

**Health and Well-being of Family Carers in Ireland:**

**Results of a survey of recipients of the Carer's Allowance**

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## **Abstract**

Family carers play a vital role in the community, which often goes unrecognised and inadequately supported. This research explores family carers' health and well-being and the factors that appear to influence them. A random sample of 2,834 family carers in receipt of a state carer payment was sent a self-completion questionnaire. This group of family carers, by virtue of the eligibility criteria for receipt of this state payment, may be considered to be full-time carers with low to moderate income.

It was found in comparison to the general population that those family carers who responded were less likely to report themselves in excellent or very good health. No significant difference was found between the general population and carers in terms of satisfaction with health, but carers did present a considerably less positive picture of quality of life in comparison to the general population. Carers also reported comparatively high levels of depression, back pain and anxiety.

Negative aspects associated with family caring identified in this report included restricted leisure hours and a high risk of being exposed to stress, emotional strain and social isolation. The extent of limitation posed by caring on leisure/recreation appears to be a key factor both in likelihood of health suffering due to caring and in likelihood of low quality of life for carers.

**Key Words:** Family, Carer, Health

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## Abbreviations

CA – Carer’s Allowance

CB – Carer’s Benefit

DSFA – Department of Social and Family Affairs

SLÁN 02 – Survey of Lifestyle Attitudes and Nutrition

## **Glossary of Terms**

**Family Carer:** Defined in the Census 2006 questionnaire as 'someone who provides regular, unpaid personal help for a friend or family member with a long-term illness, health problem or disability' (CSO, 2007)

**Carer's Allowance:** A payment for carers on low incomes who live with and look after certain people in need of full-time care and attention. Currently, recipients of Carer's Allowance aged 66 years and over receive €239 per week; those under 66 years receive €220.50 per week

**Carer's Benefit:** A payment made to insured persons who leave the workforce to care for a person(s) in need of full-time care and attention. Currently, recipients of Carer's Benefit receive €221.20 per week

**Respite Care Grant:** An annual payment (currently of €1,700) for carers who look after certain people in need of full-time care and attention. The payment is made regardless of the carer's means but is subject to certain conditions

**Logistic Regression** - This is a model used for the prediction of the probability of occurrence of an event by fitting data to a logistic curve. It makes use of several predictor variables that may be either numerical or categorical. It is a technique that enables the relative influence of each of the different factors, on their own, to be determined

**Multivariate Analysis:** A statistical procedure where more than one variable (i.e. a measurable factor, characteristic or attribute) is analysed at the same time. The goal of multivariate analysis is to identify statistical relationships between the variables, or to measure the dependence of the variables on each other

**Social Exclusion;** This describes the process whereby certain groups are pushed to the margins of society and prevented from participating fully by virtue of their poverty, low education or inadequate life-skills. This distances them from job, income and education opportunities as well as social and community networks. They have little access to power and decision-making bodies, little chance of influencing decisions or policies that affect them and little chance of bettering their standard of living.

## **Executive Summary**

There is little Irish research that documents the self-reported health status of family carers. This research published by Care Alliance Ireland examines the relationship between caring and health and well-being and offers suggestions for future policy development.

Low-income, full-time family carers are hypothesised to be a group that is particularly vulnerable to poor health. A sample of 10 per cent (2,834) of the recipients of the state Carer's Allowance (CA) payment was surveyed in April 2007 using a self-administered questionnaire, with the sample being representative of CA recipients in terms of marital status, age, gender and county of residence. This sample is not however necessarily representative of the entire family carer community in the Republic of Ireland. Eligibility for the Carer's Allowance is dependent on several criteria; significantly that the caring is full-time and that income is below a certain level. The 2006 Census figures indicate that three quarters of family carers report providing care on a part-time basis (i.e. less than 43 hours per week). This group of family carers sampled, therefore, may be considered to be a sample of full-time carers with low to moderate income. A response rate of 50 per cent was achieved. Just over 80 per cent of respondents were female and 20 per cent were male.

It was considered important to compare key responses of the questionnaire with a wider population sample, and for that purpose the responses were compared with the SLÁN 02 survey, based on a national population. In order to ensure accurate comparison, the data from the SLÁN '02 survey were weighted for various factors including age, gender and educational attainment.

## Findings

Carers presented a considerably less positive picture of quality of life in comparison to the general population. In the SLÁN survey, 27.7 per cent reported themselves to have a very good quality of life whilst in the carers survey only 16.0 per cent did so. At the other end of the spectrum, carers were a lot more likely to report their quality of life to be neither good nor poor, and also more likely to report it to be poor or very poor.

Carers were less likely to report themselves in 'very good' or 'excellent' health as opposed to 'good' health compared to the general population. Amongst the carers, 36 per cent said they were in very good or excellent health, whilst for the SLÁN survey 44.9 per cent said they were in very good or excellent health. The data does show a statistically significant pattern of carers reporting being less healthy than do the general population. A majority of carers (70.1 per cent) were either satisfied or very satisfied with their health. Comparisons with SLÁN found no significant difference between carers and the general adult population in this regard.

Reflecting on the profile of recipients of the Carer's Allowance, the carers in this survey were mainly concentrated in the 35 to 64 years age range. Ninety per cent were providing at least 40 hours of care per week, with the majority of these providing more than 59 hours per week. There was a mix of caring situations, mainly falling into three groups: people caring for their children (both young and grown up), for their spouse/partner and for a parent/parent-in-law.

More than one-half were caring for someone aged 60 years or older, either people caring for a parent/parent-in-law or one partner in an older couple caring for the other. As regards type of care needs, nearly one-half were caring for someone described as having a physical disability (this included older people with physical disabilities also), one-in-six were caring for someone described as having an intellectual disability and almost one-in-nine were caring for someone with both.

The majority of respondents are relying solely on the Carer's Allowance as an income. Whilst the payment is low relative to the minimum wage or the average industrial income, this does not necessarily point to the individual experiencing

income poverty, as this is a complex area. In addition we do not know the extent to which other household members are supplementing the household income.

### **Other key findings**

- Two-in-five carers reported having experienced stress/ nervous tension and one-in-nine carers reported having their daily activity limited by ill-health or disability in the past twelve months
- When family carers were asked to report negative impacts of caring on their health and well-being, nearly one-third reported that their health had suffered due to their caring responsibilities and almost one-half stated their leisure or recreational activities had been limited quite a lot or a great deal
- Emotional issues, stress, being constantly on-call and lack of sleep/ tiredness were frequently mentioned amongst the most difficult aspects of caring
- Talking to friends and watching TV were the most frequently mentioned coping strategies for carers, followed by praying/faith and exercise. Amounts of support from family and others varied widely, with about one-half of carers being without a major source of support and about one-quarter with little or no support at all. Carers, when compared with the weighted SLÁN 02 sample, reported considerably lower levels of overall support
- Carers were significantly more likely to be smokers and less likely to be regular drinkers than the general population, and seem to have about the same likelihood of being injured.

### **Multivariate analysis**

- Two socio-demographic factors were also found to be important. Firstly, being a male was associated with a 1.6 times greater likelihood of lower quality of life than being a female

- Secondly, not having a spouse/partner in full-time employment was associated with a 1.9 times greater likelihood of lower quality of life
- The results show that likelihood of reporting that health has suffered was strongly associated with whether or not caring impacts on leisure. Where leisure is limited a great deal, negative health impacts were 7.8 times more likely to be reported than where leisure is not affected at all
- Significantly increased likelihood of negative health impacts were also found when caring is reported to cause stress (3.2 times more likely), lack of sleep/tiredness (2.7 times more likely), emotional strain (2.7 times more likely) and isolation (1.7 times more likely)
- The results again show the importance of impacts of caring on leisure time. Where leisure is limited a great deal there was a 3.3 times greater likelihood of lower quality of life being reported in comparison to where leisure is not limited at all. Significantly increased likelihood of lower quality of life was also found where caring causes stress (1.9 times more likely), isolation (1.9 times more likely), lack of sleep/ tiredness (1.7 times more likely) and emotional strain (1.5 times more likely)
- The extent of support available was also a key factor. Where there is little or no support there was a 2.7 times greater likelihood of lower quality of life being reported in comparison to where there is more than one good source of support
- Talking with friends as a coping strategy was strongly associated. Where this strategy is not reported there was a two times greater likelihood of lower quality of life being reported. However, where use of prayer/faith as a coping strategy is reported there was a 1.5 times greater likelihood of reporting lower quality of life
  - Finally, having had an injury (other than a back injury) in the past two years was associated with a 2.1 times greater likelihood of reporting lower quality of life.

The extent of limitation posed by caring on leisure/recreation appeared to be a key factor both in likelihood of health suffering due to caring and likelihood of low quality



of life for carers. Those caring for longer hours, being constantly on call and caring for certain types of needs (particularly where there are specific physical and/or intellectual disabilities combined with old age) were especially likely to report substantial limitations on their leisure/recreation activities. Stress, lack of sleep/tiredness, emotional strain and isolation were also important factors in the likelihood of negative impacts on health. On the positive side, availability of good support and talking to friends as a coping strategy were used by family carers to keep going.

## **Key recommendations**

### **1. Increase opportunities for breaks for family carers**

When caring severely restricts leisure/recreational opportunities family carers are a lot more likely to report that their health has suffered and/or a lower quality of life. This emphasises the importance of policy efforts to ensure that carers have breaks and time to themselves. Respite services have a key role to play in this, as well as active efforts to encourage and support carers to have a life beyond caring.

Alongside restricted leisure time, lack of sleep/ tiredness is a big factor in the likelihood of carers experiencing negative impacts of caring on their health and well-being. Policy efforts should therefore give attention to implementing supports that help carers to get enough sleep and rest and not have an unreasonable care burden to manage. Night-time respite services could have an important role in relation to lack of sleep. There are also promising developments in technologies that can monitor the person being cared for so that the carer can get enough sleep. More generally, sufficient home care support needs to be provided to avoid carers becoming overburdened and over-tired. In addition, it is vital that respite services respect the needs of both the carer and the care recipient.

### **2. Promoting awareness of family carers and their support needs**

Carers who have little or no support from family, friends or others are especially likely to report low quality of life, as are carers who report isolation. Policy efforts aimed at

increasing the general awareness of caring and the importance of providing support (both practical and emotional) to carers could have an important role to play.

### **3. Reducing carer stress**

Stress and emotional strain are frequently reported by carers and these, in turn, are linked to a greater likelihood of carers reporting that their health has suffered and/or a lower quality of life. Policy efforts aimed at reducing the stress and emotional strains on carers are therefore important. Improvement of existing services and supports for carers would be an important first step. With the recent provision of significant resources for family carer training, it is important that any training models proposed and accepted are evidence-based. Evaluations of such interventions should inform the more widespread roll-out of such programmes as appropriate.

### **4. Carer entitlements and income**

Whilst the entire sample surveyed was in receipt of Carer's Allowance, the vast majority of the group had no other income. Low income, coupled with long hours of caring that restricts carers' opportunities to take up employment, make them a group at risk in terms of likelihood of experiencing income poverty. Future carers policy would need to take into account the loss of economic opportunities due to caring work and also the cost of caring where in some circumstances carers have to cover the extra costs of disability when caring for a disabled relative.

### **5. Targeting male carers**

This research has identified male carers being at particular risk of reporting both lower quality of life and being less satisfied with their health than female carers. Innovative ways of identifying, engaging with and supporting male carers need to be actively considered.

## 1 Introduction

*Informal and family carers play a very valuable role in our society particularly in enabling older people and people with disabilities to remain in their home*  
(Office of Social Inclusion, National Action Plan for Social Inclusion, 2007:65)

The Census data for 2006 show that there are 160,917 carers in Ireland (CSO, 2007:119). The Carers Association in Ireland in its 2008 pre-budget submission estimated that the annual monetary value of family care in Ireland is in the region of €2.1 billion (Carers Association, 2007).

There is little Irish research that documents the self-reported health status of family carers. This research, published by Care Alliance Ireland, examines the relationship between caring and health and well-being and offers suggestions for future policy development.

This report, undertaken by Care Alliance Ireland with primary funding from the Combat Poverty Agency, presents the main results from a survey of a sample of recipients of the Carer's Allowance (CA) that was undertaken in April 2007. Carer's Allowance is a means-tested social welfare payment available to family carers who satisfy particular criteria, the main one being that household income is below a certain level and that full-time family care is needed and provided.<sup>1</sup>

### 1.1 Aims

The aim of the research was to examine the health and well-being of family carers in Ireland, with a focus on those carers in receipt of state carer payments.<sup>2</sup> Low-income, full-time family carers are hypothesised to be a group that is particularly vulnerable to poor health. The examination of carer health and well-being includes, where possible, comparisons with the general population using data available from

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<sup>1</sup> As of July 2008, the levels of payment are: €214 for carers under 66 and €232 for those 66 and over. Additional ½ rate payments are made for those caring for more than one dependent person. The income disregards for Carer's Allowance are €332.50 per week for a single person and €665 per week for a couple. A GP is required to complete a section of the application form outlining the degree of dependency of the cared-for person.

<sup>2</sup> The term family carers and carers are used interchangeably in this report. However, the vast majority (98.3 per cent) of respondents indicated that they were caring for a family member.

the SLÁN 02<sup>3</sup> survey. For the purposes of this research, comparisons were made with the SLÁN 02 survey. The most recent SLÁN findings were not available to the researcher at analysis stage.<sup>4</sup>

## 1.2 Methodology

The methodology for this research involved surveying a stratified random sample of 10 per cent of the 28,340 individuals who were in receipt of the CA payment at the time the questionnaire was sent out (April 2007). A total of 2,834 recipients of the CA was surveyed, with the sample being representative of CA recipients in terms of marital status, age, gender and county of residence. This sample is not however necessarily representative of the entire family carer community in the Republic of Ireland. Eligibility for the Carer's Allowance is dependent on several criteria, significantly that the caring is full-time and that income is below a certain level. The 2006 Census figures indicate that three quarters of family carers report providing such care on a part-time basis (i.e. less than 43 hours per week).

The survey did not include specific questions on household income. Lengthy consideration was given towards the inclusion of more detailed income questions in this survey. As the entire sample satisfies a means test, it was considered reasonable to assume that the income of all respondents was below this level. The omission of more detailed questions on both household and/or individual income is a limitation. However, a question was included regarding any additional income the respondents had. There is some evidence that detailed questioning of income (either individual and/or household) in surveys reduces both the completion rate and the overall response rate.<sup>5</sup>

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<sup>3</sup> SLÁN is a national health and lifestyle survey commissioned by the Health Promotion Unit of the Department of Health and Children. The survey was first undertaken in 1998, repeated in the summer of 2002 and again most recently in 2006. See Appendix IV for more details of 2002 survey.

<sup>4</sup> Specifically the following questions in the survey (See Appendix I) were identical to those used in the SLÁN 02 survey: A1, A2, A4, A5, C1, C2, D1, E9, E10, E11, F1. The following were used with modifications: A6, D2.

A self-completion questionnaire<sup>6</sup> was posted by the Department of Social and Family Affairs (DSFA) with Freepost return envelopes enclosed. A cover letter from the DSFA alongside a cover letter from Care Alliance Ireland was also enclosed (see Appendices II and III). A dedicated phone-line to deal with general queries on questionnaire completion was set up as well as a dedicated e-mail address.

In part due to limited resources no reminder letters or reminder questionnaires were sent out. Another reason for the lack of reminders was that the DSFA, who both controlled and facilitated access to the sample, did not consider that it was appropriate to issue more than one item of non-payment related mail to customers.

The number of valid returned questionnaires was 1,411, giving a response rate of 50 per cent. This response rate is considered adequate but not particularly high. The rate needs to be viewed in light of the very limited resources at the disposal of the researcher, and the gatekeepers refusal to allow additional follow up communication with potential respondents. It is of note that the SLAN 02 survey, with its considerable resources and several number of follow up and types of follow up approaches achieved a response rate of 53%.

### **1.3 Limitations of the research**

We acknowledge that this research has not addressed the issue of young family carers under the age of 18 years. However, we do recognise the recent commissioning of the Child and Family Research Centre, NUI Galway by the Office of the Minister for Children to conduct a study of young carers in Ireland and we eagerly await its outcome.

We also acknowledge that this research has not elicited the views of the approximately 75 per cent of family carers who do not receive the Carer's Allowance.

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<sup>5</sup> Pers. Comm., ERSI Official, c Sept 2006

<sup>6</sup> See Appendix I for the questionnaire used in the survey. The questionnaire was piloted in late 2005 with family carers from Cavan, Monaghan and Donegal. Each respondent in the pilot received a €10 book voucher in thanks.

Further research of interest might be a comparison of carers' experience between those who receive CA and those who do not.

**1.4 Sample representativeness**

The survey sample of returned questionnaires was checked for its representativeness of the overall population of those in receipt of the Carer's Allowance. Details for the gender and age of recipients were available from the DSFA (2007) report *Statistical Information on Welfare Services: 2006* and these were compared with those of the sample.

The gender balance of the survey respondents (81.1 per cent female, 18.9 per cent male) equates almost exactly to the gender balance of recipients of Carer's Allowance overall (80.5 per cent/9.5 per cent, respectively), as does the distribution for age (Table 1.1). Therefore the respondents can be considered to be representative of recipients of Carer's Allowance in these regards.

**Table 1.1 Age profile of the CA survey sample and all CA recipients**

Per cent	25-	30-	35-	40-	45-	50-	55-	60-	65-	70+	
Age	< 25	29	34	39	44	49	54	59	64	69	70+
Survey sample	0.9	3.2	5.2	9.9	13.6	12.6	14.0	13.4	12.2	8.8	6.3
All CA recipients	1.1	2.7	5.4	9.9	13.0	14.0	13.4	13.5	11.9	8.1	7.0

The 2006 Census contains data for family carers in the general population. In total there were 160,917 people in 2006 who reported providing upwards of 1 hour per week family care (CSO, 2007:119). The majority (58 per cent, 93,363) reported providing between 1 and 14 hours of care per week. Smaller numbers reported providing between 15 and 28 hours per week (11 per cent, 17,093) and between 29-

42 hours per week (6 per cent, 9,578). A significant minority reported providing what might be considered full-time care that is greater than 42 hours per week (25 per cent, 40,883) (CSO, 2007:119).

Recipients of the Carer's Allowance at the time the survey was undertaken comprised a little more than one-sixth of all carers (CSO, 2007:119).

In comparison to the full population of carers, carers in receipt of Carer's Allowance can be expected to have a greater likelihood of providing longer hours of care. This is because a key determinant of eligibility of this payment is that the carer must be providing a high level of care.

Almost 90 per cent of the survey respondents reported providing 40 or more hours of care per week. Based on hours of care provided, therefore, the current survey can be considered to mainly concern this key sub-group of 'full-time' carers and, within this group, carers in lower-income circumstances in particular due to the means-tested nature of the payment.

In the 2006 Census data, the gender balance for carers overall was 37.7 per cent male and 62.3 per cent female and for 'full-time' carers was quite similar (34.3 per cent and 65.7 per cent, respectively), so carers in receipt of Carer's Allowance are even more likely to be female (80.5 per cent) than are carers in general (62.3 per cent) (CSO, 2007:120-121).

Given the traditional roles of women as carers, it is to be expected that such a gender bias exists. The reasons for the gender bias being even more pronounced in this sample are likely to be complex. They may include the reluctance of men to apply for what might be considered a women's payment (i.e. Carer's Allowance), men's somewhat higher average income/wealth levels than women, and by association the greater opportunity cost to them of staying out of the formal labour market. Such contentions would need to be tested. Male carers are more likely to report full-time caring as well as being in paid employment. The 2006 Census reports that 54 per cent of male carers who reported providing full-time care also reported being in paid employment. This compares with 31 per cent of female full-time carers (CSO, 2007:144).

As regards age, the age distributions of carers from the Census and this survey are presented in Table 1.2.

**Table 1.2 Age profile of all carers and the carers in the CA survey<sup>7</sup>**

Per cent						
Age	< 25	25-34	35-44	45-54	55-64	65+
Census						
2006 – all carers	7.3	11.8	24.1	28.9	16.8	11.0
Census						
2006 – 'full-time' carers	3.0	9.1	20.8	25.1	20.4	21.6
CA recipients						
survey	0.9	8.4	23.5	26.5	25.6	15.1

It can be seen that CA recipients are more likely to be aged 65+ compared with carers in general but less likely to be in this age category compared with 'full-time' carers in general. CA recipients are more likely to be in the 55-64 years age group compared with both carers in general and full-time carers in general.

<sup>7</sup> Table 1.2 is an adaptation of statistics from the 2006 Census on carers and statistics from the survey administered as part of this research.



## 1.5 Structure of the report

The analysis and presentation of results in the report aim to build a profile of carers' health and well-being and of the mechanisms that underpin particular types of outcomes for carers. The report provides a descriptive presentation of the health and well-being related experiences of carers and then examines the factors that are especially associated with negative outcomes for carers. The results of this type of analysis are especially useful for policy. They provide pointers to where interventions may best be targeted to better support carers in their caring roles and help avoid or reduce negative health and well-being impacts for carers.

The remainder of the report is structured into seven additional Chapters:

- Chapter 2 presents research findings from a number of countries, with a particular focus on the relationship between caring and carers' health and well-being
- Chapter 3 presents a profile of the sample of carers who responded to the survey in terms of their socio-demographics, income and the characteristics of their caring situations
- Chapter 4 examines the general health and well-being of carers who responded to the survey and compares them with the wider population in this regard
- Chapter 5 examines the impacts of caring on the carers who responded to the survey and the types of difficulty they experience, as well as the coping strategies they use and the extent to which they have supports from family, friends and others
- Chapter 6 looks at wider lifestyle issues – smoking, alcohol consumption and injury – that are not necessarily linked to caring *per se* but may affect carers' health
- Chapter 7 presents an analysis of factors that are especially associated with negative outcomes for carers who responded in two regards – negative impacts on health and lower quality of life

- Finally, Chapter 8 provides a conclusion and specific policy recommendations and points to opportunities for further research.

## **2 Literature review**

### **2.1 Introduction**

This chapter presents existing literature which focuses on the complex relationship between health and caring and specifically on the impact of caring on health and well-being. It also considers the relationship between caring, health and income.

Firstly it looks at the context in which carers in Ireland exist, from a statistical and policy/legislative perspective. It then presents findings related to carers' health and associated issues from Ireland and then from the UK and Internationally.

### **2.2 Carers in Ireland**

Carers in the census are defined as 'providing unpaid personal help for a friend or family member with a long-term illness, health problem or disability' (CSO, 2006:5). The type of care provision ranges from one to fourteen hours per week which is carried out by 93,363 people; to 43 hours and over which is carried out by 40,863 people (CSO, 2007:120-121). Currently 35,670 individuals are in receipt of either the full rate of Carer's Allowance (26,296) or the more recently introduced ½ rate payment (9,374, specifically for those in receipt of another social welfare payment).<sup>8</sup> It is estimated that approximately 2,000 family carers receive Carer's Benefit, a non-means tested state payment that is similar in level to that of the Carer's Allowance but is limited in time to two years duration. The difference in numbers of CA recipients and carers' numbers from the Census can partly be explained by the criteria for qualifying for allowances from the state.

The Carers Association document (2006) *Towards a Family Carers Strategy* asserts that family carers in Ireland provide more than three million hours of caring per week.

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<sup>8</sup> Pers. Comm. Helen Bannon, AP, Longford DSFA 3 April 2008. Note that this figure is considerably different to the number in receipt of this payment when the questionnaire was distributed, in March 2007(28,340). This is primarily due to the introduction in September 2007 of this ½ rate payment.

This caring is not included as part of the Gross Domestic Product. It is argued that its absence undervalues the work of carers and that consequently the true costs of care provision are underestimated (The Carers Association, 2007:9).

### **2.3 Irish policy and legislative context**

It is argued that carers are covered under two pieces of Irish equality legislation. The recent report from the Equality Authority entitled *Implementing Equality for Carers* states the following in relation to the relevance of equality legislation to carers (2005:III):

The family status ground covers some people with caring responsibilities. The gender ground is also particularly relevant to carers as discrimination against those with caring responsibilities could involve indirect discrimination on the gender ground. All nine grounds have a relevance to carers given the diversity of people who are carers. The age ground and the disability ground have a relevance for those who need care.

It is expected that the current development of a National Carers Strategy, due to be completed in the Autumn of 2008, will provide a framework for the future support of informal and family carers in Ireland. Ireland's current government policy on the provision of care alludes to the promotion of strategies to support people in remaining in their homes for as long as possible. In the latest national agreement, *Towards 2016* (Government of Ireland, 2006:51,57), its goals relating to carers include expanding the income limits for the Carer's Allowance so that all those whose joint income (i.e. self and partner) are on or below average industrial wages can qualify for this payment. There is also a commitment to implementing significant increases in the value of the respite care grant.<sup>9</sup> The agreement further re-iterates the commitment to family carers support under the goals contained within long-term care services of older people, where it states that 'use of community and home-based care should maximise and support the important role of family and informal care'.

The *National Action Plan for Social Inclusion 2007-2016* (Government of Ireland, 2007a:65) recognises the role that family carers play in supporting government policy of caring in the home and community and suggests that carers require a range of supports including financial, education and training. Further policy commitments for carers can be found in the *National Development Plan* (Government of Ireland, 2007b:257) which recognises that respite/day-care service places need to be part of a comprehensive community service to give a much needed break to carers in the home. Other policy developments include the Equality Authority report entitled *Implementing Equality for Carers* (2005) which provides practical recommendations to ensure that carers are adequately supported.

#### **2.4 Link between caring and health – Irish research**

A South Eastern Health Board (2000) study found that whereas the vast majority (89.3 per cent) of carers rated their emotional health as having been very good (40.7 per cent) or good (48.6 per cent) before becoming a carer, these ratings fell to 19.2 per cent and 40.7 per cent, respectively, following engagement in the care-giving role.

In relation to physical health, O'Connor and Ruddle (1988) found that 68 per cent of the carers in their study reported that they suffered from some chronic health problem themselves, with 24 per cent reporting being in poor health. Almost one-third (30 per cent) believed that their health had suffered due to the demands of caring. Ruddle and O'Connor (1993) found a slightly more optimistic picture, with only 11 per cent of respondents rating themselves as having poor or very poor health, although 38 per cent of the carers did say that they had experienced health problems. In this context it is important to note that while many of those cared for are people with disabilities, many carers are also people with disabilities (Cullen et al, 2004:46).

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<sup>9</sup> This is an annual payment (currently of €1,700) for carers who look after certain people in need of

Blackwell et al's (1992) report appears to be the first report in Ireland that made quantifiable comparisons between carers and non-carers. The researchers found that almost one-third (29.5 per cent) of carers in their study had a level of psychological distress that put them at risk of clinically diagnosable anxiety/depression and that this was a lot higher than the one-in-six (16.5 per cent) of the general population reporting similar symptoms. In terms of specific strains associated with caring, the most frequently cited were the experience of caring as confining (65 per cent) and the physical efforts required (46 per cent).

O'Donoghue (2003:3) in her research on family carers in West Clare, reported that

most carers take on the job of caring with no specialist knowledge or training. They have to learn as they go along, often at considerable cost to their physical and psychological health and often at great expense.

O'Donoghue also points to the importance of looking at the health of both the care recipient and carer together rather than in isolation (2003:5). The carers in this study identified issues such as isolation and depression as being significant to them. Twelve per cent stated that their health was fair, while 82 per cent were in good health. Six per cent reported to be in poor health. O'Donoghue acknowledges the limitations of this research (2003:23). For instance, the inadequacy of the questionnaire as a means of documenting personal data was noted.

In a 2004 report published by the Equality Authority entitled *Caring, Working and Public Policy*, Cullen et al (2004:10) argue that

caring responsibilities may preclude the fulfilment of a full social life. Indeed, a number of studies have shown that caring can take a toll on the carer's mental, emotional and physical health. Many carers have their own chronic health problems or disabilities.

They quote O'Connor and Ruddle (1988) as having investigated experiences of strain in terms of physical and emotional well-being, family relationships, financial circumstances, free time and personal and social life. They were reported to have found that emotional strain was the most evident impact on carers. Two-thirds of

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full-time care and attention. The payment is made regardless of the carer's means but is subject to certain conditions.

carers (66 per cent) found the changes in the older person upsetting and one-in-three (30 per cent) found problems such as incontinence or memory loss difficult to cope with. Over one-third of the carers reported having felt completely overwhelmed with worry about the person being cared for. Twenty-five per cent indicated that caring had involved major emotional adjustments (Cullen et al, 2004:46).

The report also refers to Ruddle and O'Connor's (1993) detailed exploration of the experience of strain among carers of people with dementia. It was found that 38 per cent of carers experienced 'a great deal' of stress in caring, with a further 19 per cent describing themselves as experiencing 'quite a lot' of stress. Sources of stress included never being able to get away from caring, aggression of the person with dementia, need for constant surveillance, feeling under pressure to get things done and seeing the changes and deterioration as the condition progresses (Cullen et al, 2004:46).

## **2.5 Link between caring and health – international research**

### **2.5.1 General health**

Maher and Green (2002) found, from the UK Census of 2001, that approximately 700,000 carers reported they were not in good health and that nearly 250,000 carers who provided over 50 care hours per week had indicated that their health had suffered in some way. The Princess Royal Trust for Carers (2003) found that 52 per cent of carers say that their health is 'good' (only 7 per cent 'very') but that 37 per cent say it is 'not very good' and 10 per cent 'not at all good'. Scholfield et al (1998) found higher rates of self-reported ill-health and use of medication, more negative effects, and less life satisfaction and perceived social support, among carers than among women non-caring in the comparison group. A 2004 study commissioned by the Alliance for Caregiving and AARP found that persons who provided the most intensive caring reported substantially poor health (NAC, 2004).

In Australia, O'Connell et al (2003) found that carers responding to their survey experienced compromised physical and mental health (n=1,076). Many carers reported being unable to participate in social and health-type activities as they were unable to leave the care recipient. Seventy-five per cent of the carers noted that they suffered from various health problems, with arthritis (26 per cent), high blood pressure (25 per cent) and impaired mobility (21 per cent) being cited as the most common health problems for this group of carers (O'Connell et al, 2003: 80). O'Connell et al point to other Australian research that reports many carers experiencing poor quality of life associated with profound social isolation and a large burden of care (ibid, 2003: 78).

LoGiudice et al (1998) found that the psychosocial health of carers of people with dementia is impaired. Social and recreational activities appear most affected in the carers. Morris (2001) found that more women than men provide the more demanding forms of care and that women carers experience more health consequences, more disruption of everyday life, more negative impacts on employment and career, and greater likelihood of long-term financial consequences.

### **2.5.2 Mental health**

Further research carried out by Carers UK in 1998 found that 52 per cent of respondents providing substantial amounts of care had been treated for a stress-related disorder (Henwood, 1998). An Australian report by Cummins (2007) found that carers who look after frail, disabled or mentally ill relatives suffer extraordinary rates of depression and have the lowest level of well-being of any group in society. This unhappiness was linked to their reduced opportunities to interact socially because of care duties. The report found that, from the carers studied, their levels of dissatisfaction with life were higher than those of other marginalised groups such as the unemployed. In comparing the carers' experience of depression, it was found that 56 per cent of carers classified themselves as being moderately depressed.

Kolbuszewski (2001) found that half of respondents suffered depression as a result of their caring role. It also revealed that 68 per cent of carers spent 50 hours or more



per week caring. Boden (2002) found that 43 per cent of the respondents in their research indicated that they were depressed. Carers UK also refer to what they describe as a major national survey (Carers UK, 2006) of over 5,600 carers, where more than three-quarters (79 per cent) of carers said that their health was affected by caring, with stress and depression being amongst the most common complaints. Almost as many (71 per cent) said that health problems affected their ability to care. Singleton et al (2002) found that women were more likely to report mental health problems and that people who cared for more than 20 hours a week had worse mental health problems than those spending less time caring.

### **2.5.3 Changes in health**

A report published by Carers UK which analysed the British Household Panel Survey demonstrated that the health of carers was more likely to deteriorate over time than the health of non-carers and that many of the detrimental changes may be attributed to the caring role (Hirst, 2004a). Further research by Hirst indicates that the physical health of carers is more likely to decline after the first year of caring. This research also identified spouse carers and mothers looking after a disabled child as being most at risk of psychological distress and that the period immediately after caring ends as a period where ill-health is likely to increase (Hirst, 2004b).

### **2.5.4 Comparative health**

A 2001 study of Northern Ireland Households (Department of Health, 2001:23) found that carers reported a higher level of longstanding illness than non-carers (42 per cent compared to 38 per cent). The distinction was significantly greater for those caring for someone in their own household as compared to caring for someone living elsewhere (49 per cent compared to 36 per cent). Men who cared for someone for more than 20 hours per week reported the greatest incidence of ill-health (58 per cent). Carers were twice as likely to report suffering from stress. Thirty-seven per cent of carers spending more than 20 hours per week caring showed signs of

psychiatric morbidity compared to 20 per cent of the non-carer population (ibid, 2001:23),

Research carried out by Carers UK (2004) found that carers who provided high levels of care for sick relatives, unpaid, were more than twice as likely to suffer from poor health as compared to people without caring responsibilities. The research also found that contributing factors to carers' poor physical and mental health were lack of information and lack of support.

In stark contrast, Kersten et al (2001) found that carers in their UK study experienced a similar health status to people in the general population. Carers who had reported an unmet need for short breaks had significantly poorer levels of mental health and vitality than carers who had not reported this.

The Carers UK report found that nearly 21 per cent of full-time carers in the UK say they are in poor health compared to less than 11 per cent of the non-carer population (Carers UK, 2004:1). The report concludes that not all carers experience ill-health as a result of caring. It argues that this is dependent, not only on the stresses of caring, tasks, amount of support, etc. but also on how the carer personally is able to cope with the stresses of caring. The same report also found that carers in younger age groups (16-44) were found to be significantly more likely to suffer ill-health than non-carers of the same age.

The results of the 2001 UK Census seem to corroborate earlier surveys such as the UK General Household survey which found that almost three-quarters (72 per cent) of carers providing over 50 hours a week reported that their health was affected in some way and 35 per cent of those caring for 20 hours or more reported a limiting longstanding illness (Maher and Green, 2002). The Carers UK report concludes that the Census may be under-reporting ill-health amongst the carer population (Carers UK, 2004:3).

### **2.5.5 Health and employment**

Young et al (2006:28) noted that previous studies have suggested that caring may have a negative influence on health status and may lead to reduced participation in the labour market. In their study of carers based on the 2001 UK census figures, they were not able to conclude that employment status and poor health are a consequence of care-giving or a causal factor in care provision (Young et al, 2006: IIIV). However, they found that for the population aged 35-59 who were employed in 2001, higher proportions of heavy care providers were in poor health than those who provided less or no care (Young et al, 2006:IX).

They concluded that withdrawal from the labour marker may precede rather than be a consequence of care-giving. They also concluded that the lower levels of economic activity among those providing extensive care clearly have implications for their current and future income and their need for benefits and other supports.

### **2.5.6 Self-care**

Evercare (2006) reported that care-giving (the term used widely in the US for family care) has an impact on various aspects of care-givers' overall well-being (2006:14). Seven-in-ten (72 per cent) of the carers in this US study reported they had not gone to the doctor as often as they should since they began providing care. The main reasons carers gave for not going to the doctor is that carers put their family's needs over their own (67 per cent say this is a *major* reason) or their care recipient's needs over their own (57 per cent). Fifty-one per cent say a *major* reason they do not go to the doctor as often as they should is because they have no time to take care of themselves, given their other responsibilities. Nearly half say they are simply too tired (49 per cent *major* reason) (ibid, 2006:14).

## **2.6 Link between caring and income**

Measuring poverty, in particular relative income poverty, is a complex process. The sample chosen for this research is a group whose individual income is likely to be low

to moderate. There is a demonstrated and widely accepted link between income and health.

Various organisations involved in supporting family carers have repeatedly called for the rate of Carer’s Allowance to be set at a level that equates to a living wage. Some have suggested that the equivalent home help full-time weekly wage be used as a benchmark; others have called for the rate to be set at or above the minimum wage. The suggested figures below show the increases required to meet such demands.

**Current Rate (Nov 2007)<sup>10</sup>**

Carer’s Allowance	€ 200/€218
Minimum Wage (based on 39-hour week)	€337.35
Home Help (based on Point One of scale)	€519.15

The only Irish study that looked at the relationship between caring and finances was O’Shea’s (2000) report which found that ‘over two-thirds of carers interviewed expressed difficulty in making ends meet and therefore are likely to have suffered some sort of financial strain as a result of having caring responsibilities’.

Research carried out by Carers UK (2000) found that six out of ten carers providing substantial care said worry about their finances was affecting their health. Carers often live on low incomes; they may have given up work as a result of taking on the caring role or are of pensionable age. A report entitled *Caring on the Breadline* presented the survey results of a questionnaire sent to over 16,000 carers in the UK. Seventy-seven per cent of those who responded stated that they had become worse off since becoming carers. Six out of ten had to give up work due to becoming a carer and this resulted in a significant drop in income.

Salway et al (2007) have demonstrated the link between carers and poverty and loss of opportunity. The researchers studied Pakistani, Bangladeshi, Ghanaian and White

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<sup>10</sup> Source: Department of Health and Children Consolidated Salary Scales effective from June 2007. [http://www.welfare.ie/publications/sw19/sw19\\_sect5.html#5.7](http://www.welfare.ie/publications/sw19/sw19_sect5.html#5.7)  
[http://www.citizensinformation.ie/References/case-studies/cim\\_casestudy.2006-10-09.5449712545](http://www.citizensinformation.ie/References/case-studies/cim_casestudy.2006-10-09.5449712545)

English people of working age and found that carers were more likely to report ill-health, low levels of income and reduced social interaction.

## **2.7 Summary**

There is some Irish research and considerable international research that documents the relationship between caring and ill-health. Most research on the matter points to high levels of reported ill-health amongst at least some carer populations, particularly those who provide long hours of care. This piece of research by Care Alliance Ireland attempts to go some way to addressing the current gap in research on family carers and support informed decision-making by policy-makers, advocates and service providers.

### 3 Profile of the carers and their caring situations

This chapter presents a profile of the carers who responded to the survey in terms of their socio-demographics and the characteristics of their caring situations.

#### 3.1 Socio-demographics and income situation

Table 3.1 shows that more than four-in-five of the carers surveyed were female, reflecting the pattern amongst CA recipients. Relatively few of the carers were aged under 35, about one-quarter were to be found in each of the 35-44, 45-54 and 55-64 age groups, and just over one-in-seven were aged 65 years or older. This matches the profile of CA recipients overall.

**Table 3.1 Socio-demographic profile of respondents**

		Per cent of carers
<b>Gender</b>	Male	18.9
	Female	81.1
<b>Age</b>	<25	0.9
	25-34	8.4
	35-44	23.5
	45-54	26.5
	55-64	25.6
	65+	15.1
<b>Education</b>	None/primary	27.2
	Some secondary	37.7
	Secondary	22.3
	Some 3rd level	7.9
	Completed 3rd level	4.8
<b>Marital status</b>	Married/cohabiting	72.1

	Widowed	2.8
	Divorced/separated	6.6
	Single/never married	18.4
<b>Location</b>	Rural	56.7
	Urban	43.3
<b>Household composition</b>	1 person	1.6
	2	31.2
	3	23.9
	4	16.8
	5	13.0
	6	8.3
	7+ persons	5.1
<b>Household with person &lt;16 yrs</b>		37.2

Apart from the gender and age differences in comparison to the wider population, the respondents also showed a picture of considerably lower educational attainment. For example 4.8 per cent of carer respondents had completed third level, whilst 22.4 per cent of the SLÁN 02 respondents had (see Appendix V for full details).

Almost three-quarters (72.1 per cent) of respondents were married/cohabiting and just over one-quarter (27.9 per cent) were single, widowed or separated/divorced. Just over one-half (56.7 per cent) were living in a rural location and just under one-half (43.3 per cent) in an urban location.

Very few of the carers were living alone, reflecting the fact that the majority care for someone living in the same household. More than one-third (37.2 per cent) were in households with at least one child aged under 16 years.

Table 3.2 presents the main income-related characteristics of the carers. It can be seen that a large majority (86.1 per cent) were in receipt of the full Carer's Allowance,

with just over one-in-eight (13.9 per cent) in receipt of a partial allowance. Three-quarters (74.6 per cent) had no other income of their own. About one-in-ten had a part-time job or reported doing odd-jobs or occasional work. Only a very small proportion reported income from relatives/friends. Finally, just over three-quarters (75.5 per cent) had a medical card.

**Table 3.2 Income-related characteristics of the carers**

		Per cent of carers
<b>Carer's Allowance</b>	In receipt of full CA	86.1
	In receipt of partial CA	13.9
<b>Medical card</b>	Have a medical card	75.5
<b>Other sources of income</b>	No other sources of income	74.6
	Part-time job	9.6
	Odd job/occasional labour	1.8
	Other social welfare payments	3.3
	Income from relatives/friends	4.8
	Other	5.9
<b>Spouse/partner status</b>	Not living with spouse/partner	28.0
	Spouse full-time employed	25.4
	Spouse part-time employed	4.7
	Spouse unemployed	6.3
	Spouse receiving disability pay	17.0
	Spouse a pensioner	15.0
	Spouse in education/training	0.7
	Other	3.2

Looking at household income more generally, it is clear that the majority of carer households were mainly or fully dependent on social welfare income. More than one-



quarter (28.0 per cent) were not living with a spouse/partner and for almost one-third their spouse/partner was either receiving a disability payment (17.0 per cent) or was a pensioner (15.0 per cent). One-quarter (25.4 per cent) were living with a spouse/partner in full-time employment and for one-in-twenty (4.7 per cent) their spouse/partner was in part-time employment.

The level of unemployment of the spouses at first appears relatively low, at 6.3 per cent, but given that a large proportion of this sample (32 per cent) was not in the active labour market (i.e. are Pensioners, or on Disability Allowance), if you exclude this group, the rate of unemployment rises to over 9.5 per cent, which is almost twice the national average. This is likely to have implications for household risk of income poverty.<sup>11</sup>

Until 2006 the Carer's Allowance had been set at a rate almost equivalent to most social assistance rates. In 2006, a break was made bringing the rate to a level approximately 8 per cent higher than the lowest social assistance rates. In 2007, the allowance was raised to €200/€218 (under 66 years; 66 years and over). This more or less maintained the differential between Job Seeker's Allowance (the lowest social assistance payment) and Carer's Allowance (€185.80 vs. €200/€218). This is significant, because almost two-thirds of respondents reported that the Carer's Allowance was their only source of income.<sup>12</sup>

Virtually all the respondents shared a home with at least one other person (98.4 per cent) as opposed to living alone (1.6 per cent). Given that we have little detailed knowledge of the income of the other members of their household, it is virtually impossible to accurately assess whether or not the respondents and/or members of

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<sup>11</sup> In Ireland, relative income poverty is measured by calculating the median income – the mid-point on the scale of all incomes in the State from the highest to the lowest – and setting the line at 60 per cent of the median. People whose incomes fall below this line are said to be *at risk of poverty*. The most recent figures show 18.5 per cent of the population at risk of poverty (Combat Poverty Agency, 2007). Using the most recent information gathered in the EU-SILC survey for 2005, the CSO established that the median income per adult in Ireland during 2005 was €321.23 per week. Consequently, the 60 per cent of median income poverty line for a single adult derived from this value was €192.74 a week (CORI, 2007:2). Updating this figure to 2007 levels, using predicted increases in average industrial earnings (from the ESRI Medium-Term Review), produces a relative income poverty line of €208.61 for a single person. In 2007, any adult below this weekly income level will be counted as being at risk of poverty (CORI, 2007:2).

<sup>12</sup> The rates of payment differ depending on age. In 2007, those under 66 years received €200 per week, while those 66 years or over received €218 per week. Over 75 per cent of the respondents are under 66 years of age.

their household live below the poverty line, based on a household measurement of income.

**3.2 Characteristics of the caring situation**

As shown in Table 3.3, the vast majority of carers (86.5 per cent) were caring for just one person, although just over one-in-eight (12.9 per cent) reported caring for two people and small numbers reported caring for three or more people.

**Table 3.3 Amount and location of caring**

		Per cent of carers
<b>Number of people cared for</b>	1	86.5
	2	12.9
	3	0.5
	4	0.1
<b>Hours of care provided</b>	0-19	1.7
	20-39	8.7
	40-59	13.6
	More than 59	76.0
<b>Living with person cared-for</b>	Co-resident	86.8
	Live in different households	13.2

More than three-quarters (76.0 per cent) reported providing more than 59 hours of care per week and a further one-in-seven (13.6 per cent) reported providing between 40 and 59 hours. Just over one-in-ten carers (10.4 per cent) reported providing less than this. The majority (86.8 per cent) were caring for someone living in the same

household, with just over one-in-eight (13.2 per cent) caring for someone living elsewhere.

**3.2.1 Age profile of person cared for**

Table 3.4 presents the age profile of the persons cared for. It can be seen that just over two-in-five (41.1 per cent) were caring for someone aged 70 years or over, and one-in-nine (11.2 per cent) were caring for someone aged between 60 and 69. A little over one-quarter (27.3 per cent) were caring for someone aged between 18 and 59 and one-in-five (20.4 per cent) were caring for someone under 18.

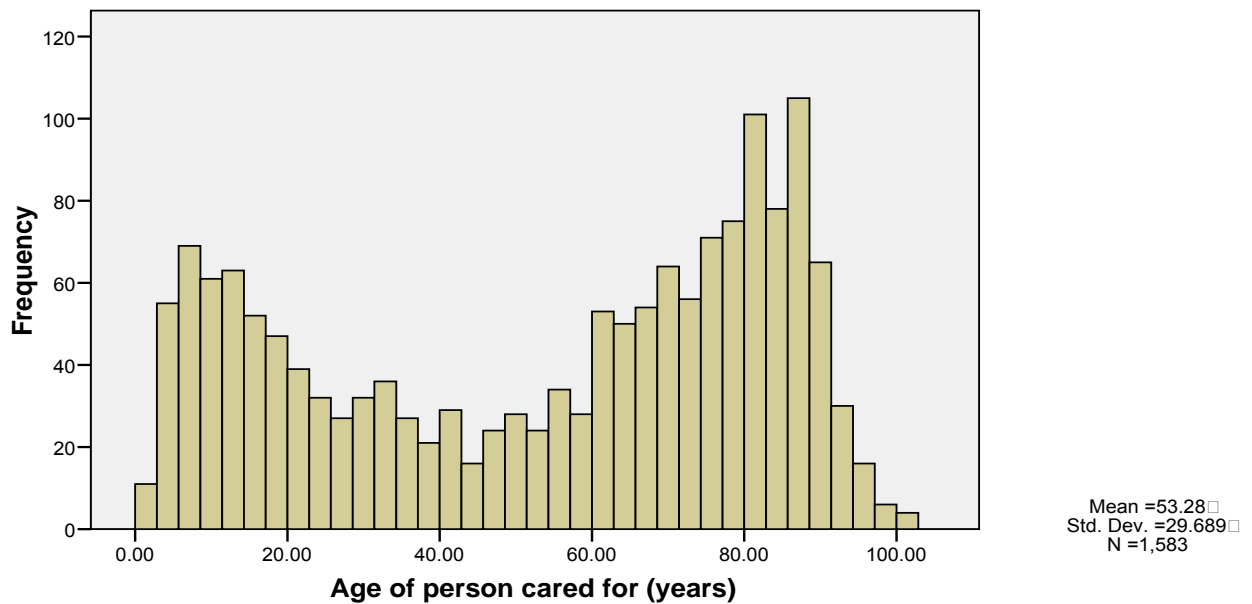
**Table 3.4 Age of persons cared for**

<b>Age of person cared for</b>	<b>Per cent of carers*</b>
< 18	20.4
18-29	9.0
30-39	6.7
40-49	5.1
50-59	6.5
60-69	11.2
70 +	41.1

*(\*Base: all persons being cared for; missing data = 29)*

Overall, as illustrated in Figure 3.4, it can be seen that those being cared for tended to be concentrated mainly in two age categories – children and people aged over 70.

**Figure 3.1 Age of person being cared for**



**3.2.2 Relationship with person cared for**

Table 3.5 shows the main types of relationships between carers and those that they cared for amongst carers caring for one person. Three main types of relationship predominate – caring for a child (33.5 per cent), caring for a parent/parent-in-law (30.0 per cent) or caring for a spouse/partner (25.6 per cent). Amongst those caring for a child, there were somewhat more individuals found to be caring for a child aged under 18 years (18.6 per cent) than for adult children (14.9 per cent). About one-in-eleven (9.3 per cent) reported caring for another relative and a small percentage (1.7 per cent) for a neighbour/friend/other person.

**Table 3.5 Main types of relationship with person cared for**

	Per cent of carers
Child	33.5
Child < 18	(18.6)
Child ≥ 18	(14.9)
Spouse/partner	25.6

Parent/parent-in-law	30.0
Other relative	9.3
Neighbour/friend/other	1.7

*(Base: carers caring for one person; missing data = 11)*

As already noted, just over one-in-eight carers were caring for more than one person. The vast majority of these were caring for two people. The main types of relationships in this case were caring for two children (27.2 per cent), for two parents/parents-in-law (23.9 per cent), for a spouse and another family member (20 per cent), for a parent/parent-in-law and another family member (18.3 per cent), and for various combinations of family members/neighbours/friends/others (10.6 per cent).

Figure 3.2 presents the age profiles in relation to main relationship with the carer. As regards carers caring for a spouse/partner, it can be seen that there is a tendency for this to increase in likelihood with age until about 70 and then fall off in likelihood with increasing age after that, with a concentration of this situation especially in the 50 to 70 age range.

**Figure 3.2 Age of person cared for by his/her relationship to person caring**

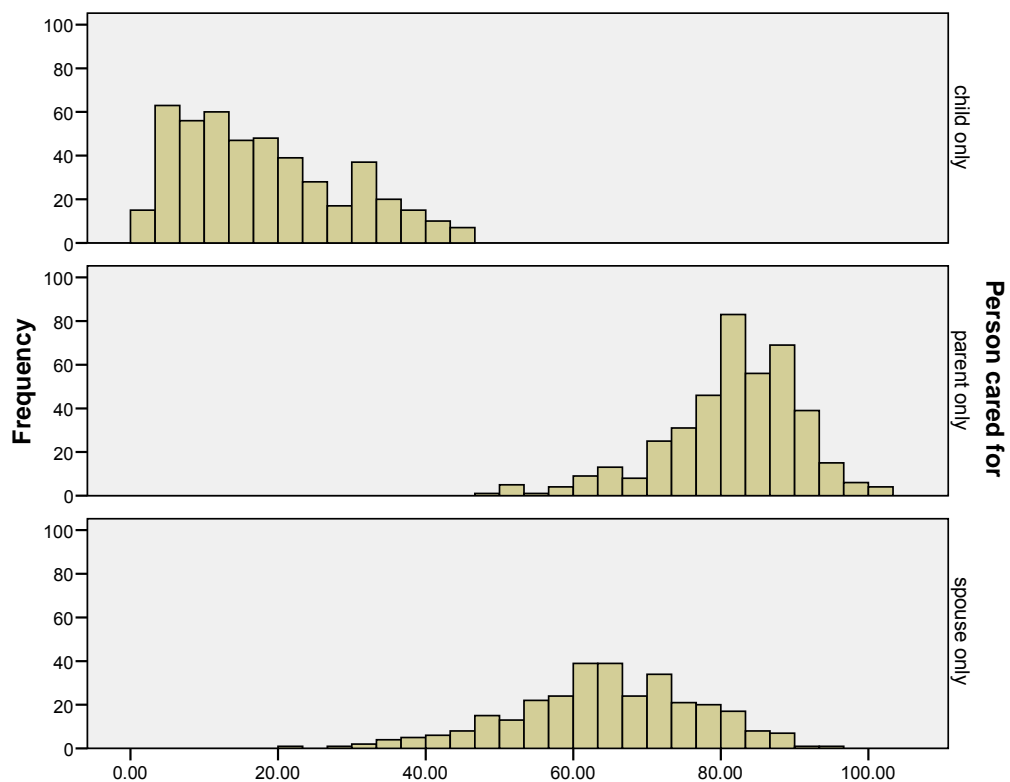


Table 3.6 presents details of the specific relationships involved. It can be seen that in the case of spouse/partners, overall men were more likely to be cared for and women were more likely to be the carer. In the case of parents/parents-in law, those being cared for were more likely to be women (reflecting, in the main, the greater life expectancy of women).

**Table 3.6 Specific relationships with the person cared for**

Relationship to carer	Per cent of carers
Husband/ male partner	18.9
Wife/ female partner	6.4
Mother/ mother-in-law	26.3

Father/ father-in-law	9.2
Sister	2.2
Brother	3.6
Daughter	15.7
Son	21.5
Cousin	0.4
Grandparent	0.6
Other relative	4.0
Neighbour	0.5
Friend	0.9
Other	0.6

(Base: total sample of carers, multiple responses; missing data = 13)

### 3.2.3 Description of persons cared for

Carers were asked to describe the person they care for in terms of a number of categories – ‘elderly/old person’, ‘person with a physical disability’, ‘person with an intellectual disability’ or ‘other’ – with the possibility to assign a person to more than one category. The results are summarised in Table 3.7, broken down according to the age of the person cared for.

The patterns with regard to the age of the person being cared for are interesting. Overall, it can be seen that, with just a few exceptions, it is only when the person being cared for is aged 70 or over that carers described them as being ‘elderly/old’. However, even amongst this age group, some carers focused only on the disability, describing the person being cared for as having a physical or intellectual disability, or both, rather than as being elderly/old *per se*. On the other hand, some carers of people in the older age groups described the person both in terms of being elderly/old and in terms of having one or other, or both, forms of disability.

**Table 3.7 Carers' description of the person cared for**

	Per cent carers				
	< 18	18-49	50-69	70+	Total
Elderly/old	0	0	1.7	32.5	34.2
<i>Elderly/old, unqualified</i>	0	0	0.6	19.9	20.5
<i>With physical disability</i>	0	0	0.7	10.0	10.7
<i>With intellectual disability</i>	0	0	0.2	1.1	1.3
<i>With physical &amp; intellectual</i>	0	0	0.2	1.5	1.7
Physical disability	6.2	7.8	12.0	7.4	33.3
Intellectual disability	6.2	7.4	1.6	0.6	15.8
Physical and intellectual	3.9	3.7	1.6	0.4	9.5
Other	2.1	1.8	2.2	1.1	7.2
Total	18.4	20.6	19.1	41.9	100.0

*(Base: carers caring for one person; missing data = 94)*

Interpreting the data from a different perspective, overall one-in-five (20.5 per cent) of those being cared for were described as being 'elderly/old' without mentioning any particular disability; nearly one-half (44.4 per cent) were described as having a physical disability; just over one-in-six (17.1 per cent) were described as having an intellectual disability; almost one-in-nine (11.2 per cent) were described as having both a physical and intellectual disability; and just over one-in-thirteen (7.2 per cent) were described as having some other form of need for care (for example, mental illness).



### **3.3 Summary and conclusions**

Reflecting on the profile of recipients of Carer's Allowance more generally, the carers in this survey were predominantly but not exclusively female and were mainly concentrated in the 35-to-64 years age range. Ninety per cent were providing at least 40 hours of care per week, with the majority of these providing more than 59 hours per week. There was a mix of caring situations, mainly falling into three groups: people caring for their children (both young and grown up), for their spouse/partner and for a parent/parent-in-law.

More than one-half were caring for someone aged 60 years or older, either people caring for a parent/parent-in-law or one partner in an older couple caring for the other. As regards type of care needs, nearly one-half were caring for someone described as having a physical disability (this included older people with physical disabilities also), one-in-six were caring for someone described as having an intellectual disability and almost one-in-nine were caring for someone with both.

The majority of respondents are relying solely on the Carer's Allowance as an income.

## 4 General health and well-being of carers

This chapter looks at the general health and well-being of the carers who were surveyed. Where possible, comparisons are made with the wider population, based on the data from the SLÁN survey.

### 4.1 Quality of life

Table 4.1 shows that the majority of carers reported their quality of life to be good or very good (68.1 per cent), but almost one-in-four (23.3 per cent) reported it to be neither good nor poor, and about one-in-twelve (8.5 per cent) reported it to be poor or very poor.

**Table 4.1 Self-reported Quality of Life (QoL)**

QoL rating	Carers	SLÁN (weighted)
	per cent of carers	per cent of adult population
Very poor	2.0	1.2
Poor	6.5	2.8
Neither good nor poor	23.3	13.5
Good	52.1	54.8
Very good	16.0	27.7
Total	100 per cent	100 per cent

*(Base: total sample of carers, missing data = 30;  $\chi^2$ df,4=177.6, p<.0001)*

Table 4.1 also shows that carers presented a considerably less positive picture of quality of life in comparison to the general population<sup>13</sup>. In the SLÁN survey, 27.7 per cent reported themselves to have a very good quality of life whilst in the Carers survey only 16.0 per cent did so. At the other end of the spectrum, carers were a lot

<sup>13</sup> This pattern is also reflected in the mean scores of the two groups, with the mean score on quality of life for carers being, statistically, significantly lower than that found in the SLÁN (2003) survey (Carer survey mean=3.74±0.9, SLÁN mean=4.05±0.8, F(df 1,6839)=165.2 p<.0001).

more likely to report their quality of life to be neither good nor poor, and also more likely to report it to be poor or very poor.

A large gender difference is reported, where female carers are almost twice as likely to report a very good quality of life as compared to male carers (17.4 per cent vs. 9.6 per cent) Female carers are also considerably less likely to report to have a poor or very poor quality of life. (7.6 per cent vs. 13 per cent). Further analysis of this is warranted. This finding does however provide some evidence to support the development of tailored interventions targeted specifically at male carers.

**4.2 Self-reported general health<sup>14</sup>**

Table 4.2 presents the self-reported general health of the respondents. It can be seen that more than one-third (36 per cent) of carers reported their health to be ‘very good’ or ‘excellent’, a little under one-half (46.1 per cent) reported their health to be ‘good’, and fewer than one-in-five (17.9 per cent) reported their health to be only ‘fair’ or ‘poor’.

**Table 4.2 Self-reported general health**

Health rating	Carers	SLÁN (weighted)
	Per cent of carers	Per cent of adult population
5 Excellent	10.5	12.9
4 Very good	25.5	32.0
3 Good	46.1	37.5
2 Fair	16.1	14.8
1 Poor	1.8	2.8
Total	100 per cent	100 per cent

*(Base: total sample of carers, missing data = 13;  $\chi^2$ df,4=46.6, p<.0001)*

<sup>14</sup> Clearly there are limitations to the exclusive use of self-reported health as a health measurement. Unfortunately, budgetary and logistical constraints prevented the use of more objective measurement tools: for example GP assessments etc.

This picture can be reasonably compared with the picture for the general population as found in SLÁN. It is necessary to take into account the fact that the SLÁN survey covers the national population of adults, which differs considerably from the Carer's Allowance population along key dimensions such as gender, age and educational attainment. Comparisons therefore require that the SLÁN data be weighted to make it more comparable to the Carer sample. The fact that detailed information on respondents income was not asked of in the survey does impact on our ability to control fully for this variable. This is particularly important given the well documented relationship between income and health. By controlling for educational attainment, we have attempted to go some way to separating the effect income has on the reported health of the respondents. (See Appendix V for further details of weighting)

From Table 4.2 it can be seen that carers were less likely to report themselves in 'very good' or 'excellent' health as opposed to 'good' health compared to the general population. Amongst the carers, 36 per cent said they were in very good or excellent health, whilst for the SLÁN survey 44.9 per cent said they were in very good or excellent health. Although the differences may not seem especially dramatic the data show a statistically significant<sup>15</sup> pattern of carers reporting being less healthy than does the general population.

#### **4.3 Satisfaction with health**

As shown in Table 4.3, the majority of carers (70.1 per cent) were either satisfied or very satisfied with their health. Comparisons with SLÁN found no significant difference between carers and the general adult population in this regard. This seems, at least in part, to be due to carers being somewhat more likely to express relatively high satisfaction with a health rating of 'good'.

There is a gender dimension to this data, with male carers being less likely to report being very satisfied with their health (11.7 per cent vs. 15.1 per cent) and more likely to report being very dissatisfied with their health (4.3 per cent vs. 3.3 per cent).

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<sup>15</sup> This pattern is also reflected in the mean scores of the two groups, with self-reported general health amongst carers being, at least statistically, significantly lower than that found in SLÁN 2003 (Carer

**Table 4.3 Satisfaction with health**

Satisfaction rating	Carers	SLÁN (weighted)
	Per cent of carers	Per cent of adult population
Very dissatisfied	3.4	2.5
Dissatisfied	9.3	9.2
Neither satisfied nor dissatisfied	17.1	18.2
Satisfied	55.4	53.1
Very satisfied	14.7	17.0
Total	100 per cent	100 per cent

(Base: total sample of carers, missing data = 40;  $\chi^2_{df,4}=8.9$ , n.s.)

#### 4.4 Specific health problems experienced

Carers were also asked whether over the past 12 months they had experienced any of a range of specific health problems. The percentages reporting each problem are presented in Table 4.4 in order of frequency of occurrence.

**Table 4.4 Specific health problems experienced in past 12 months**

Experienced in past 12 months	Per cent of carers
Stress/ nervous tension	40.8 per cent
Headaches	29.8 per cent
Lower back pain	26.3 per cent
Aching joints	25.8 per cent

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survey mean=3.27±0.9, SLÁN mean=3.37±1.0, F(df 1,6839)=12.7 p<.001), although the absolute difference is quite small.

Anxiety	22.6 per cent
Depression	17.6 per cent
High blood pressure	15.8 per cent
Urinary problems	8.4 per cent
Rheumatoid arthritis	8.2 per cent
Osteo-arthritis	7.7 per cent
Asthma	6.8 per cent
Diabetes	3.8 per cent
Chest/lung disease	2.6 per cent
Angina	1.8 per cent
Stroke	0.6 per cent
Cancer	0.6 per cent
Heart attack	0.4 per cent

*(Base: total sample of carers for each specific health problem)*

It can be seen that stress and nervous tension was the health problem experienced most by carers. Headaches, back pain and aching joints were the next most frequent, followed by anxiety and depression.

Whilst there is uncertainty as to the causal connection, nonetheless we can say that family carers are reporting relatively high levels of specific health problems.

#### **4.5 Activity limitation**

Finally, carers were asked whether their daily activity was limited by a long-term illness, health problem or disability. From Table 4.5 it can be seen that just over one-in-nine carers (11.3 per cent) reported such activity limitation.

**Table 4.5 Daily activity limited by health or disability**

<b>Daily activity limited by health or disability</b>	<b>Per cent of carers</b>
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Yes	11.3
No	88.7
Total	100 per cent

*(Base: total sample of carers; missing data = 25)*

#### **4.6 Summary and conclusions**

The results show that health issues are important for carers. They report an overall less positive picture in terms of self-reported health and substantially lower quality of life than that of the general population. In addition, two-in-five carers report having experienced stress/ nervous tension and one-in-nine carers report having their daily activity limited by ill-health or disability in the past twelve months

**5 Impacts of caring, coping strategies and support**

This chapter turns to an examination of whether carers report direct impacts of caring on their health and well-being and what aspects of caring pose most difficulties for them. It also looks at the coping strategies that carers use to help deal with the challenges of caring and at the levels of support that carers have to help them in their caring role. Effective coping strategies and good support from others are important for anyone, including carers, when dealing with challenging circumstances and can reduce the likelihood of negative impacts on health and well-being (Smedley and Syme, 2001; Berkman, 1995; Berkman and Kawachi, eds, 2000).

**5.1 Health**

When carers were asked whether their health had suffered due to their caring responsibilities, just under one-third (29.5 per cent) said that it had (Table 5.1).

**Table 5.1 Reported impact of caring role on health**

<b>Health has suffered</b>	<b>Per cent of carers</b>
Yes	29.5
No	70.5
Total	100 per cent

*(Base: total sample of carers; missing data = 30)*

**5.2 Leisure or recreational activities**

When asked whether their leisure or recreational activities were limited by their caring work, almost one-half of the carers (45.4 per cent) said that these activities were limited quite a lot or a great deal (Table 5.2).



**Table 5.2 Perceived impact of caring role on leisure/ recreational activities**

<b>Leisure limited</b>	Per cent of carers
Not at all	16.0
A little	38.6
Quite a lot	26.9
A great deal	18.5
Total	100 per cent

*(Base: total sample of carers; missing data = 39)*

### **5.3 Most difficult things about caring**

Carers were asked which of a variety of specific aspects of caring were the most difficult. The response categories were formulated during the literature review which identified the key difficulties as reported by family carers. As such they are not validated scales *per se*. The responses are listed in Table 5.3 in order of frequency of occurrence.

Sadness for the person cared for, being constantly on call and stress were each reported by around one-half of carers. Emotional strain and lack of sleep/ tiredness were reported by about two-in-five. Frustration, isolation and guilt were also reported, although less frequently.

**Table 5.3 Specific difficulties experienced by carers**

<b>Most difficult things about caring</b>	Per cent of carers
Sadness for person I care for	55.6
Being constantly on call	50.9
Stress	49.2
Emotional strain	43.1
Lack of sleep/ tiredness	42.1

Frustration	31.7
Isolation	22.8
Guilt	14.7

*(Base: total sample of carers, multiple response; missing data = 80)*

#### **5.4 Coping strategies**

Carers were asked which of a range of specific strategies they used to assist them in the caring role. The response categories are based primarily on the ones used in SLÁN 02, with additional carer specific categories added (namely use of respite, attendance at support group and use of phone line support). Carers were asked to tick those that applied to their situation. These response categories are listed in Table 5.4 in order of frequency of occurrence.

Talking to friends and watching TV were by far the most frequently reported coping strategies that were used to keep going, with praying and exercise being the next most frequent.

**Table 5.4 Strategies to cope with caring role**

<b>Strategies used to keep going</b>	<b>Per cent of carers</b>
Talk to friends	65.7
Watch TV	62.5
Praying/ Faith	39.6
Exercise	35.9
Smoking	19.0
Use respite	13.2
Take medication	11.1

Drink alcohol	9.0
Attend support group	6.8
Use phone line support	4.5
Alternative medicine	4.0

*(Base: total sample of carers, multiple responses; missing data =50)*

## 5.5 Support

Again, for comparison purposes the question used in SLÁN 02 was replicated here. Carers were asked about the level of support they had available to them from people in their household, as well as from their wider family, friends and people in the workplace (where relevant). These were used to construct a composite support scale that attempted to reflect the amount and quality of support carers reported overall (Table 5.5).<sup>16</sup>

**Table 5.5 Support from household, wider family, friends and people in the workplace**

Level of support	Per cent of carers
Little/None	18.7
Some, but no major source	29.0
One major source	32.0
More than one major source	20.3
Total	100 per cent

*(Base: total sample of carers)*

It can be seen that there is considerable variability across the carer population, with about one-half reporting little/none (18.7 per cent) or some but no major source of support (29.0 per cent) and the other half reporting having one (32.0 per cent) or more than one (20.3 per cent) major source of support.

<sup>16</sup> 'Little/None' is where the carer does not report support, or reports only minimal support, from any source. 'Some, but no major source' is where the carer reports some support from at least one source but none of the sources gives a lot of support. 'One major source' is where the carer reports a lot of support from one source, and 'More than one major source' is where the carer reports a lot of support from more than one source.

**5.5.1 Overall comparative support scores**

To collate the support domains, we made overall support a constructed measure (Table 5.6), where a carer level of support for each of the 7 sources of support (Spouse/Partner, Parents, Children, Other Close Relatives, Friends, Employer/Boss, Colleagues) was added together. The minimum overall support a carer could have was 0 and the maximum was 35 (i.e. 7x5 where 5 is the max of each 5-point scale).

**Table 5.6 Overall comparative support score**

Survey	Mean	N	St Deviation
Carers	8.776	1413	5.98409
SLÁN 02 (Weighted)	12.8647	5525	9.06480

We can see that the overall average support score reported amongst the respondents is considerably lower than those in SLÁN.

**5.6 Summary and conclusions**

The results show that many carers reported negative impacts of caring on their health and well-being. Nearly one-third reported that their health had suffered due to their caring responsibilities and almost one-half said that their leisure or recreational activities had been limited quite a lot or a great deal. Emotional issues, stress, being constantly on-call and lack of sleep/ tiredness were frequently mentioned amongst the most difficult things about caring.

Talking to friends and watching TV were the most frequently mentioned coping strategies for carers, followed by praying/faith and exercise. Amounts of support from family and others varied widely, with about one-half of carers being without a major source of support and about one-quarter with little or no support at all. Carers, when compared with the weighted SLÁN 02sample, reported considerably lower levels of overall support.

**6 Other health-related lifestyle factors**

In order to get a better understanding of factors influencing carers' health and well-being, carers were also asked about health-related lifestyle issues not necessarily linked to caring *per se*, in particular smoking and alcohol consumption, and injuries.

**6.1 Smoking**

The survey found that about one-quarter (25.9 per cent) of carers reported smoking regularly and a further 4.8 per cent reported smoking occasionally. Comparison with the SLÁN survey shows that carers are significantly more likely to smoke than the general population.

**Table 6.1 Smoking**

<b>Smoking cigarettes/cigars now</b>	<b>Carers</b>	<b>SLÁN (weighted)</b>
	Per cent of carers	Per cent of adult population
Smoke regularly	25.9	21.0
Smoke occasionally	4.8	3.3
Do not smoke	69.3	75.7
Total	100.0	100.0

*(Base: total sample of carers, missing data = 23;  $\chi^2_{df,2}=24.4, p<.001$ )*

**6.2 Alcohol consumption**

Carers are significantly less likely than the general population to report drinking alcohol and, if they do, they reported drinking less frequently (Tables 6.2 and 6.3).

**Table 6.2 Drinking alcohol – frequency (1)**

<b>Last time had alcoholic drink</b>	<b>Carers</b>	<b>SLÁN (weighted)</b>
	Per cent of carers	Per cent of adult population

During last week	30.1	54.6
One week to 1 month ago	18.6	13.8
One month to 3 months ago	9.4	5.6
Three months to 12 months ago	8.5	3.6
More than 12 months ago	11.5	5.9
Never had alcohol beyond sips or tastes	21.9	16.6
Total	100.0	100.0

(Base: total sample of carers, missing data = 53;  $\chi^2df,5=296.6$ ,  $p<.00001$ )

**Table 6.3 Drinking alcohol – frequency (2)**

Days drinking per week	Carers	SLÁN (weighted)
	Per cent of carers	Per cent of adult population
1	53.5	28.2
2	23.7	28.5
3	11.4	18.0
4	3.8	10.8
5	2.7	6.3
6	0.5	1.8
7	4.3	6.4
Total	100.0	100.0

(Base: people who drank in last 12 months;  $\chi^2df,6=140.6$ ,  $p<.00001$ )

### 6.3 Injuries

Carers were a little more likely than the general population to have had an injury serious enough to interfere with their daily activities in the past two years (Table 6.4). Amongst those carers who did report an injury, almost two-thirds were back injuries. Such injuries may in some cases have been as a result of caring (e.g. lifting or moving the person being cared for) although we do not have the information

available to enable determination of this. Whatever the cause, back injury may pose additional challenges for carers who must lift or move the person that they care for.

**Table 6.4 Injuries interfering with daily activities**

<b>One or more injuries in last 2 years serious enough to interfere with daily activities</b>	<b>Carers</b>	<b>SLÁN (weighted)</b>
	Per cent of carers	Per cent of adult population
Any injury	14.0	13.0
(Of which back injury)	(61.1)	-
No injury	86.0	87.0
Total	100.0	100.0

*(Base: total sample of carers, missing data = 55;  $\chi^2$ df,1=2.0, n.s.)*

#### **6.4 Summary and conclusions**

Carers are significantly more likely to be smokers and less likely to be regular drinkers than the general population, and seem to have about the same likelihood of being injured. Other factors such as level of exercise and nutritional intake were unfortunately not within the scope of this study.

## **7 Factors associated with negative outcomes for carers**

This chapter brings together the results from the previous chapters to examine what factors are associated with negative outcomes for carers. The analysis looks at whether particular carers or caring situations are more likely to have negative outcomes and what factors are most important in relation to whether or not negative outcomes occur. This can provide pointers to where policy efforts may especially need to focus.

The analysis focuses on two types of negative outcome:

- Carers reporting that their health had suffered due to being a carer
- Carers reporting lower quality of life (neither good nor poor, poor or very poor quality of life)

The five main sets of variables included in this analysis were:

- Socio-demographic (age, gender, etc.)
- Characteristics of the caring situation (relationship to person cared for, age and description of person cared for, hours caring, number cared for, whether living with the person cared-for or not, and description of the type of person being cared-for)
- Types of care-related impacts (leisure limited by caring and the various specific difficulties experienced)
- Potential moderating factors (coping strategies and levels of support)
- Other health-related lifestyle factors (smoking, drinking, injuries)

Logistic regression was used for this purpose, a technique that enables the relative influence of each of the different factors, on their own, to be determined.

### **7.1 Health**

In the stepwise logistic regression carried out for this indicator, the final model had seven variables reaching statistical significance (see Appendix VI for details).



Together, these factors account for 48 per cent of the variation in whether or not a carer reports that his/her health has suffered due to being a carer, and thus the set of factors in question are important ones for policy attention.

These variables were, in order of statistical significance:

- leisure limited by caring
- stress
- lack of sleep/ tiredness
- emotional strain
- injury in the past two years
- talking to friends (as coping strategy)
- isolation

Table 7.1 presents the results of the logistic regression in terms of the separate influences of each factor on likelihood of reporting health has suffered, independent of the influences of any of the other relevant factors.

The results show that likelihood of reporting that health has suffered is strongly associated with whether or not caring impacts on leisure. Where leisure is limited a great deal, negative health impacts are 7.8 times more likely to be reported than where leisure is not affected at all. Significantly increased likelihood of negative health impacts were also found when caring is reported to cause stress (3.2 times more likely), lack of sleep/ tiredness (2.7 times more likely), emotional strain (2.7 times more likely) and isolation (1.7 times more likely).

**Table 7.1 Factors increasing the likelihood of carers reporting their health suffering due to being a carer**

Dimension	Specific factor	Relative likelihood of reporting health has suffered (compared with the first category in each case)
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Type of care-related impact	1. Leisure limited by caring	
	– not at all	1
	– a little	(1.8)
	– quite a lot	4.6
	– a great deal	7.8
	2. Stress	
	– no	1
	– yes	3.2
	3. Lack of sleep/ tiredness	
	– no	1
	– yes	2.7
	4. Emotional strain	
	– no	1
	– yes	2.7
	7. Isolation	
	– no	1
	– yes	1.7
Moderators	6. Talk to friends (as coping strategy)	
	– yes	1
	– no	1.7
Health-related lifestyle	5. Injury in past two years	
	– no	1
	– yes	3.1

*Note: the specific factors are numbered 1 to 7 in order of their statistical significance.*

Talking with friends as a coping strategy was also strongly associated. Where this strategy is not reported negative health impacts are 1.7 times more likely to be reported.

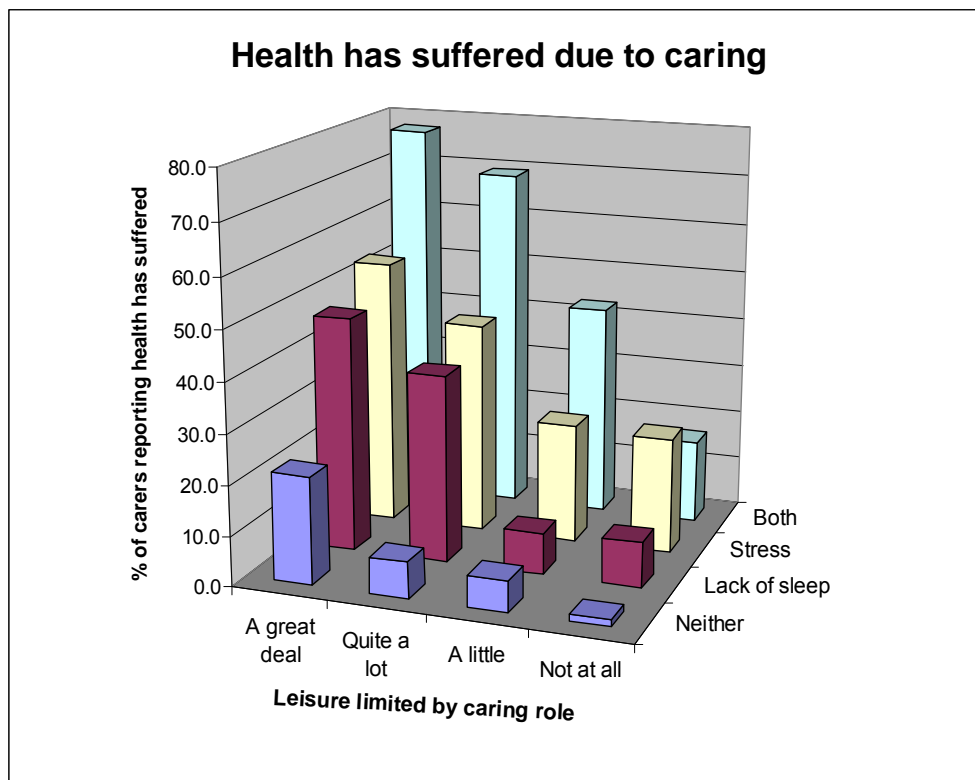
Finally, where an injury in the past two years is reported, negative health impacts are 3.1 times more likely to be reported. In this case the direction of causality is not clear.

In some cases it may be that an injury un-related to caring has been a factor in making caring more damaging to the carer's health; in other cases it may be that the injury occurred in relation to caring and thus is a direct health impact in itself.

### 7.1.2 Combined effects of key factors

These factors not only have influence on their own but often have additive impacts such that when two or more factors are involved the impacts are much greater. To illustrate this, Figure 7.1 presents the separate and combined associations between the first three of the significant variables in Table 7.1 and the likelihood of reporting negative health impacts from caring. It can be seen that more than three-quarters of carers who experience a great deal of leisure limitation *and* stress *and* lack of sleep report that their health has suffered due to caring.

**Figure 7.1 Additive effect of stress, lack of sleep, and interference with leisure on whether health suffers due to caring responsibilities**



## 7.2 Quality of life

A similar analysis was carried out to examine what factors are associated with greater likelihood of reporting lower quality of life. In the stepwise logistic regression carried out for this indicator, the final model had eleven variables reaching statistical significance (see Appendix VI for details). Together, these factors account for 32 per cent of variation in whether or not a carer reports lower quality of life, and thus the set of factors in question are important ones for policy attention.

These variables, in order of statistical significance, were:

- leisure limited by caring
- availability of support
- stress
- talking to friends (as coping strategy)
- isolation
- spouse in full-time employment
- lack of sleep/ tiredness
- emotional strain
- gender
- prayer/faith (as coping strategy)
- injury in the past two years (other than back injury)

Table 7.2 presents the results of the logistic regression in terms of the separate influences of each factor on likelihood of reporting lower quality of life, independent of the influences of any of the other relevant factors.

**Table 7.2 Factors increasing the likelihood of carers reporting lower quality of life**

Dimension	Specific factor	Relative likelihood of low quality of life (compared with the first category in each case)
Type of care-related impact	1. Leisure limited by caring – not at all – a little – quite a lot – a great deal	1 (1.6) 3.0 3.3
	3. Stress – no – yes	1 1.9
	7. Lack of sleep/ tiredness – no – yes	1 1.7
	8. Emotional strain – no – yes	1 1.5
	5. Isolation – no – yes	1 1.9
	Moderators	4. Talk to friends (as coping strategy) – yes – no
10. Prayer/faith (as coping strategy) – yes – no		1 1.5

	2. Support – more than 1 major source – 1 major source – some, but no major source – little/none	1 (1.2) 1.6 2.7
Health-related lifestyle	11. Injury in past two years (not back) – no – yes	1 2.1
Socio-demographic	9. Gender – female – male	1 1.6
	6. Spouse in full-time employment – yes – no	1 1.9

*Note: the specific factors are numbered 1 to 11 in order of their statistical significance.*

The results again show the importance of impacts of caring on leisure time. Where leisure is limited a great deal there is a 3.3 times greater likelihood of lower quality of life being reported in comparison to where leisure is not limited at all. Significantly increased likelihood of lower quality of life is also found where caring causes stress (1.9 times more likely), isolation (1.9 times more likely), lack of sleep/ tiredness (1.7 times more likely) and emotional strain (1.5 times more likely).

Two socio-demographic factors were found to be important. Being a male is associated with a 1.6 times greater likelihood of lower quality of life than being a female. Not having a spouse/partner in full-time employment, which is likely to result in a relatively low household income level, is associated with a 1.9 times greater likelihood of a lower quality of life. Finally, having had an injury (other than a back injury) in the past two years is associated with a 2.1 times greater likelihood of reporting lower quality of life.

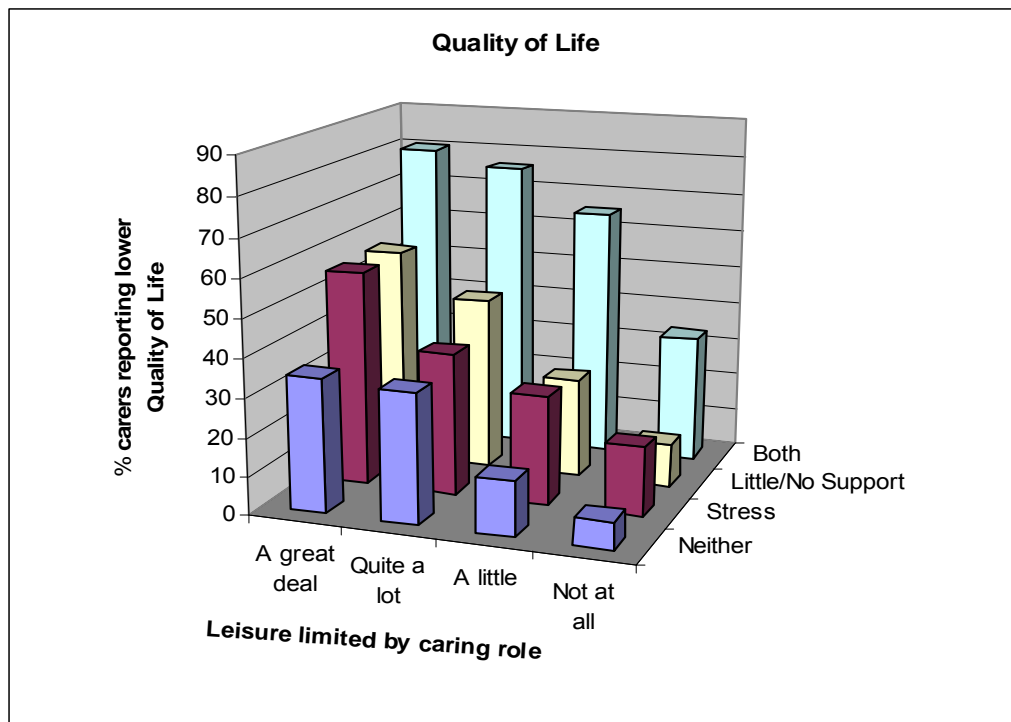
The extent of support available is also a key factor. Where there is little or no support there is a 2.7 times greater likelihood of lower quality of life being reported in comparison to where there is more than one good source of support.

Talking with friends is used as a coping strategy and is also strongly associated. Where this strategy is not reported there is a two times greater likelihood of lower quality of life being reported. However, where use of prayer/faith as a coping strategy is reported there is a 1.5 times greater likelihood of reporting lower quality of life.

### **7.2.1 Combined effects of key factors**

Again, these factors not only have influence on their own but often have additive impacts such that when two or more factors are involved the impacts are much greater. To illustrate this, Figure 7.2 presents the separate and combined associations between the first three of the significant variables in Table 7.2 and likelihood of reporting low quality of life.

**Figure 7.2 Additive effect of interference with leisure, stress and lack of support on quality of life among carers**



It can be seen that more than three-quarters of carers who experienced a great deal of leisure limitation *and* stress *and* little or no support reported a lower quality of life.

### 7.3 Leisure and recreation

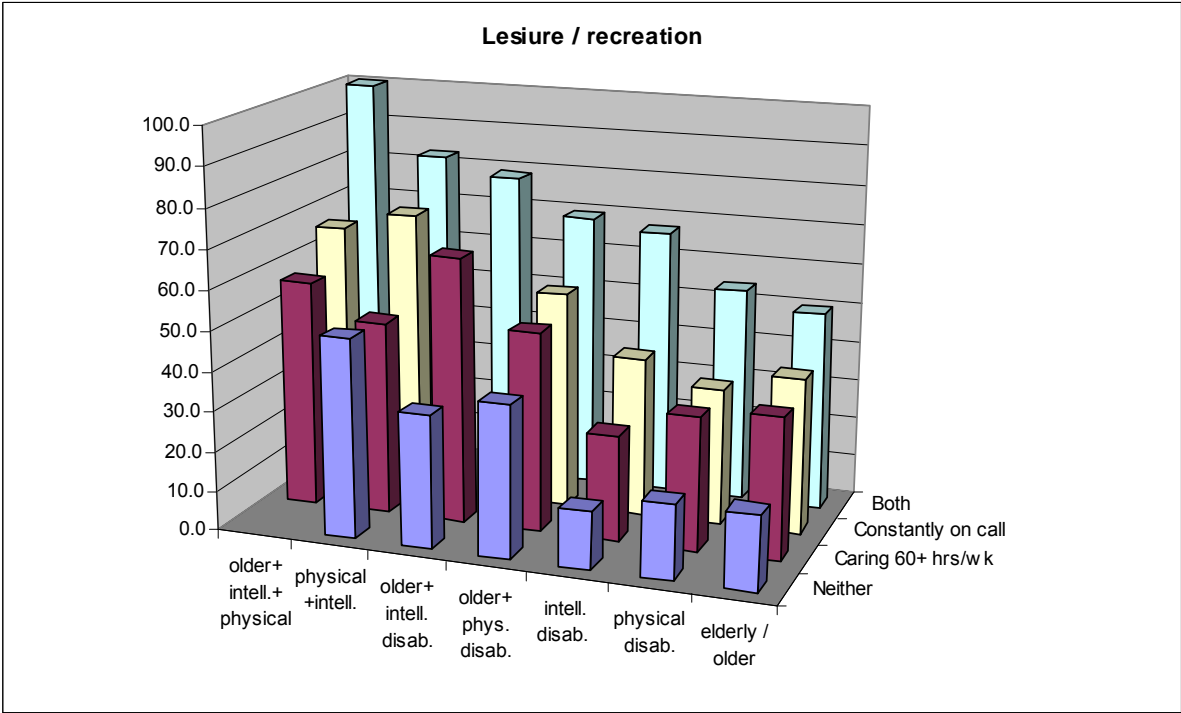
The results for both health suffering due to caring and lower quality of life point to the major role that the impact of caring on leisure/recreation activities plays in the underlying processes. An examination of whether certain carers and caring situations are more likely than others to be associated with limited leisure/recreation found three aspects that are especially linked with likelihood of substantial limitations in leisure/recreation due to caring:

- greater hours of caring per week
- being constantly on call
- needs of person being cared-for (as described by the carer)

Figure 7.3 presents an illustration of the effects of these three factors.



**Figure 7.3 Additive effects of hours of care, being constantly on call and type of needs on limitation of leisure/recreation activity**



It can be seen that a combination of caring for people with multiple/ more challenging needs, providing long hours of care and being constantly on call has a major impact on leisure/recreation activities for the vast majority of carers concerned.

**7.4 Summary and conclusions**

The analysis in this chapter has identified some key factors that increase the likelihood of negative outcomes for carers. The extent of limitation posed by caring on leisure/recreation appears to be a key factor both in likelihood of health suffering due to caring and likelihood of low quality of life for carers. Those caring for longer hours, being constantly on call and caring for certain types of needs (particularly where there are specific physical and/or intellectual disabilities combined with old age) are especially likely to report substantial limitations on their leisure/recreation activities. Stress, lack of sleep/ tiredness, emotional strain and isolation are also important factors in likelihood of negative impacts on health.

## **8. Conclusion**

This research has attempted to develop our understanding of the relationship between caring and the health and well-being of a significant group of full-time family carers in Ireland. Comparisons with the general population were made, controlling for the three key variables of age, gender and educational attainment.

### **8.1 Key findings**

Carers presented a considerably less positive picture of quality of life in comparison to the general population. In the SLÁN 02 survey, 27.7 per cent reported themselves to have a very good quality of life whilst in the carers survey only 16.0 per cent did so. At the other end of the spectrum, carers were a lot more likely to report their quality of life to be neither good nor poor, and also more likely to report it to be poor or very poor.

Carers were less likely to report themselves in 'very good' or 'excellent' health as opposed to 'good' health compared to the general population. Amongst the carers, 36 per cent said they were in very good or excellent health, whilst for the SLÁN 02 survey 44.9 per cent said they were in very good or excellent health. The data show a statistically significant pattern of carers reporting being less healthy than does the general population.

A majority of carers (70.1 per cent) were either satisfied or very satisfied with their health. Comparisons with SLÁN 02 found no significant difference between carers and the general adult population in this regard.

#### **Other key findings**

- Two-in-five carers reported having experienced stress/ nervous tension and one-in-nine carers reported having their daily activity limited by ill-health or disability in the past twelve months

- When family carers were asked to report negative impacts of caring on their health and well-being, nearly one-third reported that their health had suffered due to their caring responsibilities and almost one-half stated their leisure or recreational activities had been limited quite a lot or a great deal
- Emotional issues, stress, being constantly on-call and lack of sleep/ tiredness were frequently mentioned amongst the most difficult things about caring
- Talking to friends and watching TV were the most frequently mentioned coping strategies for carers, followed by praying/faith and exercise. Amounts of support from family and others varied widely, with about one-half of carers being without a major source of support and about one-quarter with little or no support at all. Carers, when compared with the weighted SLÁN 02 sample, reported considerably lower levels of overall support
- Carers were significantly more likely to be smokers and less likely to be regular drinkers than the general population, and seem to have about the same likelihood of being injured.

### **Multivariate analysis**

- Two socio-demographic factors were also found to be important. Firstly, being a male was associated with a 1.6 times greater likelihood of lower quality of life than being a female
- Secondly, not having a spouse/partner in full-time employment was associated with a 1.9 times greater likelihood of lower quality of life
- The results show that likelihood of reporting that health has suffered was strongly associated with whether or not caring impacts on leisure. Where leisure is limited a great deal, negative health impacts were 7.8 times more likely to be reported than where leisure is not affected at all
- Significantly increased likelihood of negative health impacts were also found when caring is reported to cause stress (3.2 times more likely), lack of sleep/ tiredness (2.7 times more likely), emotional strain (2.7 times more likely) and isolation (1.7 times more likely)

- The results again show the importance of impacts of caring on leisure time. Where leisure is limited a great deal there was a 3.3 times greater likelihood of lower quality of life being reported in comparison to where leisure is not limited at all. Significantly increased likelihood of lower quality of life was also found where caring causes stress (1.9 times more likely), isolation (1.9 times more likely), lack of sleep/ tiredness (1.7 times more likely) and emotional strain (1.5 times more likely)
- The extent of support available was also a key factor. Where there is little or no support there was a 2.7 times greater likelihood of lower quality of life being reported in comparison to where there is more than one good source of support
- Talking with friends as a coping strategy was strongly associated. Where this strategy is not reported there was a two times greater likelihood of lower quality of life being reported. However, where use of prayer/faith as a coping strategy is reported there was a 1.5 times greater likelihood of reporting lower quality of life
- Finally, having had an injury (other than a back injury) in the last two years was associated with a 2.1 times greater likelihood of reporting lower quality of life.

The extent of limitation posed by caring on leisure/recreation appeared to be a key factor both in likelihood of health suffering due to caring and likelihood of low quality of life for carers. Those caring for longer hours, being constantly on-call and caring for certain types of needs (particularly where there are specific physical and/or intellectual disabilities combined with old age) were especially likely to report substantial limitations on their leisure/recreation activities. Stress, lack of sleep/ tiredness, emotional strain and isolation were also important factors in likelihood of negative impacts on health. On the positive side, availability of good support and talking to friends as a coping strategy seemed to provide a buffer against negative impacts.

Returning to the hypothesis, the research can conclude that there is some evidence that low-income, full-time family carers are indeed a group that are particularly vulnerable to poor health.

## **8.2 Policy recommendations**

### **Key recommendations**

#### **1. Increase opportunities for breaks for family carers**

When caring severely restricts leisure/recreational opportunities family carers are a lot more likely to report that their health has suffered and/or a lower quality of life. This emphasises the importance of policy efforts to ensure that carers have breaks and time to themselves. Respite services have a key role to play in this, as do active efforts to encourage and support carers to have a life beyond caring.

Alongside restricted leisure time, lack of sleep/ tiredness is a big factor in the likelihood of carers experiencing negative impacts of caring on their health and well-being. Policy efforts should therefore give attention to implementing supports that help carers to get enough sleep and rest and not have an unreasonable care burden to manage. Night-time respite services could have an important role in relation to lack of sleep. There are also promising developments in technologies that can monitor the person being cared for so that the carer can get enough sleep. More generally, sufficient home care support needs to be provided to prevent carers becoming overburdened and over-tired. In addition, it is vital that respite services respect the needs of both the carer and the care recipient.

#### **2. Promoting awareness of family carers and their support needs**

Carers who have little or no support from family, friends or others are especially likely to report low quality of life, as are carers who report isolation. Policy efforts aimed at increasing the general awareness of caring and the importance of providing support (both practical and emotional) to carers could have an important role to play.

### **3. Reducing carer stress**

Stress and emotional strain are frequently reported by carers and these, in turn, are linked to a greater likelihood of carers reporting that their health has suffered and/or a lower quality of life. Policy efforts aimed at reducing the stress and emotional strains on carers are therefore important. Improvement of existing services and supports for carers would be an important first step. With the recent provision of significant resources for family carer training, it is important that any training models proposed and accepted are evidence-based. Evaluations of such interventions should inform the more widespread roll-out of such programmes as appropriate.

### **4. Carer entitlements and income**

Whilst the entire sample surveyed was in receipt of Carer's Allowance, the vast majority of the group had no other income. Low income, coupled with long hours of caring that restricts carers' opportunities to take up employment, make them a group at risk in terms of likelihood of experiencing income poverty. Future carers policy would need to take into account the loss of economic opportunities due to caring work and also the cost of caring where in some circumstances carers have to cover the extra costs of disability when caring for a disabled relative.

### **5. Targeting male carers**

This research has identified male carers being at particular risk of reporting both lower quality of life and being less satisfied with their health than female carers. Innovative ways at identifying, engaging with and supporting male carers need to be actively considered.

### **8.3 Opportunities for further research**

It is hoped that access will be negotiated to the raw data from the most recent SLÁN research, SLÁN 07 (Morgan et al, 2008). This would enable further more comprehensive up-to-date and weighted comparisons to be made between this sample of the carer population and the national population. Specifically the SLÁN 07 data on reported general health, quality of life and specific health problems will be of use.

There is also a case to be made for qualitative research that looks more closely at the mediating factors for carers' health and well-being.

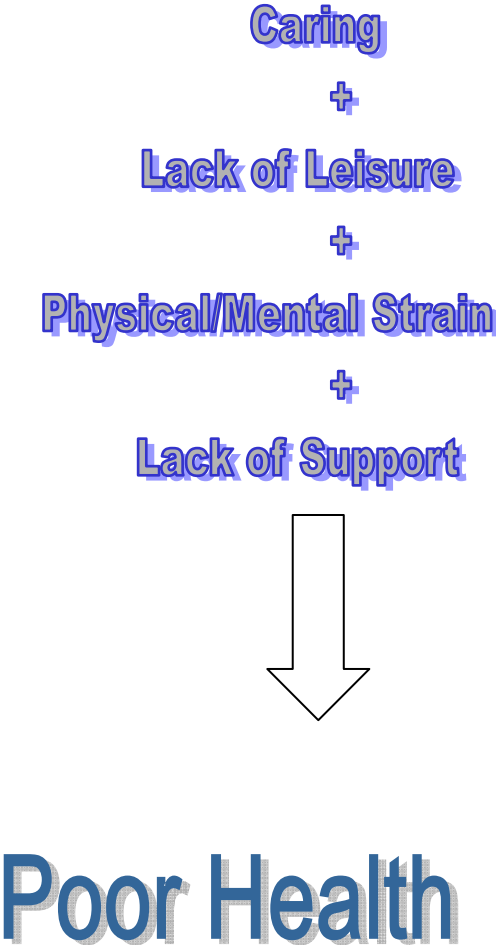
The finding that carers did not report a statistically different tendency to being satisfied with their health is of interest. It is possible that this may be linked to a tendency for some carers to neglect or have low expectations in relation to their own health. This assumption will need further qualitative research. The current survey data do not allow deeper examination of this. It is anticipated that future qualitative research will shed further light on the various coping mechanisms identified by the respondents.

The extent of support available was also a key factor. Where little or no support was reported there was a 2.7 times greater likelihood of lower quality of life being reported in comparison to where there is more than one good source of support. Linked to this issue, the term 'support' as used in SLÁN 02 and replicated in this research is very generic, and as such can mean different things to different people. Hence, its use as a generic term, without exploration, limits its contribution to our understanding of the issues. Qualitative research exploring the respondents' meaning of the term support and how do they maximise it may be warranted.

Male carers have been identified in this research as being at particular risk of reporting low quality of life. Further research in this area is warranted. Census 2006 reports that 54 per cent of male carers who reported providing full-time care also reported being in paid employment. This compares with 31 per cent of female full-time carers (CSO, 2007:114). It may be that many male carers who provide full-time care may also be working long hours in paid employment, which may have a negative effect on their own quality of life.

In a cross-sectional survey like this it is not possible to establish the direction of causality between these variables. We therefore propose that testing of this hypothesis should become the subject of future research (see model below).

***Proposed hypothesis model of causal connections***





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**Appendices**

**Appendix I Survey questions**



Family Carer Health Survey

2007

*For Office Use Only*

**Received:**

**Survey No:**

### *About this survey*

- The survey is in seven sections
- The survey is intended to be anonymous. Please do not write your name, address, PPS number or any other identifying information on this survey
- It should take you about 10 – 15 minutes to complete
- Your response is very important, even if you feel a particular section does not apply to you
- Most questions are designed to be answered using a tick in a box but there are a few where you are asked to write in the space provided
- Please answer each question by ticking the box that best describes your situation
- If you have any questions about this survey, please don't hesitate to contact us on our dedicated survey phone number (01) 440 4350. Alternatively you may e-mail us at [research@carealliance.ie](mailto:research@carealliance.ie)



**Section A: General health status**

**A1. In general, would you say your health is...**

Excellent 1      Very good 2      Good 3      Fair 4      Poor 5

**A2. Is your daily activity limited by a long-term illness, health problem or disability?**

Yes 1      No 2

**If yes, please state the nature of your long-term illness, health problem or disability:**

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**A3. During the past 30 days, for about how many days did poor physical or mental**

**health keep you from doing your usual activities, such as looking after yourself, work or recreation?**

Number of days \_\_\_\_\_ None 1

**A4. How would you rate your quality of life?**

Very poor 1      Poor 2      Neither good nor poor 3      Good 4      Very good 5

**A5. How satisfied are you with your health?**

Very dissatisfied 1      Dissatisfied 2      Neither satisfied nor dissatisfied 3  
Satisfied 4      Very satisfied 5

**A6. Have you had any of the following in the last 12 months?**

Asthma \_\_\_\_\_ 1  
Chronic bronchitis, chronic lung disease (COPD), emphysema \_\_\_\_\_ 2  
Heart attack \_\_\_\_\_ 3  
Angina \_\_\_\_\_ 4  
Stroke \_\_\_\_\_ 5  
Rheumatoid arthritis (inflammation of joints) \_\_\_\_\_ 6

- Osteo-arthritis (arthrosis, joint degeneration)\_\_\_ 7
- Lower back pain or other chronic back condition 8
- Diabetes \_\_\_\_\_ 9
- Cancer (malignant tumour, leukaemia or lymphoma) 10
- Urinary incontinence, problems in controlling the bladder 11
- Anxiety \_\_\_\_\_ 12
- Depression \_\_\_\_\_ 13
- Aching joints \_\_\_\_\_ 14
- High blood pressure \_\_\_\_\_ 15
- Headaches \_\_\_\_\_ 16
- Stress / nervous tension \_\_\_\_\_ 17
- Other (please specify) \_\_\_\_\_ 18

**A7. Has your health suffered due to your caring responsibilities?**

Yes 1      No 2

**If yes, please describe how it has affected your health?**

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**A8. Are your leisure/recreational activities limited by your caring work?**

Not at all 1      A little 2      Quite a lot 3      A great deal 4

<b>Section B: Your caring</b>
-------------------------------

**B1. What are the most difficult things about caring? (Please tick all that apply)**

- Lack of sleep / tiredness 1
- Isolation 2
- Stress 3
- Emotional strain 4
- Being constantly on call 5
- Frustration 6
- Sadness for the person I care for 7
- Guilt 8
- Other (please specify) 9 \_\_\_\_\_

**B2. How many hours of care do you provide each week?**

- 0-19 1
- 20-39 2
- 40-59 3
- Over 59 4

**B3. What strategies do you use to keep you going in your caring role?  
(Please tick all that apply)**

- Talk to friends 1
- Watch TV 2
- Exercise 3
- Drink alcohol 4
- Smoke 5
- Take medication 6
- Use respite 7
- Attend support group 8
- Use phone line support 9
- Alternative medicine 10
- Praying / faith 11
- Other (please specify) 12 \_\_\_\_\_

**Section C: Lifestyle**

**Tobacco**

**C1. Do you smoke cigarettes/cigars now?**

- No 1
- Yes, regularly 2
- Yes, occasionally (usually less than 1 per day) 3

**Alcohol (optional)**

Whether you drink alcohol or not please answer the following questions.

**C2. How long ago did you last have an alcoholic drink?**

- During the last week 1
- One week to 1 month ago 2
- One month to 3 months ago 3
- Three months to 12 months ago 4
- More than 12 months ago 5 go to question D1
- Never had alcohol beyond sips or tastes 6 go to question D1

**C3. On the days that you drank alcohol, how many drinks did you have on average?**

A drink is:           a half pint/glass of beer, lager, stout or cider  
                          a single measure of spirits (e.g. whiskey, rum, vodka, gin)  
                          a single glass of wine, sherry, port  
                          pre-mixed drinks (e.g. Twodogs, Bacardi Breezer, Hooch)

Number of drinks \_\_\_\_\_

**C4. How many days during a typical week would you have an alcoholic drink?**

\_\_\_\_\_

**Section D: Accidents and injuries**

**D1. In the last two years have you had one or more injuries serious enough to interfere with your daily activities?**

Yes 1      No 2      If no go to question E1

**D2. What was the nature of your injury ?**

Back injury 1      Other 2 (please specify) \_\_\_\_\_

**D3. What was the cause of your injury ?**

\_\_\_\_\_

**Section E: About you and your household**

**E1. Are you**      Male 1      Female 2

**E2. What county do you live in?** \_\_\_\_\_

**E3. What age are you at present?** ..... years .....months

**E4. How many people do your provide care for?** .....

**E5. What age is the person you are caring for ?** ..... years .....months

(If you are receiving Carers Allowance for caring for more than one person, please provide the ages of each person you are caring for)

\_\_\_\_\_

**E6. The person I care for is my:**

- |                             |                             |
|-----------------------------|-----------------------------|
| Partner / husband / wife    | <input type="checkbox"/> 1  |
| Mother / mother in law      | <input type="checkbox"/> 2  |
| Father / father in law      | <input type="checkbox"/> 3  |
| Sister                      | <input type="checkbox"/> 4  |
| Brother                     | <input type="checkbox"/> 5  |
| Daughter                    | <input type="checkbox"/> 6  |
| Son                         | <input type="checkbox"/> 7  |
| Cousin                      | <input type="checkbox"/> 8  |
| Grandparent                 | <input type="checkbox"/> 9  |
| Other relative              | <input type="checkbox"/> 10 |
| Neighbour                   | <input type="checkbox"/> 11 |
| Friend                      | <input type="checkbox"/> 12 |
| Other (please specify)_____ | <input type="checkbox"/> 13 |

**E7. Do you live with the person you are providing care for?**    Yes 1    No 2

**E8. How would you describe the person you care for? (Please tick all that apply)**

- Elderly / old person 1  
Person with a physical disability 2  
Person with an intellectual disability 3  
Other (please specify) \_\_\_\_\_ 4

**E9. What age were you when you left school? ..... years**

**E10. What did your education include?**

- No schooling 1  
Primary school only 2  
Some secondary school 3  
Complete secondary education 4  
Some third level education at college, university, RTC / IT 5  
Complete third level education at college, university, RTC/ IT 6

**E11. What is your present marital status?**

- Married 1    Cohabiting 2    Widowed 3  
Separated 4    Divorced 5    Single / never married 6

**E12. Do you live with a partner or spouse?**

- Yes 1    No 2

**E13. If yes, is your partner / spouse?**

- In full-time employment 1  
In part-time employment 2  
Involved in education/training programme 3  
Unemployed 4  
Receiving disability payment 5  
Pensioner 6  
Other (please specify) \_\_\_\_\_ 7

**E14. How many people are there in your household? \_\_\_\_\_**

**E15. Do you live in a rural or an urban area?                      Rural 1                      Urban 2**  
(Urban is a town with a population of more than 1,500 people)

**E16. Are there any children aged 15 years or under in your household?**

Yes 1

No 2

If yes, how many \_\_\_\_\_



## Section F: Family and social networks and neighbourhood

### F1. How would you rate the support you are getting from those within your household, wider family, and people in your workplace?

(Please tick the most appropriate box in each case)

	Not applicable in my situation	Very little support	Little support	So-so support	Some support	A lot of support
From your spouse / partner	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
From your parents	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
From your children	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
From other close relatives	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
From friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
From employer / boss	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
From others in the workplace	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

## Section G: Income (optional)

**We are aware that as a carer in receipt of Carer's Allowance you are allowed to engage in paid work for up to 15 hours per week.**

### G1. Do you receive:

- The full rate of the Carer's Allowance? 1  
 The partial rate of the Carer's Allowance? 2

### G2. Do you have a current medical card?

- Yes 1          No 2

### G3. Do you have any other sources of income?

- No other sources of income 1  
 Part-time job 2  
 Odd jobs / occasional labour 3  
 Other social welfare payment (eg; UK pension) 4  
 Relatives / partners / friends 5  
 Other (please specify) \_\_\_\_\_ 6

Thank you very much for your help

Please put the questionnaire in the freepost envelope provided and return it as soon as possible. You do not need to put a stamp on the envelope.

If you have mislaid the return envelope, please post the questionnaire to:

Family carers Health Survey  
c/o Care Alliance Ireland  
Coleraine House  
Coleraine Street  
Dublin 7

***We gratefully acknowledge permission to use parts of the questionnaire used in the SLÁN Health and Lifestyle Survey, 2002, given by Professor Cecily Kelleher, Department of Epidemiology & Public Health, UCD. We also gratefully acknowledge permission to use parts of the questionnaire used in the Slán Survey 2006, given by the SLÁN-06 Consortium.***

***This survey is jointly funded by the Combat Poverty Agency, the Department of Social and Family Affairs and Care Alliance Ireland.***

## Appendix II Cover letter to respondents from the DSFA



An Rionn Gnóthaí Sóisialacha  
agus Teaghlaigh  
Áras Mhic Dhiarmada  
Sráid Stórais  
Baile Átha Cliath 1.



Department of Social  
and Family Affairs  
Áras Mhic Dhiarmada  
Stores Street  
Dublin 1.

April 2007

Dear Sir or Madam,

### Survey of Carers' Health

I am writing to request your co-operation in a survey of the health of recipients of carer's allowance which is being carried out by Care Alliance Ireland. Care Alliance Ireland is a voluntary organisation working to support family carers and family carer organisations.

The Department of Social and Family Affairs is facilitating Care Alliance Ireland by sending its questionnaire to a random sample of carer's allowance recipients. Please be assured that no information of any kind has been provided to Care Alliance. In addition, I guarantee you that any information you provide will be on an anonymous basis. It will not be possible for the Department or Care Alliance Ireland to identify any individual carer or carer's household.

An 8 page questionnaire is attached which will take between 10 and 15 minutes to complete. It would be very helpful if you would complete this and return it in the enclosed pre-paid envelope to Care Alliance Ireland as soon as possible and in any event by Wednesday May 23<sup>rd</sup>. A cover letter from Care Alliance Ireland explaining the purpose of the survey is also enclosed for your information.

I realise that it may be difficult for you, for a number of reasons, to complete this questionnaire but I would ask you to do so if you are able.

If you have any questions about this survey, please don't hesitate to contact Care Alliance Ireland on its dedicated survey phone number (01) 440 4350 or by emailing [research@carealliance.ie](mailto:research@carealliance.ie).

Yours sincerely,

Anne Vaughan  
Principal  
Planning Unit

Social & Family Affairs

## Appendix III Cover letter to respondents from CAI



# Care Alliance Ireland

*The National Network of Voluntary Organisations for  
Family Carers*

April 2007

A Chara,

Care Alliance is a voluntary organisation working to support family carers and family carer organisations. We want to enhance the health and well-being of family carers throughout Ireland. We first need to find out more about the health of family carers at present.

We are asking you to help us with this important survey. It should take you no longer than 15 minutes to complete.

You have been selected to take part in this survey from a random sample of family carers in receipt of the Carer's Allowance. The survey is intended to be anonymous. To ensure this, the Department of Social and Family Affairs is sending you this letter on our behalf. We have no details of those people selected to take part. Only the researchers involved in this study will see your answers and they will ensure complete confidentiality. We ask that you do not put your name, PPS number, or any other identifying information on the survey.

We have enclosed a freepost envelope so that you can return the completed survey without any cost to you.

Please fill in the enclosed survey and return it by **Wednesday May 23<sup>rd</sup>** at the latest.

If you have any questions about this survey, please don't hesitate to contact us on our dedicated survey phone number (01) 440 4350. Alternatively you may e-mail us at [research@carealliance.ie](mailto:research@carealliance.ie).

Thank you for taking the time to support us in our work.

A handwritten signature in black ink, appearing to read "Liam O'Sullivan", with a horizontal line extending to the right.

Liam O'Sullivan  
Health Status Research Co-ordinator  
Care Alliance Ireland

Encl.

*Patron: Dr. Moeve Hillery  
Coleraine House, Coleraine Street, Dublin 7  
Telephone: (01) 874 7776 Mobile: 087 207 3265  
E-mail: [ndo@carealliance.ie](mailto:ndo@carealliance.ie)  
Charity No: 14633*

## ***Appendix IV Description of SLÁN 02***

### ***SLÁN 2002***

The national health and lifestyle survey, SLÁN, was first undertaken in 1998 and repeated in the summer of 2002. The work was commissioned by the Health Promotion Unit of the Department of Health & Children and carried out at the Centre for Health Promotion Studies at NUI Galway and at the Department of Public Health Medicine and Epidemiology, University College Dublin (now UCD School of Public Health and Population Science).

The main aims of these surveys are to:

- **Produce reliable data** of a nationally representative cross-section of the Irish population in order to inform the Department of Health and Children's policy and programme planning;
- **Maintain a survey protocol** which will enable lifestyle factors to be re-measured so that trends can be identified and changes monitored to assist national and regional setting of priorities in health promotion activities.

In 2002, as in 1998, a representative cross-section of the Irish adult population was surveyed, whereby a national postal sample was generated randomly and proportionately distributed based on health board population size and urban rural breakdowns so that each county of the Republic of Ireland was represented. Final selection was at district electoral division.

There were eight sections in the questionnaire which covered general health (including self-reported height and weight), exercise, tobacco, illegal substances, accidents, household details and dietary habits.

The total number of respondents was 5,992.

## APPENDIX V Weightings, Cross-Tabulations

### Family Carer Health Survey 2007: Making comparisons with SLÁN 02

In order to determine whether being a carer has an impact on health-and-wellbeing, this needs to be compared to a comparable group in the general population. The SLÁN 02 study provides data for a sample of adults aged 18 years and over in the general population. However, as would be expected, the composition of the Carer sample is very different to that of the SLÁN 02 sample on key demographic variables such as gender, age and educational attainment. The different distributions for these variables are shown in the tables below.

#### Gender \* Survey Crosstabulation

% within Survey

		Survey	
		Carers	Slan
Gender	Male	18.9%	41.0%
	Female	81.1%	59.0%
Total		100.0%	100.0%

#### Educational attainment \* Survey Crosstabulation

% within Survey

		Survey	
		Carers	Slan
Educational attainment	no schooling	.6%	.3%
	primary only	26.6%	17.9%
	some secondary	37.7%	22.5%
	secondary	22.3%	24.8%
	some 3rd level	7.9%	12.1%
	completed 3rd level	4.8%	22.4%
Total		100.0%	100.0%

#### Age group \* Survey Crosstabulation

% within Survey

		Survey	
		Carers	Slan
Age group	18-24.5	.9%	9.5%
	24.55-29.5	3.2%	7.7%
	29.55-34.5	5.2%	8.8%
	34.55-39.5	9.9%	12.2%
	39.55-44.5	13.6%	14.1%
	44.55-49.5	12.6%	10.6%
	49.55-54.5	14.0%	8.3%
	54.55-59.5	13.4%	5.7%
	59.55-64.5	12.2%	4.9%
	64.55-69.5	8.8%	4.6%
	69.55+	6.3%	13.3%
Total		100.0%	100.0%

In order to provide a valid comparison for the health status measure, the SLÁN 02 sample was therefore weighted for these three variables so that its composition reflected that of the Carers sample.

Example of impacts of weighting...

Health rating	Carers ( per cent)	SLÁN ( per cent)	
		Unweighted	Weighted
5 Excellent	10.5	16.5	12.9
4 Very good	25.5	37.2	32.0
3 Good	46.1	32.9	37.5
2 Fair	16.1	11.4	14.8
1 Poor	1.8	2.1	2.8
Total	100 per cent	100 per cent	100 per cent

With the exception of the CA recipients, as would be expected, being much more likely to have a medical card, there were few differences in other characteristics of the samples.

#### What is your present marital status ? \* Survey Crosstabulation

% within Survey

		Survey	
		Carers	Slan (weighted)
What is your present marital status ?	Married	68.5%	63.2%
	Cohabiting;	3.6%	2.4%
	Widowed	2.9%	10.0%
	Separated	4.7%	4.6%
	Divorced	1.9%	1.5%
	Single / never married	18.4%	18.3%
Total		100.0%	100.0%

**County \* Survey Crosstabulation**

% within Survey

		Survey	
		Carers	Slan (weighted)
County	Carlow	.8%	1.0%
	Cavan	2.5%	1.6%
	Clare	2.8%	2.0%
	Cork	9.2%	10.6%
	Donegal	8.3%	4.0%
	Dublin	12.6%	28.0%
	Galway	7.4%	5.6%
	Kerry	4.7%	3.0%
	Kildare	3.2%	2.0%
	Kilkenny	2.8%	2.2%
	Laois	1.5%	3.3%
	Leitrim	1.8%	1.2%
	Limerick	5.3%	6.0%
	Longford	1.6%	2.0%
	Louth	1.8%	3.2%
	Mayo	6.8%	2.7%
	Meath	1.9%	3.0%
	Monaghan	1.4%	1.4%
	Offaly	2.6%	2.5%
	Roscommon	2.1%	1.3%
	Sligo	2.0%	1.4%
	Tipperary	6.4%	4.5%
	Waterford	2.2%	2.3%
	Westmeath	1.3%	1.6%
	Wexford	4.5%	2.0%
	Wicklow	2.8%	1.7%
Total		100.0%	100.0%

**Do you live in a rural or an urban area ? \* Survey  
Crosstabulation**

% within Survey

		Survey	
		Carers	Slan (weighted)
Do you live in a rural or an urban area ?	Rural	56.7%	54.5%
	Urban	43.3%	45.5%
Total		100.0%	100.0%



**Anyone under 15 years \* Survey Crosstabulation**

% within Survey

		Survey	
		Carers	Slan (weighted)
Anyone under 15 years	Yes	37.2%	34.8%
	No	62.8%	65.2%
Total		100.0%	100.0%

**Do you have a current medical card ? \* Survey Crosstabulation**

% within Survey

		Survey	
		Carers	Slan (weighted)
Do you have a current medical card ?	Yes	75.5%	35.9%
	No	24.5%	64.1%
Total		100.0%	100.0%

## APPENDIX VI Results of logistic regressions

### Likelihood of carers reporting health has suffered due to caring

	Factors	Relative likelihood of reporting health suffering
Type of care-related impacts		
1	Leisure limited by caring	p<.000
	Not at all	1
	A little	(1.8)*
	Quite a lot	4.6
	A great deal	7.8
2	Stress	p<.000
	Not reported	1
3	Reported	3.2
	Lack of sleep/tiredness	p<.000
4	Not reported	1
	Reported	2.7
4	Emotional strain	p<.000
	Not reported	1
7	Reported	2.7
	Isolation	p<.01
	Not reported	1
	Reported	1.7
Moderators		
6	Talk to friends (as coping strategy)	p<.003
	Reported	1
	Not reported	1.7
Life-style		
5	Injury in last two years	p<.000
	No	1
	Yes	3.1

Model accounted for 48 per cent of variance

Number of observations = 1030

(\* brackets indicate value is not significantly different from the reference category value indicated by '1')

## Likelihood of carers reporting low quality of life

	Variables	Adjusted odds ratio
<b>Care-related impacts</b>		
1	Leisure limited by caring	p<.000
	not at all	1
	a little	(1.6)
	quite a lot	3.0
	a great deal	3.3
3	Stress	p<.000
	not ticked	1
	ticked	1.9
7	Lack of sleep/tiredness	p<.001
	not ticked	1
	ticked	1.7
8	Emotional strain	p<.03
	not ticked	1
	ticked	1.5
5	Isolation	p<.001
	not ticked	1
	ticked	1.9
<b>Moderators</b>		
4	Talk to friends	p<.000
	ticked	1
	not ticked	2.0
10	Prayer	p<.05
	not ticked	1
	ticked	1.5
<b>Carer characteristics</b>		
2	Support	p<.000
	little/none	2.7
	some	1.6
	quite a lot	(1.2)
	a great deal	1
11	Other injury in last two years (not back)	p<.05
	not ticked	1
	ticked	2.1
<b>Demographic</b>		
9	Gender	p<.05
	male	1.6
	female	1
6	Spouse in full-time employment	p<.002
	ticked	1
	not ticked	1.9

Model accounted for 32 per

Number of observations = 1028

cent of variance

---

(\* brackets indicate value is not significantly different from the reference category value indicated by '1')