



**Carers of the Terminally ill and Employment Issues:
a comprehensive literature review.**

**Final Report to Help the Hospices
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Carers of the Terminally Ill Project.**

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Executive Summary with Recommendations

Introduction

ES1 Help the Hospices, in collaboration with the Tubney Trust, commissioned this literature review to help inform service and policy development, and to influence and advocate policies that enable carers of someone with advanced progressive illness to combine working and caring roles.

ES2 Maintaining work whilst continuing to care is vitally important, not only in economic terms but as a potential buffer against the stress of caring and in securing continuity after a relative has recovered or died. Recent legislation in employment rights has provided some limited flexibility to those in employment with caring responsibilities. However, with the increase in flexible working practices in the UK, much evidence points to the fact that, for many individuals, flexible working remains an organisational goal rather than a reality in practice.

Key Recommendation 1: There is a need to examine the extent to which the differential experience of employer flexibility across different sectors of the economy impact on those looking after someone with advanced progressive illness.

ES3 Understanding the push and pull factors that are specific to those caring for a person with advanced progressive illness in terms of maintaining employment will help us to understand the relative merits of differing approaches to maintaining work and caring, and in developing employer and national policies to support them in both caring and work roles.

ES4 There are indications that an understanding of mastery and resilience are important in understanding the position carers take in relation to

employment. Understanding the ways in which to maintain the positive features of caring marks an important move away from singularly negative models of stress, strain and adaptation. More research is needed in this area.

ES5 Caring for a dying relative or friend is generally viewed as less protracted and predictable than for many other life long carers. However, the increasing trend towards caring for a dying relative at home means that issues about care and employment are likely to increase in the future.

ES6 Whilst there is increasing understanding of the type of activities and experience of carers in a palliative care setting, there is insufficient data available to distinguish the number of carers providing such care from carers in general. No statistical or empirical data is therefore available which establishes the number of hours of care provided or the distribution of different forms of care provided by carers in palliative care settings.

ES7 Understanding employment and care issues will be dependent upon a detailed breakdown of the type of care provided the level (ie the number of hours provided per week) the distribution of employment characteristics of those providing care for the terminally ill.

Key Recommendation 2: There is a need to identify for the 500,000 people estimated to be providing care for a terminally ill person the nature of the care provided and the age distribution as a comparator to carers as whole.

ES8 The impact of the Carers Equal Opportunities Bill (Date), which is aimed in part at supporting carers in employment, is yet to be assessed in terms of its outcomes for carers caring for someone with a terminal illness.

ES9 There are certain idiosyncratic issues or features of caring in a palliative care setting that may affect a carers' response to employment. These include: uncertainty of the caring context, particularly in relation to the dying trajectory; a lack of consideration of the long and short term consequences of deciding to take on caring at a time of high emotional stress; a policy of encouraging home care for those dying of advanced progressive illness; a general and pervasive view that the family will be willing and able to provide care for someone with advanced progressive illness. Carers therefore have to opt-out rather than opt-in to caring.

Key Recommendation 3: Some work looking at trajectories and the likely impact of different calls on carers' time may help in establishing relevant and appropriate policies and interventions.

The Review

ES10 No studies examined in this review took as their main interest employment in relation to those caring for dying relatives. Five papers were identified that considered these issues as one aspect of a wider consideration of individual carers concerns.

Family Carers, Employment and Palliative Care Issues

ES11 If studies of the affect of caring on employment are correct, a majority of carers will find their work affected in some way by their caring responsibilities. Grunefeld et al (2004) found that 5% of the caregivers in their sample had to quit their jobs, decline advancement as well as losing hours, taking special leave and using holidays to care. Furthermore they were more likely not to be able to work regular hours. This implies an increase in the unpredictability in the care that is required. It would therefore appear that the effects on employment

occur early on in the care trajectory but are sustained into the terminal phases.

ES12 Income security may be viewed as being achieved through additional payments of benefits by Government direct to the carer or via employment law and policies such as those outlined in the introduction to this report. However, which is best and how the two might be related to ensure continuity, may be a key issue.

Key Recommendation 4: There is a need to consider some form of income security, particularly during the terminal phase where care responsibilities become greater and where constant care is required.

Key Recommendation 5: Systems seeking to maintain economic security may be through Government benefits or via employment law and policies. More work is required to ensure that the relative merits of both are tested and that the links between the two work seamlessly so as to cause least stress to the family carer.

ES13 The move towards palliative care in the home inevitably increases the demands on informal caregiving. Hayley (2003) argues that this will have implications on their ability to sustain employment.

Key Recommendation 6: Some consideration needs to be made about the impact of caring on employment in terms of the carers' assessment and new sections of assessment relating to equal opportunities and employment.

ES14 Given et al (2004) found an increase in the perception of stress and burden amongst unemployed spouse and non-spouse caregivers of the same generation as their patients who were more depressed than

employed spouse and non-spouse care-givers. Employed adult children were found to be significantly more depressed (Given et al. 2004, p.1110). This is alerting us to the differential impact of employment and unemployment dependent upon the relationship to the person being cared for as well as to stage of disease. It seems to indicate that spouses see work as a form of buffer to stress whereas adult children see care as an additional burden alongside their employment. There is support in these findings for both the 'role conflict' model (Stull et al, 1994; Murphy et al. 1997) as well as for the compensatory model (Staines, 1980; Shearn and Todd, 2000). Which model seems to work best seems to be dependent upon age.

Key Recommendation 7: More needs to be known about the impact of age, symptom severity, carer relationship to person being cared for in order to understand the differential impact on employment and stress. A general rule for the latter seems to be that the further away from the person in terms of age or relationship the greater the stress felt in caring and in having to give up work for that person.

ES15 Potentially work commitments may impact on the carers support networks and activities. Svavarsdottir (2005) examined parents of children with cancer at three points over a two year period in relation to caregiving demands, well-being and perceptions of their child's health. Caregiving demands were seen to decrease over time. In the study 85% of fathers worked and only 39% of the mothers were in part time work. Yet the fathers did not see work outside as their most time-consuming role. However, emotional support to their child and partner was found to be very difficult.

Key Recommendation 8: There is a need to look at mastery as a means of explaining reductions in stress. In this model there would be a need to look at mastery, adaptation and resilience as being affected

by the balance between employment, income and caring.

ES16 Harding et al (2003) found that one reason for a lack of attendance at the carer support group they evaluated was the timing of the event, which was during a normal working day. This is potentially significant as it is likely that working carers may already be taking time off work to assist the ill person with medical and health related appointments in addition to any crisis or acute medical care requirements. To be seen to take yet more time for “social” activities may be more than could be tolerated by employer and employee.

ES17 The detailed consideration of the five articles which best meet the search strategy for this study have indicated that we know very little in research terms about employment and caring for a dying relative. What the evidence indicates is that the experience is likely to be highly varied and that this variation will be dependent upon number of potential variables: Age of carer and person being cared for; level of dysfunction, impairment and support need; perceived levels of stress; capacity for resilience; predictability of care required; economic security from savings, employment or government; social networks and networks of support; and other demographic factors.

Key Recommendation 9: A study that examines the extent to which services cannot be accessed due to other commitments (employment and others) would be useful. The nature of service support should be organized so as not to provide additional burdens to carers.

Carers, Policy and Employment Issues

ES18 Policy initiatives surrounding caring and employment are introducing policies to legislate and encourage the combination of caring and

employment. However, this work has centred around care and employment for families with children. This has disadvantaged those carers of older people.

Key Recommendation 10: Evaluating the impact and outcome of the Carers Equal Opportunities Bill needs to be considered.

Key Recommendation 11: Policy initiatives surrounding caring and employment need to fully recognize the age range of individuals requiring care and the increasing number of older people in this group.

Key Recommendation 12: Studies of the health problems of those caring for a dying relative will establish the extent to which their own health becomes a key issue in maintaining employment.

Key Recommendation 13: Understanding the balance between financial and emotional costs will help carers make informed decisions about how they manage the balance between care and employment. Data on the effect of different decision-making in this regard will be vital in helping carers in making informed choices.

ES19 Supporting carers back into work will require considerable individual support and encouragement. Identification of the factors that may be involved in this process for carers who may also be experiencing bereavement is unclear.

Key Recommendation 14: Key factors important in supporting carers back into work should be

considered by health and social care professionals supporting carers in palliative care situations.

Effects of Caring on Employment

ES20 Despite more recent work exploring the positive benefits of caring, it is largely viewed as negative and resulting in stress and burden for the carer. Increased social support and social ties are associated with more favourable mental health outcomes of caregivers. However, in the terminal phase work may be viewed as a distraction and as taking away precious time from caring for the dying person.

Key Recommendation 15: More needs to be known about the perceived benefits and costs of carers who remain in or choose to leave work when caring for someone with advanced progressive illness.

Carers, Gender, and Employment Issues

ES21 Women are more likely than men to be involved in combining caring and work roles. The result is an increasing number of hours worked, and an impact on income and career progression. How carers are able to maintain this balance may be dependent in part on their ability to access both informal and formal services.

Key Recommendation 16: More needs to be known about the extended support services provided to carers combining employment and work in order to be able to identify and plan supportive service and employment provision.

Carers and Employment Issues

ES22 Key factors have been identified in supporting carers back into work (Arsky 2003). These issues may be important post bereavement for carers who have given up work to be involved in caring roles within the terminal phase.

Key Recommendation 17: A substantial number of employee friendly work practices have been implemented in relation to carers. However, nothing is yet known about which of these initiatives works best for carers who are looking after someone with a terminal illness.

ES23 There is some evidence to support the notion that the extended informal support network may be sustaining the family caregiver to maintain their role (Arsky 2003, 2004). As one reason for unplanned admission to hospital or hospice (Thorpe 1993) remains a break down in the informal caring network, the provision of emotional and instrumental support provided by family and friends to primary carers in palliative care may be an important issue that health and social care professionals need to take into account when providing support for carers. Particularly in the case of adult children, providing emotional or instrumental support may have an adverse effect on their own emotional well being that could impact on their employment roles.

ES24 Supporting both employee and employer in maintaining and combining care requires considerable commitment and advice.

Key Recommendation 18: Raising the awareness of the issues and presenting some methods and suggestions as to ways of achieving these goals will make it more likely that a positive choice can be taken by carers to combine their caring and

employment roles, or for carers to consider a return to work post-bereavement.

Key Recommendation 19: To enable carers to fully consider the implications (both financial and emotional) of maintaining or leaving work to undertake caring activities in the terminal stages of the cared for persons life.

Carers, Retirement and Pension Issues

ES25 For palliative care, issues affecting carers who are near retirement or considering reducing their work hours or giving up work are important. Given the age range of people with advanced progressive disease requiring palliative care and the likely age range of non-spouse adult children carers who may be providing or assisting in caring there is a likely socioeconomic impact that requires consideration.

Key Recommendation 20: The potential loss of income or pension rights needs to be highlighted to potential carers. Employers should be encouraged to consider carer friendly policies in addition to family friendly policies.

Key Recommendation 21: The needs of women in terms of their double disadvantage (as those chosen to care and those most likely to lose employment) need to be addressed as a priority in policy.

Priorities for Further Research

ES26 If the carer decides to remain in employment then the appropriate provision of formal and informal service support may facilitate this process. Further close work with employers who are interested in, or attempting to conform to carer friendly policies, would be beneficial.

- ES27 To be able to ascertain the specific services and employment strategies that are effective requires further investigation and understanding of the complex nature of the caring situation and the range of individuals who may potentially be involved in providing informal supportive palliative care. Such studies currently do not exist within the palliative care literature.
- ES28 A number of groups are frequently missing from the general caring and employment literature, such as those who are self-employed, ethnic minorities, the homeless and refugees. Further work with these groups of carers is called for as without more detailed knowledge and information about the particular concerns or difficulties experienced it is unlikely that appropriate strategies for employment and care may be undertaken.
- ES29 There is clearly a gap in the knowledge about the impact and supportive strategies required by carers to maintaining or re-enter employment. The development of appropriate strategies and interventions to enable carers to combine caring and work roles is an important area of caring research that needs to be considered and examined more closely in order to develop and provide appropriate and timely support to carer in palliative care settings.