

National Council on Ageing and Older People



CARERS

Ageing In Ireland Fact File No. 9

Many older people are completely independent in activities of daily living and do not rely on their family for care. They contribute greatly to Irish family life. There is considerable evidence of their contribution through everyday emotional support, companionship and advice, gifts, care for ill and dependant relatives, care for grandchildren, shopping and running errands for relatives and doing housework or repairs.

For some dependent older people, however, the family is an important source of care and support. There is no doubt that family carers make an enormous contribution to care of older people in the community, often at a substantial personal cost in terms of opportunities foregone, as well as physical and mental strain. Yet there is limited recognition by policy-makers of the role played by carers. Indeed, certain community services have in the past been refused to dependent older persons on the grounds that a relative was present in the household.

The Need for Care

- The HeSSOP report (2001) found that 12% of older people living in the community usually needed help with one or more daily tasks.¹
- The same study found that 19% of the sample usually needed help shopping, getting into and out of the car or doing housework, while 16% of older people reported requiring help with personal grooming and 13% had difficulty with reaching.¹
- This report also found that housework (11%), caring for feet and toenails (10%) and shopping (also 10%) were the activities for which the highest number of older people reported needing help.¹
- People aged 80 years or older reported much higher levels of difficulty carrying out these tasks than those people who were younger than 80. Among those 80 years of age or older, 43% reported they had 'much difficulty' or were 'unable' to do housework without help. The women interviewed for this study also reported higher levels of difficulty than men.¹

Carers

- Council reports in the past have noted that health and social services and, in particular, community services for older people in Ireland are underdeveloped and fragmented.¹⁵ The main implication of this is that the responsibility for caring falls mainly on families, and many older people only come into contact with services in the event of a crisis.²
- A study published in 2000 stated that there were 97,000 households in Ireland that contained a carer who was looking after a person aged 65 or over who either lived with them or in another house.²
- A 1994 study found that nine out of ten carers were relatives. Half (50%) of dependent older people were cared for by a member of their own household.²
- This study also found that carers were usually women. One in five carers was a daughter of the older person and wives accounted for 17% of carers. A further 14% of carers were daughters-in-law.²
- A comparison of the 1994² and 1988⁴ studies shows more people receiving care (up from 17% to 21%), but fewer being cared for by a member of their own household. Women, and especially female relatives, are still by far the most common source of care for older Irish people in the community.¹
- The HeSSOP (2001) study found that 44% of the older people interviewed reported receiving help from one or more informal carers on a regular basis. On average, 21% of the sample of older people received a high level of informal help from one or more people (most of the day continuously, including the night).¹
- This study also found that spouses or partners and other relatives living in the household provided a great deal of help, namely 25% and 26% respectively. Relatives who lived elsewhere provided support for 24% of respondents, while neighbours provided 12% of the sample with support.¹
- Of the sample of older people in the HeSSOP (2001) study, 8% reported that they were carers themselves. Around two thirds of these carers were women, and 13% of them were over 80 years old.

Supply and Demand Issues

- There are various estimates as to what the future demand for and supply of carers will be. Evidence indicates that the population of older people requiring home care is expected to rise, while the number of carers available is predicted to fall over the next ten years. As a result, it is likely that there will be a shortfall in the number of carers required to meet demand.

- Based on current morbidity patterns, population growth and care provisions, between 100,000 and 110,000 older people will require home care by the year 2011, an increase of 30% on the corresponding figures for 1996.¹⁰ This will increase further if the Department of Health's target of at least 90% of persons aged 75 years or more living in their own homes is achieved.¹¹ According to the Council's population projections, there will be an extra 64,000 people over 75 years living in the community, if this target is reached.¹¹
- Remaining in one's present home with family members taking care of all needs and the health board providing respite services was the preferred option of the older people interviewed. Regarding long-term care preferences, slightly over half of the respondents to the HeSSOP (2001) study reported that they would prefer informal care to formal care provided by the health boards.¹
- The future supply of carers will be influenced by a number of factors, most of which will exert a downward pressure on the number of carers available. A crude measure of caretaker potential is the ratio of women aged 45–68 years (given that the majority of carers are in this group) to the number of people aged 70 years or more.¹² In 1991 the ratio was 1.4 and is expected to decline, reaching 1.3 by 2021.
- A further downward pressure on the number of available carers in Ireland is the increasing proportion of married women joining the labour force. While much of the work that women returners do is part-time, it is likely in many situations to reduce the amount of time available for care of relatives, especially during the day.⁴
- Increased urbanisation and geographic mobility mean that the distance that people live from their relatives is likely to increase, making contact and caring arrangements more difficult. Divorce may fragment families and might have particular effects on the level of care provided by spouses.

Costs of Caring

- For some older people, the help that they receive from carers is an important daily and sometimes continuous support line. Without this help, some of these older people would not be able to remain living in their own homes and in the community for as long as they would like to. As a result, carers have responsibilities that can take up significant amounts of time and energy, especially when there are limited and fragmented back-up services in place to support their efforts.
- Carers are currently providing high levels of care, at a huge personal cost in terms of time, money and emotional distress. Research has shown that sacrifices involved in caring are often very great.²
- In 2000, it was reported in a Council study that the amount of time devoted to family care provision was quite high. The constant nature of care involved in caring for a person with dementia (of which there are an estimated 22,000 living in the

community), for example, was reflected by the finding that around twenty hours a day were spent on surveillance by both groups of carers involved in the study.²

- The same study also found that over two thirds of carers interviewed expressed difficulty in making ends meet and therefore suffered some form of financial strain as a result of having these caring responsibilities.⁴
- Carers show greater than average levels of psychological distress, with almost one third of carers believing that their health has suffered because of the strains of caring.⁵ Previous Council research demonstrated that over half of the carers for people that had Alzheimer's disease interviewed for the study found that caring was completely overwhelming.⁴
- The vast majority of carers experienced feelings of confinement due to caring. Most of the carers in two surveys for the study conducted on behalf of the Council in 2000⁴ reported that much higher levels of adjustment were needed in their lives due to their caring responsibilities than reported in previous surveys of carers of mainly physically dependent elderly people.⁵

Supporting Carers

- The major issues that arose in the 1988 Review of the Carer's Allowance related to carers' demands for a comprehensive needs assessment tool, a direct payment for caring services, a lack of recognition for the care provided and the inadequacy of respite and other health care services.¹³
- In the 1988 Review,¹³ 87% of carers reported that they received high levels of practical or emotional support from family, friends or neighbours. However, they reported that they lacked assistance in other areas. Some 29% of the carers stated that visits from the public health nurse were not frequent enough and 21% said visits were not long enough. Home help and meals-on-wheels services were received by only 1.5% and 0.5% respectively of those being cared for by co-residing carers. In addition, it was reported that, in the past, certain community services were refused to dependent older persons on the grounds of a relative being present in the household.
- The HeSSOP study (2001) reported that carers wanted to receive three main types of support from the state. These were the desire for direct payment for caring services, information and advice on health and social services, and information on welfare entitlements and relief care of various kinds.
- The vast majority of carers expressed a desire for direct payment for caring services. This would recognise both the value of the work performed by carers and allow them to purchase other forms of support should they need to do so.¹
- It was felt that the Carer's Allowance Scheme was restrictive because of the means test and low in comparison to the effort involved.¹

- In order to qualify for the Carer's Allowance, a carer must live with or in very close proximity to the person that they are looking after. This allowance is means-tested⁷ but the means test is more favourable than the means tests for other benefits because of the size of the income disregards that it allows².
- Around 80% of carers receive the maximum allowance. People who qualify for the Carer's Allowance are also entitled to a free travel pass in their own right, an annual respite care payment and free telephone rental allowance.
- Carer's Benefit came into effect in October 2000. This is a payment made to insured persons who leave the workforce to care for (a) person(s) in need of full-time care and attention. Since the allocation of this new benefit is based on the number of employment contributions made, people who were carers before the new payment came into effect are not eligible.
- The Carer's Benefit is payable for fifteen months and is assessed on an individual basis. Payment is also made to those who are not living with the person requiring care once they satisfy a number of conditions. The conditions include providing full-time care and attention, a direct system of communication (ie a telephone or alarm system must exist between the carer's residence and that of the care recipient). In addition, the care recipient must not have previously been receiving full-time care and attention within his/her own residence from another person.⁸
- There is an increased payment of the Carer's Benefit where the carer is caring for more than one person. The benefit is taxable.
- Under the Carer's Leave Bill, carers may be entitled to 'job protected leave' in order to avail of Carer's Benefit. Eligibility for the Carer's Benefit is not a prerequisite for Carer's Leave entitlement.
- The HeSSOP (2001) report also stated that a second support most frequently sought by carers in Ireland was information and advice on health and social services, and on welfare entitlements. Carers also wanted to be able to access information about the long-term prognosis and treatment options related to the medical condition of the person they were caring for. Information is a relatively low cost method of providing support and it would diminish the burden of care for carers.¹
- The third support most frequently sought by carers who were interviewed for the HeSSOP (2001) study was relief care of various kinds. The fact that the carers remain constantly in the home and are confined on a daily basis was the most frequently cited stress of caring.¹
- In the HeSSOP study, 8% of the sample of older people reported being the main person providing the necessary care for someone else in the past twelve months. Only five of the seventy-eight persons reporting to be carers said that they had received respite services within the last year.¹

- In two surveys carried out as part of Council research in 2000, respondents stated that they wanted more respite care in a hospital setting or nursing homes. On average, carers felt that they would require an additional 29–31 respite days per year.⁴
- Carers could benefit from the provision of a range of respite options, including day care places, short-term relief beds, night-sitting and domiciliary relief provided by home helps during the day.¹²
- It has been reported that people with dementia often have disturbed sleep patterns that can create intolerable burdens on the carer.¹⁴ As a result, there is a need for secure night-time beds in community facilities for those older people who suffer from dementia.
- The Carer's Association provides a number of respite services for carers which include care resource centres, home care assistance and flexible home care. Other respite services are more specifically targeted at the carers themselves. These include personal development groups, Care in the Home training courses, art therapy weekends, carers' IT centres or writing competitions. There are also some carers' support groups in existence, most of which are affiliated to the Carers' Association.

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