



Care Alliance Ireland

The National Network of Voluntary Organisations for Family Carers

Family Caring in Ireland

May 2010

This report is intended for use by those with an interest in Family Carer issues in Ireland.

Notes:

- ***This report is a living document, and we will be updating it on a regular basis. The latest version is available at <http://www.carealliance.ie/publications.php>***
- ***Should you notice any inaccuracies or omissions please inform us by email to ndo@carealliance.ie***
- ***Should you be undertaking research in the area we would be delighted to receive your final report so we can consider it for inclusion in any updated versions. Please send to ndo@carealliance.ie***

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What is a Family Carer?

A Carer is 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 (including problems which are due to old age).¹ The care they provide is unpaid.

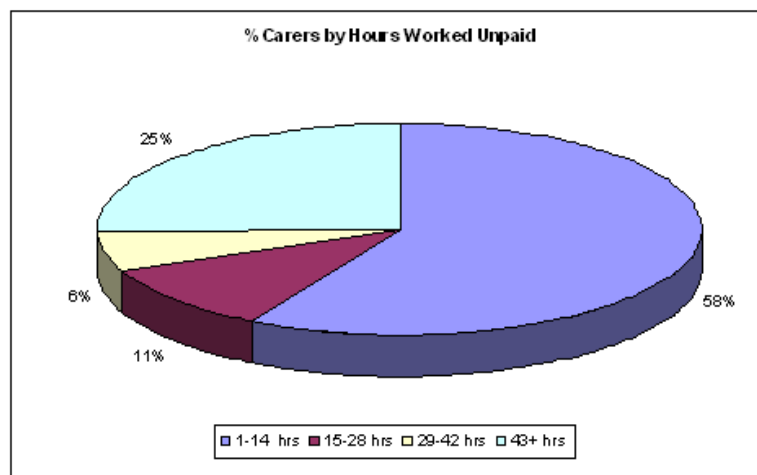
The vast majority of respondents (98.3 per cent) in a 2008 Care Alliance Ireland report on full-time Carers in Ireland indicated that they were caring for a family member.² However, there is an increasing use of the term 'carer', to such an extent that it is often used to refer to a vast array of health care professionals. For these two reasons it is considered appropriate to use the term Family Carer to clearly differentiate the contribution of paid care workers or health care professionals from that of unpaid *Family Carers*.

It is difficult to pinpoint the exact number of Family Carers in the Republic of Ireland. The 2006 Census indicates that there are in the region of 161,000 Family Carers, with almost 41,000 full-time Family Carers.³ This means that the cared-for person requires full-time care and attention.⁴ 148,754 people indicated that they provide unpaid care in Census 2002, so there is an ongoing increase in Family Carers.⁵ Family Carers comprise 4.8 % of the total population of the country, varying from a low of 4.2% in Kildare to a high of 5.5% in Mayo.⁶

In total there were 160,917 people in 2006 who reported providing upwards of one hour per week family care. The majority (58%; 93,363) reported providing between one and 14 hours of care per week. Smaller numbers reported providing between 15 and 28 hours per week (11%; 17,093) and between 29-42 hours per week (6%; 9,578). A quarter reported providing what might be considered full-time care; that is greater than 42 hours per week (25%; 40,883).⁷ A recent review by Care Alliance Ireland of the average number of hours of care provided suggests an average of 35 hours per week, but with those reporting providing full time care (ie>43 hours per week) the average for this group of full time carers is 110 hours per week.

Figure 1 below shows the breakdown of Carers based on the hours worked in 2006. As can be seen, the vast majority of Carers worked either full-time (43+ hours) or did less than 14 hours, these two groups constituting over 83% of Carers⁸.

Figure 1 Carers by Average Hours Worked Unpaid per Week 2006



The importance of Family Carers

Family Carers are currently registered in relevant statistics as economically inactive. However, they are providing vital care to family members in the home, thus saving the exchequer considerable amounts of money. It is estimated that Family Carers contribute over €2.5 billion to the economy every year; this figure would otherwise have to be spent by the health service. It is also estimated that every week 3.7 million hours are worked by 161,000 Family Carers across Ireland.⁹

For comparison purposes, the weekly salary (mid-point on the HSE scale) of a home help worker is €557, based on a 39 hours working week.¹⁰ This equates to €28,987 per annum. In addition the estimated cost of nursing home care is in the region of €800-€1,000 per week, whilst the cost of acute hospital care is in the region of €7,850 per week.¹¹ These weekly figures amount to €41,600-€52,000 per annum for nursing home care and circa €408,000 per annum for acute hospital care. Both nursing home and acute hospital care options have often become the default provision as opposed to the appropriate provision due to the lack of capacity within community care. Enhancing the capacity of family care, with adequate community-based supports for such care, can directly contribute to a reduction in demand for expensive and inappropriate institutional care.¹²

Who are the Family Carers in Ireland?

Women are more likely to be Family Carers than men. In the 2006 Census data, the gender balance for carers overall was 37.7% male and 62.3% female, and for 'full-time' Carers it was quite similar (34.3% and 65.7%, respectively). Carers in receipt of Carer's Allowance are even more likely to be female (80.5%) than are Carers in general (62.3%).¹³

In terms of the age of those who identified themselves as Carers in the 2006 Census, the largest number fell into the 45–54 year old age group; totalling 45,797. Following closely, 38,236 Carers were in the 35–44 year old age group. 27,083 Carers were aged between 55–64 years old, while 18,152 Carers were aged 65 years and over.¹⁴ Indeed the key age cohort for Carers is the 45–64 year group, with 10% of women and 6% of men in this cohort of the population providing care.

Although Carers aged 65 years and over represent just 11% of the total population of Carers, they represent 22% of those providing at least 43 hours of care per week.¹⁵ These are significant figures to note given that while the cared for person may have complex health needs, as the Family Carer ages they will have their own set of health needs.

In 2006 there were 90,544 working Family Carers in Ireland who also in paid employment outside of the home¹⁶ This represents 56 % of the 161,000 Family Carers in the country. Of these 14,068 (16%) are providing full-time care to a loved one. 55 % of working Carers are female¹⁷.

19,363 individuals aged between 25-34 years old identified themselves as Carers in 2006. A significant number of young carers were identified in the Census (12,286 in the 15–24 year old category).¹⁸ However, based on the experiences of other countries, it is assumed that there are an unquantified number of children (ie; under 18 years) performing significant caring roles in Ireland. Currently those Carers aged under 15 years old are not accounted for in the Census but will be in the 2011 Census.

In terms of marital status, nearly two thirds of Family Carers identified in the 2006 Census were married; 100,619 individuals (equivalent to 62.53% of the overall Carer population). Following from this, 27.83% Family Carers were single (44,784), just over 6% of Family Carers were separated (9,702), while 3.6% identified themselves as widowed (5,812).¹⁹

Census 2006 figures show that Family Carers come from all occupational groups with a similar proportion of each group involved in the provision of unpaid care. The lowest proportion of unpaid care is undertaken in the building/construction workers and manufacturing groups, with each occupation

providing 3% of unpaid care. In contrast, the highest proportion of unpaid care is undertaken in the farming, fishing and forestry group, with 7% of those in the occupation providing unpaid care.²⁰

There were a total of 90,265 Carers (just over 56% of all Carers) identified as living in urban areas and 70,652 (almost 44%) living in rural areas in Ireland. Research from the UK suggests that Carers in rural areas have the same needs as carers living elsewhere.²¹ However, the rural setting in which they live means they face additional barriers of physical and social isolation and lack of services (both in terms of access and availability). Additional issues which Family Carers in rural areas may face include: lack of specialist services; lack of respite; difficulty in accessing medical support; isolation and lack of companionship; lack of privacy; information gaps; lack of alternatives to family care; poverty and the additional cost of living in a rural area; difficulties with transport and employment.²²

Family Carers in Northern Ireland

The 2001 UK/Ni Census was the first to include a question on Carers in Northern Ireland.²³ Comparative data on changes in the caring population in Northern Ireland will be available following the next Census, due to be completed in 2011. Census 2001 identified 185,086 Carers in Northern Ireland,²⁴ representing 11% of the total population¹. It is interesting to note that double the percentage of people in the UK/Ni Census 2001 identified themselves as carers in comparison with the figures from the Irish Census (2006). A reason for this may be the somewhat different wording of questions between the two, a different societal or cultural view of the term carer, different expectations around state social services and/or a different level of carer self identification.

59% of Carers from Northern Ireland identified were female, while 31% were men. 25% of those who identified themselves as carers (46,912) were providing 50+ hours of care per week, while three-fifths were providing care for one to 10 hours per week and 15% for 20–49 hours. 93,000 carers identified were aged over 60 years old, representing almost half of the total population of Carers in Northern Ireland. In addition, 30,000 individuals were caring for more than one person, while 83,000 (45%) carers were found to combine caring with paid employment.²⁵ The 2001 Census identified carers as an at risk group of poor health. Those caring for 50 hours were twice as likely to report poor health as the non-carer population and this was true across all age ranges.²⁶

In 2006, the Northern Ireland Life and Times (NILT) Survey identified 23% of adults with caring responsibilities.²⁷ 17% of men and 27% of women said they were carers and almost one half (49%) of those identified were aged between 53 and 54 years. 31% of carers identified were found to spend 30 hours a week or more caring, and 62% cared for someone 5-7 days per week. Interestingly, while 61% of respondents in a similar survey undertaken in 1994 felt that the government should provide care for older people, the equivalent figure for 2006 rose to 73%. This was matched by a fall in the percentage of respondents thinking that a relative should provide the care – from 28% in 1994 to 19% in 2006.²⁸

Carers' issues have in recent years risen higher on the political agenda in the North. For example, the passage of the Carers and Direct Payments Act (NI) 2002, The Northern Ireland Act (Section 75), The Work and Families (Northern Ireland) Order 2006, and Employment Rights (Northern Ireland) Order 2006; the formation of a Carers Strategy: *Caring for Carers: Recognising, Valuing and Supporting the Caring Role* (2006); and the inclusion of Carers in numerous other policy initiatives including *The Review of Community Care* (2002).²⁹

What do Family Carers do?

The role which Family Carers play can differ depending on the condition of the cared for person and as his/her situation changes, so too will the level of care provided. The following categories illustrate the different levels of care that Family Carers may be involved in,³⁰ providing care to a loved one as an indicator in assessing Carer activities:

- Low level caring – mainly companionship with some caring assistance
- Medium level caring with chores – cooking, shopping, housework, driving
- Medium level caring, as above, plus some personal assistance with washing, dressing, lifting, use of toilet
- High level caring, all of above, where the person receiving the care cannot be of much or any assistance to the Family Carer with his/her personal care

How are Carer Support Services delivered in Ireland?

The state supports Family Carers in many ways. For a full list of the supports offered to carers see:

[http://www.carealliance.ie/pdfs/Services%20directlyforortoassistcarersDSFANovember2009\[1\].pdf](http://www.carealliance.ie/pdfs/Services%20directlyforortoassistcarersDSFANovember2009[1].pdf)

Many full-time Family Carers receive a weekly payment – either Carers Allowance or Carers Benefit. As these payments are means tested, many Family Carers do not receive financial support.

For full details see: <http://www.welfare.ie/EN/Pages/carers.aspx>

In some regions some carer support services such as phone line support, outreach, training, carer support groups and home/institutional respite are contracted out to non-profit organisations, most of whom are members of Care Alliance Ireland. See:

<http://www.carealliance.ie/membership.php>

In addition, in some HSE areas a co-ordinator is employed to oversee Carer support services. See: http://www.hse.ie/eng/services/Find_a_Service/Older_People_Services/Carers_and_Relatives/HSE_Carer_Managers.html

Impacts of caring

Providing care can be both an enriching and rewarding experience, in cases where expectations placed on Family Carers are reasonable and adequate supports are provided. However, caring can also be a source of burden and stress. While care of a loved one may be willingly provided, there may be costs to many aspects of the Family Carer's life – emotionally, physically, socially and financially.

Health Impact

Family Carers' health is of fundamental importance for the sustainability of care to a loved one. In the UK, researchers found that Family Carers are three times more likely to report ill-health than the non-carer population.³¹ In Australia, Carers have been found to be unable to participate in social and health activities, due to the burden of care.³² The greater the intensity in the type or quantity of assistance provided, the greater the magnitude of health effects on the caregiver, which are largely due to chronic stress.³³ Research in Ireland carried out thus far has shown that caring for a loved one at home can take a toll on the Family Carer's mental, emotional and physical health, with high levels of burden.³⁴ The most extensive piece of Irish research to date examining the health status of

Family Carers found that, in comparison to the general population, those Family Carers who responded to the survey (n=1,411) were less likely to report themselves in excellent or very good health.³⁵ Family Carers presented a considerably less positive picture of their quality of life in comparison to the general population. Family Carers also reported comparatively high levels of depression, back pain and anxiety. Negative aspects associated with caring included restricted leisure hours and a high risk of being exposed to stress, emotional strain and social isolation. The extent of the limitation imposed by caring on leisure and recreation appeared to be a key factor both in the likelihood of health suffering due to caring and of low quality of life for Family Carers.³⁶

An even more recent (2009) Irish study of Family Carers found that 71% reported their health as 'quite good' or 'very good', but well over half experienced being mentally and physically "drained" by their role. The types of caring tasks most reported to cause ill-health were; dealing with verbal/emotional abuse, coping with bizarre/inconsistent behaviour, and getting up in the night. Over half reported having a medical problem, the most frequent being back injury, and over half reported a significant mental health problem, the most frequent being anxiety disorder. Most carers worried how the person they cared-for would cope if they could not care any longer due to illness or death, and that they had no time for themselves due to caring.³⁷

Qualitative research undertaken in 2009 exploring the health and wellbeing of Family Carers of people with Parkinson's disease has found that the role of Family Carer is both physically and emotionally demanding, particularly as the person's condition deteriorates and their caring needs intensify.³⁸ High blood pressure, tiredness, lack of physical energy, back problems and arthritis were all seen as consequences of caring. Feelings of loneliness, anxiety and depression were expressed as a result of the physical demands of caring.³⁹

Internationally, Family Carers' health has been shown to worsen the longer they are providing care. The physical health of Carers has been found to be more likely to decline after their first year of caring.⁴⁰ In addition, spousal Carers and mothers caring for a disabled child have been found to be most risk of psychological distress, and the period immediately following the cessation of caring has been identified as a time when ill health was likely to increase.⁴¹ Other factors which have been found to contribute to poor health among Family Carers are low income and lack of respite breaks.⁴²

Social Impact

As a result of providing care, Family Carers may suffer barriers to social participation, isolation, poverty and lack of recognition and respect for their role. The definition of poverty currently used by the Irish Government is: *'People are living in poverty if their income and resources (material, cultural and social) are so inadequate as to preclude them from having a standard of living which is regarded as acceptable by Irish society generally. As a result of inadequate income and resources people may be excluded and marginalised from participating in activities which are considered the norm for other people in society.'*⁴³ This definition currently underpins the Irish Government's strategic response to tackling poverty and social exclusion, as set out in the National Action Plan for Social Inclusion 2007–2016. However, Family Carers are not identified as a priority target group within current social inclusion policy. Furthermore, the postponement in March 2009 of the publication of the National Carers Strategy, which had the potential to provide a roadmap for the future, is particularly concerning.

Caring responsibilities often limit the time available to Family Carers to have a life of their own. Many Family Carers do not have access to supports to allow them significant time off from their caring duties to have a social life or to more generally participate in the community and wider society.⁴⁴ The majority of Family Carers in an Irish study reported major restrictions in their social or leisure activities and that isolation was a problem for many. This results in stress, a lower quality of life, and other negative health impacts for many Family Carers.⁴⁵ Other Irish research has confirmed these findings,

showing that providing care resulted in significant limitations to personal interests and hobbies.⁴⁶ Analysis of Census 2006 figures shows that 23% of older Carers did not have access to a car.⁴⁷

Financial Impact

Only one Irish study thus far has looked at the relationship between caring and financial situation.⁴⁸ It 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 in the UK found that 72% of Carers were financially worse off as a consequence of becoming a Carer.⁴⁹ The reasons given included the additional costs of disability, giving up paid employment to provide care, the inadequacy of current benefits and charges for services. Family Carers may face higher bills than the non-carer population, such as extra heating, laundry and transport costs.⁵⁰

Recent UK research outlines that two thirds of Family Carers are spending their own income or savings to pay for care.⁵¹ In addition, many Carers were found to be suffering from financial hardships, including: experiencing debt, struggling to pay essential bills, inability to afford house repairs, cut backs on food to make ends meet, and difficulties paying rent or mortgage.⁵²

Young Carers

A lot of children and young people help look after a family member who has a disability or health problems. The Child and Family Research Centre at the National University of Ireland, Galway has recently (2009) completed a study of these young people throughout Ireland, funded by the Office of the Minister for Children.

See [http://www.carealliance.ie/pdfs/DSFA_presentation_CFRC_16_11_09\[1\].pdf](http://www.carealliance.ie/pdfs/DSFA_presentation_CFRC_16_11_09[1].pdf)

The report found that the majority of respondents were providing care for someone with an intellectual disability. Significant proportions of those interviewed were the primary carer of a family member, with their caring roles including intimate and emotional care as well as domestic tasks and childcare. Respondents looked for more information, advice and home help to support them in their caring. The report considers the impact of caring and concludes that any policy response designed to support and assist young carers should be guided by the principles of:

- Protection of children's rights
- A family support approach
- Multi-agency and multi-departmental response

The report also recommends that a National Forum take place, guided by the findings of this research.

Care Alliance Ireland is keen to ensure that the findings of this research on young carers are widely distributed, reflected on and acted on. Within the Family Carer sector here in Ireland, The Carers Association has already demonstrated its interest in and commitment to the area by way of an annual award for young carers. The theme for the organisation's 2010 conference in May will be young carers and the report in full will be launched at The Carers Association Conference in Dublin on May 7th 2010. The Crosscare Carer Support programme is also planning to set up a pilot project for young carers in the Autumn of 2010.

In the UK, and in Scotland in particular, the youth service is actively involved in both identifying and supporting young carers and as such has demonstrated effective interventions.

A key academic in the field is Dr Saul Becker. See <http://www.saulbecker.co.uk/>

Family Carers in the workplace

90,544 Family Carers in the 2006 Census reported to be in paid employment. This represents 56.27% of the overall Carer population identified. 54.73% of working Carers are female, while 54.27% are male.⁵³ Of the Carers working, 16% (14,068) were also providing full-time care to a loved one. Male Carers are more likely to report full-time caring as well as being in paid employment. 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.⁵⁴ On average, Family Carers who are working outside of the home provide 19 hours of unpaid care per week.⁵⁵

The importance of work for many Family Carers may not only be financial. Paid employment may also be vital for their well-being and in order to maintain social contact.

The vast majority of Family Carers are of working age. However, combining paid employment outside of the home and providing care can prove to be very difficult; even so many Family Carers may have to juggle both due to financial constraints. An Irish survey of working Carers was recently completed.⁵⁶ Findings illustrate that working Carers are struggling to juggle numerous pressures involved in managing both employment and caring. 25% of respondents (n = 56) were providing full-time care for a person outside of their normal work hours. 56% were unaware of the services and supports available to assist them in their caring role; 20% were providing care to two people; 15% described their own health as not very good; and 100% had to take holiday time to provide care. 18% of care provided by Carers took place at the weekends. In addition, providing care was shown to cost Carers on average €110 per week. A 2004 Equality Authority report provides a good analysis of the issues faced by Family Carers in juggling their caring and working responsibilities⁵⁷.

The findings of a survey of Carers of working age in the UK found that many working Carers were in poor health and struggling to make ends meet.⁵⁸ Many Carers stressed that they were keen to continue to work, although over a third had considered giving up work to care. Almost half of those working part-time said they were only in work of this type because of their caring responsibilities. In addition, most Carers acknowledged that their caring responsibility affected their job. Other research highlighted that nearly one in five Carers in the UK had left a job or been unable to take a job because of their caring responsibilities.⁵⁹

It is vital that Family Carers who want to work outside the home are supported to do so; both in the workplace and at home, through the provision of additional supports. Family Carers need flexible working arrangements, tailored supports and understanding employers in the workplace. At home, there is a need for significant expansion of flexible, mostly home-based services, especially respite and home help, as well as occupational therapy, chiropody, social work and counselling services.⁶⁰ At the same time, it is of equal importance that Family Carers who are unable to work receive adequate financial support in their role.

When Caring Ends/Changes

There is strong evidence to show that the psychological, social and physical health consequences of caring may leave some Family Carers poorly equipped for life after care.⁶¹ Many former Carers' lives have been found to involve three distinct phases: the post-caring void, closing down 'the caring time', and constructing life post-caring.⁶² Indeed, many Family Carers find themselves totally unprepared for life after caring, such as returning to work.

Looking after a loved one may have taken up a massive part of many Family Carers' lives, with the needs of the cared for person taking priority. When this caring ends, whether due to the death of the person, moving into residential care or because the Carer may no longer need to provide care, many Family Carers find it difficult to deal with this significant change to their life circumstances. It is of vital importance that former Family Carers are adequately supported in the period immediately following the

cessation of care through bereavement and counselling services, returning to work, training and education programmes, and social inclusion programmes.

Following a successful joint research bid in late 2009 between Care Alliance Ireland and The School of Nursing and Midwifery, Trinity College Dublin to the Irish Research Council for Humanities and Social Sciences (IRCHSS), a research project has begun in the area of post-caring and specifically the experiences of Family Carers after their caring at home has ceased. This research is exploring the needs and experiences of former at-home carers whose loved ones have recently (i) died, or moved to either (ii) a nursing home or (iii) hospice. Existing international research studies have indicated that these are the three types of post-caring transitions that carers experience. It is this conception of post-caring that is being adopted because of the potential for identifying a variety of different experiences. The researchers recognise that the caring role generally continues but in an altered way after at-home caring has ceased and the care-receiver has moved into either a nursing home or hospice. This qualitative research is being conducted by Dr. Marianne Breen (breenm@tcd.ie).

At a European level, Care Alliance Ireland is a partner in an EU Supported Gruntvig Exchange project on post-caring involving four other European NGOs. See www.lifeaftercare.eu for further details.

Change over time

It is imperative to note that the need for Family Carers is growing and will continue to grow over the coming years due to a number of factors. Firstly, demographic changes pose serious future challenges. For instance, women, who traditionally performed most caring roles, are now more likely to be working outside of the home and their incomes are often vital. In addition, Ireland's population is ageing rapidly. It is forecast that the share of the population over 65 years will rise to almost one-fifth by 2036 (equivalent to 1.24 million) compared with 11% in 2006 (462,000).⁶³ Another issue is that the projected demand for Carers in Ireland is determined significantly by the future population of those with a disability who are resident at home. By projecting the population of this group, it is estimated there will be an increase in demand by 2021 for more than 40,000 Carers, with more than 25,000 required by 2016. This represents a 28% and 17% increase on the 2006 demand for Carers respectively. This will result in a population of Carers in excess of 200,000 by 2021.⁶⁴ Herein lies the importance of comprehensive support mechanisms for Family Carers in Ireland.

Key Policy Documents

A 2002 report on Carers, published by The Citizens Information Board (previously known as Comhairle) gives a useful insight into some of the key issues facing carers at the time, issues that are unlikely to have changed since its publication in 2002⁶⁵. The report is one in a series of the organisations social policy reports which addressed social policy concerns identified by the users and providers of Citizens Information Services. This report which dealt with the situation and needs of Family Carers in Ireland summarised the available research at the time. This was informed by feedback from Citizens Information Centres (CICs) on issues identified by CIC clients. It highlighted the demographic pressures that, while not yet urgent, was considered likely to lead to both an increase in the need for care services and a decrease in the supply of those services by the traditional care providers (Family Carers). It found that the relatively low proportion of older people in the Irish population and low labour market participation rates among women had provided the underpinnings of the informal care system in Ireland. However, changes in family structures, women's labour market participation and population ageing were considered to be making this model of support less sustainable.

Issues relating to Family Carers in Ireland are visible in several recent policy documents. The *National Action Plan for Social Inclusion 2007-2016* 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.⁶⁶

Policy commitments for carers can be found in the *National Development Plan* which recognises that respite and day-care service places need to be part of a comprehensive community service to give a much needed break to Carers in the home.⁶⁷ Other policy developments include the Equality Authority report entitled *Implementing Equality for Carers* which provides practical recommendations to ensure that carers are adequately supported.⁶⁸

The National Partnership Agreement *Towards 2016* contained a commitment to develop a National Carers Strategy.⁶⁹ This was to set out the Government's vision for Family Carers and establish a set of goals and actions in areas such as income support, health care and services, housing, transport, information services, labour market issues, programmes of training, social inclusion, and research and technology development. However, the Government took the decision in March 2009 that the long promised strategy would not be published, citing the economic situation which they claimed 'makes it difficult to commit to major advances in services for carers'.⁷⁰ Much of the Family Carer sector believe that by postponing the publication of the National Carers Strategy, the Government is sending out the following message to an essential group in Irish society: that the Government undervalues the contribution and needs of Family Carers and is not willing to sufficiently recognise and support the enormous contribution they make to Irish society.⁷¹

It is envisaged that Family Carers will form an important part in the *National Positive Ageing Strategy*. The development of the Strategy is currently in the consultation phase. A joint submission was made in October 2009 by Care Alliance Ireland and The Carers Association.⁷² The preparation of the National Positive Ageing Strategy takes forward the commitment in the Programme for Government 2007-2012 to better recognise the position of older people in Irish society. The intention behind the strategy is to put in place arrangements that would ensure that issues affecting older people are mainstreamed in policy making at all levels and across all sectors and will contribute to the best quality of life for older people in the years to come.⁷³

Family Carers in Europe

A *European Parliament Special Interest Group on Carers* was launched in June 2007. The Group has been active and proven itself an invaluable tool in supporting, awareness raising, and influencing current and future EU health and social policy development. Following the European Elections in June 2009, the group was re-established in February 2010 with the support of Eurocarers and Marian Harkin, MEP. Currently approximately 30 MEPs are members of the group. The Interest Group has the potential to provide an effective platform for concrete contributions to EU policy initiatives. Many of the current EU policy initiatives have a bearing on care provision and carers, and entry points include the following initiatives:

- the upcoming post-Lisbon consultation
- future Communication on long-term care provision
- the European Employment Strategy
- Equal Opportunities initiatives
- Open Method of Co-ordination in health and long term care
- EU Health Programme and Health Strategy
- Alzheimer initiatives
- European Mental Health Pact
- FP7 and FP8
- the PROGRESS programme
- upcoming European Years (Social Exclusion 2010, Volunteering 2011 and Active Ageing 2012)

Eurocarers, the European association working for carers, was also launched in 2007. Eurocarers is a non-government organisation (NGO) that seeks to represent and act on behalf of all informal Carers, irrespective of their age or the health needs of the person they are caring for. Eurocarers brings

together organisations representing carers and those involved in research and development. Among its principal aims are:

- Contributing to policy development at national as well as European level supported by evidence-based research: by acting as a voice for informal carers and issues relevant to carers, and by translating relevant EU policy developments to members operating at national and regional level.
- The exchange, gathering and dissemination of experience, expertise and good practice, as well as innovations.

Eurocarers also aims to collaborate with other interest and advocacy groups at national and EU level – including organisations representing disabled people and their families, women’s organisations, organisations campaigning against social exclusion and poverty – in order to promote recognition of carers and carers’ interests and shape a policy environment that is more favourable to carers. Other organisations such as AGE, Coface and Alzheimer Europe also have a keen interest in carers’ issues, often acting as advocates for carers at a European level.

Further details are available on the Eurocarers website: www.eurocarers.org

About Care Alliance Ireland

Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers. Our aim is to support Family Carer organisations and Family Carers throughout Ireland through the provision of support, information, education and training, regarding the needs of Family Carers. We carry out research relating to Family Carers, and promote inter-agency collaboration. We are involved in making policy submissions and input into policy development through participation in various committees.

We were founded in June 1995. We currently have 70 member organisations, a staff of two and a representative board of 10 directors. Care Alliance Ireland is a registered charity (CHY No: 14644).

Our research reports, position papers, newsletters and other publications are available on our website <http://www.carealliance.ie/publications.php>

Care Alliance Ireland Research

Care Alliance Ireland (2008) developed an initial understanding of the relationship between Family Caring and health in an Irish context from a quantitative research project examining the health status of Family Carers: *The Health Status of Family Carers’ in receipt of the Carers’ Allowance*. The aim of this research was to quantify the reported Family Carer health of a random sample of 2,834 Family Carers in receipt of a state carer’s payment as compared in part to the national non-carer population of the SLAN 2002 Survey. It was found that, in comparison to the general population, those Family Carers who responded (n=1,411) were less likely to report themselves in excellent or very good health. No significant difference was found from the general population in terms of satisfaction with health, but carers did present a considerably less positive picture of quality of life in comparison with the general population. Carers also reported comparatively high levels of depression, back pain and anxiety. Negative aspects associated with family caring included restricted leisure hours and a high risk of being exposed to stress, emotional strain and social isolation. The extent of the limitation imposed by caring on leisure and recreation appeared to be a key factor both in the likelihood of health suffering due to caring and of low quality of life for carers.⁷⁴

We have now built on this research; specifically through a qualitative piece of work that aimed to look more closely at the mediating factors for family carers’ health and wellbeing: *The Caring Reality of Family Carers: An Exploration of the health status of a specific group of Family Carers*. This research has been conducted in partnership with the Parkinson’s Association of Ireland and is due to be

published in June 2010. Twenty Family Carers of people with Parkinson's disease took part in semi-structured individual interviews. In continuing the initial work undertaken in the 2008 Care Alliance Ireland Survey, this research project does more than develop a greater understanding of the current health status of Family Carers in Ireland – the findings give a picture of the 'story of caring' and the experiences of a specific group of Family Carers. Preliminary findings show that the role of the Family Carer was both physically and emotionally demanding, particularly as the cared-for person's condition deteriorated and their caring needs intensified. Providing care had powerful physical impacts, with significant changes to daily routines noted. High blood pressure, tiredness, lack of physical energy, back problems and arthritis were seen as consequences of caring. As a result of the physical demands of caring, feelings of loneliness, anxiety and depression were all expressed. Providing care also resulted in significant limitations to personal interests and hobbies. Current periods of respite and state-provided home care support were viewed as inadequate by many. Experiences of support from healthcare professionals differed greatly. Family members' support had an important social inclusion aspect. Current levels of financial assistance were seen as insufficient in meeting Family Carer needs. Support received by various NGOs was seen as highly beneficial. However, issues regarding joint support meetings were problematic. A training programme for Family Carers was singled out as a crucial intervention that would assist Family Carers in building up the necessary physical and emotional skills for providing care to a person with Parkinson's disease, thus impacting positively on their health status.⁷⁵

Following a successful joint research bid in late 2009 between Care Alliance Ireland and The School of Nursing and Midwifery, Trinity College Dublin to the Irish Research Council for Humanities and Social Sciences (IRCHSS), a research project has begun in the area of post-caring and specifically the experiences of Family Carers after their caring at home has ceased. This research is exploring the needs and experiences of former at-home carers whose loved ones have recently (i) died, or moved to either (ii) a nursing home or (iii) hospice. Existing international research studies have indicated that these are the three types of post-caring transitions that carers experience. It is this conception of post-caring that is being adopted because of the potential for identifying a variety of different experiences. The researchers recognise that the caring role generally continues but in an altered way after at-home caring has ceased and the care-receiver has moved into either a nursing home or hospice. This qualitative research is being conducted by Dr. Marianne Breen (breenm@tcd.ie).

Family Carer Research Group

Care Alliance Ireland established a national research alliance on Family Carers issues in 2007, with the following key aims:

- To progress and develop an agreed research agenda within the Family Carer sector.
- To facilitate relationship building between NGOS, statutory agencies and academics in relation to Family Carers research issues.
- To act as a means of sharing research information relating to Family Carers.
- To inform and update members of the group on research being carried out in other organisations, which may be relevant to their own work.
- To work together to develop and promote evidence-based research and publications on Family Carers, that can be used to support policy and to develop appropriate services.
- To identify possible gaps in research and help set priorities for new work in the area of Family Carers.
- To identify possible relevant research funding opportunities.
- To develop partnerships for possible future research.
- To promote the use of research to inform policy and practice in the Family Carer arena.
- To support members of the group in securing a more central recognition of Family Carers within their own organisations.

Membership is open to all organisations and individuals working on issues relating to Family Carers. The Family Carer Research Group meets on a quarterly basis in Dublin.

If you would like further information on the Family Carer Research Group or would be interested in attending the next meeting, please e-mail: research@carealliance.ie

Additional information on Family Carers issues

- In 2009 The Carers Association of Ireland compiled a comprehensive, mostly quantitative report entitled *Carers in Ireland – A Statistical and Geographical Overview*. It is recommended reading and is available to download at http://www.carersireland.com/library_census.php
- In November 2009 Eurocarers updated their Factsheet entitled *Caring in Europe*. It provides a comprehensive summary of research on and the position of Family Carers in Europe. The report will be available to download shortly on the following website: www.eurocarers.org

Carers Week

Carer Week takes place in the UK and in Ireland each June. The week celebrates the role played by Family Carers and the contribution they make to their communities.

The week is co-ordinated by Care Alliance Ireland and 8 other NGO's who provide support to Family Carers and their dependants. (The Alzheimer Society, The Carers Association, The Disability Federation, The Hospice Foundation, The National Rehabilitation Hospital, Headway, Extracare, Bri.)

Hundreds of events for Family Carers take place throughout Ireland. Carers Week in 2010 will take place from 14-20 June.

See www.carersweek.ie www.carersweek.co.uk

Irish Carers Organisations

- The Carers Association www.carersireland.com
(For a copy of their Carers Information Pack, please go to: http://www.carersireland.com/library_other.php)
- Caring for Carers Ireland www.caringforcarers.org

Other Organisations Supporting Carers.

- The Alzheimer Society of Ireland <http://www.alzheimer.ie/eng/Alzheimer-Dementia/I'm-a-Carer>
- Acquired Brain Injury Ireland <http://www.abiireland.ie/about.html>
- Age Action Ireland <http://www.ageaction.ie/home.htm>
- Aware <http://www.aware.ie/>
- Bodywhys <http://www.bodywhys.ie/>
- Cheshire Ireland <http://www.cheshire.ie/>

- Cross Care Carers Support http://www.crosscare.ie/community_services_carers_support.htm
- Extracare <http://www.extracare.ie/>
- Headway <http://www.headway.ie/information/carers.html>
- HealthTrainingUnitedCare <http://www.healthtrainingunitedcare.ie>
- Huntingtons Disease Association of Ireland <http://www.huntingtons.ie/>
- Independent Age <http://www.independentage.ie/>
- Inclusion Ireland <http://www.inclusionireland.ie>
- Irish Cancer Society www.cancer.ie
- Irish Hospice Foundation <http://www.hospice-foundation.ie>
- Irish Osteoporosis Society <http://www.irishosteoporosis.ie/index.php>
- Irish ME/CFS Association <http://www.irishmecfs.org/>
- Irish Motor Neuron Disease Association <http://www.imnda.ie/>
- Irish Red Cross <http://www.redcross.ie/>
- Irish Wheelchair Association <http://www.iwa.ie/>
- MS Ireland <http://www.ms-society.ie/>
- Newry and Mourne Carers <http://www.carers-nm.org/>
- Parkinsons Association of Ireland <http://www.parkinsons.ie/>
- West Cork Carers Support Group <http://www.westcorkcarers.ie/>
- Volunteer Stroke Scheme <http://www.strokescheme.ie>
- www.carers.ie (Information and support website for carers of people with life-threatening illness)

Statutory Organisations and Government Departments (Ireland)

- Citizens Information www.citizensinformation.ie
An overview of public services and supports for Carers is provided as part of the *Citizens Information Disability Fact Sheet Series*. Please follow link below for a pdf copy:
www.citizensinformationboard.ie/publications/downloads/disability_factsheet3_2008.pdf
- Department of Social and Family Affairs <http://www.welfare.ie/EN/Pages/carers.aspx>
- Department of Health and Children www.dohc.ie
- Health Service Executive – Managers and Co-ordinators of HSE Carers Services
http://www.hse.ie/eng/services/Find_a_Service/Older_People_Services/Carers_and_Relatives/HSE_Carer_Managers.html

International Carers Organisations

- Eurocarers www.eurocarers.org
- Carers Northern Ireland <http://www.carersni.org>
- Carers UK <http://www.carersuk.org>
- Princess Royal Trust for Carers (UK) <http://www.carers.org/>
- Coalition of Carers in Scotland <http://www.carersnet.org/>
- Carers Australia www.carersaustralia.com.au/
- New Zealand Carers <http://www.carers.net.nz/>
- Canadian Caregiver Coalition <http://www.ccc-ccan.ca/>
- Family Caregiver Alliance <http://www.caregiver.org/caregiver/jsp/home.jsp>
- Mezzo (Netherlands) www.mezzo.nl

Carer Research/Academic Organisations

- Rosalyn Carter Institute for Caregiving (US) <http://www.rosalynncarter.org/>
- Social Policy Research Unit – Adults, Older People and Carers Team (UK) <http://www.york.ac.uk/inst/spru/research/aoc.html>
- Centre for International Research on Care, Labour and Equalities (CIRCLE) <http://www.sociology.leeds.ac.uk/circle/about/>
- Social Work Leadership Institute (US) <http://socialworkleadership.org/nsw/cap/search.php>
- Carers Research Partnership, The Robert Gordon University (UK) <http://www.rgu.ac.uk/carers/general/page.cfm>
- Young Carers Research Group, Loughborough University (UK) <http://www.lboro.ac.uk/departments/ss/centres/YCRG/>

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