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Family Carers in Palliative Care

‘White Paper’

**Sheila Payne, Peter Hudson, Gunn Grande, David Oliviere,
Carol Tishelman, Sabine Pleschberger, Pam Firth, Sheila Hawker
and Christine Kerr**

Prepared on behalf of the EAPC Task Force on Family Carer

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Family Carers in Palliative Care

Executive Summary

1. Family carers are central to the provision of palliative care for patients.
2. This document highlights what evidence is available about the role of family carers as providers of informal support to patients and to recognise and acknowledge their own needs and the impact of caring upon their physical, psychological, emotional, social and financial welfare.
3. The information presented in this white paper is the result of a scoping of the literature that focussed upon the situation and issues faced by carers in palliative care settings internationally.
4. It is written for clinicians, managers, educators and policy makers working in, or responsible for, palliative care and hospice services in Europe.
5. Family carers occupy dual roles in that they are both providers of care to patients and they may be recipients of care from health and social services. Some carers find their role to be ambiguous and this may mean that they are reluctant to express their own needs.
6. Since many family carers have pre-existing family relationships with the patient and others people in the family, they may not identify with the term 'carer'. This means that they may not take up services described in this way.
7. Recommendations are made for: carers services and interventions, future research, and public awareness and policy developments.

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Family Carers in Palliative Care

Introduction

The purpose of this paper is to highlight the contribution of family carers to the care of patients in the palliative phase of illness. It is written for clinicians, managers, educators and policy makers working in, or responsible for, palliative care and hospice services in Europe. The information presented in this white paper is the result of a scoping of the literature that focussed upon the situation and issues faced by carers in palliative care settings internationally. While not a systematic literature review, it constitutes an integrative review of papers published in recent years by recognised researchers in the area of palliative care. The information presented here draws on the most relevant, significant and oft cited papers from the palliative care literature published between 2004-2009.

This white paper will focus on the contribution to care made by patients' families and friends and explains why their work is a significant and vital resource in palliative care. Our aim is to describe the roles of carers and explain why carers are so important for patients who are nearing the end of life. We will outline the social changes that affect families' ability to offer informal care especially in the long term. We will identify who is providing care to palliative care patients, establish their needs and examine the ways in which carers are supported by palliative care professionals. The theories and models that have been developed to describe the role of carers will be presented alongside the assumptions that underpin them. Based on the extant literature, we will outline the challenges facing the families and carers of palliative care patients and suggest optimal ways for service providers, stakeholders and decision makers to work in partnership with family carers for the benefit of both patients and family carers. Finally we will make recommendations for the development of future initiatives and research.

This paper concerns those people who are family, friends and in other significant non-professional or paid relationships to the patient who provide care to a person with

advanced illness and during their dying phase. The terms ‘caregivers’ and ‘informal carers’ are used interchangeably in some of the literature with ‘carers’. Hereafter we refer to this group of people as ‘carers’. Carers are in a dual position; they provide care for the patient but may be recipients of support themselves. The paper focuses on the role of these people and their support needs during care-giving but not following bereavement. The paper will focus on care provided by adults to adults who are in the palliative phase. It will cover care provided in a range of settings including the home, hospital, care home (nursing home) for older people, hospice and other places. It covers the care provided by people associated by family and kinship, including adult children and friends. Children under 16 years may be both the recipients and providers of care and this is worthy of further consideration but will be beyond the scope of this paper.

Background

In recent years the European Association of Palliative Care (EAPC) commissioned a survey on the development of palliative care in European Countries (Centeno et al 2007). This evaluation showed that while common structures across Europe do exist there is great diversity in the structure of service development and care delivery across countries and regions within Europe. It was found that these differences are partly related to different understandings of the underlying concepts and terms used in palliative care.

In Europe, as in the rest of the world, the lack of common terminology has hampered the development of international standards in palliative care. Across Europe commonly used terms include ‘hospice’, ‘hospice care’, ‘continuing care’, ‘end of life care’, ‘thanatology’, ‘comfort care’, ‘palliative medicine’ and ‘supportive care’ (Pastrana et al 2008; Radbruch et al 2009). In order to accommodate the scope of languages and cultures within Europe, the EAPC uses the following working definition of palliative care and hospice care:

Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. Palliative care is

interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.

(EAPC IMPaCCT 2007)

In an effort to improve common understandings an EAPC Delphi study focussed upon developing ‘standards and norms’ as an aid to reaching agreement on quality goals to improve palliative care across European countries and regions (Radbruch et al 2009).

Despite the acknowledged differences in national approaches to palliative care a series of common values and principles can be identified. What is of particular relevance for this paper is that, as in the above definition, it is widely recognised that during the dying period and after the death, palliative care teams should include care and support for the families and carers as well as the patient. There are a number of different definitions of carers including those that focus primarily on ‘hands-on’ care provision, but the one used in this paper will encompass a more inclusive and extended role. In the United Kingdom the National Institute for Clinical Excellence (NICE, 2004) defines carers as follows:

Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotional management. (p.155)

The notion of family is contested and changes over time. We offered the following broad definition drawn from the United Kingdom’s National Institute for Clinical Excellence (2004).

Family includes ‘those related through committed heterosexual or same sex partnerships, birth and adoption, and others who have strong emotional and social bonds with a patient. (p.155)

This conceptualisation of family includes not only formalised relationships, but also those that are self-defined or patient-defined as significant. Health and social care professionals may not recognise that family caregiving is largely hidden work that is often taken for granted yet it is crucially important if dying people are to receive good care and eventually achieve 'a good death'. The sustainability of keeping terminally ill patients at home depends upon how close their family relationships are and how willing and able families are to provide care (Higginson and Sen-Gupta 2000; Harding and Higginson 2001). While acknowledging that carers are not a homogeneous group, there is agreement that carers should be supported in their role and helped to prepare for the loss of the patient before the death in addition to being offered bereavement support afterwards where required. The situation is made more complex because caregiver needs may be different from, and sometimes even incompatible, with the patient's needs. This can be challenging for health care professionals who have to discern whose needs should take priority (Hudson and Payne 2008).

Within Europe there are estimated to be 100 million carers whose contribution to care often exceeds the financial expenditures of their countries on formal nursing services although it is difficult to estimate exactly how many are engaged in caring for a person near the end of life (Eurocarers 2008). Despite the important work that carers contribute in palliative care settings there is increasing evidence that they are often unprepared for the many demands they might face and they experience considerable physical, psychological, social and financial challenges (Hudson & Payne 2008).

Supporting carers is not straight forward because they occupy an ambiguous role; both as provider and receiver of services and many carers do not define themselves as a 'carer'. For many, particularly women, it is an inevitable part of life and a cultural expectation of them. Caring for a family member may be seen as a 'natural' element of family relationships. It can give satisfaction and be an expression of altruism, duty and kinship obligation. In developed countries, many carers will be older people (Payne 2007). While care-giving can be rewarding, it is also demanding, particularly if the ill person is approaching the end of their life. These demands can be physical, psychological, social and financial (Grande et al 2009). In the palliative care context, the needs of caregivers can exceed those of the patient (Higginson and Sen-Gupta

2000). Ideally in palliative care settings health professionals, social care professionals and carers work in partnership to plan care for the patient and manage their illness yet it is important that the support needs of the carers are also addressed by the palliative care team.

1. Caring in Context

There have been significant social, economic and demographic changes in Europe during the last 35 years. These changes have affected all aspects of social life and therefore also impacted heavily on areas of health and social care. As a consequence it is likely that in the future there will be fewer carers yet more people dying with complex care needs (Seale 2000). This will have implications for maintaining high standards of care across the range of settings in which care occurs. It is likely that carers will face increasing role conflicts and increasing care burdens in the future.

Family and Households

During the last quarter of the 20th century trends in family and household composition became less predictable as established family patterns began to change (Allan, Hawker and Crow, 2001). In many developed countries family size has declined to one or two children per partnership following declines in the birth rate, and in the UK approximately 10% of women remain childless (Payne & Hudson, 2008). In many European Union countries, rapidly rising divorce rates with over one million divorces annually, have led to more complex family formations including re-marriage, single parent households, co-habiting couples and stepfamilies becoming commonplace (Dugan 2008). It cannot be assumed that people in roles such as ex-partners and step-children following changed family constellations, will provide care. Changing complex family relationship and family reconfigurations can leave older people, particularly men, living alone. This means that care provision at home may not be possible.

Employment

Families are also affected by the shifting requirements of a global economy. Changes in the employed workforce, and varying patterns of employment have seen increasing numbers of women employed outside the home leaving fewer people available to

undertake a full-time caring role. The demand for a geographically mobile workforce has led to higher levels of migration within and into European societies resulting in household disruption and changed family constellations (Allan, Hawker and Crow, 2001). For example in many Eastern European countries, high levels of economic migration in younger people leave older family members without practical support towards the end of life (Kellehear 2007). The European Union (EU) is currently concerned about increasing the workforce and EU policies and current economic pressures mean that more women have paid jobs, people work longer hours and for more years before retirement, than in the past. The impact of these developments means that fewer people are likely to be available to provide unpaid care at home. These changes in the employment sector are likely to increase the tensions between work and caring responsibilities (Eurocarers 2008). While providing care for the people near the end of life is a time-limited activity associated with progressive losses, it may entail focusing solely on the patient for the duration of their illness, in the knowledge that it is a temporary situation because the patient will die (Harding and Higginson 2003). Consequently family carers may stop paid work or reduce working hours to care for their relatives. A study suggests that the economic cost of informal care is twice as high as that of formal care (Andersson et al 2003). Economic pressures on families are likely to impact on their ability to provide care at home.

Demographic changes and ageing

International demographic patterns indicate that in most parts of the world people are living longer, and that dying typically occurs in later life, and these demographic trends are predicted to continue into this century (Davies and Higginson 2004). Continuing developments in medical technology alongside improving living conditions have resulted in changed patterns of mortality. One of the most salient issues now facing European countries and regions is that of ageing populations. As more people live longer there are now growing numbers of the 'old old' (people over 85 years) and these numbers will increase over the next 20 years. As an example it is predicted that in the UK the percentage of deaths amongst those aged 85 and over will rise from 32% in 2004 to 44% in 2030 (Department of Health 2008). Most patients receiving specialist palliative care services are in middle or later life and as a result, many carers themselves are older people who may have health problems of their own.

It is estimated that by 2050 the total population of Europe will have dropped by 1% and half the population will be aged over 50 years. As the demand for palliative care rises the overall decline in the population will mean that there will be fewer people available to provide paid and unpaid care. This will have the potential to considerably compromise the quality of care to patients requiring palliative care.

Causes of death

Each year 1.6 million patients in the European region will die from cancer while approximately 5.7 million will die from non-cancer chronic diseases (Radbruch et al 2009). To date specialist palliative care services and hospice care have been predominately associated with palliative care for patients with cancer in most countries in Europe. The numbers of adults living with cancer and requiring palliative care is expected to increase due to raised public awareness, earlier diagnosis and advances in treatments. Epidemiological changes combined with public health and medical advances in most European countries mean that older people increasingly live with one or more chronic conditions including cancer, organ failure and dementia, for some years before they die (Davies and Higginson, 2004). Hence, there are a significant number of older people who must cope with one or more chronic conditions and for some, an awareness of prolonged and uncertain 'dying', for considerable periods before their actual death. People are likely to die in older age suffering from a number of co-morbidities, sensory and cognitive impairments which mean that demands on carers will be more complex.

2. Who Provides Care?

Patterns of social support and the extent of social networks before the need for palliative care arises are thought to affect the subsequent active involvement of families in patients' end of life care (Gomes & Higginson, 2006), with those having more social support and more enmeshed social networks predicted as more likely to die at home. Families are often assumed to be readily available and willing to care for dying family members, although this is not always the case. In many societies strong social norms mean that care-giving within family networks are obligations that people fulfil out of duty, filial piety and reciprocal altruism. However it should be noted that

family members are not always supportive of each other, families can be conflict ridden which can affect their willingness to act as carers as well as the standards of care they are able to offer a palliative care patient (Monroe and Oliviere 2008). This means that health and social care professionals need to be sufficiently trained and resourced to meet the often complex needs of family carers.

Palliative care during a final illness takes place within an ongoing social relationship. Carers can benefit from mutual support if caring responsibilities can be shared within the family. There is more within generational care than cross generational caregiving at the end of life as most carers are spouses (Payne & Hudson, 2008). While care may not lie at the core of the relationship at the outset, over time the caring process can change the nature of the relationship (Eurocarers 2008). While this may be acceptable to some people, others are distressed by the transformation or ending of valued aspects of their previous relationships. This reinforces that the role of family carer is not limited to instrumental tasks such as hygiene care but carries with it significant psychological and social implications.

More research is required into the effects of the personal characteristics of the carers such as age, gender, health, education, resources, life experience and the relationship with the patient as these are all likely to impact upon caring and the willingness to take on the role of carer. In addition, more needs to be known about the quality of caring and the demands facing carers who need to deal specific challenges such as incontinence.

Caregiving can be regarded as a gendered activity; more women than men provide care and in palliative care differential life expectancies mean that the majority of older carers are women. For example all caregivers in the UK, there are more women (approximately 3.0 million) than men (2.9 million) who provide general care (Mather and Green 2002). There is evidence to suggest that women may be better prepared or at least socialised into anticipating that a period of their life will be spent providing care to older parents for example. There may be more informal support from family and friends for women carers than for men who take on this role.

Caring for a dying person is not a role to which most people aspire. The term 'carer' is often an 'ascribed' role placed on family members or friends by health and social care workers. The individuals themselves may describe themselves as 'husband', 'wife', 'son', or 'daughter' and so on. Many people engage with the tasks and responsibility of care but may resist the label of 'carer' (Grande et al 2009). Carers may not see their contribution as 'care' which is often equated with the purely physical tasks like lifting, personal care and help with mobility (Rabow et al 2004) although it is argued here that the carer role encompasses far more than this. Health professionals may also assume that there is a 'main' or principal carer who will be the recipient of their advice and instructions. However the reality is that in most cases there is a network of support and care which may include friends and other social contacts. This suggests that we need to think about 'family' in a more extended way to include friends and other people in supportive relationships but necessarily related through kinship. In addition not all members of the caring network may live with the patient (Payne & Hudson, 2008). It is therefore important that health professionals should be proactive in identifying who is providing different types of care to the patient in order that all carers can be offered the types support that they may require. However, this has major workforce, resource and training implications. The appointment of a key worker to co-ordinate the various helpers, both formal and informal may be important.

3. Place of care and death

Place of death differs considerably within and between European countries, largely dependent upon the availability and funding of health and social care services, and family patterns. Research shows that many people would prefer to be cared for at home if high quality care can be assured and as long as they do not place too great a burden on their families and carers (Agar 2008). Home deaths can represent both the best and worst experiences (Thorpe 1993). Currently there is emphasis in the UK and other European countries on enabling patients to die at home if that is their wish. Death at home is more likely for those who have someone living with them (Houttekier et al, 2009). Enabling end of life care and death to take place at home is heavily dependent on carers (Gomes and Higginson, 2006) as most of the last year of life is spent at home. Death at home can place considerable burdens on family and

friends of the patient yet few studies have considered the preference of the carers as well as those of the patient (Higginson and Sen-Gupta 2000). Care at home, and by implication, death at home can sometimes be the result of a lack of care alternatives. It is clear that carers are less likely than patients to report a preference for a home death (Grande, 2008); one reason being that these data are rarely recorded. The issue for carers is that there may be implicit pressure to agree with the patient's wishes (Stajduhar and Davies 2005). This reinforces the challenge for health and social care professionals as they attempt to meet the needs of both patient and family.

The shift of dying patients from hospital to home may well prove to be cheaper for health care services. However the hidden costs for carers are largely unrecognized and unreported. The limited and often inconsistent availability of practical assistance to support care has a crucial impact on the carer's experience of caring. It is argued that the current imperatives to enable people to die at home may place undue moral pressure on families to provide this care whatever the cost to them (Payne, 2007). The move in some countries to formalise 'advance care planning' may increase this pressure on carers (Horne et al 2009).

Despite the increase in numbers of older people in modern society outlined above, the reality of death and dying is rarely discussed. Most deaths currently occur in hospitals and care homes and are therefore removed from people's direct experience. Consequently there is now much less familiarity with death and dying than in the past. Many people will not have had to deal with a close family member or close friend dying until they are into their mid-life years, and some will not have seen a dead body until this time. While family carers may be anxious to comply with the patient's last wishes, few carers will be prepared for the physical practicalities of death and dying (Hudson 2003).

4. What are the impacts on caregivers?

Impact on physical and mental health

Carers have been shown to neglect their own health. Lifting the patient may cause back injuries, and fatigue is common (Payne & Hudson 2008). Many carers are older and consequently may have their own health problems. Over a third of carers

experience psychological distress including feelings of powerlessness and helplessness, and these effects can be long lasting (Milberg et al 2004). A large Italian study found that a quarter of caregivers experienced emotional suffering when caring for a dying relative. Powerlessness, anger, remorse, guilt, fear and a feeling of vacuum after the patient died have all been reported by family carers (Morasso 2008).

Impact on family communication

There is a large body of evidence from psychiatry that focuses on family communication patterns and conflict and the implications of different interaction and communication behaviours upon family members during care provision and in bereavement (Kissane et al 1994; Kissane et al 1996; Kissane et al 1998; Kissane and Bloch 2002). Family carers will need to develop skills in communicating with a range of people including health professionals to obtain information to contribute to caregiving, to advocate for the patient, and negotiation skills between themselves, professionals and other family members. They are often the mediators of information and transfer 'good' and 'bad' news across others in their family. This can be stressful and demanding.

Social impact

Likewise, (Monroe and Oliviere 2008) highlight the social implications of assuming a carers' role and acknowledge that family structures may be strained both before and during the care of a dying family members. They caution against simplistic notions that the family as a social entity always mutually sustaining and supportive. Moreover, providing care at home highlights the notion that 'home' is not merely a physical space, but the social and emotional relationships therein are crucial (Exley and Allen 2007).

Impact on work and finances

The social impact of care provision may be visible in the effects on employment and leisure. For younger carers, education may be interrupted. Being tied to the home and away from normal employment affects a caregiver's social and working life (Smith et al 2006). Negotiating leave from work or reducing working hours can be difficult and future employment prospects including promotion may be jeopardised. Whilst potentially providing greater flexibility to caregiving, some types of employment such

as self-employed business people or farmers may find it virtually impossible to reconcile the demands of providing caring and maintaining a business. The resulting financial burden compounds the difficulties faced by the carer. Pensions may be affected and the complicated rules of many national benefit systems can become even more daunting when a person is debilitated by caring. Some financial supports may be discretionary and families may find themselves dependent on assistance from charitable funds in order to sustain the care. A Korean study (Park et al 2009) found that caregivers' unmet needs negatively affected both the quality of end of life care they delivered and their workplace performance. Flexible working practices, extended leave and back to work training would be helpful (Payne & Hudson 2008). Caring at home is expensive and there may be the extra costs of travel to and from hospital appointments, special diets and the need for extra equipment and alterations to the home (Grande et al 2009). Currently across Europe many carers receive insufficient financial support.

Impact on social identity

There are reported to be changes to social identity in carers (Soothill et al 2001). Caregiving may be an isolating experience, with little opportunity to engage in recreational activities.

Positive impacts

In spite of the difficulties outlined above, care-giving can be both challenging and fulfilling (Hudson 2004). A person's ability to cope with caregiving is a reflection of their individual circumstances and resources and may change throughout the person's illness (Payne 2007). The resilience and adaptability of families means that the role of carer may move around the family, even between the patient and carer at times. It has been argued that personal characteristics including hardiness, positivity and laughter are factors that predict better outcomes for carers (Bonnano, 2004). The attitude with which the carer approaches the task of caring may distinguish how well they will cope. Some people may be naturally pessimistic, others optimistic. Some may have more inherent resilience. If a person gains enhanced self-esteem from caring, experiences social approval and believes they are in control, then they will benefit from the role. Love and moral duty may also be factors. An Australian study reported that some carers found they felt a sense of reward and were able to think positively

about the meaning of the experience of caring for their dying relative, which helped them to come to terms with their loss (Wong & Ussher 2009). Personal growth and improvement in family relationships were identified as positive aspects of caregiving in an Italian study (Morasso et al 2008). The carers' approach to life; the patient's illness experience; the relationship with the dying person; the patient's recognition of the contribution made by the carer and carer's sense of security were all important factors identified in a recent Canadian study of carers' ability to cope with providing palliative care (Stajduhar 2008).

Caregiver support

Studies have shown that caregivers need psychological support, information, personal, domestic and medical care for the patient, out of hours support, respite and financial help. Previous research has focused on repairing problems like stress rather than preventing them (Payne & Hudson 2009, Grande et al 2009). The unpredictability of caring for a person at the end of life is an important factor when determining carer needs. The condition of a patient who is receiving palliative care can change quickly. There may be uncertainty about the duration and nature of the patient's illness and particularly for conditions other than cancer it is difficult to predict the dying trajectory. Carers may be in this role for a relatively short time and therefore require a rapid response to their needs (Heatley 2006). While the focus of care is primarily on the patient, carers may be reluctant to express their own needs.

Most of the existing research focuses on primary family caregivers and lacks information on the diversity of experiences of certain groups. These include male caregivers, children, new immigrants and non English-speakers. There is also little information about caring for non-cancer patients (Payne & Hudson 2008). Caregiving in the final phase of life raises some specific issues and we discuss these below:-

Psychological support (emotional, social, bereavement and spiritual)

Caring for a person and knowing they will die has an emotional cost. The psychological support provided by carers to the cared for person has been referred to as 'emotional labour' (Payne 2007). The experience of caring for a dying person is likely to be perceived as stressful and most caregivers will feel anxiety (Stajduhar 2003). The closer the relationship, the greater the impact may be (Payne & Hudson

2008). Carers need to deal with their ‘own sorrow and sense of impending loss’ (Candy et al 2009:2). Carers may benefit from help to prepare for loss and grief, and to receive bereavement support after the patient’s death (Help the Hospices 2009). This means that psychology support should be provided to carers through the illness trajectory.

Information

All carers need to know how to access health and social care services, both for the patient and for themselves. They need to receive information that prepares them for supporting their relative (Payne & Hudson 2009). This includes information about giving practical care and support to the patient, and hospital discharge planning. Carers also need to know how to minimize the burden placed on them, how to survive the experience. When a patient is nearing the end of life there is also a need for information about disease progression and prognosis, and how to deal with the dying process. However, this must be given in a way appropriate to the caregiver’s, as well as the patient’s needs. These may not be the same. After death, caregivers may need information about the practical arrangements that they need to make. If information is lacking, ‘families typically feel out of control, disempowered to make decisions and unable to cope with the physical care of [the] relative on a day to day basis’ (Bee et al 2008). This means that carers need access to the same information as the patient and additional information about care provision and bereavement support.

Help with personal, nursing and medical care of the patient

Support with managing the patient’s symptoms, including pain control, organising medication and nursing care are important aspects of caring for someone at home in the final months of life. Medical equipment and aids may be required in the home. Extra washing and cleaning, special diets, and getting the shopping become difficult. Advances in medical treatment can increase survival times for patients of all ages and care for the patient can become unexpectedly protracted. If a person wishes to die at home, a major task may be the coordination of the different providers of support and carers may require a key worker to take on an organising role. This means that resources such as paid care workers should be made available to carers.

Out of hours and night support

Carers of patients with end stage disease are particularly vulnerable at night, or when normal health care services not available. Strategies to deal with queries and forward planning may avoid crises and unnecessary transfers to hospital (Ingleton et al 2009). This means that services should design mechanisms to provide support day and night such as dedicated telephone helplines.

Respite

Caregivers may need to take a planned or unplanned break from the physical and emotional burden of caring. However, providing respite in this context is not straightforward. Caregivers may not want to leave a patient who may die while they are away from them (Ingleton et al 2003). This means that respite provision should be offered in the home such as by night or day time 'sitters' as well as in-patient admissions.

Financial help

In some countries caregivers are entitled to receive state funded allowances to enable them to relinquish paid employment during end of life care. There may also be additional funds available from charities or through state welfare provision to assist with the costs of additional household expenditure such as heating, laundry and special foods; and transport costs to enable the patient to attend hospitals or hospices and for family carers to visit them. Carers may require advice and assistance in understanding what benefits they are entitled to claim and support in preparing the claim forms.

5. What support is available to caregivers?

While there is growing evidence of the types of practical support, education and information and services which may improve the wellbeing of carers, (Harding and Higginson 2003) note that few interventions are supported by rigorous research. Their systematic review of interventions and their effectiveness found only six interventions that had been evaluated, and called for more rigorous evaluations of services for carers. The authors recognised that carers valued self-reliance and independence, and that there was a need to understand the barriers to them accepting

help. Evaluations of interventions rarely assess specific outcomes for carers and matters are made worse by the well-reported challenges of doing palliative care research (O'Mara et al 2009). A search of recent examples of interventions published in peer reviewed journals includes only two from the United Kingdom, and none from other European countries. Most of the research has been done in Canada, Australia and the USA. Interventions consisted of support groups where caregivers have the opportunity to share concerns; bereavement support; specialist palliative care; educational programmes and advance care planning (Lorenz et al 2008).

The following sections highlight examples of the types of care and support that might be provided to carers. It should be noted that many palliative care providers will seek to encompass several of the aspects of care and support illustrated below within their remit. While a lot of carer provision fits into everyday palliative care provision, there remain a challenge to raise the profile of carers needs when they are often reluctant to request support for fear of diverting resources from patient care.

Psychological support (emotional, social, bereavement and spiritual)

Psychological support can be delivered to individuals in counselling sessions, or as part of a group, where members can interact and support each other. These encounters are often also used to provide information about services available to carers.

Evaluated examples include a psycho-educational programme (3 weekly group sessions) to prepare carers for the role of supporting a relative with advanced non-curative cancer at home (Hudson et al 2009: Australia); 'Friday afternoon tea' a support group for carers of patients in a palliative care unit (Parsons 2009 Canada); and an 8-week bereavement support group in a hospital setting (Maruyama 2008 USA). Many cancer support centres address stress reduction and relaxation for both patients and carers, generally through complementary therapies or relaxation classes. St. Christopher's Hospice in London gives free access to complementary therapies (aromatherapy, reflexology, hypnotherapy & relaxation) in the community, by dual trained specialist palliative care nurses. A hospice in the north of England (Butterwick Hospice) has an aromatherapy service that includes education in massage techniques for carers. There are wide ranging classes, self-help groups and complementary therapy services available to carers throughout Europe, though little evidence of

research in this area. There was little evidence of interventions designed specifically to offer spiritual support.

Information

This can include education (individual or group) as well as communication with health professionals and institutions. Examples include a study from the USA that evaluated a short question prompt sheet to encourage family caregivers to discuss end of life concerns (Hebert 2009). A coping and communication support intervention for advanced cancer patients and their families also provides psychological support. (Bowman 2009) Information giving is often part of general carer support groups.

Help with personal, nursing and medical care of the patient

These services are usually provided into the home and are aimed to support carers although few provide 24 hours care. They may be described as community care, home nursing, out-reach, domiciliary or ambulatory care or in the UK as Hospice at Home (HAH) and may be provided by specialist palliative care services or general health care services. Illustrations of evaluated services are a domiciliary occupational therapy service for patients in the palliative stage of cancer which supplied equipment and adaptations for patients and their carers (Kealey & McIntyre 2005), and a HAH service to provide 'hospice-style' care at home for people in the last days of their life. A project leader coordinated the day-to-day running of the service, which included one clinical nurse specialist and a number of staff nurses, enabling people to die at home (Exley and Tyler 2005). (McLaughlin et al 2007) surveyed bereaved caregivers for their views of a HAH service that provided practical nursing care during the day and at night; access to equipment and emotional support.

Out of hours and night support

Advice and support is provided by Hospice at Home, special night services and helplines which are usually based in hospices. (King et al 2004 UK) reported carer's views of an Out of Hours (OOH) support service which provided night sitters, crisis contact numbers, OOH access to drugs and equipment and 24 hour support from District Nurses. A dedicated telephone line, 'Palcall' was used by hospice nurses to provide out of hours support and advice to palliative care patients, carers, GPs and

health professionals. It was found that the majority of calls were from caregivers (Campbell et al 2005 UK).

Respite care

Provided by hospices, hospitals and care homes or sitting services. An example of an evaluated service is inpatient respite care in a hospice with 33 inpatient beds. Eight beds are used specifically for planned respite (four male, four female). Referrals are from GPs and health care professionals. Patients and their carers are offered planned inpatient respite care for a two week period, once a year. Some emergency respite is available (Skilbeck et al 2005). Another service, aimed at children with life-limiting conditions offers respite at no cost to families in 10 children's and eight family rooms. Respite is planned in advance, for 3-4 days at a time and families can stay to help with the care. This is supplemented by a respite care at home service (Eaton 2008). The question of carers' reluctance to leave a person who is near to death, however, has rarely been discussed in the literature (Harding & Higginson 2003).

Financial help

There is access to information about financial support for carers through government websites and signposting from cancer support services. One initiative developed at St Christopher's Hospice, London evaluated a service which offered teaching sessions to carers to address their financial concerns (Levy and Payne 2006). There appears to be little research in this area.

6. Goals and Challenges

Carer services and Initiatives

Future challenges include identifying gaps in service to carers and making suggestions for improvement on the following:

Information – carers need practical but also financial information (welfare benefits, charities, modifications to home, grants etc).

Psychological support – counselling, stress management, relaxation and other techniques are needed to promote well-being and reduce anxiety and depression.

Interventions to enable carers to prepare for managing their grief, loss and bereavement, during the period of care-giving and afterwards.

Education – nature of disease, disease progression, practical education like lifting etc, medical education including medication, nutrition, symptom control plus how to offer emotional support patient (Bee, Barnes & Luker 2008) Such initiatives have to be timely, and there remain debated on when is the best time for this is.

Out of Hours - support is vital (Campbell et al 2005) Continuity of care can help prevent unnecessary hospital admissions.

Prevention of crises - palliative care professionals should work towards crisis prevention for carers and patients rather than reactive assessment and intervention (Gomes & Higginson, 2006)

Respite care - recognition that carers often don't want to leave dying person so a diversity of models of respite (in home and in institutional respite) should be available (Harding & Higginson 2003; Ingleton et al 2003).

Assessment of carers' needs – there is need for robust, short and acceptable assessment tools that are available for use in routine practice (Payne 2007; Help the Hospice 2009; Grande et al 2009).

Research

Demographic and information systems on carers – a major challenge for undertaking systematic research is the lack of recorded information about family carers in health records. Better recording of the demographic and preferences of carers will mean they are more accessible for research purposes. As carers are currently seen by health professionals and ethical review board predominantly in relation to patients, it is difficult to identify or access them in their own right. Both patients and health professionals tend to function as 'gatekeepers' to recruiting carers into research studies.

Under researched groups – older carers, non-cancer patients, ethnic minorities, male carers (Malcolm et al 2008), migrants, people who already have disabilities and people with dementia. Also carers of patients dying in acute hospitals. Need to consider how to access these people. Need to recruit them earlier and conduct longitudinal studies. Plus international comparisons would be desirable.

Under researched illness groups - limited research on informal care for some illness groups including people with cardiovascular disease and heart failure (Small et al 2009). People with rare cancers are often overlooked.

Research tools - lack of assessment tools and theoretical models to guide their use (Grande et al 2009).

Evaluation – need to evaluate interventions in terms of efficacy and cost effectiveness.

A life course perspective on caregiving - people may move from caring for a dying parent (or other relative) in middle age, to caring for a spouse/partner when they are older. What are the different experiences and demands placed on carers in different age cohorts? There is need to focus research on exploring the needs of older carers.

Public awareness and policy development

Raise awareness of carers needs within the wider community plus government recognition (Lynch et al 2009).

Paid employment and caring - recognition of the problems of combining of caring and employment - legislation to protect employment and pension rights, access to education and skills retraining on re-entry to the workforce.

Benefits and financial support for carers of dying patients (as implemented by Canadian government in 2004) (Gomes & Higginson 2006) would ease the burdens on family caregivers. Within Europe legal regulations for palliative care leave for carers is available only in Austria and France. Similar regulations should be implemented in other European countries.

The lack of material and financial resources available to carers resulting from inadequate investment, bureaucratic government systems or political instability

Complex households - health professionals must take into account the complexity of modern families when providing support for carers

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Appendix 1

Examples of interventions directed at caregivers that have been evaluated and peer reviewed (Europe)

Reference Where it is based	What is delivered Target Group	Notes
<p>Sampson, E. L. et al, London UK. <i>BMC Palliative Care</i> 2008; 7, 8</p> <p>Palliative care in advanced dementia; A mixed methods approach for the development of a complex intervention</p>	<ol style="list-style-type: none"> 1. To define needs of patients and carers 2. Pilot an intervention 3. Produce a framework for advanced care planning for patients <p>Intervention for people with dementia</p>	<p>Ongoing, 1st phase completed</p>
<p>Kennedy C et al, Edinburgh, UK <i>International Journal of Palliative Nursing</i> 2008; 14(5) 230-237</p> <p>Supporting children and families facing the death of a parent: part 2</p>	<p>Bereavement support service for families.</p> <p>Children and families where a parent is dying from cancer.</p>	<p>FINDINGS: Children and families with complex and/or enduring needs benefited from the specialist expertise and interventions provided by this service.</p> <p>CONCLUSIONS: Risk assessment procedures should be used to identify need and ensure limited resources are directed appropriately. Many children and families can be supported within the community drawing on their own social networks.</p>

Appendix 2

Examples of interventions directed at caregivers that have been evaluated and peer reviewed (worldwide)

Reference Where it is based	What is delivered Target Group	Notes
<p>Hebert et al; USA <i>Am J Hosp Palliative Care</i> 2009; 26 (1): 24-32 Pilot testing of a question prompt sheet to encourage family caregivers of cancer patients and physicians to discuss end-of-life issues</p>	<p>A short question prompt sheet to encourage family caregivers to discuss end of life concerns.</p>	<p>Caregivers wanted to discuss medications, symptoms, support services, and what to expect. The majority reported that the question prompt sheets made it easier for them to ask questions.</p>
<p>Hudson et al; Australia <i>Journal of Pain Symptom Management</i> 2009; doi.org/10.1016/j.jpainsymman Teaching family carers about home-based palliative care: final results from a group education program</p>	<p>Psycho-educational programme (3 weekly group sessions) to prepare caregivers for the role of supporting a relative with advanced non-curative cancer at home.</p>	<p>A group education programme is effective.</p>
<p>Parsons S. & Anderson, C.; Canada <i>International Journal of Palliative Nursing</i> 2009, 15 (2): 74-78 The meaning of Friday afternoon tea for informal caregivers on a palliative care unit</p>	<p>'Friday afternoon tea' support group for caregivers of patients in a palliative care unit .</p>	<p>It is important for healthcare team members to organise informal support groups for caregivers.</p>
<p>Bowman K. et al; USA <i>Cancer Nurse</i> 2009, 32 (1): 73-81 Family caregiver engagement in a coping and communication support intervention tailored to advanced cancer patients and families</p>	<p>Coping and communication support intervention for advanced cancer patients and their families.</p>	<p>Caregiving demands were their primary problem. Other problems raised initially by more than 40% of the sample included psychological, practical, and communication with healthcare providers.</p>
<p>Abernethy, A. P., et al; Australia <i>Supportive Care Cancer</i>, 2008, 16 (6): 585-597 Specialized palliative care services are associated with improved short and long-term caregiver outcomes</p>	<p>Specialist Palliative Care Services (SPCS) for people with life-limiting illness. The effects on long-term family caregiver.</p>	<p>When SPCS were involved carers reported fewer unmet needs and more caregivers were able to 'move on' with their lives.</p>
<p>Hudson et al; Australia <i>Palliative Medicine</i> 2008, 22 (3): 270-280 Evaluation of a psycho-educational group programme for family caregivers in home-based palliative care</p>	<p>Group family caregiver psycho-educational programme focusing on preparing family caregivers for the role of supporting a relative with advanced cancer at home.</p>	<p>Positive effect of the intervention were preparedness for the caregiving role; caregiving competence and rewards and having information needs met.</p>
<p>Maruyama N. C. and Atencio C.V.; USA <i>Palliative Support.Care</i> 2008, 6 (1): 43-49 Evaluating a bereavement support group</p>	<p>8-week bereavement support group in a hospital setting.</p>	<p>Men and women respond differently in these groups. Bereaved people with high anger and tension may require more help.</p>

Appendix 3

Examples of services that are of INDIRECT benefit to carers, from the carer's perspective

Reference Where it is based	What is delivered Target Group	Notes
<p>Exley and Tyrer 2005; UK International Journal of Palliative Nursing; 11(5): 242-246</p> <p>Bereaved carers' views of a hospice at home service</p>	<p>Specialist palliative care in the home Respondents mentioned:</p> <ul style="list-style-type: none"> - giving carers opps for sleep - giving carers opps to go out for short periods - supporting carers after the death - training carers to administer drugs <p>Patients and carers</p>	<p>11 semi structured interviews with 12 bereaved carers.</p> <p>Views on caring at home; formal care from the HAH; access to out of hours care and provision of specialist equipment were positive. Problems were with out of hours services and removing equipment at inappropriate times.</p>
<p>King et al 2004; UK International Journal of Palliative Nursing; 10 (2): 76-83</p> <p>Family carers' experiences of out-of-hours community palliative care: a qualitative study</p>	<p>Out of hours and support services Including:</p> <ul style="list-style-type: none"> - Night sitters - Crisis contact numbers - Out of hours access to drugs and equipment - 24hr support from DNs <p>Carers of palliative care patients</p>	<p>Semi-structured interviews with 15 bereaved caregivers Findings generally positive ex. night sitters valued But areas for improvement highlighted including:</p> <ul style="list-style-type: none"> - carers need clear information resources of support - mechanisms for handover forms should be used - inflexibility of services at times
<p>McLaughlin et al 2007;UK Support Cancer Care; 15: 163-170</p> <p>Hospice at home service: the carer's perspective</p>	<p>Hospice at home service in one area of the UK</p> <ul style="list-style-type: none"> - practical nursing care, day and night - accessing equipment - emotional support <p>Patients who wish to die at home and their carers.</p>	<p>Postal survey of bereaved caregivers (128 responses – 41% response rate)</p> <p>Most very satisfied with service but identified need for improvement in practical support, increased awareness of services available and bereavement support.</p>

Appendix 4

Examples of services that are of **INDIRECT** benefit to carers, from mixed perspectives (i.e. patients, health professionals, patients & carers)

Reference Where it is based	What is delivered Target Group	Notes
<p>Campbell et al 2005; UK International Journal of Palliative Nursing; 11 (11): 586-590</p> <p>Introducing 'Pacall': an innovative out-of-hours telephone service led by hospice nurses</p>	<p>Out of hours support and advice from hospice nurses via dedicated telephone line.</p> <ul style="list-style-type: none"> - palliative care patients - carers - GPs - health professionals 	<p>Evaluation of service after 18 months.</p> <p>Updating clinical records was an on-going challenge. Communication about subsequent outcomes between hospice and community staff could be improved.</p> <p>Majority of calls (64%) from carers. Majority of calls between 11am-5pm (62.5%).</p>
<p>Collins F 2004; UK Nursing Times; 100 (33): 34</p> <p>An evaluation of palliative care services in the community</p>	<p>Community palliative care services – (Macmillan, Marie Curie, district nurses)</p> <p>Palliative care patients and their carers</p>	<p>A mapping exercise 61 completed questionnaires (49% patients, 25% carers, 26% both) Respondents identified gaps in service including -</p> <ul style="list-style-type: none"> - Access to advice and support outside the normal working week - Lack of 24-hour nursing cover - Confusion about whom to contact - Inequity of services
<p>Kealey & McIntyre 2005; UK European Journal of Cancer Care; 14, (3): 232-243</p> <p>An evaluation of the domiciliary occupational therapy service in palliative cancer care in a community trust: a patient and carers perspective</p>	<p>Equipment and adaptations</p> <p>Palliative care patients and their carers.</p> <p>Domiciliary occupational therapy for patients in the palliative stage of cancer care</p>	<p>Structured interviews with 30 patients and their carers.</p> <p>Patients and carers value the service but identified some gaps in provision and a lack of understanding of the role and services of the occupational therapist.</p>
<p>Lewis & Anthony 2007; UK International Journal of Palliative Nursing; 13(5):230-236</p> <p>A patient and carer survey in a community clinical nurse specialist service.</p>	<p>Specialist palliative care in patients' homes. Services mentioned including -</p> <ul style="list-style-type: none"> - emotional support - liaison with other services - carer support <p>Patients with cancer and non-malignant, life-limiting diseases and their carers.</p>	<p>Audit – postal survey exploring patient and carer satisfaction with CNS service. 91 Q's returned (44%). 138 respondents (78 patients, 60 carers)</p> <p>Pats and carers generally positive but areas for improvement highlighted. Continuity of personnel and regular visits highly valued.</p>
<p>Lucas et al 2008; UK BMC Palliative Care; 7: 9</p> <p>A reassuring presence: an evaluation of Bradford District Hospice at Home service</p>	<p>Specialist Palliative Care</p> <p>Patients who wished to remain at home in the final stages of their terminal illness and their carers</p>	<p>Evaluation. Postal questionnaire of bereaved carers (289), district nurses (508) and GPs (444).</p> <p>Positive responses from all respondents – carers' report it 'a reassuring presence'. Small number of service failures identified. The service has not fulfilled aim of facilitating an increased number of home deaths.</p>

Appendix 5

Examples of respite care from the perspective of caregivers

Reference Where it is based	What is delivered Target Group	Notes
<p>Skilbeck J, Payne S, Ingleton C, Nolan M, Carey I and Hanson A, 2005 (UK)</p> <p>Palliative Medicine 2005; 19: 610 - 618</p> <p>An exploration of family carers' experience of respite services in one specialist palliative care unit</p>	<p>Inpatient respite care in a hospice with 33 inpatient beds. Eight beds used specifically for planned respite admissions (four male, four female). Referrals from GPs and health care professionals. Patients and their carers offered planned inpatient respite care for a two week period, once a year. Some emergency respite.</p> <p>Patients receiving palliative care and their caregivers.</p>	<p>Prospective study exploring experiences of family carers whose relative had been admitted for respite care. Semi-structured interviews at two time points.</p>