

## Qualitative research in support of employed carers

There are 2.7 million carers in Australia who provide informal care to family, friends or neighbours. The care provided can improve the quality of life of care recipients, supporting them to remain living at home. Carers make a vital social and economic contribution. The benefits of informal care extend from those providing and receiving care to the wider community and the economy. The provision of care, however, can have detrimental effects on carers' wellbeing. Carers are more likely than the rest of the population to experience ill health and lower socioeconomic status.

The Carers NSW Carer Survey is conducted every two years to collect information about carers in NSW and inform the organisation's support and advocacy for carers in NSW. A main report on the key findings of the Carers NSW 2014 Carer Survey was published in October 2014. The main report's findings identified several issues to be explored further. This report investigates the issue of carers and employment. It analyses qualitative data about carers' experiences at work, focusing on the impact of care on carers' employment, especially the economic and social impacts.

The qualitative data under analysis substantiates existing research and the findings suggest that a support work environment and flexible work arrangements enhance carers' ability to manage work and caring responsibilities. The implementation of such strategies to maximise carers' employment opportunities is particularly relevant to an ageing population where an increasing number of people will be challenged to simultaneously work and care.

## About this report

This report was prepared by Adrienne Vallentine in completing a social research internship with Carers NSW. This internship was a requirement of completing a Master of Policy and Applied Social Research degree at Macquarie University.

## 1. Literature review

Carers play an important role in the lives of people who need support with daily activities because of disability, mental illness, drug or alcohol issues, chronic conditions, terminal or serious illness, or frailty due to ageing<sup>1</sup>. The provision of unpaid, individualised assistance can contribute to the care recipient's quality of life so that they may remain living at home. Since the 1980s, there has been a progressive shift from institution-based care of people with a disability to a home-based community care model<sup>2</sup>. Parallel to this shift has been the development of policy and practice to 'age in place', where older people receive home-based support that allows them to remain living at home for longer<sup>2</sup>.

### 1.1. Extent of care

According to the Australian Bureau of Statistics (ABS) 2012 Survey on Disability, Ageing and Carers (SDAC), almost 2.7 million Australians (12% of the population) are informal carers<sup>3</sup>. 56 per cent of all carers are women – usually the mothers, partners or daughters of the person receiving care<sup>2</sup>. 45 per cent of carers are aged between 45 and 64 years. There are more female than male carers across all age groups up to 75 years of age, at which point more men than women are carers<sup>3</sup>.

The ABS estimates that there are 769,800 primary carers in Australia, representing 29 per cent of all carers and 3.4 per cent of the Australian population aged 15 years and older<sup>3</sup>. 65 per cent of primary carers are between 35 and 64 years of age and 70 per cent of all primary carers are women. As primary carers age beyond 65 years, however, the female to male ratio decreases so that over the age of 75 years there are equal numbers of female and male primary carers. Over 25 per cent of primary carers are over 65 years of age, the large majority of whom care for their partner<sup>3</sup>. A breakdown of primary carers by age and gender is shown in Table 1.

**Table 1. Primary carers by age group and gender**

*Source: ABS Survey of Disability, Ageing and Carers, Australia: Summary of Findings, 2012.*

Age group (years)	Female		Male		All	
	'000	% of all primary carers	'000	% of all primary carers	'000	% of all primary carers
15-24	14.0	1.8	9.1	1.2	23.2	3.0
25-34	58.8	7.6	16.0	2.1	74.5	9.7
35-44	110.7	14.4	23.6	3.1	133.7	17.4
45-54	117.8	15.3	42.5	5.5	158.6	20.5
55-64	126.7	16.5	60.9	7.9	187.5	24.3
65-74	73.5	9.5	48.2	6.2	122.0	15.8
75 and over	36.5	4.7	35.1	4.6	72.3	9.4
<b>Total</b>	<b>536.7</b>	<b>69.8</b>	<b>233.1</b>	<b>30.6</b>	<b>769.8</b>	<b>100</b>

The care provided by a primary carer is often intense, performed daily and extended over a number of years<sup>4</sup>. Table 2 shows the weekly hours of care provided by female and male primary carers according to the 2012 SDAC<sup>3</sup>. The Carers NSW 2014 Carer Survey, which comprised 92 per cent primary carers, found that 54 per cent of caring relationships required over 20 hours of care per week, and that 27 per cent required over 70 hours of care per week<sup>1</sup>.

**Table 2. Hours of weekly care provided by primary carers by gender**

Source: ABS Survey of Disability, Ageing and Carers, Australia: Summary of Findings, 2012.

Primary carer	Less than 20 hours		20-39 hours		40+ hours		Total	
	'000	% of all primary carers	'000	% of all primary carers	'000	% of all primary carers	'000	% of all primary carers
<b>Female</b>	195.0	26.0	101.2	13.6	222.6	30.0	518.8	69.5
<b>Male</b>	100.8	14.0	49.4	6.6	77.0	10.0	227.2	30.5
<b>All primary carers</b>	<b>296.4</b>	<b>40.0</b>	<b>150.3</b>	<b>20.0</b>	<b>299.3</b>	<b>40.0</b>	<b>746.0</b>	<b>100</b>

Australian longitudinal research suggests an even greater incidence of care than indicated by the cross-sectional data outlined above. Hill and colleagues estimated that between 240,000 and 320,000 working-age Australians (3-4 per cent) become carers each year<sup>5</sup>. Bittman, Hill and Thomson found that 12 per cent of women and 6 per cent of men had provided over five hours of care per week at some time during the three years between 2001 and 2004<sup>6</sup>.

Over longer periods of time, the probability of becoming a carer increases. British research has found that during a 12 month period, five per cent of women and 3.6 per cent of men provided over 20 hours of care per week, and these proportions doubled for a five year period<sup>7</sup>. Further, these researchers estimated that 67 per cent of women and nearly 50 per cent of men will have provided one or more periods of at least 20 hours of care per week by the time they research 75 years of age<sup>7</sup>.

Another dimension to the incidence of care is the duration of time that care is provided. Table 3 shows the number of years of care provide by primary carers at 2012 as estimated by the ABS. It shows that over 60 per cent of primary carers had provided care for five years or more, and over one third for ten years or more<sup>3</sup>. These findings are supported by the Carers NSW 2014 Carer Survey which found that 65 per cent of carers had provided care for over five years and 20 per cent had provided care for more than 20 years<sup>1</sup>.

**Table 3. Number of years of care provided by primary carers to main recipient of care***Source: ABS Survey of Disability, Ageing and Carers, Australia: Summary of Findings, 2012.*

Gender	Years of care provided				
	Less than 2	2-4	5-9	10-24	25+
	% of primary carers				
Female	9.9	16.5	18.6	18.9	5.2
Male	3.9	7.7	7.6	8.2	1.9
All primary carers	13.9	24.1	26.2	27.1	7.0

## 1.2. Carers and employment

Current research suggests that carers relinquish work hours to provide care. SDAC results in Table 4 indicate that carers as a cohort experience lower labour force participation than non-carers. Non-carers are two and a half times more likely than primary carers to be in full-time employment. Interestingly, carers are just as likely as non-carers to be in part-time employment. The unemployment rate for carers (particularly primary carers) is also higher than for non-carers<sup>3</sup>.

**Table 4. Carers by labour force status and sex***Source: ABS Survey of Disability, Ageing and Carers, Australia: Summary of Findings, 2012.*

Employment status	Primary carers (%)			All carers (%)			Non-carers (%)		
	Female	Male	Total	Female	Male	Total	Female	Male	Total
Full-time	15	27	18	22	44	32	32	60	46
Part-time	24	11	20	27	13	20	28	12	20
Unemployed	7.5	10	8.2	6.5	7.6	7.1	5.2	4.8	5.0

Other previous research has found that caring challenges a person's ability to sustain their pre-care level of employment and in some cases precludes employment<sup>5,6,8,9</sup>. Carers NSW found that 48 per cent of working carers had reduced their hours of work because of care responsibilities, and that more than half of carers who were not employed had stopped working to provide care<sup>1</sup>.

A further influence of care on labour force participation is the inverse relationship between hours of care provided and hours of employment – the more time spent caring, the fewer hours of employment are undertaken<sup>1,3,6,10</sup>. This is particularly relevant for primary carers who provide the highest amount of weekly care. They may be unemployed or under-employed for a prolonged period.

The value of informal care is recognised in part through the financial assistance provided by the Carer Payment (CP). It is an income and assets tested income support payment for those whose caring responsibilities preclude substantial workforce participation. Despite monetary support for carers, their reduced labour market participation translates into financial disadvantage for individual carers. As a cohort, the financial status of carers is notably below that of non-carers. ABS data on household income places 65 per cent of primary carers in the lowest two quintiles, compared with 36 per cent of non-carers, whereas 7 per cent of primary carers have an income that falls in the highest quintile compared to 23 per cent of non-carers<sup>3</sup>. These data suggest that government financial assistance does not fully compensate carers for the loss of income due to care responsibilities.

Bittman and colleagues found that the annual income of carers with intense care responsibilities (defined as more than 20 hours per week) is proportionally lower than that of non-carers – 70 per cent for men and 80 per cent for women<sup>6</sup>. Also, as the duration of care increases, the average yearly income of carers significantly decreases<sup>6</sup>. Carers are further financially disadvantaged by the burden of costs directly associated with care provision, such as equipment, medications and home modifications<sup>9</sup>. Carers are also more likely than non-carers to receive an income support payment from the government – 55 per cent of primary carers rely on government assistance for their main source of income, compared to 20 per cent of non-carers<sup>3</sup>.

Apart from the more immediate financial disadvantage experienced by carers, there are longer term considerations of their reduced labour force participation. Carers as a cohort benefit less from the compulsory superannuation guarantee scheme, reducing their capacity to save for retirement<sup>11</sup>, which suggests carers will have a greater reliance on government support in their retirement.

Recent research suggests that there is a tendency for carers to experience conflict between their caring and work roles that results in reduced levels of employment. This conflict will be exacerbated by an ageing population, marked by an increase in demand for care and a falling supply of carers. The likelihood of an individual becoming a carer will increase and the pressure for working-age people, particularly older women, to provide care will increase. Employees taking on care responsibilities may experience a reduction in labour force participation as the demands for them to fulfil their care responsibilities outweigh their ability to sustain pre-care work levels. Under these circumstances, greater numbers of carers will become less economically engaged. They will earn less, experience a decline in socioeconomic status, be more dependent on government financial support when of working age, contribute less tax, accumulate less superannuation, and have greater dependence on government financial support during retirement age<sup>10</sup>.

### **1.3. Work practices of carers**

The lower labour force participation of carers as a cohort results from the adjustment to work practices made by individual carers to accommodate their care responsibilities. Carers report that, in order to provide care, they have adjusted their work practices in the following ways: stopped work to provide care, changed jobs, reduced their hours of work, taken up another position that provided shorter or more flexible hours, changed from full-time to part-time work, changed from permanent to casual work, or taken leave<sup>8,9</sup>. Such adjustments essentially equate to devoting more time to care and less time to paid employment.

In addition, the professional development of many carers is forfeited. Carers report that they have refused a new job because it was not compatible with caring, that caring had interrupted their career progression, and that they had accepted a job that was beneath their experience, skills or qualifications in order to fulfil their caring responsibilities<sup>8,9</sup>.

Findings from the Carers NSW 2014 Carer Survey are consistent with the existing research. To accommodate their caring responsibilities, 48 per cent of working carers had reduced the amount they worked, 32 per cent had refused a new job or promotion, and 35 per cent were working in a lower level job or had experienced an interruption to their career progression<sup>1</sup>. The following quotes from the Carer Survey lend support to the quantitative results:

*Had to leave professional career and take up semi-skilled work because of caring for my son.*

*It is a very difficult situation. I have had to refuse several new jobs due to the hours so I am available to care for my wife.*

*My choices for advancement are limited by my caring role.*

*Whilst I enjoy my work role, I only earn a minimal amount. My caring duties have meant that I can only work part time and in a lower grade position than previously.*

*I am in the process of looking for part time work closer to home to fit my caring responsibilities. The work I currently do is full time and cannot be changed to part time...*

Existing research suggests that the partial or full withdrawal from the labour force to assume care responsibilities could be mitigated by the availability of greater flexibility in work arrangements. Hill and colleagues identified certain employment characteristics that increased the likelihood of an individual leaving employment once they assume caring responsibilities, including: being a casual rather than permanent employee, having no supervisory responsibilities, not belonging to a union, working for a smaller organisation, and lack of access to carer-friendly workplace arrangements<sup>5</sup>. Conversely, access to at least one carer-friendly workplace arrangement – such as special leave for caring, flexible start and finish times, or home-based work – improved the likelihood of staying in employment, and that access to permanent part-time work was the most significant predictor of new carers remaining employed<sup>5</sup>.

The Carers NSW 2014 Carer Survey results echoed the findings of the aforementioned study. It found that over 70 per cent of working carers found workplace arrangements helpful to their care responsibilities, specifically flexible start and finish times (74 per cent), carers' leave (73 per cent), and being able to leave work at short notice for emergencies (71 per cent)<sup>1</sup>. Comments from carers in the survey suggest a need for employment arrangements to be compatible with their caring responsibilities<sup>1</sup>. Below are samples of responses about flexible work practices:

*Although my manager at work doesn't know about my caring responsibilities, my immediate supervisor does and she is very happy to work around me. I work casually because it suits me better and my supervisor is quite happy to give me extra work if I am able to and also is fine if I can't work a particular day because of my caring responsibilities.*

*I am lucky enough to have a CEO that allows some flexibility for my work.*

*I have been able to go for shorter working hours when the caring job gets too much.*

*I have stayed in the one job for a lengthy time as it is a flexible working environment and I often need to take time off for my daughter's medical/therapy appointments. However, I feel that my career has been stagnated because of this as other jobs I have looked at would not be able to provide the flexibility that I currently have.*

*It's hard I'm just lucky my employer allows me to leave as my son becomes very sick quickly when I need to I can.*

## 2. Methodology and results

The comments provided by employed carers in the Carers NSW 2014 Carer Survey were analysed further to identify and explore the key issues for working carers.

There were 14 key issues identified through the analysis. The majority of these issues fell largely into two main themes: 'supportive work environment' and 'flexible work practices'.

Positively and negatively framed comments were analysed to determine the distribution of key issues. The frequency of issues is shown in Table 5.

**Table 5. Distribution of issues within positive and negative responses**

Issue	Frequency within sample (n=273)	Positive response (n=72)	Negative response (n=82)
Supportive work environment	64	50	1
Isolated/unsupported by work	42	3	26
Lack of flexibility in work arrangements	38	4	18
Loss of opportunity to progress career, over skilled	35	3	18
Anxiety/stress around employment	33	4	16
Flexible work practices	37	31	2
Leave entitlement issues	28	3	15
Find work to fit in with caring	21	1	6
Tired/exhausted	16	4	5
Uncertainty due to work insecurity	13	2	6
Conflict between policy and practice	12	0	9
Victimised/discriminated	11	0	6
Juggle caring and work	10	0	5

Of the 72 positive responses, all but one mentioned a supportive or understanding supervisor, work environment or organisation, and/or flexible work arrangements (e.g., start and finish times, working from home, job sharing, part-time work, making up for time off). By far, the issue most commonly mentioned by carers who commented positively about their work experiences was a supportive work environment (70 per cent). The other prominent issue was flexible work arrangements (43 per cent), which is in fact a strategy for a supportive work environment. The frequency of each of the less desirable issues was quite low, though more of them were identified.

The negative responses predominantly mirrored the positive responses, mainly commenting on lack of support from work, loss of career opportunity, inflexible work practices, anxiety and stress, and leave entitlement issues. The issue of support again ranked highly in the frequencies, although in this instance expressed in the negative. The issue most frequently mentioned by carers who commented negatively about their work experiences was feelings isolated or unsupported. Other issues mentioned with a moderate degree of frequency included: loss of opportunity to progress career/over-skilled, lack of flexibility in work arrangements, anxiety/stress around employment, and leave entitlement issues.

These results suggest there are a number of issues that make the combination of caring and work difficult but only two main factors which enhance positive work experiences (i.e., supportive work environment and flexible work arrangements). In the absence of these two factors, carers are more likely to experience feelings of isolation, anxiety, and discrimination. Conversely, these undesirable experiences are reduced or even absent when carers feel they are supported and are able to adjust work to accommodate their care responsibilities.

The key finding is that carers are less likely to experience isolation, anxiety and discrimination when they have a supportive work environment and access to flexible work arrangements. The presence of these two factors appears to reduce the conflict between carers' work and care roles, enabling carers to better manage work and care. Further, the increased manageability of the work and care roles may help to maximise employment opportunities which will improve the income of carers.

The broader economic benefits of supporting carers to work are related to the potential increased labour force participation rate of carers. As a cohort, carers will be more economically engaged, they will contribute more income tax, accumulate greater superannuation, and be less reliant on government financial support during and after their work-life. In addition, a genuine, systemic support of carers in the workplace would contribute to the development of a social culture that acknowledges and values carers – one that recognises the significant and positive contribution carers bring to the lives of those for whom they care and to the wider community.

The results indicate that there is an important role for employers to play in the enhancement of carers' work experiences. Employers could endeavour to provide and promote a work environment that acknowledges and supports employees with caring responsibilities. The workplace would have characteristics such as flexible work practices, the promotion of a positive awareness of carers, and the implementation of policy (e.g., leave entitlement, flexible work arrangements) free from prejudice and professional penalty.

Given the importance of a supportive work environment for carers to successfully manage work and care, it would be constructive to identify other strategies to support working carers. This could conceivably be an area of further research where to adoption of successful international employment schemes and practices could be considered.

### 3. References

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