



Feidhmeannacht na Seirbhíse Sláinte  
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## **Irish Government and Health Care Policy** **on** **Family Carers/Older People**

The Government's National Action Plan for Social Inclusion 2007-2016 acknowledges that

*'informal carers and family carers play a valuable role in our society particularly in enabling Older People and those with disabilities to remain in their own homes for as long as possible'.*

There has also been a formal recognition of a carer role in social welfare provisions with the establishment of the Carers Allowance in 1990 as a specific welfare payment for those defined as eligible carers, and, in social insurance and employment provisions with the introduction of Carer's Benefit in 2000 and of Carer's Leave in 2001.

Government policy supports initiatives to promote and maintain the care of older people in their own homes and communities. The *'Care of the Aged Report'* was the first significant report in Ireland for older people, which included a recommendation for the establishment of a policy to enable older people to remain in their homes for as long as possible (Department of Health, 1968).

Subsequently, the National Council on Ageing and Older People (NCAOP) published *'The Years Ahead-A Policy for the Elderly'* in 1988. This policy emphasised the need to maintain older people at home for as long as possible, with a primary focus on the promotion of dignity and independence (NCAOP, 1988). The Irish Health Strategy *'Shaping a Healthier Future'* emphasised "strengthening the role of the general practitioner, the public health nurse, the home help and other primary care professionals in supporting older people and their carers who live at home" (Department of Health, 1994: 67). The target was to ensure that not less than 90% of those over 75 years of age continue to live at home (Department of Health, 1994).

In 2001, the Government *'White Paper on Supporting Voluntary Activity'* was published which made the following priority recommendation: "Programmes to support informal caregivers through the development of informal networks, the provision of basic training and the greater availability of short-term respite care will be developed and implemented" (Department of Social, Community and Family Affairs, 2001: 32).

In the same year, the Irish Health Strategy entitled *'Quality and Fairness-A Health System for You'* was published. One of the key objectives of this strategy was to ensure that "appropriate care is delivered in the appropriate setting" (Department of Health and Children, 2001a: 79).

In this strategy some examples of people receiving services in an inappropriate setting were illustrated, such as, older people being cared for in acute hospitals due to the unavailability of more appropriate extended care facilities or community supports (Department of Health and Children, 2001a). In the same year, the Primary Care Strategy *'Primary Care-A New Direction'* was published. With relevance to older people, the strategy stated that “a variety of supports will be provided, such as, health care assistants to support patients in the home, and thus reduce the need for crisis hospital admissions” (Department of Health and Children, 2001b: 29).

Against this back drop of Irish Health Policy, informal/Family carers continue to provide the vast bulk of care and support in the community. The situation is similar in the United Kingdom with Jones (1992) highlighting that the largest support for older people comes from relatives and friends who are crucial to community care. However, significant changes in the nature of society have implications for this informal care system. For example, smaller families, higher divorce rates and changes in employment patterns and more women in paid employment (Central Statistics Office, 2007).

## **Impact of Caring on Carers Health**

It is well recognised that caring for an older person or a person with a disability, often places social, emotional physical and financial pressures on the carer (McConaghy and Caltabiano, 2005; Visser-Meily, 2004; Given and Given, 1991; Klein, 1989; George and Gwyther, 1986; Poulshock and Deimling, 1984).

UK and Irish surveys highlight the large number of carers who are aged themselves, and who are unable to continue in the caring role due to poor health (Walker, 1993; Blackwell et al, 1992). O'Connor and Ruddle (1988) found that 68% of the carers in their Irish study reported that they had suffered from some chronic health problem themselves, with 24% reporting being in poor health and almost one-third believed that their health had suffered due to the demands of caring and emotional strain was found as having the most evident impact on carers.

Collins and Jones (1997) suggest that carers, particularly spouses of frail older people at home, experience considerable psychological distress. The findings of the study by Collins and Jones (1997) suggests the need for greater collaboration between formal and informal care, which supports the findings of an earlier Irish study by Blackwell et al (1992). Blackwell et al's (1992) Irish study further found that in terms of the specific strains associated with caring, the most frequently cited were the experience of caring as confining (65%) and the physical efforts required (46%).

A common theme throughout the literature pertaining to carers was a sense of loneliness and isolation, linked with anxiety and depression in the lives of caregivers (Banks and Cheeseman, 1999; Zarit et al, 1999; Collins and Jones, 1997). The totality of the caring role, and the overwhelming effect this has on carers' lives was demonstrated in a study of informal caring in Northern Ireland. For many, caring constituted more than a full-time job with most carers spending more than 40 hours per week caring (DHSS, 1996). Research undertaken in the former Western Health Board in Ireland found similar results. The majority of carers (59%) spent more time as a carer than they would in most full-time jobs (more than 40 hours

per week), and 40% of the carers spent more than 80 hours per week providing care. One in ten carers spent every hour of the week looking after the person they were caring for (O'Neill and Evans, 1999).

More recently, Harrison (2007) in an evaluation of the Home Care Package Scheme in a community care area in the west of Ireland found that the mean number of hours per week of informal care being provided to home care package recipients was 113.76, and over one-third of the informal carers (39%; n=15) were providing 168 hours of informal care per week i.e. 24/7 care, and, further evidenced that the mean quality of life of informal carers was low at 35.39.

Research undertaken by Care Alliance Ireland in November 2008 found that carers were a lot more likely to report their quality of life to be poor than compared to the general population, and the extent of limitation posed by caring on leisure/recreation appeared to be a key factor both in the likelihood of health suffering due to caring and the likelihood of low quality of life for carers (Care Alliance Ireland, 2008).

The first Family Carers Health Survey in Ireland undertaken by the College of Psychiatry of Ireland in conjunction with the Carers Association, found that almost two-thirds (63%) experienced being mentally/emotionally drained by their role, and over half (56%) experienced being physically drained. The most common medical problem reported by carers in this survey was back injury/ back ache (reported by one-third of carers, of which 59% stated that caring made the condition worse) (O'Brien, 2008).

Annerstedt et al (2000) found that the amount of caregiving time each week and the carers impaired sense of own identity i.e. the "isolation" factor, were among the main factors in predicting the 'breaking point' for the carers in their study who were caring for people with dementia.

**To ameliorate carer burden, the authors recommend that measures enabling greater availability of private time, and, improving care giving skills through training and education, should be encouraged.**

More recently, Molyneux et al (2008) found high levels of depression in the primary carers of community-dwelling patients attending an old age psychiatric service in the West of Ireland, with depression being found in 21% of the carers (i.e. a score of 5 or more on the Geriatric Depression Scale-15). The more problem behaviours identified and the greater the functional impairment of the patient, the higher the carer strain scores and the more likely the carer was to be depressed.

## **Impact of Caregiver Burden on Hospital Admission and Nursing Home Entry**

A number of studies have examined measures related to nursing home admission among older people. The strongest and most consistent predictors of nursing home entry are *functional status* (i.e. the poorer the functional ability of the older person the greater the risk of nursing home admission, such as, older people with poor mobility and a higher risk of falls (Kao and Stuijbergen, 1999)), *mental status* (such as, dementia, is associated with an increased risk of institutionalization (Eaker et al, 2002)), and *age* (Steinbech, 1992; Wollinsky et al, 1992; Foley et al, 1992; Liu et al, 1991; Kemper and Murtagh, 1991; Newman and Struyk, 1990; Greene and Ondrich, 1990; Morris et al, 1988; Cohen et al, 1986; Shapiro and Tate, 1985; Branch and Jette, 1982; McCoy and Edwards, 1981; Vincent et al, 1979; Palmore, 1976).

In addition, the absence of family ties is strongly associated with an increased risk of institutionalisation (Murashima and Asahara, 2003; Sauvaget et al, 1997; Townsend, 1957). Analysis of the literature suggests that changes in the physical and mental health of carers, are more significant than changes in the person with dementia in affecting the decision to place the person with dementia in a long term care facility. Chenoworth and Spencer (1986) found that 72% of patients with Alzheimer's in their US study were institutionalised due to the carer being overwhelmed by the 24-hour demand of care. Gort et al (2007) found that caregiver burden and collapse in caregiving at home (accompanied by an increase in hospital visits or institutionalisation) by the main carer was very frequent (burden 73% and collapse in caregiving at home 50%).

References can be obtained from:

**Siobhan Mc Eniff, Carers Development Officer, St. John's Hospital, Sligo 071/9142606  
ext: 269 or 0879080832**