

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, Mr Richard Hockey and
Prof Annette Dobson



Transitions into and out of caring and their effects on health and use of community services in women born between 1921 and 1926



Detailed report for the Australian Government Department of Health and Ageing
Carers Project, Stage 2, Phase 3

September 2009

Summary of findings

Context

This report examines the transitions into and out of caring among 12432 women from the 1921-1926 cohort of ALSWH. It also examines the needs of carers for health services. The report describes exploratory and longitudinal analysis of data from Surveys 2, 3, 4 and 5. These surveys were examined because the question about providing care was asked consistently across them and it provided information about where the carer lived relative to the care recipient. Survey 1 data were not included in the analysis as it was not possible to determine whether the carer was living with the care recipient.

Transitions

Women were classified into transition groups according to the pattern of their caring across Surveys 2-5. Three groups included women whose caring roles remained the same. These were carers who consistently cared for someone who lived with them, carers who consistently cared for someone who lived elsewhere and women who consistently did not provide care for anyone across Surveys 2-5. The majority of the women did not care for anyone at any survey.

There were nine further transition groups created from the participants' caring status between consecutive surveys. These nine transition groups fell under five broad categories of not providing care, started to provide care, stopped providing care, changed where they lived relative to their care recipient (changed caring) and stayed providing care in the same living relationship to their care recipient.

The 12 transition groups were the main factor explored in the analysis of health and use of community services, i.e., whether there was any association between these different types of care groups, and transitions between them, and health and use of community services. In addition to transition groups, exploratory analysis of the data was conducted to determine other factors that may have affected health and use of community services.

Carer needs

Ten factors were examined including transition group, time of survey, education, country of birth, area of residence, ability to manage on available income, caring for grandchildren, need for care, sleep difficulty and memory decline. The seven health and community services outcomes included mental health, physical health, number of visits to the general practitioner (GP), and use of nursing or community health services, respite services, homemaking services and home maintenance services.

Women who never provided care typically had better outcomes compared to carers who lived with their care recipients but worse outcomes compared to carers who lived elsewhere. Generally, women who used the services or had poorer health outcomes transitioned into or out of providing care for a care recipient who lived with them, and in the case of homemaking services, their use of services was more apparent earlier, at Survey 3. However, women who had better mental health were more likely to have transitioned into or out of providing care for a care recipient who lived elsewhere.

The combination of factors that was related to poorer health, visiting the GP five or more times and use of services, is:

- Transitioning into or out of providing care for a live-in care recipient
- Reporting difficulties managing on available income
- Not providing care for grandchildren
- Needing care themselves
- Reporting sleep difficulties
- More memory decline.

Women with these characteristics would be potential candidates for appropriate policies and services.

Possible policy implications

- Policies should recognise that older women who are carers have diverse caring situations that may change over time.
- Results indicate that carers who transitioned into or out of providing care for a care recipient who lived with them had poorer health outcomes than carers who lived elsewhere. Policies should consider the particular needs of carers who live with the person for which they care. As these carers may experience difficulty leaving their care recipient at home, adequate respite services to allow carers to visit health services, or in-home health visits, may be necessary to ensure adequate access to services.
- In particular, older women who are carers are at risk of poorer outcomes if they also have difficulties managing on their available income, do not provide care for grandchildren, need care themselves and report sleep difficulties and memory decline. This finding emphasises the importance of adequate financial provision and health services for carers. Framing the needs of the carer(s) and care recipient as a system where each affects the other may assist health services to provide for the needs of both in an efficient manner.

Table of contents

Summary of findings	1
Context	1
Transitions	1
Carer needs	1
Possible policy implications.....	2
Table of contents	3
List of tables	4
List of figures	4
Chapter 1 Background.....	5
1.1 Overview of the Australian Longitudinal Study on Women’s Health.....	5
1.2 Background to research on caring.....	5
1.3 Aims of this report	7
1.4 Methodology of the longitudinal study of the 1921-1926 cohort.....	7
1.4.1 Sample.....	7
1.4.2 Transition groups	8
1.4.3 Exploratory analysis	10
1.4.4 Longitudinal analysis	12
Chapter 2 Exploratory analysis results.....	14
2.1 Profile of women in the 1921-1926 cohort	14
2.2 Participant frequencies in the 1921-1926 cohort	17
2.3 BADLs and IADLs	19
Chapter 3 Longitudinal analysis results.....	22
3.1 Mental health	22
3.2 Physical health.....	24
3.3 Number of visits to the GP	24
3.4 Use of nursing or community health services	26
3.5 Use of respite services	28
3.6 Use of homemaking services	29
3.7 Use of home maintenance services	31
Chapter 4 Discussion and conclusions.....	33
4.1 Transitions	33
4.1.1 What are the transitions into and out of caring over the lifespan?.....	33
4.2 Carer needs	33
4.2.1 What is the broad impact of caring on women’s lives?	33
4.2.2 What needs, unmet or under met, can be identified for carers?.....	35
Chapter 5 References.....	36
Appendix.....	37

List of tables

Table 1 Three hypothetical caring scenarios for women of the 1921-1926 cohort	10
Table 2 Profile of women in the 1921-1926 cohort for Surveys 3 to 5	15
Table 3 Attrition across Surveys 1 to 5 in the 1921-1926 cohort of the ALSWH. The number of women and percentage of the original sample (n=12,342) are presented.....	16
Table 4 Frequency of BADL categories for Surveys 4 and 5, by transition group.	20
Table 5 Frequency of IADL categories for Surveys 4 and 5, by transition group.	21
Table 6 Effect of significant factors on the mental health of women in the 1921-1926 cohort.....	23
Table 7 Effect of significant factors on the physical health of women in the 1921-1926 cohort.....	25
Table 8 Effect of significant factors on the number of visits to the GP in women of the 1921-1926 cohort.....	26
Table 9 Effect of significant factors on the use of nursing or community health services in women of the 1921-1926 cohort	27
Table 10 Effect of significant factors on the use of respite services in women of the 1921-1926 cohort.....	28
Table 11 Effect of significant factors on use of homemaking services in women of the 1921-1926 cohort.....	30
Table 12 Effect of significant factors on use of home maintenance services in women of the 1921-1926 cohort.....	32
Table A 1 Least squares means, standard errors (SE) and p-values for the fixed effects for all factors for mental health and physical health.....	37
Table A 2 Associations between selected factors and the number of visits to the GP in women of the 1921-1926 cohort.....	38
Table A 3 Associations between selected factors and the use of nursing or community health services in women of the 1921-1926 cohort.....	40
Table A 4 Associations between selected factors and the use of respite services in women of the 1921-1926 cohort.....	41
Table A 5 Associations between selected factors and the use of homemaking services in women of the 1921-1926 cohort.....	42
Table A 6 Associations between selected factors and the use of home maintenance services in women of the 1921-1926 cohort.	44

List of figures

Figure 1 Factors that may affect the outcomes of health and use of community services in the longitudinal analysis	13
Figure 2 Frequency of carers who lived with their care recipients, carers who lived elsewhere and noncarers for Surveys 2 to 5	17
Figure 3 Frequency of the transition groups for Surveys 3 to 5	18

Chapter 1 Background

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. In addition, the study investigates how these factors influence lifestyle choices around family and workforce participation at key points in women's lives. The ALSWH advances understanding of the factors that enhance or inhibit good health in women.

In 1994, the Australian Government 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 ALSWH began in 1995 and is projected to run for at least 20 years. It provides information on trends in areas such as healthy ageing, chronic conditions, partner violence, health service use, weight, physical activity, alcohol consumption, tobacco and other drugs, mental health, paid work, and planning for retirement, on women in metropolitan, rural and remote areas of Australia. The ALSWH also collects information about caring for family members or friends. Linkage with the Medicare and Pharmaceutical Benefits Scheme datasets provides additional information on the health service use of women.

In 1995, the ALSWH commenced and recruited over 40000 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 12000 women in each of three age cohorts: women born between 1973 and 1978 who are aged 31-36 years in 2009; women born between 1946 and 1951 who are aged 58-63 years in 2009; and women born between 1921 and 1926 who are aged 83-88 years in 2009.

Each cohort has a similarly aged pilot study group of women, not included in the main sample, who 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 14 years of data available. The women born between 1973 and 1978 are being 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).

1.2 Background to research on caring

Stage 1: In 2006 and 2007 researchers in the ALSWH team at the University of Queensland were contracted to provide detailed analyses of caring 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: Preliminary report. Employed carers in mid-life: Findings from the Australian Longitudinal Study on Women's Health (Lucke et al. 2006)
- Report 2: Detailed report. Changes in caring roles and employment in mid-life: Findings of the Australian Longitudinal Study on Women's Health (Berecki et al. 2007)
- Report 3: Pilot study report. Service use and the impact of family caregiving on Mid-aged women from the Australian Longitudinal Study on Women's Health (Watson, Lucke & Dobson 2007).

Stage 2: In 2008 researchers in the ALSWH team at the University of Queensland, were contracted to provide further detailed analyses of caring 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 area of residence) 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 into 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?

The first report (Phase 1 of Stage 2) examined caring and use of services in women born between 1946 and 1951 (McKenzie, Tooth, Lucke & Dobson 2009). The study was a substudy of the ALSWH and included 296 women (97 carers, 199 noncarers) that participated in pilot surveys for the 1946-1951 cohort. The detailed report showed that carers were not a homogenous group. Women who were live-in carers reported higher carer strain and were more likely to be the main care provider, have been caring for a longer time, care for younger recipients (who were typically their husbands/partners), perform more activities of daily living (particularly the more intensive activities of daily living) and work part-time, if in the labour force. However, carers who

did not live with their care recipient were more likely to care for older recipients (who were typically their parents), perform only instrumental activities of daily living and work full-time, if in the labour force.

The second report (Phase 2 of Stage 2) examined caring and use of services in women carers born between 1921 and 1926 (McKenzie, Tooth, Lucke, Mendis et al. 2009). The study was a nested cross-sectional substudy of the ALSWH, involving data from 280 carers who cared for someone who may have used community services. The detailed report showed that carers had poorer mental and physical health compared to the entire 1921-1926 cohort of the ALSWH. The carers who completed the survey provided the majority of the help for the care recipients compared to other unpaid carers or paid services. Use of services was low. However, when the services were used, the carers reported that they were easy to access, they were of a good quality and that they received as much as they wanted.

This third report (Phase 3 of Stage 2) describes exploratory and longitudinal analysis of data from Surveys 2, 3, 4 and 5 of the 1921-1926 cohort of the ALSWH to examine carer needs and transitions.

1.3 Aims of this report

This third report, Phase 3 of Stage 2, aims to address the following questions:

1. Transitions:
 - a. What are the transitions into and out of caring over the lifespan?
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?

1.4 Methodology of the longitudinal study of the 1921-1926 cohort

1.4.1 Sample

This study involves analysis of data from the 1921-1926 cohort of the ALSWH. The data were collected according to standard ALSWH procedures, which have been fully described elsewhere (Brown et al. 1998; Lee et al. 2005). ALSWH data collection was approved by the University of Queensland Medical Research Ethics Committee (Approval number: 2004000224) and the University of Newcastle Ethics Committee (Approval number: H-076-0795).

Surveys 2, 3, 4 and 5 were conducted in 1999, 2002, 2005 and 2008, respectively. These four surveys were examined because the question about providing care was asked consistently across these surveys and it provided information about where the carer lived relative to the care recipient. In Surveys 2-5, participants were asked about providing care in the following question: "Do you regularly provide care or assistance (eg personal care, transport) to any other person because of their long-term illness, disability or frailty? (*Mark all that apply*)". The response options were 'yes, for someone who lives with me', 'yes, for someone who lives elsewhere', and 'no, I do not provide care'. Previous reports from both Stage 1 and Stage 2 have highlighted the importance of knowing if the carer lived with the care recipient. Therefore, Survey 1 was not examined because the question about caring only included the response options 'yes'

or 'no' which meant that the data could not be combined with data from other surveys to examine transitions into and out of caring over time.

Therefore, in this Phase 3 report, carers were classified into three caring status groups at each survey for Surveys 2, 3, 4 and 5:

- **Not:** Women who did not provide care
- **With:** Women who cared for a care recipient who lived with them
- **Elsewhere:** Women who cared for a care recipient who lived elsewhere.

1.4.2 Transition groups

To examine the transitions into and out of caring across Surveys 2, 3, 4 and 5, transition groups were created. First, women whose caring status did not change across the four surveys were categorized into three groups:

- **Always With carers:** Women who provided live-in care for a care recipient who lived with them at all four surveys
- **Always Elsewhere carers:** Women who provided care for a care recipient who lived elsewhere at all four surveys
- **Never Carers:** Women who did not provide care at any of the four surveys.

The remaining women transitioned into and out of caring at some point across the surveys. Therefore, for these women, transition groups were created for each consecutive pair of surveys: Surveys 2-3, Surveys 3-4, Surveys 4-5. For instance, transitions groups for Survey 3 were determined by combining the caring status groups (Not, With or Elsewhere as described in the last paragraph of Section 1.4.1) at Survey 2 and Survey 3. Therefore, for example, participants who were not providing care (Not) at Survey 2 and provided live-in care (With) at Survey 3 were classified in the Not-With transition group for Survey 3.

These paired combinations resulted in nine further groups, which were classified under five categories:

Not caring

- **Not-Not:** Women who did not provide care at both time points

Started caring

- **Not-With:** Women who started providing live-in care for a care recipient who lived with them
- **Not-Elsewhere:** Women who started providing care for a care recipient who lived elsewhere

Stopped caring

- **With-Not:** Women who stopped providing live-in care for a care recipient who lived with them
- **Elsewhere-Not:** Women who stopped providing care for a care recipient who lived elsewhere

Changed caring

- **With-Elsewhere:** Women who provided care at both time points, but the carer lived with a care recipient at the first time point and lived elsewhere at the second time point

- **Elsewhere-With:** Women who provided care at both time points, but the carer lived elsewhere from a care recipient at the first time point and lived with a care recipient at the second time point

Stayed caring

- **With-With:** Women who provided live-in care for a care recipient who lived with them at both time points
- **Elsewhere-Elsewhere:** Women who provided care for a care recipient who lived elsewhere at both time points.

Transitions groups were created for Survey 3 (using caring status groups at Surveys 2 and 3), Survey 4 (using caring status groups at Surveys 3 and 4) and Survey 5 (using caring status groups at Surveys 4 and 5). Caring transitions groups could not be created for Survey 2 because the caring question in Survey 1 did not provide information on where the carer lived relative to the care recipient.

Please note that women who were categorized into these nine transition groups provided care at some point across the surveys and their caring status changed across the surveys. If their caring status did not change across the surveys, they would have been categorized into one of the three groups that did not transition. For instance, women who were categorized into the Not-Not transition group did not provide care at those two time points. However, they did provide care at some other time across the surveys; otherwise, they would have been classified as Never Carers. Similarly, women who were categorized into the With-With transition group provided live-in care at those two time points. However, they would not have had live-in caring status across all surveys, because if that were the case, they would have been classified as Always With carers.

To illustrate how these paired combinations show how women may transition into or out of caring across the surveys, three hypothetical caring scenarios for women in the 1921-1926 cohort are presented in Table 1 and in the following text.

1. Mrs G was married and lived with her husband. At Survey 2, she did not provide care (Not), but by Survey 3, she had started to provide live-in care (With) for him. Her husband passed away before Survey 4 so she was not providing care at Survey 4 (Not). However, by Survey 5 she had started to care for a friend who lived elsewhere (Elsewhere). Therefore, Mrs G's transition groups at Surveys 3, 4 and 5 would be:
 - Survey 3: Not-With
 - Survey 4: With-Not
 - Survey 5: Not-Elsewhere
2. Ms W provided care for a sister who lived elsewhere at Survey 2 (Elsewhere). By Survey 3, Ms W had moved in with her sister and was providing live-in care (With). At Survey 4, she was still providing live-in care (With) for her sister. However, by Survey 5, the sister had moved into a nursing home and Ms W was no longer providing care for her (Not). Therefore, Ms W's transition groups at Surveys 3, 4 and 5 would be:
 - Survey 3: Elsewhere-With
 - Survey 4: With-With
 - Survey 5: With-Not
3. Mrs S lived with her husband and their adult-age daughter who required care. At all surveys, Ms S provided live-in care for her daughter (With). Therefore,

she did not transition into or out of caring and was in the Always With transition group.

Table 1 Three hypothetical caring scenarios for women of the 1921-1926 cohort

	Survey 2 1999	Survey 3 2002	Survey 4 2005	Survey 5 2008
Mrs G				
<i>Caring status</i>	Not	With	Not	Elsewhere
<i>Transition group</i>	x	Not-With	With-Not	Not-Elsewhere
Ms W				
<i>Caring status</i>	Elsewhere	With	With	Not
<i>Transition group</i>	x	Elsewhere-With	With-With	With-Not
Mrs S				
<i>Caring status</i>	With	With	With	With
<i>Transition group</i>	x	Always With	Always With	Always With

x Caring transition groups could not be created for Survey 2 because the caring question in Survey 1 did not provide information on where the carer lived relative to the care recipient.

These 12 transition groups were the main factor explored in the analysis of health and use of community services, i.e., whether there was any association between these different types of care groups, and transitions between them, and health and use of community services. In addition to transition groups, exploratory analysis was used to explore the data to determine other factors that may affect health and use of community services.

1.4.3 Exploratory analysis

Exploratory analysis is a technique in which the data are examined by summarising them in more basic terms, such as means, medians or frequencies, to gain insight about a set of data. Exploratory analysis was used to determine the variables that had the most important and meaningful relationships with caring. Results of these analyses for the 1921-1926 cohort are presented in Chapter 2.

The data were explored by observing patterns in frequencies or median and quartile values across the surveys for the following variables:

Demographic

- **Marital status:** categorized as 'married or de facto', 'separated or divorced', 'widowed' or 'single'.

- **Education:** the highest qualification completed was categorized as 'higher school certificate or higher', 'school certificate' or 'no formal qualifications'.
- **Country of birth:** categorized as 'non-English speaking country', 'other English-speaking country' or 'Australia'.
- **Area of residence:** based on the ARIA+ system, which is determined by remoteness based on the distance to the nearest service centre, and was categorized as 'outer regional or remote', 'inner regional' or 'major city'.
- **Ability to manage on available income:** categorized as 'difficult' (which included 'it is difficult some of the time', 'it is difficult all of the time' and 'it is impossible') or 'not difficult' (which included 'it is not too bad' and 'it is easy').

Lifestyle

- **Care for grandchildren:** participants were asked if they regularly provided care for their grandchildren or other people's children and the responses were categorized as 'yes' or 'no'.

Health-related

- **Insurance coverage:** participants were asked if they had Department of Veterans' Affairs coverage for health services or if they had private insurance for hospital or ancillary.
- **Need for care:** participants also indicated if they regularly needed help with daily tasks and the responses were categorized as 'yes' or 'no'.
- **Sleep difficulty:** was measured by a modified Nottingham Health Profile sleep subscale (Hunt et al. 1981). The scale was categorized as 'major sleep difficulties', 'minor sleep difficulties' and 'no sleep difficulties'.
- **Memory decline:** age-related memory decline was measured by the Memory Assessment Clinic-Q (Crook, Feher & Larrabee 1992). Scores range from 7 to 35 with higher scores indicating greater decline in memory.
- **Mental health and physical health:** measured by the Medical Outcomes Study Short Form 36 using the Physical Functioning and Mental Health Index subscales (Ware et al. 1993). Higher scores indicate better quality of life.
- **Number of visits to the GP** in the previous 12 months: categorized as '0 to 4 visits' or '5 or more visits'.
- **Use of community services** in the previous 6 months: were categorized as 'yes' or 'no' for
 - nursing or community health services
 - respite services (in home, day care or inpatient)
 - homemaking services (eg. home care service, laundry service)
 - home maintenance services (eg. odd jobs, gardening).

Activities of daily living

Participants were asked specific questions about their difficulty performing, and dependence on others to help them perform, Basic Activities of Daily Living (BADLs) and Instrumental Activities of Daily Living (IADLs) in the previous month.

- **BADLs** include the personal tasks of daily life, such as washing, dressing or grooming.
- **IADLs** include further life activities, such as managing money or using the telephone.

The responses to the difficulty and dependency questions were asked in Surveys 4 and 5. The scores for BADLs and IADLs were categorized as 'no difficulty or help required' or 'some difficulty and/or help required'.

1.4.4 Longitudinal analysis

The data were then analysed using complex repeated measures analytic techniques (called "mixed models") to examine both the effect of the transition groups and other factors on health and use of community services. The analyses were *longitudinal* because data for the variables listed in Section 1.4.3 were examined *over time* at more than one time (at Surveys 3, 4 and 5). Therefore, the variable 'time' (categorized as Surveys 3, 4 and 5) was analysed as a factor in these analyses. The other factors included in the analyses were education, country of birth, area of residence, ability to manage on available income, caring for grandchildren, need for care, sleep difficulty and memory decline. The health and community services outcomes included mental health, physical health, number of visits to the GP, and use of nursing or community health services, respite services, homemaking services and home maintenance services. These factors and outcomes are illustrated in Figure 1.

Marital status was not included in the analyses because it was so highly related to transition group that including both marital status and group in the analyses would have been redundant. Insurance coverage was not included because it was not relevant to all of the outcomes. However, descriptive information on insurance coverage is presented in Section 2.1. BADL and IADL scores could not be included in the analyses because they were only available at Surveys 4 and 5. Therefore, descriptive information about them is presented in Section 2.3.

These longitudinal analyses required that there is a reference group for each factor. Therefore, comparisons between categories of a factor were compared to a reference group. For instance, Never Carers was the comparison group for the transitions group factor, while the comparison group for time (Surveys 3, 4 and 5) was Survey 3. The relevant comparison group for each factor is denoted with an asterisk in the tables in the results sections.

For the current report, the term 'statistically significant' is used for analyses where the associations or differences are statistically significant to the level of $p \leq 0.001$. The results of the longitudinal analysis are presented in Chapter 3.

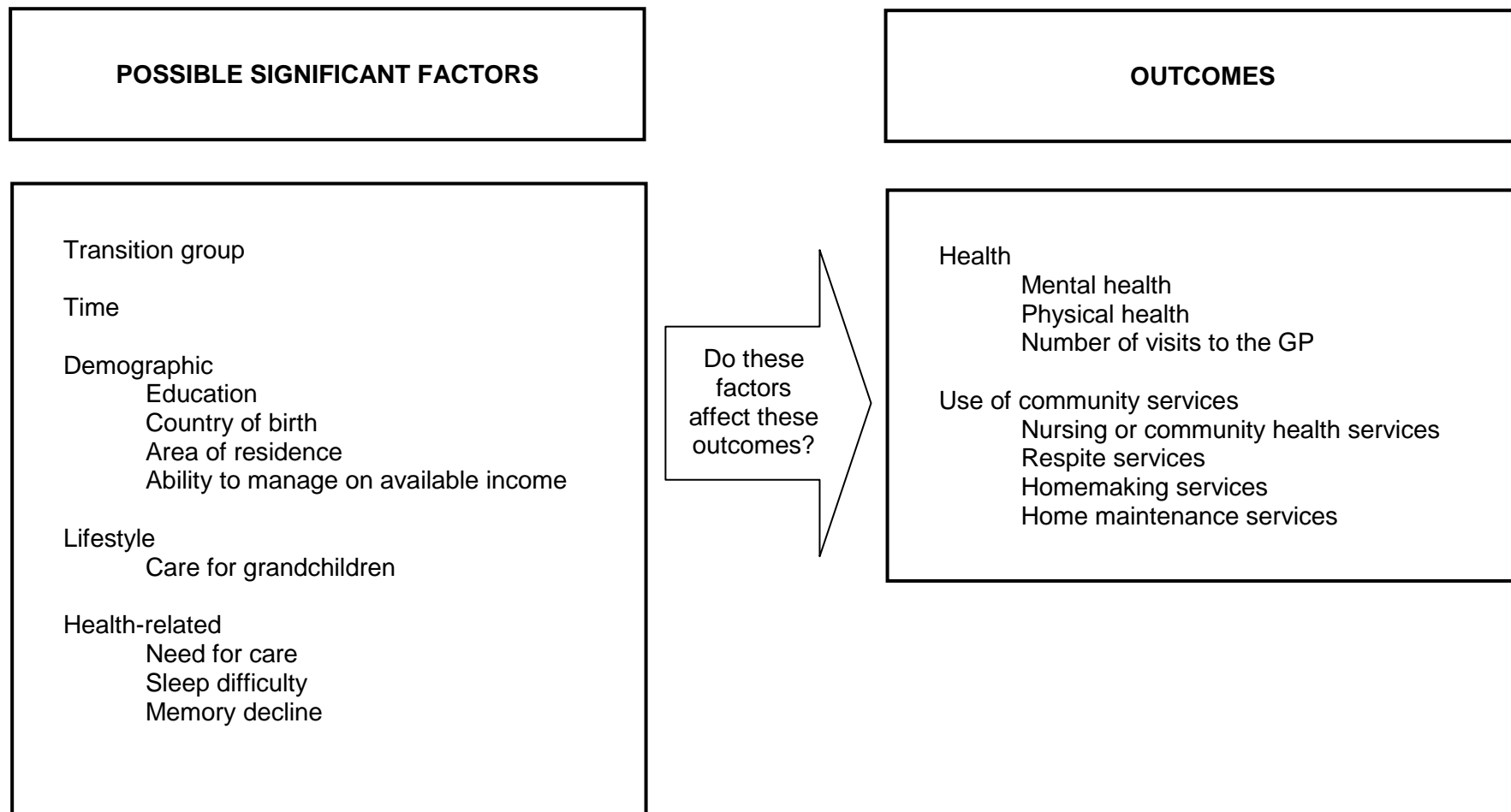


Figure 1 Factors that may affect the outcomes of health and use of community services in the longitudinal analysis

Chapter 2 Exploratory analysis results

The exploratory analysis of the women in the 1921-1926 cohort is presented in this chapter. This chapter includes the profile of the women, including demographic, lifestyle and health-related variables, as well as the frequencies of the women in the caring status and transition groups.

2.1 Profile of women in the 1921-1926 cohort

In general, the women of the 1921-1926 cohort were aged an average of 78, 81 and 84 years old at Surveys 3, 4 and 5, respectively (see Table 2). Most of the women were married or widowed and the proportion of women who were widowed increased as they grew older. Approximately one-third of the women were in each education category while most of the women were born in Australia. Approximately half of the women lived in a major city and most women did not report difficulty managing on available income.

The frequency of caring for grandchildren greatly reduced at Survey 5. The proportion of women who had private insurance for hospital or ancillary decreased as the women aged, while the proportion of women with Veterans' Affairs cover increased. Most women did not need regular care for daily tasks. Approximately one-third of the women were in each sleep difficulty category. Memory decline and mental health remained stable as the women aged while physical health worsened as they aged.

The women visited the GP more frequently as they aged. In addition, their use of nursing, respite, homemaking and home maintenance services increased. Homemaking and home maintenance services were used the most while respite was used the least.

Information on BADLs and IADLs was available for Surveys 4 and 5. A higher proportion of women had difficulty or required help for IADLs than BADLs at both surveys. More women at Survey 5 had difficulty or needed help with BADLs and IADLs than at Survey 4.

As shown in the sample size values (n) presented in Table 2, the overall number of participants decreased as the women aged. This was due to several reasons: participants may have died, withdrew due to frailty, withdrew due to other reasons or were lost to follow up. The proportion of women who responded to all Surveys 1-5 and the reasons for attrition are presented in Table 3.

Table 2 Profile of women in the 1921-1926 cohort for Surveys 3 to 5

	Survey 3 (n=8646*)	Survey 4 (n=7158*)	Survey 5 (n=5559*)
Time of survey	2002	2005	2008
Demographic			
Age (years) [mean (SD)]	78.3 (1.5)	81.2 (1.4)	84.2 (1.4)
Marital status (%)			
Married or de facto	45	37	30
Separated or divorced	5	4	4
Widowed	47	56	64
Single	3	3	2
Education [†] (%)			
Higher school certificate or higher	27		
School certificate	39		
No formal qualifications	34		
Country of birth [†] (%)			
Non-English speaking country	10		
Other English-speaking country	13		
Australia	77		
Area of residence (%)			
Outer regional or remote	19	18	17
Inner regional	37	37	38
Major city	44	45	45
Manage on income (%)			
Difficult	25	21	18
Not difficult	75	79	82
Lifestyle			
Care for grandchildren (%)			
Yes	38	32	19
No	62	68	81
Health-related			
Insurance cover [‡] (%)			
Veterans' Affairs cover	19	22	24
Private hospital insurance	47	39	40
Private ancillary insurance	32	27	26
Need for care (%)			
Yes	13	12	17
No	87	88	83
Sleep difficulties (%)			
Major sleep difficulties	25	39	34
Minor sleep difficulties	41	35	38
No sleep difficulties	34	26	28
Memory decline [mean (SD)]	25.6 (4.3)	25.6 (4.4)	25.5 (4.6)
Mental health [mean (SD)]	78.8 (15.8)	78.9 (15.9)	78.4 (16.6)
Physical health [mean (SD)]	57.9 (28.2)	53.2 (28.5)	48.2 (28.2)
Number of visits to GP (%)			
0 to 4 visits	39	37	34
5 or more visits	61	63	66

Nursing or community health services use (%)			
Yes	10	10	13
No	90	90	87
Respite services use (%)			
Yes	3	5	6
No	97	95	94
Homemaking services use (%)			
Yes	16	24	33
No	84	76	67
Home maintenance services use (%)			
Yes	29	28	32
No	71	72	68
BADLs [§] (%)			
No difficulty or help required		67	61
Some difficulty and / or help required		33	39
IADLs [§] (%)			
No difficulty or help required		35	26
Some difficulty and / or help required		65	74

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

† Questions about education and country of birth were asked only at Survey 1

‡ Percentages do not add up to 100 as women could have selected more than one response

§ Questions about BADLs and IADLs were asked only at Surveys 4 and 5

SD=standard deviation

Table 3 Attrition across Surveys 1 to 5 in the 1921-1926 cohort of the ALSWH. The number of women in each attrition category and percentage of the original sample (n=12342) are presented.

	Survey (year)									
	1 (1996)		2 (1999)		3 (2002)		4 (2005)		5 (2008)	
	n	%	n	%	n	%	n	%	n	%
Respondent	12432	100	10434	84	8646	69	7158	58	5559	45
Deceased	0	0	553	4	1236	10	2287	18	3530	29
Frail	0	0	103	1	317	3	543	4	628	5
Withdrawn	0	0	581	5	1116	9	1357	11	1418	11
Lost to follow up	0	0.0	761	6	1117	9	1087	9	1297	10
Total	12432	100	12432	100	12432	100	12432	100	12432	100

2.2 Participant frequencies in the 1921-1926 cohort

The 1921-1926 cohort consisted of 12432 women. Caring status was determined at Surveys 2-5 and the frequency of the caring status groups (carers who lived with their care recipients, carers who lived elsewhere and noncarers) is presented in Figure 2. From these caring status groups, 12 transition groups were created for Surveys 3-5. The frequency of the transition groups is presented in Figure 3.

These transition groups were the main factor explored in the analysis of the health and use of community services. However, the nature of caring for women in the 1921-1926 cohort did not relate to only one variable at a time or one aspect of a woman's life. Therefore, more complex analysis was needed that took into account all of the relevant factors presented in Figure 1 and determined their impact on the outcomes. This report focuses on this analysis, which is presented in Chapter 3.

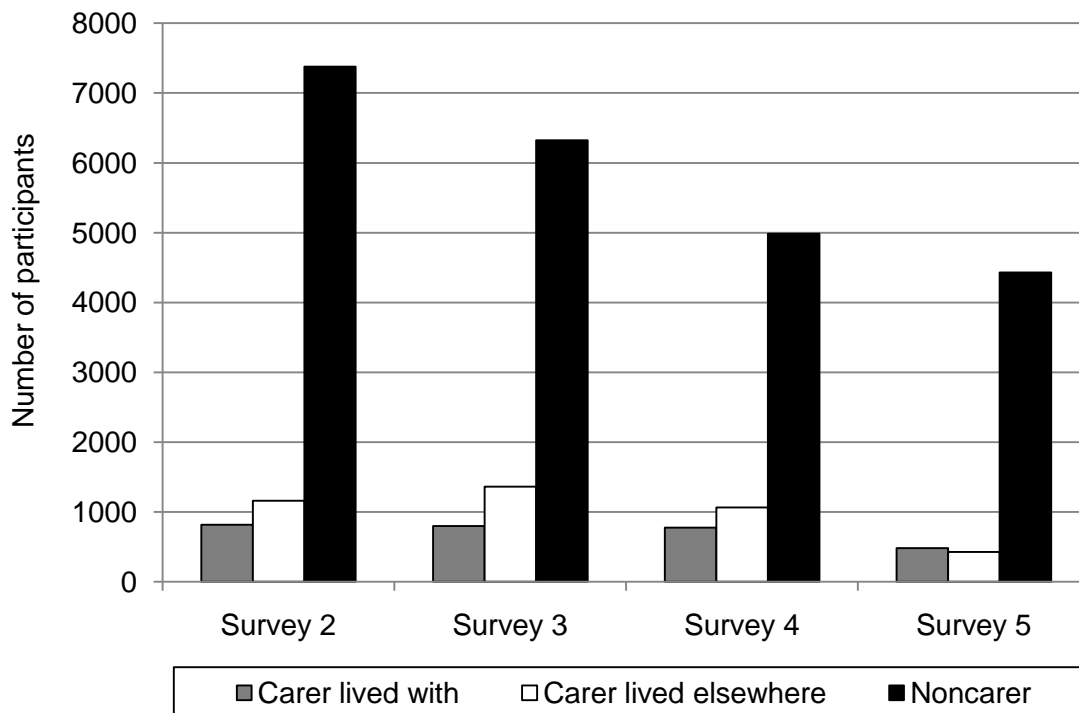


Figure 2 Frequency of carers who lived with their care recipients, carers who lived elsewhere and noncarers for Surveys 2 to 5

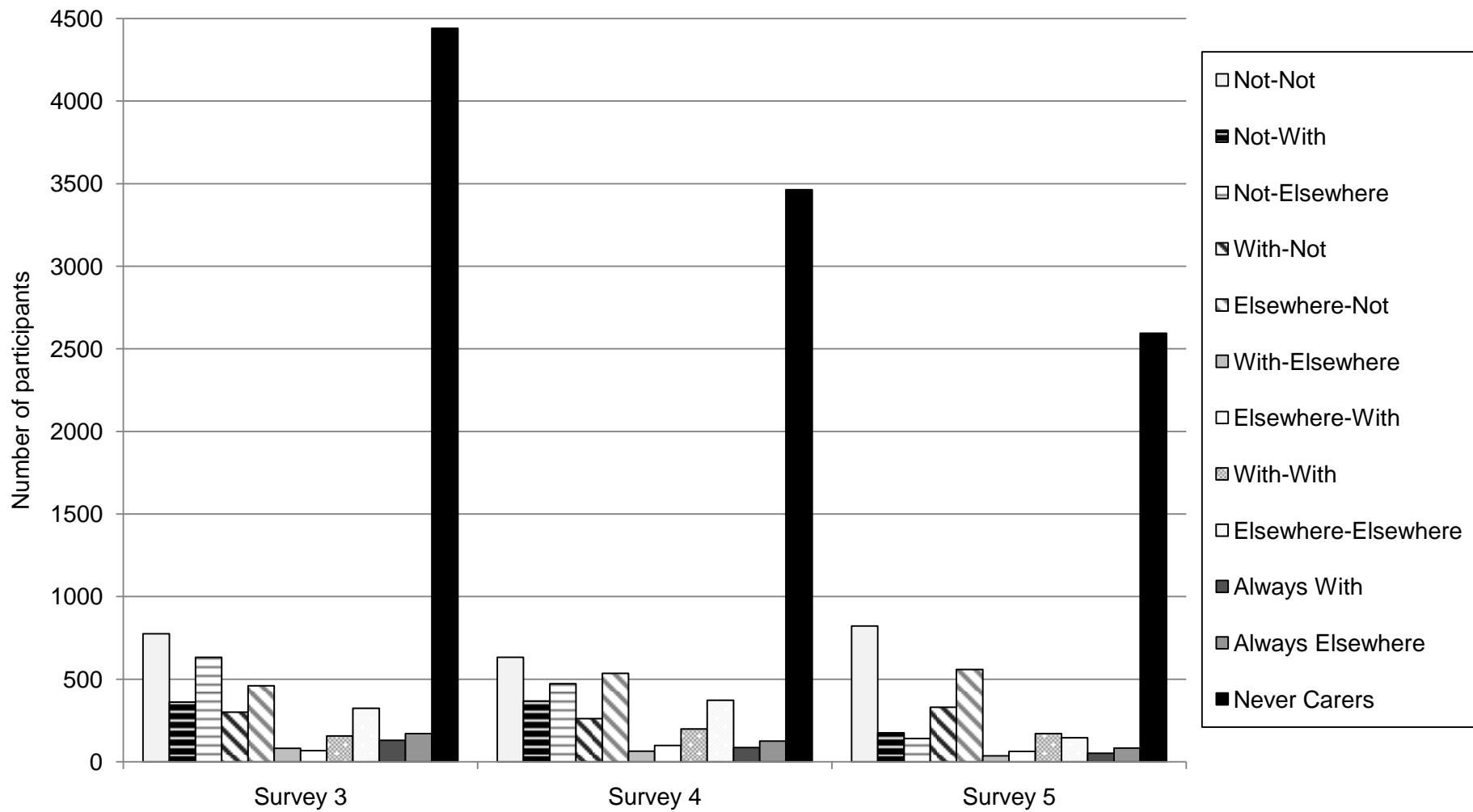


Figure 3 Frequency of the transition groups for Surveys 3 to 5

2.3 BADLs and IADLs

BADL and IADL scores could not be included in the longitudinal analyses because they were only available at Surveys 4 and 5. Therefore, descriptive information about them is presented here for Surveys 4 and 5 and the transition groups. The frequencies of BADL categories for Surveys 4 and 5 by the transition groups are presented in Table 4. IADL categories are presented in Table 5.

More women had difficulty and/or needed help with IADLs than BADLs. As the women aged, they were more likely to have reported that they had difficulty or needed help with BADLs and IADLs. A smaller portion of women in the Elsewhere-Elsewhere group had difficulty or needed help with IADLs than the other transition groups for both surveys. There was no single prominent pattern for BADLs. At Survey 4, a smaller portion of women in the Not-Elsewhere, With-With and Always Elsewhere groups had difficulty or needed help with BADLs compared to the other transition groups. At Survey 5, these groups reported similar low percentages. However, the Elsewhere-Elsewhere and Always Elsewhere groups had even lower portions of women who had some difficulty or needed help with BADLs.

Table 4 Frequency of BADL categories for Surveys 4 and 5, by transition group. Elsewhere has been abbreviated as 'Else'.

	Transition groups												
	Not caring		Started caring		Stopped caring		Changed caring		Stayed caring		Always caring		Never caring
	Not-Not	Not-With	Not-Else	With-Not	Else-Not	With-Else	Else-With	With-With	Else-Else	Always-With	Always-Else		
%	%	%	%	%	%	%	%	%	%	%	%		
Survey 4													
No difficulty or help required	66	69	77	64	69	72	66	74	73	64	75	64	
Some difficulty and / or help required	34	31	23	36	31	28	34	26	27	36	25	36	
Survey 5													
No difficulty or help required	58	66	72	61	63	57	65	70	74	67	73	60	
Some difficulty and / or help required	42	34	28	39	37	43	35	30	26	33	27	40	

Table 5 Frequency of IADL categories for Surveys 4 and 5, by transition group. Elsewhere has been abbreviated as ‘Else’.

	Transition groups												
	Not caring		Started caring		Stopped caring		Changed caring		Stayed caring		Always caring		Never caring
	Not-Not	Not-With	Not-Else	With-Not	Else-Not	With-Else	Else-With	With-With	Else-Else	Always-With	Always-Else		
%	%	%	%	%	%	%	%	%	%	%			
Survey 4													
No difficulty or help required	34	35	42	26	35	37	36	32	45	26	43	33	
Some difficulty and / or help required	66	65	58	74	65	63	64	68	55	74	57	67	
Survey 5													
No difficulty or help required	23	21	31	25	33	29	23	24	41	21	27	25	
Some difficulty and / or help required	77	79	69	75	67	71	77	76	59	79	73	75	

Chapter 3 Longitudinal analysis results

The results of the longitudinal analyses are presented in this chapter. These analyses take into account all of the relevant factors and their effect on the outcomes of health and use of community services (as depicted in Figure 1). The results for each of the seven outcomes (mental health, physical health, number of visits to the GP and use of nursing or community health, respite, homemaking and home maintenance services) are presented here.

The analyses required that comparisons between categories of a factor were compared to a reference group. For instance, Never Carers was the comparison group for the transition group factor. The relevant comparison group for each factor is denoted with an asterisk in the tables of this chapter. All relationships discussed in this chapter are statistically significant.

3.1 Mental health

Transition group, education, country of birth, ability to manage on income, caring for grandchildren, need for care, sleep difficulty, and memory decline, all played a role in affecting the mental health of women in the 1921-1926 cohort. The effects of these factors are presented in the following text and Table 6.

Women who transitioned into and out of live-in caring (With-With, With-Not and Not-With groups) had poorer mental health than women who were the Never Carers group. Conversely, women who were in the Elsewhere-Elsewhere, Not-Elsewhere and Not-Not groups had better mental health than those women who were in the Never Carers group.

Women who had no formal qualifications had poorer mental health than women who had a school certificate or higher. Women born in non-English speaking countries had poorer mental health than Australian born women. Further, women who reported having difficulties managing on their available income had poorer mental health than women who did not report having difficulties.

Women who provided care for grandchildren had better mental health than women who did not provide other care. In addition, women who needed regular care themselves had poorer mental health than women who did not need care. Women who had no sleep difficulties had better mental health than women who had minor or major sleep difficulties. In addition, as memory decline worsened, so did mental health.

Least squares means, standard errors and p-values for these effects on mental health are presented in Table A 1.

Table 6 Effect of significant factors on the mental health of women in the 1921-1926 cohort

Significant factors	Mental health	
	Better mental health	Poorer mental health
Group		
Not-Not		
Not-With		
Not-Elsewhere		
With-Not		
Elsewhere-Not	Elsewhere-Elsewhere, Not-Elsewhere, Not-Not <i>compared to</i> Never carers	With-With, With-Not, Not- With, <i>compared to</i> Never Carers
With-Elsewhere		
Elsewhere-With		
With-With		
Elsewhere-Elsewhere		
Always With		
Always Elsewhere		
Never Carers*		
Education		
Higher school certificate or higher	School certificate and higher school certificate or higher	No formal qualifications
School certificate		
No formal*		
Country of birth		
Non-English speaking country	Australia	Non-English speaking country
Other English-speaking country		
Australia*		
Manage on income		
Difficult	Not difficult	Difficult
Not difficult*		
Care for grandchildren		
Yes	Provided care for grandchildren	Did not provide care for grandchildren
No*		
Need for care		
Yes	Did not need care	Needed care
No*		
Sleep difficulties		
Major sleep difficulties	No difficulties	Minor and major difficulties
Minor sleep difficulties		
No sleep difficulties*		
Memory decline	Less memory decline	More memory decline

* Reference category

3.2 Physical health

Transition group, time, education, ability to manage on income, caring for grandchildren, need for care, sleep difficulty and memory decline, all played a role in affecting the physical health of women in the 1921-1926 cohort. The effects of these factors are presented in the following text and Table 7.

All groups had better physical health than the Never Carers group, except for With-Not and Always With carers who had similar scores. The women had poorer physical health at Surveys 4 and 5 than at Survey 3.

Women who had no formal qualifications had poorer physical health than women who had a school certificate or higher. Furthermore, women who reported having difficulties managing on their available income had poorer physical health than women who did not report having difficulties.

Women who needed care had poorer physical health than woman who did not need care, and those who provided care for grandchildren or other people's children had better physical health than women who did not provide other care. Women who had no sleep difficulties had better physical health than women who had minor or major sleep difficulties. As memory decline worsened, so did physical health.

Least squares means, standard errors and p-values for these effects on physical health are presented in Table A 1.

3.3 Number of visits to the GP

Education, area of residence, ability to manage on income, caring for grandchildren, need for care, sleep difficulty, and memory decline, all played a role in affecting the number of visits to the GP for women in the 1921-1926 cohort. The effect of these factors is presented in the following text and Table 8.

Women who visited the GP five or more times were compared to women who visited the GP up to four times. Women who visited the GP five or more times were more likely to have no formal qualifications than a higher school certificate or higher education. They were also more likely to live in a major city than an inner or outer regional or remote area, and were more likely to have reported difficulties managing on income.

Further, these women were less likely to care for grandchildren, were more likely to need care and were more likely to have minor or major sleep difficulties than no sleep difficulties. Women who visited the GP five or more times were also more likely to have more memory decline.

The frequencies, odds ratios, 95% confidence intervals of the odds ratios and p-values for these effects on the number of visits to the GP are presented in Table A 2.

Table 7 Effect of significant factors on the physical health of women in the 1921-1926 cohort

Significant factors	Physical health	
	Better physical health	Poorer physical health
Group		
Not-Not		
Not-With		
Not-Elsewhere		
With-Not		
Elsewhere-Not	All groups had better physical health, except With-Not and Always With, compared to Never Carers	
With-Elsewhere		Never Carers
Elsewhere-With		
With-With		
Elsewhere-Elsewhere		
Always With		
Always Elsewhere		
Never Carers*		
Time		
Survey 5		
Survey 4	Survey 3	Surveys 4 and 5
Survey 3*		
Education		
Higher school certificate or higher	School certificate and higher school certificate or higher	
School certificate		No formal qualifications
No formal qualifications*		
Manage on income		
Difficult	Not difficult	Difficult
Not difficult*		
Care for grandchildren		
Yes	Provided care for grandchildren	Did not provide care for grandchildren
No*		
Need for care		
Yes	Did not need care	Needed care
No*		
Sleep difficulties		
Major sleep difficulties	No difficulties	Minor and major difficulties
Minor sleep difficulties		
No sleep difficulties*		
Memory decline	Less memory decline	More memory decline

* Reference category

Table 8 Effect of significant factors on the number of visits to the GP in women of the 1921-1926 cohort

Significant factors	GP visits	
	0-4 visits	5+ visits
Education		
Higher school certificate or higher	More likely to have higher school certificate or higher education than no formal qualifications	More likely to have no formal qualifications than higher school certificate or higher education
School certificate		
No formal qualifications*		
Area of residence		
Outer regional or remote	Less likely to live in a major city than inner or outer regional or remote areas	More likely to live in a major city than inner or outer regional or remote areas
Inner regional		
Major city*		
Manage on income		
Difficult	Less likely to report difficulties	More likely to report difficulties
Not difficult*		
Care for grandchildren		
Yes	More likely to care for grandchildren	Less likely to care for grandchildren
No*		
Need for care		
Yes	Less likely to need care	More likely to need care
No*		
Sleep difficulties		
Major sleep difficulties	More likely to have no sleep difficulties than major or minor difficulties	More likely to have major or minor sleep difficulties than no difficulties
Minor sleep difficulties		
No sleep difficulties*		
Memory decline	Less likely to have more memory decline	More likely to have more memory decline

* Reference category

3.4 Use of nursing or community health services

Transition group, area of residence, ability to manage on income, caring for grandchildren, need for care, sleep difficulty and memory decline, all played a role in affecting the use of nursing or community health services for women in the 1921-1926 cohort. The effect of these factors is presented in the following text and Table 9.

Women who used nursing or community health services were compared to women who did not use these services. Women who used nursing or health community services were more likely to be in the With-With group than the Never Carers group. Conversely, women were less likely to be in the Not-Elsewhere group than the Never Carers group.

In addition, the women were less likely to live in a major city than inner or outer regional or remote areas and were more likely to have reported difficulties managing on available income. The women were also less likely to provide care for grandchildren and were more likely to need care. The women were more likely to have more memory decline.

The frequencies, odds ratios, 95% confidence intervals of the odds ratios and p-values for these effects on the use of nursing or community health services are presented in Table A 3.

Table 9 Effect of significant factors on the use of nursing or community health services in women of the 1921-1926 cohort

Significant factors	Nursing or community health services	
	No	Yes
Group		
Not-Not		
Not-With		
Not-Elsewhere	Less likely to be in the	More likely to be in the
With-Not	With-With group <i>compared</i>	With-With group <i>compared</i>
Elsewhere-Not	to the Never Carers group	to the Never Carers group
With-Elsewhere		
Elsewhere-With	More likely to be in Not-	Less likely to be in Not-
With-With	Elsewhere group	Elsewhere group
Elsewhere-Elsewhere	<i>compared to the Never</i>	<i>compared to the Never</i>
Always With	Carers group	Carers group
Always Elsewhere		
Never Carers*		
Area of residence		
Outer regional or remote	More likely to live in a	Less likely to live in a
Inner regional	major city than inner or	major city than inner or
Major city*	outer regional or remote	outer regional or remote
	areas	areas
Manage on income		
Difficult	More likely to report not	More likely to report
Not difficult*	difficult	difficulties
Care for grandchildren		
Yes	More likely to care for	Less likely to care for
No*	grandchildren	grandchildren
Need for care		
Yes		
No*	Less likely to need care	More likely to need care
Sleep difficulties		
Major sleep difficulties	More likely to have no	More likely to have major
Minor sleep difficulties	sleep difficulties than major	sleep difficulties than no
No sleep difficulties*	difficulties	difficulties
Memory decline		
	Less likely to have more	More likely to have more
	memory decline	memory decline

* Reference category

3.5 Use of respite services

Transition group, ability to manage on income, caring for grandchildren and need for care, all played a role in affecting the use of respite services in the 1921-1926 cohort. The effect of these factors is presented in the following text and Table 10.

Women who used respite services were compared to those who did not use these services. Women who used respite were more likely to be in the groups, Not-With, With-With and Always With, than the Never Carers group. In addition, those who used respite were more likely to have reported difficulties managing on available income. The women were also less likely to provide care for grandchildren and were more likely to need care.

The frequencies, odds ratios, 95% confidence intervals of the odds ratios and p-values for these effects on the use of respite services are presented in Table A 4.

Table 10 Effect of significant factors on the use of respite services in women of the 1921-1926 cohort

Significant factors	Respite services	
	No	Yes
Group		
Not-Not		
Not-With		
Not-Elsewhere		
With-Not		
Elsewhere-Not	Less likely to be in Not-	More likely to be in Not-
With-Elsewhere	With, With-With and	With, With-With and
Elsewhere-With	Always With groups	Always With groups
With-With	<i>compared to the Never</i>	<i>compared to the Never</i>
Elsewhere-Elsewhere	Carers group	Carers group
Always With		
Always Elsewhere		
Never Carers*		
Manage on income		
Difficult	Less likely to report	More likely to report
Not difficult*	difficulties	difficulties
Care for grandchildren		
Yes	More likely to care for	Less likely to care for
No*	grandchildren	grandchildren
Need for care		
Yes	Less likely to need care	More likely to need care
No*		

* Reference category

3.6 Use of homemaking services

The interaction between group and time, education, country of birth, area of residence, caring for grandchildren, need for care and sleep difficulty, all played a role in affecting the use of homemaking services in the 1921-1926 cohort. The effect of these factors is presented in the following text and Table 11.

Women who used homemaking services were compared to those who did not use these services. There was an interaction between time and group, which means that the use of homemaking services was related to the time at which the women were in their groups. Therefore, the results need to be presented for the transition groups by each survey in comparison to the Never Carers group at Survey 3. In general, women were more likely to use homemaking services at Surveys 4 and 5 than at Survey 3. However, if they were younger (at Survey 3), the women were more likely to have transitioned into or out of caring for someone who lived with them.

In particular, women who used homemaking services at Survey 5 were more likely to be in all of the groups, except Elsewhere-With, than the Never Carers group at Survey 3. Women who used homemaking services at Survey 4 were more likely to be in the Not-Not, Not-With, With-Not, With-With, Always With and Never Carers groups than the Never Carers group at Survey 3.

Women who used homemaking services at Survey 3 were more likely to be in With-Not, With-With and Always With groups than the Never Carers group at Survey 3. In addition, women were less likely to be in the Not-Not group at Survey 3 than the Never Carers group at Survey 3.

Women who used homemaking services were more likely to have a higher school certificate or higher than no formal qualifications. They were more likely to be born in Australia than a non-English speaking country. Furthermore, they were less likely to live in a major city than an inner or outer regional or remote area. The women were also less likely to provide care for grandchildren and were more likely to need care. They were more likely to have minor or major sleep difficulties than no sleep difficulties.

The frequencies, odds ratios, 95% confidence intervals of the odds ratios and p-values for these effects on the use of homemaking services are presented in Table A 5.

Table 11 Effect of significant factors on use of homemaking services in women of the 1921-1926 cohort

Significant factors	Homemaking services		
		No	Yes
Group by time interaction			
Not-Not			
Not-With			
Not-Elsewhere	All groups at Survey 5, Survey 4 and Survey 3	Less likely at Surveys 4 and 5	More likely at Surveys 4 and 5
With-Not			
Elsewhere-Not	Never Carers at Survey 3*	However, if they were younger (at Survey 3), the women were less likely to have transitioned into or out of caring for someone who lived with them	However, if they were younger (at Survey 3), the women were more likely to have transitioned into or out of caring for someone who lived with them
With-Elsewhere			
Elsewhere-With			
With-With			
Elsewhere-Elsewhere			
Always With			
Always Elsewhere			
Never Carers			
Education			
Higher school certificate or higher		More likely to have no formal qualifications than higher school certificate or higher	More likely to have higher school certificate or higher than no formal qualifications
School certificate			
No formal qualifications*			
Country of birth			
Non-English speaking country		Less likely to be born in Australia than a non-English speaking country	More likely to be born in Australia than a non-English speaking country
Other English-speaking country			
Australia*			
Area of residence			
Outer regional or remote		More likely to live in a major city than an inner or outer regional or remote area	Less likely to live in a major city than an inner or outer regional or remote area
Inner regional			
Major city*			
Care for grandchildren			
Yes		More likely to care for grandchildren	Less likely to care for grandchildren
No*			
Need for care			
Yes		Less likely to need care	More likely to need care
No*			
Sleep difficulties			
Major sleep difficulties		Less likely to have minor or major sleep difficulties than no sleep difficulties	More likely to have minor or major sleep difficulties than no sleep difficulties
Minor sleep difficulties			
No sleep difficulties*			

* Reference category

3.7 Use of home maintenance services

Transition group, time, education, country of birth, area of residence, sleep difficulty, caring for grandchildren and need for care all played a role in affecting the use of home maintenance services in the 1921-1926 cohort. The effect of these factors is presented in the following text and Table 12.

Women who used home maintenance services were compared to women who did not use these services. Women who used homemaking services were more likely to have changed caring (With-Elsewhere, Elsewhere-With), stayed caring (With-With, Elsewhere-Elsewhere), or be in the With-Not group than the Never Carers group. The women were less likely to use the services at Survey 4 than Survey 3.

They were more likely to have a higher school certificate or higher than no formal qualifications. They were more likely to be born in Australia than a non-English speaking country. They were less likely to live in a major city than an inner regional area. Furthermore, they were less likely to provide care for grandchildren and were more likely to need care. They were more likely to have minor or major sleep difficulties than no difficulties.

The frequencies, odds ratios, 95% confidence intervals of the odds ratios and p-values for these effects on the use of home maintenance services are presented in Table A 6.

Table 12 Effect of significant factors on use of home maintenance services in women of the 1921-1926 cohort

Significant factors	Home maintenance services	
	No	Yes
Group		
Not-Not		
Not-With		
Not-Elsewhere		
With-Not	Less likely to be in With-Elsewhere, Elsewhere-With, With-With,	More likely to be in With-Elsewhere, Elsewhere-With, With-With,
Elsewhere-Not		
With-Elsewhere		
Elsewhere-With	Elsewhere-Elsewhere and With-Not group <i>compared to the Never Carers group</i>	Elsewhere-Elsewhere and With-Not group <i>compared to the Never Carers group</i>
With-With		
Elsewhere-Elsewhere		
Always With		
Always Elsewhere		
Never Carers*		
Time		
Survey 5		
Survey 4	More likely at Survey 3	Less likely at Survey 4
Survey 3*		
Education		
Higher school certificate or higher	Less likely to have a higher school certificate or higher than no formal qualifications	More likely to have a higher school certificate or higher than no formal qualifications
School certificate		
No formal qualifications*		
Country of birth		
Non-English speaking country	Less likely to be born in Australia than a non-English speaking country	More likely to be born in Australia than a non-English speaking country
Other English-speaking country		
Australia*		
Area of residence		
Outer regional or remote	More likely to live in a major city than an inner regional area	Less likely to live in a major city than an inner regional area
Inner regional		
Major city*		
Care for grandchildren		
Yes	More likely to care for grandchildren	Less likely to care for grandchildren
No*		
Need for care		
Yes	Less likely to need care	More likely to need care
No*		
Sleep difficulties		
Major sleep difficulties	More likely to have no difficulties than minor or major difficulties	More likely to have minor or major sleep difficulties than no difficulties
Minor sleep difficulties		
No sleep difficulties*		

* Reference category

Chapter 4 Discussion and conclusions

This chapter discusses and summarises the results in terms of the areas of requirement for which this research was commissioned, which were:

1. Transitions:
 - a. What are the transitions into and out of caring over the lifespan?
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?

4.1 Transitions

4.1.1 What are the transitions into and out of caring over the lifespan?

Three groups of women did not transition into or out of caring. These women either remained stable in their caring roles (Always With carers, Always Elsewhere carers) or did not provide care across Surveys 2-5 (Never Carers). The majority of the women did not provide care at any time. The remaining women provided care at some point across the surveys and formed the nine further transition groups. These groups fell under five categories of not providing care, started providing care, stopped providing care, changed where they lived relative to their care recipient (changed caring) and stayed providing care in the same living relationship to their care recipient.

The 12 transition groups formed the transition group factor and the effects of this factor, and other relevant factors, are presented in the following section.

4.2 Carer needs

4.2.1 What is the broad impact of caring on women's lives?

There were ten possible factors that could affect the seven outcomes.

Transition group

Group was a statistically significant factor in all outcomes, except for the number of visits to the GP. Generally, women who provided care for someone who lived elsewhere were faring better than women who provided live-in caring. The Never Carers group typically had better outcomes compared to carers who lived with their care recipients but worse outcomes compared to carers who lived elsewhere.

For example, women who had poorer mental health transitioned into or out of live-in caring by starting (Not-With), stopping (With-Not) or staying caring (With-With) for a care recipient who lived with them. However, women who had better mental health were more likely to have stayed (Elsewhere-Elsewhere) or started (Not-Elsewhere) providing care for someone who lived elsewhere or did not provide care (Not-Not) than the Never Carers group. Similarly, women who had better physical health were more likely to be in any of the groups that transitioned into or out of providing care for someone who lived elsewhere (Elsewhere).

In addition, women who used nursing or community health and respite services were more likely to be women who stayed caring (With-With) or who always provided care for someone who lived with them (Always With) than the Never Carers group.

However, women who used home maintenance services were more likely to have changed caring (With-Elsewhere, Elsewhere-With), stayed caring (With-With, Elsewhere-Elsewhere), or be in the With-Not group than the Never Carers group.

Time

Time was a statistically significant factor for physical health and use of home maintenance services and was part of an interaction with group for use of homemaking services. The women were less likely to use home maintenance services at Survey 4 than Survey 3, but had poorer physical health.

The interaction between transition group and time for homemaking services indicated that women who used homemaking services at a younger age (Survey 3) were more likely to be women who stopped (With-Not), stayed (With-With) or always provided care for someone who lived with them (Always With). These groups used these services as they grew older. However, of the women who used the services, women were also more likely to be in the other groups more so when they were older (Survey 5).

Education

Education was a statistically significant factor for mental and physical health and use of homemaking and home maintenance services. Women who had better mental and physical health were more likely to have a school certificate or higher than no formal qualifications. If the women used homemaking and home maintenance services, they were also more likely to have a higher school certificate or higher than no formal qualifications.

Country of birth

Country of birth was statistically significant factor for mental health and use of homemaking and home maintenance services. Women who had better mental health or those who used homemaking and home maintenance services were more likely to be born in Australia than a non-English speaking country.

Area of residence

Area of residence was a statistically significant factor for number of GP visits and use of all services, except respite services. Women who visited the GP five or more times were more likely to live in a major city, while women who used community services, such as nursing or community health, homemaking or home maintenance services were less likely to live in a major city.

Income

Income was a statistically significant factor in all outcomes, except for use of homemaking and home maintenance services. Women who had poorer mental and physical health were more likely to have reported difficulties managing on their income. Similarly, women who used nursing or community health and respite services were more likely to have reported difficulties.

Care for grandchildren

Providing care for grandchildren was a statistically significant factor in all outcomes. Women who had poorer mental or physical health or who visited the GP five or more times, or used any of the community services, were less likely to care for grandchildren.

Need for care

Needing regular care was a statistically significant factor in all outcomes. Women who had poorer mental or physical health or who visited the GP five or more times, or used any of the community services, were more likely to need regular care.

Sleep difficulties

Sleep difficulties was a statistically significant factor in all outcomes, except use of respite services. Women who had poorer mental or physical health were more likely to have reported sleeping difficulties. In addition, women who visited the GP five or more times, or who used nursing or community health, homemaking or home maintenance services, were more likely to have reported sleeping difficulties.

Memory decline

Memory decline was a statistically significant factor in mental and physical health and use of nursing or community services. Women who had poorer mental and physical health as well as those who visited the GP five or more times or used nursing or community health were more likely to have more memory decline.

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

Generally, carers who transitioned into or out of providing care for a care recipient who lived with them had poorer outcomes than carers who lived elsewhere, and as in the case of homemaking services, their use of services was more apparent earlier, at Survey 3.

The combination of factors that was related to poorer health, visiting the GP five or more times and use of services, is:

- Transitioning into or out of providing care for a live-in care recipient
- Reporting difficulties managing on available income
- Not providing care for grandchildren
- Needing care themselves
- Reporting sleep difficulties
- More memory decline.

Women with these characteristics would be potential candidates for appropriate policies and services.

Chapter 5 References

- Berecki, J, Lucke, J, Hockey, R & Dobson, A 2007, *Changes in caring roles and employment in mid-life: Findings from the Australian Longitudinal Study on Women's Health. Detailed report for the Australian Government Department of Health and Ageing Carers Project, Report 2.*
- Brown, WJ, Bryson, L, Byles, JE, Dobson, AJ, Lee, C, Mishra, G & Schofield, M 1998, 'Women's Health Australia: recruitment for a national longitudinal cohort study', *Women & Health*, vol. 28, no. 1, pp. 23-40.
- Crook, TH, Feher, EP & Larrabee, GJ 1992, 'Assessment of memory complaint in age-associated memory impairment: The MAC-Q', *International Psychogeriatrics*, vol. 4, no. 02, pp. 165-76.
- Hunt, SM, McKenna, SP, McEwen, J, Williams, J & Papp, E 1981, 'The Nottingham Health Profile: Subjective health status and medical consultations', *Social Science & Medicine. Part A: Medical Sociology*, vol. 15, no. 3, Part 1, pp. 221-9.
- Lee, C, Dobson, AJ, Brown, WJ, Bryson, L, Byles, J, Warner-Smith, P & Young, AF 2005, 'Cohort profile: The Australian Longitudinal Study on Women's Health', *International Journal of Epidemiology*, vol. 34, no. 5, pp. 987-91.
- Lucke, J, Tooth, L, Hockey, R & Dobson, A 2006, *Employed carers in mid-life: Findings from the Australian Longitudinal Study on Women's Health. Preliminary report for the Australian Government Department of Health and Ageing, Report 1.*
- McKenzie, SJ, Tooth, L, Lucke, J & Dobson, A 2009, *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.*
- McKenzie, SJ, Tooth, L, Lucke, J, Mendis, S & Dobson, A 2009, *Caring for carers: Caring and use of services in women carers born between 1921 and 1926. Detailed report for the Australian Government Department of Health and Ageing Carers Project, Stage 2, Phase 2.*
- Ware, J, Snow, K, Gandek, B & Kosinski, M 1993, 'SF-36 health survey: Manual and interpretation guide'.
- Watson, M, Lucke, J & Dobson, A 2007, *Service use and the impact of family caregiving on Mid-aged women from the Australian Longitudinal Study on Women's Health. Pilot substudy report for the Australian Government Department of Health and Ageing Carers Project, Report 3.*

Appendix

Least squares means, standard errors and p-values are presented in Table A 1 for the factors relating to mental and physical health. The means presented are the mental and physical health scores for each particular factor, considering all of the other factors are equal. For instance, all else being equal, women of the 1921-1926 cohort had a mean mental health score of 80.2 if they were in the Not-Not transition group.

Table A 1 Least squares means, standard errors (SE) and p-values for the fixed effects for all factors for mental health and physical health. Significant associations are emboldened.

Selected factors	Mental health			Physical health		
	Mean	SE	<i>p</i>	Mean	SE	<i>p</i>
Group						
Not-Not	80.2	0.3	0.0003	55.7	0.5	<0.0001
Not-With	76.8	0.5	0.0002	55.4	0.8	<0.0001
Not-Elsewhere	80.4	0.4	0.0003	57.8	0.7	<0.0001
With-Not	76.2	0.5	<0.0001	54.1	0.8	0.003
Elsewhere-Not	79.8	0.4	0.02	55.6	0.6	<0.0001
With-Elsewhere	79.8	1.0	0.30	56.8	1.5	0.001
Elsewhere-With	78.6	0.9	0.83	58.6	1.4	<0.0001
With-With	76.6	0.6	0.001	55.1	1.0	0.001
Elsewhere-Elsewhere	80.7	0.5	0.0004	59.1	0.8	<0.0001
Always With	75.2	1.2	0.005	52.9	2.2	0.56
Always Elsewhere	80.8	1.1	0.07	61.8	1.8	<0.0001
Never Carers*	78.8	0.2		51.6	0.4	
Time						
Survey 5				48.0	0.4	<0.0001
Survey 4				53.3	0.3	<0.0001
Survey 3*				58.4	0.3	
Education						
Higher school certificate or higher	80.4	0.3	<0.0001	56.2	0.5	<0.0001
School certificate	78.9	0.2	<0.0001	53.8	0.4	0.0003
No formal qualifications*	77.4	0.3		51.5	0.5	
Country of birth						
Non-English speaking country	74.1	0.5	<0.0001			
Other English-speaking country	79.0	0.4	0.41			

Australia*	79.4	0.2				
Manage on income						
Difficult	76.4	0.3	<0.0001	50.9	0.4	<0.0001
Not difficult*	79.6	0.2		54.7	0.3	
Care for grandchildren						
Yes	79.7	0.2	<0.0001	56.7	0.4	<0.0001
No*	78.6	0.2		52.7	0.3	
Need for care						
Yes	72.0	0.3	<0.0001	36.0	0.5	<0.0001
No*	80.0	0.2		56.5	0.3	
Sleep difficulties						
Major sleep difficulties	75.8	0.2	<0.0001	50.6	0.4	<0.0001
Minor sleep difficulties	79.1	0.2	<0.0001	54.2	0.3	<0.0001
No sleep difficulties*	82.2	0.2		57.3	0.4	
Memory decline			<0.0001			<0.0001

* Reference category

Table A 2 Associations between selected factors and the number of visits to the GP in women of the 1921-1926 cohort. Significant associations are emboldened.

Selected factors	Number of visits to the GP		Odds ratio	(95% CI)	p
	0-4 visits n=935 %	5+ visits n=6960 %			
Group					
Not-Not	15	11			
Not-With	5	5			
Not-Elsewhere	8	8			
With-Not	4	4			
Elsewhere-Not	6	6			
With-Elsewhere	1	1			
Elsewhere-With	1	1			
With-With	3	2			
Elsewhere-Elsewhere	6	5			
Always With	1	2			
Always Elsewhere	2	2			
Never Carers*	48	53			ns
Time					
Survey 5	34	66			
Survey 4	37	63			
Survey 3*	39	61			ns
Education					
Higher school certificate or higher	37	28	0.74	(0.67-0.82)	<0.0001

School certificate	38	40	0.93	(0.84-1.02)	0.12
No formal qualifications*	25	32		1.00	
Country of birth					
Non-English speaking country	8	9			
Other English-speaking country	13	12			
Australia*	79	79			ns
Area of residence					
Outer regional or remote	24	18	0.63	(0.57-0.71)	<0.0001
Inner regional	42	36	0.67	(0.61-0.73)	<0.0001
Major city*	34	46		1.00	
Manage on income					
Difficult	15	27	1.34	(1.22-1.46)	<0.0001
Not difficult*	85	73		1.00	
Care for grandchildren					
Yes	42	37	0.80	(0.74-0.86)	<0.0001
No*	58	63		1.00	
Need for care					
Yes	4	15	2.64	(2.35-2.99)	<0.0001
No*	96	85		1.00	
Sleep difficulties					
Major sleep difficulties	17	27	1.91	(1.74-2.10)	<0.0001
Minor sleep difficulties	41	42	1.28	(1.18-1.39)	<0.0001
No sleep difficulties*	42	31		1.00	
Memory decline			1.02	(1.01-1.03)	<0.0001

* Reference category

Table A 3 Associations between selected factors and the use of nursing or community health services in women of the 1921-1926 cohort. Significant associations are emboldened.

Selected factors	Use of nursing or community health services		Odds ratio	(95% CI)	p
	Yes n=1837 %	No n=3661 %			
Group					
Not-Not	8	15	0.88	(0.73-1.06)	0.18
Not-With	6	5	1.33	(1.04-1.69)	0.019
Not-Elsewhere	6	10	0.57	(0.42-0.76)	0.0002
With-Not	5	4	1.29	(1.02-1.64)	0.04
Elsewhere-Not	7	6	1.03	(0.84-1.25)	0.79
With-Elsewhere	1	1	0.96	(0.56-1.67)	0.90
Elsewhere-With	1	1	1.85	(1.21-2.82)	0.005
With-With	3	2	2.23	(1.68-2.96)	<0.001
Elsewhere-Elsewhere	5	6	0.66	(0.47-0.93)	0.018
Always With	2	1	1.55	(1.02-2.35)	0.04
Always Elsewhere	2	2	1.38	(0.84-2.28)	0.21
Never Carers*	54	47		1.00	
Time					
Survey 5	13	87			
Survey 4	10	90			
Survey 3*	10	90			ns
Education					
Higher school certificate or higher	29	32			
School certificate	41	40			
No formal qualifications*	30	28			ns
Country of birth					
Non-English speaking country	7	7			
Other English-speaking country	13	13			
Australia*	80	80			ns
Area of residence					
Outer regional or remote	25	18	2.15	(1.84-2.52)	<0.0001
Inner regional	42	35	1.60	(1.40-1.82)	<0.0001
Major city*	33	47		1.00	
Manage on income					
Difficult	29	22	1.28	(1.13-1.44)	0.0001
Not difficult*	71	78		1.00	
Care for grandchildren					
Yes	32	42	0.72	(0.62-0.82)	<0.0001
No*	68	58		1.00	

Need for care					
Yes	26	5	6.07	(5.36-6.86)	<0.0001
No*	74	95		1.00	
Sleep difficulties					
Major sleep difficulties	32	24	1.44	(1.24-1.66)	<0.0001
Minor sleep difficulties	41	40	1.06	(0.92-1.23)	ns
No sleep difficulties*	27	36		1.00	
Memory decline			1.03	(1.01-1.04)	0.0002
* Reference category					

Table A 4 Associations between selected factors and the use of respite services in women of the 1921-1926 cohort. Significant associations are emboldened.

Selected factors	Use of respite services		Odds ratio	(95% CI)	p
	Yes n=771 %	No n=4254 %			
Group					
Not-Not	10	14	0.21	(0.07-0.68)	0.009
Not-With	7	5	3.39	(2.05-5.60)	<0.0001
Not-Elsewhere	6	10	0.64	(0.29-1.41)	0.27
With-Not	5	4	1.79	(0.96-3.33)	0.07
Elsewhere-Not	6	6	0.37	(0.13-1.01)	0.05
With-Elsewhere	1	1	1.31	(0.31-5.43)	0.71
Elsewhere-With	2	1	3.47	(0.99-12.12)	0.05
With-With	6	2	9.87	(5.65-17.23)	<0.0001
Elsewhere-Elsewhere	4	6	0.43	(0.10-1.77)	0.23
Always With	3	1	4.19	(1.91-9.22)	0.0004
Always Elsewhere	1	2	0.95	(0.22-4.05)	0.94
Never Carers*	49	48		1.00	
Time					
Survey 5	6	94			
Survey 4	5	95			
Survey 3*	3	97			ns
Education					
Higher school certificate or higher	29	32			
School certificate	43	40			
No formal qualifications*	28	28			ns
Country of birth					
Non-English speaking country	8	7			
Other English-speaking country	12	13			
Australia*	80	80			ns
Area of residence					
Outer regional or remote	20	19			

Inner regional	39	37			
Major city*	41	44			ns
Manage on income					
Difficult	30	23	1.40	(1.15-1.69)	0.0006
Not difficult*	70	77		1.00	
Care for grandchildren					
Yes	30	41	0.58	(0.46-0.73)	<0.0001
No*	70	59		1.00	
Need for care					
Yes	32	7	7.65	(6.46-9.07)	<0.0001
No*	68	93		1.00	
Sleep difficulties					
Major sleep difficulties	33	24			
Minor sleep difficulties	38	41			
No sleep difficulties*	29	35			ns
Memory decline					ns

* Reference category

Table A 5 Associations between selected factors and the use of homemaking services in women of the 1921-1926 cohort. Significant associations are emboldened.

Selected factors		Use of homemaking services			Odds ratio	(95% CI)	p
		Yes n=3227 %	No n=2700 %				
Group*time interaction							
Not-Not	Survey 5	19	15	3.40	(2.80-4.13)	<0.0001	
Not-With	Survey 5	4	3	2.76	(1.86-4.11)	<0.0001	
Not-Elsewhere	Survey 5	3	3	3.22	(2.14-4.84)	<0.0001	
With-Not	Survey 5	8	6	3.09	(2.30-4.15)	<0.0001	
Elsewhere-Not	Survey 5	11	12	2.75	(2.21-3.43)	<0.0001	
With-Elsewhere	Survey 5	1	0	7.17	(3.60-14.26)	<0.0001	
Elsewhere-With	Survey 5	1	1	2.39	(1.26-4.56)	0.008	
With-With	Survey 5	4	3	4.13	(2.89-5.89)	<0.0001	
Elsewhere-Elsewhere	Survey 5	2	4	2.06	(1.34-3.17)	0.0009	
Always With	Survey 5	1	1	5.60	(2.68-11.74)	<0.0001	
Always Elsewhere	Survey 5	1	2	3.09	(1.70-5.62)	0.0002	
Never Carers	Survey 5	45	50	2.32	(2.03-2.65)	<0.0001	
Not-Not	Survey 4	11	10	1.98	(1.58-2.47)	<0.0001	
Not-With	Survey 4	6	5	1.90	(1.42-2.55)	<0.0001	
Not-Elsewhere	Survey 4	6	9	1.45	(1.09-1.93)	0.01	
With-Not	Survey 4	5	3	3.59	(2.67-4.82)	<0.0001	
Elsewhere-Not	Survey 4	8	9	1.48	(1.14-1.92)	0.003	
With-Elsewhere	Survey 4	1	1	2.10	(1.12-3.92)	0.02	

Elsewhere-With	Survey 4	2	1	2.25	(1.34-3.79)	0.002
With-With	Survey 4	4	3	2.45	(1.71-3.51)	<0.0001
Elsewhere-Elsewhere	Survey 4	5	7	1.50	(1.11-2.02)	0.009
Always With	Survey 4	1	1	4.07	(2.44-6.80)	<0.0001
Always Elsewhere	Survey 4	2	2	2.05	(1.21-3.47)	0.007
Never Carers	Survey 4	49	49	1.67	(1.49-1.87)	<0.0001
Not-Not	Survey 3	10	15	0.62	(0.47-0.82)	0.0007
Not-With	Survey 3	6	4	1.55	(1.15-2.09)	0.004
Not-Elsewhere	Survey 3	7	11	0.76	(0.57-1.01)	0.06
With-Not	Survey 3	5	3	1.86	(1.39-2.50)	<0.0001
Elsewhere-Not	Survey 3	7	6	0.94	(0.70-1.27)	0.69
With-Elsewhere	Survey 3	1	1	1.79	(0.97-3.28)	0.06
Elsewhere-With	Survey 3	1	1	1.38	(0.69-2.76)	0.36
With-With	Survey 3	3	2	2.01	(1.36-2.99)	0.0005
Elsewhere-Elsewhere	Survey 3	5	6	0.91	(0.63-1.31)	0.60
Always With	Survey 3	2	1	2.74	(1.74-4.33)	<0.0001
Always Elsewhere	Survey 3	2	1	0.91	(0.51-2.64)	0.76
Never Carers*	Survey 3	51	49		1.00	
Education						
Higher school certificate or higher		31	31	1.44	(1.26-1.64)	<0.0001
School certificate		41	39	1.20	(1.06-1.36)	0.004
No formal qualifications*		28	30		1.00	
Country of birth						
Non-English speaking country		6	8	0.60	(0.49-0.74)	<0.0001
Other English-speaking country		11	15	0.80	(0.68-0.93)	0.005
Australia*		83	77		1.00	
Area of residence						
Outer regional or remote		20	19	1.31	(1.14-1.50)	0.0001
Inner regional		40	34	1.31	(1.18-1.46)	<0.0001
Major city*		40	47		1.00	
Manage on income						
Difficult		27	21			
Not difficult*		73	79			ns
Care for grandchildren						
Yes		34	43	0.70	(0.64-0.78)	0.0001
No*		66	57		1.00	
Need for care						
Yes		22	3	4.47	(3.98-5.01)	0.0001
No*		78	97		1.00	
Sleep difficulties						
Major sleep difficulties		30	22	1.66	(1.47-1.86)	0.0001
Minor sleep difficulties		42	40	1.28	(1.15-1.43)	0.0001
No sleep difficulties*		28	38		1.00	
Memory decline						ns

* Reference category

Table A 6 Associations between selected factors and the use of home maintenance services in women of the 1921-1926 cohort. Significant associations are emboldened.

Selected factors	Use of home maintenance services		Odds ratio	(95% CI)	<i>p</i>
	Yes n=3961 %	No n=2216 %			
Group					
Not-Not	11	15	1.11	(0.98-1.26)	0.09
Not-With	6	4	1.13	(0.95-1.33)	0.16
Not-Elsewhere	9	10	1.09	(0.93-1.26)	0.29
With-Not	5	3	1.41	(1.19-1.66)	<0.0001
Elsewhere-Not	7	6	1.21	(1.06-1.38)	0.006
With-Elsewhere	1	1	2.12	(1.52-2.94)	<0.0001
Elsewhere-With	1	1	1.83	(1.35-2.47)	0.0001
With-With	3	2	1.67	(1.35-2.06)	<0.0001
Elsewhere-Elsewhere	5	6	1.35	(1.13-1.61)	0.001
Always With	2	1	1.46	(1.03-2.08)	0.04
Always Elsewhere	2	1	1.36	(1.05-1.77)	0.02
Never Carers*	48	50		1.00	
Time					
Survey 5	32	68	0.25	(0.21-0.28)	0.07
Survey 4	28	72	0.90	(0.83-0.97)	0.005
Survey 3*	29	71		1.00	
Education					
Higher school certificate or higher	33	28	1.46	(1.30-1.63)	<0.0001
School certificate	40	40	1.17	(1.05-1.30)	0.003
No formal qualifications*	27	32		1.00	
Country of birth					
Non-English speaking country	6	9	0.65	(0.55-0.78)	<0.0001
Other English-speaking country	12	14	0.86	(0.75-0.98)	0.02
Australia*	82	77		1.00	
Area of residence					
Outer regional or remote	18	20	1.05	(0.93-1.18)	0.44
Inner regional	40	35	1.22	(1.11-1.34)	<0.0001
Major city*	42	45		1.00	
Manage on income					
Difficult	25	23			
Not difficult*	75	77			ns
Care for grandchildren					
Yes	37	42	0.86	(0.79-0.94)	0.001
No*	63	58		1.00	

Need for care					
Yes	15	6	1.61	(1.44-1.79)	<0.0001
No*	85	94		1.00	
Sleep difficulties					
Major sleep difficulties	28	23	1.42	(1.28-1.57)	<0.0001
Minor sleep difficulties	41	40	1.25	(1.14-1.37)	<0.0001
No sleep difficulties*	31	37		1.00	
Memory decline					ns

* Reference category



www.alswh.org.au

women's
health
australia

