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# Carers NSW 2016 Carer Survey

Main Report

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## List of Abbreviations

%SM	Percentage of Scale Maximum
ABS	Australian Bureau of Statistics
AWALI	Australian Work and Life Index
CALD	Culturally and Linguistically Diverse
CHC	Commonwealth Home Care
ICD-10	International Statistical Classification of Diseases and Related Health Problems (10 <sup>th</sup> Revision)
JSS	Job Satisfaction Subscale
K10	Kessler Psychological Distress Scale
LGBTI	Lesbian, Gay, Bisexual, Trans, and/or Intersex
LOTE	Languages Other Than English
MSPSS	Multidimensional Scale of Perceived Social Support
NDIS	National Disability Insurance Scheme
NSW	New South Wales
PAC	Positive Aspects of Caregiving
PWI	Personal Wellbeing Index
SDAC	Survey of Disability, Ageing and Carers
SPSS	Statistical Package for the Social Sciences

## Foreword and Acknowledgements

I am pleased to present the Main Report of the Carers NSW 2016 Carer Survey. This survey represents one of the major ways in which we utilise the rich experiences of carers to improve our understanding of caring. Carers NSW aims to continually raise public awareness of carers and contribute to public discussions that will ultimately improve the lives of carers in NSW. This significant piece of research has built on the strengths of previous Carers NSW Carer Surveys, which has resulted in a rich source of information.

I 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:

- Dr Christina Aggar
- Dr Hugh Bainbridge
- Professor Michael Fine
- Dr Trish Hill
- Professor Sandra Jones
- Dr Lyn Phillipson
- Dr Leah Ruppenner

Thanks is also extended to Caitlan Oehm for her valuable assistance with data entry and coding. Carers NSW acknowledges the work of Dr Timothy Broady as the Principal Investigator on this project and particularly in the preparation of this report.

Finally, and most importantly, I would like to acknowledge and thank 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.

This report not only makes a valuable contribution to the evidence base regarding carers in NSW, it highlights important areas where increased attention is necessary in order to improve the recognition of, and support for carers throughout society. These findings will help direct our organisational planning, services and supports, and our systemic advocacy in a meaningful and informed way.



Elena Katrakis  
CEO  
Carers NSW

October 2016

## Executive Summary

The Carers NSW Carer Survey collects information about carers in NSW to provide an evidence base that informs the organisation's direction, support, and systemic advocacy for all carers across NSW. The 2016 survey built on the success of the 2014 survey, utilising the same framework to collect extensive data across a number of important areas of carers' lived experiences. This report provides an overview of the main findings from the 2016 survey data. Future publications will investigate specific issues in greater depth.

The survey was completed by 1,958 carers and 123 former carers. Over 80% of carers were female, and almost half were aged between 45 and 64 years. The vast majority were the main providers of care for those they supported, and approximately one third had experienced a long-term illness or disability themselves within the previous 12 months. In line with previous Carers NSW Carer Surveys (and the broader carer research literature), the present sample is not representative of the wider NSW carer population, thus limiting the generalisability of findings. However, a wide range of caring experience was evident across the sample, with a strong representation across a number of specific carer sub-populations (e.g., culturally and linguistically diverse (CALD), Aboriginal and Torres Strait Islander, young carers, working carers, and more). More detailed analysis is therefore possible within these sub-groups.

More than one quarter of carers had been in their role for more than 20 years, and almost half reported providing more than 70 hours of care per week (including a significant proportion who considered their role to be 24 hours a day, 7 days a week). Not only do these findings highlight the major role carers hold within the community, more extensive caring demands were associated with an increased prevalence of long-term illness or disability.

Respondents were most commonly caring for their own son or daughter, with substantial proportions caring for a spouse or partner, or a parent. A wide range of care recipients' conditions were reported, including many with multiple diagnoses, with mental and behavioural disorders being the most prevalent by far. In line with the large amount of time spent caring, care recipients generally could not be left alone for long periods of time (more than one quarter could not be left alone at all).

As has been widely reported in research literature, carers' reported wellbeing was low when compared to the general Australian population. Despite low reports of wellbeing, carers still reported more positive aspects of caring than negative. Certain groups were identified as reporting particularly low wellbeing, including those experiencing a long-term illness or disability, those living outside Greater Sydney, those from CALD or Aboriginal and Torres Strait Islander backgrounds, and those receiving government financial assistance. In addition, the majority of carers did not feel that their caring role was recognised or valued by their community.

Carers reported that caring had impacted on their employment in many ways, most commonly by preventing them from working more, forcing them to reduce working hours, or leaving the workforce altogether. Of those who were not employed, over half had stopped working because of caring responsibilities, with many indicating that they would like to be back in the workforce. Amongst working carers, nearly two thirds ideally would have liked to either increase or decrease the amount they worked. A vast majority of employers know about carers' caring roles, though significantly fewer carers felt supported to balance work and care. Unsurprisingly, carers generally reported high levels of work-to-life conflict, with more conflict associated with decreased job satisfaction. This was particularly the case amongst those who did not feel that their employer supported them to balance work and care. Despite the challenges of balancing work and care, over 40% of working carers had rarely or never considered quitting. Working carers also reported on the availability and use of supportive workplace practices, with carer's leave and being able to leave at short notice when

necessary being the most readily available, and working from home being particularly sought after (though often unavailable).

Less than half of the carers responding to this survey utilised each of the following services: respite, counselling, carer support groups. Interestingly, many indicated that they did not want to access these supports. The majority of carers who cared for someone who was receiving supportive services were satisfied with service providers, with three quarters reporting that they personally experienced benefits, such as a reduction in the amount of care they provided. Carers reported that significant others were the best source of social support, while friends were generally perceived as more supportive than family. Perceived support was lower amongst those who provided more hours of care per week and those who had been caring for longer.

Former carers (including current carers who also had previous caring roles) mostly reported having cared for a parent, and that caring roles had ended when care recipients had died. Very few former carers reported withdrawing from a caring role because they could no longer cope. When compared to current carers, former carers reported better health and wellbeing across a range of measures. Importantly, health and wellbeing continued to improve as the time since the end of caring roles increased.

The emerging findings presented in this report will be used to direct additional in-depth analysis of the survey data. This work will continue to inform a range of advocacy and research work across Carers NSW. Most importantly, the Carers NSW Carer Survey continues to contribute to a growing evidence base regarding carers in NSW. The main findings of this report, in collaboration with findings from previous surveys and broader carer research literature raise important implications for the recognition and support of carers by governments, service providers, and the community.

## Aims and Objectives

The 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 2016 survey built on the framework that was established in the 2014 survey, and aimed to continue the quality improvement of data collected. Particular consideration was given to ensuring that results could be compared to previous surveys and could continue to be compared in future surveys.

In refining the content of the survey, an expert reference committee was convened. Reference committee members were invited based on their professional experience in conducting research on carer related issues and previous partnerships with Carers NSW. Several members also had caring experience themselves. This process enabled the methodological rigour of the survey to be further strengthened.

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, results of previous Carers NSW Carer Surveys, and consultation with the reference committee. The following sections were included:

- Carer demographics
- The person(s) cared for
- Service access and social support
- Employment
- Health and wellbeing

Most of the data collected can be directly compared with results of previous Carers NSW Carer Surveys, enabling some trends to be tracked over time. 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. Along with a retrospective analysis of previous Carers NSW Carer Survey data, this survey will also inform a Carers NSW 40<sup>th</sup> Anniversary report reflecting on the state of caring in NSW over the past 40 years. Importantly, the Carers NSW Carer Survey continues to make 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 five separate sections. The content of these sections is outlined below.

### 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, cultural background, and the conditions, disabilities, or illnesses for which they required care. They were also asked if care recipients lived with them, if anyone else helped provide care, how long care recipients could be left alone, and how long they had been caring for them.

### 2. Service access and social support

Carers were asked if they had received supportive services as a carer, or if they would like to. They were also asked about their satisfaction with services received by the person(s) they cared for, and any experiences with either the National Disability Insurance Scheme (NDIS) or Commonwealth Home Care (CHC) Packages. Participants also completed the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988) – a validated scale measuring social support from friends, family, and significant others.

### 3. Your employment

Participants were asked to indicate whether or not they were in paid employment. Working carers were asked further details, including weekly hours of employment, industry, job title, and organisation size. Drawing on previously validated scales – namely the Australian Work and Life Index (AWALI; Chapman, Skinner, & Pocock, 2014), the Job Satisfaction Subscale (JSS) from the Michigan Organizational Assessment Questionnaire (Cammann, Fichman, Jenkins, & Klesh, 1979) and a single item job turnover intentions measure (Spector, Dwyer, & Jex, 1988) – working carers were asked to report on their work-life balance, job satisfaction, intention to quit, and workplace culture. Participants were also asked about their use of flexible working arrangements, and any impacts of being a carer on their career progression.

### 4. Your health and wellbeing

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

- Personal Wellbeing Index (PWI; International Wellbeing Group, 2006)
- Positive Aspects of Caregiving (PAC; Tarlow et al., 2004)
- Kessler Psychological Distress Scale (K10; Kessler et al., 2003)

A single item, self-reported health question was also included. In this section, participants were asked to indicate the extent to which they felt that their caring role was recognised and valued by their communities.

### 5. About you

This section collected a range of demographic data about respondents, including: age, gender, cultural background, geographic region, education, income, amount of care provided, and LGBTI status.

## Procedure

The survey was made available online through Survey Monkey and as a paper questionnaire. Paper questionnaires were distributed with the Carers NSW bi-monthly newsletter, *Carers News*, to over 5,500 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 30<sup>th</sup> April, 2016. 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

A total of 2,519 responses were received. Of those, 438 were screened out before completion – 23 did not live in NSW, 61 indicated they were not carers (and 23 did not answer this screening question), 25 were paid care workers, 9 were formal volunteers, and 9 did not answer this screening question. The Participant Information Sheet informed carers that not submitting a completed survey would be considered a withdrawal of their consent to participate – 286 responses were excluded from analysis for this reason. For ethical reasons, only carers aged 16 years and over were invited to participate, with 2 responses being screened out for being under this age limit.

This resulted in a final sample of 2,081 – 1,958 of whom were current carers, and 657 were former carers (534 participants indicated they were both a current *and* former carer).

1,273 (61.2%) completed the online version and 808 (38.8%) completed the paper version. A demographic profile of participants is provided in the Results section of this report (see page 9).

## Ethics

Ethics approval was granted by the University of Wollongong Human Research Ethics Committee (Health and Medical) (HE15/477).

## Survey Results

This section provides an overview of results from the Carers NSW 2016 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. Some reported percentages do not add up to 100% due to rounding or missing data. Details regarding statistical analyses will be made available in future, more detailed reports and publications, or by contacting the Carers NSW Research Team (02 9280 4744; [research@carersnsw.org.au](mailto:research@carersnsw.org.au)).

### Profile of carers

Selected demographic characteristics of the sample of carers in this survey are shown in Table 1. These results are provided alongside the sample from the Carers NSW 2014 Carer Survey and the demographic characteristics of the broader population of carers in NSW as estimated by the Australian Bureau of Statistics (ABS) 2012 Survey of Disability, Ageing and Carers (SDAC; ABS, 2012b).<sup>1</sup>

*Table 1. Demographic characteristics of Carers NSW 2016 Carer Survey respondents compared to Carers NSW 2014 Carer Survey respondents and ABS estimates of the total NSW carer population*

		<b>Carers NSW 2016 Carer Survey</b>	<b>Carers NSW 2014 Carer Survey</b>	<b>SDAC 2012</b>
Total population		1,958	1,684	857,200
Gender:	Female	80.6%	84.0%	55.9%
	Male	15.5%	14.9%	44.0%
Age:	<45 years	17.3%	19.9%	37.0%
	45-64 years	48.1%	51.7%	41.3%
	65+ years	28.5%	27.4%	21.2%
Employed*		37.0%	42.8%	52.5%
Education:	Bachelor or higher	31.3%	30.8%	17.0%
	Certificate/diploma	35.2%	35.8%	30.6%
	High school	16.5%	7.3%	13.7%
	Less than high school	11.6%	23.5%	37.8%
LGBTI		3.2%	-	-
Disability <sup>‡</sup>		32.9%	32.1%	31.1%
Primary carer		92.8%	91.8%	29.4%

N.B. Individual categories may not add up to 100% due to missing data

\* 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

<sup>1</sup> This report will be updated to reflect 2015 SDAC data when they become available.

The data presented in Table 1 indicate that the overall demographic profile of the current sample is very similar to that from the Carers NSW 2014 Carer Survey. However, there are several key areas in which these samples are not representative of the wider NSW carer population. Most significantly, the current sample has a much higher proportion of female carers than the wider population, and is highly dominated by primary carers. The representation of carers aged under 45 years is also much lower than the wider population. Compared to SDAC estimates, carers in the current sample had completed higher levels of formal education, but were less likely to be in paid employment. Despite these differences, the proportion of carers reporting having experienced a long-term illness or disability themselves over the previous 12 months was very similar to ABS estimates. These key demographic differences must be considered when interpreting findings from other sections of this survey.

For the first time, the survey asked if respondents identified as lesbian, gay, bisexual, transgender, or intersex. 3.2% of carers indicated identifying as LGBTI.

75.6% of carers reported caring for one person and 20.4% were caring for two people. The remaining 3.9% were caring for three or more people. 27.3% of carers also indicated they had previous caring roles that had ended. Compared to those caring for one person, carers with multiple caring roles were:

- Even more likely to be female (91.2% vs. 81.3%)
- Older on average (58.0 years vs. 53.1 years)
- More likely to identify as Aboriginal and/or Torres Strait Islander (5.6% vs. 3.0%)
- More likely to report having someone else help in providing care (67.8% vs. 44.1%)
- More likely to have been caring for longer, as illustrated by Figure 1

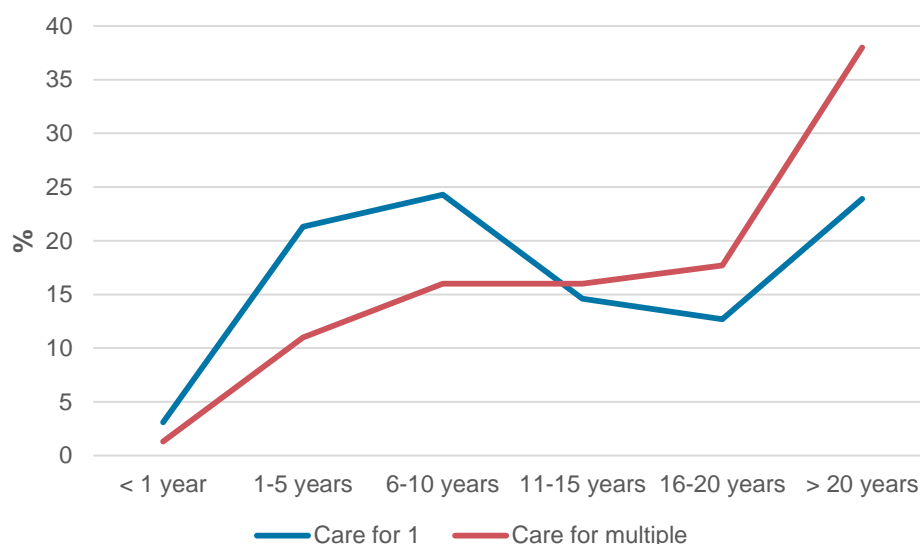


Figure 1. Length of time caring by number of caring roles

## Cultural background

A majority of carers identified as Australian (70.8%), with 16.6% identifying as being from a culturally and linguistically diverse (CALD) background. The most commonly identified cultural backgrounds (after Australian) were:

- English (8.9% of sample)
- Italian (2.1%)
- Chinese (1.6%)
- Dutch (1.5%)
- Indian (1.2%)
- Greek (1.1%)
- Filipino (1.1%)
- New Zealand (1.1%)
- Scottish (1.1%)
- Maltese (1.0%)
- Irish (1.0%)

In addition, 3.4% of respondents identified as Aboriginal and/or Torres Strait Islander.

13.0% of respondents reported speaking a language other than English at home. The most commonly spoken languages were: Italian (1.3% of respondents), Arabic (1.0%), Tagalog (0.9%), Cantonese (0.8%), German (0.8%), Spanish (0.8%), Dutch (0.6%), Vietnamese (0.6%), and Greek (0.5%).

## Region

Approximately half (50.1%) of respondents reporting living in Greater Sydney. The percentage of carers living in various regions of Greater Sydney is depicted in Figure 2, and the percentage living in other areas of NSW is shown in Figure 3.<sup>2</sup>

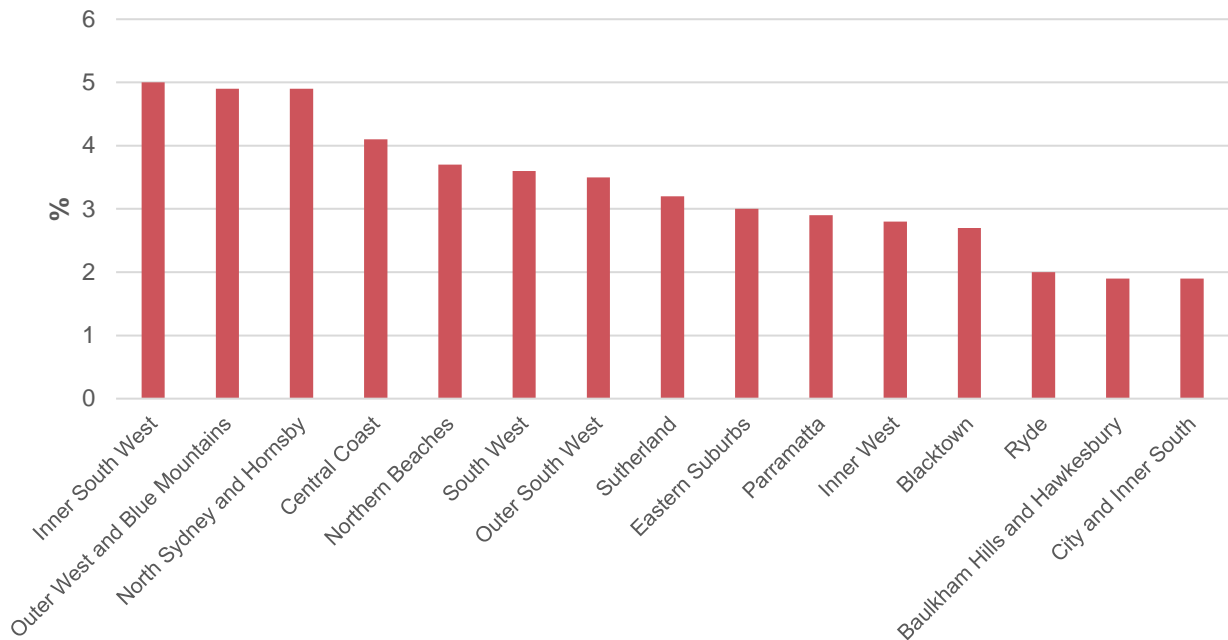


Figure 2. Percentage of carers living in geographical regions of Greater Sydney

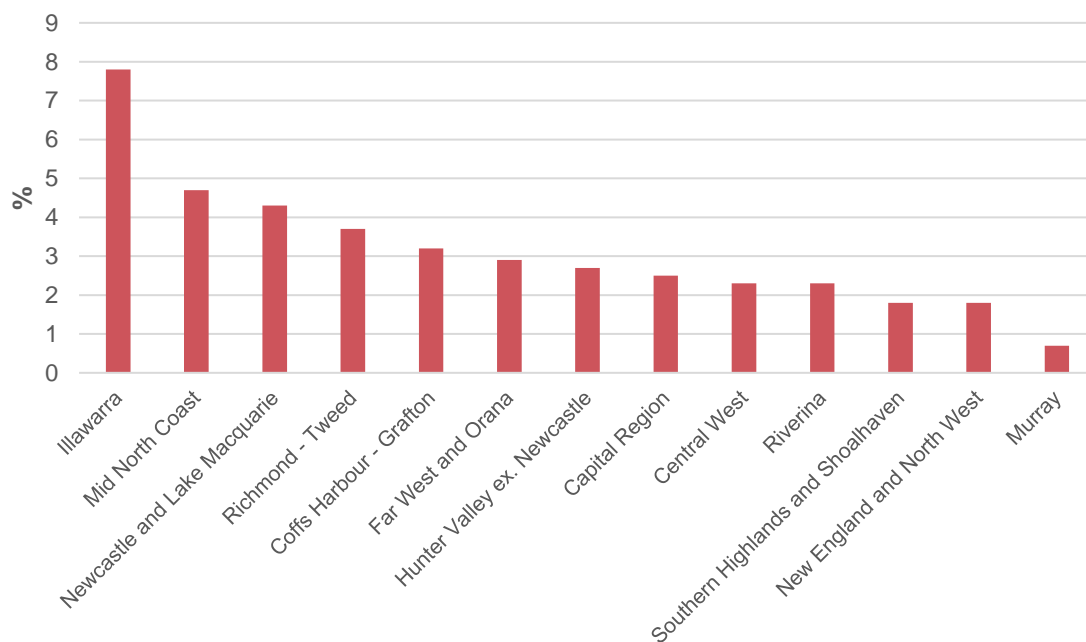
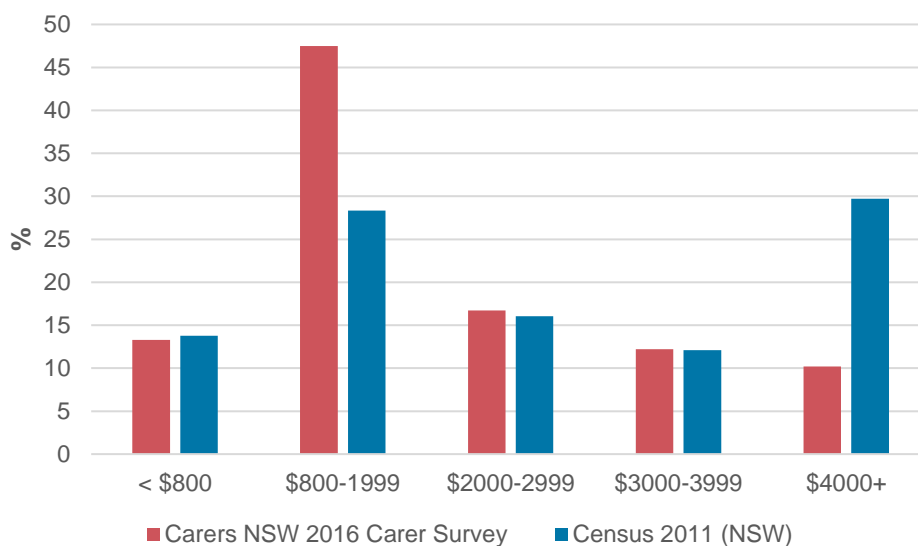


Figure 3. Percentage of carers living in geographical regions of NSW (outside Greater Sydney)

<sup>2</sup> The regions referred to in these figures represent Statistical Areas – Level 4, as defined by the Australian Bureau of Statistics (ABS, 2016).

## Finances

Approximately 15% of survey respondents declined to disclose their household income. The fortnightly household incomes of those who did respond are shown in Figure 4, alongside comparative Census data reflecting the household incomes of the general NSW population (ABS, 2011).<sup>3</sup>



*Figure 4. Fortnightly household incomes of carers compared to general NSW population*

Nearly three quarters (73.0%) of carers reported that they were receiving some form of government financial assistance. 63.7% were receiving Carer Allowance, 25.6% were receiving Carer Payment, and 27.8% were receiving some other government allowance (note that many carers indicated that they were receiving more than one source of government financial support).

<sup>3</sup> This report will be updated to reflect 2016 Census data when they become available.

### Time caring

A range of caring experience was evident, with participants ranging from being a carer for less than one year, through to 60 years (M=15.9 years). Significantly, more than one in four carers (27.0%) had been caring for over 20 years (see Figure 5).

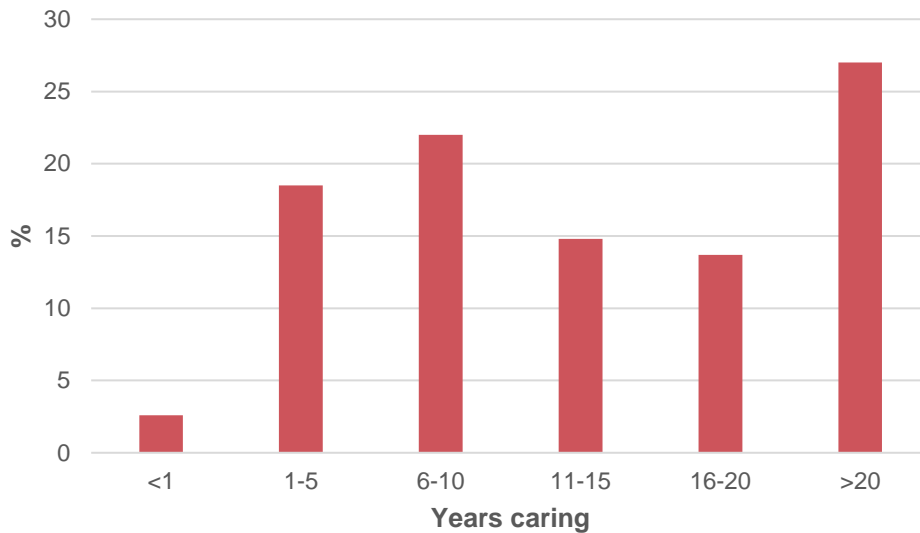


Figure 5. Length of time as a carer

Those who had been caring for longer were more likely to report having experienced a long-term illness or disability themselves over the past 12 months (see Figure 6). This trend was evident even when controlling for carer age.

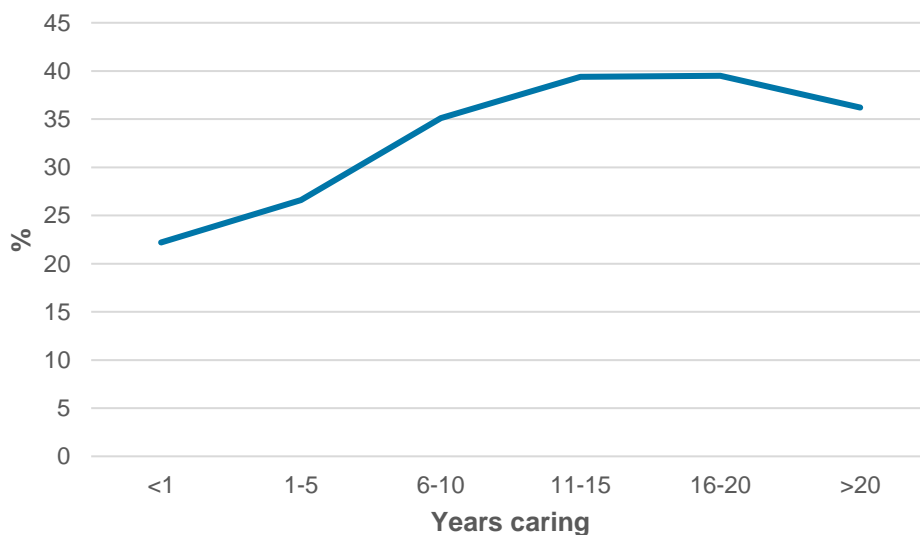


Figure 6. Percentage of carers reporting long-term illness or disability by length of time as a carer



Carers were also asked how many hours per week (on average) they spent caring (see Figure 7).

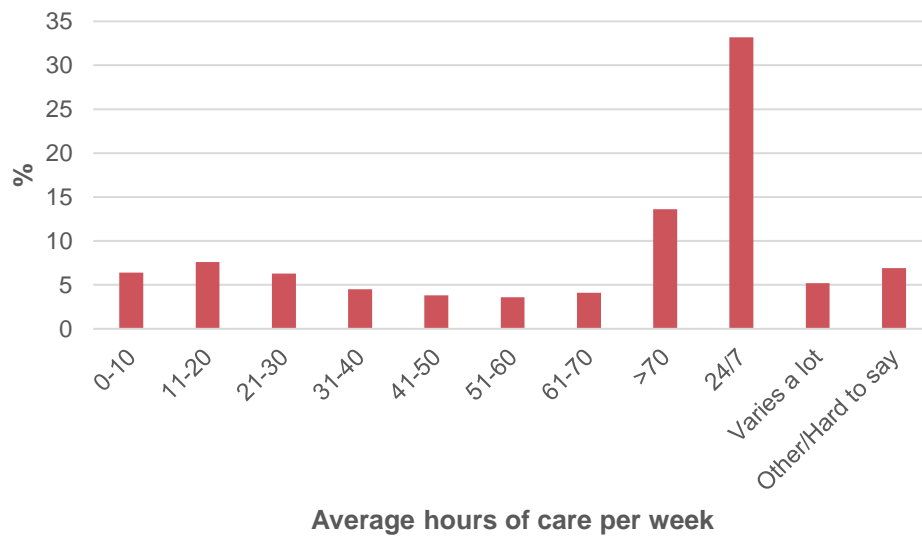


Figure 7. Average hours of care provided per week

It is notable that such a high proportion of respondents (46.8%) indicated that they provided more than 70 hours per week, including 33.2% who considered their role to be 24 hours a day, 7 days a week. An additional 12.1% were unable to quantify the amount of care they provided. Those who had been carers for longer reported providing more hours of care per week on average than those who were newer to their caring roles (see Figure 8), with those who had been caring for 11-15 years most likely to be providing more than 40 hours of care per week.

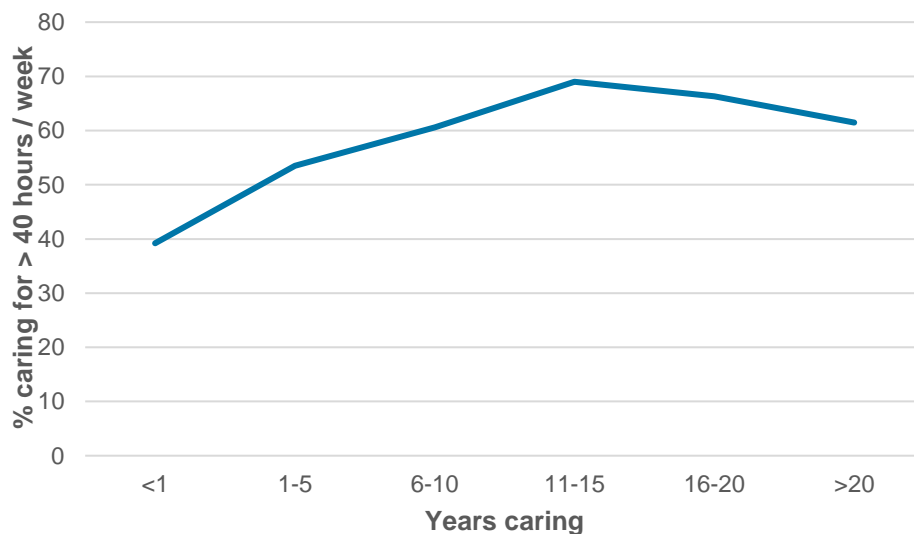


Figure 8. Percentage of carers providing more than 40 hours of care per week by length of time as a carer

## Carers NSW membership

Over half of the sample (57.2%) were 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=1120)	Non-members (n=736)
Average age	59.0 years	53.2 years
Average time caring	17.5 years	13.1 years
Care for: Parent	17.7%	27.0%
Spouse/partner	36.8%	26.0%
Provide over 70 hours care per week	59.9%	50.4%
Living with care recipient	85.2%	79.4%
Other carer	45.2%	56.3%
LOTE	14.7%	11.0%
Education: Bachelor or higher	29.2%	38.7%
Government allowance: Carer Allowance	75.2%	54.9%
Carer Payment	36.6%	22.0%
Other	35.9%	23.9%
Household income: < \$2000 / fortnight	67.9%	50.4%
\$2000+ / fortnight	32.2%	49.6%

### Summary and implications

- The Carers NSW 2016 Carer Survey was completed by more carers than any previous survey conducted by Carers NSW. This sample is not representative of the wider NSW carer population (most notably with an overrepresentation of females, primary carers, and metropolitan based carers), so caution must be exercised in generalising any findings.
- A significant amount of diversity was evident amongst the present sample, including cultural background, sexuality, age, and socioeconomic status. Further analysis is warranted to highlight specific issues faced within these sub-populations of carers.
- One in four carers reported caring for more than one person, with these carers demonstrating an increased likelihood of long-term caring roles. This illustrates the significant complexities that can arise within individual caring situations.
- More than one in four carers had been caring for over 20 years, and nearly half reported providing more than 70 hours of care per week. Those who had been caring for over 10 years reported the highest number of hours per week, highlighting the extensive and very long-term nature of many caring roles.

## The person(s) you care for

The 1,958 carers who completed the survey reported caring for a combined total of 2,526 people. 55.3% of care recipients were male and 43.9% were female. Care recipients' ages ranged from 1 to 103 years old (M=48.2 years). The distribution of care recipient age is shown in Figure 9.

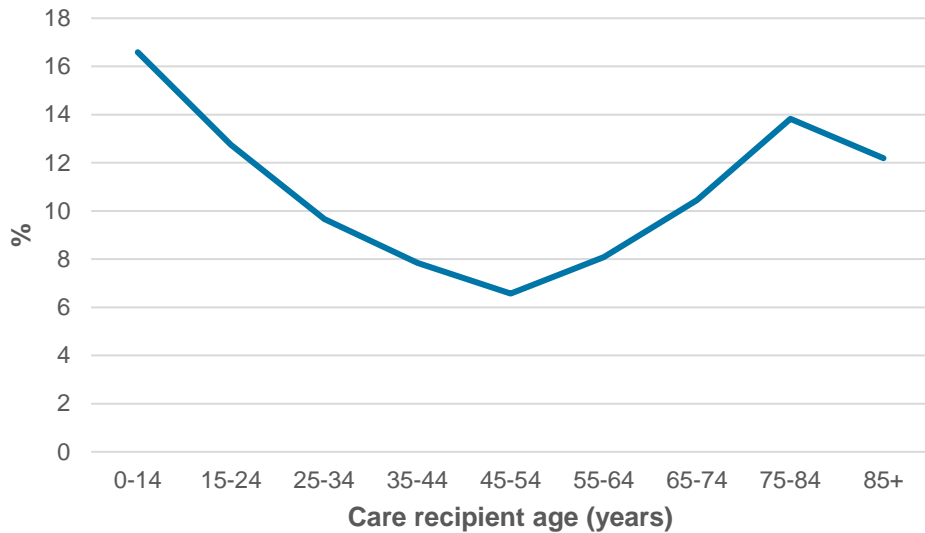


Figure 9. Distribution of care recipient ages

Care recipients were most commonly the carers' sons/daughters (44.1%), followed by spouses/partners (25.3%) and parents (18.8%), as illustrated by Figure 10.



Figure 10. Care recipients' relationship to carers

Carers were asked to identify the conditions/disabilities/illnesses for which care recipients needed their care. Responses were coded according to the International Statistical Classification of Diseases and Related Health Problems, 10<sup>th</sup> Revision (ICD-10; WHO, 2016). The percentage of care recipients within each chapter of the ICD-10 is shown in Table 3. Examples of specific conditions are provided in the most commonly reported categories.

Table 3. Percentage of care recipients within each chapter of ICD-10 classifications

ICD-10 Chapter		% care recipients (n=2,526)
I	Certain infectious and parasitic diseases	0.4%
II	Neoplasms	4.6%
III	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	0.4%
IV	Endocrine, nutritional and metabolic diseases	4.4%
V	Mental and behavioural disorders (e.g., depression, anxiety, dementia, autism, schizophrenia)	61.9%
VI	Diseases of the nervous system (e.g., Parkinson's disease, cerebral palsy, multiple sclerosis, epilepsy)	17.9%
VII	Diseases of the eye and adnexa	4.2%
VIII	Diseases of the ear and mastoid process	2.2%
IX	Diseases of the circulatory system (e.g., heart disease)	8.0%
X	Diseases of the respiratory system	2.5%
XI	Diseases of the digestive system	1.2%
XII	Diseases of the skin and subcutaneous tissue	0.3%
XIII	Diseases of the musculoskeletal system and connective tissue (e.g., arthritis, osteoporosis)	10.3%
XIV	Diseases of the genitourinary system	2.1%
XV	Pregnancy, childbirth and puerperium	-
XVI	Certain conditions originating in the perinatal period	0.4%
XVII	Congenital malformations, deformations and chromosomal abnormalities (e.g., Down syndrome; spina bifida, microcephaly, Fragile X syndrome, Kabuki syndrome, Cru di Chat syndrome)	7.6%
XVIII	Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (e.g., frailty, chronic pain)	17.2%
XIX	Injury, poisoning and certain other consequences of external causes (including brain injury)	7.0%
XX	External causes of morbidity and mortality	-
XXI	Factors influencing health status and contact with health services	2.1%
XXII	Codes for special purposes	-

N.B. Percentages do not add up to 100% due to a combination of missing data and reports of multiple diagnoses

A significant majority of care recipients (75.7%) were reported to be living with their carers. An additional 17.0% were living in their own homes, while 4.0% lived in care facilities, and 2.0% lived in supported accommodation.

26.3% of care recipients could not be left alone at all, and just 19.4% could be left alone for a few days or longer (see Figure 11).

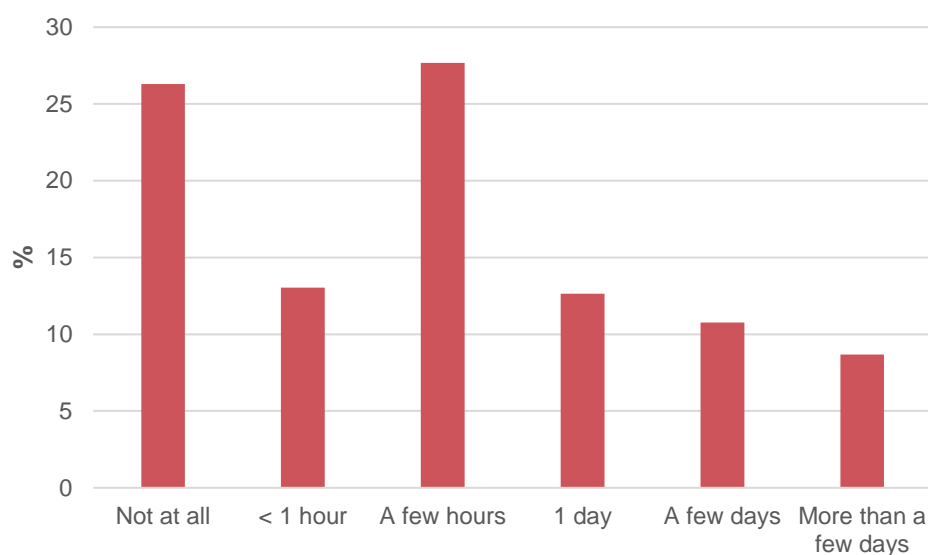


Figure 11. Length of time care recipients could be left alone

### Summary and implications

- For the first time, care recipients' conditions, disabilities, and illnesses were categorised according to an established framework (ICD-10). Mental and behavioural disorders were the most commonly reported, with a wide range of diagnoses across ICD-10 classifications. This framework will provide a useful basis for comparing the caring experience across conditions.
- Three out of four care recipients were reported to live with their carers. Future research should focus on carers who do not live with care recipients, including a focus on how carers perceive their caring role when care recipients move into care facilities or supported accommodation.
- High levels of support were required for many care recipients, with a majority unable to be left alone for more than a few hours. Further analysis is warranted in exploring carers' experiences across varying levels of required support.
- The comprehensive data collected about care recipients will allow for in-depth analysis of carer experiences across a range of specific caring contexts.

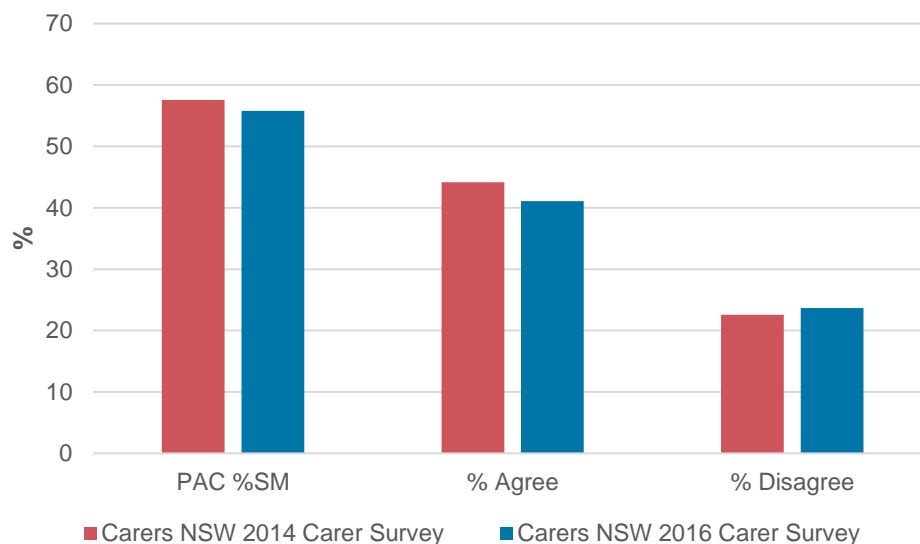
## Health, wellbeing, and carer recognition

Carers' health and wellbeing were measured using a number of different validated scales that have been widely used in Australian and international research (including the Carers NSW 2014 Carer Survey). For the purpose of reporting 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).

### Positive aspects of caregiving

The Positive Aspects of Caregiving scale (PAC) measures the extent to which participants agree with a range of statements regarding potential positive aspects of their caring roles, e.g., "caring has made me feel more useful," "caring has made me feel appreciated," and "caring has strengthened my relationship with others." 41.1% of responses indicated agreement with these statements, compared to 23.7% indicating disagreement.

Results from the PAC were very similar to those reported in the Carers NSW 2014 Carer Survey, both in terms of overall scale scores, and the rates of agreement and disagreement, as shown in Figure 12.



*Figure 12. Comparison of Positive Aspects of Caregiving scores from Carers NSW 2014 and 2016 Carer Surveys*

The following differences between groups of carers were evident in relation to their PAC scores:

- Male carers reported more positive aspects of caring than female carers.
- CALD carers reported more positive aspects than those who did not identify as being from a CALD background.
- Carers who experienced a long-term illness or disability themselves reported fewer positive aspects than those without an illness or disability.
- Carers living within Greater Sydney reported more positive aspects than those living outside Sydney.
- Those who identified someone else who helped provide care reported more positive aspects than those who did not receive this informal assistance.

## Personal wellbeing

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 in a variety of contexts, including 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 with the PWI. These findings are presented alongside the mean PWI score of carers in the Carers NSW 2016 and 2014 Carer Surveys in Figure 13. Across these three surveys of carers, reported wellbeing continues to be significantly lower than the normal range reported by the general Australian population.

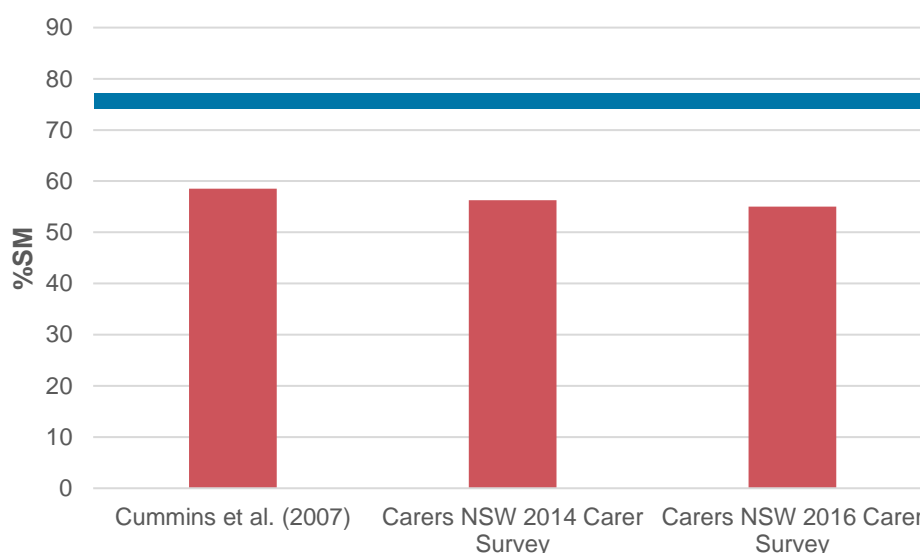


Figure 13. Comparison of PWI scores from Carers NSW 2016 Carer Survey and previous research<sup>4</sup>

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 14, along with comparative Australian normative data.

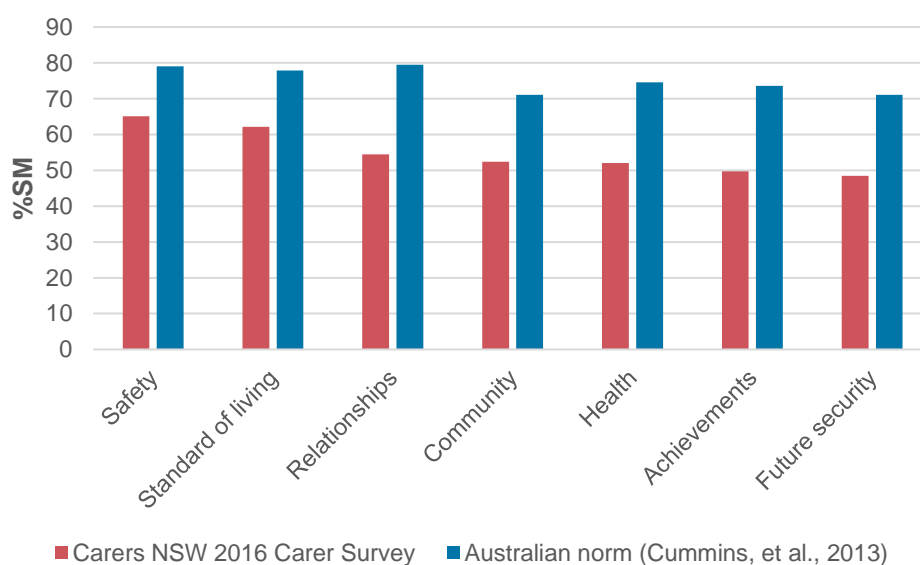


Figure 14. Mean scores across PWI domains

<sup>4</sup> The blue bar indicates the normal range reported by the general Australian population (73.8-76.7%SM) (Cummins et al., 2013).

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

- Wellbeing was higher amongst male carers than female carers.
- Wellbeing was lower amongst CALD and Aboriginal and Torres Strait Islander carers than those not identifying with these cultural backgrounds.
- Wellbeing was lower amongst carers who were experiencing their own long-term illness or disability than those who were not.
- Wellbeing was higher amongst those carers living within Greater Sydney than those who lived outside Sydney.
- Wellbeing was lower amongst carers who were receiving government financial assistance than those who were not.
- Wellbeing was higher amongst those who indicated that another carer helped provide care than those who did not have this support.

### 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 Carers NSW 2014 Carer Survey results, and ABS (2012a) normative data in Figure 15.

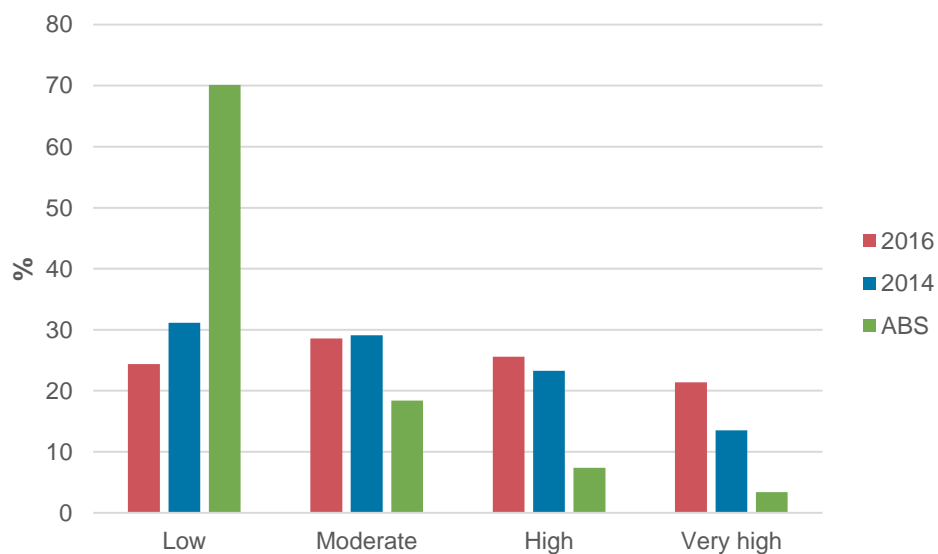


Figure 15. Comparison of K10 categories from Carers NSW 2016 and 2014 Carer Surveys, and ABS Health Survey (2012a)

Compared to data from the ABS Health Survey (2012a), significantly fewer carers in both the Carers NSW 2014 and 2016 Carer Surveys reported low levels of psychological distress, while larger proportions reported medium, high, and very high levels of distress.



Reflective of the results on the PWI outlined above, the following group differences in mean K10 scores were found:

- Female carers reported higher levels of distress than male carers.
- Carers identifying with CALD or Aboriginal and Torres Strait Islander backgrounds reported higher levels of distress than those who did not identify with these cultural backgrounds.
- Carers living within Greater Sydney reported lower levels of distress than those living outside Sydney.
- Carers receiving government financial assistance reported higher levels of distress than those not receiving financial assistance.
- Carers experiencing their own long-term illness or disability reported higher levels of distress than those without an illness or disability.

Carers' reports of psychological distress generally decreased with increasing age, as demonstrated by Figure 16.

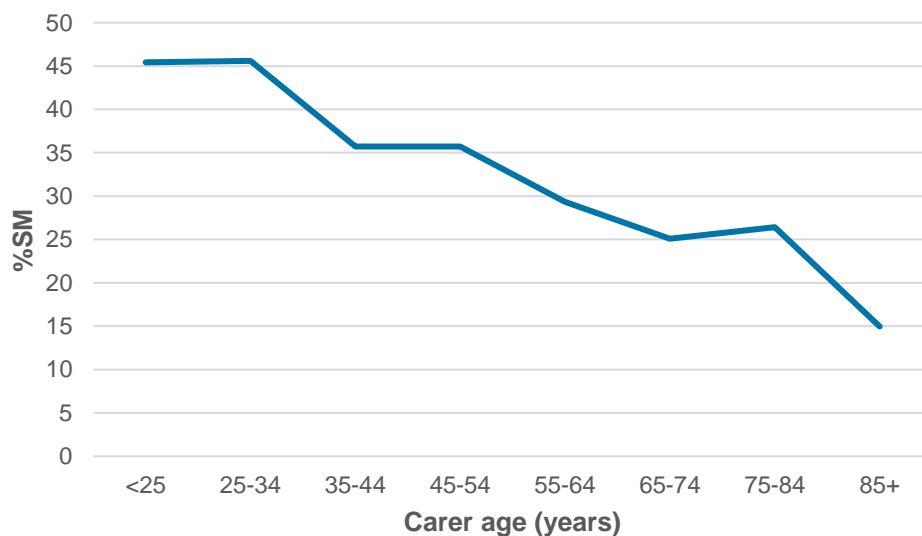


Figure 16. Mean K10 scores by carer age group

Levels of psychological distress were also found to increase with increasing hours of care per week provided, as shown in Figure 17.

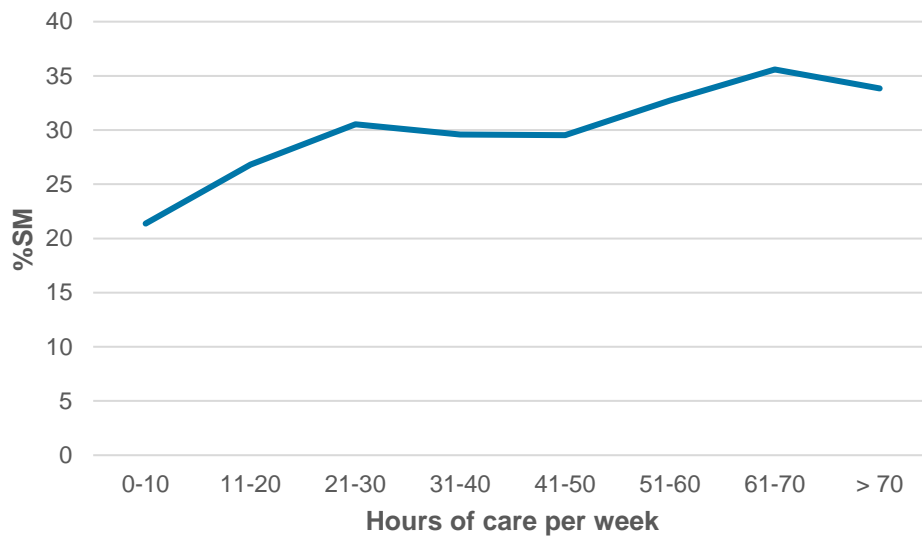


Figure 17. Mean K10 scores by hours of care per week

## Health

In addition to the above wellbeing measures, carers were asked a single, self-report question about their health, with over half (54.3%) indicated that their health was “good” or better (see Figure 18).

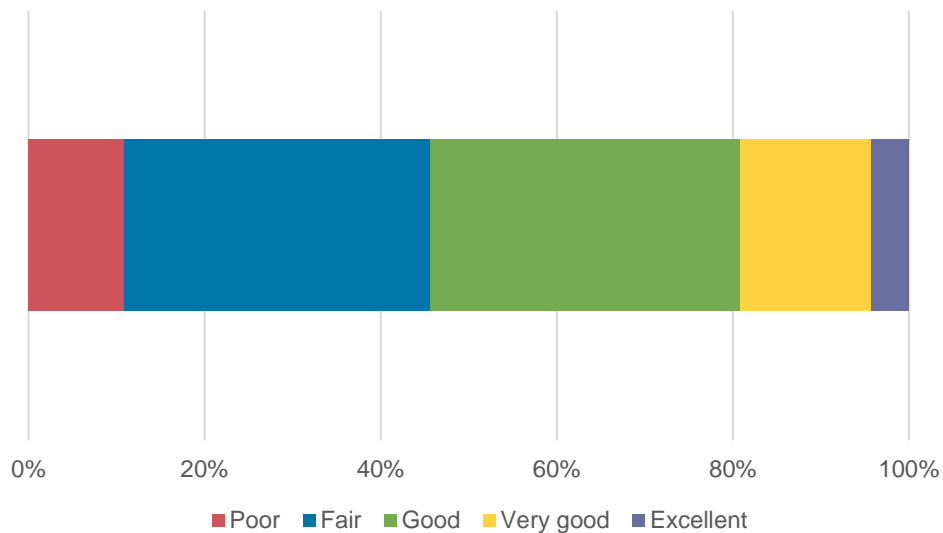


Figure 18. Carers' self-reported health status

Carers were also asked to compare their current health to 12 months ago, with 44.6% indicating their health status had not changed, and 10.4% reporting some health improvements. 44.9% reported that their health had worsened to some degree (see Figure 19).

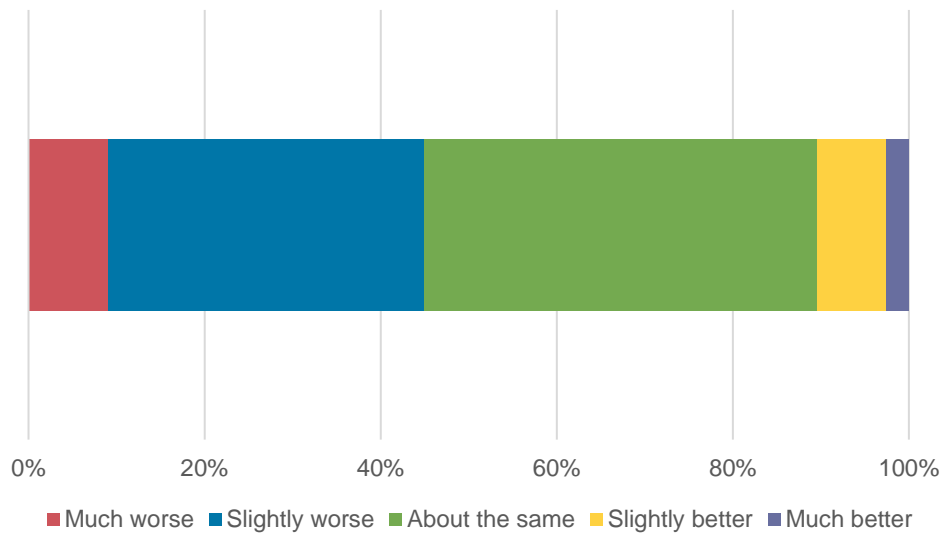


Figure 19. Carers' self-reported health compared to 12 months ago

The single-item self-reported health measure was correlated with other reported measures of wellbeing utilised in this survey. Specifically, better self-reported health was associated with higher wellbeing (PWI), more positive aspects of caring (PAC), and lower psychological distress (K10), as illustrated in Figure 20.

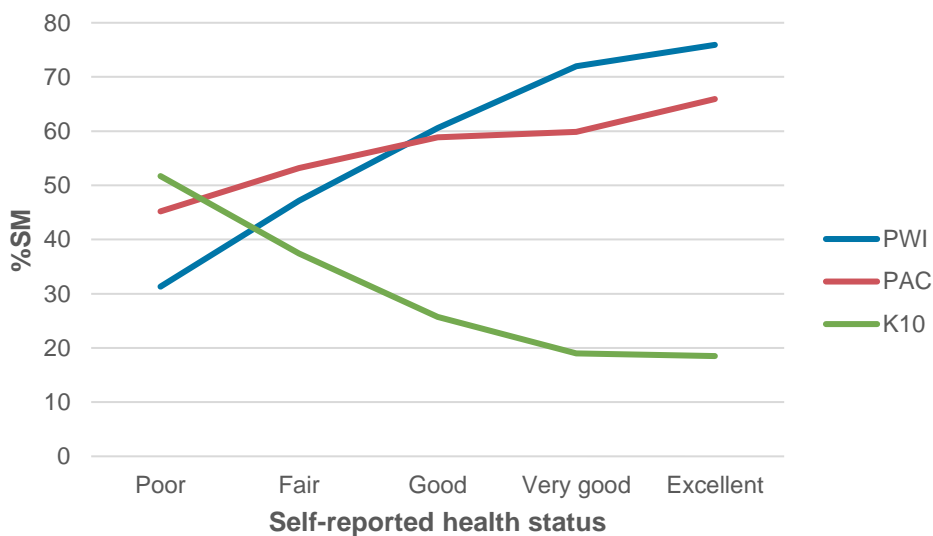


Figure 20. Correlation between self-reported health and other wellbeing measures

## Carer recognition

Carers were asked the extent to which they agreed that their caring role was recognised and valued by their community, outlined in Figure 21.

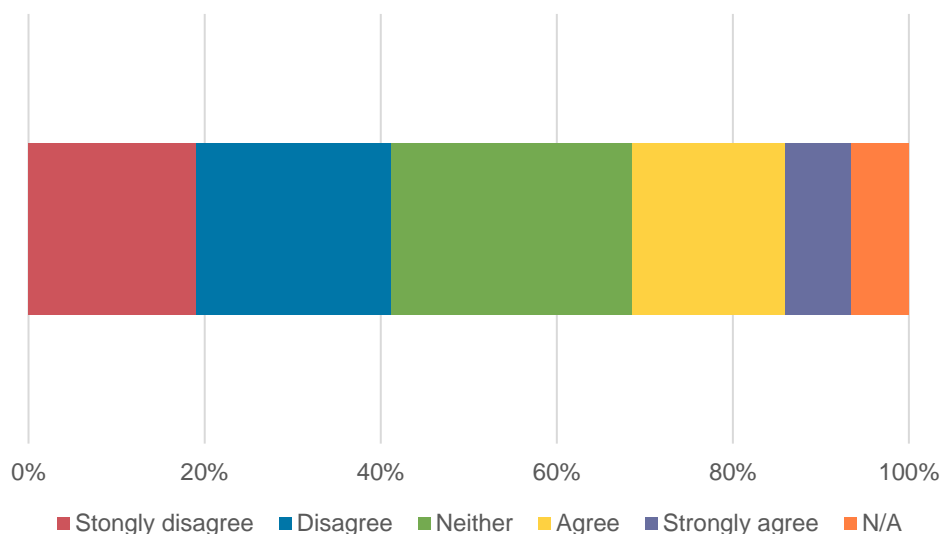


Figure 21. Carers' agreement with being recognised and valued by the community

Participants were also invited to make additional comments regarding this issue. In line with the spread of responses demonstrated in Figure 21, these comments suggested a diverse range of experiences, as illustrated by the following quotes:

*You are acknowledged and supported when people see you doing things (taking the person on an outing, visiting them in hospital etc.). All the extra hours, the hard things – nights, toileting, washing, cleaning etc., no-one sees these or acknowledges you then. They are the hardest times.*

*Recognised and valued by my close circle but not the wider community.*

*The people I know are kind, caring and try to be supportive, but in general most people are glad they do not have to be a carer.*

*Increasingly I am getting the feeling that Government is not interested in supporting carers – programs for carers have been scrapped and the focus is on the person cared for. This has increased my anxiety for the future because I feel I will no longer get the support I need to care for my loved ones who need me on a daily basis.*

*We don't care for our loved ones to be recognised or valued.*

*Unless you are a carer you don't understand the full impact it has on you, your family and your friends.*

*No value at all. You complete any document where it asks your occupation. Caring is never even on there. If you put it in they change it to "home duties". Yes I am a mother but what I do is different. It really upsets me that I feel like I am not valued, that what I do is not important and also I have had people say I have thrown away my education.*

*The Supported Living Fund (pre-NDIS) makes me feel appreciated and supported in my role as a carer.*

*The community in general doesn't care. Out of sight, out of mind.*

*My small rural community is very supportive of us both.*

*Some people recognise how important and exhausting caring is + just how much thought and love goes into it. To others, carers are invisible until they are in that situation themselves.*

*I feel a lot community don't want to know about my caring role at all & don't understand & don't want to understand.*

*Sadly, I don't feel a part of my community simply because 'time' is needed to be a part of anything.*

*People are increasingly well intentioned but even close friends do not understand how debilitating a carer's life can be.*

*My community doesn't even know I exist.*

*In higher education, this role is hardly recognised. When approached, university administration admits they understand it, but in fact little is done to assist young carers to achieve educational potential.*

*I certainly felt valued by the community during my caring role; however, now that the role has ended (due to death) I no longer feel supported.*

*If caring was valued, you would get a pension that would allow you to pay rent, purchase fresh quality food and pay bills. I live in poverty. My children live in poverty.*

### Summary and implications

- In line with previous research and Carers NSW Carer Surveys, the reported wellbeing of carers was poorer than the general Australian population.
- Despite reporting low wellbeing on average, widespread agreement was found with positive aspects of caring.
- Certain groups of carers were identified as being at higher risk of poor wellbeing, namely: female carers, Aboriginal and Torres Strait Islander carers, those receiving government financial assistance, those living outside Greater Sydney, and those experiencing their own long-term illness or disability. Carers who reported that someone else assisted them with caring responsibilities demonstrated higher levels of wellbeing than those without that support. Further analysis is warranted to investigate the relationship between these variables and to ascertain the strongest predictors of carer wellbeing.
- CALD carers were identified as being at risk of poorer wellbeing, but simultaneously reported more positive aspects of caring than their non-CALD counterparts. Further research is warranted into the potential cultural impacts of care around these issues.
- Better health, higher wellbeing, and lower psychological distress were all highly related.
- Perceived recognition and value of caring roles by the community was low, indicating a need for continued advocacy and awareness raising.

## Carers' employment

As mentioned in Table 1, 37.0% of current carers reported being in paid employment, while 62.9% were not. The demographic characteristics of these groups are provided in Table 4.

*Table 4. Demographic comparison of working carers and those not working*

		<b>Employed (n=725)</b>	<b>Not employed (n=1231)</b>
Gender:	Female	85.9%	77.7%
	Male	9.7%	19.0%
Age:	<45 years	22.9%	14.1%
	45-64 years	64.7%	38.3%
	65+ years	6.1%	41.8%
Hours of care per week:	0-20	22.6%	8.9%
	21-40	13.5%	9.3%
	41-70	14.1%	10.0%
	> 70	32.8%	55.1%
Education:	Bachelor or higher	45.8%	22.7%
	Certificate/diploma	33.5%	36.2%
	High school	9.4%	20.8%
	Less than high school	6.2%	14.8%
CALD		15.0%	17.6%
Aboriginal and Torres Strait Islander		5.2%	2.4%
LGBTI		3.6%	2.9%
Receive Government financial assistance		55.2%	83.7%
Disability <sup>‡</sup>		25.4%	37.4%
Carers NSW member		42.5%	66.0%

Notable differences can be seen in age distributions, with working carers unsurprisingly having a far smaller representation of over 65 year olds. It is also not surprising that employed carers tended to provide fewer hours of care per week, and were less likely to receive government financial assistance. Finally, it is worth noting that working carers were more likely to have completed higher levels of formal education than those who were not employed.

Carers were asked to indicate if caring had impacted their working lives in a number of ways. Figure 22 indicates the percentage of carers, working carers, and not working carers who reported experiencing each of the listed career outcomes.

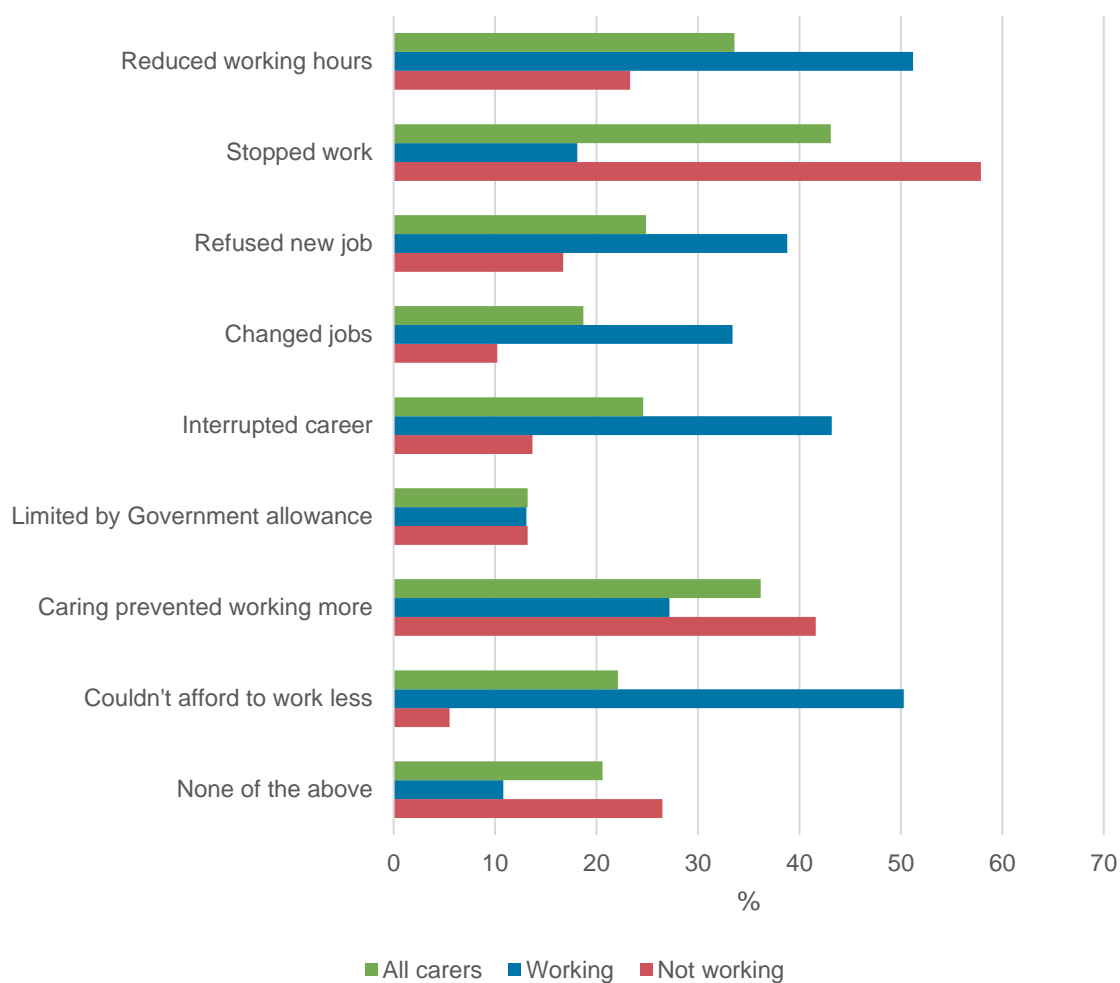


Figure 22. Percentage of carers reporting impacts of care on work by current employment status

Across all carers, stopping work, being prevented from working more, and reducing working hours were the most common career impacts of caring. Less than 1 in 5 (18.1%) of working carers indicated that they had previously stopped work because of care, suggesting the potential difficulty of returning to the workforce after taking time away from employment for caring responsibilities. An important financial consideration of balancing work and care is also evidenced by the finding that one in two (50.3%) working carers indicated that they could not afford to work less, even though they would have liked to.

## Non-working carers

Of those carers who indicated they were not in paid employment, nearly one third (29.3%) reported that they would like to be. Over half (52.6%) were retired, and 56.5% had stopped working because of their caring responsibilities.

A small proportion of non-working carers (3.2%) indicated that they had never been in paid employment. Others reported having stopped work from within the previous year, through to 64 years ago (mean = 11.1 years ago).

Those carers who stopped work because of caring responsibilities were more likely to have left the workforce within the last 10 years than those who were retired, who were more likely to have been out of the workforce for longer periods of time. A comparison of the length of time since last employment between these carers is shown in Figure 23 (N.B. these categories are not mutually exclusive).

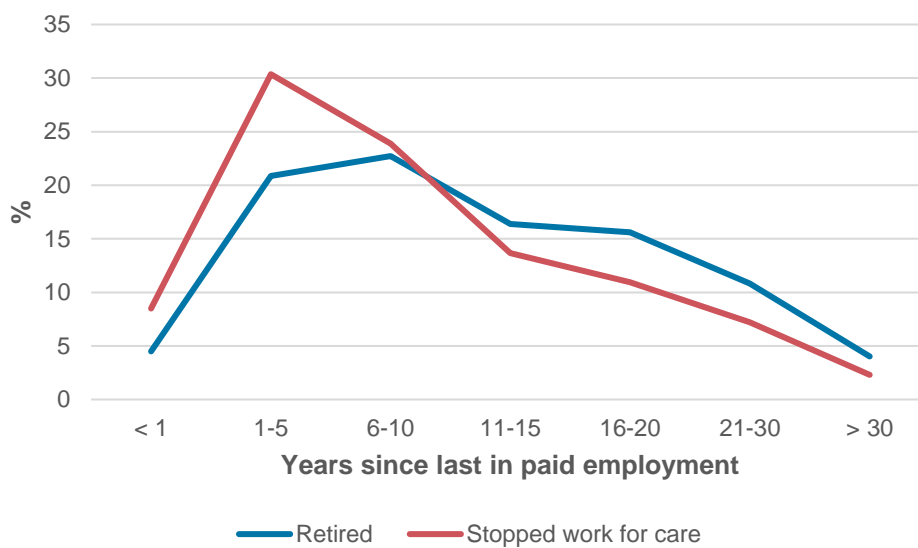


Figure 23. Length of time since last in paid employment



## Working carers

### Employment characteristics

Amongst working carers, 39.0% indicated that they were in full time employment, 40.3% were working part time, 14.6% were casually employed, and 8.4% were self-employed.

As mentioned in Table 4, the vast majority (85.9%) of working carers were female (just as the vast majority of the overall sample was female). Female working carers were far more likely to be in part time positions than males, as demonstrated in Figures 24 and 25.

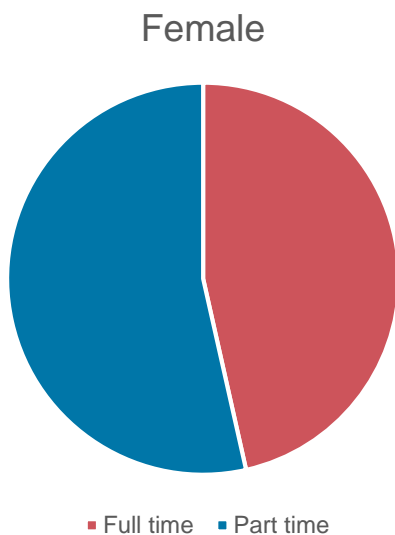


Figure 24. Employment status of female working carers

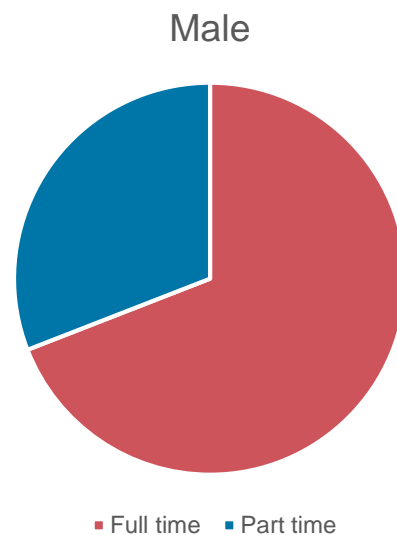


Figure 25. Employment status of male working carers

Carers reported an average of 26.6 hours of paid work per week. Responses to this question were categorised into an equivalent number of working days per week, where each work day represented up to 8 hours (i.e., 0 to 8 hours = 1 day; more than 8 and up to 16 hours = 2 days; and so on). The average number of days worked per week is depicted in Figure 26.

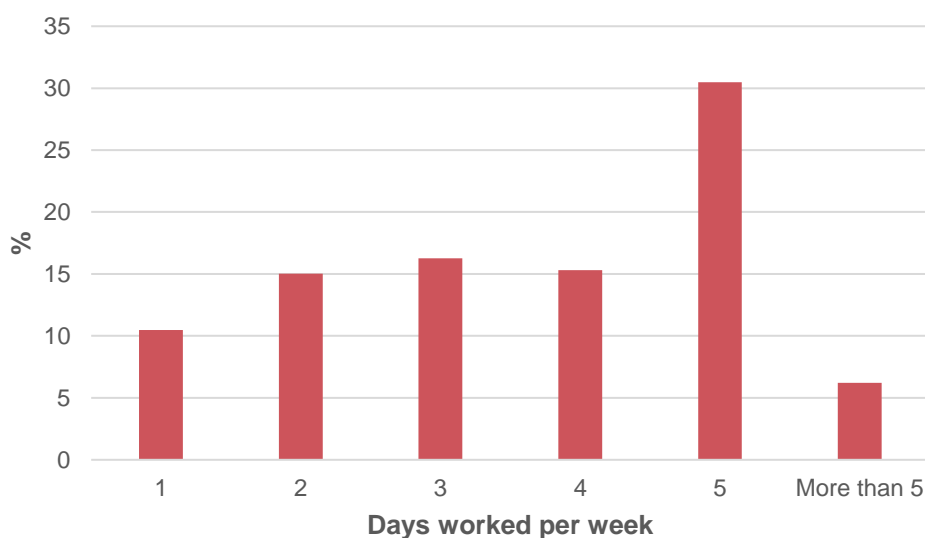


Figure 26. Average number of days worked per week

Participants were also asked how many hours they would choose to work per week, if given the choice. The average response was 24.9 hours – 1.7 hours less than the average hours worked. Responses ranged from wanting to work 43 hours more per week, through to wanting to work 42 hours less per week. Using the same method of categorising hours into work days, carers' desired changes to working arrangements are demonstrated in Figure 27. More than one in four working carers (26.5%) reported not wanting any change in their working arrangements, while 37.2% reported wanting to work less and 26.2% wanted to work more.

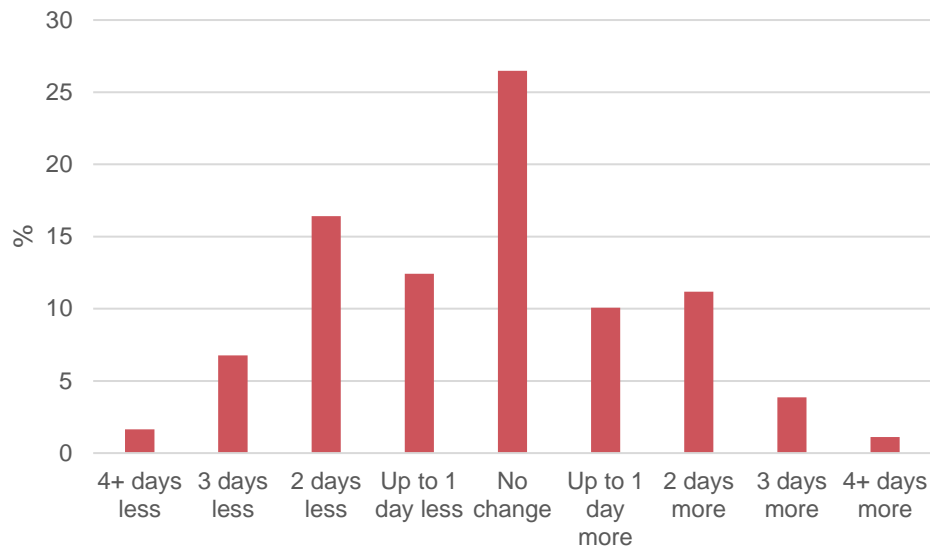


Figure 27. Ideal amount of work compared to current arrangements

Carers were most commonly employed in four main industries: health, community/non-profit, government/public sector, and education/training. A breakdown of the percentage of carers employed in different industries is shown in Figure 28.

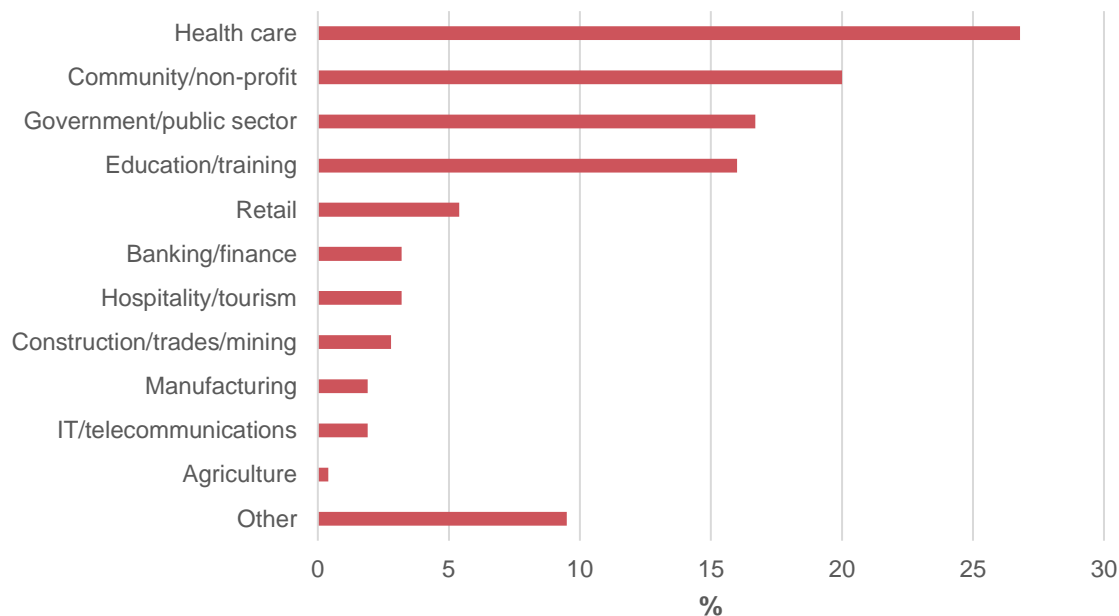


Figure 28. Carers' employment sectors

Working carers were most likely to be employed in organisations with fewer than 100 employees (see Figure 29).

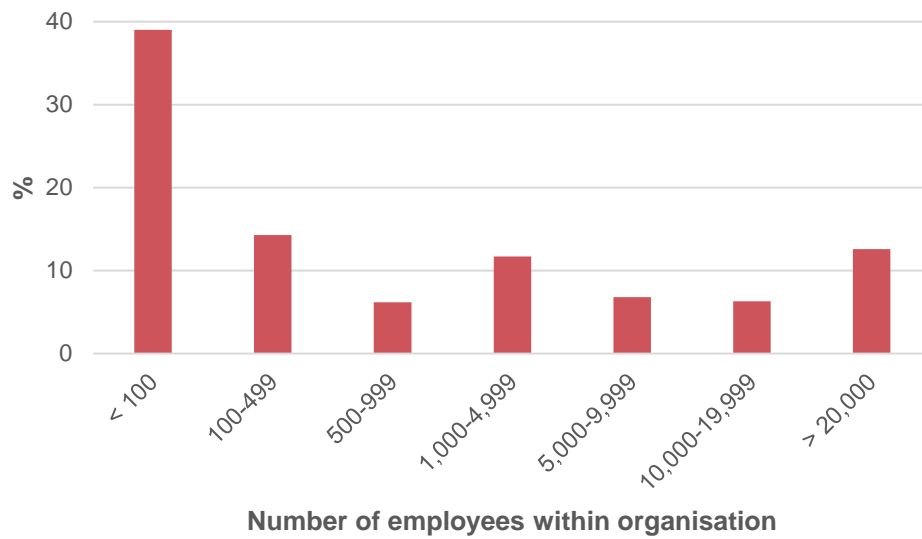


Figure 29. Size of employing organisation

Carers were asked to identify the term that most closely corresponded to their job title, with the results illustrated in Figure 30.

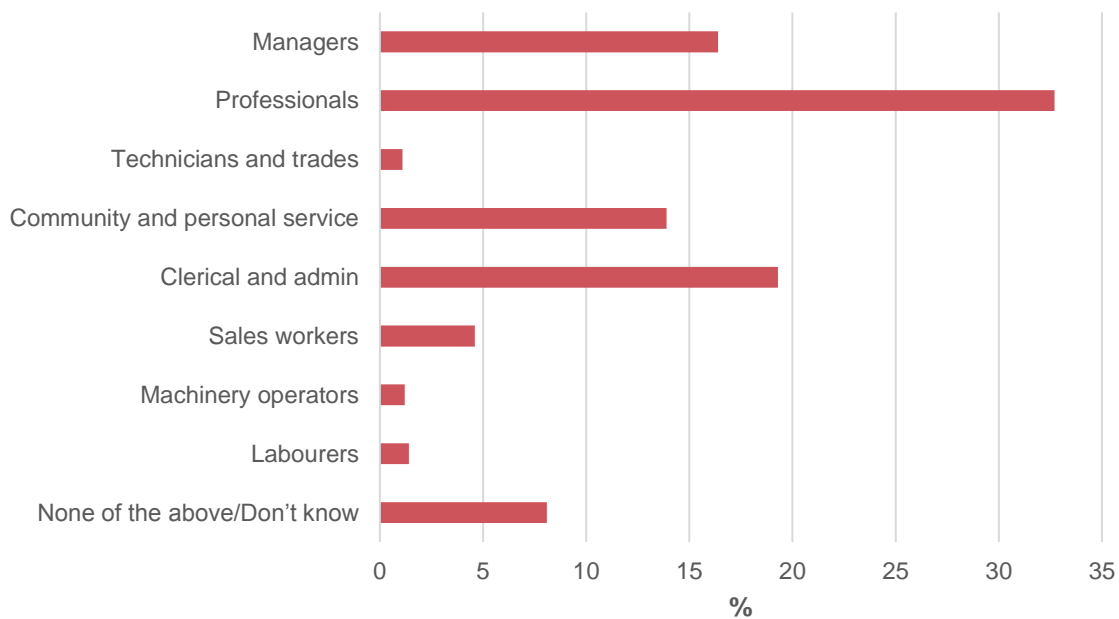


Figure 30. Carers' job titles

## Workplace culture, work-life balance, and job satisfaction

A significant majority of working carers (85.4%) indicated that their employers knew about their caring responsibilities. Employers' awareness levels were high across all employment conditions and sectors.

Carers were asked to provide insight into their satisfaction with work and the level of interference between work and the rest of their lives. Firstly, participants completed the Australian Work and Life Index (AWALI), which measures perceptions of work-to-life interference. The mean AWALI score of carers in the Carers NSW 2016 Carer Survey is compared to sub-populations from the 2014 AWALI survey (Skinner & Pocock, 2014) in Figure 31. The blue columns refer to participants from the 2014 AWALI survey who reported either no caring responsibilities, child care responsibilities, elder care responsibilities, or both child and elder care responsibilities.

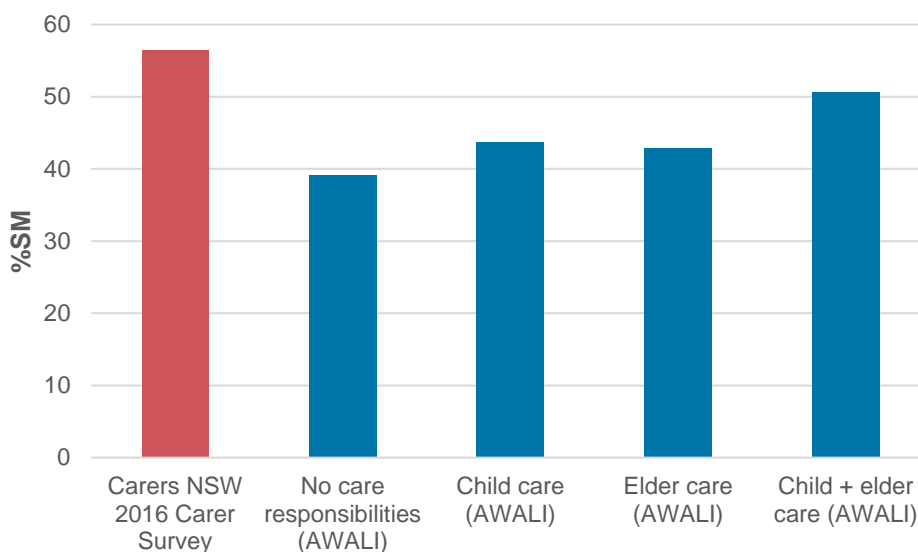


Figure 31. Mean AWALI score of Carers NSW Carer Survey respondents compared to sub-populations from 2014 AWALI survey

The results from the 2014 AWALI survey indicate that work-to-life interference increases as caring demands increase. Respondents from the Carers NSW 2016 Carer Survey reported higher levels of work-to-life interference than any of categories of carers identified by the AWALI 2014 survey.

The following differences in mean AWALI scores between groups of carers were apparent:

- Work-to-life interference was higher amongst those working longer hours, and also amongst those with larger discrepancies between actual and ideal working hours (both those who wanted to work more and less).
- Work-to-life interference was lower amongst those providing fewer hours of care per week, but remained stable amongst those providing more than 20 hours of care per week (regardless of how many more hours of care were provided).
- Aboriginal and Torres Strait Islander carers reported higher work-to-life interference than those who did not identify with an Aboriginal and Torres Strait Islander background.
- Carers experiencing their own long-term illness or disability reported higher work-to-life interference than those without an illness or disability.

Working carers' satisfaction with their jobs was assessed using the Job Satisfaction Subscale (JSS) from the Michigan Organizational Assessment Questionnaire (Cammann et al., 1979). Overall, 77.9% of working carers indicated that they were satisfied with their jobs. Job satisfaction was lower amongst working carers who had a long-term illness or disability than those who did not, and satisfaction was also higher amongst LGBTI carers than their non-LGBTI counterparts. Unsurprisingly, job satisfaction was negatively correlated with work-to-life interference, as demonstrated by Figure 32. This figure also shows that job satisfaction generally increased with increasing age (with the exception of those working carers under the age of 25 years).

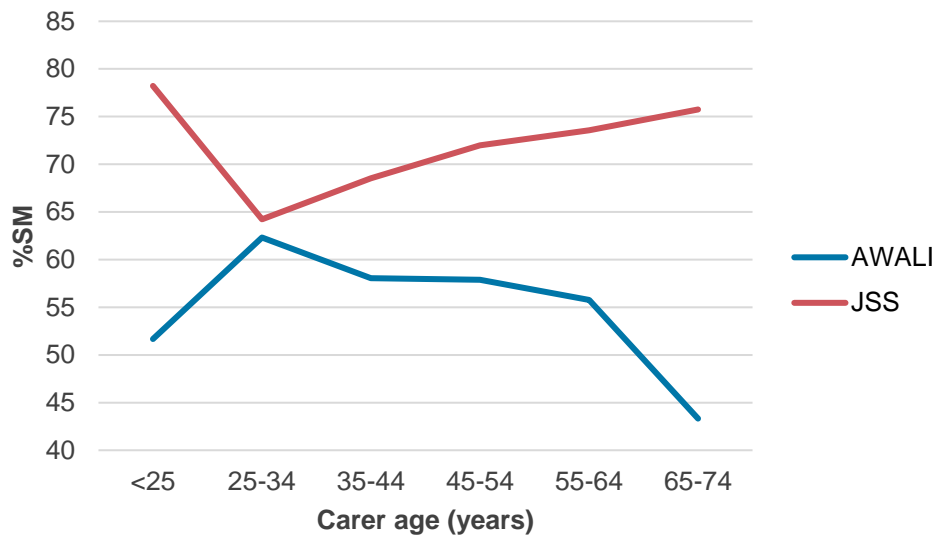


Figure 32. Work-life interference (AWALI) and job satisfaction (JSS) by carer age

As well as this measure of job satisfaction, a single item of job turnover intentions was included, with participants asked how often they had seriously considered quitting their current job over the past 6 months (Figure 33). While two in five working carers (40.9%) had rarely or never considered quitting, 28.3% had considered quitting at least fairly often.

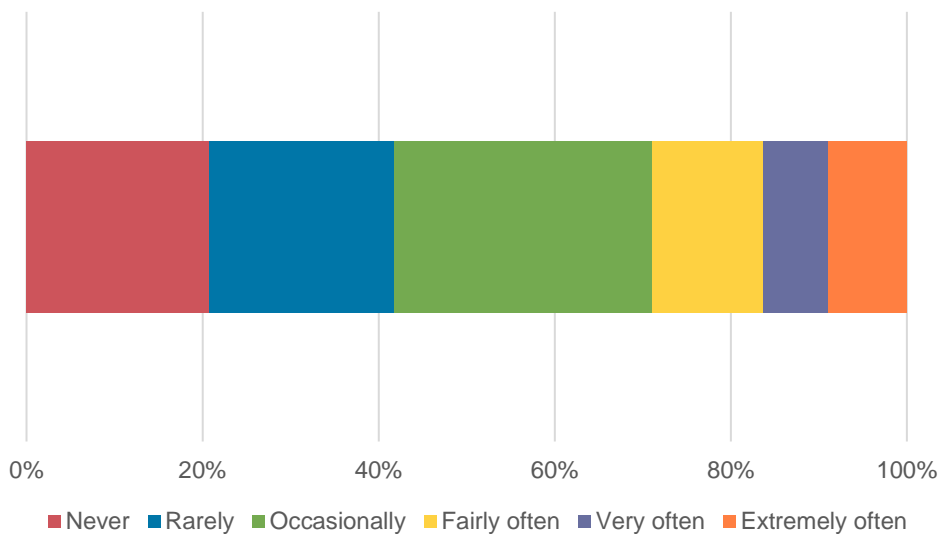


Figure 33. Frequency of considering quitting current job

The nature of support within the workplace appeared to be inconsistent amongst respondents, with 63.2% indicating that they were comfortable telling others at work about their caring responsibilities. In addition, just over half (52.7%) reported that their workplace supported them to combine work and care. Those who felt that their workplace did support them to combine work and care reported higher job satisfaction and lower work-to-life interference than those who did not feel supported (Figure 34).

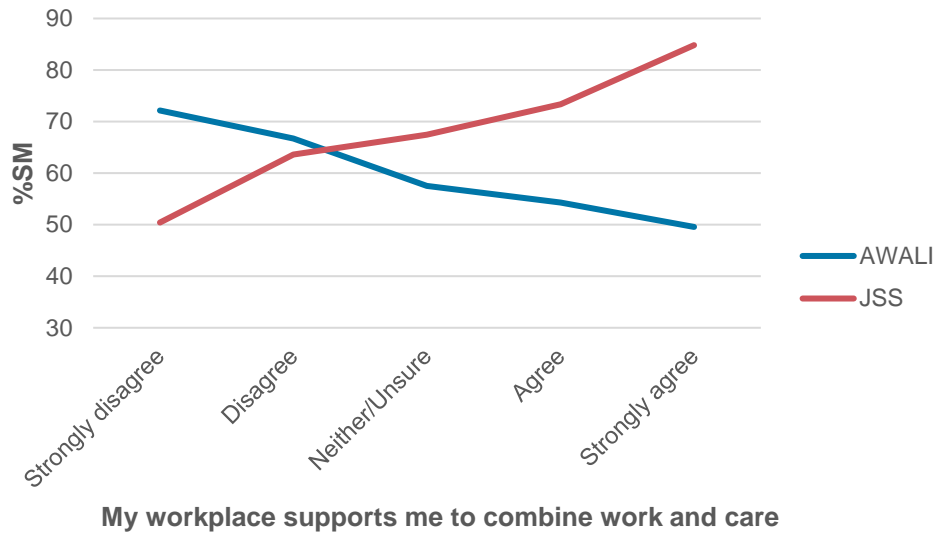


Figure 34. Work-life interference and job satisfaction by workplace support for combining work and care

Working carers were also asked about the availability, and their use of a range of supportive workplace practices. A breakdown of responses is shown in Figure 35.

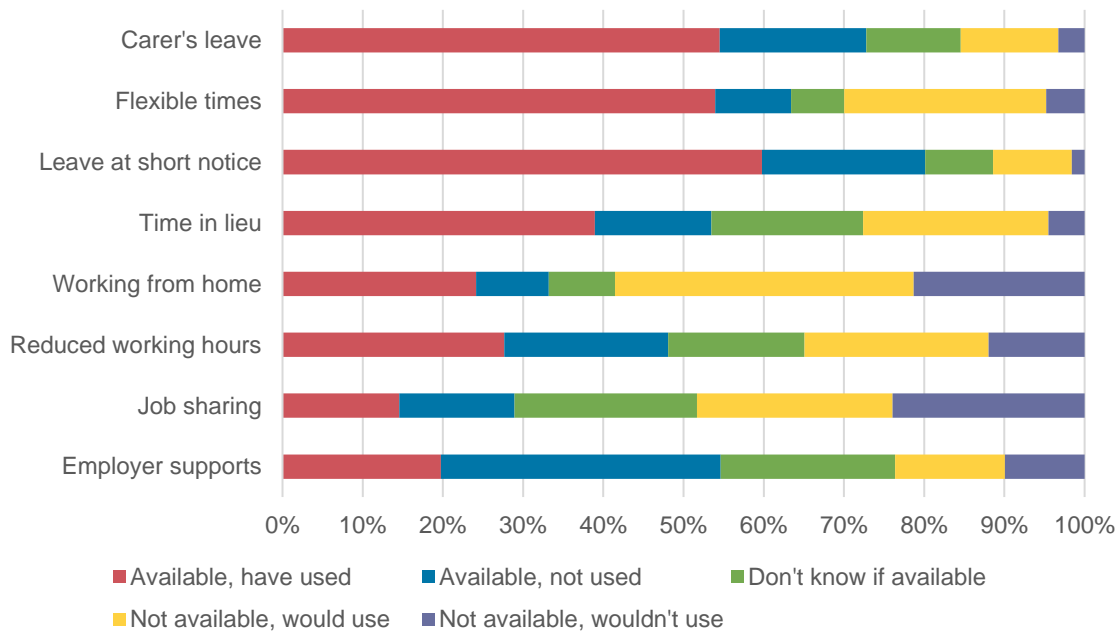


Figure 35. Availability and use of supportive workplace practices

The most commonly used practice was leaving at short notice for emergencies, followed by carer's leave and flexible start/finish times (all utilised by more than half of the working carers in this sample). Conversely, job sharing and employer supports (e.g., employee assistance programs) were the least utilised, used by less than 20% of working carers. Despite being utilised by fewer than one in five working carers, over half indicated that formal employer supports were available to them. Although workplace legislation dictates that all full and part time employees are entitled to carer's leave, 9.7% indicated that it was not available to them, suggesting a lack of awareness of their entitlements. Arrangements to work from home were utilised by less than one quarter (22.2%) of working carers, and only 8.3% of working carers indicated that they had not worked from home when the option was available. This flexible working arrangement was highly sought after, however, with more than one in three working carers (34.2%) reporting that it was not available, but they would use it if they could.

Participants were also invited to make comments about their experiences at work, with many positive and negative experiences reported:

*While I love my work, I am starting to find conflict between carer responsibilities and work.*

*Work is very flexible and that is one of the things I look for when I'm looking for a job. Flexibility is more important than money at this stage.*

*Since starting work I have become a much more rounded person and have overcome a great deal of depression and lack of self worth. I feel much more confident and this is reflected in being able to perform my caring role with more confidence.*

*My workplace claims to support working carers but the reality of lived experience says something else.*

*While we have a number of great policies in the workplace, how these are implemented is dependent on individual managers. If those managers choose not to support individual staff, then the HR system is supportive of the employer. Due to issues in relation to confidentiality many staff have decided not to use the resources that are available to them.*

*To most of them you are just a problem member of staff that is best replaced with a younger person that doesn't have family issues.*

*I am very knowledgeable about my rights as a carer and I am able to self advocate but still feel that I am discriminated in terms of being given access to opportunities to further my career due to my caring responsibilities.*

*If my employer knew about my caring responsibilities, it would jeopardise my job and career.*

*They are very flexible but I can't afford to cut back on hours.*

*Spend a lot of unpaid hours doing work to make up for feeling guilty about not being at work fulltime.*

*I have lost a lot of good jobs because of my role as a carer. Now I am on minimum wage and less hours as I am formally unreliable but a valued team member.*

*My employer is understanding up to a certain point. Initially, they are flexible but as mum's illness or hospitalisation goes on (and it can be weeks) there is less flexibility.*

*They are very flexible and accommodating to caring to my child and own mental health issues but they also need to be sure I can cope with the workload and I am not having more time off than on. I have a job to do, responsibilities and program to fulfil. Sometimes that is a hard balanced.*

*I feel discriminated against as colleagues with small children are given more flexibility with time than I am.*

*I feel my job empowers me to feel valued, and gives me respite from caring.*

*I am a hard working and competent person as management have informed me and I deserve to be treated better with my hectic home life in addition to full-time employment.*

*The above list of current workplace practices is the first time I have seen possibilities for combining work and caring roles more effectively.*

*My manager is extremely supportive of my family needs, in turn I do my best to return with best possible work. This is a great working relationship to have.*

### Summary and implications

- Caring had impacted many carers' career paths, particularly by preventing them from working more, requiring them to reduce working hours, or resulting in them stopping work altogether.
- Of those who were not working, over half had stopped working as a direct result of caring responsibilities. A significant proportion indicated that they would like to be working.
- While 37% of working carers indicated wanting to work less, more than one in four wanted to work more.
- There was a high level of awareness of caring responsibilities amongst employers, though perceived workplace support was much lower, with just over half of working carers feeling that they were supported to balance work and care.
- High levels of work-to-life interference were reported, particularly amongst those with longer working hours and larger discrepancies between actual and ideal working hours.
- Better workplace support and lower work-to-life interference were associated with increased job satisfaction.
- A range of support workplace practices were identified, with leave entitlements and flexibility in working hours being the most widely utilised. Despite the option of working from home not being widely available, results suggest that it would be valued and utilised by working carers if given the option.



## Service access and social support

### Formal support services

Carers were asked about their usage and desired usage of three particular support services: respite, counselling, and carer support groups (Figure 36).

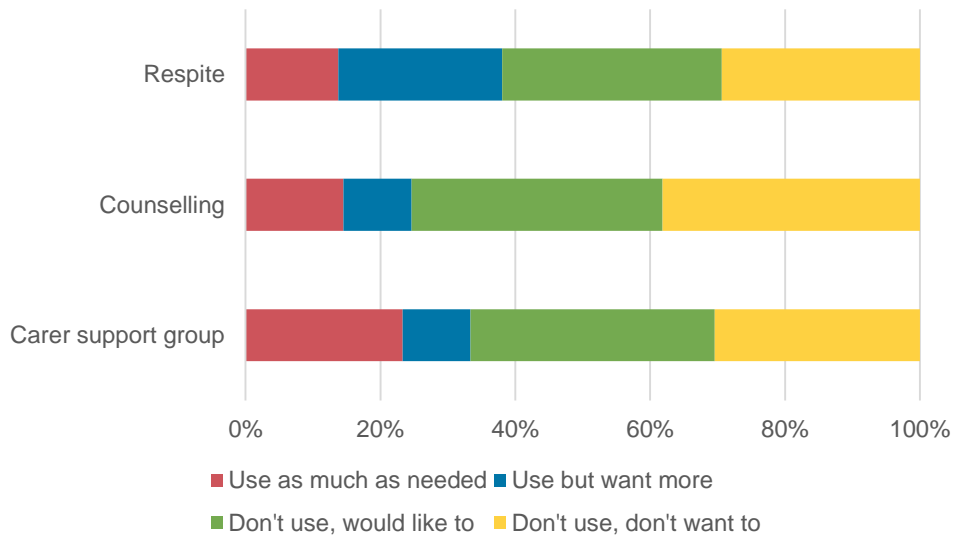


Figure 36. Carers' use of services

Less than half of carers in this survey indicated that they were using each of these services, and roughly half of those not using these services indicated that they did not want to. Of these services, respite was the most commonly used (38.0% of respondents), though 63.9% of those using respite reported that they would like to use more.

Just under half (49.6%) of respondents reported that the person/s they cared for received formal support/services. These carers were asked about their satisfaction with these services, and how their caring roles were influenced by care recipients' access of formal supports.

The majority of carers indicated satisfaction with care recipients' services (74.0%), while only 9.6% expressed dissatisfaction (see Figure 37).

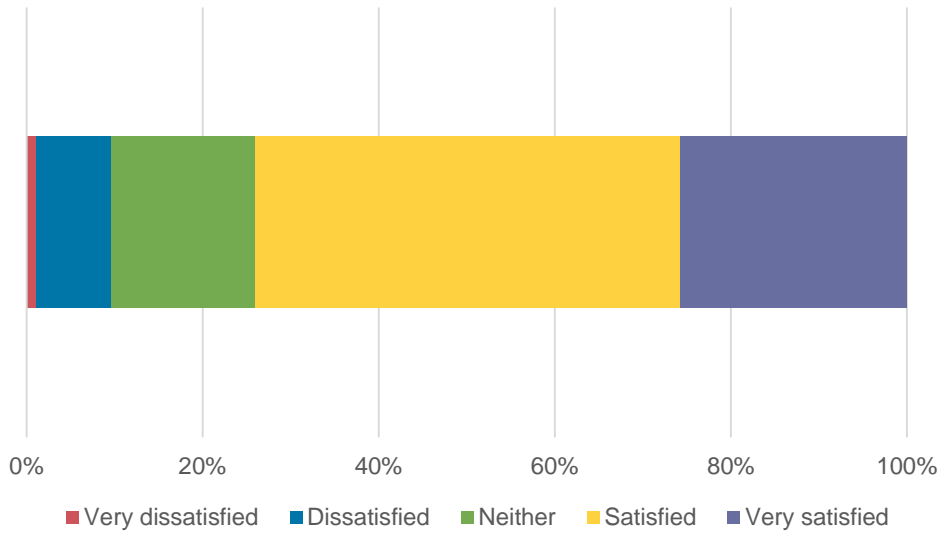


Figure 37. Carers' satisfaction with care recipient services

Reflective of this satisfaction, 75.1% of carers indicated that they had personally benefitted from the services received by those they cared for (Figure 38).

Do these services benefit YOU as a carer in any way?

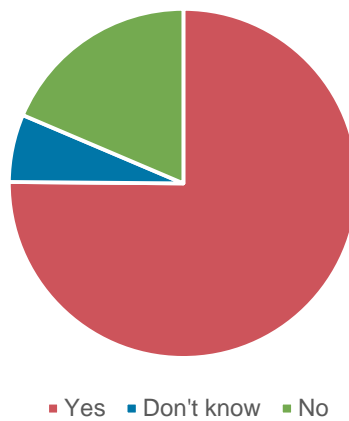


Figure 38. Carers' reports of care recipients' services benefiting them as carers

One of the benefits of these services for carers was perceived in a reduction in the amount of care provided. As shown in Figure 39, 27.5% of carers did not feel that the amount of care they provided had reduced at all, while the remaining 72.5% indicated that the amount of care they provided was reduced to some extent by care recipients' services.

### Do these services reduce the amount of care you provide?

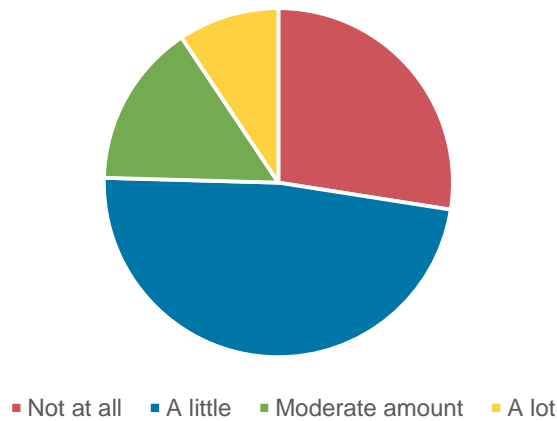


Figure 39. Amount by which care recipients' services reduced amount of care provided by carers

Carers were asked to identify if they cared for a person with a National Disability Insurance Scheme (NDIS) plan, or a person who received services through a Commonwealth Home Care (CHC) Package. 109 carers indicated caring for someone with a NDIS plan, and 327 cared for a person received a CHC package. The extent to which they agreed that these initiatives had made their lives better as carers is demonstrated in Figure 40.

### Has made my own life better as a carer

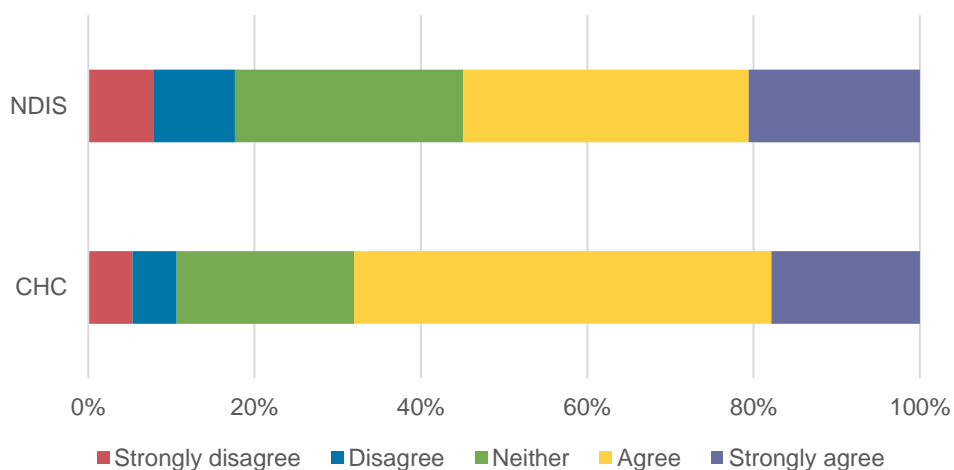


Figure 40. Agreement with whether the NDIS or CHC has made carers' lives better

Carers were invited to make comments about the NDIS, CHC, or supportive services in general, with some of the main points illustrated in the quotes listed below:

*I can't wait for the NDIS to come so that we actually have real choice and control to support our loved one to have the very best life they can have.*

*They came rather unexpectedly from having my wife ACAT assessed. They were a surprise and a great relief.*

*They are very professional and we are satisfied with the support we receive.*

*Staff are changed very often, consistency of care is not common practice. Service providers do not seem to recognise the importance of the consistency of care staff for clients with dementia and high care needs.*

*Client directed care is not useful for all and many feel bullied by a system that is supposed to create flexibility but often is more rigid because of the cost structures imposed.*

*We feel invisible and unsupported. The system for supporting people with disabilities and their carers is truly broken...*

*Nursing home care is OK, but definitely not great. There aren't enough staff on and there is no stimulation or activities. If my family members or myself don't turn up I worry that they get ignored both in terms of care and in terms of having any activities or conversation.*

*The services that my family members receive are very good. However, getting them into the correct services is a very long and painful journey with very little support along the way.*

*Respite is a godsend. It would be great if it was able to be accessed when needed. And to also have more than the pitiful 63 days a year.*

*They are very knowledgeable, kind and helpful. They adapt to whatever situation we find ourselves in and quickly find and give information or emergency care in desperate times. I don't feel so alone now.*

*There are not enough services that are free. I cannot afford them.*

*My son receives weekly home care service – domestic assistance. It makes him more organised, more independent. I can spend more time enjoying my relationship with him as a mother, not just a carer.*

*Living in rural NSW, services of any kind are few and far between. At times, this has a substantial impact on my ability to be the best carer I can be as often I am exhausted, feel isolated and overwhelmed.*

*I find it sad that my child at 36 resides in an aged care facility. He needs constant nursing care, I feel that young people's nursing care facilities could be established that would meet his needs, not just the offer of a group home.*

*Most of the services in this area do not really run after hours much and if I am working full time I cannot really utilise any of them.*

*It's great that we can pick and choose the type of care/support we need. The person-centred approach really made our service providers up their game.*

## Social support

The social support experienced by carers was measured using the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1988). This scale provides a measure of overall social support, as well as measuring perceived support from three separate sources: significant others, family, and friends. Carers perceived the most support from significant others, while the family was comparatively least supportive (Figure 41).

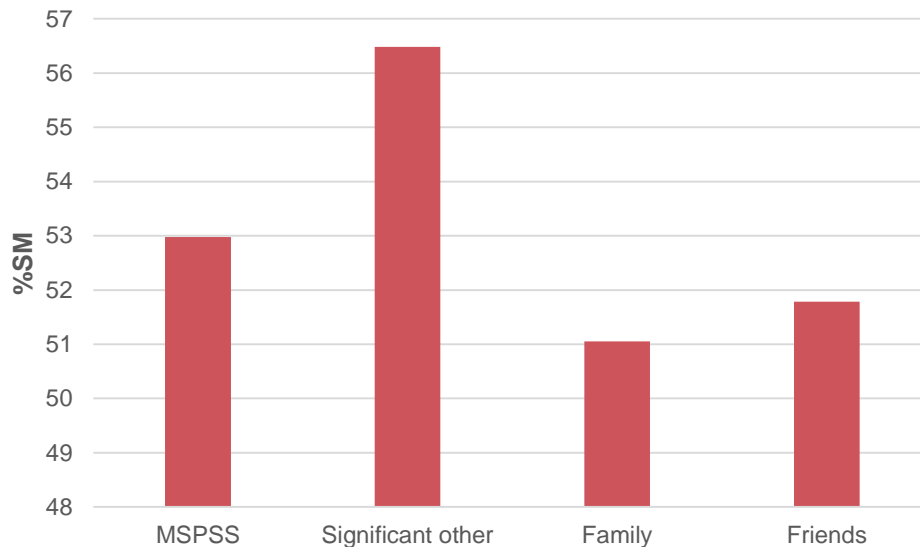


Figure 41. Mean MSPSS (and subscale) scores

The importance of social support is underscored by the finding that higher scores on the MSPSS were associated with better self-rated health, higher wellbeing (PWI), more positive aspects of caring (PAC), and lower psychological distress (K10).

The following group differences in mean MSPSS scores were found:

- Carers who identified as Aboriginal and Torres Strait Islander reported less perceived social support than those who did not.
- Those living within Greater Sydney reported more social support than those living outside Sydney.
- Carers who experienced their own long-term illness or disability, and those who were receiving government financial support reported less social support than those without an illness or disability, or those not receiving financial support.
- Working carers reported more social support than those who were not working.
- CALD carers reported less social support from their significant others and their friends than those who were not from CALD backgrounds.
- Females reported more social support from significant others than males.

Carers' perceived social support generally increased with increasing age (see Figure 42), though this support also tended to decrease with an increase in the length of time caring (see Figure 43).

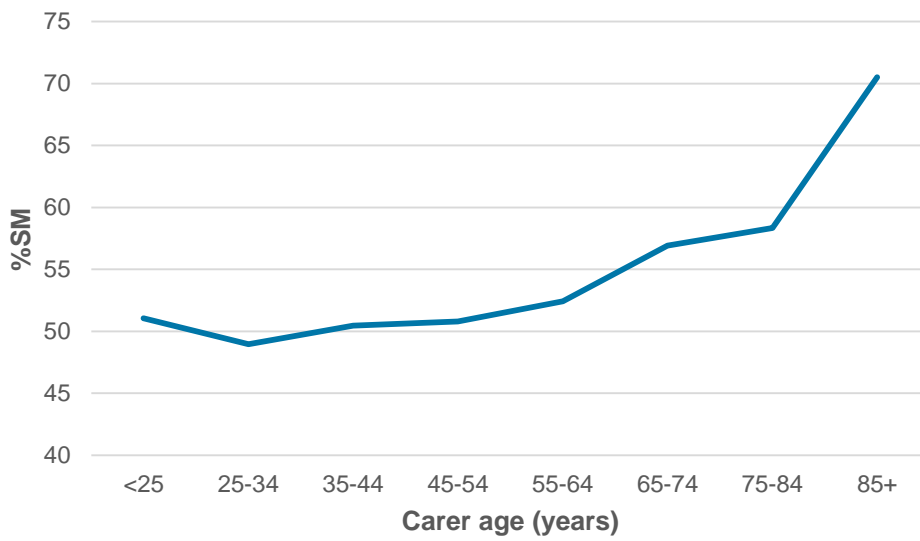


Figure 42. Mean MSPSS score by carer age

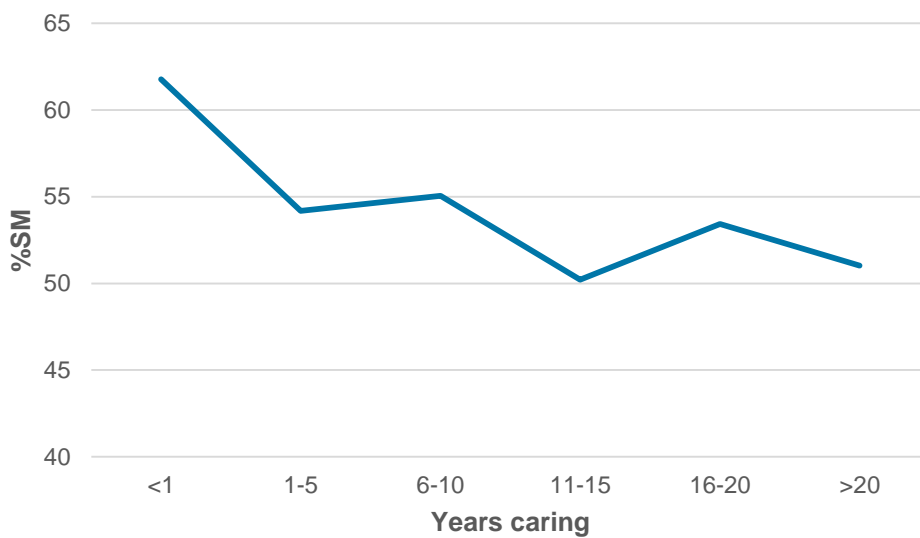


Figure 43. Mean MSPSS score by years caring

Taken together, these results suggest that those who commence caring at a younger age and remain in the role for an extended period of time are particularly at risk of perceiving less support from social sources.

As the number of hours of care provided per week increased, carers reported a decrease in perceptions of social support (Figure 44).

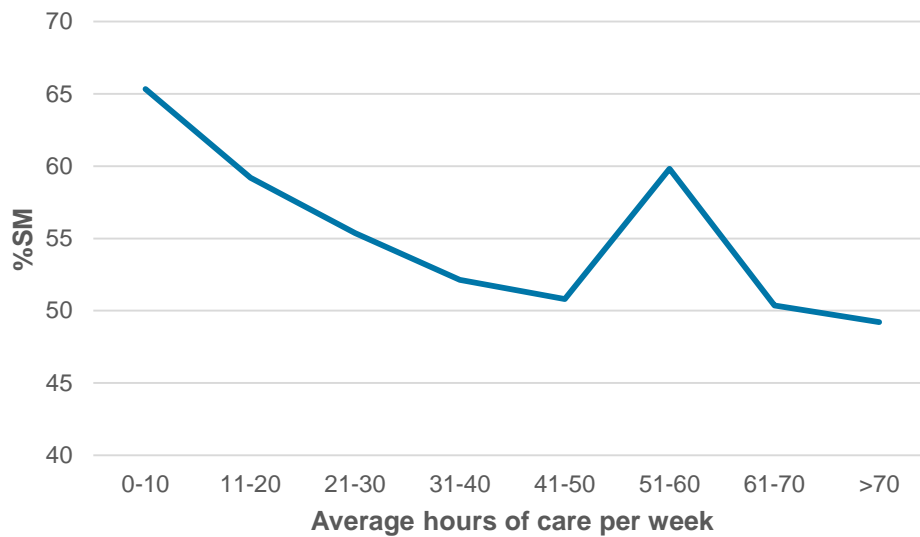


Figure 44. Mean MSPSS score by average hours of care provided per week

#### Summary and implications

- Results show significant gaps in service delivery, with substantial proportions of carers wanting increased access to respite, counselling, and carer support groups.
- Satisfaction with services received by care recipients was high, with three out of four carers personally benefitting from these services.
- Those carers who cared for people involved in the NDIS or CHC initiatives were generally positive about their implementation, with a majority agreeing that their lives had been made better as a result.
- Carers' significant others were the best source of social support, with the wider family reported as comparatively less supportive.
- Social support was perceived most positively amongst the following groups: working carers, non-Aboriginal and Torres Strait Islander carers, older carers; those providing fewer hours of care per week, those living within Greater Sydney, those not receiving government financial assistance, and those not experiencing their own long-term illness or disability. Further analysis and research is warranted in exploring their positive social interactions, and also to assist those groups at risk of lower social support.

## Former carers

A total of 657 participants indicated that they had previously held caring roles that had now ended. Of those, 534 were still caring for someone else and 123 were no longer carers. A breakdown of the proportion of current and former carers is shown in Figure 45.

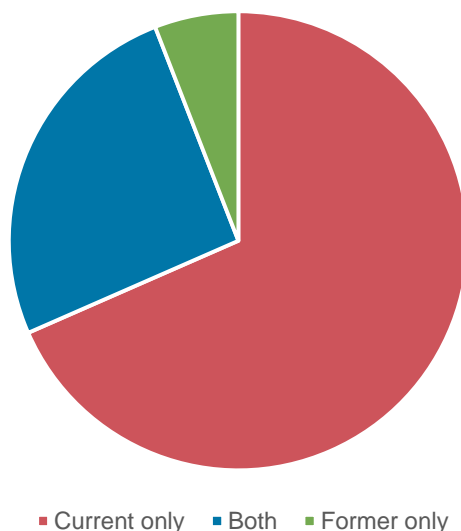


Figure 45. Proportion of current and former carers

A comparison of the demographic characteristics of these three groups is provided in Table 5.

Table 5. Demographic characteristics of current and former carers

	Current only	Both	Former only
Total population	1,424	534	123
Gender:			
Female	78.8%	85.6%	68.3%
Male	17.3%	10.7%	21.1%
Age:			
<45 years	19.0%	12.7%	7.3%
45-64 years	46.5%	52.2%	28.5%
65+ years	28.4%	28.8%	52.0%
Employed	36.6%	38.2%	33.3%
Education:			
Bachelor or higher	30.6%	33.0%	22.0%
Certificate/diploma	34.8%	36.3%	41.5%
High school	17.3%	14.4%	13.8%
Less than high school	11.8%	11.0%	9.8%
CALD	16.7%	16.5%	13.8%
Aboriginal and Torres Strait Islander	2.5%	5.8%	0.8%
LGBTI	2.5%	5.1%	1.6%
Disability <sup>‡</sup>	30.6%	39.1%	28.5%

N.B. Individual categories may not add up to 100% due to missing data

<sup>‡</sup> Percentage of carers who had experienced any long-term illness or disability themselves during the last 12 months



The most notable differences between these groups related to gender and age. Those who were no longer caring were more likely to be male, and those with both current and former caring roles were most likely to be female. Those who were no longer caring were also older on average, with 52.0% aged 65 years and over.

Most former carers in this sample had their caring roles end within the last three years (66.7% - see Figure 46), and most had previously cared for one person (see Figure 47).

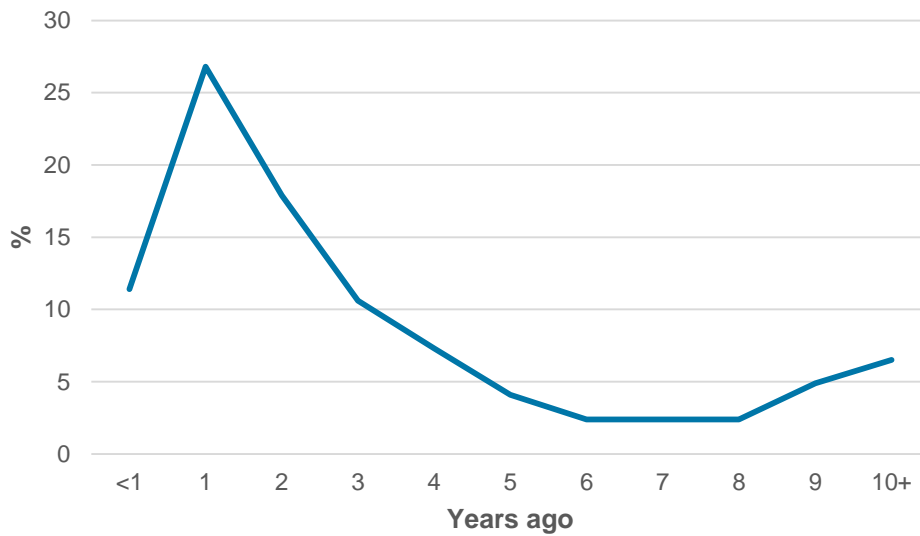


Figure 46. How long ago caring roles ended (former carers only)

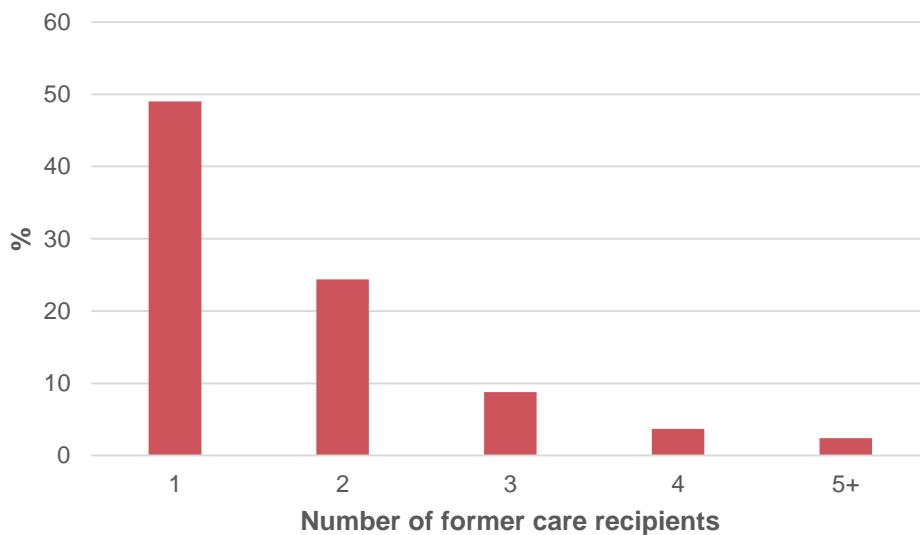


Figure 47. Number of people previously cared for

Parents were by far the most common former care recipients, having been cared for by 62.1% of former carers (Figure 48).

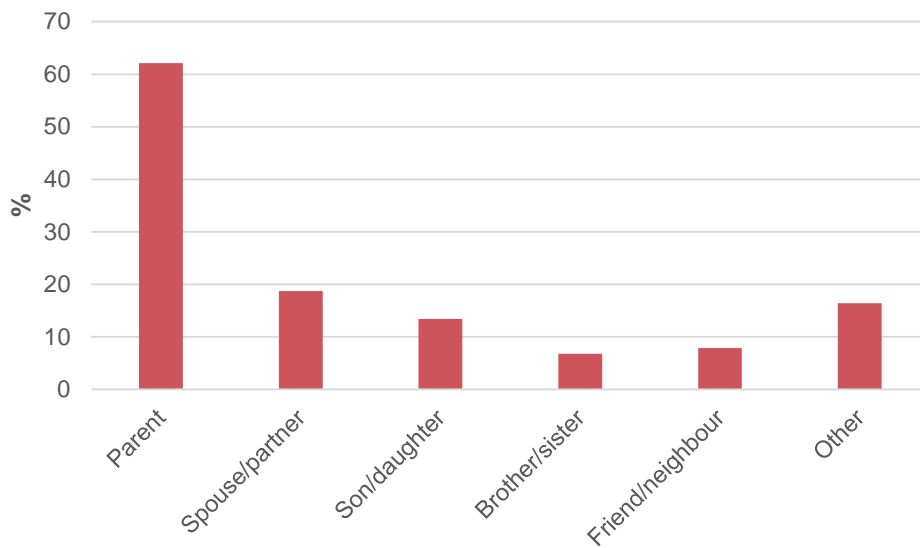


Figure 48. Relationship of former care recipients

More than two-thirds of former carers (68.3%) reported that their caring roles ended because of care recipient death. Only 5.3% reported that it was due to them not being able to cope. Nearly one in five (19.3%) former carers reported caring roles ending due to care recipients being admitted into residential care. This is a noteworthy figure, considering admission into residential care does not necessarily equate to the end of a carer's caring responsibilities.

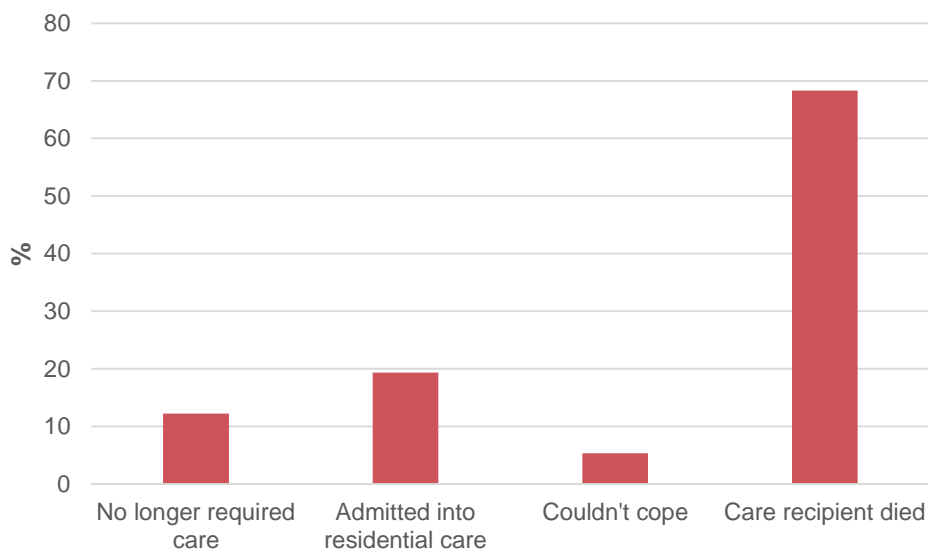


Figure 49. Reasons caring roles ended

Reports of health, wellbeing, and social support were compared across respondents who were current carers only, former carers only, and had both current and former caring roles (Figure 50).



Figure 50. Mean wellbeing measures by carer status

There were no differences between current only carers and those with both current and former caring roles in terms of mean scores on these scales. However, participants who were no longer caring reported significantly better wellbeing across all five of the measures shown in Figure 50. Furthermore, wellbeing was found to improve across all of these measures as the time since caring roles had ended increased (Figure 51).

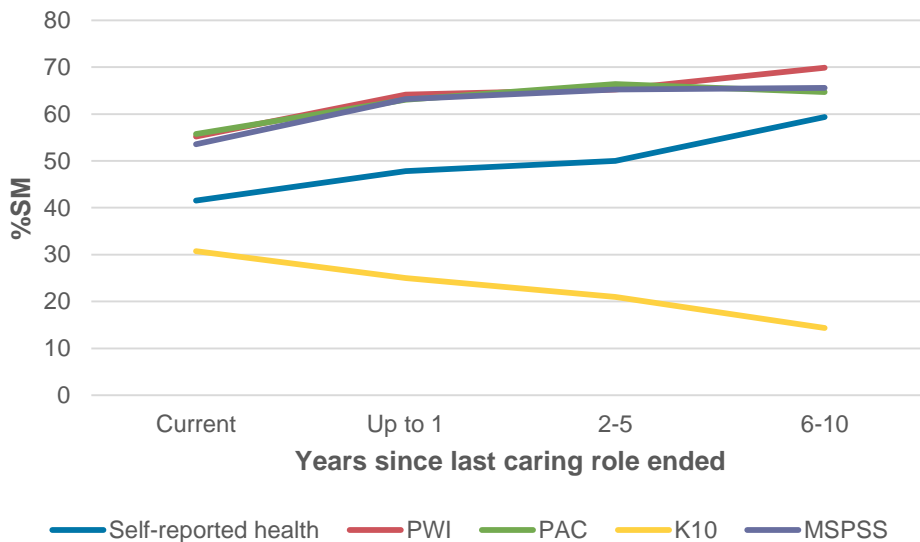


Figure 51. Wellbeing measures by length of time since last caring role ended

### Summary and implications

- This is the most detailed information the Carers NSW Carer Survey has ever collected about former carers. Further analysis will investigate this group in more detail, with the intention of informing future research into carers' experiences and support needs at the end of their caring roles.
- Former carers had most commonly cared for parents, and their caring roles had most commonly ended when care recipients had died. Comparatively very few former carers made the decision to stop caring, suggesting high levels of dedication and resilience amongst this group.
- Compared to those with current caring responsibilities, former carers reported better health, higher wellbeing, more social support, lower distress, and reflected more positively on their caring experiences. These outcomes were more positive amongst those whose caring roles had ended longer ago.

## Discussion

This report has outlined the main findings from the Carers NSW 2016 Carer Survey. These results provide a general overview of emerging trends, and more extensive analysis is still required to more fully understand carers' experiences across the areas investigated. Regardless, many of the issues raised in this report hold significance regarding the ongoing support and recognition of carers across NSW.

### Caring situations

As with previous Carers NSW Carer Surveys, the results from the Carers NSW 2016 Carer Survey highlighted the potential complexities of caring situations, as well as the high levels of care provided by many carers. This is exemplified by the finding that one in three carers in this survey considered their role to be 24 hours a day, 7 days a week. While the current sample is not representative of the wider NSW carer population, the finding that those who had been caring for more than 10 years provided the most care per week shows the significant role that many carers hold within the community. These findings serve to support research such as that conducted by Deloitte Access Economics (2015), who estimated that the replacement costs of informal care in Australia was approximately \$60.3 billion per annum. With so many carers providing such extensive amounts of care, it is not surprising that the costs to replace their support are so large.

The potential complexities of caring situations are further highlighted by the wide range of care recipient conditions, disabilities, and illnesses reported by carers. As noted earlier, over 60% of care recipients were reported as having a mental or behavioural disorder. However, 19 out of the 22 chapters of the ICD-10 were represented throughout this sample. As this is the first time that the Carers NSW Carer Survey has utilised the ICD-10 as a framework for categorising care recipients' conditions, this presents an opportunity to investigate carers' experiences in caring for individuals with a range of different conditions and diagnoses.

It is beyond the scope of this report to investigate specific caring situations in detail. However, it is important to reiterate the wide variety of diverse caring situations that are represented within this dataset. Not only does this allow for the opportunity to conduct further, in-depth analysis, it also emphasises the importance of recognising that all caring situations are unique, just as all carers are themselves unique. While research such as the Carers NSW Carer Survey allows for general trends across carer groups to be identified, it is imperative that carers' individuality is simultaneously acknowledged and respected.

### Carers' health and wellbeing

In line with a great deal of existing literature (including previous Carers NSW Carer Surveys), carers in this survey reported lower wellbeing than the general population. Present results suggest that carers are at risk of poor wellbeing outcomes across a range of indicators, including health, life satisfaction, and psychological distress. Despite these concerning findings, survey results also suggest that many carers derive positive experiences through providing care for a family member or friend.

Unsurprisingly, participants' scores on each of the health and wellbeing measures utilised in this survey were correlated with each other. Those reporting better health also reported higher life satisfaction, lower psychological distress, more positive aspects of caring, as well as better social support. These relationships are to be expected, and they emphasise the importance of supporting carers towards improved health and wellbeing. Despite being unable to determine causal relationships from this survey, such improvements appear likely to benefit carers across all wellbeing domains. Similarly, those carers who are at risk of poorer wellbeing are at risk of detrimental outcomes across each of these domains.

Importantly, this survey identified several groups of carers who were at risk of comparatively poorer wellbeing outcomes than the rest of the sample, including: female carers, Aboriginal and Torres Strait Islander carers, those receiving government financial assistance, those living outside Greater Sydney, and

those with their own long-term illness or disability. Further analysis is necessary to fully explore the relationship between these characteristics and reduced wellbeing outcomes, particularly as the cross-sectional nature of this survey means that causality cannot be determined. That is, carers belonging to these demographic groups were more likely to report poorer outcomes, but these characteristics are not necessarily the reason for their lower wellbeing. However, targeted support and advocacy for these groups is also warranted. This is particularly the case considering groups such as Aboriginal and Torres Strait Islander carers, those in regional and rural areas, and those experiencing financial hardships have been widely identified as being marginalised and in the greatest need for support.

Cultural differences in the perception of caring responsibilities were indicated by wellbeing measures. CALD carers reported poorer wellbeing than those who did not identify as being from a CALD background, yet CALD carers also identified more positive aspects of caring. The results of this survey are unable to provide in-depth detail into the cultural experience of caring for a family member or friend, however, they do suggest that caring is perceived differently across cultural backgrounds.

## **Carers' employment**

The Carers NSW 2016 Carer Survey collected more detailed information regarding carers' employment than any previous Carers NSW Carer Survey. The results from this section are particularly relevant as Carers NSW continues to advocate for carers in the workplace and provides support for employers as they aim to, in turn, support carers within their staff.

Reflective of existing literature, carers widely reported disruptions to their working careers as a result of caring, including limited career progression, reduced working hours, and withdrawal from the workforce. These career impacts are likely to hold long-term implications for carers, such as financial disadvantage (e.g., welfare dependence, reduced superannuation) and broader psychosocial outcomes due to a lack of opportunities for interaction with colleagues or to feel accomplished in a professional capacity. Many carers expressed discontent with working arrangements, with sizable proportions of working carers wanting to work either more or less hours than they currently were working. Discontent with working arrangements was associated with reduced job satisfaction, and the consequent likelihood of job turnover. Conversely, those who reported satisfaction with their current working arrangements remained committed to their jobs, therefore increasing the likelihood of being a valuable employee.

While carers reported a high level of awareness of caring responsibilities amongst their employers, they felt comparatively unsupported by their workplaces to balance work and care. Alongside this, relatively high levels of work-to-life interference were evident. There is a clear need for individual workplaces to become more aware of carers within their workforce, and also for them to establish both formal procedures and informal cultures that enable working carers to feel valued and supported in their roles. This was further evidenced by results regarding the availability and carers' use of supportive workplace practices. Working carers' lack of awareness of some workplace supports may reflect communication issues between workplaces and employees, while the minimal use of many supports may indicate that current practices are not universal enough to suit all carers and their diverse situations. Future research would benefit from identifying additional options for workplace support, as well as attempting to understand the factors related to carers' use of existing supportive practices

## Carers' services and social support

This survey did not investigate carers' experiences with support services in detail, due to the likelihood that any results would quickly become outdated or would lack relevance in light of the changing nature of the service sector landscape. However, findings indicate that there are significant gaps in service delivery to carers, with many wanting greater access to respite, counselling, and carer support groups. Reasons as to why these carers had not accessed the amount of formal support they would have liked were not investigated in this survey, however, previous Carers NSW Carer Surveys have identified a range of barriers to service access, including cost, not knowing what is available, and caring responsibilities taking priority (Carers NSW, 2014). With the rollout of person centred initiatives such as the NDIS, service providers, carers, and care recipients have the opportunity to work collaboratively to develop plans that can most suitably meet the needs of all members within caring networks. Results from this survey give some cause for optimism in this area, with a majority of carers who were caring for people accessing either the NDIS or CHC generally reporting that their lives had improved as a result. This positivity was not universal, however, with between 10-20% of carers disagreeing that their lives had improved. As such, there is a clear opportunity for improvement in the services provided under these initiatives. It was beyond the scope of this survey to conduct a detailed investigation into these issues, however, the broad findings from this sample will inform ongoing research, consultation, and advocacy for carers as service sector reforms continue.

Alongside receiving support from formal sources, informal social support is particularly important for carers. The importance of social support was highlighted in this survey by the finding that higher levels of perceived social support was associated with higher wellbeing, better health, lower psychological distress, and more positive views of caring. Carers' significant others were perceived as providing the most social support, while the wider family was comparatively less supportive than significant others and friends. Perceived social support was found to be higher when carers were working, when providing fewer hours of care per week, and amongst those living within Greater Sydney. Social support was lower amongst Aboriginal and Torres Strait Islander carers, those receiving government financial assistance, and those experiencing their own long-term illness or disability. The groups of carers who reported lower social support warrant targeted attention in terms of ongoing support. This is particularly the case as many of the groups reporting lower social support also reported poorer wellbeing. There is clearly a need to provide all carers (and particularly those at greater risk of lower social support) with formal services to meet their support needs, and also to facilitate their involvement and connection with their local communities. Enhanced connection with the community and establishing strong social connections is likely to provide many carers with a support base that may assist in mitigating many of the potential negative outcomes that can result from an intensive caring role.

## Former carers

By including former carers in this survey sample, comparisons could be made between individuals who were currently caring, those who had previously been carers, and those who had both current and former caring roles. In line with findings from the Carers NSW 2014 Carer Survey (Carers NSW, 2014), the majority of caring roles reported in this survey had only ended at the point of care recipient death. Very few carers chose to cease caring prior to this point, indicating high levels of dedication to caring for their family members and friends. Future research is warranted in investigating former carers' experiences around the end of their caring roles, particularly qualitative research to explore personal narratives to more fully understand relational impacts and emotional responses.

Compared to current carers, respondents who no longer had caring responsibilities reported better health, improved wellbeing, lower distress, more social support, and also reflected more positively on their caring experiences. These improvements appeared to continue to increase over time, though longitudinal research is needed to more accurately track these trends over time.

## Limitations

Certain limitations of this survey should be noted when interpreting the findings presented in this report. Most notably, the current sample is not representative of the wider NSW carer population. This is particularly evident in the large overrepresentation of primary carers, resulting in a likely increase in the proportion of carers who were providing extensive amounts of care on a regular basis. The current sample also included a higher female representation than the broader carer population, were older on average, had completed higher levels of formal education, and were less likely to be employed. Caution is therefore necessary in generalising findings to wider carer populations. However, the data collected in this survey provide the opportunity for detailed analysis into specific sub-groups of carers.

It must also be noted that a convenience approach was taken to sampling, with carers nominating themselves to participate. This may result in certain response biases, such as carers choosing to participate on the basis of particularly positive or negative experiences. As the survey was promoted through regular Carers NSW communication avenues, and through stakeholder organisations with ongoing connections with Carers NSW, the sample is likely to be biased towards those carers who have more contact with support and advocacy organisations. While the research would have benefitted from a broader sample of carers, this recruitment approach was chosen as it was the most ethical and appropriate way of attempting to engage with carers.

Due to this survey being cross-sectional, it is not possible to determine any causal relationships between variables. However, many questions replicated those from previous Carers NSW Carer Surveys, which will enable some degree of comparison over time. Despite this limitation, ongoing analysis will still be able to investigate relationships between variables in such a way as to provide detailed insights into carers' experiences.

## Future analysis and research directions

As a result of the detailed demographic data captured in this survey, there are substantial opportunities to conduct in-depth analyses into specific groups of carers. In particular, coding care recipients' conditions according to the ICD-10 will allow for comparisons between carers of people different conditions to a greater extent than has previously been possible.

Several sub-groups of carers were repeatedly mentioned throughout this report, particularly in relation to being at risk of negative outcomes. Most notably, groups such as CALD carers, Aboriginal and Torres Strait Islander carers, those living outside Greater Sydney, those receiving government financial assistance, and those experiencing their own long-term illness or disability warrant further investigation. Future analysis will explore these groups in greater detail to further highlight areas in which additional support and advocacy may be required. These results will also have the potential to inform future targeted research projects around the issues raised by this survey.

The Carers NSW 2016 Carer Survey collected more detailed data about working carers' employment experiences than any previous Carers NSW Carer Survey. As such, there is significant scope to explore employment related issues in greater detail. In particular, the effectiveness of supportive workplace practices in enabling carers to balance work and care warrants further investigation. Similarly, characteristics and situations that may help to enhance carers' job satisfaction and reduce their turnover intentions will have mutual benefits for working carers and their employers.

The structure of this survey closely replicated the Carers NSW 2014 Carer Survey, and it is intended that this structure will be replicated again in future surveys. The potential therefore exists to establish a longitudinal subset of responses, which would allow for changes in key variables to be tracked over time.



## Conclusion

This report has provided an overview of some of the major findings from the Carers NSW 2016 Carer Survey. The results hold importance in terms of recognising and supporting carers in the valuable role they play within the community, and as such, will be used to inform ongoing advocacy and support for carers in NSW. The report has also highlighted many areas in which more detailed analysis is warranted. In-depth analysis on key issues will continue, and further reports and publications on the results of this survey will be released in the future. Importantly, the Carers NSW 2016 Carer Survey has provided an extensive and detailed dataset which will enable a thorough investigation of key issues facing carers across NSW. This ongoing contribution to the broader evidence base regarding carers in NSW will have important implications for the recognition and support of carers by governments, service providers, and the wider community.

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