

Australian Longitudinal Study on Women's Health
submission to the

Productivity Commission Enquiry into Carer's Leave

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Introduction

The Australian Longitudinal Study on Women's Health (ALSWH) has tracked the health and wellbeing of over 57,000 Australian women since 1996. The Study surveys four cohorts of women encompassing the adult lifespan. The cohorts comprise women born in 1989-95, 1973-78, 1946-51, and 1921-26. Data from ALSWH are widely used to assess women's health status in Australia and investigate the behavioural and socio-demographic characteristics that affect health and the use of health services at different life stages.

The Australian Government Department of Health and Aged Care funds ALSWH to provide scientifically valid information relevant to the development of health policy and practice in women's health. The Study is managed by the University of Queensland and the University of Newcastle.

The ALSWH surveys have tracked carers' experiences in the 1921-26, 1946-51, and 1973-78 cohorts since 1996. In 2006 and 2007, ALSWH researchers were contracted to provide detailed analyses of caregiving by women born between 1946-51, 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.

In 2008, the then Department of Health and Ageing contracted researchers in the ALSWH team to provide further detailed analyses of caregiving by women born between 1946-51 and 1921-26. These analyses examined the influence of factors such as where carers lived (in relation to the care recipient and in terms of area of residence), care recipient needs (such as functional dependency levels), and the frequency and amount of care. The research was commissioned to address questions on caregiving transitions, carer needs, interventions and services used by carers.

The study's 2018 major report, part of an ongoing series for the Department of Health and Aged Care, re-examined informal caregiving across the life course. The report, *From child care to elder care: Findings from the Australian Longitudinal Study on Women's Health*, presented an analysis of the caregiving patterns by Australian women across the life course. It used data from women aged 18 to 97 to investigate the socio-demographic factors associated with caregiving patterns and the impact of caregiving on social, employment and health outcomes, including health service use.

The ALSWH has reported on the impact of caregiving on carers' health and wellbeing for over 15 years and has made numerous policy recommendations. On behalf of the Study staff and its hundreds of collaborating researchers, we welcome the Productivity Commission's Carer Leave Inquiry.

Summary and recommendations

The ALSWH surveys ask women about their experiences providing care for someone on the basis of disability, illness, or frailty in old age. Unless specified, the analyses presented do not distinguish between caring for the elderly versus adult partners (who may be elderly) and adult children.

Summary

The circumstances in which people become informal carers of older Australians

Among mid-age women from the 1946-51 cohort:

- Occupation made no difference to their likelihood of taking on a caregiving role.
- Women who were not in paid work were more likely to be live-in carers.
- Women with high-status jobs were more likely to remain in full-time employment whilst providing care.
- Taking on a caring role accelerated women's departure from the workforce.
- Women in the workforce did not self-selecting into caring roles because they already worked fewer hours. Instead, taking up caring was associated with a subsequent decrease in women's labour force participation
- 67% of live-in carers and 54% who lived elsewhere reported a gradual transition into caregiving rather than a sudden change.
- 89% of carers providing low levels of care made a gradual transition into caring.
- Carers with high to medium demands on their time were more likely to make a sudden change into caregiving compared to carers who provided care less frequently.

How formal and informal care interact in the aged care sector

- At age 70-75, only 8.7% of women from the 1921-26 cohort required regular help. This rose to 40.2% of women at 94-100.
- Between ages 75 and 90, 70% of the 1921-26 cohort accessed Home and Community Care Services (HACC).

Evidence on how informal carers of older people are affected by their caring responsibilities

What causes informal carers to have lower labour force participation, incomes, or poorer health and wellbeing?

- Mid-age women in poor health tend to self-select into caregiving roles. Poor health and disengagement with the workforce continues when caregiving stops.
- Caring for people with both physical and cognitive impairments is more burdensome and impacts the carer's quality of life more than caring for someone with only one type of impairment.
- Emotional strain is highest when caring for someone with a cognitive impairment.

- Young women engaged in ongoing caregiving or transitioning into caregiving are more likely to have difficulties managing on their income and reduced participation in the labour force.
- At age 53-58, poorer socioeconomic status (no occupation, part-time employment, financial stress) was associated with ongoing caregiving but not with starting caregiving. By mid-age, self-selection into caregiving roles may not be as strongly influenced by opportunity costs related to socioeconomic factors.

Are different groups more or less affected?

- Compared to caregivers who live elsewhere to the care recipient, caregivers who live with the person they care for are more likely to provide high levels of care, care for younger people (a partner vs older parents), have lower participation in the workforce, have poorer physical and mental health, have a higher number of chronic illnesses, and to be obese, inactive, or smoke.
- 1 in 20 mid-age women are caregivers and survivors of intimate partner violence. Women with both life experiences have twice the odds of experiencing depressive symptoms and stress. They also have worse physical health than other women.
- Sandwich or multigenerational carers look after someone who is ill, disabled, or frail and care for grandchildren or someone else's children.
- 65-70-year-olds from the 1946-51 cohort are at risk of being overburdened by multigenerational caregiving; they have higher rates of depression and anxiety, more general practitioner visits, more sedentary lifestyles, and are less likely to rate their health as excellent or very good than women who only provides care for someone they live with.
- In contrast, 37-42-year-olds who cared for their children and another adult who lived with them tended to fare better than women who only provided life-in care for another adult.
- Young women caring for someone they lived with were likely to have more children (33% have three or more children).

Costs and benefits of leaving formal employment to provide informal care that carers don't take into consideration

- Live-in carers were more likely to rate the ability to access government pensions or benefits as an important factor in the decision to retire.
- Overall, carers were more likely to rate the number of people dependent on financial support and the need to care for a spouse or other family member as important factors in the decision to retire.

How many employees who take extended unpaid carer leave would subsequently return?

- Caregiving is highly transitory. From age 45-72 (across eight consecutive surveys) 24-30% of women from the 1946-51 cohort provided care at some point. However, only 4% of the women reported caregiving at each survey.
- When mid-aged women stopped caring, some returned to their former employment status but proportionally more decreased their working hours.
- Women who have better physical health while caring are more likely to take up work again when they stop providing care.

How should an entitlement to unpaid leave be designed?

- Leave entitlements should be made available to both live-in carers and those who live elsewhere to the care recipient
- Leave entitlements should not be limited to family relationships.
 - About 15% of mid-age caregivers care for a friend, 5% for a neighbour, and a further 5% care for someone 'other' than family.
 - The traditional social expectation of receiving care from your children in old age will be challenged as the number of childfree adults increases in successive generations.

Income supports and services currently offered to informal carers

- 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.

Alternative supports for carers of older people

- Additional financial support is needed to complement the introduction of extended unpaid carers leave - at age 37-42, 26% of live-in carers and 20% of carers living elsewhere from the 1973-78 cohort found it impossible or very difficult to manage on their income.

Should reforms to supports for carers of older people apply to other carers too?

- Yes – at age 65-70, about 10% of the 1946-51 cohort were caring for their adult children.

Recommendations

1. In addition to unpaid leave entitlements, flexible working arrangements would enhance the ability of caregivers to continue participating in the workforce – for example greater availability and acceptance of part-time work, flexible hours, and job sharing.
2. Carers need the flexibility to take leave in a block, or spread across an extended period to support their ability to maintain part-time employment.
3. Additional support in the form of respite and in home community care, should be made available for women caring for people with both cognitive and physical impairments.
4. Women caring for people with cognitive impairments could benefit from additional counselling, training, and respite.
5. Policies should take into account the life stage of carers, and not generalise findings from one age group to another.
6. Live-in carers require additional supports to maintain their health and wellbeing. Regular access to respite services is vital to ensure they have the time to visit health

services and engage in self-care. Targeted mental health interventions as well as greater access to (and acceptance of) community support services would also help to reduce the burden on live-in carers.

7. Up to 1 in 20 mid-age women are impacted by the cumulative impacts of intimate partner violence and caregiving. Younger generations of women report much higher levels of intimate partner violence. Additional support programs aimed at increasing resilience and maintaining social supports will be vital as the next generation steps up to care for our ageing population.
8. More accessible and affordable child care options for parents returning to work may reduce the burden on grandparents of caring for their grandchildren.
9. More research is needed to investigate the impact of long-term multigenerational caregiving among those who are reaching retirement age, and who are experiencing their own age-related health issues.
10. While child care and respite care may be available to caregivers, these are rarely, if ever, offered as a coordinated support service. The complex support needs of caregivers in this position warrant assessment at the individual level.
11. To maximise the number of women returning to work after extended unpaid carer leave caregivers need to maintain their own physical health. Access to regular respite care is a necessary support to provide carers with time for self-care.
12. Increasing access to affordable child care will also decrease the burden on caregivers and allow more women to return to work.
13. Unpaid leave should be made available to both live-in carers and those who live elsewhere to their care recipient.
14. Leave entitlements should not depend on a family relationship, this will become particularly relevant as younger generations age. Traditionally, care for the elderly comes from partners and children. An increasing proportion of adults are childfree and will not be able to call upon these relationships as they age.
15. Caregiving is highly transitory so the entitlement should be made available to a wider range of circumstances, as caregivers may be required to care for adult children, partners, parents and parents-in-law.
16. Live-in carers may need to be targeted for more formal support.
17. Policies should consider the particular needs of live-in carers who are likely to have a high care index, be strained and help their care recipients with more personal and demanding tasks.
18. Policies should endeavour to improve acceptance of, or reduce the stigma about, using services.
19. A carer's leave payment, similar to the Parental Leave Pay offered by the Australian Government would reduce the financial impact of taking unpaid leave to provide care and improve the wellbeing of carers.
20. Carer's Leave entitlements should be made available regardless of whether care is provided to someone because they are elderly, ill, or disabled.

Terms of reference

The circumstances in which people become informal carers of older Australians.

How often does the decision to become a carer necessitate changed work arrangements or leaving the workforce?

Occupation, caregiving, and employment status

In a 2006 study of mid-age women from the 1946-51 cohort, researchers investigated the relationships between caregiver's employment status (full-time, part-time, or not employed) and their occupational classification (managers/professionals, trades/higher skilled, labourers/low or unskilled, and no paid job). They found that employment status (how much they worked) was related to the type of care the women provided (e.g., live with the recipient, live elsewhere, non-carer). However, there were no differences between the type of care women provided and their occupation. Live-in carers comprised 6-7% of the three occupational classifications but 12.2% of those with no paid job (Lucke, 2006).

Higher status occupations were associated with a higher likelihood of working full-time whilst providing care, with 61% of managers and professionals working full-time compared with 47% of higher skilled workers and 30% of unskilled workers. Unskilled workers were most likely to work part-time (65%) compared with 50% of higher skilled workers and 35% of managers and professionals. No relationship was found between caregiving and education levels. However, women who were more educated were more likely also to work full-time (Lucke, 2006)

Continuing labour force participation vs. reducing or stopping work

Two analyses have investigated the order of events leading to informal caregiving and changes in labour force participation among women in the 1946-51 cohort.

Women who started to provide care were more likely to decrease working than women who provided ongoing care between the two surveys (22% vs 18%) or women who stopped caregiving or never provided care (19% and 17%, respectively). A substantial proportion of these women (12%) started work or increased work hours and started caregiving (Berecki, 2007).

In mid-aged women, taking on a caring role appeared to accelerate the women's departure from the workforce. Overall, women's employment levels decreased in their 50s. Between the surveys, the percentage of women providing care increased from 12 to 14%, while paid employment participation decreased from 67 to 62%. The researchers found that mid-age women were not self-selecting into caring roles because they worked fewer hours.

Transitioning into caregiving at Survey 4 was not associated with how many hours women had spent in paid employment at Survey 3. Instead, taking up caring was associated with a subsequent decrease in women's labour force participation. The authors concluded that policies to support continuing labour force participation during caregiving could include creating flexible working arrangements (Berecki-Gisolf et al., 2008).

Recommendations:

- In addition to unpaid leave entitlements, flexible working arrangements would enhance the ability of caregivers to continue participating in the workforce – for example greater availability and acceptance of part-time work, flexible hours, and job sharing.
- Carers need the flexibility to take leave in a block, or spread across an extended period to support their ability to maintain part-time employment.

How often is this a planned decision versus an impromptu decision triggered by an emergency?

Planned vs. sudden care requirements

In 2007, the Commonwealth Government commissioned the ALSWH to conduct a substudy investigating caregiving transitions among 355 women aged 56-61. The women included in the substudy were from the ALSWH 1946-51 pilot group.

The research showed that 67% of live-in carers and 54% of carers who lived elsewhere reported a gradual transition into caring rather than a sudden change or other situation.

The intensity of care needed also provides insight into the circumstances in which participants in the substudy became carers. The intensity of care measure used in the substudy was divided into high, medium and low categories. These are defined in Table 1. There was a trend for carers in the high (28%) and medium care index (34%) 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 (McKenzie S, 2009).

Table 1: Caregiving intensity index

Low	Caregiving once per week for one hour at a time; or caregiving every few weeks for several hours at a time
Medium	Caregiving several times per week for several hours at a time; or caregiving every day for about an hour
High	Caregiving all day, several times a week, or caregiving every day for several hours at a time

Reasons for becoming a carer

The mid-age carers in the 2007 substudy were also 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 (McKenzie S, 2009).

Evidence on how formal and informal care interact in the aged care sector.

How many older Australians receive informal care and formal in-home care?

The ALSWH survey does not distinguish between formal and informal care. Participants from the 1921-26 cohort are asked the question, "Do you regularly need help with daily tasks because of long-term illness, disability or frailty (e.g., personal care, getting around, preparing meals etc.)?"

At their first survey in 1996, aged 70-75, only 8.7% of women required regular help. By age 85-90 in 2011, 22.7% of the cohort required regular help (*Databook for the 1921-26 cohort, 2011*).

From 85-90 onwards, this cohort switched to regular six-monthly surveys. Between the ages of 85-90 to 94-100, the number of women requiring regular help rose rapidly from 30.2% to 40.2% (*Data Book for the 1921-26 Cohort Surveys 1-6, 2020*).

How many older Australians rely solely on informal care? In what circumstances, or for what reasons does this occur?

The ALSWH surveys do not provide data on formal vs. informal care. An analysis of additional linked aged care datasets has been used to estimate the proportion of older women who did and did not use formal aged care services from 2001-2011, when the women were between 75 and 90 years old.

Approximately 70% of women accessed Home and Community Care (HACC) services during this period. Women who received Veteran's Affairs cover were 36% less likely to use HACC (Rahman, Efird, Kendig, et al., 2019).

In a separate analysis, about 41% of the 1921-26 cohort were classified as 'mostly non-users' of HACC services. This is because their use of aged care services and mortality increased when the women were aged 85 and over. Women who didn't use HACC services were more likely to live in a major city, have difficulty managing on their income, live with a partner or other family member, or provide care to grandchildren or other people's children (Rahman, Efird, & Byles, 2019).

Evidence on how informal carers of older people are affected by their caring responsibilities:

What other evidence should the Commission consider relating to what causes informal carers to have lower labour force participation, or incomes, or poorer health and wellbeing compared to those without caring responsibilities?

As a longitudinal study, ALSWH allows researchers to investigate which factors may contribute to lower labour force participation and incomes or poorer health and wellbeing among caregivers. Several authors have examined changes in caregiving over time for ALSWH participants and the associations of such transitions with various socio-demographic status, health status and health behaviour factors.

Health

Poor health before and after caregiving roles

Poorer physical and mental health and reduced quality of life are known impacts of taking on the burden of caregiving. There is a possible compounding relationship between poor health before caregiving, and the negative impacts of caregiving on health.

Research published by Lee and Gramotnev in 2007 investigated transitions into and out of caregiving. They analysed data from 9555 women in the 1946-51 cohort between Survey 2 and Survey 3 (when the women were aged 47-55). The women were classified as continuing to give care (3%), stopped caring (5%), started caring (3%), or were never caregivers (89%).

At both surveys, women in the three caregiver groups showed poorer physical and emotional health, greater use of health services, poorer health behaviours and lower engagement in the paid workforce compared with never caregivers. The authors concluded that mid-aged women in poorer health tend to self-select into caregiving because they were already less engaged with the paid workforce. Their poor health and disengagement from the paid workforce continued even when caregiving stopped.

Impact of care recipient impairment on the health of their carer

The burden on caregivers has also been linked to their care recipient's type of impairment. Physical care needs are often appraised as being more manageable. The care recipient's needs can be met in planned time periods and supported by community care – e.g. meals on wheels, home nursing, or domestic care. In contrast, cognitive and personality changes in the care recipient (e.g. dementia, stroke and other neurological disorders) may be more difficult to manage due to the requirement for constant supervision and uncooperative or oppositional behaviour.

An analysis of level and burden and quality of life among carers in the 1921-26 cohort found that 60% cared for people who had both cognitive and physical impairments. The carers were 78-83 years old and mostly cared for their elderly husbands.

Those who looked after people with both physical and cognitive impairments found caregiving to be objectively more burdensome and had worse physical limitations in their own lives than those caring for someone with only one type of impairment. Levels of emotional strain was highest in women caring for people with cognitive impairments, regardless of whether they also had physical impairments (Tooth et al., 2008).

Socio-demographic factors related to ongoing vs transitory care

Tooth and Mishra (2014) investigated longer-term transitions in caregiving in women in the 1973-78 cohort (over 13 years, from Surveys 1-5) and the 1946-51 cohort (over nine years, from Surveys 3 to 6) and associations between these transitions and the women's baseline demographic, socioeconomic status, health status and health behaviour characteristics.

The study included 14,202 women in the 1973-78 cohort and 12,282 women in the 1946-51 cohort, and latent class analysis was used to identify 'classes' or 'trajectories' of women who have similar patterns of caregiving over time.

For the 1973-78 cohort, five caregiving trajectories were found to represent distinct groups of caregivers. However, most women (94%) were in a single class which had the lowest probability of being a caregiver over the period, and most women had 'never' provided care. The other four classes were: 'ongoing' with the highest probability of caregiving across the 5 surveys (1%), 'starting' with an initial low probability of caregiving which increased over time (2%), 'short-term' with an initial low probability of caregiving which spiked and then dropped to low (3%), and 'early high then fluctuating' (1%).

Indicators of poorer socioeconomic factors at baseline (difficulties with income management, reduced labour force participation) were associated with the latent classes representing 'ongoing' and 'starting' caregiving. However, the socioeconomic factors associated with the latent class representing 'short-term' caregiving were more mixed. While they represented financial hardship at baseline, they also reflected varying levels of labour force participation (from no work or study up to full-time work and study) and both low and high educational qualifications (≤ 10 years and also trade/certificate/diploma). In a further contrast, no socioeconomic factors were associated with the latent class representing 'fluctuating' caregiving. The authors suggested this may indicate that self-selection into more transitory caregiving behaviours by young women may be less influenced by socioeconomic factors, or that young women who participate in transitory caregiving may comprise distinct groups. There were mixed and inconsistent findings on the associations between health and health behaviours on caregiving (Tooth & Mishra, 2014)

For the 1946-51 cohort, three trajectories of caregiving were identified representing 'ongoing' (21% of women with the highest probability of being a caregiver across the 4 surveys), 'starting' (9% of women, who showed an initial low probability of caregiving which increased over time) and 'never' caregiving (70% of women with the lowest probability of being a caregiver across all surveys).

Poorer socioeconomic status (no occupation, part-time employment, difficulties with income management) were associated with 'ongoing' caregiving, but not 'starting' caregiving. The authors suggested that by mid-age, self-selection into new caregiving roles may not be as strongly influenced by opportunity costs related to socioeconomic factors (that is, if a woman assesses she has less to lose by becoming a caregiver she may be more likely to self-select into caregiving compared to a woman who assesses she has more to lose). No associations between health factors and trajectories of caregiving were found. (Tooth & Mishra, 2014).

Recommendations:

- Additional support in the form of respite and in home community care, should be made available for women caring for people with both cognitive and physical impairments.
- Women caring for people with cognitive impairments could benefit from additional counselling, training, and respite.
- Policies should take into account the life stage of carers, and not generalise findings from one age group to another.

Are different groups of informal carers (for example, women, young people, older carers, etc) more or less likely to be affected? Why?

Live-in carers

ALSWH's ongoing research into caregiving highlights the differences between caregivers who live with the care recipient and those who lived elsewhere.

At age 53-58, live-in carers from the 1946-51 cohort were less likely to be in the workforce. About 56% of live-in carers participated in the workforce compared to 73% of women caring for someone who lived elsewhere and a similar percentage of women without caring duties. They also reported lower emotional or informational support and had poorer health (Lucke, 2006).

Women who were live-in carers, compared to those who lived elsewhere, were more likely to be providing higher intensity care (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 care recipients were more likely to use paid services (McKenzie S, 2009).

By age 65-70, a higher percentage of live-in carers from the 1946-51 cohort reported having three or more chronic conditions, and fewer had no chronic conditions than caregivers living elsewhere and non-caregivers. Live-in carers had poorer self-reported health compared with other caregivers and non-caregivers. A higher percentage of live-in carers were obese, inactive, and smoked than caregivers who lived separately from their care recipient or non-caregivers. Live-in carers also had poorer mental health – they had higher levels of stress, a higher percentage reported anxiety than non-caregivers, and a higher rate reported depression than caregivers living elsewhere and non-caregivers (Tooth L, 2018).

Recommendations:

- Live-in carers require additional supports to maintain their health and wellbeing. Regular access to respite services is vital to ensure they have the time to visit health services and engage in self-care. Targeted mental health interventions as well as greater access to (and acceptance of) community support services would also help to reduce the burden on live-in carers.

Caregivers with a history of intimate partner violence

Research on the impact of caregiving usually focuses on current relationship dynamics rather than looking at how past experiences affect a woman's capacity to provide care and remain healthy. Intimate partner violence is associated with poor personal resources in women – financial stress, lower education levels and poor social support – and this lack of resources remains a factor for women years after the violence stops.

Ferreira, Loxton and Tooth (2017) followed 8453 women aged between 45 and 65 from ALSWH's 1946-51 cohort to investigate the impact of domestic violence on women who were

also caregivers. The experience of violence may have been historical, and the women did not disclose if they provided care for the perpetrator or someone else.

Nearly 1 in 20 mid-aged women from the ALSWH 1946-51 cohort are carers who have also experienced intimate partner violence. Women with both these life experiences have twice the odds of experiencing depressive symptoms and stress – and they also have worse physical health than other women.

When the researchers compared these two very different, very stressful life events, they found the impact on the women's health was almost the same, even though one was perpetrated against the individual (violence) and one was undertaken with a degree of personal control (caregiving). The researchers found the association between poor health, caregiving and the experience of intimate partner violence was reduced when women had better personal resources like resilience and social support to draw on for support (Ferreira et al., 2017).

Recommendations:

- Up to 1 in 20 mid-age women are impacted by the cumulative impacts of intimate partner violence and caregiving. Younger generations of women report much higher levels of intimate partner violence. Additional support programs aimed at increasing resilience and maintaining social supports will be vital as the next generation steps up to care for our ageing population.

'Sandwich generation' caregivers

Estimates of economic impact narrowly define informal caregiving as looking after the ill, disabled or frail and don't usually include childcare. Multigenerational caregivers, sometimes known as the 'Sandwich generation', provide care for both younger and older generations. Care provided to spouses, adult children, and one or both parents is often due to illness, disability or problems associated with ageing. Grandchildren are often cared for to support adult children returning to work or undergoing medical treatment.

The ALSWH 2018 Major Report on Caregiving (Tooth L, 2018) investigated the health, health behaviours and health service use of women from the 1973-78, 1946-51, and 1921-26 cohorts who provided care for children/grandchildren or any other person because of a long-term illness, disability or frailty. The report's findings on this topic are summarised below.

At age 37-42, about 11% of the 1973-78 cohort women were caring for children as well as someone who was ill, disabled or frail. Women caring for an adult they lived with were likely to have more children - 33% had three or more children compared with 25% of those caring for someone elsewhere or non-caregivers. Those who provided child care and cared for another person due to illness, disability or frailty were more likely to have fair/poor self-rated health, sedentary lifestyle, and higher levels of perceived stress and depression than women who only cared for children.

By age 65-70, 25% of the women in the 1946-51 cohort provided care to someone who was ill, disabled or frail, and a grandchild or other child. They were more likely to report having depression, made more visits to the GP, had a higher perceived level of stress and were less likely to rate their health as very good or excellent than non-caregivers and caregivers who provided other types of care.

A qualitative analysis of participant comments in the caregiving report found that multigenerational caring is often challenging and stressful. Although caregiving duties fluctuate, many women provided care for their families over many years. Some women reported providing care and support for three generations (their parents, children and grandchildren) at the same time. Many women reported lacking time to focus on their own health and wellbeing, and it seemed there was a lack of support beyond the family unit to assist with this care (Tooth L, 2018).

Recommendations:

- More accessible and affordable child care options for parents returning to work may reduce the burden on grandparents of caring for their grandchildren.
- More research is needed to investigate the impact of long-term multigenerational caregiving among those who are reaching retirement age, and who are experiencing their own age-related health issues.
- While child care and respite care may be available to caregivers, these are rarely, if ever, offered as a coordinated support service. The complex support needs of caregivers in this position warrant assessment at the individual level.

Costs and benefits of leaving formal employment to provide informal care that carers don't take into consideration.

To what extent and how do carers consider the following factors when deciding whether to provide informal care:

- *their ability to return to work*
- *their future income, including retirement income*
- *the health and wellbeing of the care recipient*
- *their own health and wellbeing*
- *the cost of alternative care arrangements*
- *any other important matters?*

The decision to retire

At age 53-58, live-in carers were more likely to be retired. Live-in carers were more likely to rate the ability to access government pensions or benefits as an important factor in the decision to retire. Overall, carers were more likely to rate the number of people dependent on financial support and the need to care for a spouse or other family member as important factors in the decision to retire (Lucke, 2006).

How many employees who would take leave would return to work once they had ceased caring?

Caregiving transitions

ALSWH data shows that caregiving is a highly transitory role. Data from ALSWH's 2018 Major Report on Caregiving shows that from age 45-72 (across eight consecutive surveys), 24-30% of women from the 1946-51 cohort provided care at some point. However, only 4% of the women reported caregiving at every survey (Tooth L, 2018).

The table below highlights the transitory nature of caregiving. At each survey, women who provided care (for people living with them or elsewhere) are depicted in the dark purple band, while those not providing care are in the light purple band. Figure 1 shows a high degree of movement into and out of caregiving across the surveys. At Survey 3, aged 50-55, 1654 women (25% of total) were providing care for another person. Three years later, 601 (9% of total) had stopped, 1053 (16% of total) were still providing care, and 935 (14% of total) who were not providing care at Survey 3 had started doing so (Tooth L, 2018).

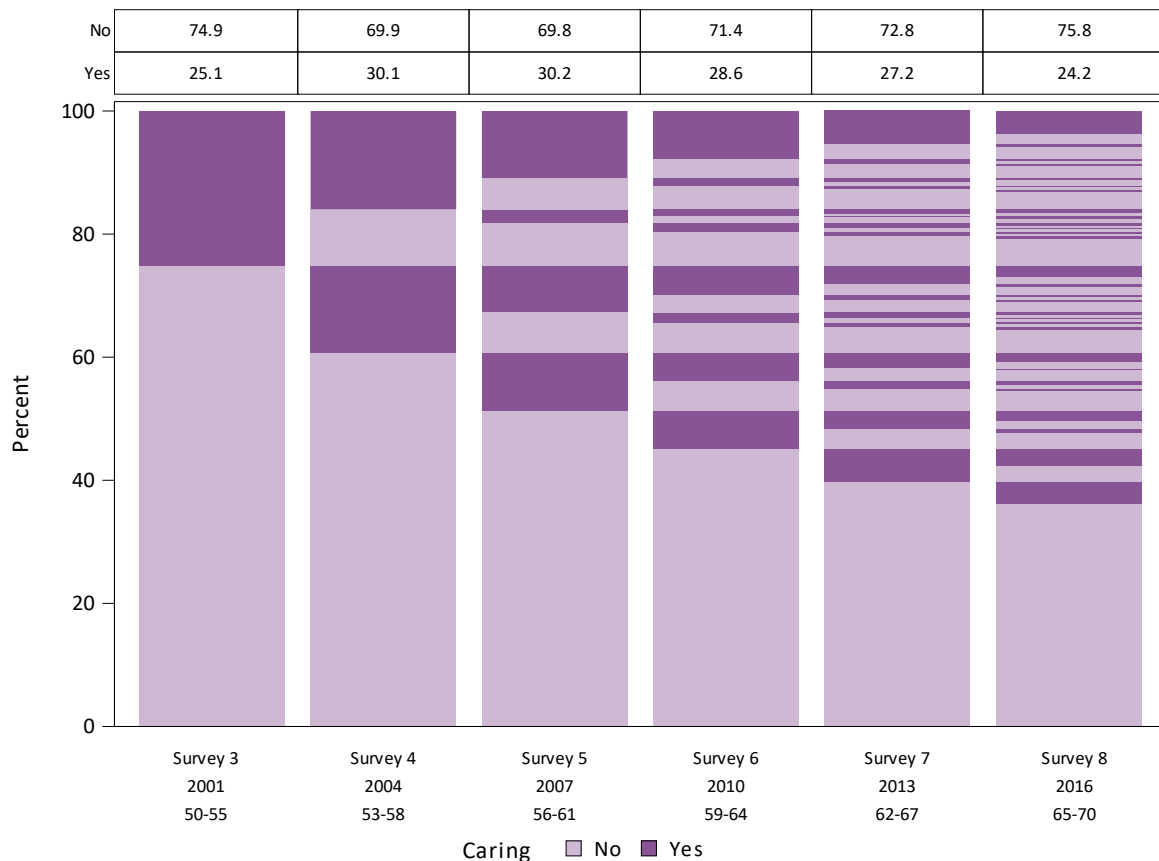


Figure 1. Percentage of women in the 1946-51 cohort at Surveys 3 to 8, by whether they provided care for any other person (dark purple) across Surveys 3 (aged 50-55) to Survey 8 (aged 65-72) (N=6598).

Factors affecting employment transitions

As part of a series of reports commissioned by the then Australian Government Department of Health and Ageing, researchers at ALSWH investigated changes in caring roles and employment in mid-aged women from the 1946-51 cohort. The analysis showed that caregiving appears to accelerate women's departure from the workforce. When working women started caregiving they reduced their working hours. When women stopped providing care, some returned to their former employment status, but proportionally more women decreased their working hours. (Berecki, 2007). The findings of the report are outlined below.

Stopping work vs. continuing to work while providing care

- Women who started caring between Survey 3 (age 50-55) and Survey 4 (age 53-58) were more likely to reduce work hours than those who did not start caring.
- Women who quit or reduced work when they started caregiving were more likely to also care regularly for children at survey 3.
- Compared to women who continued working, those who reduced/stopped working reported poor to fair health more frequently (9% vs 15%), were more likely to make >4 visits to a GP (24% vs 31%) and were more likely to have high levels of stress (Berecki, 2007).

Taking up work after caregiving vs. starting work again

A small group of women who stopped caring and were not employed at Survey 3 took up work by Survey 4. They were in better (self-reported) health than those who did not take up work. A reduction in work when taking on caregiving was associated with stress and poor health and wellbeing. Taking up work when women stopping caring was associated with greater physical wellbeing.

There were 345 women who stopped caring between Survey 3 and Survey 4 and who were not in paid employment at Survey 3. The following analysis compared those who stopped caring and started working to those who stopped caring and did not take up work. There were 267 women who did not take up work between Survey 3 and Survey 4 and only 78 who had taken up employment by Survey 4.

There were no significant differences between socio-demographic factors (such as marital status, area of residence, level of education) or health service use and lifestyle variables (such as the number of visits to a GP or a specialist and caring for grandchildren). However, there were differences in the women's self-rated health: women who continued not working were much more likely to report their health to be fair or poor (21%) compared to those who took up work (5%). The physical health component score (PCS) of the SF-36 Health Survey was higher (indicating better health) for women who took up work (median of 51.2 vs 47.5), while the mental health component score (MCS) was not statistically different. These results suggest that women with better physical health while still caring are more likely to take up work when they are no longer providing care (Berecki, 2007).

Recommendations:

- To maximise the number of women returning to work after extended unpaid carer leave caregivers need to maintain their own physical health. Access to regular respite care is a necessary support to provide carers with time for self-care.
- Increasing access to affordable child care will also decrease the burden on caregivers and allow more women to return to work.

How an entitlement to extended unpaid carer leave ought to be designed.

Who should be eligible and why? What criteria should an employee need to meet and why? For example, tenure, relationship to the care recipient, and/or the nature of care required.

Eligibility criterion

Live-in vs live elsewhere

ALSWH research on mid-age carers suggests that both live-in carers and those who live elsewhere from the care recipient could benefit from entitlement to unpaid carer leave. Overall, workforce participation among mid-age women caring for someone who lived elsewhere was similar to participation for women who did not have caring duties (around 73%). In comparison, live-in carers had an employment participation rate of 56%. However, women caring for someone who lived elsewhere were more likely to work part-time (43%) than non-carers (31%) (Lucke, 2006). Access to unpaid leave might help women to maintain employment rather than dropping to part-time, quitting or going into early retirement.

Relationships with care recipients

Any proposed carer's leave entitlement should not be limited to only caring for an elderly parent/parent-in-law or spouse/partner.

Figure 2 ALSWH Major Report on Caregiving, highlights the diversity of relationships between late mid-age caregivers and recipients. Almost 60% cared for their parents/parents-in-law or spouse/partner, 10% cared for their adult child, and about 15% were providing care for a friend (Tooth L, 2018).

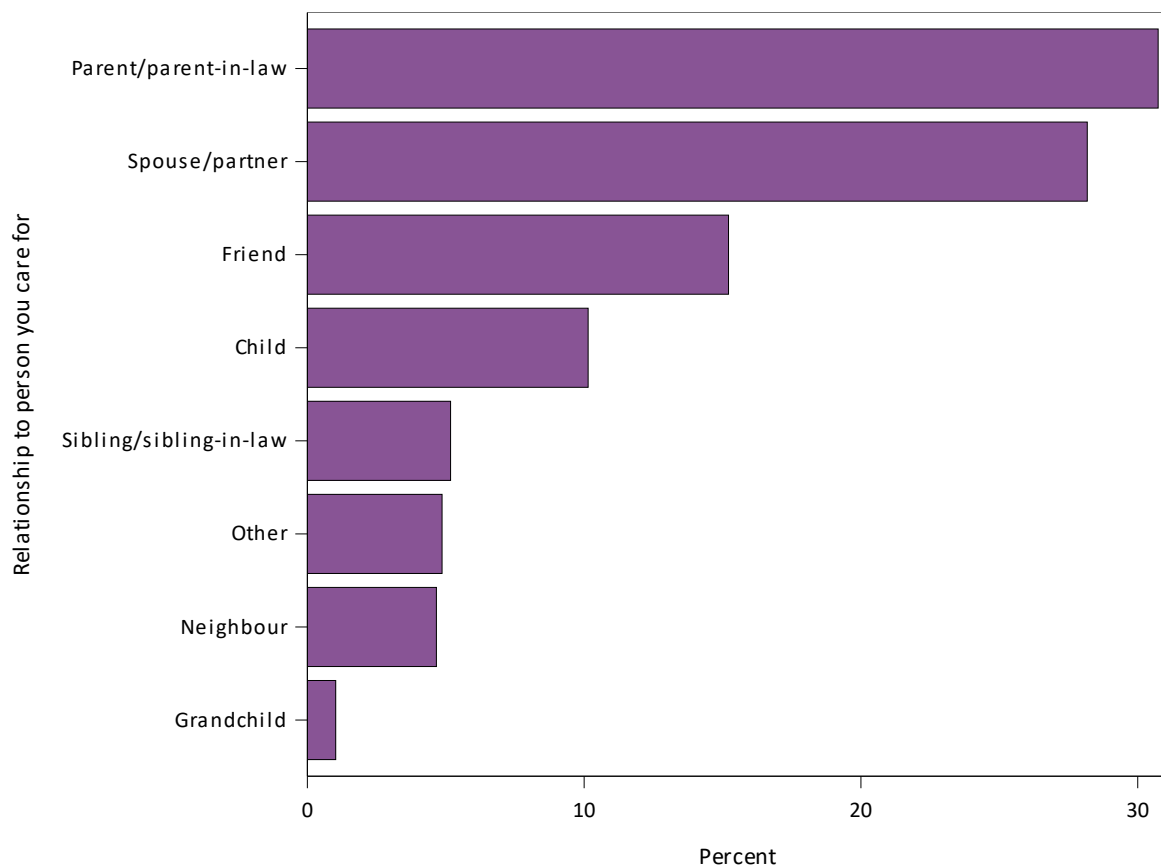


Figure 2. Percentages showing the nature of the relationship between the caregiver and the person they cared for at Survey 8 (2016) in women aged between 65 and 70 years (N=1952).

Traditionally, children care for their ageing parents. However, the traditional caring roles and relationships may start to shift towards friends and neighbours as caregivers or more institutionalised care as the next generations age.

In the 1945-51 cohort, just under 10% of women were childfree (*Data Book for the 1946-51 Cohort*, 2019). In the 1973-78 cohort, 21% of women were childfree at age 37-42 (Tooth L, 2018). The 1989-95 cohort has not yet reached their peak childbearing years. However, there are early indications that the number of child-free women in ALSWH's youngest cohort may be even higher than in older generations.

The 1989-95 and 1973-78 cohorts are at different stages of their reproductive lives but comparing the two cohorts at equivalent ages provides insight into generational differences in birth patterns. Figure 3 below is taken from *Reproductive health: Contraception, conception, and change of life – Findings from the Australian Longitudinal Study on Women's Health*, commissioned by the then Australian Government Department of Health (Loxton, 2021).

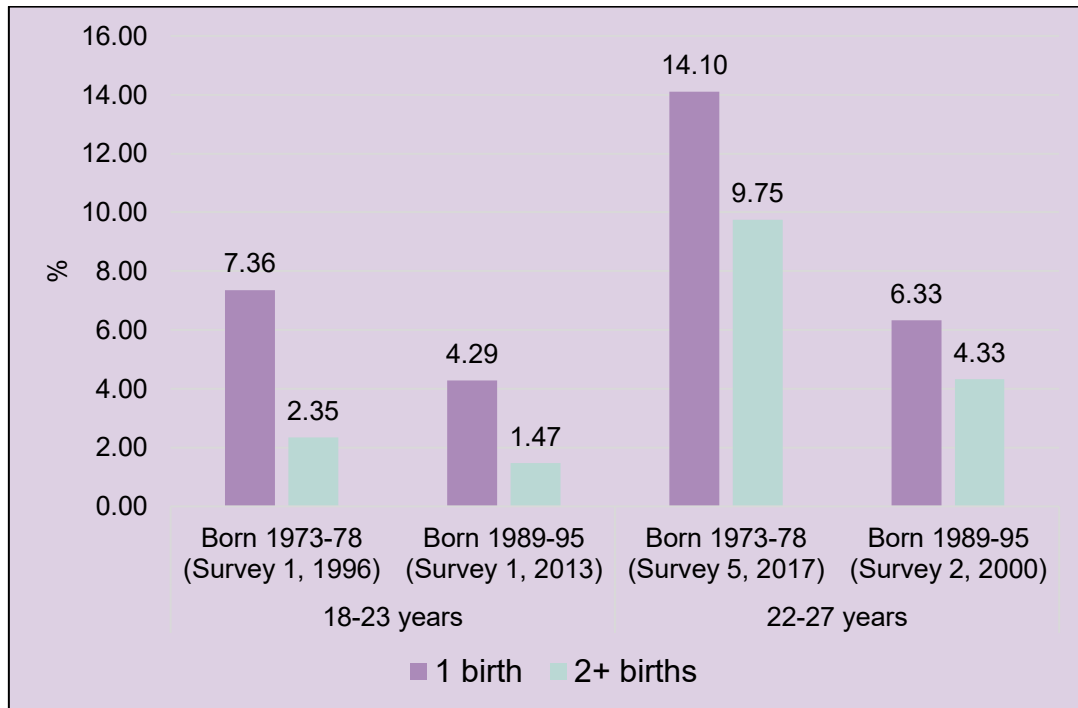


Figure 3. Births in the 1973-78 and 1989-95 cohorts at equivalent ages.

Recommendations:

- Unpaid leave should be made available to both live-in carers and those who live elsewhere to their care recipient.
- Leave entitlements should not depend on a family relationship, this will become particularly relevant as younger generations age. Traditionally, care for the elderly comes from partners and children. An increasing proportion of adults are childfree and will not be able to call upon these relationships as they age.
- Caregiving is highly transitory so the entitlement should be made available to a wider range of circumstances, as caregivers may be required to care for adult children, partners, parents and parents-in-law.

Income supports and services currently offered to informal carers.

What challenges do informal carers of older people face in accessing the supports they need?

What are the main types of supports that informal carers rely on?

An ALSWH substudy on caregiving in mid-aged women investigated the types of supports and interventions used and needed by women carers. The substudy was commissioned by

the then Australian Government Department of Health and Ageing and involved women from the 1946-51 pilot group. The ALSWH researchers found that service use by carers was low. Home maintenance and counselling were the two most used services in this substudy – however, only 8% of carers used these services (McKenzie S, 2009).

Participant comments provided some insight on why services were not used.

“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”

Findings from the 2009 substudy report, *Caring and use of services in women born between 1946 and 1951: Findings from the Australian Longitudinal Study on Women’s Health*, are summarised below.

- 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.

Recommendations:

- Live-in carers may need to be targeted for more formal support.
- Policies should consider the particular needs of live-in carers who are 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.

Alternative supports for carers of older people.

Are there particular supports that would be needed to complement the introduction of an entitlement to extended unpaid leave?

Financial support

Caregivers (particularly those living with the person they care for) report more difficulty managing on their income than non-caregivers. This is unsurprising given the associations between lower labour force participation and lower education levels and caregiving.

According to the ALSWH Major Report on Caregiving, at age 37-42, 26% of live-in carers and 20% of live-elsewhere carers from the 1972-78 cohort found it impossible or very difficult to manage on their income. In comparison, 13% of non-caregivers found it impossible to manage on their income

In the 1946-51 cohort, 16% of live-in carers and 10% of live-elsewhere carers aged 65-70 said it was impossible or very difficult to manage on their income. In comparison, 8% of on-caregivers suffered the same financial stress. (Tooth L, 2018).

While access to unpaid leave will guarantee a job to return to, it may exacerbate the financial stress experienced by many carers.

Recommendations:

- A carer's leave payment, similar to the Parental Leave Pay offered by the Australian Government would reduce the financial impact of taking unpaid leave to provide care and improve the wellbeing of carers.

How we should consider whether reforms to supports for carers of older people should apply to other carers too.

Are there reasons to have different policies for informal carers of older people than for informal carers of other types of people?

The Australian Longitudinal Study on Women's Health strongly supports the provision of carer's leave and other supports for anyone caring for another person due to an illness, disability, or frailty in old age. These measures will support the health and wellbeing of all Australians.

The majority (58%) of women from the 1946-51 cohort were caring for their parents/parents-in-law or spouse/partner at age 65-70. However, about 10% of women in late mid-age were caring for their child. While this could be due to a long-term disability, participant comments in the surveys often talk about the toll of caring for adult children after surgery or a cancer diagnosis (Tooth L, 2018).

Recommendation:

- Carer's Leave entitlements should be made available regardless of whether care is provided to someone because they are elderly, ill, or disabled.

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