

women's health *a u s t r a l i a*



the australian longitudinal
study on women's health

Dr Samantha McKenzie, Dr Leigh Tooth,
Dr Jayne Lucke, Prof Annette Dobson

Caring and use of services in women born between 1946 and 1951: Findings from the Australian Longitudinal Study on Women's Health



Detailed report for the Australian Government Department of Health and Ageing
Carers Project, Stage 2, Phase 1

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Summary of findings

Context

This report examines the transitions in and out of caring, carer needs and the use of interventions and services by carers and their care recipients. The current study was a substudy of the Australian Longitudinal Study on Women's Health and included 296 women that participated in pilot surveys for the 1946-1951 cohort. Of the participants, 199 were noncarers and 97 were carers. All participants were asked about their general health, wellbeing and access to services in the first section of the survey. The second section was relevant only to women who were currently providing care to someone with a long-term illness, disability or frailty, and asked about caring activities and access to services for the care recipient.

Caring by women

- Noncarers were more likely to be in the workforce than carers.
- Carers were similar to noncarers on other demographic characteristics, including age, marital status, residence, language spoken at home and level of education.
- The intensity of caring duties was summarised in a care index that was created by combining answers to questions on the frequency of caring and the amount of care provided at each occasion, with a high care index indicating more intense caring duties.
- Women who were live-in carers, compared to carers who lived elsewhere, were more likely to have a high care index, have been caring for longer, be the main care provider, care for younger recipients (who were typically their husbands/partners), and perform more activities of daily living, particularly basic activities of daily living.
- Carers who lived elsewhere, compared to live-in carers, were more likely to have a medium care index, care for older recipients (who were typically their parents), and the recipients were more likely to use paid services.

Transitions in Caring

- Most carers wanted to provide care and started caring gradually.
- On average, the care index remained stable over the past four years, indicating that the intensity of care was steady.
- On average, involvement in employment decreased over the past four years.
- Carers with a high and medium care index were least likely to work full-time and most likely to not be in the labour force.
- Live-in carers were more likely to have part-time employment while carers who lived elsewhere were more likely to have full-time employment.

Carer needs and impact of caring

- Carers had poorer mental health and less social support than noncarers.
- Live-in carers, who were likely have a high care index, were more strained and were more likely to report that their lives were worse from caring than carers who lived elsewhere.

- Carers showed no evident financial stress according to the Australian Bureau of Statistics financial stress indicators.
- Written comments indicated that more support for care at home, or closer to home, were needs that were not being met.

Interventions and services used, and needed, by women carers

- Service use by carers was low.
- Care recipients used services more than carers did.
- The most highly used services were home maintenance and counselling. Carers who used these services had higher carer strain and poorer mental health than carers who did not use those services.
- Carers who lived elsewhere were more likely to use paid services than live-in carers. Carers who lived elsewhere and used at least one paid service were more strained than carers who lived elsewhere and did not use paid services.
- These results may indicate that using services was not lessening the impact of caring or it may be that carers who were strained were more likely to use services. Further investigation is required to determine the causality of these associations.

Possible policy implications

- Policies need to recognise that carers and their situations are different.
- Results indicate that live-in carers may need to be targeted for more formal support. Policies should consider the particular needs of live-in carers who were likely to have a high care index, be strained and help their care recipients with more personal and demanding tasks.
- Policies should endeavour to improve acceptance of, or reduce the stigma about, using services.
- Due to constraints in sample size and selection, care should be taken when generalizing the results to the general carer population. In addition, due to the cross-sectional sampling, only associations, not causality, can be determined from these data.

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Chapter 1 General information

1.1 Overview of the Australian Longitudinal Study on Women's Health

The Australian Longitudinal Study on Women's Health (ALSWH) explores social, behavioural and economic factors and their relationship to health outcomes and use of health and related services, and how they influence lifestyle choices around family and workforce participation at key points in women's lives. The Study advances understanding of the factors that enhance or inhibit good health in women.

In 1994, the Department of Health and Ageing awarded the contract to a team of researchers based at the Universities of Newcastle and Queensland to design and conduct the study. The Study is projected to run for at least 20 years and provides information on trends in areas such as healthy ageing; chronic conditions; health service use; weight; physical activity; alcohol consumption; tobacco and other drugs; mental health; paid work; planning for retirement and partner violence; on women in metropolitan, rural and remote areas of Australia. The Study also contains information about caring for family members or friends. Linkage of the Study with the Medicare and Pharmaceutical Benefits Scheme datasets provides additional information on the health service use by participants.

The ALSWH commenced in 1995 and recruited over 40,000 Australian women. The women were randomly selected from the Australian Medicare database with intentional oversampling of rural and remote areas. The Medicare database includes all permanent residents and citizens. There are approximately 12,000 women in each of three age cohorts: women born between 1973 and 1978 who are currently aged 31-36 years; women born between 1946 and 1951 who are currently aged 58-63 years; and women born between 1921 and 1926 who are currently aged 83-88 years.

Each cohort has a similarly aged pilot group of women, not included in the main sample, that pilot test the main survey. Each cohort group is surveyed every three years and substudies may be conducted each year for the two groups not involved in a main survey. There are now 12 years of data available. The women born between 1973 and 1978 will be surveyed in 2009 for the fifth time.

In 2008, the ALSWH Steering Committee adopted a new naming convention for the three cohorts of women to better reflect the generations that are represented. The new names for cohorts (and the names replaced) are:

- 1921-1926 cohort (older cohort)
- 1946-1951 cohort (mid-aged cohort)
- 1973-1978 cohort (younger cohort)

For this report the new cohort name, 'women born between 1946 and 1951' is used.

1.2 Background to research on caregiving

Stage 1: In 2006 and 2007 researchers in the ALSWH team at the University of Queensland were contracted to provide detailed analyses of caregiving by women born between 1946 and 1951, with particular emphasis on the impact of employment and other life roles and to develop and pilot a substudy focusing on support needed for mid-aged women who provide care for someone who is frail or disabled. This research is referred to as Stage 1. The results of Stage 1 were delivered in three reports:

- Report 1: Employed carers in mid-life. Findings from the ALSWH. (Lucke et al., 2006).
- Report 2: Changes in caring roles and employment in mid-life. Findings of the ALSWH (Berecki et al., 2007).
- Report 3: Pilot study report. Service use and the impact of family caregiving on Mid-aged women from the ALSWH (Watson et al., 2007).

Stage 2: In 2008 researchers in the ALSWH team at the University of Queensland, were contracted to provide further detailed analyses of caregiving by women born between 1946 and 1951, and 1921 and 1926. These analyses were to examine the influence of factors such as where carers lived (both in relation to the care recipient and in terms of residence location, employment and ethnicity) and care recipient needs such as functional dependency levels and the frequency and amount of care.

The research was to provide evidence to address the following questions:

1. Transitions:
 - a. What are the transitions in and out of caring over the lifespan?
 - b. What factors contribute to deciding to care for a family member or friend?
 - c. How do women manage the transition to caring, particularly in relation to labour force participation?
 - d. What factors contribute to the decision to decrease working?
2. Carer needs:
 - a. What is the broad impact of caring on women's lives?
 - b. What needs, unmet or under met, can be identified for carers?
3. Interventions/services:
 - a. What types of interventions/services do carers use?
 - b. What patterns of health or community service use are demonstrated?
 - c. What information can be provided on access, information and perception of services that carers use?
 - d. What interventions/services lessen the impact of caring?
 - e. What interventions/services are effective?
 - f. What carer support strategies and interventions assist or could assist employed carers?
 - g. What type/dose/timing of respite interventions are effective in maintaining a caring relationship for the different carer types and settings?

This current first report (Phase 1 of Stage 2 research on caring by women born between 1946 and 1951) describes further detailed analysis of the pilot substudy conducted in 2007. The preliminary results of this substudy were first described in *Report 3: Pilot study report. Service use and the impact of family caregiving on Mid-aged women from the ALSWH* (Watson et al., 2007).

1.3 Aims of this report

This first report, Phase 1: Analysis of data from the pilot substudy, 'Caring for Your Health' of women born between 1946 and 1951, aims to address the following areas of requirement.

1. Transitions:
 - a. What are the transitions in and out of caring over the lifespan?
 - b. What factors contribute to deciding to care for a family member or friend?
 - c. How do women manage the transition to caring, particularly in relation to labour force participation?
2. Carer needs:
 - a. What is the broad impact of caring on women's lives?
 - b. What needs, unmet or under met, can be identified for carers?
3. Intervention/services:
 - a. What types of interventions/services do carers use?
 - b. What patterns of health or community service use are demonstrated?
 - c. What information can be provided on access, information and perception of services that carers use?
 - d. What interventions/services lessen the impact of caring?

Chapter 2 Context

2.1 Methodology of carers pilot substudy of the 1946-1951 cohort

Every three years, the pilot group of women test the main ALSWH surveys for the 1946-1951 cohort. These 1946-1951 pilot women are a convenience sample of women that predominantly live in the Wollongong and Bathurst areas and they are not included in the main 1946-1951 cohort. In 2007, researchers in the ALSWH team at the University of Queensland conducted a cross-sectional substudy of the 355 women in the 1946-1951 pilot group. The substudy was originally designed to pilot test the survey procedure and instruments before administration to the full 1946-1951 cohort.

The substudy was conducted as a postal survey and data were collected over three months. The survey consisted of two sections. The first section contained 42 questions that applied to all participants and asked about their general health, wellbeing and access to services. The second section contained 22 questions and was only relevant to women who were currently providing care to someone with a long-term illness, disability or frailty. The second section asked about caring activities and access to services for the care recipient. If a participant cared for more than one person, the participant completed the survey for the person she had cared for the longest. See Appendix 8.1 for the full survey. Of the 355 women invited to participate, 296 participated. Of these, 97 were carers and 199 noncarers. While the current small sample was intended to pilot the survey and measures for a larger study with the full 1946-1951 cohort, it is still worthwhile analysing the data for the pilot women.

The main surveys of the ALSWH have all been approved by the University of Newcastle Ethics Committee (Approval number: H-076-0795) and University of Queensland Medical Research Ethics Committee (Approval number: 200400224). This pilot substudy is covered under the main ethics approval number for the University of Queensland Medical Research Ethics Committee, but the University of Newcastle Ethics Committee provided separate ethical clearance for this project (Approval number: H-421-0407). Further details about the pilot substudy are contained in *Report 3: Pilot study report. Service use and the impact of family caregiving on Mid-aged women from the ALSWH* (Watson et al., 2007).

For the current report, the following terminology will be used:

Significant — analyses where the associations or differences are statistically significant to the level of $p \leq 0.05$.

Trend / apparent differences — analyses where clear trends exist. The current sample may be too small to detect statistically significant differences or associations for some analyses. In these cases, the absence of statistical significance does not mean that it is not potentially important.

2.2 Demographic profile of noncarers, carers and care recipients

Table 1 shows the demographic characteristics of the 296 women who participated in the pilot substudy. The table is displayed by whether they provided care or not (carer status) and whether the carer lived with the care recipient or lived elsewhere (carer group). Responses from Question 37 were used to determine carer status and carer group to best describe caring within the last 12 months.

All tables in the current report are formatted similarly for consistency and to ease comparisons between noncarers/carers and live-in carers/carers who lived elsewhere. In some analyses, carers who lived with their care recipients responded differently from carers who lived elsewhere. Therefore, the 'all carers' column is not always an accurate summary of both of these types of carers (live-in carers and carers who lived elsewhere). Discretion is advised when using the 'all carers' information in these instances.

The average age of carers was 59.7 years and the majority were married (83%). English was their primary language spoken at home (98%), and they lived in rural areas (62%), particularly Bathurst, or other metropolitan areas (30%), particularly Wollongong. There were no apparent differences between carers and noncarers for age of carer, marital status, residence, language spoken at home and level of education. There was a trend for more noncarers to be in the labour force (54%) than carers (44%). Employment is discussed further in Section 3.3.

Between live-in carers and those who lived elsewhere, there were no differences for any of the demographic characteristics.

Table 2 shows the demographic characteristics of the 97 care recipients. Care recipients who lived with their carers were significantly younger than recipients who did not live with their carers (Table 2).

Participants were deemed carers if they had cared for someone in the *last 12 months*. However, caring situations can be complex and may have changed during those 12 months. Therefore, these possible changes led to apparent discrepancies between carer groups and where the care recipient lived, presented in Table 2. For instance, most (88%), but not all, of the care recipients lived with their carers for the 'live-in carers group'. Of the care recipients who did not live with their carer, most lived alone (52%), lived in a care facility (23%) or lived with his/her family (14%).

In addition, care recipients who lived with their families were significantly younger (median=79.5, quartiles=25.8, 82.5) than those recipients who lived alone (median=85.0, quartiles=82.0, 88.0), probably due to the relationship between carer and care recipient. Care recipients who lived with their carers were most often husbands/partners (43%) while recipients who did not live with their carers were most often parents of the carer (60%). Frailty in old age was the most common condition of the care recipient.

Table 1 Demographic profile of participants, by carer status and carer group

	Carer status		Carer group	
	Noncarers (n=199*)	All carers (n=97*)	Carer lived with (n=42*)	Carer lived elsewhere (n=55*)
Age [Mean (SD)]	59.5 (1.3)	59.7 (1.4)	59.9 (1.4)	59.5 (1.4)
Marital status (%)				
Married	74	83	93	76
De facto	6	2	0	4
Separated	4	2	2	2
Divorced	9	6	0	9
Widowed	5	4	2	6
Never married	3	3	2	4
Residence (%)				
Capital city	9	9	5	9
Other metropolitan	26	30	30	30
Large rural	10	11	10	11
Small rural	28	22	23	23
Other rural	26	29	33	26
Remote	1	0	0	0
Language (%)				
English	98	98	100	96
Other	2	2	0	4
Education (%)				
No formal qualifications	10	8	10	8
School certificate	30	36	29	42
High school certificate	9	8	10	8
Trade/apprenticeship	6	8	10	8
Certificate/diploma	20	23	27	19
University degree	16	4	5	4
University higher degree	9	12	10	13
Employment (%)				
35+ hours (full-time)	22	16	2	27
1-34 hours (part-time)	32	28	43	18
Not in labour force / unemployed	46	56	55	55

*Actual sample sizes vary for each variable due to missing data.

Percentages within each column and variable may not add up to 100 due to rounding.

SD=standard deviation.

Table 2 Demographic profile of care recipients for all care recipients as well as by whether the care recipients lived with the carer

	All care recipients (n=97*)	Care recipients	
		Lived with carer (n=42*)	Did not live with carer (n=55*)
Age [median (quartiles)]	83.0 (64.0, 86.0)	67.5 (59.5, 85.0)	84.0 (81.0, 87.0)
Where recipient lived ^{**†} (%)			
Carer	40	88	4
Alone	33	8	52
His/her family	9	3	14
His/her friends	1	0	2
Nursing home/care facility	13	0	23
Other	4	3	6
Carer-recipient relationship ^{**} (%)			
Parent	46	28	60
Parent-in-law	10	10	10
Husband/partner	20	43	2
Son/daughter	12	15	10
Other relative	3	3	4
Friend	9	3	14
Other	1	0	2
Condition ^{***} (%)			
Alzheimer's/dementia	21	0	33
Autoimmune disorder	2	5	0
Cancer	19	10	25
Down syndrome	4	5	3
Frailty in old age	79	64	88
Head injury	2	0	3
Heart condition	42	39	43
Mental health problem	40	43	38
Musculoskeletal condition	18	30	10
Visual impairment	32	25	36
Paralysis	6	11	3
Respiratory condition	22	15	28
Spinal cord injury	2	0	3
Stroke	10	5	13
Substance abuse/addiction	6	10	3
Other neurological disorder	6	14	0
Other	65	78	52

*Actual sample sizes vary for each variable due to missing data.

**Percentages within each column and variable may not add up to 100 due to rounding.

†Possible changes in caring situations led to apparent discrepancies between the carer groups and where the care recipient lived. Please see Section 2.2 for more information.

***Percentages do not add up to 100 as care recipients could have had more than one condition.

Table 3 shows additional information that is specific to carers.

Table 3 Additional information specific to carers, by all carers and carer group

	All carers (n=97*)	Carer group	
		Carer lived with (n=42*)	Carer lived elsewhere (n=55*)
Number of people cared for (%)			
One person	85	88	84
Two or more people	15	13	16
Length of time caring (yr) [Median (quartiles)]	5.0 (2.0, 10.0)	6.5 (3.0, 12.0)	4.0 (2.0, 9.0)
Who provided most care (%)			
You (study participant)	66	93	44
Another unpaid carer	14	3	23
Paid services	21	5	33
Mutual Communal Behaviours Scale [Mean (SD)]	29.1 (6.4)	30.4 (6.7)	28.1 (6.1)

*Actual sample sizes vary for each variable due to missing data.

Percentages within each column and variable may not add up to 100 due to rounding.
SD=standard deviation.

Most carers cared for one person (85%) and 15% cared for two or more people (Table 3). The number of people cared for was the same for both groups of carers (those who lived with their recipient and those who lived elsewhere).

The length of time caring ranged from 4 months to 40 years for live-in carers and 1 month to 33 years for carers who lived elsewhere. Carers who lived with the care recipient had cared for them significantly longer than carers who lived elsewhere.

There was a significant relationship between carer group and who provided the most care for the care recipient. As expected, live-in carers (93%) were more likely to be the primary care providers than carers who lived elsewhere (44%). Care recipients whose carers lived elsewhere were more likely to have paid services as their main care provider (33%) than recipients who lived with their carers (5%).

Mutual communal behaviours are behavioural expressions of communal feeling, or affection, between carer and care recipient prior to illness onset. The Mutual Communal Behaviours Scale assesses the frequency of these behaviours, with responses ranging from never to always, with a higher score indicating more mutual communal behaviour (Williamson and Schulz, 1995; see Appendix 8.2 for more details on this scale). Carers who lived elsewhere and live-in carers had similar mutual communal behaviour scores (Table 3). Similarly, when care recipients did not live with their carer, there was no trend in mutual communal behaviour score by where they lived (alone, with family, with friends, in a care facility). However, if the care recipient was a parent-in-law, there was a significantly lower mutual communal behaviour score between carer and care recipient than for other carer-care recipient relationships.

2.3 Care Index

The intensity of caring duties is summarised in a care index which was developed during Stage 1 of the Research on Carers and has been used in previous reports (Lucke et al., 2006, Berecki et al., 2007). The care index was created by combining answers to questions on the frequency of caring (ranging from daily to every few weeks) and the amount of care provided at each occasion (ranging from all day and night to an hour per occasion). The resulting score was grouped into three categories:

Low: For example, caring once per week for one hour at a time; or caring every few weeks for several hours at a time

Medium: For example, caring several times per week for several hours at a time; or caring every day for about an hour

High: For example, caring all day, several times a week; or caring everyday for several hours at a time

A care index was calculated for 83 carers (the other 14 carers had missing data, which means the index could not be calculated). Nineteen carers had a low care index, while 38 had a medium care index and 26 had a high care index.

2.3.1 Association between care index and demographic characteristics

There were no apparent differences between the care index groups for age of carer, marital status, residence, language spoken at home and employment. There was a relationship trend between education and care index. Carers with a high care index were more likely to have a certificate or diploma (41%) or a school or high school certificate (41%) while carers with a medium care index were more likely to have a school or high school certificate (47%). Carers with a lower care index were more likely to have a University or higher degree (37%).

There was no apparent trend in length of time spent caring for the care index groups and no apparent association between care index and the number of people cared for. Understandably, carers with a low care index (29%) were more likely to care for recipients whose primary provider was paid service, compared to 8% of carers with a high care index and 21% of carers with a medium care index.

Carers with a high care index (median=33.0, quartiles=27.0, 36.5) had significantly higher mutual communal behaviour scores than those carers with a low index (median=26.5, quartiles=20.8, 32.5), but not a medium care index (median=29.0, quartiles=24.0, 32.0).

2.3.2 Association between care index and carer group

In the current report, the care index was significantly related to carer group (lived with the care recipient or elsewhere). Live-in carers were more likely to have a high care index (54%) than a medium (32%) or low care index (13%) while carers who lived elsewhere were more likely to have a medium care index (57%) than a high (13%) or low index (30%). This logical relationship may be due to the tasks performed by the carer; this is discussed further in Section 2.3.3.

2.3.3 Association between care index and types of activities with which the carer helps

The tasks that carers may perform fall into two categories: basic activities of daily living (BADLs) and instrumental activities of daily living (IADLs). BADLs include the personal tasks of daily life and six of these (washing, dressing or grooming, preparing meals, eating or drinking, transfers, mobility and toileting) were included in the carers pilot survey. IADLs include further life activities and four of these (household management, recreation, transportation and financial management) were included in the carers pilot survey.

As expected, live-in carers performed significantly more caring activities, both BADLs and IADLs, than carers who lived elsewhere. In addition, carers who had a high care index (higher intensity of caring) assisted care recipients with significantly more BADLs and total activities of daily living (BADL+IADL) than those with a medium or low care index. Carers who had a high care index also assisted care recipients with a high number of IADL tasks; however, carers who assisted care recipients only with IADL tasks were more likely to have a medium or low care index. This may reflect the more demanding nature of helping with BADL tasks, which are more time intensive and more personal.

Figure 1 presents the median number of BADLs and IADLs. The two types of activities of daily living are stacked within each column to indicate the total number of activities by care index and carer group.

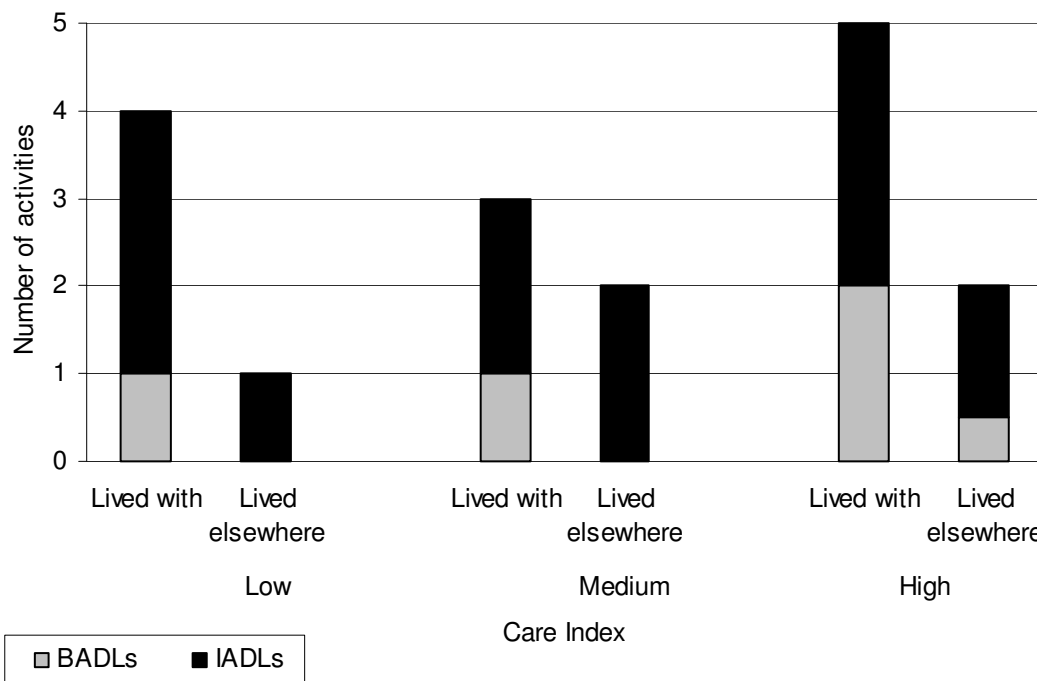


Figure 1 Median number of basic activities of daily living (BADLs) and instrumental activities of daily living (IADLs), by carer group (carer lived with care recipient or lived elsewhere) and care index

2.3.4 Association between care index and carer-care recipient relationship

More carers cared for a parent (46%) rather than a person in any other category of relationship. Husband/partner (20%) and son/daughter (12%) were the next most frequent categories (Table 2). Due to the small sample size, no associations between care index and carer/care recipient relationship were found. However, a trend was observed: carers with a high care index were more likely to care for husbands/partners and sons/daughters compared to friends/other relatives.

Therefore, a high care index indicates more frequent caring for longer amounts of time on each occasion, for which the carers were more likely to

- live with the care recipient,
- care for husbands/partners or sons/daughters,
- have higher communal behaviour scores,
- and perform more of the personal tasks of living.

Chapter 3 Transitions in caring

3.1 What are the transitions in and out of caring by women born between 1946 and 1951?

3.1.1 How caring started

There was some evidence that most participants, no matter their relationship to the care recipient, reported having a gradual transition into caring (67% of live-in carers and 54% of carers who lived elsewhere) rather than a sudden change or other situation. There was a trend for carers in the high (28%) and medium care index (34%) and groups to be more likely to make a sudden change into caring compared to carers with a low care index (6%). The majority of carers with a low care index (89%) made a gradual transition into caring.

3.1.2 Care index for the four time points

The care index was calculated for four time points: 4 years ago, 2 years ago, 1 year ago and now. On average, there was no apparent change in care index across the four time points: the proportions of carers within each care index remained stable (Figure 2). However, this does not necessarily represent individual transitions. Due to the small sample sizes, statistical analysis of individual transitions was not possible.

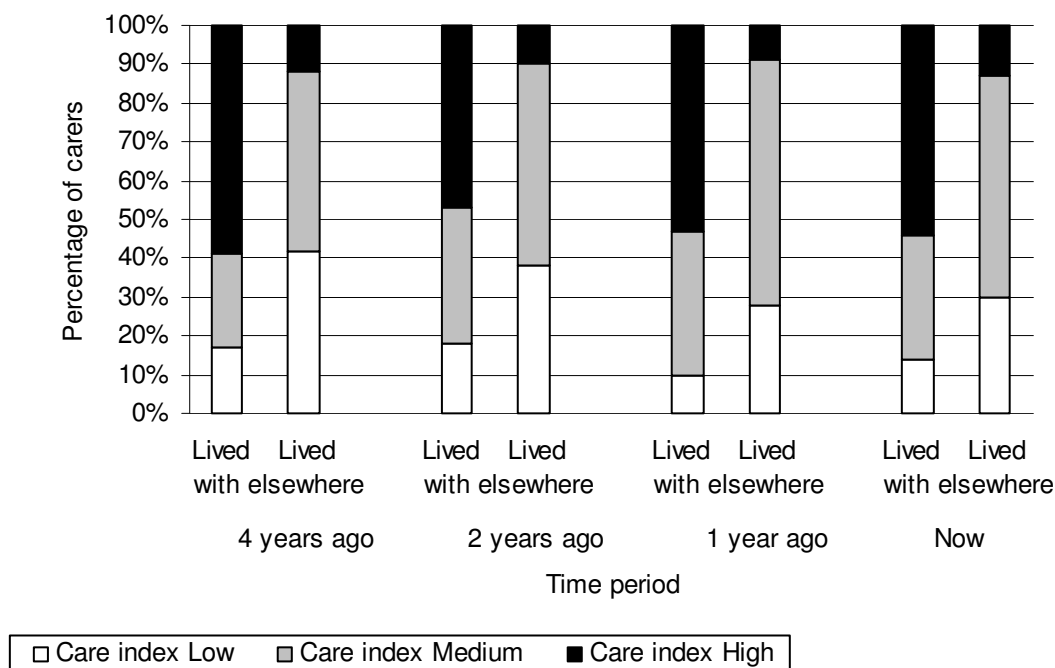


Figure 2 Percentage of carers in each care index for each time point, by carer group

3.2 What factors contribute to deciding to care for a family member or friend?

Carers were asked to indicate the reason that they started to provide care. The most highly rated response was that the participants 'wanted to become carers' (55%) followed by 'there was no one else to do it' (40%) and 'I was already caring for them to some extent' (39%). The patterns were similar between carers who lived with their care recipients and carers who lived elsewhere.

Several women specified their responses to the 'other' response option. Other individually stated reasons for becoming a carer included:

- He was my husband;
- I am also his mother, it is my responsibility;
- I know my mother would be happiest spending her last weeks in our home where she had her own room;
- I was the obvious person;
- Practical/environmental (house suitability);
- The disability unfortunately comes with the package. I did want to help him through life, although it's been more difficult than I could have imagined;
- Wedding vows "in sickness and in health."

The amount of mutual communal behaviour between the carer and care recipient before caring started may have affected the reason for becoming a carer. However, on investigation, the mutual communal behaviour scores did not differ depending on the reason for becoming a carer.

In addition, participants could select more than one reason to become a carer and there was no apparent relationship between reason and carer-care recipient relationship or care index.

3.3 How do people manage the transition to caring, particularly in relation to labour force participation?

Labour force participation and care index were documented at four time points: 4 years ago, 2 years ago, 1 year ago and now.

At the time when the participants completed the survey ('now'), but not at earlier time points, more noncarers (54%) than carers (44%) were in the labour force. Among carers, those who lived with the person they cared for were more likely to work part-time and those who lived elsewhere were more likely to work full-time (Table 4; Figure 3). This statistically significant association between employment and carer group was present at all four time points. There was also a trend for employment to decrease from 4 years ago to now for both carers and noncarers (Table 4).

Similarly, there were evident relationships between care index and employment for each of the four time points. Carers with a high and medium care index were least likely to work full-time and most likely to not participate in the labour force (Figure 4). There was no apparent pattern for carers with a low care index.

Table 4 Employment history at each time point, by carer status and carer group

	Carer status		Carer group	
	Noncarers (n=199*)	All carers (n=97*)	Carer lived with (n=42*)	Carer lived elsewhere (n=55*)
	%	%	%	%
4 years ago				
Working full-time (35 or more hours per week)	34	25	8	40
Working part-time (1 to 34 hours per week)	28	37	44	30
Not in paid work	38	38	49	30
2 years ago				
Working full-time (35 or more hours per week)	26	20	5	33
Working part-time (1 to 34 hours per week)	30	37	44	31
Not in paid work	44	43	51	37
1 year ago				
Working full-time (35 or more hours per week)	25	16	5	26
Working part-time (1 to 34 hours per week)	30	32	44	22
Not in paid work	46	52	51	52
Now				
Working full-time (35 or more hours per week)	22	16	2	27
Working part-time (1 to 34 hours per week)	32	28	43	18
Not in paid work	46	56	55	55

*Actual sample sizes vary for each variable due to missing data.

Percentages within each column and variable may not add up to 100 due to rounding.



Figure 3 Percentage of carers in the labour force at each time point, by carer group

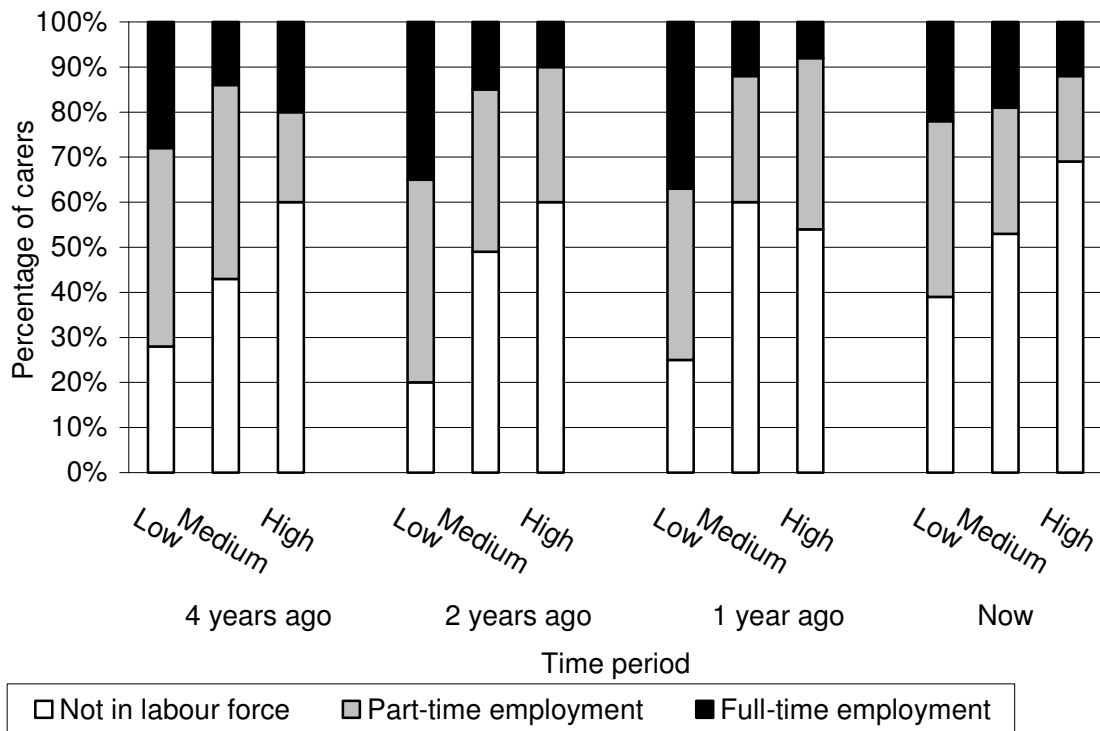


Figure 4 Percentage of carers in the labour force at each time point, by care index

Chapter 4 Carer needs and impact of caring

4.1 What is the broad impact of caring on women's lives? A comparison between noncarers and carers

The pilot survey asked all the women participants a series of questions to allow comparisons between carers and noncarers. These questions concerned health-related quality of life (physical health, mental health), resilience, social support and financial stress.

To measure these, the following variables were used:

- Self-rated health question from the Medical Outcomes Study Short Form 36
- Health-related quality of life – physical and mental health scores [measured by the Medical Outcomes Study Short Form 36]
- Resilience [measured by the Connor Davidson Resilience Scale]
- Social support [measured by the Medical Outcomes Study Social Support Index]
- Financial stress [measured by the Australian Bureau of Statistics indicators of financial stress]

Please see Appendix 8.2 for further details on these scales.

The responses to these questions will be presented by carer status, carer group, care index and by carer-care recipient relationship, where appropriate.

4.1.1 Self-rated health question from the Medical Outcomes Study Short Form 36

Carers self-rated their overall health in one question as part of the Medical Outcomes Study Short Form 36. Responses ranged from health is fair or poor to excellent. This was intended to be an overarching self-assessment of general health. Generally, the participants reported that they were in good health. Overall, carers did not report worse health than noncarers. Carers, regardless of their care index or relationship to the care recipient, were more likely to report that they were in good health (87%) than fair/poor health (13%). However, carers who lived elsewhere (22%) were significantly more likely to report fair/poor health than live-in carers were (5%).

While the participants generally reported they were in good health, specific health-related quality of life scales and other measures of wellbeing presented information that is more specific about the participants' health.

4.1.2 Health-related quality of life (mental and physical health scores)

Table 5 presents the mental and physical health scores by carer status and carer group. Carers reported significantly lower mental health scores, reflecting poorer mental health, than noncarers. Live-in carers and carers who lived elsewhere, as well as the care index groups, reported similar mental health scores.

Carers had better mental health when the care recipient was a parent (median=57.0, quartiles=50.4, 59.9) and poorer mental health when the care recipient was a friend (median=44.8, quartiles=28.4, 56.6).

There was no difference between carers and noncarers, live-in carers and carers who lived elsewhere, or the care index groups for the physical health scale. Physical health scores followed a similar trend in carer-care recipient relationship to the mental health scores with those carers caring for a parent having the best physical health and those caring for a friend having the poorest health.

Table 5 Median (and quartile) values for continuous scale scores, by carer status and carer group

	Carer status		Carer group	
	Noncarers (n=199*)	All carers (n=97*)	Carer lived with (n=42*)	Carer lived elsewhere (n=55*)
Mental health score	57.6 (50.7, 60.1)	55.6 (45.1, 59.5)	56.1 (45.6, 60.3)	55.0 (41.9, 58.9)
Physical health score	50.5 (41.3, 55.1)	48.3 (40.5, 55.9)	47.6 (42.1, 53.7)	51.4 (37.6, 56.9)
Resilience	79.5 (65.0, 89.0)	77.0 (65.0, 88.0)	80.0 (65.0, 91.0)	75.5 (63.5, 84.0)
Social support	4.5 (3.8, 5.0)	4.0 (3.2, 4.7)	4.0 (3.2, 4.7)	4.1 (3.0, 4.8)
Financial stress indicators	0 (0, 0.3)	0 (0, 1.0)	0 (0, 1.0)	0 (0, 1.0)

*Actual sample sizes vary for each variable due to missing data.

4.1.3 Resilience

There were no apparent trends in resilience between carers and noncarers, live-in carers and carers who lived elsewhere (Table 5), or the care index groups. There was a trend for carers who cared for a parent (median=80.5, quartiles=69.8, 89.8) or husband/partner (median=82.5, quartiles=66.5, 90.3) to have higher resilience than carers who cared for a son/daughter (median=53.0, quartiles=44.0, 80.0).

4.1.4 Social support

Noncarers reported significantly higher levels of social support than carers (Table 5). There was no apparent difference in level of social support between live-in carers and carers who lived elsewhere or between the care index groups. There was a trend for carers who cared for a parent (median=4.3, quartiles=3.7, 4.8) to have more social support than carers who cared for a son/daughter (median=3.5, quartiles=2.2, 3.8).

4.1.5 Financial stress

There was no evident association between fortnightly income and carer status or carer group. The majority of participants reported that 1-2 people were dependent on

household income. However, live-in carers significantly more often reported there were 3-4 people dependent on the household income than carers who lived elsewhere.

Seventy-two percent of all participants reported no financial stress indicators, suggesting that the current sample was not financially stressed according to the Australian Bureau of Statistics indicators. This pattern was present for both carers and noncarers.

While there was no difference in how carers or noncarers reported their ability to manage on the available income, there was a difference in household financial situation. Ninety-one percent of participants said they were able to break even or save money most weeks. Carers who lived elsewhere also followed this pattern, but live-in carers more frequently broke even. Therefore, although live-in carers were more likely to report they were just able to break even, it was not enough to induce financial stress.

Carers with a medium care index (8%) were less likely to care for 3-4 people than carers with a high (23%) or low care index were (28%). There was no apparent difference in the number of financial stress indicators among the care index groups. There was no evident relationship between care index and ability to manage on income or household financial situation.

There was no statistical association between the number of financial stress indicators and care index. However, due to the small sample size, the associations between carer-care recipient relationship and income, the number of people dependent on income, household financial situation and the ability to manage on income, were not analysed.

While the current sample was generally not financially stressed, according to the Australian Bureau of Statistics financial stress indicators, seven participants wrote comments on managing finances or the cost of medical services in the free space of the questionnaire (Question 42 and at the end of the survey after Question 64). Six of these seven carers had at least one Australian Bureau of Statistics financial stress indicator. These carers highlighted that it was difficult to cover the costs of the care recipient as well as their own financial needs or that specialists and psychologists' fees were too expensive. One carer discussed the difficulties of balancing the financial needs for her own medication, orthodontics for her son and her own doctor not bulk billing. Even though she is a member of a health fund, she is not able to cover the costs of her own medical needs and delays seeing doctors and filling prescriptions. Another carer indicated that the financial costs of caring for her now deceased parent have resulted in her filing for bankruptcy and she is now not able to afford required dental care.

4.2 What is the broad impact of caring on women's lives? A comparison of carers

The pilot survey asked carers a series of questions in order to better understand the impact of caring on these women's lives. These questions concerned the overall impact of caring, levels of burden, and the positive aspects of caring.

To measure these, the following variables were used:

- Overall impact of caring [a question was developed specifically for the pilot carers survey asking women what the impact of providing care was on their life overall]
- Levels of burden [measured by the Caregiver Strain Index]
- Positive aspects of caring [measured by the Positive Aspects of Caregiving scale]

Please see Appendix 8.2 for further details on these scales. The answers to these questions will now be presented in terms of carer group, care index and by carer-care recipient relationship, where relevant.

4.2.1 Overall impact of caring

Question 59 asked carers whether their lives were negatively affected by caring, neither better nor worse or positively affected by caring. Generally, all carers, no matter their care index, were most likely to report that they were neither better nor worse (53%), second most likely to report they were negatively affected by caring (33%) and least likely to report that their lives were better with caring (14%). Live-in carers reported that their lives were more negatively affected by caring than carers who lived elsewhere.

This association may be due to the relationship carers had with their care recipients. Carers who cared for husbands/partners reported that their lives were negatively affected by caring twice as often (64%) than the general trend for all carers who reported negative effects (33%), while carers who cared for a parent responded more positively (life was better) than negatively (life was worse).

Table 6 shows the overall impact of caring, carer strain and the positive aspects of caring measures by all carers and carer group.

Table 6 Impact of caring measures, by all carers and carer group

	Carer group		
	All carers (n=97*)	Carer lived with (n=42*)	Carer lived elsewhere (n=55*)
Overall impact of caring (%)			
Life was better for it	20	19	20
Neither better nor worse	50	38	59
Life was worse for it	30	43	20
Carer strain	5.0	7.0	3.5
	(3.0, 8.0)	(4.0, 8.0)	(2.0, 6.8)
Positive aspects of caring	30.0	30.0	31.0
	(26.0, 35.0)	(26.0, 34.0)	(27.0, 35.0)

*Actual sample sizes vary for each variable due to missing data.

Percentages within each column and variable may not add up to 100 due to rounding.

4.2.2 Levels of burden

Live-in carers were significantly more strained than carers who lived elsewhere. In addition, there was a trend for carers with a high care index (median=6.5, quartiles=3.8, 8.3) to be more strained than carers with a medium (median=4.0, quartiles=2.3, 7.0) or low care index (median=3.0, quartiles=2.0, 5.0).

In the current sample, most of the carers who helped with both BADLs and IADLs or just BADLs, lived with the care recipient. In particular, it was the BADL component of this help (correlation=0.36), and not the IADL component (correlation=0.13), which was most closely associated with carer strain for live-in carers. Therefore, the reason live-in carers were more strained might not only be because they lived with the care recipient and typically have higher care indexes, but also because they helped them with more demanding personal care tasks. There was no similar pattern for carers who lived elsewhere.

Similarly, there was a trend for the BADL load, and not the IADL load, to be related to worse mental health scores for carers who lived with their care recipients, possibly reflecting the higher personal burden component of caring. There was no similar pattern for carers who lived elsewhere.

4.2.3 Positive aspects of caring

There were no differences in the positive aspects of caregiving scores between live-in carers and carers who lived elsewhere or between the care index groups. However, carers caring for parents-in-law (median=20.0, quartiles=14.0, 24.0) had significantly lower positive aspects scores than carers who cared for friends (median=32.0, quartiles=27.0, 36.0), parents (median=31.0, quartiles=27.0, 35.0) or husbands/partners (median=30.5, quartiles=25.3, 34.8). There were no other apparent differences between the types of carer-care recipient relationships for positive aspects scores.

4.3 What needs, unmet or under met, can be identified for carers?

The three activities of daily life with which carers helped most were transportation (72%), household management (68%) and financial management (53%), which are all IADLs. Live-in carers were more likely to perform these tasks than carers who lived elsewhere, who were more likely to use paid services for these activities.

Carers with a high care index were more likely to perform these activities than carers with a medium or low care index. Carers with a low care index were more likely to have a paid service help with transportation or household management than carers with a medium or high care index. However, paid services were not used for financial management, except for 6% of carers with a medium care index.

Very few women reported that 'help was needed, but it was not provided.' The tasks of daily life for which carers most reported this response were preparing meals (3%), mobility (2%), household management (2%), transportation (2%) and financial management (2%). These frequencies were too low for further analysis.

Some participants provided comments in the free space of the questionnaire. Some of the comments indicated that the following needs were not being met:

- Support for care at home;
- More respite care available, particularly within a short distance between carer and care recipient;
- Inadequate coordination of services and communication between the doctors providing medical treatment for the care recipient;
- and inadequate quality of hospital and mental services.

Chapter 5 Interventions/services used, and needed, by carers

5.1 What types of interventions/services do carers use?

The services considered in this section are community services and health services. Carers were also asked to specify whether there were any activities of daily living for which the care recipient received help from a paid service.

5.1.1 Community services for carers

Carer and noncarer use of community services is presented in Table 7. The majority of carers and noncarers did not use any of the services listed. There were no apparent differences in use of these community services between carers or noncarers. If a service was used, home maintenance and counselling services were most used for both carer groups (live-in carers and carers who lived elsewhere). For carers, there were no apparent differences in their own community service use by whether they lived with the care recipient or lived elsewhere, by care index or by carer-care recipient relationship.

5.1.2 Health services for carers

Carers and noncarers were asked if they had visited a general practitioner, a hospital doctor, specialist doctor, physiotherapist, optician/optometrist, dentist and podiatrist. They were also asked if they had been admitted to hospital (Table 7).

There were no apparent differences in use of these health services between carers or noncarers. There were no trends in doctor (general practitioner/hospital/specialist) consultations, hospital admissions or other allied health (physiotherapist, optician/optometrist, dentist and podiatrist) consultations, between carers (lived with or lived elsewhere), care index or by carer-care recipient relationship.

5.1.3 Community services for care recipients

The use of community services by care recipients is presented in Table 8. When compared to Table 7, it is clear that care recipients used community services more than carers did. Furthermore, care recipients who lived elsewhere to their carers received significantly greater use of food, nursing, homemaking and home maintenance services than those who lived with their carers.

Carers were also asked to specify whether there were any daily activities for which the care recipient received help from a paid service. It is clear from Table 8 that the majority of paid services were provided to care recipients who did not live with their carers.

Table 7 Own service use in the last 12 months: percentage of noncarers and carers using community and health services, by carer status and carer group

	Carer status		Carer group	
	Noncarers (n=199*)	All carers (n=97*)	Carer lived with (n=42*)	Carer lived elsewhere (n=55*)
	%	%	%	%
Community services				
Food services	0	1	0	2
Nursing or community services	2	5	5	6
Respite services	1	1	2	0
Homemaking services	1	2	2	2
Home maintenance services	8	11	10	13
Counselling services	8	10	7	13
Ambulance service	2	4	7	2
Support and advisory groups	5	4	2	6
Other group	3	5	5	6
None of these groups	74	60	64	56
Health services				
General practitioner	94	96	98	94
Hospital doctor	14	18	14	22
Specialist doctor	64	58	55	59
Hospital admission	19	22	17	26
Physiotherapist	30	24	17	20
Optician/optometrist	67	56	41	54
Dentist	78	72	71	61
Podiatrist	20	24	17	19

*Actual sample sizes vary for each variable due to missing data.

5.1.4 Health services for care recipients

Carers reported whether care recipients had visited a general practitioner, a hospital doctor, specialist doctor, physiotherapist, optician/optometrist, dentist and podiatrist or been admitted to hospital (Table 8) in the previous 12 months.

There were significant differences in use of these health services by where care recipients lived (lived with or elsewhere from the carers) for visiting specialist doctors and podiatrists, with care recipients who lived elsewhere showing a higher consultation rate. There were no differences for the other health services.

Table 8 Community and health service use by care recipient in last 12 months: percentage of positive responses, by all care recipients and whether they lived with their carer

	All care recipients (n=97*) %	Care recipients	
		Lived with carer (n=42*) %	Did not live with carer (n=55*) %
Community services			
Food services	14	2	24
Nursing services	32	19	42
Respite services	20	14	24
Homemaking services	18	7	26
Home maintenance services	18	7	26
Counselling services	14	14	14
Ambulance service	25	21	27
Support and advisory groups	7	5	9
Other group	8	5	11
None of these groups	25	29	22
Don't know	1	2	0
Health services			
General practitioner	99	97	100
Hospital doctor	69	63	73
Specialist doctor	82	72	89
Hospital admission	60	54	65
Physiotherapist	26	24	29
Optician/optometrist	61	66	57
Dentist	43	44	42
Podiatrist	54	41	64
Paid service for BADLs/IADLs			
Washing, dressing or grooming	15	5	22
Preparing meals	17	0	31
Eating or drinking	9	0	16
Transfers	7	0	13
Toileting	7	3	10
Mobility	10	3	17
Household management	16	2	28
Recreation	12	3	19
Transportation	7	0	13
Financial management	1	0	2

*Actual sample sizes vary for each variable.

5.2 What patterns of health or community service use are demonstrated?

5.2.1 Patterns of health services for carers

Data on frequency of visits by carers to general practitioners, hospital doctors and specialist doctors, as well as duration of hospital admissions, were collected. Frequency of visits was highest for general practitioner consultations, with 66% of noncarers, 78% of carers who lived with and 76% of carers who lived elsewhere visiting their general practitioner three times or more in the previous 12 months. The number of reported visits to specialists and hospital doctors, and hospital admissions, were much less frequent among the three groups. For example, three-quarters of noncarers and carers (lived with and lived elsewhere) reported either visiting no specialist doctors or having fewer than two visits, and 86% of noncarers, 86% of live-in carers and 78% of carers who lived elsewhere reported not having seen a hospital doctor at all. No hospital admissions were reported by 82% of noncarers, 83% of carers who lived with care recipients and by 74% of carers who lived elsewhere. Of these groups, 9%, 12% and 15% respectively reported having spent at least one night in hospital in the previous 12 months.

There were no apparent differences in frequency of visits to general practitioners, hospital doctors and specialist doctors, as well as duration of hospital admissions between carer groups (lived with, lived elsewhere) or by care index.

5.2.2 Patterns of health services for care recipients

Carers reported on the frequency of visits made by care recipients to their general practitioner, a hospital doctor or specialist doctor, as well as on the duration of hospital stays, in the previous 12 months.

Of these health services, care recipients most often visited their general practitioners, and on multiple occasions. For example, 32% were reported as having 3 to 6 visits, 26% 7 to 12 visits, and 32% 13 or more visits over the previous 12 months, with only 10% having fewer than 2 visits. There was a significant difference in frequency of visits to general practitioners by whether care recipients lived with their carers or not, with those who lived with carers having a fewer number of visits compared to those who lived elsewhere.

Visits by care recipients to specialist doctors were less frequent with almost half reporting fewer than 2 visits, and 34% reporting 3 to 6 visits. Those care recipients who lived with their carers had fewer numbers of visits compared to those who lived elsewhere.

Visits to a hospital doctor were the least frequently reported, with almost three-quarters reporting fewer than two visits. There were no apparent differences by whether care recipients lived with carers or not.

Approximately 45% of care recipients had an overnight hospital stay in the previous 12 months and there were no apparent differences by whether care recipients lived with carers or not.

5.3 What information can be provided on access, information and perception of services that carers use?

Carers were asked to rate the quality of the community and health services that the care recipient used. The responses by carers to the questions about health services (access to medical specialists, hospitals, medical care in an emergency, after hours care and general practitioners who bulk bill; general practitioner hours, number of general practitioners to choose from, ease of seeing general practitioner of choice, duration of wait to see a general practitioner and outcomes of medical care) were well answered with only a small percent of missing data or 'don't know' responses. Overwhelmingly (that is, by between 60 and 90% of carers), these were rated as being of a good to excellent quality. There were no apparent differences in ratings by carer group or by care index. There is some evidence of a difference by relationship of carer to care recipient, specifically where the carer was a friend. Where carers were friends they appeared to generally rate the quality of these health services as being poorer compared to when they were family members. However, small numbers may have influenced this result and it requires further exploration.

In contrast to the high response rate for health services, the answers by carers to the questions about community services (access to food, nursing, respite, homemaking, home maintenance, counselling or other mental health, and ambulance services and support and advisory groups) were less informative. With the exception of ambulance services, all the rest had high rates of 'don't know' responses (access to food 50%, nursing 35%, respite 50%, homemaking 45%, home maintenance 50%, counselling or other mental health 46%, support and advisory groups 48%). Due to the small amount of valid data left to analyse these questions, it was not possible to identify any apparent differences in ratings of these by carer group, care index or carer-care recipient relationship.

Some of the written statements provided in the free space of the survey commented on the access, information and perception of services. Statements involving access to services, included:

- The doctors in our town have closed their books. Therefore we have no female doctor;
- I feel there is a great need for help that is affordable (and not useless) in the mental health area;
- I find it very frustrating to experience an extremely lengthy delay to gain access to my GP. Perhaps the GPs who bulk bill need to be paid at a higher rate per consultation so they don't need to book as many patients. More GPs are needed;
- Public and private health systems are so overloaded;
- Some services have a waiting time (e.g. I waited 6 months for home care for my mother) and I cannot find a GP to home visit my frail mother;
- I was working full-time when my mother fell ... Hospital rang on 3rd day and said come and get her - no warning. I had to instantly resign from work and care for her 24 hours a day until a placement became available in nursing home - 12 months later;
- I had a close friend who died from Motor Neurone Disease 19 months ago. It was extremely difficult and often demeaning for the family to access services for assistance.

Other comments indicated why services were not accessed:

- Access to health services is not the problem, getting my mother's generation to accept outside help is the problem. The only service we have used is home maintenance service. I could not have been more impressed by their service;
- I spend a lot of time driving this person to specialist or hospital. Although community transport is available, I like to be there for support. We don't need community transport as yet. This person is/was independent and is loath to get help.

Several statements commented on information and communication between services:

- Services such as the aged care assessment team need to listen and stay in contact with the family of the older frail person;
- The local community mental health team have been very supportive and provided excellent resource material for me, so I certainly have no complaints about them. BUT, I have huge issues with the hospital and psychiatrist who [discharged my mother early]. I am trying my best to deal with a very difficult situation and have not trained as a psychiatric/geriatric nurse and yet that is what I am expected to be. How am I expected to deal with this situation in the best interests of my mother, when you get contradictory advice from the "professionals"?

Other comments involved the perception of the services used:

- I sought help from Aged Care, Meals on Wheels, the Hospital, Veterans Affairs and eventually a nursing home (and the community Nurse). Most of these services were great. However Aged Care and Veterans Affairs were very difficult to deal with. ... I felt the health services were unnecessarily secretive, not sharing, obstructive and rude. There was no help or consideration for me as her carer. I don't think that, deep down, I have ever gotten over that;
- Overall, the use of public health services I find to be very poor. ... External nursing care which was promised after hospitalisation was totally useless;
- In trying to access showering services three times per week, I found the process very complicated in that there was little communication in the DVA between departments and I found myself repeating my requests over and over again;
- My father was in hospital, treatment there was good, however, he was constantly pressured to move out as he did not die quickly enough;
- I find [dealing with Centrelink] very stressful and quite demeaning.

Perceptions of services were also positive:

- The best health services for women in this state are the Women's Health Centres (NGO's);
- I used to help care for a lady with MS ... I found most health care services very easy to approach;
- We are not medically insured but he has had no trouble in getting prompt professional care and found all the health services excellent. I have several friends that are wheelchair bound and they too have the best care from Home Care and their needs are catered to kindly and caringly. No complaints at all;
- My mother lived in a hostel complex for 15 years and had a happy full life. For the last 2 years of her life she was in a nursing home due to her dementia. The care and love of the staff at the nursing home particularly in her dying weeks was inspirational. It changed my ideas on nursing homes and care of the elderly;

- As we are in a regional area our access to any health facility or practitioner is usually quite good. We are satisfied with what is available. Even though we have to travel for specialist care, we are able to access most things;
- I have found that services provided by the National Breast Cancer Network and local Breast Care Support Group have been excellent. Also the counselling service provided when first diagnosed and the ongoing support given at fortnightly clinics run by the Community Health Centre and under the auspices of the Area Health Service, particularly advice and care given by the oncology sister.

5.4 What interventions/services lessen the impact of caring?

Home maintenance and counselling were the two most used services, with 8% of carers using each service. Seventeen of the 97 carers used one or both of these services. The remaining 80 carers either did not report the use of these services or reported that they did not use them. Carers who used home maintenance or counselling services were then compared to carers who did not use these services for carer strain, mental health score, physical health score, positive aspects of caring and resilience.

Although the number of respondents were small, participants who used either home maintenance or counselling services had a higher strain and a poorer mental health score, indicating that these services were not lessening the impact of caring or that the service, in the case of counselling service, was used because of the strain and poorer mental health.

As previously highlighted, carers who lived elsewhere were more likely to use paid services for care recipients than live-in carers were. Of the carers who lived elsewhere, 27 used at least one paid service and 28 did not use any paid services. Therefore, carers who lived elsewhere and used paid services were compared to carers who lived elsewhere but did not use paid services for carer strain, mental health score, physical health score, positive aspects of caring and resilience.

Carers who lived elsewhere and used paid services had significantly more carer strain (median=5.0, quartiles=3.0, 7.5) than carers who lived elsewhere and did not use paid services (median=3.0, quartiles=1.0, 5.3). This result may indicate that using paid services was not lessening the impact of caring or it may be that carers who were strained were more likely to use paid services.

In addition to the responses to the survey questions, the written statements in the survey provided specific information on services which lessened the impact of caring. One carer indicated that she was able to care for her father at home with the help of his pension to pay for a private nursing service and the help of a local community organisation that loaned equipment to help with lifting. Another carer indicated that a nurse twice weekly bathed the care recipient and caring would have been easier on the carer, as the primary carer, if more help had been available.

Chapter 6 Summary and Conclusions

6.1 Caring by women born between 1946 and 1951 included in the pilot substudy (Chapter 2)

Carers were similar to noncarers in age, marital status, residence, language spoken at home and level of education. Noncarers were more likely than carers to be in the labour force.

Women who were live-in carers were more likely to have a high care index, have been caring for longer, be the main care provider, care for younger recipients (who were typically their husbands/partners), and perform more tasks of daily living, particularly BADLs.

Carers who did not live with their care recipient were more likely to have a medium care index, care for older recipients who were typically their parents, and the recipients were more likely to use paid services. It is possible that carers who lived elsewhere have lower care indexes because they are not the main care provider and the paid services perform the caring tasks. Alternatively, it may be that the care recipients who did not live with their carers did not have high caring requirements. However, this causality cannot be determined from the current data.

Typically, a high care index indicated more frequent caring for longer amounts of time on each occasion, for which the carers were more likely to live with the care recipient, care for husbands/partners or sons/daughters, have higher mutual communal behaviour scores, and perform more of the personal BADLs.

6.2 Transitions in caring (Chapter 3)

The majority of the women wanted to provide care and started caring gradually. On average, the care index remained stable over the past four years, whereas employment decreased. Carers with a high and medium care index were least likely to work full-time and most likely to not be in the labour force. Live-in carers were more likely to have part-time employment while carers who lived elsewhere were more likely to have full-time employment.

6.3 Carer needs and impact of caring (Chapter 4)

Generally, carers and noncarers reported that they were in overall good health. However, for specific aspects of health, carers showed poorer health than noncarers.

Carers had poorer mental health, particularly when they were caring for friends, and less social support, particularly when they were caring for a sons/daughters, than noncarers.

Live-in carers, who were likely to be caring for their husbands/partners and have a high care index, were more strained and were more likely to report that their lives were worse from caring than carers who lived elsewhere. The burden experienced by live-in carers may be because they help the care recipients with more personal and demanding tasks. Despite this, carers were not able to identify many BADL or IADL tasks for which help was needed but not provided.

Carers showed no evident financial stress, according to the Australian Bureau of Statistics financial stress indicators. Although live-in carers did show some difficulty with being able to break even, it was not enough to induce financial stress.

Written comments indicated that more support for care at home or closer to home were needs that were not being met.

6.4 Interventions and services used, and needed, by women carers (Chapter 5)

Service use by carers was low. Care recipients used services more than carers did. Carers who used the two most highly used services, home maintenance and counselling, had higher carer strain and poorer mental health than carers who did not use those services. Care recipients who did not live with their carers were more likely to use paid services (food, nursing, homemaking, home maintenance). The carers of recipients who lived elsewhere and used paid services also had higher strain than carers whose recipients lived elsewhere and did not use paid services. These results may indicate that using services was not lessening the impact of caring or it may be that carers who were strained were more likely to use services. Further investigation is required to determine the causality of these associations.

Care recipients who did not live with their carers made more visits to general practitioners and specialist doctors. Carers rated access to health services for the care recipient as being of good to excellent quality. However, there were large percentages of 'don't know' responses when rating access to community services. There were very few reports of help being needed, but not being provided, for the 10 tasks of daily living.

Several carers indicated in their written comments that it was complicated, stressful or demeaning to access services. Other carers expressed concern over the disorganisation and miscommunication within and between services that were supposed to be helping the carer and the care recipient. Two comments noted that services were not accessed because of the care recipients' perception of the stigma involved in using available services. Not all comments were negative, however. A few carers specified services with which they had positive experiences: Women's Health Centres, Home Care and Area Health Service.

6.5 Conclusions

The current study was originally designed to pilot test the survey procedure and instruments with the 1946-1951 pilot cohort before administration to the full 1946-1951 cohort. The current sample is small and was recruited from two main areas, Wollongong and Bathurst. For these reasons, care should be taken when generalizing the results to the general carer population. In addition, due to the cross-sectional sampling, only associations, not causality, can be determined from these data.

In the current sample of pilot substudy women born between 1946 and 1951, there were 199 noncarers and 97 carers. Carers were similar to noncarers on demographic characteristics, except employment: noncarers were more likely to be in the workforce. Carers were strained and caring did negatively impact on carers' lives.

Carers were not a homogenous group: live-in carers were different from carers who lived elsewhere on a number of measures. For instance, women who were live-in carers were more likely to:

- have a high care index,
- be more strained,
- be the main care provider,
- have been caring for longer,
- care for younger recipients (who were typically their husbands/partners),
- perform more activities of daily living, particularly BADLs,
- and work part-time, if in the labour force.

Carers who did not live with their care recipient were more likely to:

- have a medium care index,
- care for recipients who use paid services,
- care for older recipients (who were typically their parents),
- perform only IADLs,
- and work full-time, if in the labour force.

The burden experienced by live-in carers may be because they help the care recipients with more personal and demanding tasks. Despite this, carers were not able to identify many BADL or IADL tasks for which help was needed but not provided. In general, knowledge about and use of services was low.

Care recipients who did not live with their carers were more likely to use paid services, and these carers were likely to have a medium care index. The carers of recipients who lived elsewhere and used paid services also had higher strain than carers whose recipients lived elsewhere and did not use paid services. These results may indicate that using services was not lessening the impact of caring or it may be that carers who were strained were more likely to use services. Further investigation is required to determine the causality of these associations.

6.6 Possible policy implications

- Policies need to recognise that carers and their situations are different.
- Results indicate that live-in carers may need to be targeted for more formal support. Policies should consider the particular needs of live-in carers who were likely to have a high care index, be strained and help their care recipients with more personal and demanding tasks.
- Policies should endeavour to improve acceptance of, or reduce the stigma about, using services.
- Due to constraints in sample size and selection, care should be taken when generalizing the results to the general carer population. In addition, due to the cross-sectional sampling, only associations, not causality, can be determined from these data.

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Chapter 8 Appendices

8.1 Caring for Your Health Pilot Study Survey

women's health

a u s t r a l i a



Caring for Your Health Pilot Study

This survey asks questions about your health and wellbeing, your experience of caring for someone with a long-term illness, disability or frailty and the services you have used.

Consent

Caring for Your Health Pilot Substudy 2007

- I have carefully read and understood the Participant Information sheet and voluntarily consent to participate in this research study.
- I also consent to the researchers linking the information provided in this survey with that given in the previous surveys so that any changes in my health can be noted.

Signature _____ Date _____

Please sign above and send the completed survey back to us in the envelope supplied as soon as possible. We will detach the consent form and store it in a separate locked room.

What is your maiden name? (if applicable) _____

Help us keep in touch!

Sometimes we lose touch with our participants. It would be helpful if you could give us your mobile phone number and email address if you have these.

Mobile

Email

It would also be helpful if you could give us details of a relative or friend who will be able to help us find you.

Name

Address
 P'Code

Phone (home) () Relationship to you

Office use only - DO NOT DETACH.

How to complete this survey

Please answer every question you can. If you are unsure about how to answer a question, circle the response for the closest answer to how you feel.
Some of the questions are the same as those in previous surveys.

Please write any comments or important information on page 17 or page 26. We are not able to read comments written elsewhere throughout the survey.

Please read the instructions above each question carefully. Some require you to only answer those options which are applicable to you. Other questions require you to circle one answer on each line. The questions may also refer to different time periods.

INSTRUCTIONS:

- Use a black / blue biro
- Do not fold or bend this survey
- **Circle the numbers like this:**

In general, would you say your health is:

(Circle one only)

Excellent 1

Very good 2

Good ③ *You would circle this one if you think your health is good*

Fair 4

Poor 5

- **Print clearly in the boxes like this:**

What is your postcode?
(PRINT clearly in the boxes)

2	3	0	8
---	---	---	---

- **Correct mistakes like this:**

When you go to a General Practitioner:

(Circle one on each line)

Do you go to the same place?

Always
1

Most of
the time
②

Some-
times
③

Rarely or
never
4

If you make a mistake simply scribble it out and clearly circle the correct answer

**If you need help to answer any questions, please ring 1800 068 081
(This is a FREECALL number)**

- If you are concerned about any of your health experiences and would like some help, you may like to contact:
 - Your nearest Women's Health Centre or Community Health Centre;
 - Your General Practitioner for advice about who would be the best person in your community for you to talk to.
- If you feel distressed NOW and would like someone to talk to, you could ring Lifeline on 131 114 (local call)

These questions ask about how your health is NOW and about how your health limits certain activities NOW.

1 In general, would you say your health is:
(Circle one only)

- | | |
|-----------|---|
| Excellent | 1 |
| Very good | 2 |
| Good | 3 |
| Fair | 4 |
| Poor | 5 |

2 Compared to one year ago, how would you rate your health in general now?
(Circle one only)

- | | |
|---------------------------------------|---|
| Much better now than one year ago | 1 |
| Somewhat better now than one year ago | 2 |
| About the same now as one year ago | 3 |
| Somewhat worse now than one year ago | 4 |
| Much worse now than one year ago | 5 |

3 The following questions are about activities you might do during a typical day. Does YOUR HEALTH NOW LIMIT YOU in these activities? If so, how much?
(Circle one on each line)

		Yes, limited a lot	Yes, limited a little	No, not limited at all
a	VIGOROUS activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b	MODERATE activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	1	2	3
c	Lifting or carrying groceries	1	2	3
d	Climbing SEVERAL flights of stairs	1	2	3
e	Climbing ONE flight of stairs	1	2	3
f	Bending, kneeling or stooping	1	2	3
g	Walking MORE THAN ONE kilometre	1	2	3
h	Walking HALF a kilometre	1	2	3
i	Walking 100 metres	1	2	3
j	Bathing or dressing yourself	1	2	3

**The questions on this page and the next one ask about your health
IN THE LAST FOUR WEEKS.**

4 During the PAST FOUR WEEKS, have you had any of the following problems with your work (including your work outside the home and housework) or other regular daily activities AS A RESULT OF YOUR PHYSICAL HEALTH?

(Circle one on each line)

		Yes	No
a	Cut down on the amount of time you spent on work or other activities	1	2
b	Accomplished less than you would like	1	2
c	Were limited in the kind of work or other activities	1	2
d	Had difficulty performing the work or other activities <i>(eg it took extra effort)</i>	1	2

5 During the PAST FOUR WEEKS, have you had any of the following problems with your work or other regular daily activities AS A RESULT OF ANY EMOTIONAL PROBLEMS (such as feeling depressed or anxious)?

(Circle one on each line)

		Yes	No
a	Cut down on the amount of time you spent on work or other activities	1	2
b	Accomplished less than you would like	1	2
c	Didn't do work or other activities as carefully as usual	1	2

6 During the PAST FOUR WEEKS, to what extent have your PHYSICAL HEALTH OR EMOTIONAL PROBLEMS interfered with your normal social activities with family, friends, neighbours or groups?

(Circle one only)

- Not at all 1
- Slightly 2
- Moderately 3
- Quite a bit 4
- Extremely 5

7 How much BODILY pain have you had during the PAST FOUR WEEKS?

(Circle one only)

- No bodily pain 1
- Very mild 2
- Mild 3
- Moderate 4
- Severe 5
- Very severe 6

8 During the PAST FOUR WEEKS, how much did PAIN interfere with your normal work (including both work outside the home and housework)?
(Circle one only)

- Not at all 1
- A little bit 2
- Moderately 3
- Quite a bit 4
- Extremely 5

9 For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the PAST FOUR WEEKS:
(Circle one on each line)

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a	Did you feel full of life?	1	2	3	4	5	6
b	Have you been a very nervous person?	1	2	3	4	5	6
c	Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d	Have you felt calm and peaceful?	1	2	3	4	5	6
e	Did you have a lot of energy?	1	2	3	4	5	6
f	Have you felt down?	1	2	3	4	5	6
g	Did you feel worn out?	1	2	3	4	5	6
h	Have you been a happy person?	1	2	3	4	5	6
i	Did you feel tired?	1	2	3	4	5	6

10 During the PAST FOUR WEEKS, how much of the time have your PHYSICAL HEALTH OR EMOTIONAL PROBLEMS interfered with your social activities (like visiting friends, relatives, etc)?
(Circle one only)

- All of the time 1
- Most of the time 2
- Some of the time 3
- A little of the time 4
- None of the time 5

11 How TRUE or FALSE is EACH of the following statements for you?
(Circle one on each line)

		Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a	I seem to get sick a little easier than other people	1	2	3	4	5
b	I am as healthy as anybody I know	1	2	3	4	5
c	I expect my health to get worse	1	2	3	4	5
d	My health is excellent	1	2	3	4	5

12 Please indicate the extent that each of the following statements is true for you OVER THE PAST MONTH. Remember that there are no 'right' or 'wrong' answers to these questions. Read each statement and select the response that best indicates the degree to which you personally agree or disagree with that statement.
(Circle one on each line)

		Not at all true	Rarely true	Sometimes true	Often true	True nearly all of the time
a	I am able to adapt to change	1	2	3	4	5
b	I have close and secure relationships	1	2	3	4	5
c	I take pride in my achievements	1	2	3	4	5
d	I work to attain my goals	1	2	3	4	5
e	I feel in control of my life	1	2	3	4	5
f	I have a strong sense of purpose	1	2	3	4	5
g	I see the humorous side of things	1	2	3	4	5
h	Things happen for a reason	1	2	3	4	5
i	I have to act on a hunch	1	2	3	4	5
j	I can handle unpleasant feelings	1	2	3	4	5
k	Sometimes fate or God can help	1	2	3	4	5
l	I can deal with whatever comes my way	1	2	3	4	5
m	Past success gives me confidence for new challenges	1	2	3	4	5
n	Coping with stress strengthens me	1	2	3	4	5
o	I like challenges	1	2	3	4	5
p	I can make unpopular or difficult decisions	1	2	3	4	5
q	I think of myself as a strong person	1	2	3	4	5
r	When things look hopeless, I don't give up	1	2	3	4	5
s	I give my best effort, no matter what	1	2	3	4	5
t	I can achieve my goals	1	2	3	4	5
u	I am not easily discouraged by failure	1	2	3	4	5
v	I tend to bounce back after a hardship or illness	1	2	3	4	5
w	I know where to turn for help	1	2	3	4	5
x	Under pressure, I focus and think clearly	1	2	3	4	5
y	I prefer to take the lead in problem solving	1	2	3	4	5

13 The next set of questions asks about whether YOU have people to talk to and support you.

(Circle one on each line)

		None	Once	Twice	Three times	Four times	Five times	Six times	Seven times or more
a	How many times during the past week did you spend time with someone who does not live with you, that is, you went to see them or they came to visit you or you went out together?	0	1	2	3	4	5	6	7
b	How many times did you talk to someone (friends, relatives or others) on the telephone in the past week (either they called you, or you called them)?	0	1	2	3	4	5	6	7
c	About how often did you go to meetings of clubs, religious meetings, or other groups that you belong to in the past week?	0	1	2	3	4	5	6	7

14 The next set of questions asks about your family and friends.

(Circle one on each line)

		Hardly ever	Some of the time	Most of the time
a	Does it seem that your family and friends (people who are important to you) understand you?	1	2	3
b	Do you feel useful to your family and friends (people important to you)?	1	2	3
c	Do you know what is going on with your family and friends?	1	2	3
d	When you are talking with your family and friends, do you feel you are being listened to?	1	2	3
e	Do you feel you have a definite role (place) in your family and among your friends?	1	2	3
f	Can you talk about your deepest problems with at least some of your family and friends?	1	2	3

15 How many people in your local area do you feel you can depend on or feel very close to (other than members of your family)?

(Circle one only)

None	1
1 - 2 people	2
More than 2 people	3

16 The next set of questions asks about your friends and neighbours.
(Circle one on each line)

		Yes	No
a	Can you get help from friends when you need it?	1	2
b	If you were caring for a child and needed to go out for a while, would you ask a neighbour for help?	1	2
c	Have you visited a neighbour in the past week?	1	2
d	When you go shopping in your local area, are you likely to run into friends and acquaintances?	1	2
e	In the past 6 months, have you done a favour for a sick neighbour?	1	2

17 People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kind of support available to you if you need it?
(Circle one on each line)

		None of the time	A little of the time	Some of the time	Most of the time	All of the time
a	Someone to help if you are confined to bed	1	2	3	4	5
b	Someone to count on to listen to you when you need to talk	1	2	3	4	5
c	Someone to give you good advice about a crisis	1	2	3	4	5
d	Someone to take you to the doctor if you need it	1	2	3	4	5
e	Someone to show you love and affection	1	2	3	4	5
f	Someone to have a good time with	1	2	3	4	5
g	Someone to give you information to help you understand a situation	1	2	3	4	5
h	Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
i	Someone to hug you	1	2	3	4	5
j	Someone to get together with for relaxation	1	2	3	4	5
k	Someone to prepare your meals if you are unable to do it yourself	1	2	3	4	5
l	Someone whose advice you really want	1	2	3	4	5
m	Someone to do things with to help you get your mind off things	1	2	3	4	5
n	Someone to help with daily chores if you are sick	1	2	3	4	5
o	Someone to share your most private worries and fears with	1	2	3	4	5
p	Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
q	Someone to do something enjoyable with	1	2	3	4	5
r	Someone to understand your problems	1	2	3	4	5
s	Someone to love and make you feel wanted	1	2	3	4	5

These questions are about the services you have used in the last 12 months

18 Which of the following groups have you sought advice or help from, FOR YOURSELF, in the LAST 12 MONTHS?

(Circle all that apply)

a	Food services (eg Meals on Wheels)	1
b	Nursing or community health services	1
c	Respite services (in home, day centre, or inpatient)	1
d	Homemaking services (eg home care service, laundry service)	1
e	Home maintenance services (eg odd jobs, gardening)	1
f	Counselling or other mental health services	1
g	Ambulance service	1
h	Support and advisory groups (e.g Arthritis Foundation, Pensioner Advisory Service, Older Women's Network)	1
i	Other group, please specify _____	1
j	None of these groups	1

19 How many times have you consulted the following people for YOUR OWN HEALTH in the LAST 12 MONTHS?

(Circle one on each line)

	None	Once or twice	3 or 4 times	5 or 6 times	7-12 times	13-24 times	25 or more times	
a	A family doctor or another General Practitioner (GP)	0	1	2	3	4	5	6
b	A hospital doctor (eg in outpatients or casualty)	0	1	2	3	4	5	6
c	A specialist doctor	0	1	2	3	4	5	6

20 Have you consulted the following people for YOUR OWN HEALTH in the LAST 12 MONTHS?

(Circle one on each line)

	Yes	No	
a	Physiotherapist	1	2
b	Optician / Optometrist	1	2
c	Dentist	1	2
d	Podiatrist	1	2

21 Have you been admitted to hospital in the LAST 12 MONTHS?

(Circle one only)

No	1
Yes, day only	2
Yes, spent at least one night	3

22 Thinking about your own health care, how would you rate the following:

(Circle one on each line)

	Excellent	Very good	Good	Fair	Poor	Don't know
a Access to medical specialists if you need them	1	2	3	4	5	6
b Access to a hospital if you need it	1	2	3	4	5	6
c Access to medical care in an emergency	1	2	3	4	5	6
d Access to after-hours medical care	1	2	3	4	5	6
e Access to a GP who bulk bills	1	2	3	4	5	6
f Access to a female GP	1	2	3	4	5	6
g Hours when a GP is available	1	2	3	4	5	6
h Number of GPs you have to choose from	1	2	3	4	5	6
i Ease of seeing the GP of your choice	1	2	3	4	5	6
j How long you wait to get a GP appointment	1	2	3	4	5	6
k The outcomes of your medical care <i>(how much you are helped)</i>	1	2	3	4	5	6
l Ease of obtaining a mammogram	1	2	3	4	5	6
m Ease of obtaining a Pap test	1	2	3	4	5	6
n Access to a counselling service if you need it	1	2	3	4	5	6

These questions are about you

23 What is your date of birth?

--	--

Day

--	--

Month

19

--	--

Year

24 What is your present marital status?

(Circle one only)

- Married 1
- Defacto (opposite sex) 2
- Defacto (same sex) 3
- Separated 4
- Divorced 5
- Widowed 6
- Single 7

25 What is your postcode?

a What is your RESIDENTIAL postcode? (where you live)

--	--	--	--

b What is the postcode of your POSTAL ADDRESS
(if different to residential)

--	--	--	--

26 Do you usually speak a language other than English AT HOME?
(Circle one only)

- No, I speak only English at home 1
- Yes, Italian 2
- Yes, Greek 3
- Yes, Cantonese 4
- Yes, Arabic 5
- Yes, Vietnamese 6
- Yes, Mandarin 7
- Yes, other, please specify _____ 8

27 What is the highest qualification you have completed?
(Circle one only)

- No formal qualifications 1
- School or Intermediate Certificate (or equivalent) 2
- Higher School or Leaving Certificate (or equivalent) 3
- Trade / apprenticeship (eg Hairdresser, Chef) 4
- Certificate / diploma (eg Child Care, Technician) 5
- University degree 6
- Higher University degree (eg Grad Dip, Masters, PhD) 7

28 In a usual week, how much time in total do you spend doing the following things?
(Circle one on each line)

		I don't do this activity	1-15 hours	16-24 hours	25-34 hours	35-40 hours	41-48 hours	49 hours or more
a	Full time paid work	1	2	3	4	5	6	7
b	Part-time paid work	1	2	3	4	5	6	7
c	Casual paid work	1	2	3	4	5	6	7
d	Home duties (own / family home)	1	2	3	4	5	6	7
e	Work without pay (eg family business)	1	2	3	4	5	6	7
f	Looking for work	1	2	3	4	5	6	7
g	Unpaid voluntary work	1	2	3	4	5	6	7
h	Studying	1	2	3	4	5	6	7

29 We would like to know YOUR main occupation NOW:

(Circle one only)

- Manager or administrator** (eg magistrate, farm manager, media producer, school principal) 1
- Professional** (eg registered nurse, allied health professional, teacher, artist) 2
- Associate professional** (eg office manager, branch manager, shop manager, retail buyer, youth worker, police officer) 3
- Tradesperson or related worker** (eg cook, dressmaker, hairdresser, gardener, florist) 4
- Advanced clerical or service worker** (eg credit officer, radio despatcher, personal assistant, flight attendant, law clerk) 5
- Intermediate clerical, sales or service worker** (eg accounts clerk, checkout supervisor, data entry operator, child care worker, nursing assistant, hospitality worker) 6
- Intermediate production or transport worker** (eg machine operator, bus driver) 7
- Elementary clerical, sales or service worker** (eg filing / mail clerk, parking inspector, sales assistant, telemarketer, housekeeper) 8
- Labourer or related worker** (eg cleaner, factory worker, kitchen hand, fast food cook) 9
- No paid job** 10

30 What is the average gross (*before tax*) income that you (*and your household*) receive each week, including wages, salaries, pensions and allowances?

(Circle one only)

- Negative income 1
- Nil income 2
- \$1-\$149 per week (\$1-\$7,799 per year) 3
- \$150-\$249 per week (\$7,800-\$12,999 per year) 4
- \$250-\$399 per week (\$13,000-\$20,799 per year) 5
- \$400-\$599 per week (\$20,800-\$31,199 per year) 6
- \$600-\$799 per week (\$31,200-\$41,599 per year) 7
- \$800-\$999 per week (\$41,600-\$51,999 per year) 8
- \$1000-\$1299 per week (\$52,000-\$67,599 per year) 9
- \$1300-\$1599 per week (\$67,600-\$83,199 per year) 10
- \$1600-\$1999 per week (\$83,200-\$103,999 per year) 11
- \$2000 or more per week (\$104,000 or more per year) 12

31 How many people (*including yourself*) are dependent on this household income? (*Please write number in the box*)

--	--

32 How do you manage on the income you have available?

(Circle one only)

- It is impossible 1
- It is difficult all the time 2
- It is difficult some of the time 3
- It is not too bad 4
- It is easy 5

33 Thinking of your / your household's situation over the last 12 months, which one of the following statements best describes your / your household's financial situation?

(Circle one only)

- Spend more money than we get 1
- Just break even most weeks 2
- Able to save money most weeks 3

34 Which of the following do you / members of your household usually do?

(Circle one on each line)

		Yes	No, don't want to	No, can't afford to	No, other reason
a	A holiday away from home for at least one week a year	1	2	3	4
b	A night out once a fortnight	1	2	3	4
c	Friends or family over for a meal once a month	1	2	3	4
d	A special meal once a week	1	2	3	4
e	Buy new and not second hand clothes, most of the time	1	2	3	4
f	Spend time on leisure or hobby activities	1	2	3	4

35 If all of a sudden you / your household had to get two thousand dollars for something important, could the money be obtained within a week?

(Circle one only)

- Yes 1
- No 2

36 Over the LAST 12 MONTHS, have any of the following happened to you / your household because of a shortage of money?

(Circle all that apply)

a	Could not pay electricity, gas or telephone bills on time	1
b	Could not pay for car registration or insurance on time	1
c	Pawned or sold something	1
d	Went without meals	1
e	Unable to heat my home	1
f	Sought assistance from welfare / community organisations	1
g	Sought financial help from friends or family	1
h	None of the above	1

The following questions ask about your caring and work activities at four times: now, 1 year ago, 2 years ago and 4 years ago. Think about each time and circle the numbers that correspond to your situation at each time.

37 Do / did you regularly provide care or assistance (eg personal care, transport) to any other person because of their long-term illness, disability or frailty?

(Circle all that apply)

		A Yes, for someone who lives with you	B Yes, for someone who lives elsewhere	C No, I do / did not provide care
a	Now	1	1	1
b	1 year ago	1	1	1
c	2 years ago	1	1	1
d	4 years ago	1	1	1

38 How often in total do / did you provide this care or assistance?

(Circle one on each line)

		Every day	Several times a week	Once a week	Once every few weeks	Less often	Not applicable
a	Now	1	2	3	4	5	6
b	1 year ago	1	2	3	4	5	6
c	2 years ago	1	2	3	4	5	6
d	4 years ago	1	2	3	4	5	6

39 How much time do / did you usually spend providing such care or assistance on each occasion?

(Circle one on each line)

		All day and night	All day	All night	Several hours	About an hour	Not applicable
a	Now	1	2	3	4	5	6
b	1 year ago	1	2	3	4	5	6
c	2 years ago	1	2	3	4	5	6
d	4 years ago	1	2	3	4	5	6

40 Are / were you in paid work:

(Circle one on each line)

		Yes, working full-time (35 or more hours per week)	Yes, working part-time (1 to 34 hours per week)	No, not in paid work
a	Now?	1	2	3
b	1 year ago?	1	2	3
c	2 years ago?	1	2	3
d	4 years ago?	1	2	3

41 Which of the following statements best applies to you?

(Circle one only)

I CURRENTLY care for someone with a long-term illness, disability or frailty

1

I HAVE BEEN caring for someone with a long-term illness, disability or frailty who has passed away or moved into a nursing home or hostel in the last 12 months

2

I USED TO care for someone with a long-term illness, disability or frailty more than 12 months ago but do not actively care for them now

3

I HAVE NOT cared for someone with a long-term illness, disability or frailty

4

I CURRENTLY care for someone as part of my paid work

5

Please circle 1 or 2 and go on to the next section on page 18

OR.

Please circle 3,4 or 5 and go to question 42.

***The rest of the questions are for people who have been caring for someone with a long-term illness, disability or frailty
IN THE LAST 12 MONTHS.***

43 How many people do you care for?

(Circle one only)

1 person 1

More than 1 person 2

Please select the PERSON YOU HAVE CARED FOR THE LONGEST and complete the following questions about that person.

44 Is the PERSON YOU CARE FOR your:

(Circle one only)

Mother or father? 1

Mother-in-law or father-in-law? 2

Husband or partner? 3

Brother or sister? 4

Son or daughter? 5

Other relative? 6

Friend? 7

Other, please specify? _____ 8

45 How old is the PERSON YOU CARE FOR?

Age in years

46 How long have you been caring for this person?

Years

OR

Months

47 Does the PERSON YOU CARE FOR:

(Circle one only)

Live with you? 1

Live alone? 2

Live with his / her family? 3

Live with his / her friends? 4

Live in a nursing home or care facility? 5

Other, please describe _____ 6

48 Does the PERSON YOU CARE FOR have any of the following major medical conditions or disabilities?

(Circle one on each line)

		Yes	No
a	Alzheimer's disease / Dementia	1	2
b	Autism spectrum disorder	1	2
c	Autoimmune disorder	1	2
d	Cancer	1	2
e	Cerebral palsy	1	2
f	Down syndrome	1	2
g	Frailty in old age	1	2
h	Head injury	1	2
i	Heart condition	1	2
j	Infectious disease	1	2
k	Mental health problem (eg depression, anxiety)	1	2
l	Musculoskeletal condition (eg break / fracture)	1	2
m	Visual impairment	1	2
n	Paralysis	1	2
o	Respiratory condition (eg asthma, emphysema)	1	2
p	Spinal cord injury	1	2
q	Stroke	1	2
r	Substance abuse / addiction	1	2
s	Other neurological disorder (eg multiple sclerosis, motor neurone disease)	1	2
t	Other, please specify _____	1	2

49 Who provides the MOST HELP to the person you care for? (Help refers to assistance or supervision which is needed because the person cannot do the task safely by themselves)

(Circle one only)

You	1
Another unpaid carer (eg a relative)	2
Paid services (eg community, government or private services)	3

These questions are about your caring activities

50 Who helps the person you care for with the following activities?

(Circle one on each line)

		You	Other unpaid carer (eg relative)	Paid service	Help is needed but not provided	Help is not needed
a	Washing, dressing or grooming	1	2	3	4	5
b	Preparing meals	1	2	3	4	5
c	Eating or drinking	1	2	3	4	5
d	Getting on or off the bed, toilet, chair, etc	1	2	3	4	5
e	Managing the toilet or continence	1	2	3	4	5
f	Mobility (walking or wheelchair, stairs, etc)	1	2	3	4	5
g	Household management (eg shopping, cleaning)	1	2	3	4	5
h	Recreation or hobbies	1	2	3	4	5
i	Transportation	1	2	3	4	5
j	Management of finances, insurance, etc	1	2	3	4	5

51 In caring for the person, how useful have each of the following been?

(Circle one on each line)

		Helped a lot	Helped a little	Not helped at all	Not available to me	Help is not needed
a	Family members	1	2	3	4	5
b	Friends or neighbours	1	2	3	4	5
c	A family doctor or general practitioner	1	2	3	4	5
d	Specialist doctor	1	2	3	4	5
e	Hospital doctor	1	2	3	4	5
f	Food services (eg Meals on Wheels)	1	2	3	4	5
g	Nursing or community health services	1	2	3	4	5
h	Respite services (in home, day centre, or inpatient)	1	2	3	4	5
i	Homemaking services (eg home care service, laundry service)	1	2	3	4	5
j	Home maintenance services (eg odd jobs, gardening)	1	2	3	4	5
k	Counselling or other mental health services	1	2	3	4	5
l	Ambulance service	1	2	3	4	5
m	Support and advisory groups (eg Alzheimer's Association, Carer Resource Centre)	1	2	3	4	5

52 When did you start to care for this person?

(Circle one only)

- Within the last year 1
- Between 1 and 2 years ago 2
- Between 2 and 4 years ago 3
- Over 4 years ago 4

53 Thinking about when you started to care for this person, was it:

(Circle one only)

- A sudden change (eg after they became ill)? 1
- A gradual transition (eg they started to need more and more help)? 2
- Some other situation? Please specify 3

54 The following statements have to do with the type of interactions you had with the person you care for BEFORE they needed care. For each statement, please indicate which response you feel most accurately describes how you and the person you care for interacted before she / he needed care.

(Circle one on each line)

		Never	Sometimes	Often	Always
a	If she / he was feeling bad, I tried to cheer her / him up	1	2	3	4
b	She / he seemed to enjoy responding to my needs	1	2	3	4
c	She / he did things just to please me.	1	2	3	4
d	When she / he had a need, she / he turned to me for help	1	2	3	4
e	She / he went out of her / his way to help me	1	2	3	4
f	She / he responded to my needs	1	2	3	4
g	I enjoyed helping her / him	1	2	3	4
h	I went out of my way to help her / him	1	2	3	4
i	When making a decision, I considered her / his needs and feelings	1	2	3	4
j	She / he would have done almost anything for me	1	2	3	4

55 Why did you take on the role of carer for this person?

(Circle all that apply)

a	There was no-one else to do it	1
b	I wanted to do it	1
c	They asked me to care for them	1
d	I was already caring for them to some extent	1
e	I thought that I was the best person to do it	1
f	I felt pressured by other family members	1
g	Another reason? Please specify	1

56 These questions are about how you feel:

(Circle one on each line)

		Never	Rarely	Some times	Quite frequently	Nearly always
a	Do you feel that because of the time you spend with the person you care for that you don't have enough time for yourself?	1	2	3	4	5
b	Do you feel stressed between caring for the person you care for and trying to meet other responsibilities such as work / family?	1	2	3	4	5
c	Do you feel angry when you are around the person you care for?	1	2	3	4	5
d	Do you feel that the person you care for currently affects your relationship with family members or friends in a negative way?	1	2	3	4	5
e	Do you feel strained when you are around the person you care for?	1	2	3	4	5
f	Do you feel that your health has suffered because of your involvement with the person you care for?	1	2	3	4	5
g	Do you feel that you don't have as much privacy as you would like because of the person you care for?	1	2	3	4	5
h	Do you feel that your social life has suffered because you are caring for this person?	1	2	3	4	5
i	Do you feel that you have lost control of your life since the person you care for became ill?	1	2	3	4	5
j	Do you feel uncertain about what to do about the person you care for?	1	2	3	4	5
k	Do you feel you should be doing more for the person you care for?	1	2	3	4	5
l	Do you feel you could do a better job in caring for the person you care for?	1	2	3	4	5

57 Here is a list of things that carers sometimes find to be issues when caring for somebody. Please read each statement and circle one response for each statement as it applies to how YOU feel in caring for the PERSON YOU CARE FOR.

(Circle one on each line)

		Yes	No
a	Your sleep is disturbed (eg because they wake or need help at night)	1	2
b	It is inconvenient to care for them (eg because it takes so much time)	1	2
c	It is a physical strain (eg because of lifting, helping)	1	2
d	It is confining (eg because it stops you doing other things)	1	2
e	There have been family adjustments (eg disrupted routines, no privacy)	1	2
f	There have been changes in personal plans (eg changes to holidays, work)	1	2
g	There have been other demands on your time (eg from other family members, friends)	1	2
h	There have been emotional adjustments (eg arguments or conflict)	1	2
i	Some behaviour is upsetting (eg wetting clothes or bedding, or memory problems, or impulsiveness)	1	2
j	It is upsetting that the person you care for has changed and is not the same person as he / she used to be	1	2
k	There have been work adjustments (eg because of having to take time off or leave work)	1	2
l	It is a financial strain	1	2
m	Feeling completely overwhelmed (eg because of worry about them or concerns for how you will manage)	1	2

58 Providing help to the person you care for has:

(Circle one on each line)

		Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
a	Made me feel more useful	1	2	3	4	5
b	Made me feel good about myself	1	2	3	4	5
c	Made me feel needed	1	2	3	4	5
d	Made me feel appreciated	1	2	3	4	5
e	Made me feel important	1	2	3	4	5
f	Made me feel strong and confident	1	2	3	4	5
g	Given more meaning to my life	1	2	3	4	5
h	Enabled me to learn new skills	1	2	3	4	5
i	Enabled me to appreciate life more	1	2	3	4	5
j	Enabled me to develop a more positive attitude toward life	1	2	3	4	5
k	Strengthened my relationships with others	1	2	3	4	5

