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Chapter 1 Introduction

1.2 The socio-demographic background

Several important socio-demographic trends set the scene for this study of working carers, which is, as far as the authors know, the first of its kind to be carried out in New Zealand.

- New Zealand is ageing. In the coming half-century, the median age of the population will rise from 36 to 46; the percentage aged 65 plus will grow from 12 to 25 percent and the number of people aged 85 and over will grow by 600 percent to an estimated 290,000 (Khawaja, 2000). This age group is very likely to require support and assistance, both formal and informal. Currently, only 15% of New Zealanders aged 85 and over live in the community independent of all service provision; 36% of people aged 75 and over have a moderate disability and 18% a severe disability (Ministry of Health, 2002).
- Along with the population as a whole, the workforce is also ageing, with a current median age of 40 (Davey and Cornwall, 2003). This trend, along with declining birth rates mean that there will be a slowing in labour force growth in the coming decades (Stephenson and Scobie, 2002). This suggests that participation rates for older workers are likely to grow, as they respond to the combined incentives of labour shortages, improved health and longevity and the necessity to make greater provision for their own later lives.
- Over the past 50 years there has been rapid growth in women's participation in paid employment. This is especially true for women in mid life, from age 40 onwards. Women are contributing to the workforce in greater numbers, whereas in the past they have traditionally been the major caregivers.

These trends come together into a situation where there are more older people, especially very old people requiring care and support, but a declining number of people in their children's generation who are free from the demands of paid work. Employees in their 40s and 50s are increasingly likely to have competing responsibilities towards their employer and care giving. The emphasis is changing from caring for the younger generation to caring for the older generation, and this trend is likely to become even more important in the future. Employers will therefore increasingly need to include eldercare responsibilities as an aspect of family-friendly human resources policies.

1.2 Aims and objectives

The main aim of this study is to investigate the relationship between paid work and eldercare responsibilities. It is intended to produce benefits to the participants, their employing organisations and to wider society, including other employers, employee organisations, service providers and policy-makers. Potential exists for the study to assist in the development of appropriate policies and processes in relation to workers who have eldercare responsibilities and show the way for other employers.

The objectives of the study are to –

1. Document the nature and extent of eldercare responsibilities among the workforce of two major employers with mixed age workforces in a variety of occupations.
2. To explore ways in which employees meet their eldercare responsibilities in relation to work duties and responsibilities to employers.
3. To document measures, insofar as they exist, set in place by the employers to assist employees in meeting their eldercare responsibilities.
4. To explore ways in which eldercare responsibilities could be recognised and accommodated by employers while maintaining objectives for efficient and effective workforce operations.

1.3 Context and significance

Older workers and workforce change

Population ageing has significant implications for the labour force and for economic growth, and this emphasises the importance of maximizing the potential of older workers, maintaining and prolonging their workforce participation. The OECD has also highlighted the need for employment policies that accommodate the needs of older workers and help to overcome workplace barriers that impede their labour force participation (OECD, 2000). International research has also forecast that businesses that do not adequately prepare for an older workforce will face significant economic costs, which in turn will affect the growth of national economies (Robson, 2001).

Older workers are the group most likely to have responsibilities for the care of older people, frequently their parents. As the population ages the numbers of people with such responsibilities will increase, especially given the policy stance that encourages ageing in place. This implies that older people, often with significant disabilities or chronic health conditions, remain in their own homes in the community even if they have extensive needs for care and support. Eldercare responsibilities may be a key factor in deciding whether older workers are able to remain in the workforce and the extent of this involvement (full or part-time). Thus, with the strong policy directions towards Positive Ageing (Dalziel, 2001) and the end of compulsory retirement (Human Rights Commission, 1998), there is likely to be concurrent pressure for both men and women in midlife to stay in paid work longer, while at the same time playing increasing roles in support of their parents and family members who are ageing in place.

Work-life balance

The challenge here is not only to ensure the well-being of workers but also that vital unpaid caring work is undertaken. Most of the initiatives to promote work-life balance and family-friendly workplaces concern the needs of working parents and have taken a child-oriented perspective, such as the recent passage of legislation providing for paid parental leave. For older workers, as pointed out above, eldercare responsibilities may be significant. Employers seem less aware of these issues and fewer initiatives

have been developed to address them, certainly in New Zealand. The demands of eldercare responsibilities are not always predictable and come at a time when older workers may be considering retirement or reducing workforce participation themselves. They may, if not sympathetically handled by employers, result in the under-use of human potential in an ageing workforce.

Alternative work arrangements

Alternative work arrangements and flexible working conditions are important ways of accommodating and combining the unpaid care responsibilities of employees and this applies also to older workers. They may also be seeking more flexible work arrangements as they approach retirement. By improving the quality of the working environment, redesigning and reassigning jobs, older workers could be encouraged to continue working or to re-enter the labour force (Davies, Matthews and Wong, 1991). Flexible employment options offer benefits to both employers and employees, including higher retention rates; preservation of valuable organisational knowledge; less absenteeism; lower recruitment costs; more contented employees, who are more productive; and lower stress levels as family and work commitments become easier to balance (Clements, Hobman, Rosier and Tweedy, 2003).

Relatively little research has been conducted in New Zealand on these options. Callister (1997) reviewed the literature and concluded that while some non-standard work practices, such as shift work, have become common, others, such as job sharing and home working, are rare. More recent research by McGregor and Gray (2001) supports this finding. Less than a third of the employers they sampled offered flexitime and only 10 percent offered gradual or phased retirement.

The informal care sector

Around the world, there is increasing interest in the growth, significance and value of informal care for older people (Chappell 1992, Twigg and Atkin 1994). New Zealand research and policy development has also addressed these issues (Opie 1992, NHC 1998), and most recently, an organisation known as Carers NZ has formed and launched its own website as a focus for national advocacy on behalf of those who contribute valuable caring work in what is variously known as the voluntary, informal, unpaid, or family care sector (Carers NZ 2004). Carers working with older people were part of the drive which led to the establishment of Carers NZ, and recent entries on their website indicate a growing interest in the intersection between informal care and employment.

Bytheway and Johnson (1998, 251) trace the “dramatic history” of the concept of the carer, and show how the concept has acquired statutory status in Britain. Their work and that of others discusses how research questions have ranged from the descriptive - *Who are the carers?* - to the contextual, in which care is central to research into family relations in later life (Nolan, Davies and Grant, 2001).

Generalised and potentially stereotypical understandings have developed from this work, depicting the majority of care as being provided by women, particularly in their roles as adult daughter and daughter-in-law, and seeing this as a “natural” extension of female predominance within the domestic sector, and the household economy.

While New Zealand has removed any compulsory retirement age, the simplistic separation of working and caring roles in both mid and later life has only recently registered as raising further significant research questions, such as those addressed in this study.

Some information on informal care is available from the “Activities” question in the New Zealand Census of Population. This asks people if, in the four-week period before the census, they had cared for someone who was ill or disabled within the same household and also outside their household (there was a separate category for childcare). The age of the person cared for was not indicated, so this cannot provide a definitive picture of eldercare activities. It is suggestive only. The “From Birth to Death” database, which covered 93 percent of the usually resident census population in 2001, provides a breakdown of caring activity data by age, gender and ethnicity (Davey, 2003).

The following table gives the overall pattern of informal care for ill or disabled people in the same household and in another, for the working age population. At a total population level, women are more likely than men to be involved in both types of caring. The rates for informal caring generally increase with age and the highest levels of caring responsibility are found in the 40-59 age group. The patterns are similar by ethnicity, except that Maori, both men and women, are more likely to provide this type of care than people in other ethnic groups.

Table 1: Percentage involved in Unpaid Work, by Age and Gender, 2001

Age	Caring for ill/disabled person in same household		Caring for ill/disabled person in another household	
	Male	Female	Male	Female
15-19	4	5	3	4
20-39	7	9	5	8
40-59	6	10	7	14

Source: 2001 Census of Population (Davey, 2003)

1.4 Previous research on working carers

Very little is known in New Zealand about working carers of older adults; about what strategies they use to help them balance work and caring and about procedures or schemes to assist them. Extensive searches have not unearthed any local studies on these subjects. However, the Living Standards of Older New Zealanders study (Fergusson, Hong, Horwood, Jensen and Travers, 2001) makes it very clear that the health and employment situation of mid-lifers has a significant influence on their later life standard of living. The Transactions in the Mid-Life Family study also lays a foundation for research on working carers (Koopman-Boyden, Dharmalingam, Grant, Hendy, Hillcoat-Nalletamby, Mitchell, O’Driscoll and Thompson, 2000). From a policy perspective, some interest in eldercare responsibilities has been expressed by the Ministry of Women’s Affairs (MWA, 2002).

There is, however, evidence of significant interest in the area, expressed by a range of organisations, including the EEO Trust, Human Rights Commission, Career Services, Department of Labour (Labour Market Policy Group), Ministry of Social Development and WINZ who attended two meetings on mid-life work issues in Christchurch, in 2002 and 2003. These were organised by the New Zealand Institute for Research on Ageing (NZiRA) and hosted by the Canterbury Development Corporation Ltd and the Third Age Foundation Trust (EEO Trust, 2002).

Overseas, the literature on older workers, eldercare and work-life balance is much more extensive. It was the subject of a symposium at the British Society of Gerontology Conference in 2001, which produced some very useful papers, based on British, Canadian and Australian studies (Evandrou and Glaser, 2001, Lund, 2001, Martin-Matthews, 2001, Pickard, 2001, SPRU, 2001, TCRU, 2001a and 2001b). Of especial significance is *Juggling work and care: The experiences of working carers of older adults* (Phillips, Bernard and Chittenden, 2002). The methodology from this study has been adapted for this New Zealand research, thus allowing for international comparisons. The following discussion summarises important points from these and other overseas studies.

Phillips et al (2002) point out that while the UK employers they studied are increasingly aware of the need for “family friendly” policy and practice to support workers who care for young children, the question of eldercare responsibilities is not well recognised (SPRU, 2000). Research has also found that employers perceive that eldercare responsibilities are less demanding than childcare needs (Martin-Matthews, 2001). Further, the needs of workers combining work with childcare are very different from those of workers who care for older people. Caring for older people can involve protracted and unpredictable demands and, as older people may also be supported by community agencies, the pattern of service delivery is often complex, involving a range of providers, both paid and unpaid.

Caregiver burden has been found to have psychological, social and economic consequences (Noelker, 2001). A USA report found that caregiving responsibilities affect workers’ productivity, particularly because of their need for altered work schedules. Of the 22 percent of 45-55 year olds responsible for eldercare surveyed, 40 percent said that their caregiving responsibilities affected their advancement in their workplace (Sheel and Coleman, 2000). The personal and financial loss is high for both individuals and employers and in 1997 employers in the USA were estimated to have lost between \$11.9 and \$29 billion each year due to loss of productivity of full-time workers with caregiving responsibilities.

Moreover, it is primarily women rather than men who are hindered by the responsibility and burden of caring for older relatives (ENEPRI, 2001, Martin-Matthews, 2001, Robson, 2001). Typical elder caregivers are women in their mid forties working fulltime (Sheel and Coleman, 2000). Women also have five times greater likelihood of retiring from paid work than do men when they are responsible for caring for a dependent spouse (Dentinger and Clarkberg, 2002). The responsibility of caring for aged relatives has an economic impact on both individual women and society. Women who face disrupted work histories due to child-caregiving responsibilities in their early working life, and who then have the extra burden of eldercare in their later working life, are often forced by their responsibilities to curtail

their involvement in paid work. As a result these women have been found to be unable to save adequately for their retirement, leaving them dependent on state superannuation (Gee, Ng, Weatherall, Liu and Loong, 2000, 2002). Given the very real economic consequences for individuals, businesses, and society if older workers, and particularly older women, are restricted from participating in paid work because of their responsibilities for elderly relatives, then it is vital that workplaces assist in accommodating the needs of this group (ENEPRI, 2001).

Phillips and Bernard (2001) found that very few designated family-friendly policies were taken up and used routinely by employees. Carers tended to take up familiar policies such as annual leave or time off in lieu, that retain their privacy about their specific needs for additional assistance. These carers were found to be highly committed to their jobs, but experienced difficulty in negotiating inflexible schedules, and the pressure of their job hindered their abilities to juggle their work and caring responsibilities. Other research has found that maintaining a positive and productive attitude toward paid work on the part of working carers is significantly enhanced when they have choice about their work arrangements, and if they can flexibly organise their work around their caring commitments (Martin-Matthews, 2001). A recent examination of employment based measures to support carers resulted in a proposal to the British government to introduce specific leave allowances for working carers with responsibility for eldercare (Royal Commission on Long Term Care, 1999). Other provisions that assist employees to blend work and caregiving responsibilities include flexible working conditions, special leave arrangements for emergencies and access to basic links such as a telephone. Moreover, research has demonstrated the economic benefits to employers in implementing better work-life balance policies that assist those with caregiving responsibilities (SPRU, 2000).

Chapter 2 Methodology

As the preceding chapter shows, the issues surrounding workforce participation and the provision of informal care to older people are by no means unique to New Zealand. Recent overseas research with working carers was therefore consulted in designing the first New Zealand study to address these issues.

To aid comparability of the results, the methodological approach used by Phillips, Bernard and Chittenden in *“Juggling work and care”* (2002) was adapted, with permission, to New Zealand conditions. In Britain, the workforces which participated in the study were from two public sector organizations, a Social Services Department and a National Health Service Trust. Both were located in the West Midlands and both were in the health and community services sectors. Thus many employees (in a combined total of about 8000) had dual roles relating to the care needs of older people, through their paid employment, and also in their informal caregiving roles.

2.1 Setting the study in two city councils

The New Zealand study aimed to ensure that the participating workforces were from organizations which did not have functions related to eldercare. An earlier study of New Zealand local authorities (Gee and Glasgow, 2000) was linked to NZiRA. This scoped the ways in which such organizations have developed policies relating to New Zealand’s “ageing society”, and so provided some understanding of local authority settings, which was helpful for the working carers study.

Two local authorities, the Wellington City Council (WCC) and Christchurch City Council (CCC), were chosen as the sites for this study for several reasons, along with the fact that they offered convenience of proximity and accessibility for the two researchers. They are each large public sector employers, with mixed workforces in terms of occupational categories, age, gender and patterns of workforce participation. Christchurch has 44% male and 56% female employees; Wellington has 51% male and 49% female. On the basis of initial enquiries, the councils’ workforce shared with the British sites “the structural potential for eldercare to be a concern for employees and employers” (Martin-Matthews and Keefe, cited in Phillips et al, 2002, 3).

Together, the two workforces were large enough to inspire confidence that sufficient participants would identify themselves and be willing to take part in this study to give a valid sample size in statistical terms. At the same time the numbers were manageable to ensure that the conduct of the study would be well-focussed, feasible and productive within a constrained research timetable and funding.

This study makes no claims to be representative, except in relation to similar public sector/local authority workplaces. However, it offers a pragmatic application of a research methodology developed overseas, and is likely to have general comparability.

2.2 The research process

The UK study describes itself as using a multi-method approach and had five phases (Phillips et al 2002: 3-5):

1. establishing a profile of the workforce of the two organisations
2. use of a screening questionnaire
3. administration of a postal questionnaire
4. in-depth interviews with a purposive sample (about 20% of working carers who completed the questionnaire)
5. in-depth interviews with managers.

In broad terms, the methodology used in the New Zealand study incorporates a similar series of five steps, with the most significant adaptation relating to step 4. Here focus groups took the place of individual interviews, largely in the interest of time and resource limitations. Some of the other steps were abbreviated, again to fit the timetable and funding, but also based on the report on the UK study and contact with the UK researchers. This suggested some streamlining and modification based on their experience.

The five steps in the New Zealand research process thus followed in sequence, although there was some overlap between the steps, and some circularity in the whole process. For example, there was looping and feedback between steps 1 and 5.

Step 1 involved establishing a profile of the workforces of the two organisations. Both Councils were willing partners in the research process, and had had earlier working relationships with NZiRA researchers. Both had participated in an overview of measures which they had in place for older people (Gee and Glasgow, 2000). Secondly, Christchurch City Council, through the Canterbury Development Corporation, had hosted NZiRA-initiated meetings to discuss mid-life issues in 2002 and 2003. Contact was made with the Human Resources Department of each Council at the point of research design and as project funds were sought. This preliminary information confirmed the suitability of the sites for the research, and procedural discussions began about the conduct of subsequent steps.

Once the research contract was signed between the Department of Labour and NZiRA, through Victoria Link Ltd., application was made to the Victoria University of Wellington Ethics Committee, and approval obtained for the research to proceed on October 15, 2003.

Step 2 involved the use of the screening questionnaire, which asked employees to indicate whether or not they provided informal care to an older person or persons, defined as “looking after or giving care to anyone (one or more persons) over the age of 65 – family members, friends, neighbours or others – because they have long-term physical or mental disability or problems related to old age”. If they had eldercare responsibilities they were asked whether they were willing to be sent the questionnaire for self-completion (see Appendix I). Both Councils themselves suggested that a combined electronic and paper-based method of administering this screening questionnaire would generate the best response. Employees who were regular users of an in-house email system could “vote” with a simple email reply,

while hard copies of the screening questionnaire were circulated to staff members without regular email access at work.

Step 3 involved a self-administered questionnaire, distributed to those who indicated willingness to take part in the study through the screening question. At the end of the ten day voting period, the researchers received lists of participants who had voted by email and hard copies of the screening questionnaire. These were processed and questionnaires were sent to staff members who had identified themselves as 'working carers' and as willing to take part in the study (see Appendix II for the questionnaire and information sheet. The questionnaire is included here for reference. Organisations and individuals who wish to replicate the research are requested to contact NZiRA).

The questionnaire was designed jointly by the two researchers, working from the format of the questionnaire used by Phillips et al (2002). Some adaptations were necessary, to accommodate New Zealand features and circumstances, and to reflect the different employment sites selected in the two countries. The questionnaire was pilot tested with volunteers from non-Council workplaces in Wellington and Christchurch. This tested the form for clarity, timing and ease of completion. Minor amendments were made prior to submission for ethics approval.

The questionnaire collected basic personal information from those who have eldercare responsibilities – age, sex, ethnicity, occupation, educational and income level. It also covered -

- the length of time spent on eldercare in a typical week;
- whether the person has sole or shared responsibility for care;
- the living arrangements of the person cared for (whether in the respondent's home, their own home, a rest home or elsewhere);
- the distance of the older person from the respondent's home and from their workplace;
- the type and frequency of the care provided (including both practical help, such as dressing, meal preparation, household chores, and emotional/social support, such as taking them out);
- the length of time over which care has been provided;
- what happens in a crisis in relation to eldercare responsibilities;
- the extent to which care recipients help carers;
- assistance with care provided by community and health services;
- employment-related assistance with managing as a working carer;
- attitudes and feelings as a working carer.

The questionnaires included a stamped addressed envelope for return of the completed forms to NZiRA at Victoria University in Wellington. The Christchurch responses were copied and sent to the Christchurch researcher, so that local discussion groups could be organized, using the responses to the final section.

All questionnaire data were entered into a database at NZiRA, by a research assistant using the SPSS analysis programme. The database followed the structure of the questionnaire and coding was finalised, based on preliminary work done at the time of questionnaire design and pilot-testing. All responses were identified by a numerical

code to ensure confidentiality and care was taken to keep the identifiable information secure.

Step 4 was the conduct of group interviews in the two cities. The final page of the questionnaire asked respondents to indicate their willingness to participate in such discussions. Many respondents said that they appreciated the opportunity offered by the study for them to share problems and concerns in the field of eldercare, whether or not they were able to participate in a discussion group.

Before the groups were held, the two researchers developed a common guide for the discussion, to aid comparability of this data from the two cities; this is attached in Appendix III.

Focus or discussion groups were chosen as an appropriate method to obtain amplifying data in a short time period and also to inform the analysis of the questionnaire material. This is a standard way to draw on insights from both quantitative and qualitative perspectives in social research where research participants are likely to have individual experience of the subject under investigation (being a working carer, in this case) and some elements of shared experience (Waldegrave, 1999).

As the project took place towards the end of the working year, time constraints clearly affected the ability of staff members to attend the discussion groups, although in Christchurch, there were more volunteers than planned groups could accommodate.

The analysis of the eight focus groups in the two cities and additional non-coded comments written on the questionnaires was carried out jointly by the two researchers. Initial themes were identified, and then further elaborated and related to the patterns which were becoming evident from the analysis of the questionnaire database.

The group discussions were run by the lead researcher in each city. In all but one of the groups an assistant attended as a recorder and to assist with the taping. The group sessions were all tape-recorded (although there were technical difficulties in one) and transcribed fully to augment the written notes of the recorder. Quotes from these transcripts are included in this report, with pseudonyms used in place of the first names given. Brackets are used to indicate explanatory text, as required. In some cases, identifying detail has been removed, amended, or glossed, although where different themes emerged in the two cities this is indicated. Otherwise, the groups and additional comments have been analysed together, from both sites.

Step 5, interviews and discussions with City Council staff as employers, occurred largely at the beginning and end of the research process, and this step was less formally developed than the systematic and in-depth interview process with management staff used in the UK study. Feedback and advice was obtained from Council management at step 1, relating to the mechanisms for screening and administration of the questionnaire and focus groups. Consultation at step 5 informed the drafting of this final report. Information on staff leave policies, in areas such as domestic leave, flexible work arrangements and the use of annual leave for family care needs, was sought in writing, and meetings to discuss the draft report were held

at each site. While contact was sought with staff representatives or unions, no formal meetings were arranged, and participants in the study came from all levels within the organisation, other than elected Council members (see Chapter 3 for results and the scope of coverage in the study).

Council management, specifically Human Resources staff, had no input into the design of the questionnaire, nor any access to data from individual staff members. Similarly, staff members who took part in the discussion groups were assured of the confidentiality of material shared.

Throughout the research process, there was regular liaison between the two researchers by email, transfer of draft written material, and several face-to-face meetings. Generally, there was joint responsibility over design and conduct of the research, with NZiRA taking contractual responsibility for the research grant and data management. Each researcher had primary responsibility for liaison with their local City Council, through designated staff members, consistent with the ethical and contractual arrangements and protocols made with the various parties.

2.3 Definitions

Throughout this report, some core definitions are used, to maintain consistency and clarity of reference.

Eldercare: includes personal care, household assistance, administrative support, social and emotional support. The questionnaire gave several examples of each type of care (see Q 7 in Appendix II).

Working carers: a person who fills two roles concurrently a) as a member of the paid workforce in any sector, either full or part-time, and b) who provides eldercare as defined above on an unpaid (informal) basis.

Care recipient: the person for whom a working carer provides informal care.

Refinements of these definitions are used at some points in the report to distinguish, for instance, between primary or secondary roles as working carer or care recipient, and reference will be made as necessary to commonly accepted definitions in the literature.

Chapter 3 Patterns of Care: Giving and Receiving

3.1 Response and participation

The two city councils have about 3800 employees in total, with rather more in Christchurch than in Wellington. About a third of these responded to the screening questionnaire. From this initial screening it appears that 7.8 percent of the workforce in Christchurch and 10.8 percent in Wellington have eldercare responsibilities. This is assuming that non-respondents have the same level of involvement in eldercare as the respondents. The overall level of 9.2 percent (350 people) with eldercare responsibilities is similar to the results from the British survey on which this research is based (Phillips, Bernard and Chittenden, 2002). Of the 9.2 percent who indicated that they had eldercare responsibilities, 254 employees were willing to participate in completing the questionnaire survey.

About half of the self-administered questionnaires sent out were completed and returned – 69 in Wellington and 65 in Christchurch, a response rate of 53 percent. Twenty-five percent of the Wellington respondents and over half of those in Christchurch were willing to take part in group interviews and four sessions were completed in each centre, involving 32 respondents in all (Table 2).

Table 2: Working Carers Study – Response and Participation Rates

Wellington City Council 1777	Christchurch City Council 2032
Total workforce 3809	
Step 1 and 2 - Responded to screening questionnaire 1186 – (31 percent, Wellington 32 percent, Christchurch 31 percent)	
Involved in eldercare 350 (9.2 percent of 3809)	Not involved in eldercare 836
Step 3 - Willing to answer questionnaire 254 (73 percent of 350)	Not willing 96
Completed questionnaire 134 (53 percent of 254)	Questionnaire not returned 120
Step 4 - Willing to participate in group interviews 50 - Wellington 17, Christchurch 33	
Took part in group interviews 32 - Wellington 15, Christchurch 17	

3.2 Characteristics of working carers

Of the 134 respondents to the self-administered questionnaire, 96 were female (72 percent) and 37 male (28 percent). As a whole the combined Wellington and Christchurch workforces were much more balanced in terms of gender – 53 percent female and 47 percent male. Nearly three quarters of the respondents were aged between 40 and 59, with 9 percent 60 plus (the oldest aged 65) and 18 percent under 40 (the youngest 24 years). No information was made available on the age composition of the two workforces as a whole.

The respondents were mainly Pakeha – 89 percent - with only 3 percent Maori, 2 percent Pacific people, 4 percent “other” and 2 percent did not state their ethnic affiliation. Compared to information supplied by the city councils, Maori and Pacific respondents are under-represented among Wellington respondents, but the ethnicity of the Christchurch respondents is similar to that of the council workforce.

The respondents had generally high educational qualifications – 43 percent have undergraduate or postgraduate degrees, 25 percent trade certificates or diplomas and only 5 percent had no qualifications. While no information on income levels was collected in the research, data on qualifications suggests that many of the respondents will fall into the higher socio-economic levels.

Eighty percent of the respondents worked full-time hours (37.5 or more per week). This is higher than for the workforces as a whole, suggesting that full-time workers are over-represented among the respondents.

In order to summarise the occupational patterns of the respondents (and given the great variety of positions within the city council workforces), open-ended responses from the self-administered questionnaire have been reclassified into the categories used in the New Zealand Census of Population (www.stats.govt.nz). This shows that two-thirds of the respondents are concentrated in the professional, technical and management occupations (a higher proportion in Wellington and a lower proportion in Christchurch) and over a fifth are in clerical work. Comparatively few are in “blue collar” occupations. Information on occupations provided by the city councils could not be compared to the census categories or between the two workplaces.

Workers with eldercare responsibilities had been employed by the city councils for varying terms, but mainly between one and 20 years, with the average length of employment being 9 years.

3.3 Characteristics of care recipients

Three-quarters of the respondents cared for only one older person, but 34 people cared for two, with a total of 168 care recipients covered in the questionnaire results. These were mainly female (71 percent) and 65 percent were aged over 80. The average age of the care recipients was 81.

The most common type of disabilities being experienced by the care recipients were physical – 55 percent of the total of 168, followed by 18 percent who had a combination of physical and cognitive difficulties and 6 percent whose disabilities

were mainly cognitive. Cognitive disabilities, either alone or in combination with other types, affected almost a third of the people being cared for. Because of the challenges of caring for people with cognitive disabilities, the care recipients have been grouped into two categories – one for those with physical disabilities only and one for those with cognitive disabilities, either alone or in combination with physical problems.

The nature and extent of the disability or care needs of the older person was discussed in the groups, and certainly affected the style and level of care and support provided by working carers. Many people were coping with family members with dementia, and several people talked about their concerns, for example about the driving ability of their parent. They also had to cope with the consequences of a dementia diagnosis for effective two-way communication and emotional support. Service availability for someone trying to manage at home with dementia was also a common concern.

At a practical level, caring for someone with dementia means that it takes longer to get things done, for example, getting ready in morning, managing hospital appointments. Similarly, someone caring for a depressed parent felt that the need to spend extended time with her mother and the emotional demands that went with this particular condition were somewhat out-of-step with the busyness of her working lifestyle.

There was praise for the Alzheimer’s Society, from one carer.

Mum thinks that she joined, but I did because it is actually for carers. They are fantastic. Once a month they have a support group to find out all the fast tracks - hints about getting things done quickly and it’s the best thing I’ve ever done really. They know all the short cuts and all the places you can go.

Table 3 illustrates the relationship of the care recipients to the working carers. Mothers were the largest category. Mothers and fathers together accounted for 62 percent and including mothers and fathers-in-law the total was 74 percent. Only 9 percent of care recipients were friends. In half of the cases where more than one older person was cared for these were the parents of the working carer.

Table 3: Relationship of care recipients to working carers, by gender of recipients

	<i>Male frequency</i>	<i>Female frequency</i>	<i>Total frequency</i>	<i>Percent</i>
Mother	0	72	72	42.9
Father	32	0	32	19
Mother-in-law	0	14	14	8.3
Father-in-law	6	0	6	3.6
Aunt	0	8	8	4.8
Uncle	1	0	1	0.6
Grandmother	0	10	10	6
Grandfather	4	0	4	2.4
Other family member	2	3	5	3
Friend	3	12	15	8.9
Total	48	120	168	100

Note: Excludes non-response

Seventy percent of the care recipients lived in their own houses or apartments (including units in retirement villages). Seventeen percent lived in rest homes or some other type of residential care. Only 11 percent lived in the same household as the carer and 2 recipients were living with a sibling of the respondent. Where respondents were caring for two older persons, in most cases the recipients were both living in the same household.

3.4 Patterns of care-giving

Different types of caring relationships

As already mentioned, most of the care recipients were parents or close relatives in the parents' generation. This study did not include significant representation of spouse carers, although one spouse caring for another is a very common situation.

Supporting a widowed parent involves a reconfiguration of both tasks and emotional support, and can be a very long-term process.

I support my 78-year-old mother who lives at home who is currently being assessed for psychiatric type care. She is having a few problems with memory, depression, loneliness – my father died 5 years ago and everything seems to be coming home to roost now. She lives in her own home and is desperately trying to stay there.

Care and support provided to friends and neighbours was also described, in a way which is recognised as different from family support, and may be reciprocal.

The people I /we keep an eye on live opposite us and their family does visit, but not every day and the man has heart problems. We keep an eye on their house night and day and their personal welfare, and make sure that they are O.K. each day but rarely go past their doorstep. They in turn keep an eye on our house and collect our mail should we go on holiday.

In addition to caring for her mother, Shona also helps some other neighbours who are elderly and have various levels of disability. She describes this neighbourly help as "Not caring so much as shopping, get cats out of trees – stuff like that". Another person expresses her care role as friendship based:

The care I undertake is on a friendship level only. I am a volunteer with (name of club), which is where I met Beth. I am there when she needs me, mostly on an emotional level as she gets very frustrated and upset. She is perfectly capable of looking after herself but cannot drive as she keeps having small strokes, about 7 or 8 in total.

Another group member describes her involvement as far more peripheral.

My husband has an elderly aunt and uncle who live in a residential care facility. I do shopping for them and visit. I'm not involved in the physical care. The aunt is 92 and still going strong, while the uncle has dementia. They

have no family of their own. I missed out on doing this sort of caring for my own parents because they were in the lower South Island and my brother's families did it.

Types of care

The self-administered questionnaire for working carers asked about four types of care (see Appendix 2). These were social and emotional support, personal care, administrative care and household assistance. The most common type of care provided by the respondents is social and emotional support, which involves activities such as checking on the older person by phone, visiting, taking them out, reading to them, writing letters, playing cards, etc. This is followed by household assistance, such as help with shopping, transport, laundry, preparing meals, gardening and household maintenance. Administrative support comes third in importance and includes assistance with completing forms and documentation, managing money, arranging assistance from agencies and may also include giving them money. Personal care is the least common form reported (although still by nearly half) and may involve help with dressing, washing, eating, taking medication, or assistance required with toileting. A variety of other types of support were cited, from being on call, managing hospital visits, liaison with other family members and health professionals.

Table 4 illustrates distinct differences in the types of care provided by the sex of the working carer (most analyses of the findings will be analysed by gender, given the importance of this variable in analysing patterns of eldercare). Women respondents are more likely than their male counterparts to provide all types of care, especially social and emotional support and personal care. A higher proportion of women provide the care on a frequent basis. For example, a similar proportion of male and female carers give administrative support, but 21 percent of the women involved gave this care daily or several times a week, as opposed to 8 percent of the men. A similar proportion of male and female carers gave household assistance, but 31 percent of the women involved gave this care daily or several times a week, as opposed to 16 percent of the men.

Table 4: Types of care provided, by gender of care giver and frequency

	<i>Gave care</i>			<i>Gave Frequent Care (daily or several times a week)</i>		
	<i>Male percent</i>	<i>Female percent</i>	<i>Total percent</i>	<i>Male percent</i>	<i>Female percent</i>	<i>Total percent</i>
Social and emotional	84	95	92	45	62	58
Household assistance	84	88	87	16	31	28
Administrative support	70	73	72	8	21	19
Personal	41	50	47	27	28	29

In summary, the most common pattern of care was the delivery of social or emotional support and household assistance on a weekly basis or more frequently. The patterns were similar between the Wellington and Christchurch except for a higher proportion of Wellington respondents providing personal care.

Social support

Some working carers commented that their parents' friendship networks, and hence sources of social support, were shrinking. One person commented that her mother now has no real friends.

"I suppose you get to that stage, of course, when everyone starts popping off. She really has... no other contact apart from my sister and myself, apart from church – someone from church comes in once a week, plus she has her home help, who comes in and showers her, and does the housework, but she really is a very lonely old lady."

"It gets very hard, I also have a daughter and a husband, and a couple of grandchildren. You are pulled both ways – sort of trying to fit everybody else in, and sort of trying to live your own life, yourself, with my husband."

Administrative support

In being reassessed for her disability allowance, one respondent said that her mother had to go back 2 years of power accounts. The power company then told her that her power bill was too high. "So Mum then turns off all the lights at night, doesn't put the heater on. Older people get frightened when they are told something like that – they tend to do what they are told. We need to stick up for older people."

Household assistance

Philip and his wife had themselves recently moved house to reduce their home maintenance and gardening duties, hoping to have a lifestyle more suited to spending time with their friends and in community activities, and find it difficult now to be coping with the consequences of his father's unwillingness to consider moving to a property with a smaller garden.

Living arrangements of the care recipients

Patterns of caring are illustrated in Figure 1, which adds the dimension of frequency of care provision as well as the living arrangement of the recipient. In this case frequent care is care provided either daily or several times a week.

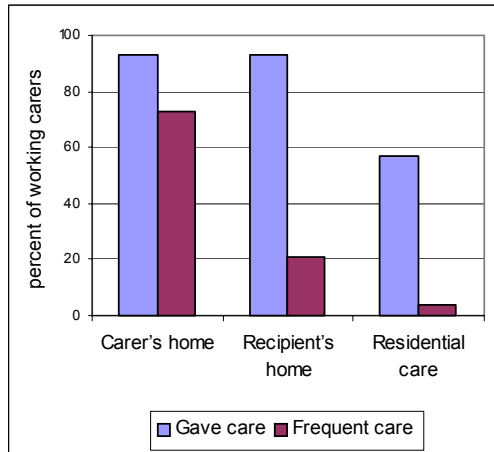
Social and emotional support is the most frequently given type of care, regardless of where the care recipient lives. Nearly half (47 percent) of carers provide this type of care daily to older persons living with them and a third provide it daily to older people living in their own homes. Where the older person is living in a rest home, social and emotional support is less likely to be provided daily, but 30 percent of carers still give it several times a week.

Over 90 percent of working carers give household assistance when the older person was living with them or in their own homes, but this falls to 57 percent when the recipients are in rest homes. Over half of carers give daily household assistance when

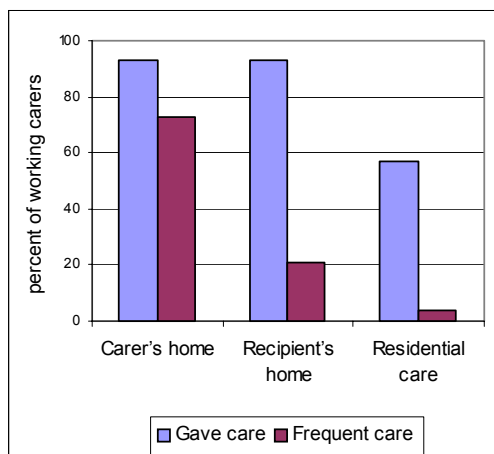
the older person is living with them. When the older person is living in their own home, a third of carers provide household assistance once a week. But household assistance for older persons living in rest homes is provided much less frequently.

Figure 1: Types of care and support provided, by living arrangement of recipient and frequency

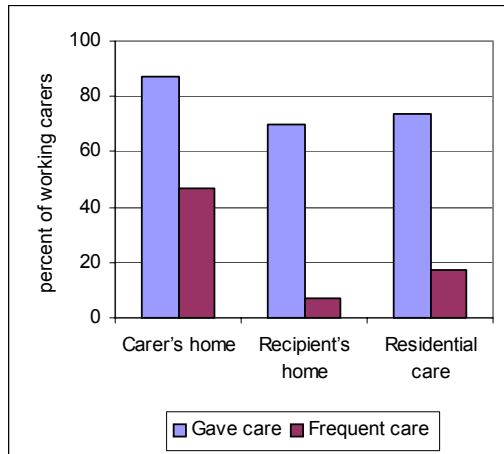
Social and emotional support



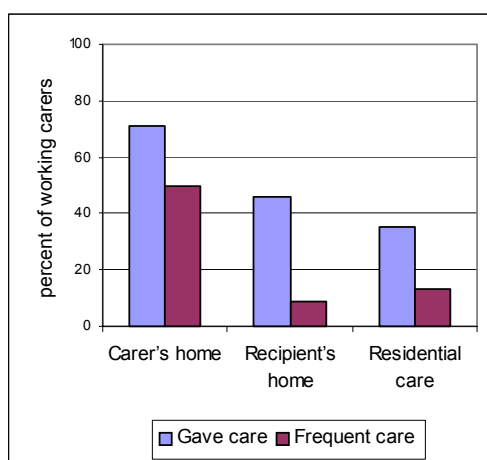
Household assistance



Administrative support



Personal care



The proportion of carers who give administrative help remains high regardless of the recipients' living arrangements, although the levels are highest where the recipient is resident with the carer. Most carers give administrative support fairly infrequently where the older people are living in rest homes or in their own homes.

Personal care is the type least likely to be provided, but is most common when the older person is living in the carer's home and least likely to be provided when the older person is in a rest home (along with household assistance and social and emotional support). Even so, 35 percent of carers said that they give personal assistance to recipients in rest homes. The level is, however, much lower when the older person lived in their own home (46 percent of carers providing personal care).

Co-resident care

Some people have found that sharing a household with an older family member offers a practical and appropriate solution, to an evolving need for care. Co-resident care takes several forms: sometimes the working carer moves in with a parent, or parents, at other times, the parent moves in with the working carer. Some families deliberately

choose a new house which suits both generations, others modify or renovate to suit changing family needs. Some arrangements are clearly temporary, while others have become long-term.

Shona took part in a discussion group: “It is better now that Mum is living with us. I still have to take time off for medical appointments and a lot of things I organise, I organise from work. Sometimes I have to work from home if mum is sick, particularly confused or upset with something... She has osteoporosis and dementia. She is still able to bath herself and dress herself, although gets confused with some articles of clothing. We provide the emotional support and companionship.”

Another person who shares a house with her mother, said: “ My Mum and I have been living together for 2 years now, my Dad died 2 years ago. I more or less do everything in the home, I do shopping, cooking - she doesn't drive; so I take her anywhere she wants to go. My Mum is fit and healthy for an 84 year old, and can look after herself when I am at work, but I wouldn't leave her overnight any more. I have a daughter who lives close by, who is very good at popping in if I am working long hours, or if Mum wanted to go to a specialist and I was working. I have one sister in Auckland - she has only been down once since Dad died, but will take her when I go on holiday next year”.

Caring for older people in their own homes

“Mum is very fit for her age and has none of the usual problems (e.g. memory loss, hearing trouble etc.) except arthritis. She is self-sufficient mostly – comes from a family of long lived (sister is 94). But she needs help around the house and garden and with some administrative matters – e.g. medical alert system.”

Caring for older people in rest homes

Many participants in the study made it very clear that the need for care does not cease when the older person enters residential care, and indeed that assisting with a move into a new care environment itself imposes particular demands on their time, requiring liaison and consultation around the family. As well as accepting that emotional needs remain a special concern for family members, several people also spoke of a lack of faith in professional carers.

In one discussion group, two women (Kim and Alice) talked about the care they provide to their mothers, both resident in hospital units within retirement villages. Kim's mother is 90 years old. She moved to her retirement village after an accident that resulted in a broken hip. Before that she had lived with Kim for 3 years. Kim visits daily after work, takes her laundry home and returns it the next evening. She has a brother, but he takes limited caring responsibility since he lives in Sydney. Kim's husband comes with her 4 nights out of 7, and also covers for her if she is unable to make it for some reason.

Alice's mother is 91 and lives in a retirement village. She has severe dementia, memory loss and depression. Alice visits about 3 times a week and takes turns with her sister, who is not employed. Her father used to live there as well, but he died earlier in the year. Her mother is very difficult to care for and was moved to the hospital wing in order to provide a higher level of care. Alice cut down her working hours to four days a week because she felt she needed some time for herself. She

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continues to find visiting and caregiving very difficult, even though she only visits for an hour or so.

Even though residential care does not remove the need for regular care from family and friends, group members were experiencing some relief from practical care requirements, when their older relative moved into a supported care setting. “I had to do much more before she moved into a retirement village. It is much easier and less time-consuming now.”

Intensity of care-giving

Around 90 percent of the working carers in the study were involved in long-term care of an older person or persons, defining this as over three months duration. Respondents had been providing care for varied periods, from under a year to over 10 years – roughly one third for less than two years, a third for 2 to 6 years and a third for over 6 years. These proportions were the same for men and women carers.

However, few provided very long periods of care per week – 52 percent provided three hours or less, 84 percent less than 10 hours, and only 10 people (8 percent), all of them women, provided more than 20 hours (Table 5). However, a time commitment of 10 or more hours per week is significant on top of a (usually) full-time job. Women carers are much more likely to be providing long hours of care than men. Most of the latter provide 3 hours or less.

Table 5: Hours of care provided per week, by gender of care giver

	<i>3 or less</i>	<i>4 to 10</i>	<i>11 to 20</i>	<i>over 20</i>	<i>Total</i>
Male percent	64	26	10	0	100
Female percent	48	34	7	11	100
Total percent	52	32	8	8	100

Apparently, Christchurch carers are on average providing longer hours of care than Wellington carers, with 55 percent giving more than three hours of care, as against 39 percent in Wellington. However, the age of the care recipient does not appear to be related to the number of hours of care given.

The distances between the homes of the carers and those of the care recipients were measured in minutes of travel. Up to 15 minutes is considered local – where carers could “pop over” frequently – and 71 percent of carers lived at this distance (excluding respondents who cared for an older person living with them). Where travel took from quarter of an hour to an hour, a visit is likely to require well over an hour in total – not something which could be done on the way to work – and 15 percent of carers lived at this distance, making 86 percent living within an hour’s travel. Where the journey took over an hour, a visit would require at least half a day and probably more. Sixteen working carers (14 percent) live at this distance from the older person(s) they are providing care for. The patterns are similar for distance from the

carers' workplaces and the discussion here is confined to distances from the carers' homes to the recipients' homes.

Caring at a distance

Beatrice cares for her parents, who live 5 hours drive away. Her father had a stroke and is paralysed on one side, has problems with speech and comprehension as well as arthritis. Her mother is diabetic, has heart problems and recently had shingles. Beatrice visits frequently to give support, as her 3 brothers live even further away (two are in Australia) and her sister lives on a farm and has six children.

Andrea cares for her parents, who live 4 hours drive away. Her father is currently in intensive care with chronic heart disease, and diabetes. He has had about 7 strokes in the last 2 years and his memory is getting worse. Her mother had 5 strokes in the last eighteen months, and has heart problems as well, but still looks after her husband (helps with medication etc). Andrea goes up there at least once a month mostly using annual leave, to look after her mother, and does the big things around the house. Her brother, helps out regularly, but doesn't appear to cope with the situation as well as Andrea does.

"My parents have chosen to live in a distant town where there is little support for them. The care I provide is long distance, but I am the closest family member and bear the onus of their care".

"My Dad passed away 3 years ago and Mum always depended on him. She misses him, can't drive and won't leave the house. They live in an area where (there is) no support from local neighbourhood. Gets strangers coming around and knocking on the door. I spent the last 2 weekends up there doing the gardening and cleaning. Have tried to get her down here with us. She's getting a bit forgetful, writing everything down now. We pre-do the meals so she can just defrost them".

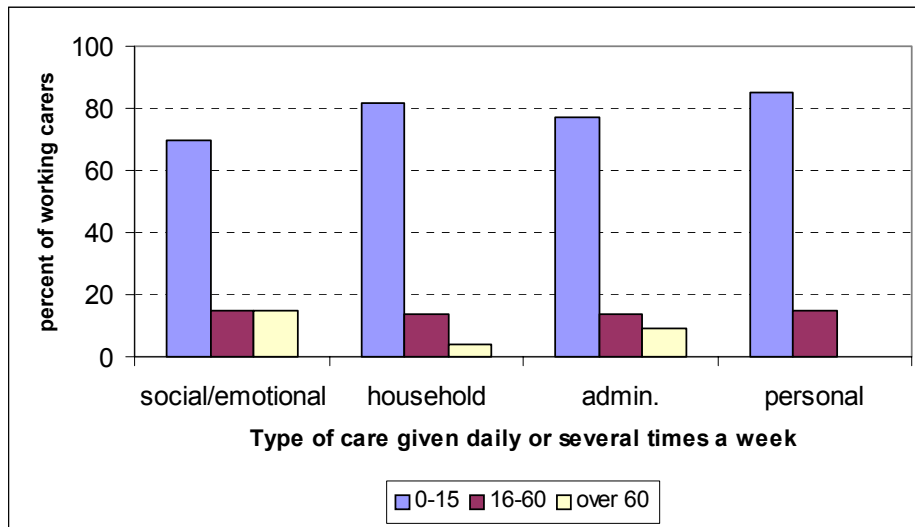
For one respondent, the pressures of caring at a distance are the reason for not being part of the study: "I don't have time to participate in this. I'm sorry as I have another job and a child to care for. My parents live in the country so I try to do all I can during the weekends."

Wellington respondents are more likely to be providing care over a distance than their Christchurch counterparts – 18 percent, as against 9 percent in Christchurch, have to travel for over an hour. This difference was also evident in the group discussions. Wellington group members talked about managing care of elders who live in Rotorua, and New Plymouth, as well as in the Kapiti Coast and Wairarapa regions. One person wrote at the end of her questionnaire -

Many Wellington people have family out of Wellington - we are a 'community' from other communities unlike other towns/cities where families can be generational. Hence when a family member becomes sick it is a distance issue. From my perspective many Wellington carers need not the flexibility to care, but the assistance and resources to arrange assistance etc. so we don't have to spend so much time finding assistance/resources that are local to our family member – i.e. a centralised resource.

As a general rule the frequency of all types of care provided was reduced in line with increasing distance between the working carers and recipients (Figure 2). However, 15 out of 134 working carers provide social and emotional care to recipients who live over an hour away and 12 live at this distance and give care daily or several times a week. Household assistance is less likely to be given frequently overall and where this type of care is provided for distant recipients it generally occurs less than once a month. The pattern is similar for administrative support. Ten carers who live more than an hour away from the recipients provide administrative support, but only 4 of these provide the support more frequently than once a month.

Figure 2: Frequent care provided by type of care and distance (in minutes of travel) between carers' and recipients' homes



Fewer carers offer personal care, generally on a less frequent basis than for social and emotional care. People giving personal care generally lived close to the recipient – only 6 are over an hour away and 5 of these provided this care only once a month or less frequently. This last statement is also true for administrative support and household support.

Assistance with eldercare

Three quarters of the working carers in the survey, both men and women, say they have help with eldercare. The proportion is high regardless of how many hours per week they provide care. In terms of responsibility, however, only 21 percent say that this is shared. About equal numbers said yes or no when asked if they had the main responsibility, but this varies between men and women – 41 percent of the women say that they have the main responsibility, as against 30 percent of the men. There are no differences in the sharing of care which relate to the gender of the recipient.

Sharing of care, especially between siblings – usually the adult children of the care recipients – is a topic which can give rise to considerable tension and resentment and was a prominent topic in the group discussions. Within families, while there might not

be conflict over the provision of care in principle, there can be conflicting demands, several differing perspectives, and sometimes difficult choices. Uneven sharing between siblings is regularly described, and perceptions of unequal load bearing are often expressed. Others acknowledged that they are currently in more of a secondary care role: “My mother is the main carer (for the respondent’s grandparents) and she finds it extremely hard going. My sister and I help out as we can and when Mum and Dad are unable.” Siblings may have different understandings and perceptions of the situation, they may have very different personal, work or domestic commitments, and their historical role and place in familial interactions can be clearly differentiated.

In other instances, inequality is accepted as being based on location or conflicting responsibilities. Diane, in a Wellington group, spoke of how she has 3 sisters, none of whom assist with caring for their mother who has multiple health problems and was recently injured in a car accident. She explained “one lives in Australia, another has no contact with family, and the third one has children and a sick husband to care for.” Being the family member who is “on the spot” poses difficulties. One respondent wonders how more distant relatives perceive her role: “An additional stress area is working with/caring for someone who has relatives outside of Wellington – do they approve of what I’m doing? Are you going too far in what you do?” Even for those from larger families, one person may develop a primary caring role, as in the following cases.

Sharing care

“I am one of 7 children still living, 4 of us in town. And the care is very much shared, but because I lived with Mum for so long, it is me that knows what to do, and me that my brothers and sister turn to when the going gets a bit tough – cos I think there’s a belief that if we need to persuade Mum to do something, I will get that done”.

“We have stopped having family meetings now. They just got really fraught and I used to get angry. As time goes you do see that they [my brothers] do care as well, but they just cope differently. We will review everything at Xmas when everyone is there”.

“Mum is a very good faker. Unless you actually live with her for a period of time you don’t get an idea that it is as bad as it is. Trying to persuade other members of the family who only see the surface that in fact things are much worse than they seem and you are not just being a doom merchant.....”.

“I know [my brothers] have real trouble with being comfortable talking about dementia”.

“My sister and I have shared care of our mother. Mum has dementia, congestive heart failure, diabetes and other various systemic problems. I am in the support role rather than primary care role at the moment, but I also principal support for a close friend whose husband is in advanced stages of Parkinson’s. She is an immensely capable woman who is not perceived as having any needs, but she needs someone she can dump on and can step in and just take over. So my role is that I am not actively caring for anyone at the moment but am doing two support roles.”

“I find being the ‘responsible’ one of the children a wee bit of a strain – I have become the one who is asked for advice and is called on for support even though my siblings live close by.”

“My father-in-law is still very strong and healthy, despite his age and we receive a lot of relief through siblings who are always keen to pay for him to join them in other parts of the country and world. His grandchildren also adore him”.

One Wellington group discussed the complex family dynamics which all participants were aware of, and which discussion of work and care had prompted. One participant asked “Would your mother ask your brothers to go and put a picture on the wall when the real reason is that she wants them there?” Another group member agreed, that asking for help in order to get company, was common in her family as well, and can have mixed consequences.

[Mum] will ring them up for anything tiny. If they get wind of it, they quite often won’t answer the phone – they just won’t come. It’s terrible really because one day she will have already cried wolf and she really needs some help. If they see her car there or see any sign of movement, they won’t go around – and their wives get really ticked off with her as well. So there is a dynamic there that they feel duty bound to their wife but they can’t go and help as much as they would like to. It’s real vicious stuff.

Formal care received by older people

The most common type of non-family assistance with eldercare, as reported by the working carers, is from general practitioners and other specialist doctors, both generally provided outside the home (and requiring transport to reach them). Less than a quarter used other health professionals such as nurses, occupational therapists and physiotherapists, who may either come to the home or operate elsewhere. The most common type of in-home assistance is for gardening and household work. Other types of assistance used included voluntary organisations (Age Concern, Blind Foundation) and other types of medical help (overseas specialists, optometrists, private hospital). As shown in Table 6, there are similarities between the types of services providing care for older men and women recipients. While men tend to use nursing services and specialist care more frequently, both groups use GP services equally. Men tend to use occupational or physiotherapists more than women.

Table 6: Formal services used, by gender of care recipients

	<i>Percent of men recipients</i>	<i>Percent of women recipients</i>	<i>Percent of carers satisfied with the service</i>
<i>Mostly outside the home</i>			
General practitioner	59	59	90
Hospital doctor/specialist	68	49	83
District or other nurse	30	23	90
Occupational/Physio- therapist	35	19	90
Day care	5	9	89
<i>In-home services</i>			
Home care	14	19	74
Private home care	16	11	100
Meals on wheels	11	12	85
Gardening	30	24	90

Levels of satisfaction with these services are high, but lowest for home care workers, other than those engaged privately. These are the perceptions of the working informal carers rather than the older recipients of the services. The use of services in the older persons' homes has the potential to reduce the demands and hence the stress placed on working carers, but only, of course, if the older people find "outside" help acceptable. Many are reported to prefer help provided by their adult children or other relatives, as in Philip's case. Philip looks after both his parents. His father has had a series of strokes involving hospital admissions, in the past year.

A nurse comes in to shower Mum, and Dad should have a nurse coming to shower him, but he's too independent, and won't allow a nurse to do this – he's very independent. The family have been at him about it.

There was considerable discussion in the group sessions about decisions made by formal carers which may increase stress on carers, such as inconvenient scheduling of appointments, cancellation of appointments, early discharge from hospital, or lack of communication with services such as meals on wheels or home care. Relationships with the older person's doctor – both general practitioners and specialists were a topic of particular discussion.

Communication between us (as carers) and health care providers (e.g. doctors, hospital etc) can at times be difficult as we don't always get the information we need ahead of time and my mother-in-law's memory is so bad that she can't communicate the facts to us.

Several people feel that their elderly parents have been treated in a somewhat "high-handed" way by parts of the health system, which seem to them to have a very limited appreciation of the difficulties older people have in finding their way through the "labyrinth of a health system". Carers find they are excluded from access to information about their parent's health condition, yet they are the ones expected to be responsible for medications and managing care at home. "We go through so much rigmarole. The whole health system is difficult to deal with".

There was discussion around the quality of health services, although these commonly involved situations where coordination had been inadequate and carers had been left filling in gaps in communication. One group member said she had made a formal complaint after her family felt that care and communication had been substandard. Carers whose relatives are now in long-term residential or hospital care also raise some quality concerns, seeing themselves as advocates. They feel that the older person needs “quality time”, but acknowledge that care staff are often unable to provide this for residents. This helps to explain the continuing provision of care to older people even when they are in residential care. A woman in one of the Wellington groups felt that she needed to check every day on the quality of care being provided to her mother.

Community support was acknowledged by a Wellington group member caring for two older people who live well outside the city.

I’m a bit lucky – if I sense meltdown in (either situation), I have links into the community up there. There are people that I can ring and various people will materialise and look after [Mum] for the afternoon. My situation is easier because I have good community support – predominantly through the church.

Other carers also mention church groups as being supportive, but declining church membership is also noted, just as the loss of the older person’s friends through death reduces the chances of combating isolation through companionship while family members are at work.

Mum has been a churchgoer for years and years. Now where are they? They used to visit regularly and give some sort of comfort. Even if they came for a day – it would be a day you didn’t need to do it. Those services that used to be there aren’t there anymore.

Giving back

The giving of care and support is not always one-way. There may be a strong element of mutuality or reciprocity, whereby the older people can, in their turn, assist their carers. This may allow them to feel less passive and dependent and is part of intergenerational relationships within families. Giving back can represent delayed reciprocity.

They gave us a huge amount of support. They were our main babysitters for our children and they were the ones that parted with cash for us when we had difficulty –my husband does casual work, so our income is either very good, or just what I bring in.

Limited opportunities for reciprocity are acknowledged. “I provide care for my father and his wife as they would do this for me were they able”. Family support continues to be two-way in some cases, and several people talked about the kind of support that elders continue to give to others within the family. This can take several forms.

I still have a meal with them each week – and I’m still debating in whose best interest that is, actually! Sometimes I think it is Mum still being a mother – my

partner commutes, so I think it is Mum having me round and making sure I am getting one good meal, a square meal as she would term it - always a mother So that's quite delightful, but yes, it certainly has evolved.

Information on care and support provided to the working carers by the care recipients (as recorded by the working carers) was collected in the self-administered questionnaire (see Appendix II). Such support is much less likely to be reported than care given to the older people, but the ranking of types of support is the same – social/emotional (reported by 48 percent of the working carers), household assistance (25 percent), administrative support (20 percent), and personal care (14 percent). “Other” types of assistance (6 percent) from the older people are varied, but in several cases take the form of giving (or paying for) meals or other food. Where care from the care recipient to the working carer is provided, it is mostly in a comparatively infrequent basis – mostly once a month or less - except for social and emotional support. Men are as likely to provide reciprocal support for their carers as women. “Giving back” care and support tends to decrease with the age of the older person, again except for emotional support, which is provided by about half of the older people to their carers, even by people in their eighties.

Another aspect of reciprocity derives from the behaviour of the care recipients, who sometimes appear to make the situation even more difficult for working carers. Several respondents identified with the following situations.

We work quite well as a family, but Dad has a very short temper, impatience, and occasionally, when he's trying to do business, he can give them both barrels, when he shouldn't So I have to go and smooth things over and sort things out a bit – that's where he is likely to lose control of his patience....

Gaye explained how her brothers limit the support they give their mother, based on personality factors.

They have young families and their own businesses. They can go and do something for Mum that takes 10 minutes but she wants much much longer. In a way she alienates herself and they don't want to come over as much and I think I have a bigger tolerance factor in terms of patience. Also I don't have a young family, although I do have grandchildren of my own which [Mum] encroaches on. I can't have them together because it is too stressful for her and too stressful for me to have them in the same house together.

Some discussion group members feel that the people they care for do not appreciate what is entailed in combining care with multiple other commitments to work, family and community. But for others their efforts are recognised. “I know that whatever I do Mum appreciates it”. A further respondent justified her caring work in several ways, bringing in further intergenerational effects. “I feel it is my turn. What I do is only little things”. While she feels in some ways, she is “storing up treasure in heaven”, she considers it is good to expose her children to this type of caring, so that they understand the “duty of care moves on”.

Chapter 4 The Effect of Caring on Work

4.1 Balancing Work and Care

Working carers report that their employers and colleagues in the two city councils are generally supportive of their situation, although most people are conscious that their workload builds up if they are away from work unexpectedly. Work colleagues and managers generally know about their caregiving situation, and also acknowledge that some situations involve less predictability than childcare responsibilities. As Beatrice says, "To be a working parent is something you plan, and you know you have to take certain things into account, but to be a working carer is not something you planned".

Balancing work and eldercare

Kim has a very demanding job, so "I can't take time off during the day, but my employer is very understanding and caring. The problem is more that a lot of time is spent with the elderly person or travelling, which you don't have for yourself".

Nina said she manages to catch up after taking time off from work to care for her mother, by accepting "I just had to do it other times. My boss is very understanding, but work doesn't just go away - it still has to be done so I worked at the weekend. One problem was that I couldn't be there for my staff, in the end it depends on what kind of role you play in the organization".

Alice explained that "I came to the council at an older part of my life, but I dealt with that problem by cutting my hours back so I can have that one morning with my mother. My boss has been fantastic, so no major problems from the employers' side".

Time pressure, and trying to squeeze segments of care into a working day, also cause several people particular strain: "Often you will get up there to pay Mum a visit and she is upset or depressed about something. Dealing with the depression is quite difficult. You cheer them up and think I've got to go back to work in 10 minutes. You have a limited timeframe".

Although there was general support in the workplace, some working carers were well aware of a pressure for efficiency and productivity in a strictly commercial sense. As Helen said:

There is a perception of the commercial model where there is no room for the frills around the edges. You are driven by those very commercial outlooks in terms of having to be efficient. The restructuring tends to still be in one direction – in terms of job retrenchment and staff rearrangements. There is still an ethos of having to work harder and smarter, with no room for the soft stuff.

Another discussion group member said that having a boss with apparently no family responsibilities "sets the benchmark. The reality is nothing like that." One or two people mention a lack of understanding on the part of younger colleagues and managers, and that eldercare could at times be a conversation-stopper in the tea room. Workplaces where there is a predominance of younger staff may be more understanding of issues with children and partners, than with elders.

Flexible working arrangements are clearly important, and most working carers in the discussion groups speak very positively about good relations within their immediate work setting to facilitate this. But they acknowledge that some units and work areas are better able than others to deal with flexibility at short notice. Although Shona now has her mother living at home with her, she needs her evenings to catch up on work she might have missed during the day:

I can't do too many night meetings. It's the time off that affects me. Sometimes I take domestic leave or sick leave, other times I just tell my manager that I need to work from home. The reality is that sometimes I don't do much work but I have my own [internet] access so I catch up at night. It's juggling work around Mum that is difficult.

Both the group discussions and the self-administered questionnaire discussed how people cope with the time demands of eldercare. Several people mention taking annual leave or domestic leave at times of particular need, when flexibility and alternative arrangements cannot be made. Some groups discussed their understandings of eligibility for various types of leave – whether, for example, domestic leave is available only if the person they care for lives with them. Others were unclear whether this was a decision made at their unit level, or more centrally at council-wide level. They are concerned about using up available leave when they might need it for a crisis later. Some people say that being unable to arrange alternative care means that they have been unable to have a “proper” holiday for some time, which impacts on their own energy and, ultimately, their health and productivity. “I do lots of travelling back and forth – I have no time for my own home – I get really tired”.

Leave Provisions in the City Councils

In fact there is variation in leave arrangements - between the councils, between units within the councils and depending on the type of employment agreement which applies in each worker's case. The following information was provided by Human Resource staff at the WCC and CCC.

Annual leave is generally 3-4 weeks per annum depending on length of service.

Sick leave is usually expected to relate to sickness affecting the employee themselves and subject to certification by a doctor. Detailed provisions vary but in Christchurch employees can take a proportion of their annual sick leave entitlement in the case of illness of a “direct dependant”. In Wellington this is covered by domestic leave.

Domestic Leave is part of WCC employment provisions and allows 5 paid leave days per year to employees to care for a dependent member of their household during illness. Under the Holidays Act 2003, this will be extended to any person who depends on an employee for care. Domestic leave will also be accruable for up to four years – giving a total of 20 days. In Christchurch care for a dependent in the same household or in another, is covered by the sick leave provisions, again under the provisions of the 2003 Act.

Leave in lieu, in Wellington, is available for employees who work on public holidays and in Christchurch it can be used by prior arrangement where employees work additional hours. This should normally be taken by mutual agreement with the unit manager.

Leave without pay. Wellington business unit managers have the discretion to approve up to 5 days leave per annum, with or without pay, to meet special circumstances, which may include family or personal emergencies when other leave has been exhausted.

Alternative working arrangements may be agreed between managers and workers on a flexible basis in both Wellington and Christchurch.

In practice, unit managers and team leaders have some discretion in allowing leave for caring and in crisis situations. Specific provisions for leave associated with eldercare are not generally specified and there is some uncertainty about what types of caring work would be covered, for example whether the care recipient should be within the same household of the employee, and the degree of relationship.

As shown in Table 7, the most common way of coping with eldercare reported during the six months prior to the survey was to take annual leave, followed by time in lieu/flexitime, sick leave and domestic leave. Very few respondents took leave without pay. The majority had provided some care during work time, if only to make telephone calls. Almost half had asked other family members to provide care but very few had arranged paid care.

Table 7: Methods of coping with eldercare, frequency of use (percent of working carers)

	<i>Never</i>	<i>Once</i>	<i>More than Once</i>	<i>Total</i>
Leave from work				
Taken leave without pay	91	2	7	100
Taken domestic leave	78	10	12	100
Taken sick leave	73	15	12	100
Taken time in lieu, or worked flexitime in consultation with supervisor/colleagues	69	11	20	100
Taken annual leave	52	20	28	100
Other methods				
Paid someone else to provide care	94	1	5	100
Arranged with another family member to provide the care	52	12	36	100
Made phone calls or provided care yourself in work time	37	9	54	100

Using the phone to assist eldercare

Participants in the discussion groups often mention the benefits of being able to use the telephone at work, to make arrangements and appointments, to check up on their family member, and to reassure themselves and others that care was at hand. “I spend a lot of time on the phone making sure she is all right”. However, the phone call can also be a source of anxiety, as another group member said. “Sometimes Mum leaves the phone off the hook, so I spend the whole day worrying.”

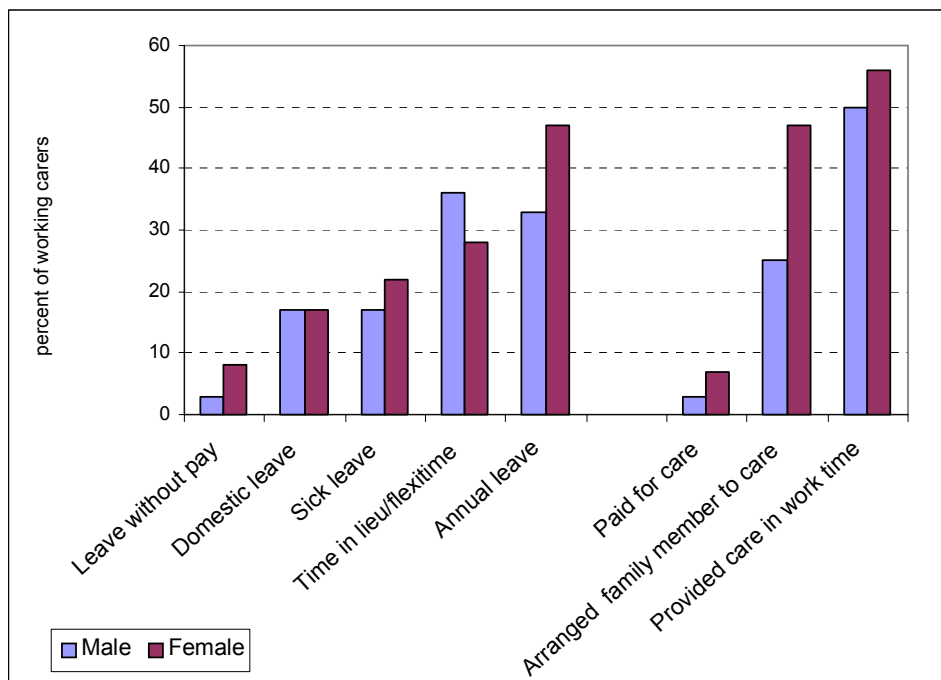
Some ambivalence is also expressed about telephone use, around privacy and guilt relating to costs and time spent, and about disturbing others’ working environments. One participant was very embarrassed, having to shout over the phone to her deaf father.

“The other thing I find is using the telephone. I am very conscious of making a toll call to ... or Mum calls me and I might be quite a long time on the telephone. It’s demanding in that way – nobody has said anything about the phone calls but I am conscious that I am making them. I would like to make more but I can’t”.

In response, another group member says: “I have the same issue with Mum living in I’ll make the odd toll call but then I will use my cell phone because I really don’t think I should”.

Some carers feel that being too readily accessible by phone can mean that they become embroiled in matters which to them are trivial and need not interfere with their work commitments, which could be left to a time when they are not at work.

Figure 3: Methods of coping with eldercare by gender of working carer



There are clear differences between the methods adopted by men and women working carers (Figure 3). Women are more likely to use annual leave, sick leave and leave without pay than men, but men are more likely to take leave in lieu or use flexitime. Women are also much more likely than men to arrange other family members to provide the care which they themselves would usually give. However there is no difference in the proportion who take domestic leave and a high proportion of both men and women carers have provided care (or made phone calls) in working time.

Arranging time off for health and professional appointments is mentioned as a tangible benefit of workplace flexibility. Some people use annual leave for these appointments: “I use my annual leave if I need to take Mum to the specialist because it is always during working hours, and my brother has to take annual leave from his job too. We have turns at doing that”.

It would be really good if you could specify appointment times so you could get there at the beginning or the end of your working day. If you have an appointment at 1 pm you have to get from work to home, to the appointment and back home again.

A further question asked about crisis situations, such as illness or accidents, which the care recipients might have experienced in the last six months. Sixty-three percent of respondents had had to deal with one crisis, 36 percent with more than one crisis, and 10 people had dealt with four or more. More than one in three respondents report having had some time off work to deal with crises; 29 percent had more than a full day off and 22 percent more than two days, with a maximum reported of 40 days. All those who took more than a week off work had had more than one crisis in the six-month period. Table 8 summarises the most common situations.

Figure 4 shows that women working carers are more likely to take time off work in a crisis than their men counterparts, and more likely to have had more than a week off work in the previous six months.

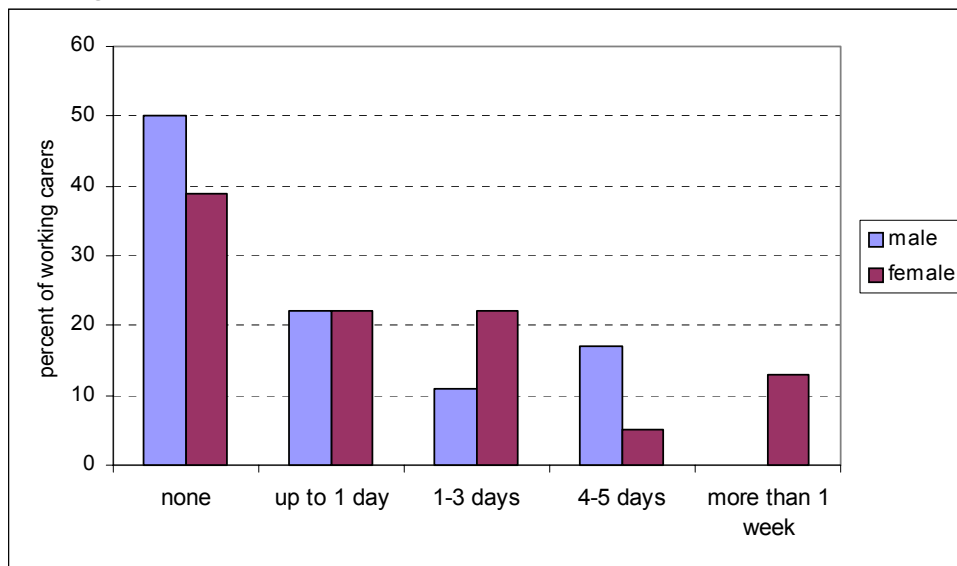
Table 8: Impact of eldercare crisis

	<i>Number of working carers</i>	<i>Percent of those who had a crisis</i>	<i>Percent of total respondents</i>
Had crisis, no time taken off work	35	42	26
Had crisis took up to 3 days off work	34	41	25
Had crisis, took more than 3 days off	14	17	13
Total who experienced a crisis	83	100	62

The type of disability suffered by the care recipient did not seem to affect whether or not the carer took time off work, but crises concerning a person with a cognitive disability seemed to lead to longer periods of time off work. Where the recipient had physical disabilities only, 6 percent of carers took more than a week off work; where the recipient had cognitive difficulties (with or without physical problems as well), 18 percent of carers took more than a week off. The older the care recipient the more likely it is that time off work has been taken by the carer. Where the recipient is under age 75, 47 percent of their carers took time off, this rose to 58 percent where the

recipient is aged 75 to 84 and 65 percent when they are 85 plus. However, there was no clear trend with the age of the recipient in the amount of time taken off.

Figure 4: Time taken off work in an eldercare crisis, by gender of working carer



Respondents appear more likely to take time off work if the older people they care for are living in their own home or in a rest home than living with the carer (Table 9). Older people who live with their carers may have a crisis situation averted or can rely on other family members to help. Older persons living in some form of residential care are more likely to have others who are able to intervene in a crisis situation. Out of 14 who were caring for people in residential care 12 took 3 days or fewer off.

Table 9: Time off work in a crisis, by location of care recipient (percent of working carers)

	<i>None taken</i>	<i>Up to 3 days</i>	<i>More than 3 days</i>	<i>Total</i>	<i>Number of working carers</i>
Living in carer's house	64	9	27	100	11
Living in own house	40	45	16	100	58
Living in rest home	36	49	14	100	14
Total	42	40	17	100	83

4.2 Strategies and Options

The self-administered questionnaire presented respondents with a range of strategies which could help in managing eldercare and paid work, asking if they had considered or used them in the previous six months. Strategies related to paid work, such as reducing work commitments or finding a job closer to the care recipient, were not highly ranked (Table 10). Two out of every three working carers had, however,

discussed care arrangements with family members and 43 percent had sought information about services.

The overall rankings of eldercare strategies were fairly similar between men and women, except that women were more likely to have put money aside and men were more likely to have looked for long term care options. Making sure the older person's affairs were in order and discussing care arrangements with other family members were the options most often cited by men and women although women were much more likely to have adopted the latter strategy, in line with their greater likelihood of calling upon family members to assist with care (see Table 10).

Table 10: Strategies for managing eldercare, by gender of working carers

	<i>Male percent</i>	<i>Female percent</i>	<i>Total percent</i>
Discussed care arrangements with other family members	53	72	66
Made sure that older person's affairs were in order	69	65	65
Sought information about community services for seniors	42	45	43
Modifying older person's home to make care provision easier	25	30	28
Looked into places that provide long term care	28	20	22
Put money aside to help meet older person's needs	11	21	18
Finding ways for you and the person(s) you care for to live closer to each other	11	20	17
Considered reducing your work commitments to meet increasing care and support needs.	8	16	13
Looked for a job that was closer to where they live	11	10	10

Coping strategies – examples from group discussions

- *Bringing the care recipients closer to the carers*

Several discussion group members referred to recent changes in residential arrangements made to address eldercare issues. Ingrid said she provides care to her mother aged 83, and her father, who is nearly 80. Four years ago her parents shifted from a small village and moved back into the city, where they had had their early married life, and bought the house next door to Ingrid. They had pooled family resources to do that, because they saw it as a next logical way for Ingrid to combine full-time work with looking out for them. Neither of the parents drives, having given up driving since they moved to the city. Ingrid describes her parents as very independent, and says they seek her moral support more than anything, and her company.

- *Changing work hours and sharing care*

“My wife is the main caregiver (used to give about 8 hours a week). She has restricted her hours to try to look after her Mum. When our children developed illness as well and the rest home would not take mother-in-law back because of risk of her doing runners all the time, we shifted her up to a secure rest home with support from brother/sister in law who live in Auckland.”

Part time workers made particular mention of the flexibility this gives them, to handle both work and care with less strain. “I am much more in the background, but if necessary would negotiate time off. My boss is good like that. Because I don’t work on Mondays, I have time to catch up hours in arrears. It is great having a ‘day up my sleeve’ so that I can go and visit”.

- *Considering alternative living arrangements for the older person*

“We as a family have recently shifted Mum into a smaller place – I have a financial interest in that place, to enable Mum to have a type of house that will suit her, so I have assisted her in that way. I spend some time each week with her. ... Otherwise most things she does herself, apart from where decisions have to be made – we make those in consultation”.

There can be differences of opinion within families about whether admission to residential care is the best option, and for whom. Several people emphasised that their parents made their own views very clear in this respect, and accepted their parent’s clearly expressed wish to be supported in their own home, even when this raised the level of care needed from family.

The working carers in this study show multiple responses to the prospect and experience of change in their caregiving situation. Some say they are waiting for the next crisis, some are making deliberate plans, some are responding to gradual change, others are anticipating and discussing change with the older people they are caring for, and within their family circles.

Considering the future

“I think something terrible will happen that will make us move on to the next step”.

“We are thinking about it – yes. Even she is giving it some thought. We haven’t gone into it that far down the track. She is terribly worried that we will stick her in a home”.

“Mum is well aware of the situation because she had her mother living with her for a while before going into full time care”.

“Mum is very comfortable at home and doesn’t want to move. She has a pool and swims every day, even in the winter. If she moves it has to have a pool – she’s been like that all her life. She wouldn’t be happy at moving, it would be detrimental to her. It will eventually not be a matter of choice but a matter of having to”.

“She could die any day. Most of her systems have largely given up. My mother’s situation will resolve itself fairly shortly – she has been in care for quite a while”.

“It’s just this transitional stage, and not knowing how it will evolve. Do we have to sell the house? We are an immigrant family and don’t have any other family that have been in this situation. We are a bit at a loss as to know where to go from here”.

“Mum wants us to buy her home because it has been the family home and she is really keen to keep it in the family”.

“Just last night, Mum sort of confronted me, and said - even though at this present time, she is able to be left on her own ... ‘what’s going to happen to me when I can’t be left on my own?’ and I said, ‘Mum I am not going to think about that at the moment’”.

“These issues are going to get bigger and bigger”.

While planning for change might be ideal, it is clear that some changes are unpredictable in terms of the demands they generate for care and support, and who might be in a position to meet them. Change in caregiving patterns itself has the potential to cause tiredness and stress, and clearly affects carers’ other relationships, social life, work context and roles, as well as personal choices.

Several discussion group members are in the middle of a situation which they describe as a state of flux: Kate’s mother had been needing significant support since she was widowed three years ago, then during 2003, she “suddenly went into hospital and since she came out of hospital, we’ve actually moved into her home, and we are giving her care ... we’ve not yet decided on what her long term care will be, taking it day by day at the present”.

Others described the extent to which issues impinging on to their work and eldercare situation had been discussed or planned within their families: “No planning, just evolved as it went along. I mean, Dad died about five years ago. Just the way it’s happened”. One respondent talked about her mother’s recent decision to move house: “that was quite a deliberate move, but that was her wish – we sat and talked about whether she would move into (a retirement village) scenario – mum didn’t want a bar of that.” Reluctance on the part of the older people to express their wishes clearly and to make well-informed choices was frequently noted.

A very strong theme in the group discussions was access to relevant and accurate information on eldercare services and how to manage work and care. The participants feel a clear need for a consolidated source of information, and discussed whether this should be web-based or telephone based.

I’ve looked at a whole lot of different web sites. In terms of care of the elderly and all the types of services available, I haven’t found a website where it is all on. It seems they are a bit behind putting it all on one site. With elder health care it doesn’t seem to be there, or I haven’t found it. Maybe they make an assumption that older people don’t look it up themselves.

Some health professionals were described as “not forthcoming” and this further adds to stress on carers. “It is terribly hard to find out about government services and support – and I work in a public library!”

Access to information

“Not having time to access information is an issue for me. It would be useful if the GP/hospital had an information pack for carers on where they can get assistance and what facilities are available, so one didn’t have to go hunting for this information. One can’t sit on the phone for hours tracking down services, so life is possibly harder

than it needs to be simply because one doesn't know what's available to assist one, and how to access that help".

"Just put it all together on a website and get providers to link to it – because then you can do the research at night – you don't have to ring up during the day".

"It would be really nice to pick up the phone and say I don't know what to do, I am stuck with this problem, where do I go from here?"

4.3 Attitudes towards caring

The majority of respondents say that they provide eldercare gladly, both men and women, although over half acknowledge that there are both positive and negative aspects to it. More women than men mention the negative aspects (Table 11). Only a third say there are no major problems – rather more men than women. However, only one in four agree it is difficult combining work with care. Finance does not seem to be a problem for many. Given the generally high educational levels of the respondents, many are likely to be in the higher income ranges. Shona, who has her mother living with her, gave an example in which information and logistics were more of a problem than finance.

We have renovated. At the moment I am trying to get railings (to improve safety for the older person) but don't know who to ask. It's just as easy for us to do it in the long run. Mum has probably got too much money – she doesn't have a community services card. So she will continue to help. If she gets much more confused, and we are probably getting close to that point now, I can do the day care thing which in way would be a relief. It's just like dropping her off at day care and bring her back, even for a couple of days a week. If it gets to the point where she can't do even day care. I can't stop work, but my husband can (Shona can earn more than her husband).

In order to summarise feelings towards eldercare, the data have been grouped to reflect positive, neutral or negative feelings derived from the dominant theme of each respondent's answers. As shown in Table 11, women carers are less likely to have positive attitudes than men.

Table 11: Attitudes towards eldercare, by gender of working carers

	<i>Male percent</i>	<i>Female percent</i>	<i>Total percent</i>
Positive attitudes	62	47	51
I do it gladly	68	60	62
I don't think there are any major problems	41	32	35
It can be deeply satisfying	21	27	25
Neutral attitudes	19	20	20
It varies, sometime fine, other times very depressing	49	58	55
I have to do it no one else will	16	22	20
Negative attitudes	19	33	29
It is difficult combining work with caring	22	28	26
It strains relationships with others I am close to	14	22	19
It can be extremely stressful	11	21	18
I worry that I am not able to do the things I want to do	11	20	17
Financially it is difficult	8	10	10

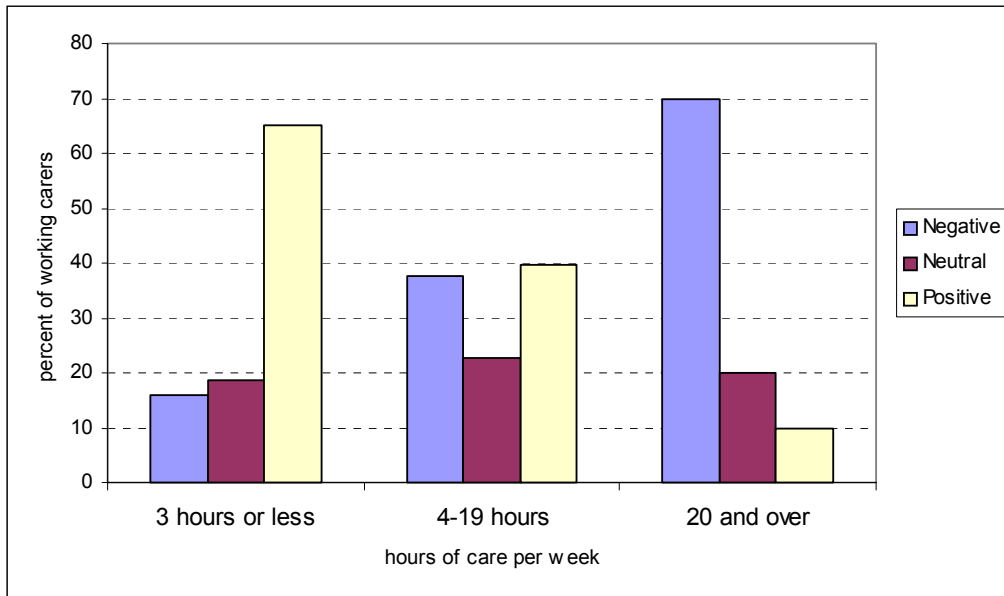
There are some interesting differences between the Wellington and Christchurch respondents. Those in Christchurch are more likely to say that they did caring gladly (Christchurch 69 percent agree, Wellington 55 percent), that caring is satisfying (Christchurch 33 percent agree, Wellington 19 percent) and that there are no major problems (Christchurch 45 percent agree, Wellington 26 percent)– all positive feelings. Those in Wellington are more likely to say that caring can be stressful (Christchurch 14 percent agree, Wellington 22 percent). This may relate to good levels of home care offered to older people in the Canterbury region, as the next chapter suggests.

People caring for friends express the highest level of positive feelings – 8 out of 9 respondents providing this type of care. More people feel positive about caring for fathers and fathers-in-law than for mothers and mothers-in-law. The highest proportions expressing negative feelings are for those caring for their mothers (39 percent felt negative).

Positive feelings about caring are four times greater than negative feelings for carers who spend 3 hours or less per week providing care (Figure 5). Negative and positive feelings are similar for those who care between 4 and 19 hours per week. But for carers who spend many hours caring (20 and over) each week, the majority (7/10) have negative feelings about their caring role.

More carers experience positive feelings when the older person has physical health issues compared to those caring for someone with a cognitive or cognitive and physical disabilities (56 percent positive as against 39 percent). Negative feelings are also more evident when working carers do not have anyone to help them regularly, although but there is not a lot of difference with respect to positive feelings.

Figure 5: Feelings towards caring and hours of care in a typical week



Negative feelings may arise when caring conflicts not only with work but also with other activities. This was evident in remarks from the group discussions: “the wife, she finds it very hard at times, plus work, and having the freedom to come and go”.

The caring situation is for my husband’s mother. My husband is not close to his parents, but they need our support at this time. The lack of relationship adds to the stress. The other difficulty is that we are caring for elderly people while in our early 30’s – a time when we want to start our own family. It seems rather strange to be visiting nursing homes, when our friends are visiting cafes, etc.

The time and energy demands of eldercare can also affect other relationships. One in five working carers thought that caring strains relationships with others they are close to.

Probing further into feelings about work and care, some group participants feel that there is always potential for guilt on the part of carers. At times they admit to feeling they are letting either their work colleagues or their family member down. Group members who are in management roles wanted both to support their staff in family care situations, but feel that they themselves might be letting down their staff, by “not being there”, due to their own eldercare commitments.

Several groups discussed their concerns about the loneliness of the person for whom they provided care, given that they themselves were at work all day. Some had helped their parent to maintain links with community organisations, and to build new ways of becoming involved, although this also has consequences for the working carer:

But with all that contact, there's still loneliness there... and I think that's what I try to fill – I mean I'll never ever fill Dad's shoes, but I'll try – (Mum's) quite lonely, but she is very with it. She has a computer- we organised that, she has access to the net. Goes to Seniornet classes, she does all that, but I still get the call, like yesterday - 'my internet access has fallen over' – I pop round on my way home, and sort that out. Mum is very active, and very well in most respects, but to me, it is the decision-making she struggles with - she virtually cannot – or will not make a decision – doesn't have the confidence to.

Finally, when asked what advice they might give to others facing similar situations as a working carer, the following advice was offered.

Do what your heart feels. It's a part of life.

Being able to live with yourself.

Chapter 5 Discussion and conclusions

The picture of life as a working carer emerging from this study in two New Zealand local authorities is generally consistent with comparable studies from the UK, Australia and Canada. It also throws light on the daily experiences of New Zealanders who are giving and also receiving care in the current policy climate, which emphasizes Positive Ageing, Ageing in Place and an “integrated continuum of care” for older people.

This report illustrates the caregiving situations which are part of the work/life context for about one tenth of the workforce in the two councils. While these caregiving situations are not generally intensive, they are often long term, include both potential and actual crisis care and clearly entail perceived strain and stress.

5.1 Key findings of the study

The characteristics of the working carers in the two council workforces (that took part in the research) are that they are predominantly Pakeha, well educated, and in professional, technical and clerical roles. Working carers are predominantly female (72 percent), employed full-time (80 percent), and are long-term employees (average 9 years).

The care recipients are also mainly female (71 percent) and 65 percent are aged over 80. The majority of care recipients (70 percent) live in their own homes, with 17 percent living in a residential care setting, and 11 percent living in the same household as the working carer. The majority are described as family members of the working carers, with 43 percent being their mothers.

The type of care provided is most commonly social and emotional support (provided by 92 percent of the working carers), household assistance (87 percent), administrative support (72 percent) and personal care (47 percent). Female working carers provide higher levels of care, over longer hours and on a more frequent basis than do their male counterparts.

Few of the working carers taking part in this study provide very long periods of care: 84 percent provide less than 10 hours per week. However, on top of full-time work, and personal or domestic commitments, this is still significant. Three-quarters of the respondents say they have help with eldercare from other family members and/or from health professionals and community services. However, only 21 percent describe the responsibility for eldercare as shared.

The predominant method of coping with eldercare responsibilities during work hours, beyond making occasional phone calls, is to use annual leave, which 48 percent of the working carers have done at least once in the six months before the survey. Time in lieu, flexitime, and sick or domestic leave are each mentioned by 30 percent of the working carers as coping strategies which they have used.

Sixty three percent of the working carers report that they had to deal with a crisis in their eldercare situation in the previous six months, and half of these people have experienced more than one crisis. More than a third report having had time off work

to deal with crises. The older the care recipient, the more likely the working carer is to have taken time off from work.

There is an inverse relationship between hours of eldercare provided per week and positive attitudes to care: those who give the longest hours of care report higher rates of negative attitudes.

The eight discussion groups which were part of this study explored in depth the ways in which eldercare responsibilities and activities relate to participants' working lives. The discussions covered attitudes towards caring for older people; the stresses and satisfactions; the use of formal care services and levels of satisfaction with current arrangements. Participants also shared strategies which have assisted in juggling work and care, both on a routine day to day basis, and in crisis situations.

Working carers indicate that improved access to information about eldercare options in their community would assist them to manage the balance between work and care. The most commonly reported strategies for future eldercare management are community and family based, rather than related to their workplace or working conditions.

Workforce development could be enhanced by more overt discussion of the interface between paid employment and informal eldercare. While there is clear employer goodwill in the examples examined, there may be questions about fairness and equity within and across complex organisations, and about how to meet the needs of workers in sections of such organisations where flexibility is structurally difficult.

5.2 Work and care

In their UK study, Phillips et al make a distinction between "balancing" and "juggling" (Phillips et al, 2002, 38). While managers and carers may appreciate one another's viewpoints, managers have a primary interest in balancing the needs of the organisation against the needs of employees. Carers express their issues more in terms of juggling multiple demands – to their employers, partners and children, their parents, their communities and to themselves.

Not surprisingly, the New Zealand working carers who participated in this study use both terms to describe their dual roles as carers and workers. They refer to balancing their responsibility to their employer with their responsibility to their family members and refer to concerns about fairness, equity and reciprocity in these relationships. They also clearly refer to their personal juggling of multiple roles. They wonder how they fit all their activities into and around their working lives and appreciate where the social fabric of their lives might be wearing thin, or becoming stretched.

The study shows how the links between caregiving situations and workplace contexts are two-way. At times caregiving impacts on work, and at other times work impacts on caregiving or capacity. Some factors mediate these effects, as this report shows, for example through gender differentials.

The employment environment in the two councils is described as flexible and supportive, despite the absence of explicit policies or procedures aimed at eldercare or the special issues or concerns of working carers. This raises questions about whether a rising demand for informal care and the implications of an ageing workforce will combine to generate clearer policy developments, or, conversely, feed ageism. This research identifies such risks and opportunities for both workforce and community development.

What might help?

At the community level, the study clearly identifies the need for working carers to have better access to information relating to the care and support of older people. It suggests that employer groups might consider developing opportunities and resources for working carers to access and share experiences and to explore information on service availability. This could be compared to the case for workplace based “pre-retirement training” packages – illustrating how employers can assist in improving the work-life balance throughout the lives of their workers.

Making relevant and accurate information widely and publicly available would also help to improve understanding of the growing need for eldercare and the situation of working carers. The study indicated the need for improved understanding among work colleagues, work supervisors and managers, in the general community and on the part of older people themselves, who may find it difficult to express their wishes clearly, and to make well-informed choices. All these were topics raised in discussion with the study participants.

Moves towards making leave provisions more explicit and relevant to those in the workforce who provide eldercare would be welcomed. It will also be important to ensure that such moves are extended in an equitable manner to workers at all levels in an organisation, and in all occupations and workplace settings.

Implications for working carers

Issues and concerns about caregiving which relate to factors outside the workplace also arose in the questionnaires and focus groups. These concerned how the participants might be better supported in their caring roles. Several people were strong and clear about the difficulties they had experienced in accessing information about support options, service availability, and sources of support in the community. Health and community services came in for particular critique.

Most working carers in this study agree that there is a clear need for service coordination, and for open dialogue about what family carers can and cannot offer. Even within the same city, people found a lack of consistency and uniformity in the service information they had gleaned through their contacts with different parts of the health system. Relationships with the older person’s general practitioner were a topic of discussion, recognising that a GP can be either a weak or a strong link in creating and managing a supportive environment for dependent elderly people.

All the discussion groups acknowledged the clearly expressed desire of the older people to maintain their independence, while at the same time having to rely on

increasing levels of family support. If the older person delays asking for help or has refused help and services offered, this can make things harder for the carers. Working carers suggest that, sometimes, family members may “know best” when the older person might find it difficult to express their needs and preferences themselves. They also caution other working carers not to ignore their own needs when negotiating with family members, both older people and those in their own and following generations - “don’t be a hero” said one person.

Some families have to work through denial or reluctance to deal with physical or mental deterioration on the part of their older members, and apprehension on the part of the older person about receiving help from outside the family. Having access to reliable and appropriate information about health and community services would also assist in bringing independent advice into family discussion, where the dynamics are not always straightforward between siblings, between parents and adult children, between marital partners and in the context of “in-law” relationships. A simplistic view of the positive value ascribed to “motherhood” is also called into question by the finding that working carers acknowledge negative attitudes towards providing elder care to their mothers.

Implications for employers

This research cannot make specific recommendations for any employer or group of employers. It is however hoped that this report will help to improve understanding of the intersection between paid employment and the delivery of informal eldercare. This ground-breaking research for New Zealand will also help to place the local situation alongside international data in a variety of employment contexts. Some employment sectors (banking, insurance, telecommunications, and health care for example), or New Zealand branches of multinational enterprises may already be aware of overseas research on which they might draw.

Formal options for the management of eldercare in relation to employment have been explored and adopted in other countries and settings. These include arrangements such as “annual hours of work” packages, “caregiving sabbaticals” or employer/worker shared support for day care and information services. In addition, the discussion groups suggested the need for support groups for working carers, along with a readily accessible information guide to services available.

Clearly, local bodies are in a unique position to pick up the implications of this research in a variety of contexts, which relate to their role as employers, their statutory role in terms of partnerships for community and social development and in the provision of services, amenities and facilities for all age groups in their community.

This report demonstrates that a partnership between social and gerontological researchers and major employers can be of mutual benefit, in terms of building a more detailed understanding of broad principles such as work-life balance, a family friendly workplace, and the implications of an ageing workforce and population.

Implications for public policy

In this study, some differences between the two urban centres have become apparent in ways which are a reminder that public policy must support and not limit the ways in which local communities manage population ageing.

Wellington working carers note that “caring at a distance” can be of particular concern for them. This is a reminder that public policy should not assume local availability of family support.

Christchurch working carers indicated that they have experience of effective care of older people in their community. This may reflect the combined effect of the city being “home” to New Zealand’s oldest home and community nursing agency (Allen, 1996) or, more recently, to the sustained local effort through the Elder Care Canterbury Project “to improve and integrate health services for older people” (Elder Care Canterbury Project, 2004). Equally, working carers in both centres make it clear that families do not cease to provide care when older members are admitted to residential care facilities. This is consistent with New Zealand research which indicates that residential care complements rather than substitutes for informal care (see Belgrave and Brown, 1997).

The working carers in this study make limited mention of the financial costs of care, which may be more significant for workforces with a higher percentage of lower paid employees. Most of the cost of services in later life will fall upon the older people themselves. In the area of housing, survey participants give examples where family resources have been pooled to develop shared housing options which are mutually advantageous for older and younger generations. Some families clearly have to negotiate such factors as the cost of renovations to meet an older person’s needs, in addition to providing day-to-day care.

Other, less tangible, costs of care are noted in this study. These are difficult to measure or are “beyond a dollar value” (Belgrave and Brown, 1997). The discussions touched on the costs of holidays not taken, time not available for personal relaxation or for spending with friends and younger family members, personal health costs and loss of goodwill in family relations. Of particular concern is the correlation between the highest levels of care and the most negative attitudes.

Implications for further research

Research of this type needs to be extended in order to lay a firmer national foundation of evidence on the relationship between paid employment and informal eldercare in New Zealand. Further research should include a wider variety of workplaces and workforces, including employers in the private and voluntary sectors – central government, manufacturing, primary industry and service delivery. In particular, employers with large numbers of low-paid workers should be covered. An extension of the research would allow deeper investigation of variations between communities, occupations and sectors, as well as differences based on gender and ethnicity. These variations might also highlight how the availability of public resources such as rest homes and community-based care for older people affects the situation of working carers. More systematic interviewing of employers and managers, and their

representative groups would also be fruitful, as well as research involving unions and workers' groups. There will also be implications for human resource management practices, which need to be explored.

This research was designed to explore the perspectives and experiences of working carers in their dual roles, as workers and as carers. It did not seek the perspectives of care recipients or of other family members with whom the research participants may share care. A multi-dimensional approach, using "triangulation", would bring together these different perspectives and produce a much richer and deeper view of informal care. A variety of methodologies and design factors would also be needed to pick up those who choose not to participate in this study (or similar studies), or those who may already have left the workforce for reasons which may be relevant to informal eldercare responsibilities or lack of workforce flexibility. While the findings of this research are well founded on the use of a sound methodology, there are undoubtedly gaps remaining and further productive lines of enquiry to be pursued.

5.3 Conclusion

Reactions to the experience of providing care to older people while still engaged in the paid workforce, which have been recorded and analysed in this report, reflect a complex and personal balancing act. The working carers in the study talk about emotional attachment to the older people they care for and about; acceptance of, and sometimes resignation to, the responsibility of care. They acknowledge that their own needs might sometimes be compromised, in terms of a curtailed social or recreational life. They acknowledge also that they are supported to a greater or lesser extent by their employers, by other family members and sometimes by friends. They seek to have effective links with health and social service agencies in order to provide better coordinated care for their elders, but they also are aware of gaps and breaks in these networks.

They express notions of reciprocity within families and communities: that this kind of care is a two-way exchange between the generations, and that the interactions and directions of this care can change in subtle ways over time.

They clearly call for improved information about options and services to meet the needs of a population which is ageing, at the same time as families and communities may be spread over larger distances and engaged in multiple commitments. They note that loneliness and social isolation of elders may call for new community responses such as day-care and activities for older people in non-residential settings.

The response of the working carers who took part in this study through the questionnaires and discussion groups also suggests that in some ways this project may have reduced their own sense of isolation. Recognition from within their workplace that they are not alone in their situation, and that there may be some prospect of effective support for working carers, is an important part of building public understanding of ageing in New Zealand today. While at any one time maybe only one in ten employees is defined as a working carer of older people, over a working lifetime it is highly likely that most workers will experience some dimensions of this dual role.

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Appendix I: Screening questionnaire circulated to total workforce

**WORKING CARERS – WELLINGTON AND
CHRISTCHURCH CITY COUNCIL SURVEY**

**New Zealand Institute for Research on Ageing
Victoria University of Wellington**

During the last six months, have you given any help or support to anyone over the age of 65 – family members, friends, neighbours or others – who have a physical or mental illness or disability, or problems related to old age?

(please TICK)

Yes *(please send me a questionnaire to complete)*

Name _____

Unit _____

Yes *(but I am not willing to complete a questionnaire)*

No

Please return the completed form to your team leader

There is more information on the survey on the back of this page

Many thanks for your time and cooperation

Appendix II: Self-administered questionnaire for working carers

Organisations and individuals who wish to replicate the research are requested to contact NZiRA, as follows -

Associate Professor Judith A. Davey,
New Zealand Institute for Research on Ageing,
Victoria University of Wellington
P.O. Box 600,
Wellington,
New Zealand

Phone: +64 4 463 6746
Fax: +64 4 463 5064
Email: Judith.Davey@vuw.ac.nz

WORKING CARERS – WELLINGTON AND CHRISTCHURCH CITY COUNCIL SURVEY

New Zealand Institute for Research on Ageing

Thank you for agreeing to fill out our questionnaire. Please answer the questions about the help or support you give to anyone over the age of 65, who has a physical or mental disability, or problems related to old age.

1. TICK the total amount of time you spend giving such care in a typical week.

- 3 or less hours a week
 4-9 hours a week
 10-19 hours a week
 20-49 hours a week
 50+ hours a week

2. Please fill in the following table for all the people you are caring for, starting with the oldest.

Please state their relationship to you, sex, age, which “physical or mental ill-health or disability, or problems related to old age” they are experiencing, and whether their need for care is short or long-term:

Short term means up to 3 months. Long term means more than 3 months

	Relationship to you	Sex	Age	Disability, or health problem(s)	Write L if need for care is long-term, S if short-term
EXAMPLE	MOTHER-IN-LAW	F	77	Arthritis, Memory problems	
Person 1					
Person 2					
Person 3					

Please complete questions 4-10 for the person you are providing the most care for, in terms of time requirements.

If you are caring for two older people in the same household, for example both of your parents or parents-in-law, please answer questions 4-10 for these people taken together.

3. For the person/persons you care for, please indicate the following:

- a) Age _____ years
 b) Hours per week of care provided _____ hours/week
 c) Do others help regularly No Yes

- d) Do you have most responsibility No Yes
 Shared equally

4. Please TICK the living arrangements of the person/persons you care for.

- Lives in your house
- Lives in their own house or apartment (owned or rented)
- Lives in a rest home
- Other (please specify) _____

5. Please indicate the time it usually takes you to travel from your home and your work to the older person(s) residence. If they live with you, write a "0" under "HOME".

HOME – Time from your home to person(s)'s residence	WORKPLACE – Time from your workplace to person(s)'s residence
_____ hours _____ minutes	_____ hours _____ minutes

6. Please TICK how often you have done each of the following for the older person(s) in the past 6 months.

	Daily	Several times a week	Once a week	Several times a month	Once a month or less
Personal care For example help with dressing & undressing, eating, taking medication, washing and using the toilet.					
Household assistance For example help with shopping, transport, laundry, preparing meals, household chores, gardening and home					
Administrative Support For example help with arranging assistance from agencies, completing forms and document (eg taxes), managing money, giving them money					
Social and Emotional Support For example checking on the person by phone, visiting, taking them out, read to, write letters, play cards with etc					

Other Please indicate any aspect of help or care not covered above.					
----------------------------------------------------------------------------------------	--	--	--	--	--

7. a. How long ago did you begin helping this person(s) in any of the ways you indicated in Question 7?

- Within the past 12 months
- 1-2 years ago
- More than two years ago

b. If you began more than 2 years ago, how long ago did you begin? _____ years

8. In the past 6 months, has the person(s) you care for helped **you** in any of the following ways (Please TICK).

	Daily	Several times a week	Once a week	Several times a month	Once a month or less
Personal care For example taking care of me when I am sick.					
Household assistance For example helping with household chores, providing care for children.					
Administrative Support For example help in managing money or giving you money					
Social Support For example visiting or phoning you.					
Other _____					

10. a. Have there been occasions **during the past 6 months** when you provided help in a crisis (e.g. an illness, accident, or family crisis) to the older person(s)?

- No (GO TO QUESTION 11)
 Yes

b. How many separate crises did you help with **the past 6 months**? _____crises

c. In all, how many days **in the past 6 months** were you away from work because of these crises?

_____hours/days (delete whichever is not applicable).

ASSISTANCE WITH CARING RESPONSIBILITIES

10. In the past 6 months, how often were you and the person(s) you care for jointly involved with the following services/ agencies? Please indicate how satisfied you were in terms of the amount of service, access to it and its quality . Please TICK the appropriate boxes.

	Frequency of Involvement			Are you satisfied?			
	Regularly	Occasionally	Never	Yes	If no, please say which aspect of the service is not satisfactory		
					Amount	Access	Quality
District Nurse or other nurse							
General Practitioner							
Hospital Doctor/Specialist							
Occupational therapist or physiotherapist							
Meals on wheels							
Day Care							
Home care worker							
Privately paid home help							
Overnight respite care							
Hospice services							
Gardening services							
Other (please specify)							
.....							
.....							

11. In the last 6 months, please indicate if you used any of the following methods to provide help and support to the person(s) you care for.

	Never	Once	More than once
Taken leave without pay			
Taken annual leave			
Used your own sick leave			
Taken "domestic" leave			
Taken time in lieu, or worked flexitime in consultation with supervisor/colleagues			
Paid someone else to provide care which you would have preferred to provide yourself			
Arranged with another family member to provide the care you normally provide			
Made phone calls or provided care yourself in work time			

12. In the past 6 months, have you done any of the following for the person(s) you care for?

No Yes

- a. Looked into places that provide long term care
 No Yes
- b. Sought information about community services for seniors
 No Yes
- c. Put money aside to help meet the their needs
 No Yes
- d. Discussed care arrangements with other family members
 No Yes
- e. Made sure that their affairs were in order
 No Yes
- f. Looked for a job that was closer to where they live
 No Yes
- g. Taken steps to prepare for future change by –
- Finding ways for you and the person(s) you care for to live closer to each other
 No Yes
 - Modifying their home to make care provision easier
 No Yes
 - Considered reducing your work commitments to meet increasing care and support needs.
 No Yes

13. In general, which comments best sum up your feelings about caring (you may TICK more than one box)

- I have to do it – no-one else will
- I do it gladly
- It is extremely stressful
- It can be deeply satisfying
- It varies, sometimes fine, other times very depressing
- Financially it is difficult
- It is difficult combining work with caring
- It strains relationships with others I am close to
- I don't think there are any major problems
- I worry that I am not able to do the things I want to do

PERSONAL DETAILS

14. How long have you been employed with the city council? _____years/months
15. What is your occupation/job title? _____
16. What number of hours do you usually work per week? _____
17. What year were you born in? 19_____
18. Are you male or female (please TICK) Male Female
19. What is your highest educational qualification? (please TICK)
- None
 - School qualifications only
 - Professional or trade certificate or diploma
 - Undergraduate degree
 - Postgraduate degree
20. What is your ethnic group? (you can TICK as many as apply to you)
- Maori
 - Pacific People
 - Asian
 - Pakeha/NZ European
 - Other (please specify) _____
21. In the next phase of this research project, we would like hold to some recorded group discussions to talk about juggling work, family and personal life. Would you be willing to participate?
- Yes No

If Yes, please supply us with your name, work unit, telephone number and email address. We will respect your confidence and will not pass your personal information on to anyone else.

Name: _____

Work unit: _____

Telephone number Home _____ Work _____

Email addresses(es) _____

22. Please let us have any additional comments below:

Thank you very much for your time and co-operation

Appendix III: Group discussion outline

WORKING CARERS – WELLINGTON AND CHRISTCHURCH CITY COUNCIL

OUTLINE FOR GROUP INTERVIEWS

Introductions:

- Confidentiality.
- Use first name, which we will replace with pseudonyms in any reports.
- Interviews will be taped, for checking of notes, but not fully transcribed.
- Review information sheet; Report of the whole project will be on Future of Work website.
- Recap on questionnaire: we are interested in describing the kind of care which Council employees provide to elders, and what service and support they provide, as well as finding out what helps, and what hinders this caregiving, in the context of your working lives.

Lead by asking each person to outline briefly *the caregiving situation* about which they responded mostly in their questionnaire: possible example if necessary....
e.g. “my situation is that my mother lives in our house, in a self-contained granny flat, and she moved in there after my father died; she doesn’t drive, so we help her with shopping, and outings, and occasional meals, as well as sharing some domestic things like washing, rubbish, maintenance, etc with her. Otherwise, she is pretty independent”

Try to give equal time to each section, but also prompt and follow up as appropriate from the discussion.

- a) We’d like to talk about how you came into this situation, how did it arise?
- b) Turning to the present situation, the “juggling act”, how do you manage? What helps? What makes it more difficult?
- c) Looking ahead, what do you think might change in this situation? What might help? How do you prepare or plan for changes which you anticipate?
- d) What have been your personal reactions to this situation? What effects do you feel that this caregiving has on other parts of your life --at work? Outside of work? Who do you talk with about this situation, if necessary?
- e) Anything else? What have we missed? What would you want to say to someone else in a similar situation?