expected that rates of illness/disability increase due to ageing related issues. However, the correlation between an increasing prevalence of illness/disability and length of caring role was much greater than it was with carers' age.

Hours of care per week

Carers were also asked how many hours per week they spent caring for each person (on average). Notably, the most common response by far was more than 70 hours per week (27.0%) and an additional 19.9% reported that their caring demands varied significantly or that it was hard to determine (see Figure 11).

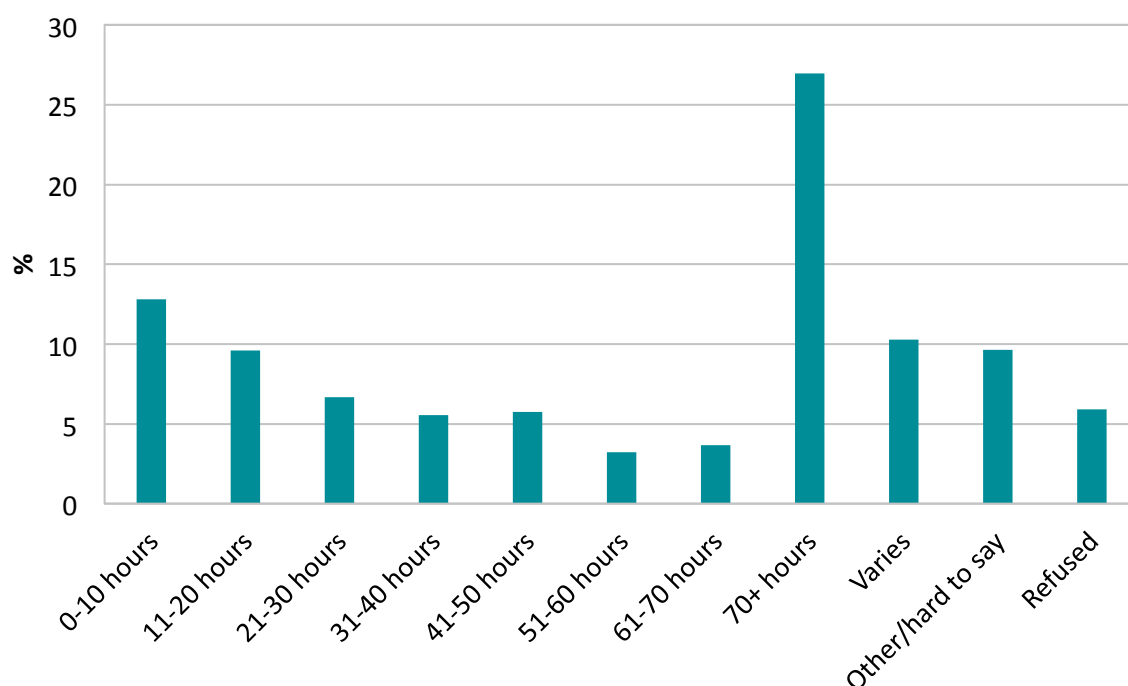


Figure 11. Hours per week spent caring for care recipients

Those who had been caring the longest generally provided the most care per week – 37.2% of those who had been caring for over five years spent over 70 hours per week caring, compared to 28.5% of those caring for less than five years.

Summary and implications

- Carers' reasons for caring were generally framed positively – more than twice as many wanted to than felt they had no choice.
- Significant proportions reported that they received no help from others or would not be able to find help if they needed a break.
- Caring for a son/daughter was the most long-term caring situation. Future research is warranted to longitudinally investigate the implications of these caring relationships over time.
- The prevalence of long-term disability or illness amongst carers increased with the length of time they had been caring, even more so than with their increasing age. This provides further evidence regarding the cumulative toll of care on people's health and wellbeing.
- More than one in four caring relationships involved more than 70 hours of care per week. This sample is therefore possibly skewed to over represent those with more extensive caring demands. Nevertheless, this raises the importance of recognising those carers whose time commitments extend beyond current conceptualisations.
- Those who have been caring for longer were more likely to report more hours of care per week. Additional detailed analysis is warranted to investigate this relationship and any impacts on carers' wellbeing over time.



Health and wellbeing

Carers' health and wellbeing were measured using a number of different validated scales that have been widely used in previous research in Australian and international contexts. For the purpose of creating results that can be easily compared, scores on each of these scales have been converted into a score out of 100 (referred to as "percentage of scale maximum", %SM).

Carers of Older People in Europe (COPE) Index

While initially developed for use with carers of older people in Europe, the COPE Index is contextually relevant to broader caring situations. Responses to this scale provide scores on three subscales:

- Negative impact of caring
- Positive value of caring
- Quality of support

Survey respondents' mean scores on each of these subscales are shown in Figure 12.

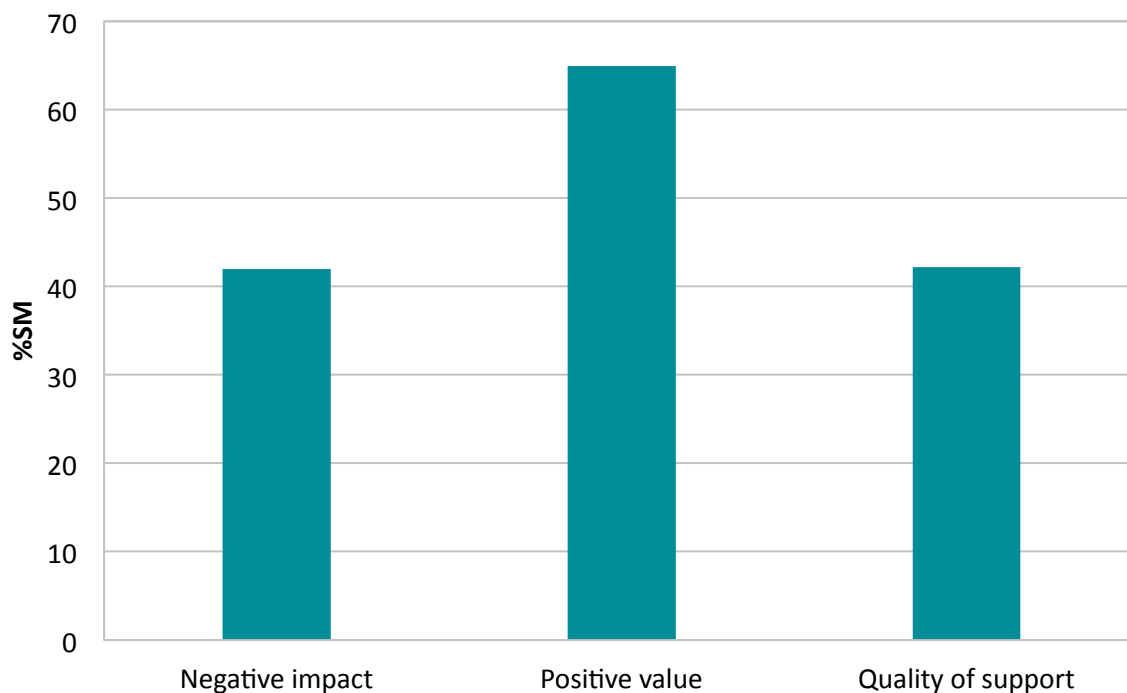


Figure 12. Mean COPE Index subscale scores

This figure indicates that carers tended to report more positive value from their caring roles than negative impacts. Positive value was highest amongst carers who:

- Were aged over 75 years
- Were male
- Had completed high school or lower education
- Were unemployed

The negative impact of caring was greatest amongst those who:

- Provided more than 70 hours of care per week
- Were aged between 45-54 years
- Were from a CALD background
- Had been caring for over 15 years

Carers who had experienced a serious illness or disability themselves in the previous 12 months reported poorer outcomes on all three subscales than carers without an illness/disability, as shown in Figure 13.

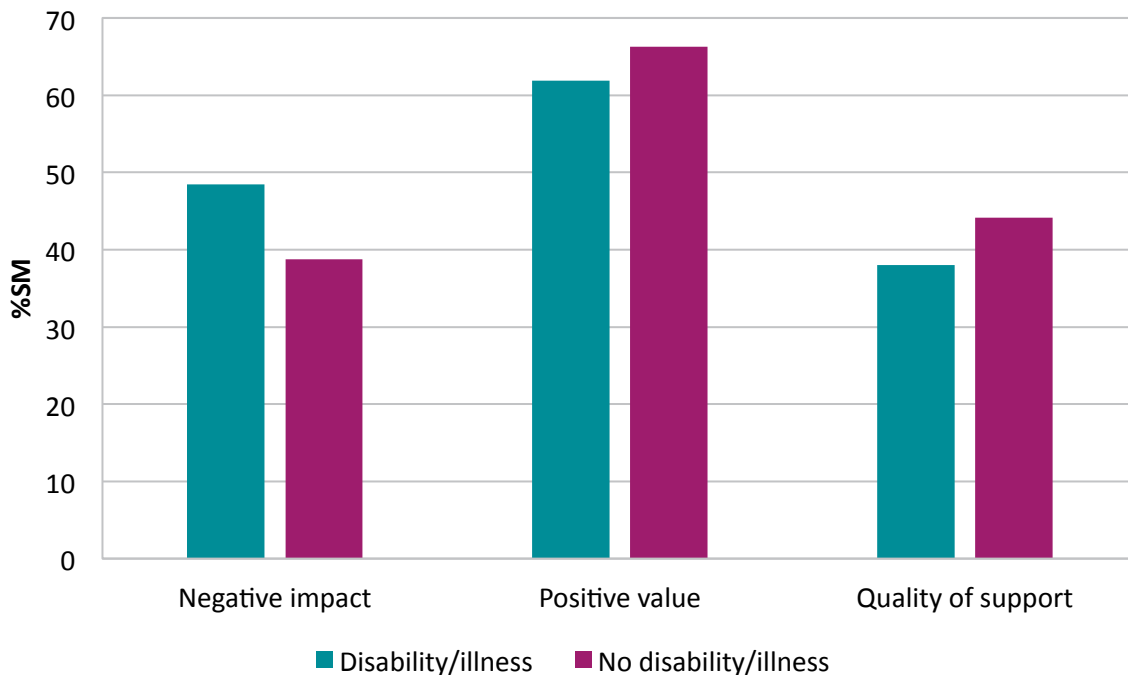


Figure 13. Mean COPE Index subscale scores by carer disability/illness status

Positive Aspects of Caregiving scale

Participants were asked the extent to which they agreed with a range of statements regarding possible positive aspects of their caring roles, e.g., “caring has made me feel more useful”, “caring has enabled me to learn new skills”. Reflective of responses on the COPE Index, 44.2% of responses indicated agreement with these statements, compared to 22.6% indicating disagreement.

The following differences between sub-groups of carers were evident in relation to their agreement with these positive aspects of caring:

- Male carers reported more positive aspects of caring than females
- CALD carers reported more positive aspects of caring than those who did not identify as being from a CALD background
- Carers experiencing a serious illness or disability reported significantly fewer positive aspects of caring than those without an illness or disability



Mean scores on the Positive Aspects of Caregiving scale declined with increasing age until carers reached 65 years, at which point mean scores increased with further ageing (Figure 14).

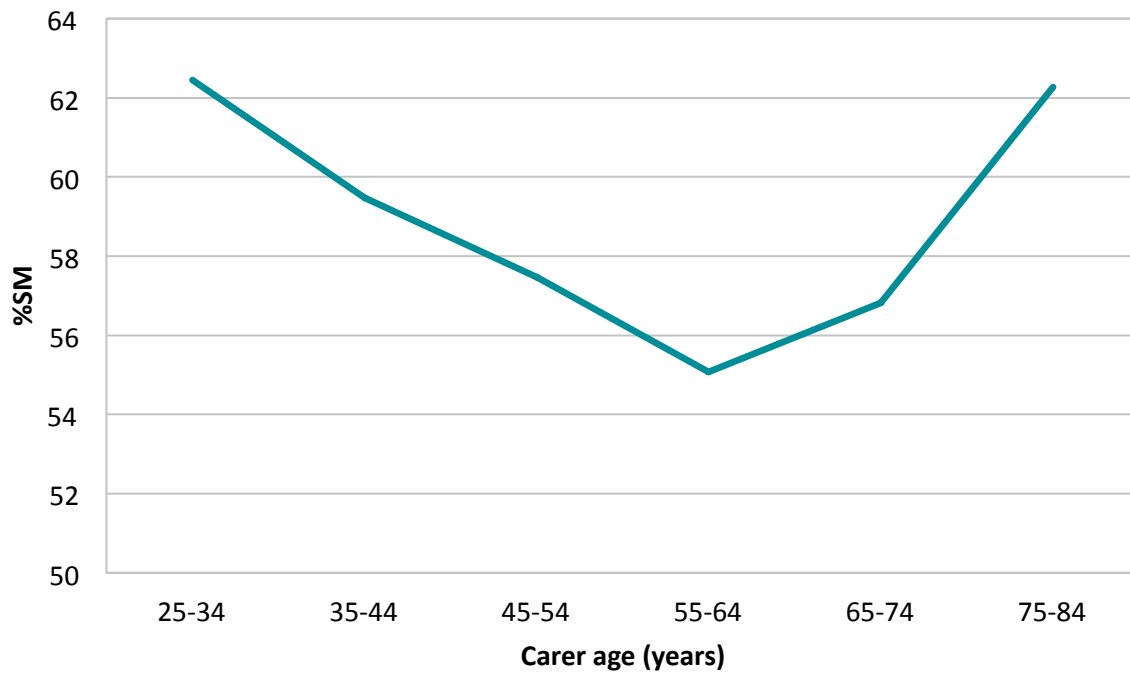


Figure 14. Mean Positive Aspects of Caregiving scores by carer age

N.B. The 16-24 years and 85+ years age groups have been omitted from this graph due to low sample size

Personal Wellbeing Index

The Personal Wellbeing Index (PWI) measures satisfaction with a range of life domains, which can either be assessed individually or collectively as an overall indication of personal wellbeing. The PWI has been used a variety of contexts, perhaps most notably to investigate the wellbeing of carers in Australia (Cummins et al., 2007). In their study, Cummins and colleagues (2007) found that carers reported the lowest wellbeing of any population group studied thus far. These findings are presented alongside the mean PWI score of carers in the Carers NSW 2014 Carer Survey in Figure 15.

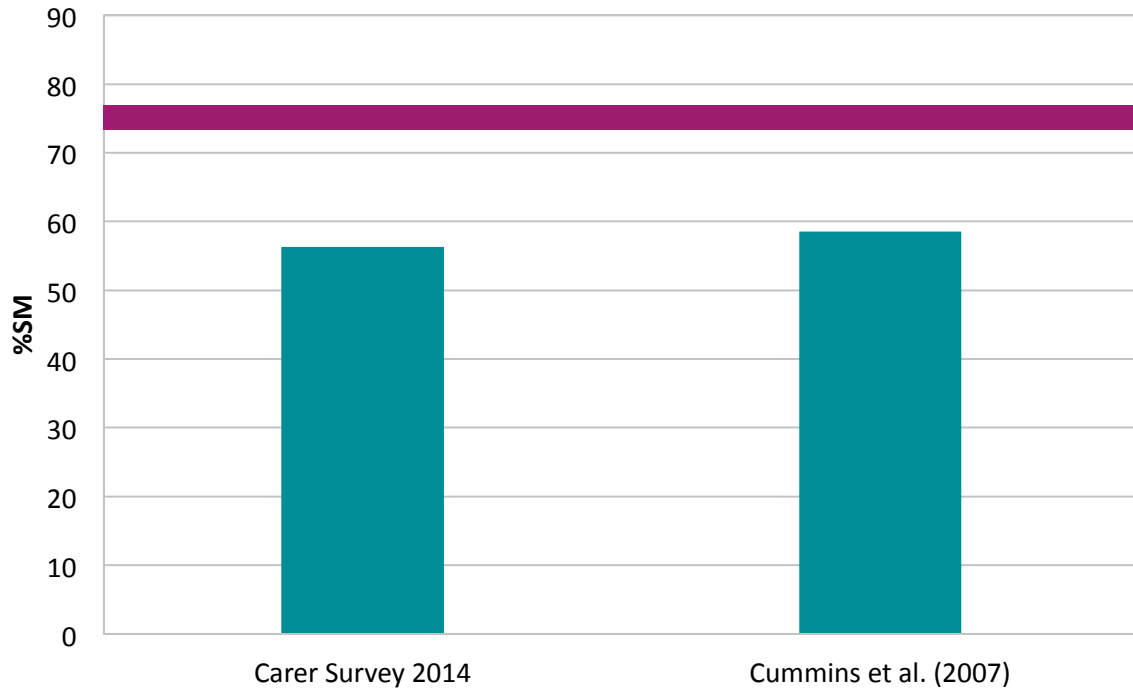


Figure 15. Mean PWI score compared to previous carer and Australian normative data
 N.B. The red bar indicates the normal range reported by the general Australian population (73.8-76.7%SM) (Cummins et al., 2013)

Across the domains measured by the PWI, carers were most satisfied with how safe they felt and least satisfied with their future security. The mean scores across each of the domains are shown in Figure 16

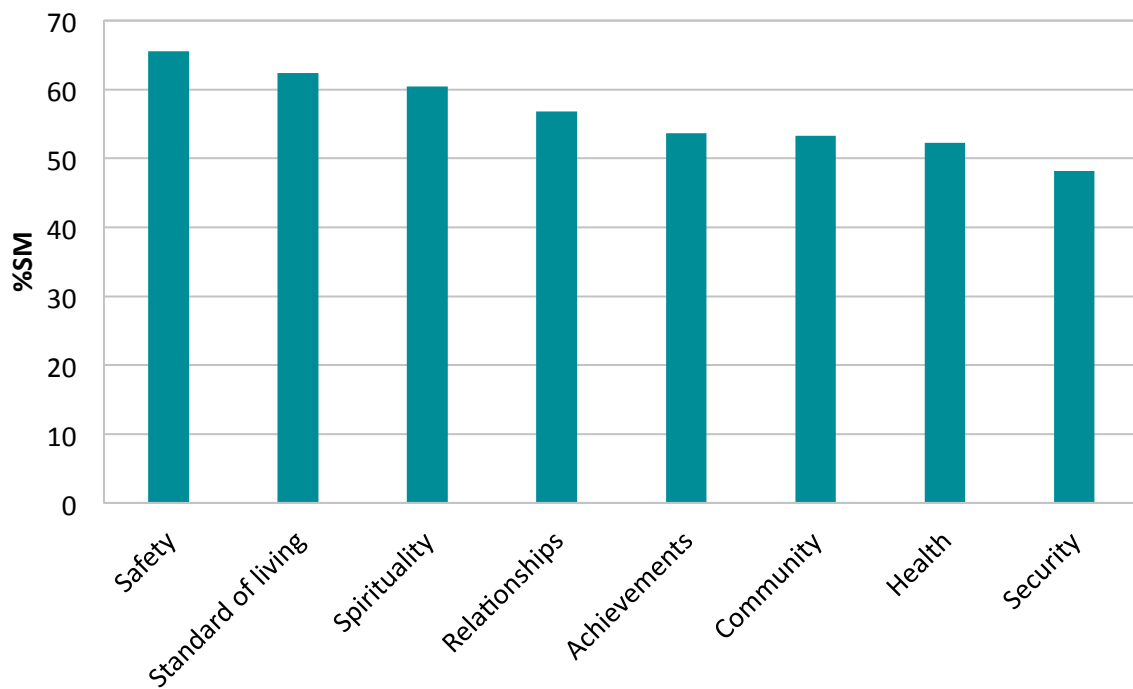


Figure 16. Mean scores across individual PWI domains

The following differences in mean PWI scores between subgroups of carers were apparent:

- Wellbeing was significantly higher amongst carers with weekly personal incomes of \$1000 or more than those with lower incomes
- Wellbeing was significantly higher amongst those who had been caring for less than five years than those who had been caring for longer
- Carers who had experienced a disability or serious illness themselves reported the lowest PWI scores, significantly lower than those without an illness or disability

Mean PWI scores also decreased as the amount of care provided per week increased, as illustrated by Figure 17.

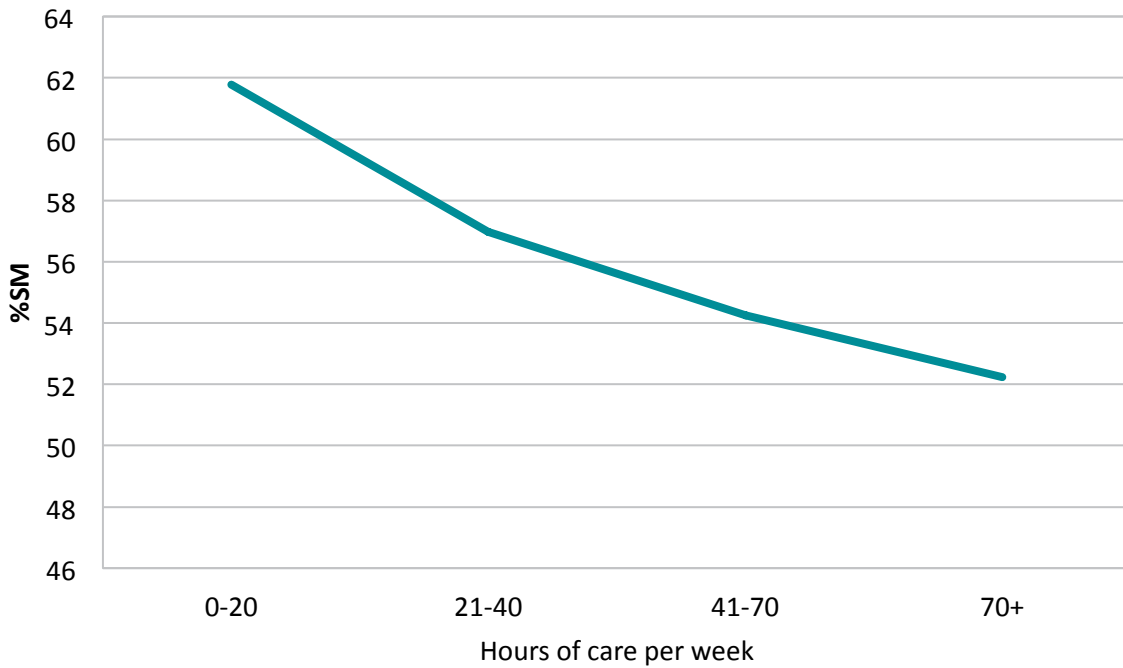


Figure 17. Mean PWI score by hours of care per week

PWI scores demonstrated a gradual increase amongst older carers, as illustrated by Figure 18.

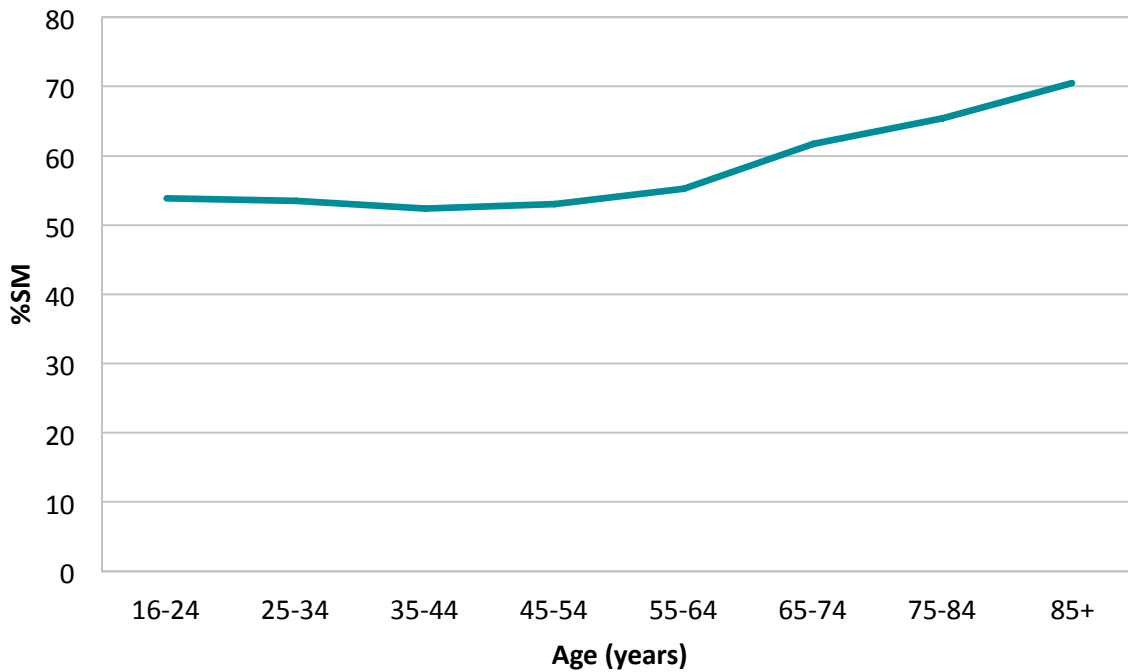


Figure 18. Mean PWI score by carer age

Psychological distress

Psychological distress was measured using the K10 (Kessler et al., 2003), which has been used in a multitude of previous research, including ABS Health Surveys. Scores on the K10 are categorised to indicate low, moderate, high, or very high levels of psychological distress. Carers' responses from this survey are compared to ABS (2012b) normative data in Figure 19.

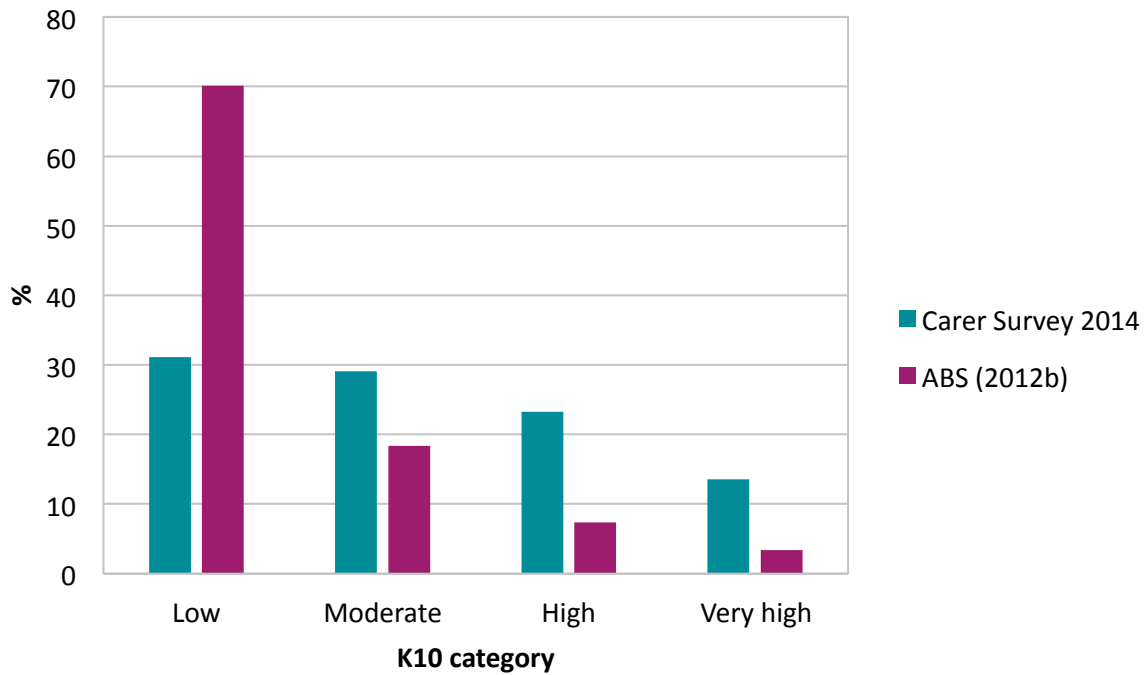


Figure 19. Carers K10 categories compared to normative Australian data

The following sub-group differences in mean K10 scores were found:

- Carers who had experienced a long-term illness or disability reported higher distress than those without an illness or disability
- Those from CALD backgrounds reported higher levels of psychological distress than those who did not identify with CALD backgrounds
- Female carers reported higher levels of psychological distress than male carers

Carers who provided less than 20 hours of care per week reported lower psychological distress levels than those caring for more hours, with distress levels remaining relatively stable amongst those caring for more than 40 hours per week, as illustrated by Figure 20.

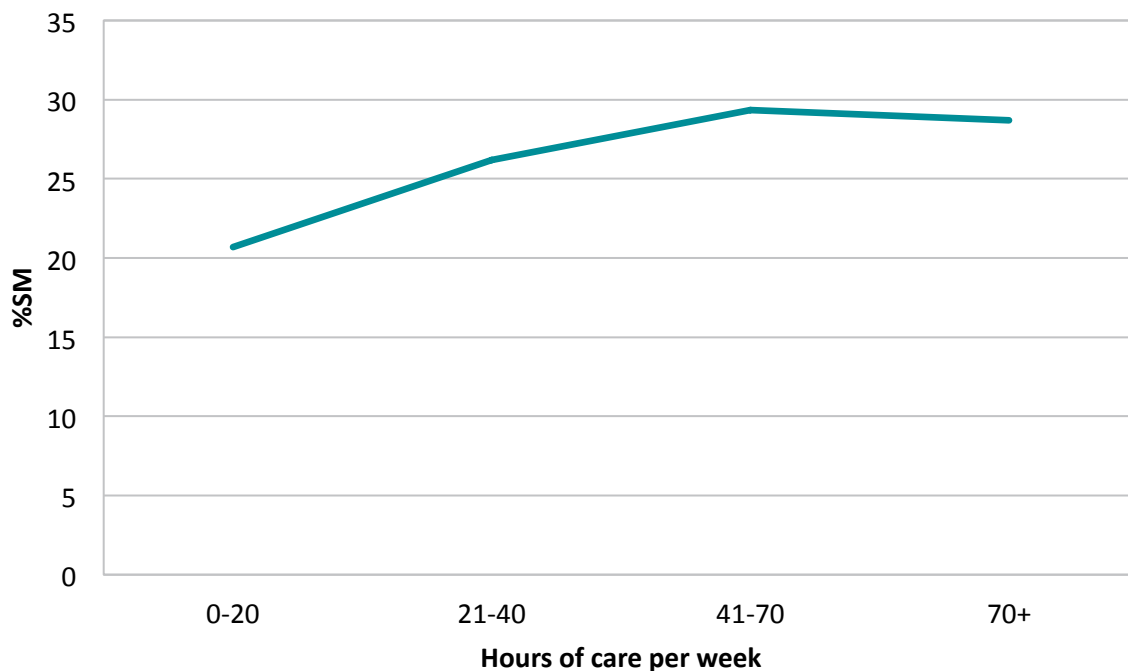


Figure 20. Mean K10 scores by hours of care per week

In keeping with the gradual increase in wellbeing with age, psychological distress gradually decreased with increasing carer age, as illustrated by Figure 21.

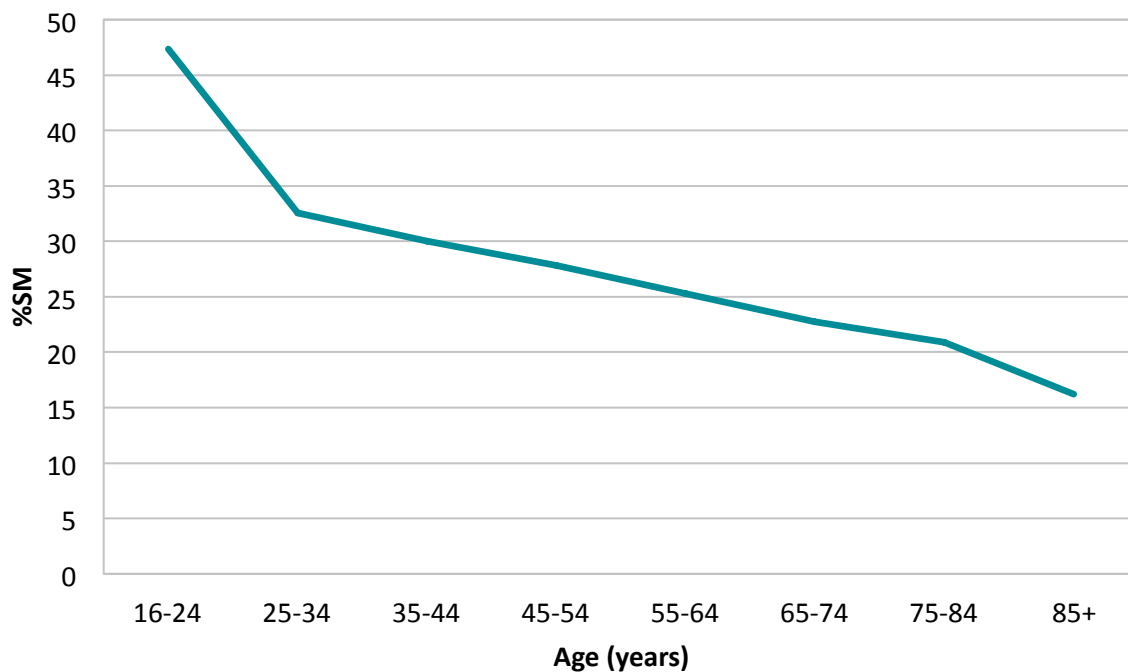


Figure 21. Mean K10 scores by carer age



Carer recognition

The recognition of carers was investigated through three questions that reflected aspects of the NSW Carers Charter. Participants indicated the extent to which they agreed with the following statements (outlined in Figure 22):

- Your individual needs and interests beyond being a carer have been acknowledged
- The contribution that carers make has been recognised by the wider community
- Your health/wellbeing has been considered by services that support the person(s) you care for

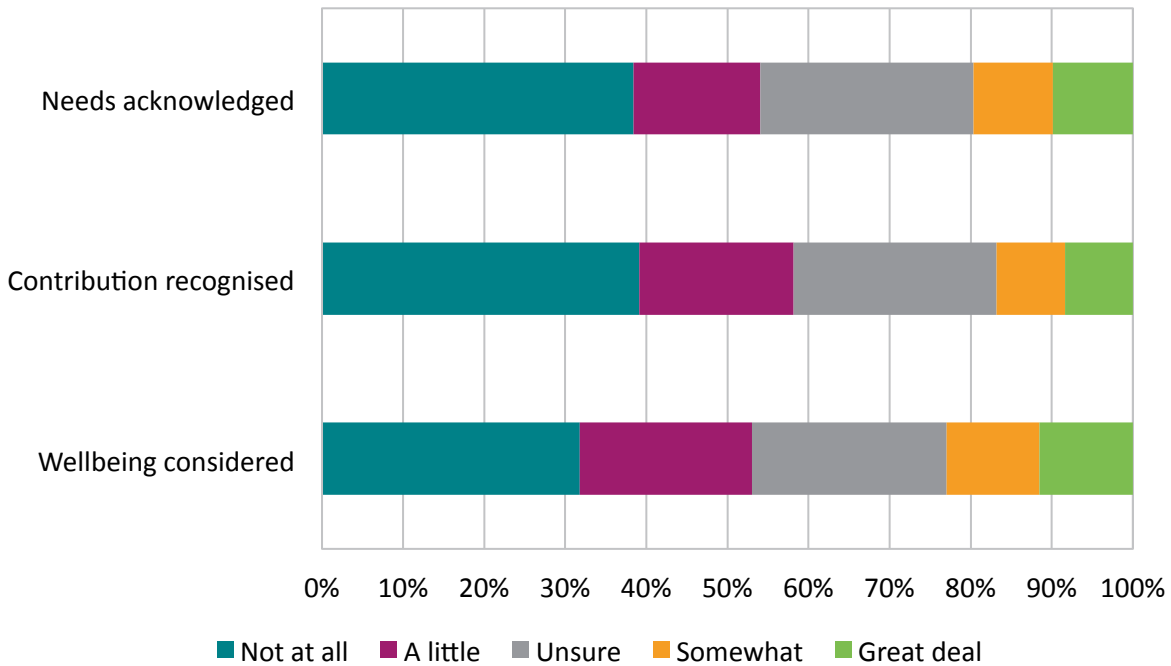


Figure 22. Carers' level of agreement with indicators of recognition

In addition, carers were asked if they had heard of the NSW *Carers (Recognition) Act 2010*, the NSW Carers Charter, or the NSW Carers Advisory Council.

Carers NSW members were significantly more likely to have heard of each of these, with 42.9% having heard of the NSW Carers Advisory Council (vs. 26.0% of non-members), 42.9% having heard of the NSW *Carers (Recognition) Act* (vs. 18.6% of non-members), and 30.3% having heard of the NSW Carers Charter (vs. 15.5% of non-members).

Summary and implications

- In line with previous research, wellbeing of carers in this sample was poor compared to normative Australian data.
- Despite reporting low wellbeing on average, the positive value of caring was consistently greater than the negative impacts.
- Carers with a long-term illness or disability reported lower wellbeing across all measures than those without an illness or disability.
- Wellbeing was also lower amongst those who had been caring for longer and provided more hours of care per week.
- Additional analysis and further research is necessary to investigate relationships between these variables.
- Male carers and older carers in this sample generally reported better wellbeing than their female and younger counterparts. Further research and detailed analysis is required to investigate why this is the case.
- Perceived recognition and acknowledgment of carers by services and the wider community was low, indicating a need for continued advocacy to increase awareness.
- Carers NSW members were more aware of carer legislation than non-members, suggesting the usefulness and importance of organisational communication strategies.



Carers' employment

As mentioned in Table 1, 42.8% of current carers reported being in paid employment, while 57.0% were not. When compared to those who were not employed, working carers were more likely to have completed a bachelor degree or higher (44.0% vs. 20.9%), and were less likely to have experienced a serious illness or disability themselves (25.1% vs. 37.5%).

Working carers were also more likely to be caring for a parent or son/daughter and less likely to be caring for a partner, as illustrated in Figure 23.

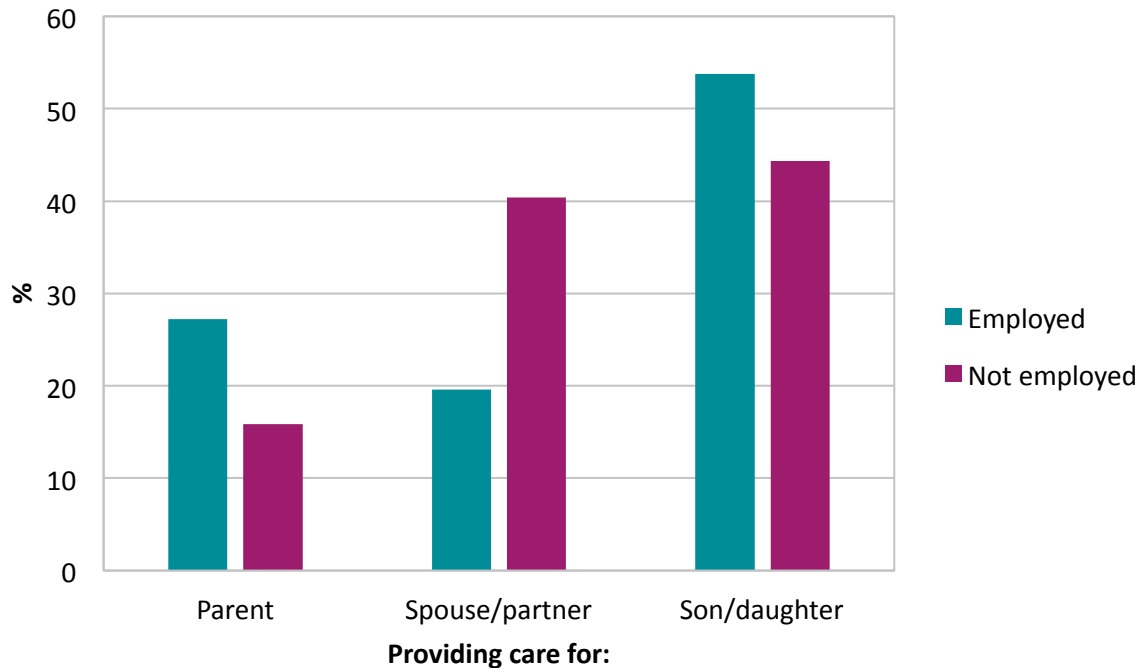


Figure 23. Relationship of care recipient by carer employment status

Unemployed carers

Amongst those who were not working, 9.2% indicated that they were looking for work and 53.8% were retired. Notably, 52.0% reported that they stopped working because of their caring responsibilities. These carers were younger on average (M=56.0 years) than those who stopped work for other reasons (M=64.9 years). They were also more likely to have multiple caring roles (29.5% vs. 18.2%), and spent more hours per week caring – 52.1% reported 70 or more hours per week (compared to 29.4% of carers who stopped working for other reasons). Importantly, carers who stopped work because of caring responsibilities reported significantly worse wellbeing across every measure used in this survey.

Working carers

Amongst working carers, 38.8% were employed in full time positions and 41.0% were employed part time. A further 12.4% held casual employment and 10.0% were self-employed. Male working carers were more likely to have full time employment (75.8%) than females (45.1%). Full time

employees were more likely than part time employees to have been caring for less than five years (39.4% vs. 26.8%) and to be providing less than 20 hours of care per week (42.3% vs. 22.0%).

Part time employees were more likely to be caring for their son/daughter, while full time employees were more likely to be caring for a parent, as shown by Figure 24.

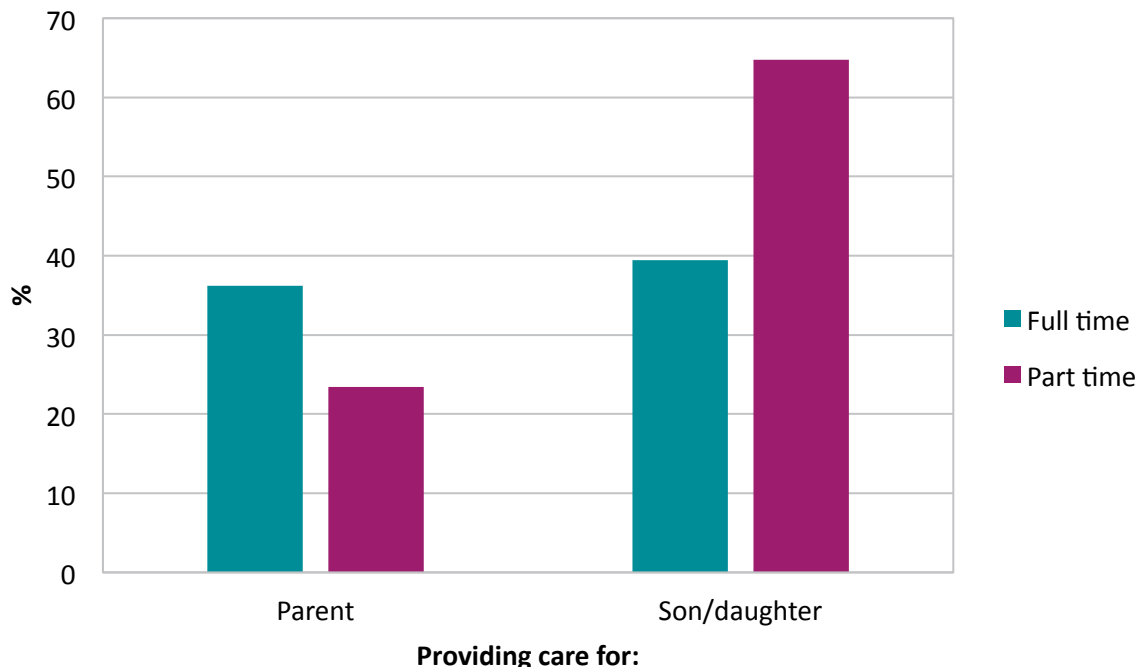


Figure 24. Relationship of care recipient by carer employment status

Carers were asked in which industry they worked. Four industries (out of 11 listed) accounted for the majority of working carers in this survey:

1. Health care (30.0% of working carers)
2. Government and public sector (20.1%)
3. Community and non-profit (16.0%)
4. Education and training (15.6%)

Additional analysis and further research is required to determine if carers are more likely to work in these industries due to their suitability for balancing work and caring responsibilities. Alternatively, the higher representations of these industries may be a function of the recruitment and advertising networks utilised for this survey.

Workplace supports

This section also investigated the extent to which carers were supported by their workplaces to combine work and care. A vast majority of working carers (84.7%) indicated that their employer knew about their caring responsibilities. Similarly, 76.7% reported feeling comfortable telling others in the workplace about their caring responsibilities, and 76.4% felt that their workplace supported them to combine work and care. Carers working in the education and training sector were most likely to report feeling comfortable telling others in the workplace about their caring responsibilities (82.1%), while those working in the community and non-profit sector were most likely to feel that their workplace supported them to combine work and care (84.3%). More part



time employees than full time employees reported that their employers knew about their caring responsibilities (90.2% vs. 83.9%), that they felt comfortable telling others in the workplace (81.0% vs. 75.3%) and that their workplace supported them to combine work and care (83.1% vs. 73.8%). Carers with weekly incomes greater than \$1000 were more likely to be comfortable telling others in the workplace about their caring responsibilities (79.0%) than those with weekly incomes of \$400-999 (77.9%) or less than \$400 (75.2%).

The availability of specific supportive workplace practices was also investigated, with working carers asked to indicate which were available to them and which they had used (Figure 25).

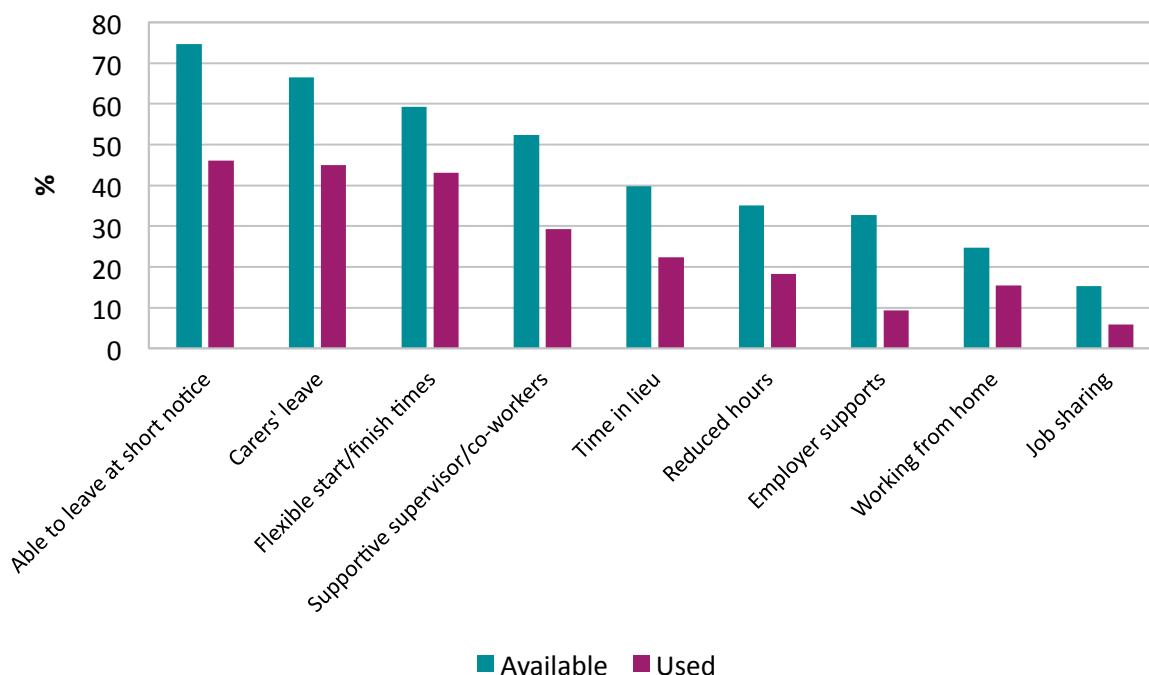


Figure 25. Availability and usage of workplace practices

It is likely that these figures are an underrepresentation of the true availability of these supports. These practices may be available to some working carers who are not aware of them. The number of carers who had used each of these practices was consistently much lower than those who indicated they were available, however, reasons for not utilising workplace practices were not investigated in this survey. Carers may have not felt they needed or wanted to use them, or may have felt that accessing supports such as these could harm their career prospects or workplace relationships.

Impacts of care on work

Nearly half of the working carers responding to this survey (47.8%) reported that they had reduced the amount they work because of their caring responsibilities. 32.3% reported refusing a new job or promotion due to the difficulties it would have meant in their caring roles and 25.1% had changed jobs to fit in with caring responsibilities. Similarly, 34.6% reported that changing work arrangements to better fit with caring had resulted in them working in a lower level job or interrupting career progression.

The potential for carers to experience conflict between work and caring roles was illustrated by the 33.8% of working carers who indicated that they would like to work less but could not afford to. Furthermore, 28.3% wanted to work more but were unable to because of their caring responsibilities. Alongside these results, 23.1% of working carers reported being happy with the amount they were currently working.

Carers were also invited to make comments about their experiences at work. Many of these comments reflected the findings outlined throughout this section, including both positive and negative experiences, and explaining some of the conflicts and struggles they experienced in attempting to manage both roles:

I work for myself cleaning as it allows me to work around my caring responsibilities. It is a job that does not reflect my experience and knowledge. I do it for the money. Money to pay for the therapy the people I care for need.

Very stressful experience managing being a carer and being in the workforce. Especially from a guilt point of view.

My employer is exceptional - I think I am one of the lucky ones.

I requested to reduce my hours to part-time. My boss refused... I find this very unfair, and it makes me angry when I think about it.

While an employer may have policies in place, in practice actually utilising the leave available may be contested.

My workplace have been very supportive of my caring role. I asked work for a reduction in working hours (one and a half hours less per day) and it has made a huge impact on my life and my caring role... If only we could educate all workplaces on flexibility for carers!



Summary and implications

- Amongst unemployed carers, more than half stopped working to care. Significantly, these carers reported poorer wellbeing than those who stopped work for other reasons.
- Amongst working carers, more were in part time positions than in full time positions.
- Part time employees had been caring for longer and provided more hours of care per week than full time employees, suggesting that working carers transition in their working situations over time. This was supported by the number of working carers who reported a reduction in their working hours or career interruptions due to their caring roles.
- Working carers were more likely to report working in certain industries. Further research is warranted to investigate whether these industries allow for working arrangements that are more conducive for balancing work and caring responsibilities, whether this representation is primarily a function of recruitment avenues, or other alternative explanations.
- A majority of working carers indicated that their employers knew about their caring responsibilities. One in four, however, did not feel supported to balance work and care. Continued advocacy is therefore required to transform workplace cultures across industries, particularly for full time employees.
- Uptake of supportive workplace practices was relatively low. Further research is warranted to investigate reasons for this. Additionally, there is a need to increase employees' awareness of those supports that are available to them.
- Working carers appeared to experience conflict in their desire or need to work either more or less in order to balance caring responsibilities, finances and career progression. Further research is warranted to investigate this conflict in more detail and determine practices that may assist carers manage these multiple demands.

Service access and social support

Carers' service use

Carers were asked to indicate any sources of support they had accessed for themselves in their caring role. The two responses that stood out were doctors (used by 87.5% of respondents) and family/friends (86.1%). Other sources of support were accessed by between 12.2-41.1% of carers, as demonstrated by Figure 26.

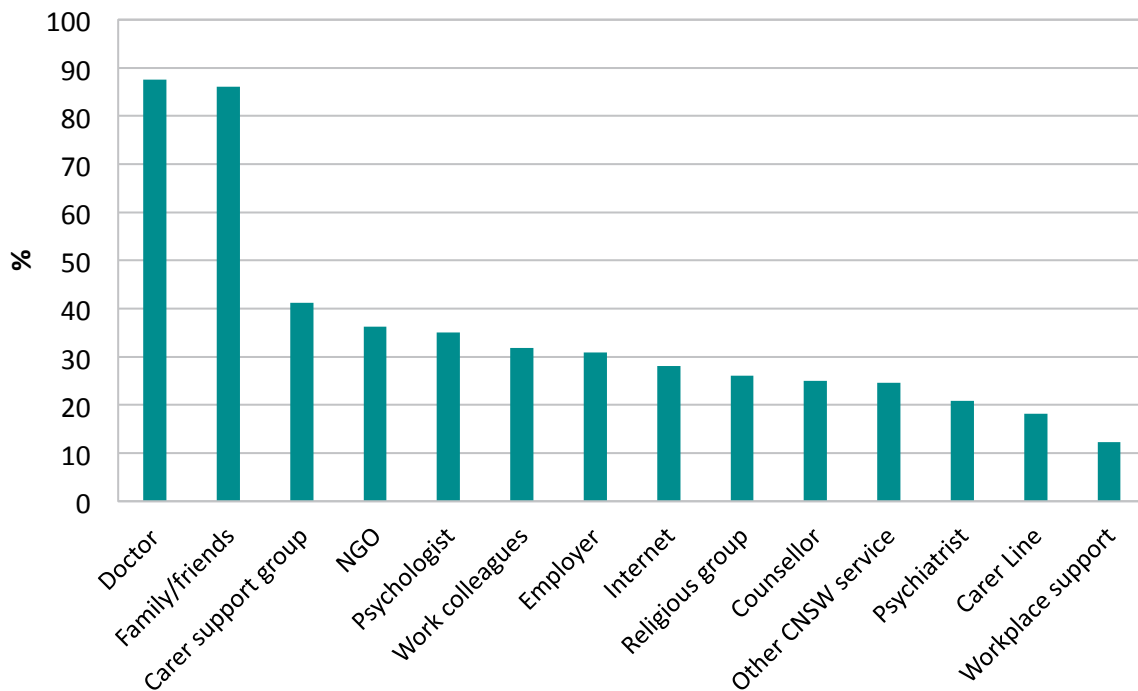


Figure 26. Sources of support used by carers

The usefulness of these supports was rated quite highly, with 78.7% of those accessed being rated as either somewhat or very useful.

Barriers to service use

Participants were also asked to identify any barriers that had prevented them from accessing services or supports. The most commonly selected responses were:

- Cost (37.1% of carers)
- Not knowing what was available (36.3%)
- Caring responsibilities taking priority (31.5%)

Cost was more commonly identified as a barrier by:

- Younger carers (56.2% of those younger than 35 years)
- Those with lower incomes (43.3% of those with incomes less than \$400 per week)
- Those providing more hours of care per week (42.9% of those caring for more than 70 hours per week)
- CALD carers (42.7%)



Not knowing what services were available was more commonly identified as a barrier by younger carers (51.7% of those younger than 35 years).

Unsurprisingly, caring responsibilities taking priority was more commonly identified as the hours of care provided per week increased, shown in Figure 27.

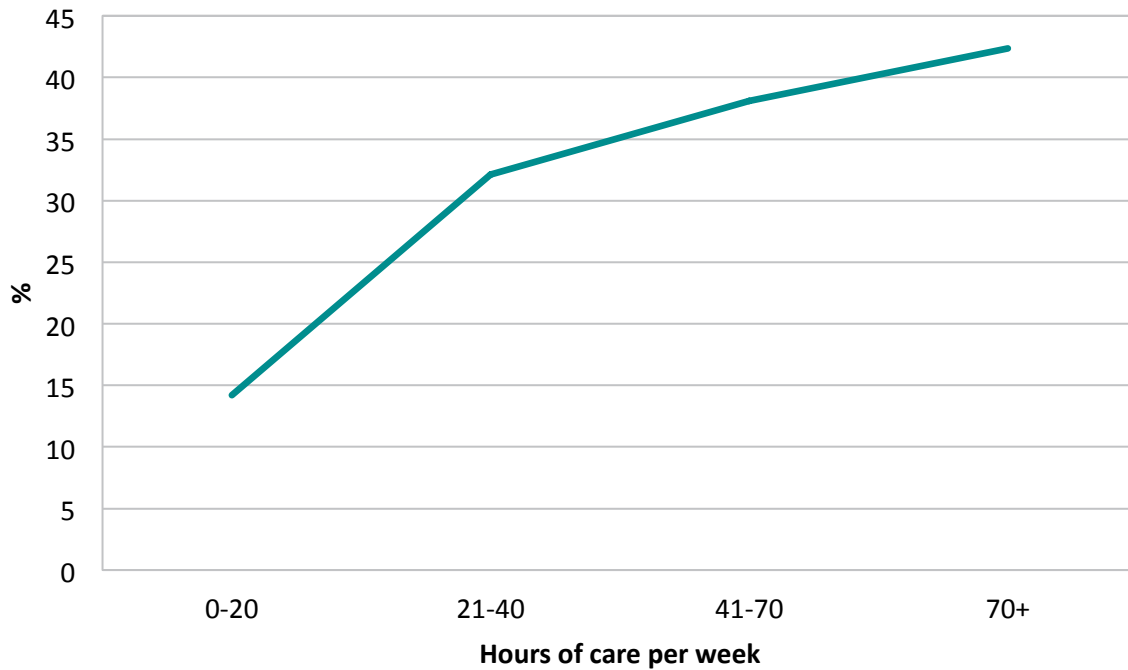


Figure 27. Percentage of carers prevented from accessing service because caring responsibilities take priority by hours of care per week

Carers who had experienced a serious illness or disability themselves were more likely than those without an illness or disability to identify each of these barriers (Figure 28).

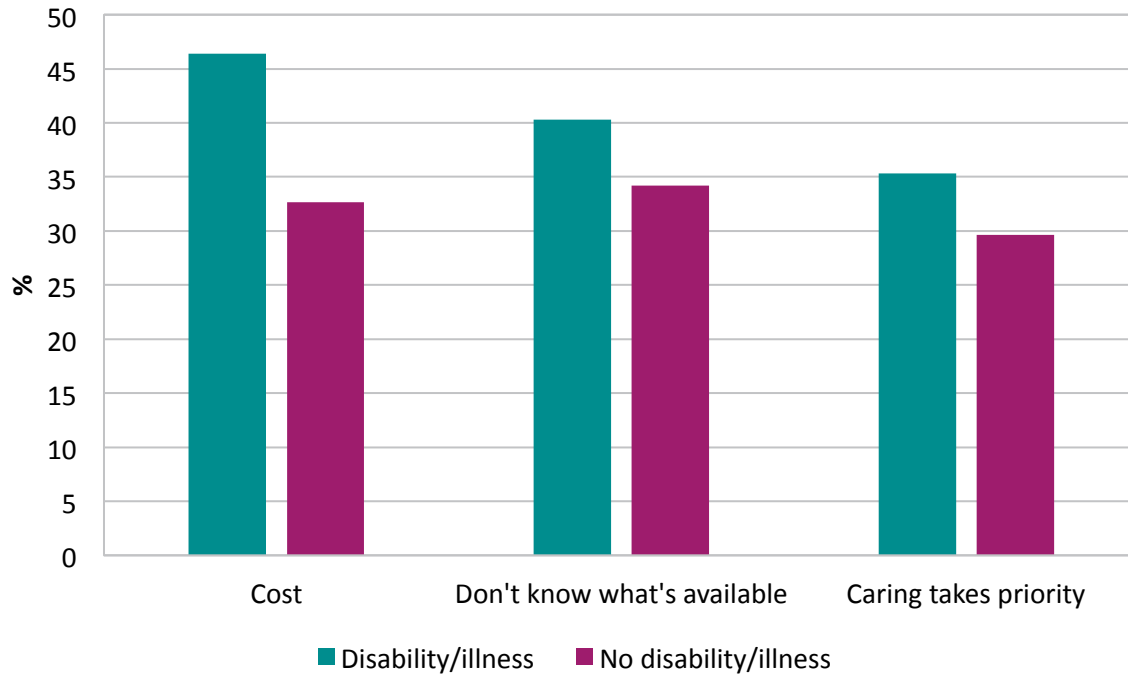


Figure 28. Barriers to service access by carers' disability status

Alongside these reported barriers, 8.3% of survey respondents indicated that they did not need any assistance. Carers who were most likely to indicate that they did not need supportive services included:

- Those providing caring for less than 20 hours per week (16.0%)
- Male carers (13.2%)
- Older carers (11.9% of those 65 years and older)

Service needs and wants

Previous Carers NSW Carer Surveys, consultations and research have identified certain services as being particularly useful in supporting carers, namely: respite, counselling, education and training, carer support groups, and community care services. Participants indicated whether or not they currently used each of these services, and whether or not they would like to use each of them more. The responses across each service type is shown in Figure 29.

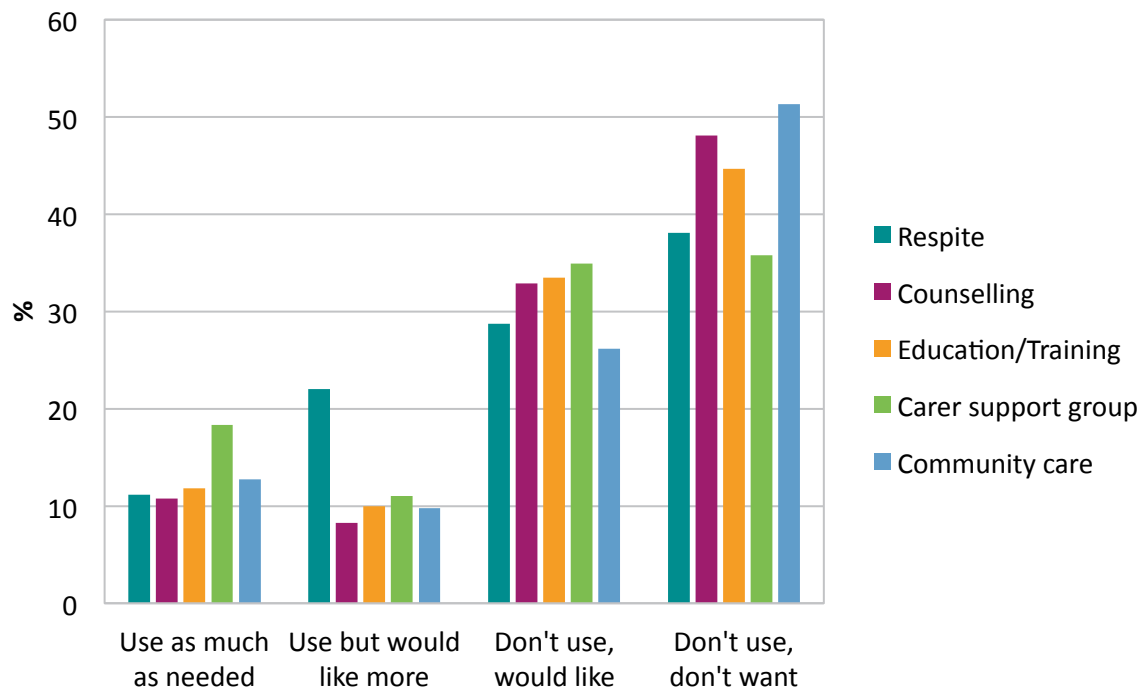


Figure 29. Carers' current service usage and wants

Interestingly, responses indicated that the majority of carers did not use these services and did not want to. Amongst the minority who were using the listed services, carer support groups were most commonly identified as being used as much as needed, and respite stood out as being wanted more. Participants were invited to make additional comments regarding their service usage, which provided some additional insight into their attitudes towards seeking help:

At this stage I am able to provide the care without any intervention. This may change in the future and then I would consider help.

Am cautious re support groups – can have a 'we're all victims' mentality.

Between work and home I don't have time to do much else.

Lots of "information" services but not a lot of services that actually practically assist carers.

I'm sure there are services that would be helpful to me but finding trying to find out about them requires time which I'd rather spend with my Mum or family.

Care recipient services

Carers' experiences with any services that supported the person(s) they cared for were also investigated. Amongst those who indicated the person(s) they cared for received services, 56.3% reported being either satisfied or very satisfied with the quality of these services, while 18.1% were either dissatisfied or very dissatisfied, as illustrated by Figure 30.

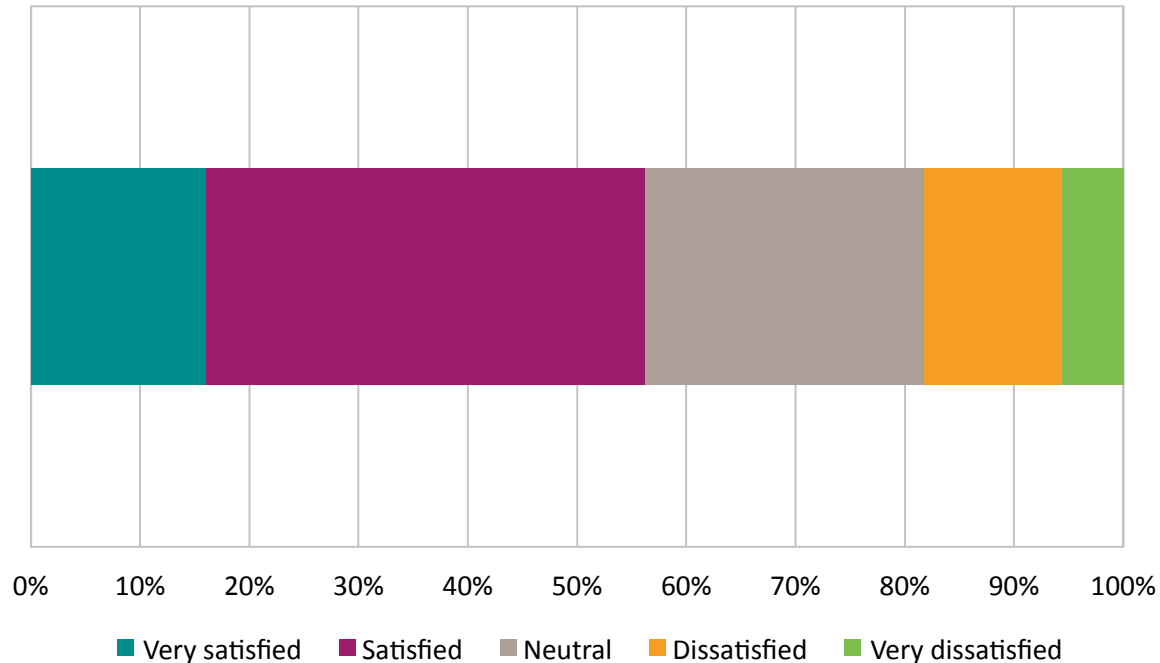


Figure 30. Carers' satisfaction with the quality of services for the person(s) they care for

Higher levels of service satisfaction were correlated with more positive reports of wellbeing, as indicated by higher scores on:

- COPE positive value subscale
- COPE quality of support subscale
- Positive Aspects of Caregiving scale
- PWI

Higher satisfaction with services was also correlated with lower scores on:

- COPE negative impact subscale
- K10



Similar results were found regarding the extent to which these services included carers in consultations, treatment plans or therapy for the person(s) they cared for. 54.5% reported that they were usually or always included, while 21.9% were rarely or never included, as illustrated by Figure 31.

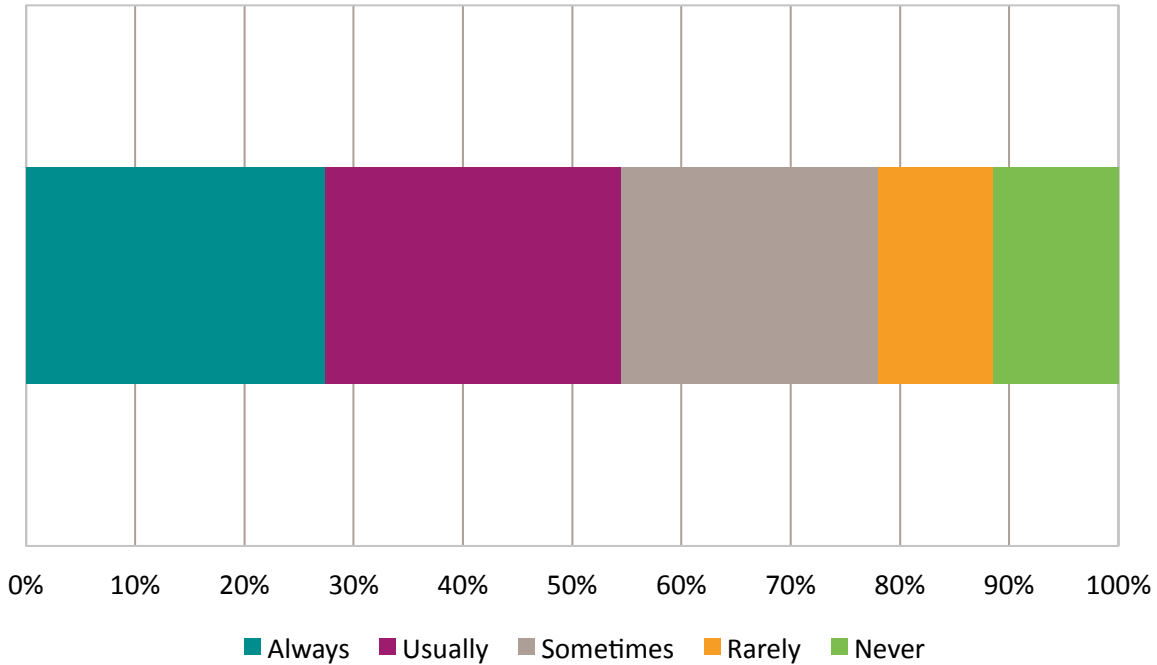


Figure 31. Extent to which services include carers in consultations, treatment plans or therapy

Increased levels of carers’ inclusion by services was also correlated with more positive reports of wellbeing, as indicated by higher scores on:

- COPE positive value subscale
- COPE quality of support subscale
- Positive Aspects of Caregiving scale
- PWI

Increased inclusion was also correlated with lower scores on:

- COPE negative impact subscale
- K10

The results highlight the significance of services acknowledging and including the contribution made by carers of their clients and also respecting their relationships.

Services were reported to reduce caring responsibilities by 44.2% of carers, yet 61.8% of carers indicated that care recipients’ services benefitted them in some way. In addition, 63.4% reported that they provided some assistance to these service providers.

Social support

Carers' social support was measured using the Duke Social Support Index (DSSI) (Koenig et al., 1993), which measures social interaction, subjective support, and overall social support.

The following differences between sub-groups of carers were found:

- Carers who had experienced a serious illness or disability themselves reported significantly lower overall social support than those without an illness or disability
- Those whose income was greater than \$1000 per week reported more social interaction than those whose income was less than \$1000 per week
- CALD carers reported less subjective support than those who did not identify with a CALD background
- Working carers reported significantly higher social interaction than unemployed carers
- Female carers reported more subjective support than male carers

Overall social support gradually decreased as the hours of care per week increased, as shown in Figure 32.

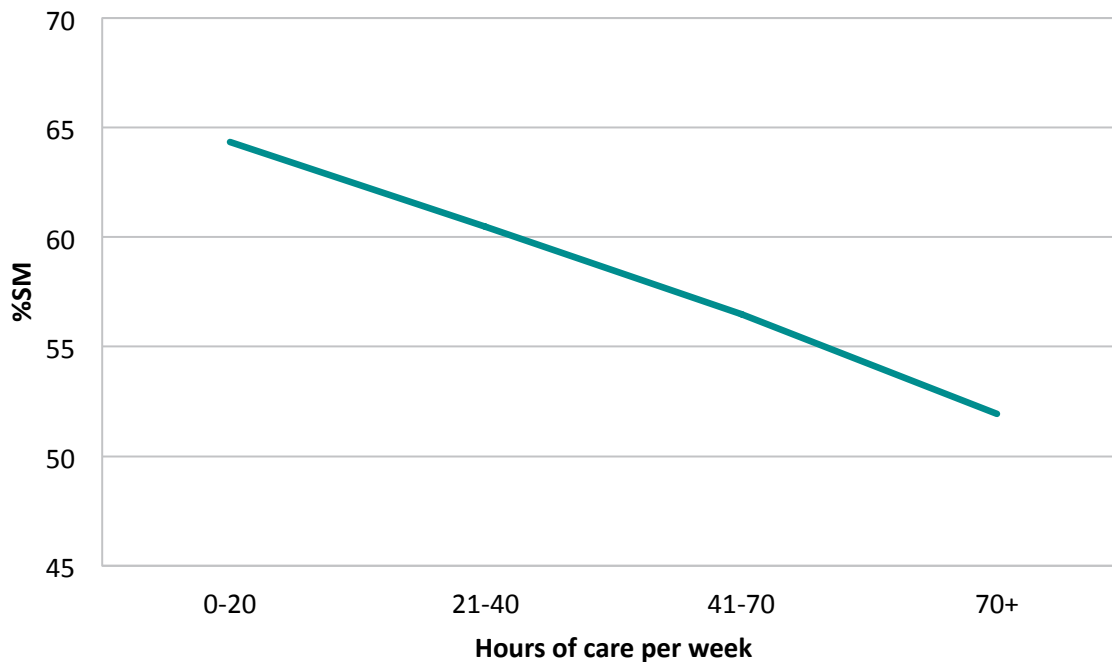


Figure 32. Mean DSSI scores by hours of care per week

Almost two-thirds of survey respondents (63.7%) reported that they were satisfied with their relationships with family and friends. Carers with no disability or serious illness were more likely to be satisfied with their relationships (68.0%) than those with a disability or illness (56.2%). Those who did not identify with a CALD background were more likely to be satisfied with their relationships (66.4%) than CALD carers (57.0%).

As carers' age increased, so too did the proportion who were satisfied with their relationships, as illustrated by Figure 33.



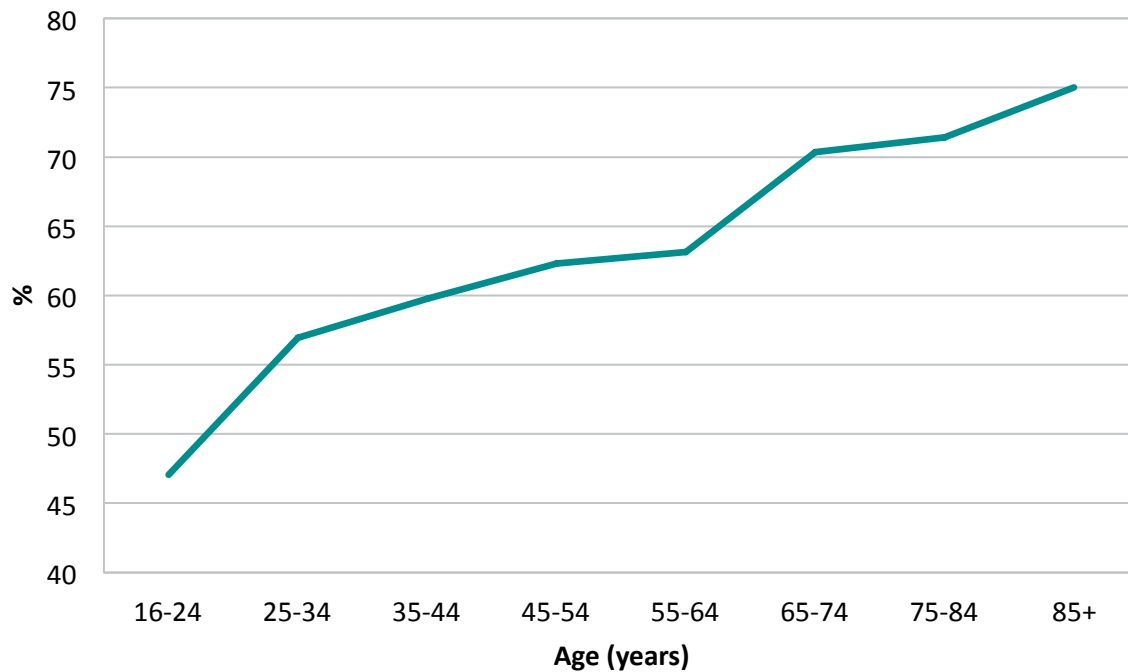


Figure 33. Carers' satisfaction with personal relationships by age

Summary and implications

- Local doctors and carers' family and friends were the most commonly utilised sources of support.
- The three main barriers to accessing services were cost, not knowing what was available, and caring responsibilities taking priority.
- Providing more hours of care per week was an indicator of increased need for supportive services, but also a significant barrier to accessing them.
- A majority of carers were not currently accessing services and did not want to. Carer support groups were most commonly identified as being accessed as much as necessary. Respite was the service carers were most likely to want to access more.
- Just over one in two carers were satisfied with the services received by the person(s) they cared for and felt included by these services. Increased satisfaction and inclusion was correlated with improved wellbeing, illustrating the importance of all services recognising, supporting and including carers.
- Carers who had experienced a long-term disability or illness reported significantly less social support and more barriers to accessing services than those without a disability or illness.

Former carers

This survey marked the second time that specific data was collected regarding former carers and their previous caring roles. A total of sample of 146 completed this section.

Previous caring roles

Former carers reported having previously cared for between one and five people, with 32.9% having cared for more than one person. A majority (74.7%) reported that their most recent caring role had ended within the last five years, and 62.3% indicated that their previous caring roles had lasted five years or longer.

By far the most common reason that caring roles had ended was that the care recipient had died (selected by 56.2% of former carers). This was followed by the care recipient being admitted into a residential care facility (30.8%). A minority of former carers (11.0%) indicated that they stopped caring because they could no longer cope. Despite being a relatively small sample of former carers, it is noteworthy that only a small proportion indicated that they stopped caring due to not coping. As reported in the health and wellbeing section of this report (and in a great deal of previous literature), carers experience significantly worse wellbeing than the general population across a range of domains. In spite of this, very few former carers reported reaching a point where they purposely ended their caring roles due to not coping (though it may be possible that in some cases care recipients' admission into residential care was associated with carers approaching this point). Former carers therefore demonstrated significant resilience and dedication to the care of their loved ones, regardless of the potential detrimental impacts to their own wellbeing.

Support needs

Former carers were asked to indicate types of support they needed when their caring roles ended, which they received, and which they would have liked to receive more. Emotional support was the most commonly identified, followed by financial support, legal advice and help to get back into work/study (Figure 34).



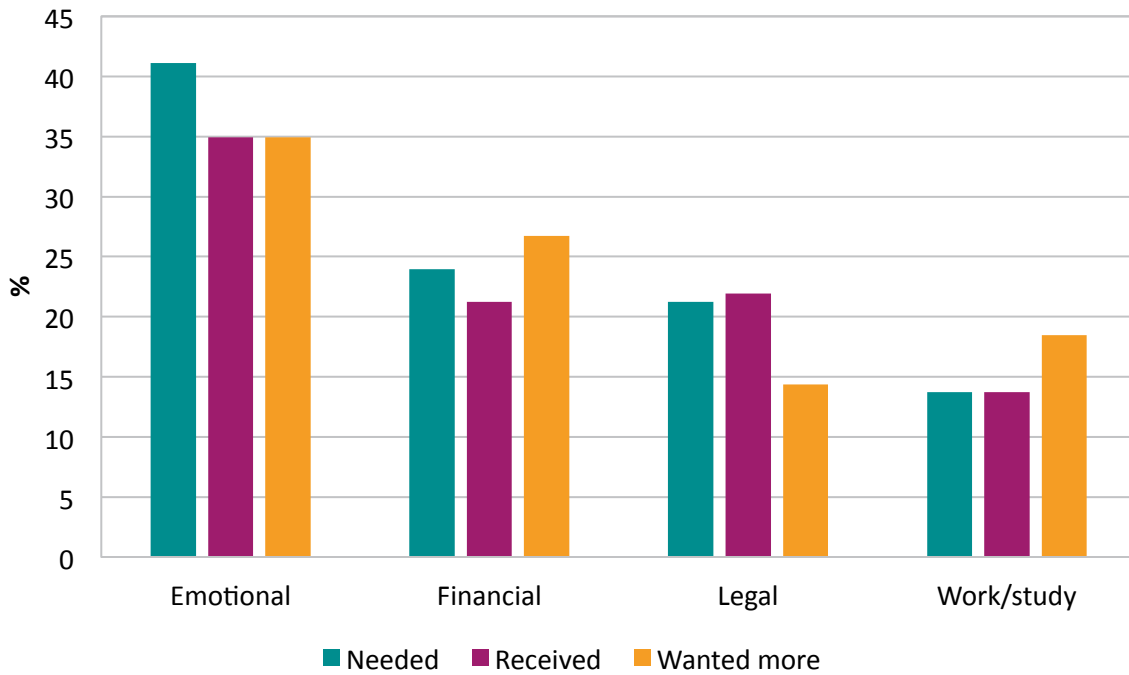


Figure 34. Former carers' support needs when caring roles ended

Similarly, former carers were asked which of these supports they currently needed, which they were receiving and which they would like to receive more. A similar pattern of support needs was apparent, although fewer former carers reported currently needing supports compared to when their caring roles ended (Figure 35).

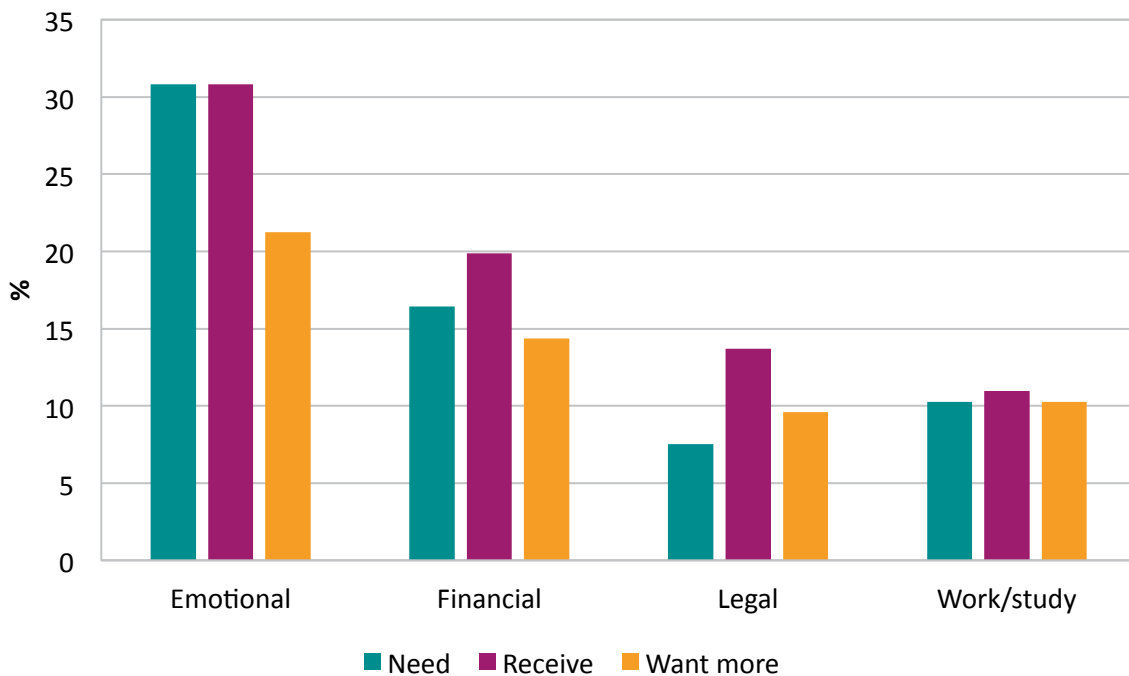


Figure 35. Former carers' current support needs

Summary and implications

- Caring roles usually ended through the death of care recipients or their admission into care facilities.
- Very few former carers reported caring roles ending because they could no longer cope, demonstrating resilience and dedication to their caring roles.
- Emotional support was the most commonly needed support at the end of caring roles.
- A significant proportion of former carers reported needing more support when their caring roles ended than they received.
- Former carers' current support needs reflected their needs at the end of caring roles, only slightly reduced. Further research is warranted to investigate how support needs change over time, including identifying factors that impact on these changing needs.
- Future surveys should target an increased sample of former carers, including improving data collection amongst current carers who have previously had other caring roles end.



Person centred approaches

An optional section on person centred approaches was included for carers of people with a disability. Only carers of people with a disability were included in this section due to person centred approaches having been initially rolled out in the disability services sector. This section replicated questions from the Carers NSW 2012 Carer Survey with the intention of tracking any changes over this two year period. A total of 701 carers responded to this section, representing an 82.9% response rate amongst carers of people with a disability.

Person centred approaches

55.5% of respondents indicated that they had heard of person centred approaches – an increase from the 39.5% of carers of people with a disability who had heard of them in 2012 (Broady, 2014).

After being provided with a brief explanation of person centred approaches, participants were asked how they expected this policy shift would affect the following outcomes:

- The control carers have over services
- The control the person(s) they care for has over services
- The choices carers have in how they live their life
- The choices the person(s) they care for has in how they live their life
- The degree to which carers' needs are met
- The degree to which the needs of the person(s) they care for are met
- Finding and organising services

Responses were significantly more positive than negative, with 48.6% reflecting an expectation that outcomes would be either a little better or much better and just 7.4% expecting worse outcomes. Alongside this, 44.0% gave neutral responses, indicating that they either expected no change or were unsure of what to expect.

Individualised funding

A similar proportion of respondents (59.3%) indicated that they had heard of individualised funding, which was a slight increase on the 51.9% of carers of people with a disability who had heard of it in 2012 (Broady, 2014). Of those who had heard of individualised funding, 28.4% indicated that either they or the person(s) they cared for received individualised funding.

Those who did not receive individualised funding were asked how they expected it would affect the same outcomes previously listed if they were to manage a funding package. Similarly, those who already received individualised funding were asked how it had already affected those outcomes. As with expectations of person centred approaches, both expectations and experiences of individualised funding were much more positive than negative, particularly amongst carers who had practical experience of receiving an individualised funding package (Figure 36). Again, a significant proportion of carers gave neutral responses, especially those who had not practically experienced individualised funding packages themselves.

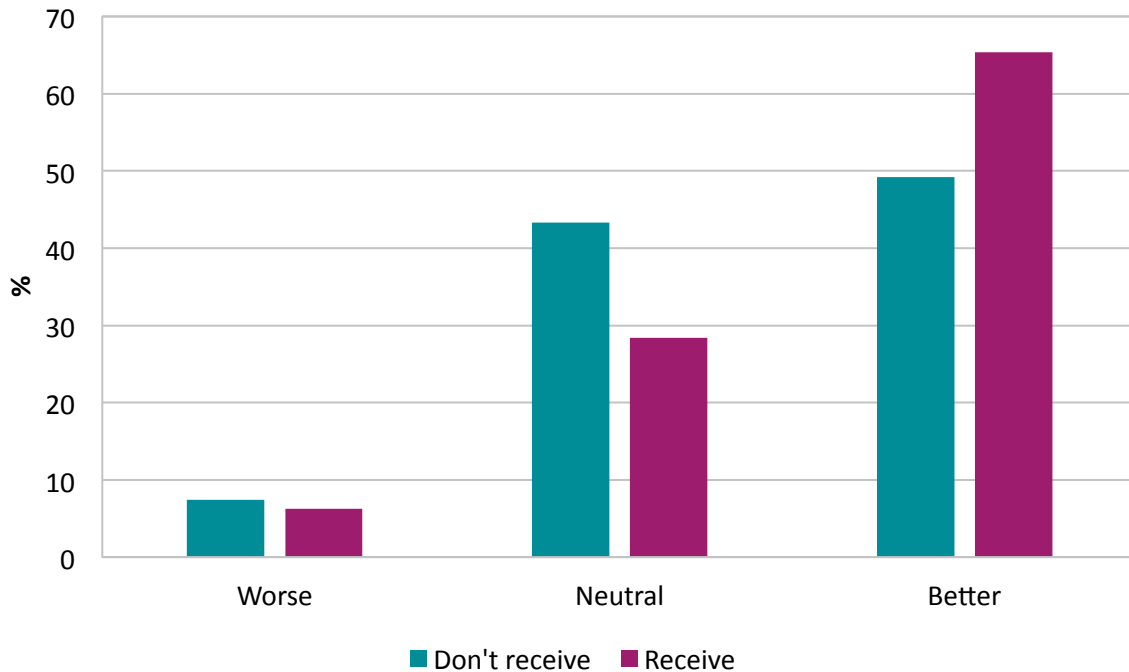


Figure 36. Carers' perceptions of expected or experienced effects of individualised funding

Carers were invited to make additional comments regarding the introduction of person centred approaches and individualised funding. Reflective of the findings outlined above, comments were generally positive and hopeful. Several carers conveyed their uncertainty regarding what these changes would mean in practice, and others expressed fears and a sense of scepticism:

THANK GOD!!!! For far too long decisions for people with disability have been made by service providers. The shift in culture to a PCP world is welcomed and supported by most individuals or those families who have members who have a disability.

We do not receive any funding for services at this point in time so I have no idea how this will affect us.

Is a really good idea and how it should be. Hopefully will be easy to implement and accepted by all users and those who need to. Am looking forward to it being implemented.

I feel this will assist by giving choice to the individual as to what they want to do - concerns around what choices you will have in small rural and isolated pockets of NSW.

Worried that existing funding + services might not continue.

We applied for individual funding, received it + then it was dictated to us which service provider we could use. We actually have gone retrograde. Our choice has decreased.



Love it! However, it really is dependent on the agency and we have found a very good one.

I am already very tired and am not sure I want to take on managing money and employing staff to work with my son.

We have been doing this for 18 months now and it is the BEST THING WE HAVE EVER DONE. Sorry, not yelling, just excited.

Sound fantastic in theory. Harder to fulfil in practice.

Summary and implications

- Compared to 2012 Carer Survey data, there was an increase in awareness of both person centred approaches and individualised funding amongst carers of people with a disability in 2014.
- Expectations of both person centred approaches and individualised funding were much more positive than negative.
- Almost half of respondents gave neutral responses, indicating no expected changes or uncertainty of what to expect.
- Carers' practical experiences of receiving individualised funding were more positive than the expectations of those who had not received any individualised funding packages. Carers' success stories may be a useful mechanism by which to encourage and support other carers as they transition into a person centred disability service system.

Discussion

This report has outlined the main findings from the Carers NSW 2014 Carer Survey. These results highlight the most significant arising issues, however, more extensive analysis is required to provide a more complete picture. Nevertheless, many important issues have been raised that have significant implications for the recognition and support of carers within the community.

Caring situations

The picture of caring situations outlined in this report is the most comprehensive collected by the Carers NSW Carer Survey to date. Detailed investigation of demographic data and information regarding individual caring situations will continue and will be made available in future publications.

Results highlight the variety of caring situations in NSW. Survey respondents reported caring for people with an extensive range of conditions, illnesses, and disabilities, with an equally vast array of multiple diagnoses. In addition, one in four carers reported that they were caring for more than one person. Individual caring situations may therefore be quite complex, particularly in terms of interactions with multiple service providers, therapists or clinicians, managing multiple treatment programs, and a range of care recipient symptoms. While the results presented in this report indicate some meaningful trends that are relevant across caring situations, the range of relationships and scenarios reported also emphasises the individual nature of caring. It is therefore important to acknowledge and respect carers and those they care for on a personal level.

Importantly, results showed the extensive nature of some caring roles, with over 25% of caring relationships requiring more than 70 hours of care per week. It is possible that this is partly due to the present sample not reflecting the wider carer population, however, it also highlights the importance of recognising the time demands of caring. There are significant personal consequences for carers who provide so many hours of care, including lower levels of wellbeing than those with less substantial caring responsibilities. Providing more hours of care was also an indicator of increased need for support, but was also a major barrier to accessing any services. Providing affordable and accessible support to carers with these significant time demands is a challenge for any service system, but is a major need identified by survey respondents. In addition, those providing more care per week tended to have been caring for longer. The impact of extensive caring demands must therefore be considered alongside the likelihood that these caring demands will exist in a long-term caring role.

Survey responses showed a number of positive trends. For example, the number of carers who indicated they started caring because they wanted to was more than double those who felt they had no choice. Similarly, the positive value of caring was consistently reported to be greater than the negative impacts. The significance of these positive trends cannot be underestimated. It is important to highlight the positive and beneficial aspects of caring relationships, rather than focusing on negative impacts. In this way, caring roles are not seen as something to be endured. Rather, the value of carers' contributions within the community can be properly acknowledged, particularly in terms of the positive influence they can have within their individual caring relationships.



Carers' health, wellbeing and ageing

Alongside these positive signs, however, a number of concerning issues were raised. Most notably, and in line with previous research (e.g., Cummins et al., 2007), the wellbeing of carers in this survey was lower than the general Australian population. A large number of carers indicated that they received no help from others in caring for their loved ones, or that they would not be able to find help if they needed to take a break. Findings such as these highlight the need for carers to be recognised and supported in their caring roles, particularly in those cases where carers do not have adequate informal support networks.

Some particularly noteworthy findings related to carers who indicated they had experienced a long-term illness or disability themselves within the previous year. The prevalence of carer illness/disability increased as the length of time they had been caring increased. This trend was more pronounced than the increase in illness/disability with increasing carer age, highlighting the potential for the toll of caring to accumulate over time and impact carers' health beyond typical ageing related health issues. The wellbeing of carers with a long-term illness/disability was a particular concern, as they reported poorer outcomes across all measures of wellbeing than carers without an illness/disability. Furthermore, carers with a long-term illness/disability reported less social support and more barriers to accessing formal support services. Survey findings therefore highlight this group of carers as needing particular focus from service providers and policy makers. There is a major need to increase the availability of appropriate supports to carers who experience an illness or disability. When considering that there is an increased risk of developing an illness or disability over the course of an extended caring role, there is a need for carers to develop support structures and coping strategies at an early stage. If effective support and management of caring demands is established, the risks associated with long-term caring demands (e.g., carer disability/illness, poorer wellbeing, less social/formal support) may be somewhat mitigated.

Employment

This survey collected detailed information regarding carers' employment, with some particularly notable findings. For example, amongst carers who were not in paid employment, more than half had stopped working because of their caring responsibilities. Furthermore, a substantial number of working carers had reduced their working hours or interrupted their careers in order to accommodate their caring responsibilities. Those who had stopped working because of care had significantly reduced levels of wellbeing. It is therefore suggested that carers should be supported by their workplaces to balance working and caring roles wherever possible. Workplace support is particularly important for carers in full time employment. Part time employees tended to report more intensive caring demands, but also had more supportive working environments than those in full time positions. While a majority of respondents indicated that their employers knew about their caring responsibilities, one in four did not feel supported in the workplace. This highlights a need for continued advocacy across all sectors to develop more supportive workplace cultures. There also appears to be a need to better inform working carers about formal workplace supportive practices that are available to them (e.g., carers' leave, employee assistance programs).

Working carers often appeared to experience certain degrees of conflict in their desires to work more, less, or at times both. It is here that a supportive workplace culture is so important. A supportive workplace is more likely to help working carers make meaningful contributions in their employment/career without neglecting their caring responsibilities. Balancing these emotional obligations and carers' financial needs can be difficult, further emphasising the need for effective workplace practices and supportive workplace cultures.

Carers' services and social supports

Carers had accessed a vast range of services and supports in their caring roles, however, local doctors, family and friends stood out as the most frequently used sources of support. The responsibility and opportunity that GPs have as carers' most commonly accessed source of formal support cannot be underestimated. It is important for them to identify carers through their practice, particularly those who do not identify as carers themselves, and also that they are able to provide relevant information or referrals in order to more fully meet carers' individual support needs. This is likely to help in addressing one of the main barriers to services carers identified in this survey – not knowing what was available.

A majority of carers in this survey indicated that they were not currently accessing regular services for themselves (e.g., carer support groups, respite, counselling). Interestingly, most did not want to. While the reasons for this were not investigated, these results suggest that many general support services for carers may not be sought or accessed. Carers who did access these services rated them highly in terms of their usefulness, suggesting that they generally do meet the needs of those using them. Further research is necessary to determine how to increase carers' interest and use of services. In light of the poorer wellbeing amongst carers than the general population, alternative ways of supportive carers may need to be considered.

One in two carers were satisfied with the services received by the person(s) they cared for, and a similar proportion felt they were included in consultations or treatment plans. The importance of this satisfaction and inclusion was illustrated by higher levels of wellbeing amongst those carers who were more satisfied and more regularly included by services. It is important that service providers acknowledge and respect their clients' caring relationships and that they consider the needs of the wider family and caring networks. It is also worth noting that carers' perceptions of being recognised and acknowledged by services and the community was low. It is therefore clear that there is a need for awareness raising and continued advocacy for carers across all community and service sectors.

Person centred approaches and individualised funding

Compared to results from the 2012 Carer Survey, carers of people with a disability in this survey demonstrated more awareness of person centred approaches and individualised funding. While their expectations regarding the impact of these systemic changes were far more positive than negative, almost half of responses were neutral, indicating that carers either expected no real impact or were unsure of what the impacts would be. Carers who had practical experiences of individualised funding were much more positive about their impact compared to the expectations of carers who had not yet experienced them. Some uncertainty may therefore be alleviated when carers have direct contact with these policy reforms, with survey results suggesting they typically experience positive outcomes.



Former carers

For the second time, the Carer Survey collected specific information on former carers. When asked why their caring roles had ended, only a small minority indicated that they stopped caring because they could no longer cope. The vast majority reported caring for their loved ones until death or admission into a residential care facility. In light of the findings that showed the likelihood of carers having high caregiving demands and also experiencing low wellbeing, these findings suggest that carers are extremely dedicated to their roles, often to their own detriment. It is therefore understandable that emotional support was the most commonly needed type of support at the end of caring roles and beyond. Importantly, many former carers needed more support than they received, suggesting that there are gaps in formal and informal support networks at the conclusion of caring roles. It is also important to recognise that carers' support needs do not cease simply because they no longer have caring responsibilities. Additional research is needed to determine how carers' support needs change after the conclusion of their caring roles, and to identify any factors that may impact on this.

Carers NSW membership

At an organisational level, survey results raise suggestions for Carers NSW and the membership base. Future membership promotion could benefit from targeting groups that appear to be underrepresented amongst Carers NSW members, such as working carers, non-spousal carers, and those who have recently commenced their caring roles. Finding a way to reach carers at the beginning of their caring role is particularly important, as this is a time when relevant information may be particularly useful. Carers NSW members in this survey were significantly better informed of carer related legislation than non-members, suggesting the effectiveness of organisational communications.

Limitations

A number of limitations of this survey should be noted. Most importantly, the current sample of carers is not representative of the wider population of carers in NSW, as outlined in the profile of carers section. In particular, there was a large overrepresentation of female carers, primary carers and those caring for a son/daughter. The sample was also older on average than the wider carer population, and had completed higher levels of formal education. Lastly, there was an underrepresentation of working carers. It is likely that at least some of these demographic characteristics were related to each other (e.g., lower employment rates due to primary caring responsibilities). In light of these demographic differences, caution should be used before generalising any findings to wider carer populations. Nevertheless, further in-depth data analysis will evaluate the impact of these differences, and will also allow for greater insight into the experiences of specific sub-groups of carers.

Respondents to this survey all nominated themselves to participate. While this was the most appropriate and ethical recruitment method, it is also possible that carers participated because they wanted to share opinions regarding particularly positive or negative experiences. Since survey promotion was largely through regular Carers NSW communications and other stakeholder organisations, the sample is likely to represent those carers who have some degree of contact with services and/or supportive organisations.

Being a cross-sectional survey, it is not possible to identify the direct cause of any of the findings in this report. A number of survey questions, however, either reflected or directly replicated those from previous Carers NSW Carer Surveys. It will therefore be possible to draw some comparisons over time. Since this survey was designed with the intention of maintaining the same structure throughout future versions, future surveys will be better able to track any changes.

Future analysis and research directions

Several areas for further in-depth analysis of survey data have been identified throughout this report. The amount of demographic data collected will enable more detailed investigations of specific carer population groups, and certain characteristics within complex caring situations. Extensive data were collected regarding the amount of care provided by carers. Future analysis will investigate the impact of increased caring responsibilities in more detail. This report has highlighted certain groups of carers who reported the poorest outcomes on wellbeing measures (e.g., those with more intensive caring responsibilities, those experiencing a long-term illness/disability). Additional analysis will investigate factors that are most significant in predicting wellbeing.

These results also provide some suggestions for improving future surveys, particularly regarding data collection. Future surveys would benefit from targeting some of the underrepresented groups of carers, such as male carers, young carers, spousal carers, non-primary carers, and former carers. As well as targeting more former carers, future surveys would benefit from investigating the experiences of carers with both current and former caring roles.

Some of the issues raised by this report provide some directions for future research projects. Carers' sons/daughters were the most common care recipients, and these caring relationships were reported as the most long-term. Longitudinal research could investigate the impact of these caring roles over time and identify areas in which carers may be most effectively supported in these long-term caring relationships. Certain groups of carers reported more positive wellbeing than others, e.g., male carers and older carers. Future research is warranted to investigate why this may be the case, particularly in terms of any issues not included in this survey. Although this survey collected more extensive data regarding carers' employment than previous Carer Surveys, further research questions have been raised from these results, in particular, the experience of balancing work and care across different industries (especially those most common amongst survey participants). Additionally, further research is necessary to investigate reasons and motivations for using or not using any supportive workplace practices that may be available for working carers.

Conclusion

The Carers NSW 2014 Carer Survey collected the most comprehensive data to date regarding carers' experiences and caring situations. This report has provided an overview of some major emerging findings, however, the wealth of data collected will enable additional detailed analysis to investigate these key issues in more depth. The main findings presented in this report hold significant implications for the recognition and support of carers across a range of contexts, by service providers, governments, and the community at large.



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Section 1: The person you care for

4. How many people do you care for?
a. _____

The following questions are about the person(s) you care for. If you care for more than one person, please complete both columns, thinking about the people you provide the MOST care for.

Person 1

5. What is his/her gender?
a. Female b. Male

6. How old is he/she?
a. _____ years

7. What is his/her relationship to you?

- He/she is my:
a. Parent
b. Parent-in-law
c. Spouse/partner
d. Ex-spouse/partner
e. Son/daughter
f. Other relative (Please specify) _____

- g. Friend or neighbour
h. Other (Please specify) _____

8. Is he/she from an Aboriginal and/or Torres Strait Islander background? (Select all that apply)

- a. Yes, Aboriginal
b. Yes, Torres Strait Islander
c. No

9. In which country was he/she born?
a. _____

10. Does he/she speak a language other than English at home?
a. Yes,
he/she speaks _____
b. No

11. For what conditions/disabilities/illnesses does he/she need your care? (e.g., dementia, autism, arthritis, frailty, depression, Down syndrome, schizophrenia, cancer, brain injury, etc.)
a. _____

Person 2

5. What is his/her gender?
a. Female b. Male

6. How old is he/she?
a. _____ years

7. What is his/her relationship to you?

- He/she is my:
a. Parent
b. Parent-in-law
c. Spouse/partner
d. Ex-spouse/partner
e. Son/daughter
f. Other relative (Please specify) _____

- g. Friend or neighbour
h. Other (Please specify) _____

8. Is he/she from an Aboriginal and/or Torres Strait Islander background? (Select all that apply)

- a. Yes, Aboriginal
b. Yes, Torres Strait Islander
c. No

9. In which country was he/she born?
a. _____

10. Does he/she speak a language other than English at home?
a. Yes,
he/she speaks _____
b. No

11. For what conditions/disabilities/illnesses does he/she need your care? (e.g., dementia, autism, arthritis, frailty, depression, Down syndrome, schizophrenia, cancer, brain injury, etc.)
a. _____



Introduction About the survey

Thank you for taking the time to complete this survey. By sharing your opinions and experiences with us, you will help us advocate for the things that matter most to you.

There are three ways you can complete the survey:

1. Online via the Carers NSW website (www.carersnsw.org.au)
2. By telephone (please call 02 9280 4744 to book a time)
3. By completing this form and returning it in the reply paid envelope by 30 June 2014

The survey should take you **15-30 minutes** depending on your responses. Please note this survey is for carers aged 16 years and over.

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

Screening questions

1. Do you live in New South Wales?
a. Yes (Go to Question 2)
b. No (Unfortunately you do not fit our respondent profile. Thank you for your interest.)
2. Do you look after someone (or help look after someone) who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal or serious illness or who is frail?
a. Yes (Go to Question 3)
b. Not currently, but I have in the past (Please go to Section 6 – Former Carers)
c. No (Unfortunately you do not fit our respondent profile. Thank you for your interest.)
3. Which of the following best describes your caring role?
a. I care for the person(s) as a family member, friend or neighbour (Go to Question 4)
b. I care for the person(s) as paid work (Unfortunately you do not fit our respondent profile. Thank you for your interest.)
c. I care for the person(s) as a formal volunteer (Unfortunately you do not fit our respondent profile. Thank you for your interest.)



Appendix – Survey questionnaire

<p>12. Why did you start caring for him/her? (Select all that apply)</p> <p>a. <input type="checkbox"/> I wanted to</p> <p>b. <input type="checkbox"/> I felt I could provide better care than someone else</p> <p>c. <input type="checkbox"/> I felt that caring was the responsibility of a family member</p> <p>d. <input type="checkbox"/> There were no other family or friends available</p> <p>e. <input type="checkbox"/> There were no other family or friends willing</p> <p>f. <input type="checkbox"/> I felt an emotional obligation</p> <p>g. <input type="checkbox"/> I/we could not afford to pay someone else to provide care</p> <p>h. <input type="checkbox"/> I was unable to organise any formal care arrangements</p> <p>i. <input type="checkbox"/> I had no other choice</p> <p>j. <input type="checkbox"/> Other reason (Please specify)</p> <hr/> <p>13. Where does he/she live?</p> <p>a. <input type="checkbox"/> At home with me</p> <p>b. <input type="checkbox"/> In his/her own home</p> <p>c. <input type="checkbox"/> In a nursing home (low level care)</p> <p>d. <input type="checkbox"/> In a nursing home (high level care)</p> <p>e. <input type="checkbox"/> In a group home</p> <p>f. <input type="checkbox"/> In a retirement village or aged care facility</p> <p>g. <input type="checkbox"/> In other supported accommodation</p> <p>h. <input type="checkbox"/> Other (Please specify)</p> <hr/> <p>14. Are you the person who provides the most care for him/her?</p> <p>a. <input type="checkbox"/> Yes b. <input type="checkbox"/> No</p> <hr/> <p>15. Does anyone else help take care of him/her? (Please don't include paid care workers)</p> <p>a. <input type="checkbox"/> No, no one else takes care of him/her</p> <p>b. <input type="checkbox"/> Yes, someone else provides a small amount of care (Please specify who this is)</p> <p>c. <input type="checkbox"/> Yes, someone else provides a significant amount of care (Please specify who this is)</p>	<p>16. If you were ill or needed a break, is there someone else who could help care for him/her?</p> <p>a. <input type="checkbox"/> Yes, I could find someone easily</p> <p>b. <input type="checkbox"/> Yes, I could find someone but with some difficulty</p> <p>c. <input type="checkbox"/> No, there is no one</p> <hr/> <p>17. On average, how many hours per week do you spend caring for him/her? (Please select your best estimate)</p> <p>a. <input type="checkbox"/> 0-10 hours per week</p> <p>b. <input type="checkbox"/> 11-20 hours per week</p> <p>c. <input type="checkbox"/> 21-30 hours per week</p> <p>d. <input type="checkbox"/> 31-40 hours per week</p> <p>e. <input type="checkbox"/> 41-50 hours per week</p> <p>f. <input type="checkbox"/> 51-60 hours per week</p> <p>g. <input type="checkbox"/> 61-70 hours per week</p> <p>h. <input type="checkbox"/> More than 70 hours per week</p> <p>i. <input type="checkbox"/> His/her care needs vary a lot (e.g., nothing one week, full time another week)</p> <p>j. <input type="checkbox"/> Other/hard to say (Please comment)</p> <hr/> <p>18. How long have you been caring for him/her? (Please select your best estimate)</p> <p>a. <input type="checkbox"/> Less than 1 year</p> <p>b. <input type="checkbox"/> 1-5 years</p> <p>c. <input type="checkbox"/> 6-10 years</p> <p>d. <input type="checkbox"/> 11-15 years</p> <p>e. <input type="checkbox"/> 16-20 years</p> <p>f. <input type="checkbox"/> More than 20 years</p> <hr/> <p>19. If left alone, could he/she care for him/herself:</p> <table border="0"> <tr> <td>For less than an hour?</td> <td><input type="checkbox"/> Yes</td> <td><input type="checkbox"/> No</td> </tr> <tr> <td>For a few hours?</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>For one day?</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>For a few days?</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	For less than an hour?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	For a few hours?	<input type="checkbox"/>	<input type="checkbox"/>	For one day?	<input type="checkbox"/>	<input type="checkbox"/>	For a few days?	<input type="checkbox"/>	<input type="checkbox"/>
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For one day?	<input type="checkbox"/>	<input type="checkbox"/>											
For a few days?	<input type="checkbox"/>	<input type="checkbox"/>											
<p>12. Why did you start caring for him/her? (Select all that apply)</p> <p>a. <input type="checkbox"/> I wanted to</p> <p>b. <input type="checkbox"/> I felt I could provide better care than someone else</p> <p>c. <input type="checkbox"/> I felt that caring was the responsibility of a family member</p> <p>d. <input type="checkbox"/> There were no other family or friends available</p> <p>e. <input type="checkbox"/> There were no other family or friends willing</p> <p>f. <input type="checkbox"/> I felt an emotional obligation</p> <p>g. <input type="checkbox"/> I/we could not afford to pay someone else to provide care</p> <p>h. <input type="checkbox"/> I was unable to organise any formal care arrangements</p> <p>i. <input type="checkbox"/> I had no other choice</p> <p>j. <input type="checkbox"/> Other reason (Please specify)</p> <hr/> <p>13. Where does he/she live?</p> <p>a. <input type="checkbox"/> At home with me</p> <p>b. <input type="checkbox"/> In his/her own home</p> <p>c. <input type="checkbox"/> In a nursing home (low level care)</p> <p>d. <input type="checkbox"/> In a nursing home (high level care)</p> <p>e. <input type="checkbox"/> In a group home</p> <p>f. <input type="checkbox"/> In a retirement village or aged care facility</p> <p>g. <input type="checkbox"/> In other supported accommodation</p> <p>h. <input type="checkbox"/> Other (Please specify)</p> <hr/> <p>14. Are you the person who provides the most care for him/her?</p> <p>a. <input type="checkbox"/> Yes b. <input type="checkbox"/> No</p> <hr/> <p>15. Does anyone else help take care of him/her? (Please don't include paid care workers)</p> <p>a. <input type="checkbox"/> No, no one else takes care of him/her</p> <p>b. <input type="checkbox"/> Yes, someone else provides a small amount of care (Please specify who this is)</p> <p>c. <input type="checkbox"/> Yes, someone else provides a significant amount of care (Please specify who this is)</p>	<p>16. If you were ill or needed a break, is there someone else who could help care for him/her?</p> <p>a. <input type="checkbox"/> Yes, I could find someone easily</p> <p>b. <input type="checkbox"/> Yes, I could find someone but with some difficulty</p> <p>c. <input type="checkbox"/> No, there is no one</p> <hr/> <p>17. On average, how many hours per week do you spend caring for him/her? (Please select your best estimate)</p> <p>a. <input type="checkbox"/> 0-10 hours per week</p> <p>b. <input type="checkbox"/> 11-20 hours per week</p> <p>c. <input type="checkbox"/> 21-30 hours per week</p> <p>d. <input type="checkbox"/> 31-40 hours per week</p> <p>e. <input type="checkbox"/> 41-50 hours per week</p> <p>f. <input type="checkbox"/> 51-60 hours per week</p> <p>g. <input type="checkbox"/> 61-70 hours per week</p> <p>h. <input type="checkbox"/> More than 70 hours per week</p> <p>i. <input type="checkbox"/> His/her care needs vary a lot (e.g., nothing one week, full time another week)</p> <p>j. <input type="checkbox"/> Other/hard to say (Please comment)</p> <hr/> <p>18. How long have you been caring for him/her? (Please select your best estimate)</p> <p>a. <input type="checkbox"/> Less than 1 year</p> <p>b. <input type="checkbox"/> 1-5 years</p> <p>c. <input type="checkbox"/> 6-10 years</p> <p>d. <input type="checkbox"/> 11-15 years</p> <p>e. <input type="checkbox"/> 16-20 years</p> <p>f. <input type="checkbox"/> More than 20 years</p> <hr/> <p>19. If left alone, could he/she care for him/herself:</p> <table border="0"> <tr> <td>For less than an hour?</td> <td><input type="checkbox"/> Yes</td> <td><input type="checkbox"/> No</td> </tr> <tr> <td>For a few hours?</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>For one day?</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>For a few days?</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	For less than an hour?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	For a few hours?	<input type="checkbox"/>	<input type="checkbox"/>	For one day?	<input type="checkbox"/>	<input type="checkbox"/>	For a few days?	<input type="checkbox"/>	<input type="checkbox"/>
For less than an hour?	<input type="checkbox"/> Yes	<input type="checkbox"/> No											
For a few hours?	<input type="checkbox"/>	<input type="checkbox"/>											
For one day?	<input type="checkbox"/>	<input type="checkbox"/>											
For a few days?	<input type="checkbox"/>	<input type="checkbox"/>											

Appendix – Survey questionnaire

Section 2: Your employment

20. As well as being a carer, are you in paid employment?
 a. Yes (Go to Question 23) b. No (Go to Question 21)
21. Are you:
 Looking for work? Yes No
 Retired?
22. Did you stop working because of your caring responsibilities?
 a. Yes (Go to Question 31) b. No (Go to Question 31)
23. Which of the following apply to you (Select all that apply)
 a. Full time work (35+ hours per week) d. Self-employed
 b. Part time work (Less than 35 hours per week) e. Fixed term contract
 c. Casual work f. Shift work (e.g., rostered on different shifts each week)
24. On average, how many hours are you employed per week (in total)?
 a. _____ hours
25. What is your occupation/job title?
 a. _____
26. In which industry do you work?
 a. Health care h. Information technology and telecommunications
 b. Government/Public sector
 c. Education and training i. Manufacturing
 d. Retail j. Agriculture
 e. Banking, finance, and insurance k. Construction, trades and mining
 f. Community and non-profit l. Other (Please specify) _____
 g. Hospitality and tourism
27. Please respond to each of these statements by selecting the response that best represents your experience at work.
- | | Yes | No |
|--|--------------------------|--------------------------|
| Does your employer know that you have caring responsibilities? | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you feel comfortable telling others in the workplace that you have caring responsibilities? | <input type="checkbox"/> | <input type="checkbox"/> |
| Does your workplace support you to combine work and care? | <input type="checkbox"/> | <input type="checkbox"/> |

28. Please indicate which of the following workplace practices are available to you, which you have used, and which have been helpful for you.

	Available	Used	Helpful
Career's leave	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Flexible start/finish times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Able to leave work at short notice for emergencies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking accumulated time in lieu when needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Working from home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reduced working hours	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Job sharing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supportive supervisors/co-workers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Employer supports (e.g., counselling, sponsoring a support group, advice on employment options, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please specify) _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

29. Which of the following apply to you? (Select all that apply)
- a. I have reduced the amount I work because of my caring responsibilities g. Changing my work arrangements to better fit with caring has meant working in a lower level job or has interrupted my career progression
- b. I have reduced from full-time to part-time work because of my caring responsibilities h. I am limited in how much I can work because of Government allowance restrictions
- c. I have switched from a permanent to a casual position to find more flexibility in my employment i. I would like to work more but am unable to because of my caring responsibilities
- d. I have stopped working because of my caring responsibilities j. I would like to work more but I am not able to find more work
- e. I have refused a new job/promotion because it would have made my caring responsibilities more difficult to manage k. I would like to work less but cannot afford to work
- f. I have had to change jobs to fit in with my caring responsibilities l. I am happy with how much I am currently working
- m. None of the above apply to me

30. Do you have any comments about your experiences at work?
 a. _____

31. Do you currently do any volunteer work?

a. Yes (Go to Question 32) b. No (Go to Question 33)

32. How many hours per week (on average) do you volunteer?
 a. _____ hours



Appendix – Survey questionnaire

Section 3: Service access and social support

This section is about any services and supports that you have received as a carer, as well as those you would like to receive.

33. Please indicate which of the following you have used for support in your caring role, and which have been useful to you.

	Not at all useful	Not very useful	Somewhat useful	Very useful	Have not used
Doctor/GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carers NSW counsellor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other counsellor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support from family/friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carer support group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non-government organisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Religious group (e.g., church, minister, priest, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Employer (manager/supervisor)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Work colleagues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Workplace support programs (e.g., support group)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carers NSW Carer Line	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other Carers NSW program/service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Internet or online support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

34. Do you have any comments on any of the above?
a. _____

35. Are there any services that you haven't used but would like to?
a. Yes b. No

36. Are there any services that you currently use but would like to use more?
a. Yes b. No

37. Please indicate which, if any, of the following have prevented you from using services or supports (Select all that apply)

a. Cost h. I don't qualify for support

b. I don't have time i. No adequate transport

c. I don't know what's available j. I don't want any/more help

d. I don't know where to go k. I don't need any/more help

e. Service not available l. None of the above

f. My caring responsibilities take priority m. Other (Please specify) _____

g. I'm on a waiting list

38. Do you currently use any of the following services?

	I currently use this as much as I need	I currently use this but would like to use more	I don't currently use this and I don't want to
Respite services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Education/training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carer support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community care services (e.g., home nursing, meal delivery, community transport, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please specify) _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

39. Do you have any comments on any of the above?
a. _____

40. Overall, how satisfied are you with the quality of services/support for the person(s) you care for?

a. Very satisfied d. Dissatisfied

b. Satisfied e. Very dissatisfied

c. Neither satisfied nor dissatisfied f. He/she does not receive any services/support (Go to Question 45)

41. Do you find that these services benefit you in any way?
a. Yes b. No c. Unsure

42. Do you feel that these services allow you to reduce your caring responsibilities or take a break when you need to?
a. Yes b. No c. Unsure

43. Do services include you in consultations, treatment plans or therapy for the person(s) you care for?
a. Always b. Usually c. Sometimes d. Rarely e. Never

44. Do you help service providers in assisting the person(s) you care for? (e.g., helping with lifting, medication, remaining on call in case of problems, etc.)
a. Yes b. No c. Unsure

Section 4: Your health and wellbeing

45. Please indicate how often each of the following apply to you.

	Never	Sometimes	Often	Always
Do you feel you cope well as a carer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you find caring too demanding?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does caring cause difficulties in your relationships with your friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does caring have a negative effect on your physical health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does caring cause difficulties in your relationships with your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does caring cause you financial difficulties?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel trapped in your role as a carer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel well supported by friends or neighbours?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you find caring worthwhile?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel supported by your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you have a good relationship with the person you care for? <i>(Please think of the person you care for most)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel well supported by health and social services?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel that anyone appreciates you as a carer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does caring have a negative effect on your emotional wellbeing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, do you feel well supported in your role of carer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

46. Please indicate how much you agree with each of the following statements.

Providing help to the person I care/cared for has:	Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
Made me feel more useful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Made me feel good about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Made me feel needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Made me feel appreciated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Made me feel important	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Made me feel strong and confident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Given more meaning to my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enabled me to learn new skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enabled me to appreciate life more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enabled me to develop a more positive attitude toward life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strengthened my relationships with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

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

48. 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
Tired out for no good reason	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nervous	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
So nervous that nothing could calm you down	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hopeless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless or frigatey	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
So restless you could not sit still	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
That everything was an effort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
So sad that nothing could cheer you up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Worthless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Appendix – Survey questionnaire

49. Please answer the following questions in relation to your family and friends other than the person(s) you care/ cared for.

	Hardly ever	Some of the time	Most of the time				
Do you feel you have a definite role/place in your family and among your friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Does it seem that your family and friends understand you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Do you feel useful to your family and friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
When you are talking with your family and friends, do you feel you are being listened to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Do you know what is going on with your family and friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Can you talk about your deepest problems with at least some of your family and friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
How satisfied are you with the kinds of relationships you have with your family and friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
How many times during the past week did you spend time with someone who does not live with you? (e.g., you went to see them, they came to see you, or you went out together)	0	1	2	3 or more			
Other than members of your family, how many persons in your local areas do you feel you can depend on or feel very close to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
In the past week, how many times did you talk to someone – friends, relatives or others? (e.g., on the telephone, SMS, Facebook)	0	1	2	3	4	5	6 or more
In the past week, about how many times did you go to meetings of clubs, religious meetings, or other groups that you belong to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

50. In general over the last 12 months, please indicate how much you think that:

	Not at all	A little	Unsure	Some-what	A great deal
Your health/wellbeing has been considered by services that support the person(s) you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The contribution that carers make has been recognised by the wider community?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your individual needs and interests beyond being a carer have been acknowledged? (e.g., by family, services, or the public)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

51. Have you heard of the following?

a. NSW Carers (Recognition) Act 2010
 i. Yes ii. No iii. Unsure

b. NSW Carers Charter
 i. Yes ii. No iii. Unsure

c. NSW Carers Advisory Council
 i. Yes ii. No iii. Unsure

Section 5: About you

52. Are you
 a. Female b. Male

53. How old are you?
 a. _____ years old

54. Are you from an Aboriginal and/or Torres Strait Islander background? (Select all that apply)
 a. Yes, Aboriginal b. Yes, Torres Strait Islander c. No

55. In which country were you born?
 a. _____

56. What cultural background(s) do you identify with? (e.g., Italian, Indian, German, Maltese, Chinese, Greek, English, Australian, etc.)
 a. _____

57. Do you speak a language other than English at home?
 a. Yes, I speak _____ b. No, English only

58. In which suburb do you live?
 a. _____

59. What is the postcode where you live?
 a. _____

60. What is the highest level of education you have completed?
 a. Less than year 10 e. Diploma/Advanced diploma
 b. High school year 10 or equivalent f. Bachelor degree or higher
 c. High school year 12 or equivalent g. Other (Please specify)
 d. TAFE/VET Certificate

61. Are you currently enrolled in any formal education?
 a. Yes (Go to Question 62) b. No (Go to Question 64)

62. In what formal education are you enrolled?
 a. High school d. Bachelor degree or higher
 b. TAFE/VET Certificate e. Other (Please specify)
 c. Diploma/Advanced diploma

Appendix – Survey questionnaire

63. On average, how many hours per week do you spend studying (including attending classes)?
 a. _____ hours

64. From which of these sources do you personally receive income?
 a. Wages/salary
 b. Your own business
 c. Carer Payment
 d. Carer Allowance
 e. Other Government pension/allowance
 f. None
 g. Other (Please specify) _____

65. What is your personal total weekly income (before tax)? If you do not know the exact amount, please give an estimate.
 a. \$1 - \$199 per week (\$1 - \$10,399/year)
 b. \$200 - \$299 per week (\$10,400 - \$15,599/year)
 c. \$300 - \$399 per week (\$15,600 - \$20,799/year)
 d. \$400 - \$599 per week (\$20,800 - \$31,199/year)
 e. \$600 - \$799 per week (\$31,200 - \$41,599/year)
 f. \$800 - \$999 per week (\$41,600 - \$51,999/year)
 g. \$1000 - \$1249 per week (\$52,000 - \$64,999/year)
 h. \$1250 - \$1499 per week (\$65,000 - \$77,999/year)
 i. \$1500 - \$1999 per week (\$78,000 - \$103,999/year)
 j. \$2000 or more per week (\$104,000 or more/year)
 k. No income
 l. Don't know/Prefer not to answer

66. What is your household's weekly income (before tax)? Please include your partner's and/or other family members' income (e.g., pension, disability support pension). If you do not know the exact amount, please give an estimate.
 a. \$1 - \$199 per week (\$1 - \$10,399/year)
 b. \$200 - \$299 per week (\$10,400 - \$15,599/year)
 c. \$300 - \$399 per week (\$15,600 - \$20,799/year)
 d. \$400 - \$599 per week (\$20,800 - \$31,199/year)
 e. \$600 - \$799 per week (\$31,200 - \$41,599/year)
 f. \$800 - \$999 per week (\$41,600 - \$51,999/year)
 g. \$1000 - \$1249 per week (\$52,000 - \$64,999/year)
 h. \$1250 - \$1499 per week (\$65,000 - \$77,999/year)
 i. \$1500 - \$1999 per week (\$78,000 - \$103,999/year)
 j. \$2000 - \$2999 per week (\$104,000 - \$155,999/year)
 k. \$3000 - \$3999 per week (\$156,000 - \$207,999/year)
 l. \$4000 - \$4999 per week (\$208,000 - \$259,999/year)
 m. \$5000 or more per week (\$260,000 or more/year)
 n. No income
 o. Don't know/Prefer not to answer

67. What best describes your living situation?
 a. I own my home without a mortgage
 b. I own my home with a mortgage
 c. I rent my home
 d. I live in Public Housing
 e. I live in Community Housing
 f. I live in Aboriginal Housing
 g. I live in a home that belongs to my family or relatives
 h. I live in a retirement village
 i. Other (Please specify) _____

68. Who do you live with? (Select all that apply)
 a. My spouse/partner
 b. My child/children (including step-children)
 c. Other family member(s) (Please specify) _____
 d. Friend(s)
 e. I live alone
 f. Other (Please specify) _____

69. 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?
 a. Yes
 b. No

70. Are you a member of Carers NSW?
 a. Yes
 b. No

71. How did you hear about this survey? (Select all that apply)
 a. Carers News
 b. Carers NSW e-Bulletin
 c. Carers NSW website
 d. Family/friend
 e. Carer support group
 f. Service provider (Please specify) _____
 g. Other (Please specify) _____

We have a few additional questions we would like to ask carers of people with a disability. It will take an extra 5 minutes to answer them. If you care for a person with a disability and would like to answer these optional questions, please go to Question 72. Otherwise, you have completed this survey – thank you for your input!

Remember, if you feel upset or have any concerns about anything from this survey, we strongly encourage you to call the Carers NSW Carer Line (1800 242 636) or Lifeline (13 11 14).

Optional section on person centred approaches

72. Have you heard of person centred approaches?
 a. Yes
 b. No
 c. Unsure

In a person centred system, the rights of people with a disability, and their families and carers, to make choices about their own lives are respected. Instead of the government telling people with a disability what support service they will receive, they can decide what services they want. People with a disability, their families and carers can decide how these services are delivered, how often, and by what service provider.

Disability services are moving towards more person centred approaches in the way they support people with a disability, their families and carers.



Appendix – Survey questionnaire

73. How do you expect person centred approaches to affect:

	Much worse	A little worse	No change/ Unsure	A little better	Much better
The control you have over services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The control of the person(s) you care for has over services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The choices you have in how you live your life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The choices the person(s) you care for has in how they live their life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The degree to which your needs are met	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The degree to which the needs of the person(s) you care for are met	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Finding and organising services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

74. Have you heard of individualised funding?

a. Yes b. No c. Unsure

Individualised funding means that individuals and their families have their own 'package' of funds and control over how it is used. There are examples of individualised funding in some disability programs. In these programs, individuals are allocated a funding amount based on their assessed needs and can choose their services and service providers.

75. Do you (or the person(s) you care for) receive individualised funding?

a. Yes (Go to Question 77) b. No (Go to Question 76) c. Unsure

76. If you decided to manage your own funding, how do you think it would affect:

	Much worse	A little worse	No change/ Unsure	A little better	Much better
The control you have over services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The control of the person(s) you care for has over services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The choices you have in how you live your life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The choices the person(s) you care for has in how they live their life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The degree to which your needs are met	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The degree to which the needs of the person(s) you care for are met	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Finding and organising services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(Go to Question 78)

77. How has individualised funding affected:

	Much worse	A little worse	No change/ Unsure	A little better	Much better
The control you have over services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The control of the person(s) you care for has over services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The choices you have in how you live your life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The choices the person(s) you care for has in how they live their life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The degree to which your needs are met	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The degree to which the needs of the person(s) you care for are met	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Finding and organising services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

78. Do you have any comments about person centred approaches and/or individualised funding?

a. _____

79. Does the person you care for currently receive funded supports as a participant in the National Disability Insurance Scheme (NDIS)?

a. Yes (Go to Question 80) b. No (You have finished this survey – thank you for your input!)

80. Please briefly outline any:

a. Benefits the person you care for has experienced from the NDIS

i. _____

b. Difficulties the person you care for has faced because of the NDIS

ii. _____

c. Benefits you have experienced as a carer from the NDIS

iii. _____

d. Difficulties you have faced as a carer because of the NDIS

iv. _____

*You have finished this survey – thank you for your input!
Remember, if you feel upset or have any concerns about anything from this survey, we strongly encourage you to call the Carers NSW Carer Line (1800 242 636) or Lifeline (13 11 14).*

Section 6: Former carers

This section is for former carers. Please only complete this section if you have had a caring role that ended.

81. Which of the following best describes your former caring role?
- a. I cared for the person(s) as a family member, friend or neighbour (Go to Question 82)
 - b. I cared for the person(s) as paid work (Unfortunately you do not fit our respondent profile. Thank you for your interest.)
 - c. I cared for the person(s) as a formal volunteer (Unfortunately you do not fit our respondent profile. Thank you for your interest.)
82. How many people have you previously cared for?
- a. _____ years
83. How long ago did your most recent caring role end?
- a. _____ years
84. How long did you care for that person?
- a. _____ years
85. Why did that caring role end? (Select all that apply)
- a. I chose not to be a carer any more
 - b. The person(s) I cared for no longer required care
 - c. The person(s) I cared for moved away
 - d. The person(s) I cared for was/were admitted into a residential care facility (e.g. nursing home)
 - e. I couldn't cope any more
 - f. The person(s) I cared for chose a different source of care
 - g. The person(s) I cared for died
 - h. Other (Please specify)

86. When you were caring for them, how often:

	Never	Some-times	Often	Always
Did you feel you coped well?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you find caring too demanding?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did caring cause difficulties in your relationships with your friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did caring have a negative effect on your physical health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did caring cause difficulties in your relationships with your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did caring cause you financial difficulties?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you feel trapped in your role as a carer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you feel well supported by friends or neighbours?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you find caring worthwhile?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you have a good relationship with the person you cared for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you feel well supported by health and social services?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you feel that anyone appreciated you as a carer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did caring have a negative effect on your emotional wellbeing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, did you feel well supported in your role of carer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

87. Please indicate which of the following support you needed when your caring role ended, and which you received. (Select all that apply)

	I needed this support	I received this support	I would like to have received more of this support
Emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help to get back into work or study	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Legal advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

88. Please indicate which of the following support you need now, and which you receive. (Select all that apply)

	I need this support	I receive this support	I would like to receive more of this support
Emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help to get back into work or study	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Legal advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

89. Are you in paid employment?

- a. Yes (Go to Question 92) b. No (Go to Question 90)

90.

- Are you:
- Looking for work? Yes No
 - Retired? Yes No

91. Did you stop working because of your caring responsibilities?

- a. Yes (Go to Question 96) b. No (Go to Question 95)

92. Which of the following apply to you? (Select all that apply)

- a. Full time work (35+ hours per week)
- b. Part time work (Less than 35 hours per week)
- c. Casual work
- d. Self-employed
- e. Fixed term contract
- f. Shift work (e.g., rostered on different shifts each week)



Appendix – Survey questionnaire



93. On average, how many hours are you employed per week (in total)?

a. _____ hours

94. What is your occupation/job title?

a. _____

95. In which industry do you work?

a. Health care

b. Government/Public sector

c. Education and training

d. Retail

e. Banking, finance, insurance

f. Community and non-profit

g. Hospitality and tourism

h. Information technology and telecommunications

i. Manufacturing

j. Agriculture

k. Construction, trades and mining

m. Other (Please specify) _____

96. Do you currently do any volunteer work?

a. Yes (Go to Question 97) b. No (Go to Question 46)

97. How many hours per week (on average) do you volunteer?

a. _____ hours

Please go to Question 46 and continue the survey

