



## The Characteristics and Experiences of Older New Zealand Caregivers.

### Findings from the Health, Work and Retirement Study.

#### Summary

Caregiving is an important societal role supplementing care provided through the health and social services systems. Caregiving among older people in our society, is an unpaid and under acknowledged activity. Using data from the 2013 wave of the Health, Work and Retirement Study we examined the characteristics and experiences of caregivers (aged 55-79) and described the people they care for. In addition we explored the support caregivers themselves receive and the impact of caregiving on loneliness, health and quality of life. In summary:

#### Older caregivers

- Around half care for their partners (46%) and approximately half (54%) live with the care recipient.
- 40% were in paid employment and most were unaware of their right to flexible work arrangements due to their responsibilities as a caregiver.
- The time involved in caring averaged 27 hours a week.
- Frailty was the main reason for care being required, followed by cancer, a respiratory condition and mental health issues.
- The most common forms of support provided were shopping for groceries, preparing meals, transportation, laundry and managing money.
- The most helpful support for caregiving was provided by family/whānau, community health services, ambulance services and respite services.

#### The impacts of caregiving

- Although some people felt their life was worse as a result of being a caregiver, 30% were unaffected and 41% considered themselves to be better off.
- Those who were financially better off reported coping better in their caregiving role.
- People who reported coping better with the caregiving role also reported better health, greater life satisfaction and less loneliness than those who were coping less well.

#### Work and caregiving

- Just over a quarter of working caregivers were aware of their rights to caregiving leave.
- Around one third were using sick leave, annual leave and unpaid leave to be available to their care recipients.

#### Future planning

- The majority of caregivers have investigated options to plan for future events or to make caring easier.

## Objectives

This research aimed to describe the experiences of older caregivers in New Zealand, to explore the impacts of caregiving, and determine whether coping differs according to demographic factors and health.

## Methods

The current report is from the 5th wave of the Health, Work and Retirement study. In 2006 a population sample was randomly selected from the New Zealand Electoral Roll and surveyed at 1-2 year intervals. Māori were oversampled using the Māori descent indicator. Data presented are from 168 participants aged 55-79 from the 2013 postal survey wave who indicated they had provided practical assistance for at least 3 hours per week for a person with a long-term condition, disability or frailty in the previous 12 months.

## Sample characteristics

Caregivers had an average age of 67.5 years and 68.7% were female. NZ Europeans made up 55.3% of the sample, 39% were Māori and 5.7% were Pacific people. The majority (81.6%) lived in an urban location and 20.4% lived alone. Just over seventy percent (71.1%) were married or in a de-facto relationship, 9% were divorced or separated, 15.4% widowed and 4.5% single. A tertiary qualification was held by 29.6%, 32.1% had a post secondary/trade qualification, 21.4% secondary school and 17% had no qualifications. At least some financial hardship was reported by 17.7% of the group, 34% were financially comfortable and 48.2% described their financial status as good or very good. Close to half of the caregivers were retired (44.3%), another 40.2% were in employment (25.4% part-time and 14.8% full-time), 8.2% were homemakers and 4.1% were unable to work due to a disability. Only 1.6% were currently unemployed and seeking work.

## Findings

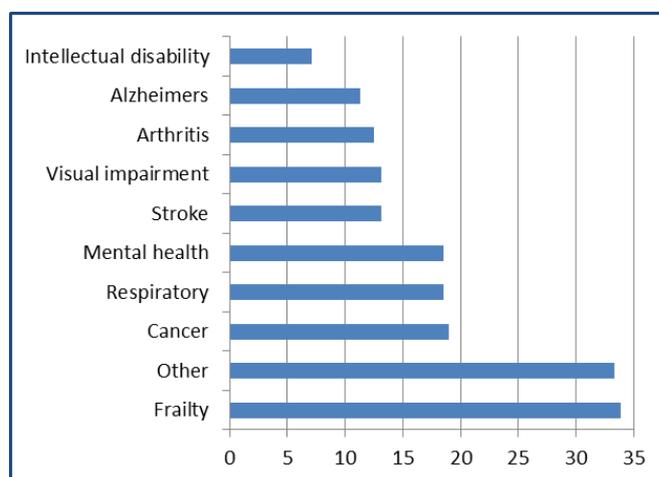
### Care recipients

Almost half (46.4%) of carers identified the person they had cared for the longest to be their spouse/partner, with 16.9% identifying a parent, 10.2% a friend, 9.0% a child, 4.8% a sibling, 1.8% in-laws, 5.4% another relative and 5.5% cared for

unspecified others. The age of the care recipients ranged from 1 to 104 years (mean = 70.4) and the length of time they had been cared for ranged from less than 1 to 52 years (mean = 10.2). Over half of the care recipients lived with the caregiver (54.2%), others lived with their family/whānau (12.3%), alone (21.3%) in a care facility (7.7%) or somewhere else (4.5%).

The health of the people requiring care included both mental and physical health conditions (Figure 1) with the number of identified conditions ranging from 1 to 5 (mean = 1.9).

**Figure 1: Conditions of people being cared for expressed as a percentage.**



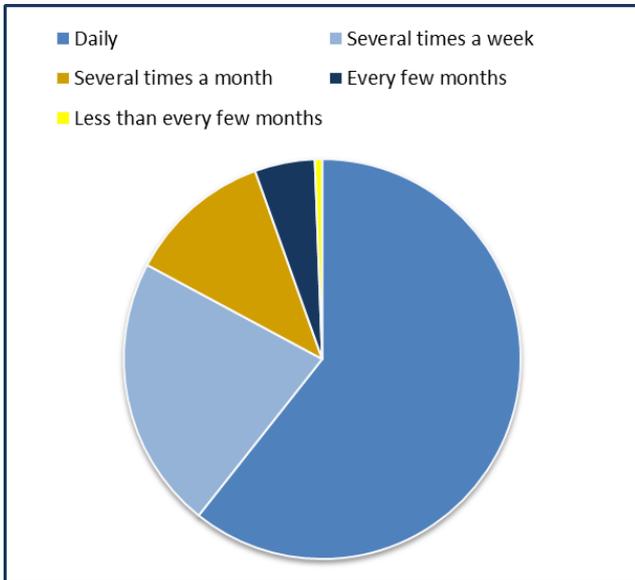
### Care provision

Frequency of care provision ranged from daily to less than once every few months (Figure 2). The hours spent providing care each week ranged from 1 to 168 with an average of 27.4. The need for care had been a gradual transition for 59.3% of carers (e.g. recipient started to need more and more help) while a sudden change (e.g. due to illness) resulted in the need to provide care for 31.3% of participants.

### Forms of care provided

Caregivers were asked which of nineteen listed activities of daily living they personally provided the care recipient assistance with and which were provided by others (paid or unpaid).

**Figure 2: Frequency of care provision.**



**Figure 3: Types of care most (top 5) and least (bottom 5) often provided by caregiver and others, paid or unpaid.**

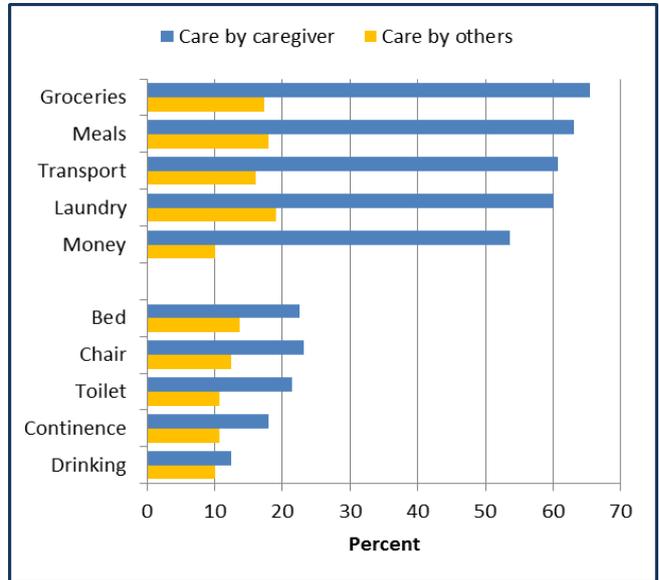
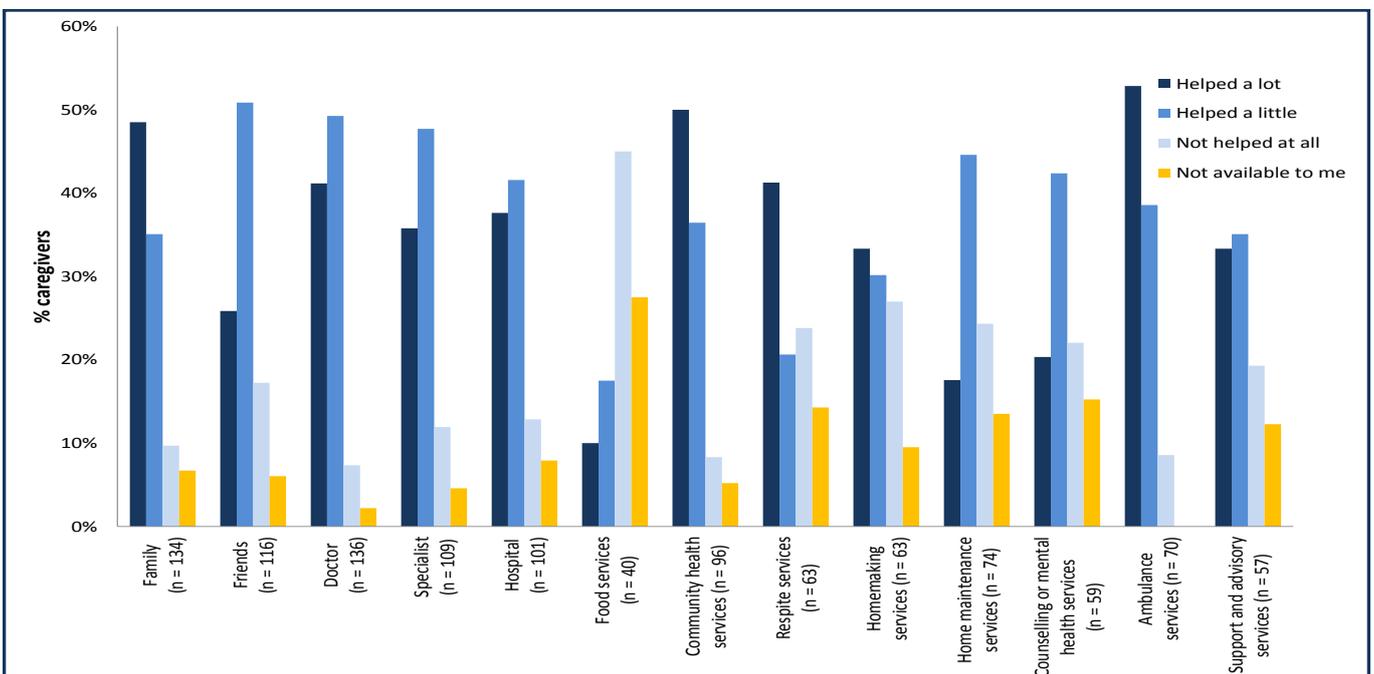


Figure 3 presents the percentages for the five most and five least frequently provided forms of care. Most frequent forms of care were helping the care recipient shop for groceries, followed by preparing meals, transportation, doing laundry and managing money (e.g. paying bills, keeping track of expenses). Caregivers also indicated which of these types of care were supported by other paid or voluntary caregivers. Most common were laundry, meals and grocery shopping.

**Usefulness of community, health and allied services**

Caregivers were asked to indicate whether they had needed help from paid or voluntary caregivers and agencies in caring for the care recipient and, if so, how helpful each had been. Figure 4 displays the number of persons who reported needing a group or service, as well as caregivers' ratings of how helpful these groups and services had been. Family/whānau and doctors were the most frequently identified sources of needed help. Family/whānau, community health, ambulance, and respite services were reported as having provided the most helpful assistance.

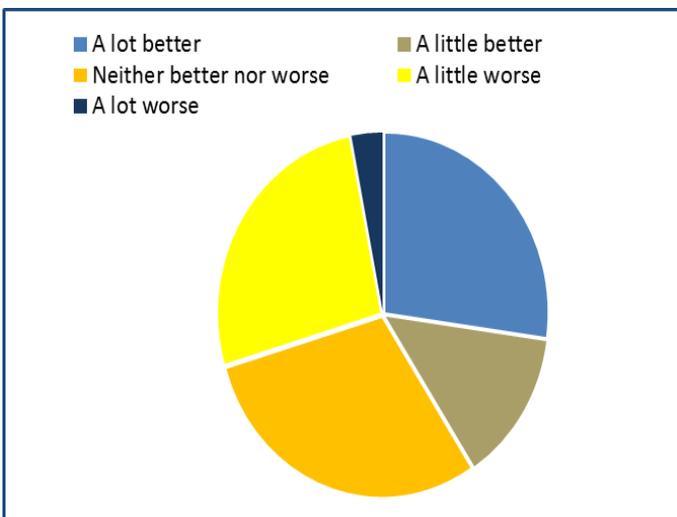
**Figure 4: Helpfulness of groups and services in caregiving.**



**Impact on caregivers**

The overall effect of the caregiving role on the caregivers' life was perceived to be negative by 29.6% of respondents, neutral by 29.6% and positive by 40.8% (Figure 5). Those indicating a positive impact of caregiving were more likely to be male, provide fewer care hours per week, and report being less lonely. Perceived impact on life was not associated with urban/rural residency, employment status or being of Māori descent.

**Figure 5: The impact on the carers' lives of providing care for others.**



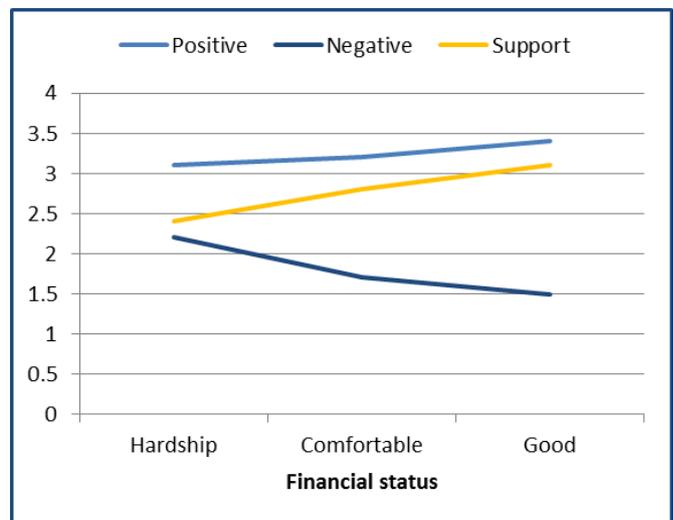
**Coping**

The degree to which carers coped with their caring role was measured using the COPE Index, a 15 item measure containing three scales; perceived positive value in caregiving role, perceived negative impact of caregiving, and perceived quality of support in caregiving (score range 0-4).

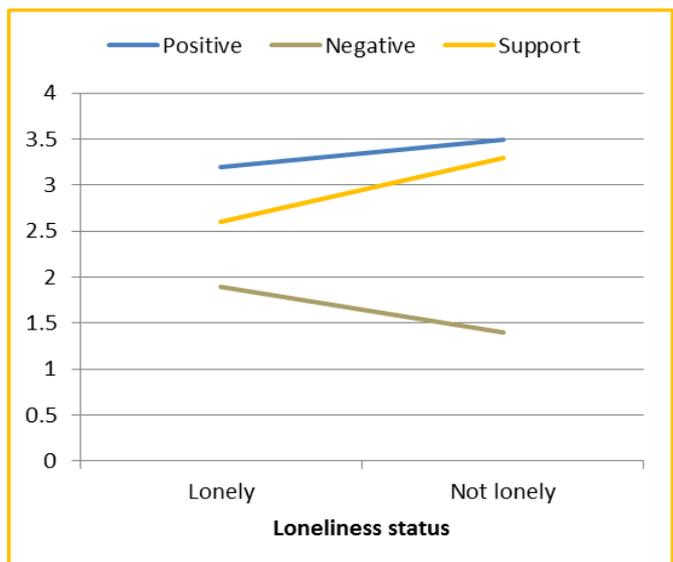
None of these three coping indices differed according to age, sex, marital status, urban vs. rural residence or being of Māori descent. However scores did vary by respondent's financial status (Figure 6) as those who were better off reported more positive value, less negative impact of caregiving, and a higher quality of support.

In relation to health, all three coping indices were significantly correlated with physical and mental health (SF-12), current health status, life satisfaction and loneliness. Those with better health, greater life satisfaction and less loneliness were more likely to report higher positive value and quality of caring support and lower levels of negative impact of caring. This effect is illustrated for loneliness in Figure 7.

**Figure 6: Mean scores on positive value, negative impact and quality of support by financial status.**



**Figure 7: Mean scores on positive value, negative impact and quality of support in caregiving by loneliness.**



### Combining work and caring

#### Awareness of rights under legislation

Legislation introduced in 2008 provided the right for a person who has worked for the same employer for at least six months and who has caring responsibilities for any person to request flexible work arrangements. Of the 40.2% of caregivers who were in paid employment, only just over a quarter (28%) were aware of this right. (Note: since this 2013 data collection the right to request flexible work arrangements has been extended to all workers).

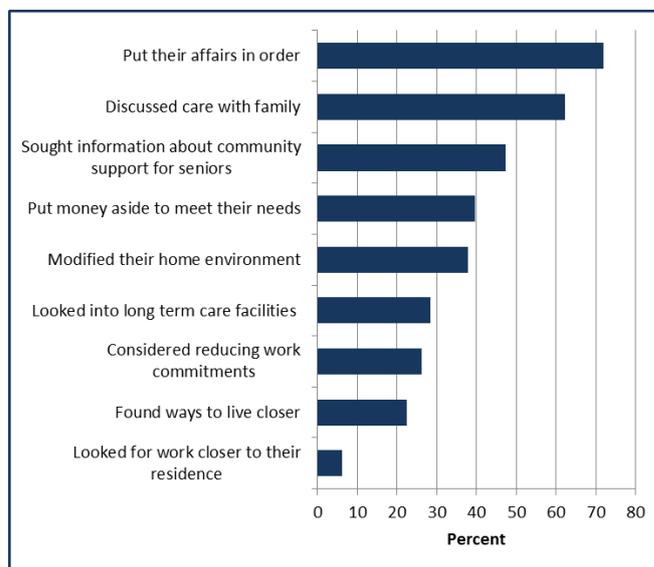
#### Accessing leave for caring

Those balancing work and care giving activities indicated taking unpaid leave (28%), sick leave (34%) or annual leave (37%) in order to provide care when needed. This often occurred at short notice as they reported providing crisis care resulting from illness, an accident or family crisis, an average of 7 times during the previous 12 month period.

#### Future planning

Caregiving is not a stable activity due to the likelihood of the status of the care recipient changing over time. We consequently asked whether the carers had investigated options to plan for future events or to make caring easier. Nine options were listed with an average of 3 selected by the caregiving sample, and only 12.5% indicated that they had not explored any of them. A large proportion (71.9%) had made sure that the affairs of the person being cared for were in order, 62.2% had discussed care arrangements with other family members, 47.3% had sought information about community services for seniors, 39.6% had put money aside to help meet their needs, 37.9% had modified their home to ease care provision, 28.3% had looked into long term care locations, 26.1% had considered reducing work commitments, 22.4% had found ways to live closer to the person they cared for, and 6.2% had looked for work closer to the person being cared for (Figure 8).

**Figure 8: Frequency of positive responses to different ways in which caregivers plan for the future.**



#### Implications of findings for public policies on caregiving

Although providing care is often found to be burdensome, providing care can be a positive experience, and this is particularly true if caregivers are given sufficient and appropriate support.

A large proportion of caregivers in this study were providing support for someone who was frail. The trend in New Zealand toward ageing in place means that many more frail, ill or disabled older people with high levels of dependency will be cared for within the community by family members. The negative impact of providing care was highest among female participants. Caregiving is largely undertaken by women and women are likely to experience greater caregiver burden than men.

Women may be at higher risk of experiencing the detrimental effects of caregiving due to existing vulnerabilities such as having fewer resources to call upon including income, wealth and stable employment. Female caregivers have also been found to receive less informal assistance and to have more restricted social roles due to caregiving responsibilities than male caregivers. Investigating the availability and uptake of both informal and formal supports by male and female caregivers may provide opportunities to ameliorate the greater experience of burden for women in caregiving roles.

Caregivers expressing greater negativity from providing care also reported greater loneliness. This highlights the importance of helping older caregivers to maintain their existing social networks. The provision of appropriate options for respite care and home support services can not only alleviate caregiver burden, but can also assist caregivers to continue to participate in social activities. These types of assistance have been shown to be related to lower levels of social and emotional isolation for caregivers.

Caregivers' reports of coping with the caregiving role were related to financial status. Providing care is associated with considerable out-of-pocket expenses for informal carers. In addition, attempts to combine paid work and care can result in opportunity costs such as lower wages, poorer career prospects, and reduced retirement savings. Public policy that supports informal carers to cope with the burden of care should include adequate income support and financial assistance with housing, transportation, health-care and home support services.

Finally, the use of leave provisions (unpaid leave, sick leave and annual leave) by working caregivers to provide care to family members highlights the importance of flexible work arrangements that are easy to understand and access; and the need for a dedicated carers' leave policy in New Zealand.

