

White Paper on improving support for family carers in palliative care: part 1

Recommendations from the European Association for Palliative Care (EAPC) Task Force on Family Carers

In this official position paper of the European Association for Palliative Care (EAPC), **Sheila Payne** and her colleagues from the **EAPC Task Force on Family Carers** outline the roles and needs of carers and make recommendations for their support

1. Introduction

This is a two-part paper: Part 1 provides the background and context of the challenges facing family carers of dying patients, Part 2 makes some recommendations for improving support and services to carers.

The purpose of this European Association for Palliative Care (EAPC) *White 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 focused on the situation of, and issues faced by, carers in palliative care settings internationally. It offers an integrative review of the most relevant, significant and oft-cited papers from the palliative care literature published between 2004 and 2009 by recognised researchers.

This *White Paper* will focus on the contribution to care made by patients' families and friends, and explain why their work is a significant and vital resource in palliative care. Our aim is to describe the roles of carers and to explain why they are so important for patients who are nearing the end of life.

We will outline the social changes that affect the ability of families to offer informal care, especially in the long term. We will identify who is providing informal care to palliative care patients, establish carers' 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 concepts 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 carers. Finally, we will make recommendations for future initiatives and research.

This *White Paper* concerns family members, friends and other people who have significant non-professional or unpaid relationships with a patient who they care for during advanced illness and the dying phase. The terms 'caregivers' and 'informal carers' are used interchangeably with 'carers' in some of the literature. Hereafter, we refer to this group as 'carers'. Carers are in a dual position; they provide care, but may themselves be recipients of support. This *White Paper* will focus on the role of carers and their support needs during caring, but not during bereavement. Children under 16 years of age may be both the recipients and providers of care, and this is worthy of further consideration, but they are beyond the scope of this paper (see Box 1).

2. Background

Recently, the EAPC commissioned a survey on the development of palliative care in European countries.¹ This survey showed that, while common structures do exist, there is great

diversity in the structure of service provision and care delivery across the different countries and regions in Europe. It was found that these differences are partly related to different understandings of the underlying concepts and terms used in palliative care.

Definitions of terms

In Europe, as in the rest of the world, the lack of a 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'.^{2,3} To accommodate the scope of languages and cultures within Europe, the EAPC uses the following working definition of palliative care and hospice care:⁴

'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.'

In an effort to improve understanding, an EAPC Delphi procedure was recently conducted to develop standards and norms as an aid to reaching agreement on quality goals to improve palliative care across European countries and regions.^{3,5} Despite the acknowledged differences between national approaches, 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 palliative care phase and after death, palliative care teams should provide care and support to families and carers as well as to patients.

There are a number of definitions of carers, including some that focus on 'hands-on' care provision, but the one used in this paper encompasses a more inclusive and extended

Box 1. Scope of the EAPC White Paper on improving support for family carers in palliative care

- This *White Paper* focuses on care provided by children over 16 years of age to adults who are in the palliative phase
- It covers care provided in a range of settings, including the home, hospital, care home (nursing home) for older people and hospice
- It covers care provided by people who have family and social links with patients, including children over 16 years of age and friends

role. We have adopted the definition used in the UK by the National Institute for Health and Clinical Excellence (NICE), which is as follows:⁶

'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 emotion management.'

The definition of family is contested and changes over time. We have adopted the following one, again drawn from NICE.⁶

'A broad definition of "family" is used, including those related through committed heterosexual or same sex partnerships, birth and adoption, and others who have strong emotional and social bonds with a patient.'

This definition 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 caring is largely hidden work that is often taken for granted, yet 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 on how close their family relationships are and how willing and able families are to provide care.^{7,8}

While acknowledging that carers are not a homogeneous group, there is agreement that they should be supported in their role and helped to prepare for the loss of the patient before death, in addition to being offered bereavement support afterwards.

The situation is made more complex because carers' needs may be different from, and sometimes even incompatible with, patients' needs. This can be challenging for healthcare professionals, who have to discern whose needs should take priority.⁹

In Europe, there are an estimated 100 million carers whose contribution to care often exceeds the financial expenditures of their countries on formal nursing services – although it is difficult to calculate exactly how many people are

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engaged in caring for a person near the end of life.¹⁰ 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 experience considerable physical, psychological, social and financial challenges.⁹

Role ambiguity

Supporting carers is not straightforward because carers occupy an ambiguous role; they may be both providers and receivers of services, and many carers do not define themselves as carers. For many, particularly women, caring is an inevitable part of life and something that is simply expected from 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.¹¹ While caring 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.¹² In the palliative care context, the needs of carers can exceed those of patients.⁷ Ideally, in palliative care settings, healthcare 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.

3. Caring in context

There have been significant social, economic and demographic changes in Europe during the past 35 years. These changes have affected all aspects of social life and, therefore, have also had a heavy impact on health- and social care. As a consequence, it is likely that, in future, there will be fewer carers, yet more people dying who have complex care needs.¹³ This will have implications for maintaining high standards of care across the range of settings in which caring occurs. It is likely that, in future, carers will face increasing role conflicts and increasing care burdens.

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.¹⁴ In many developed

countries, family size has declined to one or two children per partnership following falls in the birth rate and, in the UK, approximately 10% of women remain childless.¹⁵ In many European Union (EU) countries, rapidly rising divorce rates, with more than one million divorces annually, have led to more complex family structures, including remarriages, single-parent households, cohabiting couples and stepfamilies.¹⁶ It cannot be assumed that, following changed family constellations, family members such as ex-partners and stepchildren will provide care. Changing and complex family relationships 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 between, and to, European countries, resulting in household disruptions and changed family constellations.¹⁴ For example, in many Eastern European countries, high levels of economic migration among younger people leave older family members without practical support towards the end of life.¹⁷ The EU is currently concerned about increasing its workforce; EU policies and current economic pressures mean that more women have paid jobs, and people work longer hours and for more years before retirement, than in the past.

The impact of these developments is 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.¹⁰ While caring for people near the end of life is a time-limited activity associated with multiple progressive losses for all involved, it may entail focusing solely on the patient for the duration of their illness, knowing that this is a temporary situation because the patient will eventually die.⁸ 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.¹⁸ Economic pressures on families are likely to have a negative impact on their ability to provide care at home.

Demographic changes and aging

International demographic patterns indicate that, in most parts of the world, people are living longer and that dying typically occurs later in life. These demographic trends are predicted to continue well into this century.¹⁹ 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 aging populations. As more people live longer, there are growing numbers of the 'old old' (people over the age of 85). These numbers will continue to increase over the next 20 years, with a predicted 44% of all deaths occurring in those aged 85 and over in 2030, compared with 32% in 2004.²⁰

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 of it will be aged over 50. 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 compromise considerably the quality of care provided to patients requiring palliative care.

Causes of death and co-morbidities

Each year, 1.6 million patients in the European region die from cancer, while approximately 5.7 million die from non-cancer chronic diseases.³ To date, in most European countries, specialist palliative care and hospice care have been predominately delivered to cancer patients. The numbers of adults living with cancer and requiring palliative care is expected to increase due to raised public awareness of the benefits of palliative care, earlier diagnosis and advances in treatments. Epidemiological changes, combined with better public health and medical advances in most European countries, mean that, for some years before they die, older people increasingly live with one or more chronic conditions, including cancer, organ failure and dementia.¹⁹ There is a significant number of older people who must cope with one or more chronic conditions and

the prospect of a prolonged and uncertain 'dying' for a considerable time before their actual death. People are more and more likely to die in older age suffering from a number of co-morbidities and sensory and cognitive impairments, which means that demands on carers are becoming more complex.

4. 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 involvement of families in patients' end-of-life care,²¹ patients with better social support and more closely knit social networks being predicted to be more likely to die at home.

Families are often assumed to be readily available and willing to care for dying family members, but this is not always the case. In many societies, strong social norms mean that caring within family networks is an obligation 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 and that families can be conflict-ridden, which may affect their willingness to act as carers as well as the standard of care they are able to offer.²² This means that health- and social care professionals need sufficient training and resources to meet the often complex needs of family carers.

Palliative care takes place within ongoing social relationships. Carers can benefit from mutual support if caring responsibilities can be shared within the family. There is more within-generational caring than cross-generational caring at the end of life, as most carers are spouses.¹⁵ While care may not lie at the core of the relationship at the outset of a patient's illness, over time, the caring process can change the nature of the relationship.¹⁰ While this may be acceptable to some people, others are distressed by the transformation, or ending, of valued aspects of their previous relationship. This reinforces the notion that the role of family carer is not limited to instrumental tasks, such as hygiene care, but has significant psychological and social implications.

Caring can be regarded as a gendered activity; more women than men provide care, and differential life expectancies mean that, in palliative care, the majority of older carers are women. For example, among all carers in the UK, there are more women (approximately three million) than men (2.9 million).²³ There is

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evidence to suggest that women may be better prepared for the fact, or at least socialised into anticipating, that a period of their life will be spent providing care to, for example, older parents. 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 ascribed to family members or friends by health- and social care workers. The individuals themselves may describe themselves as 'husband', 'wife', 'son', 'daughter', and so on. Many may take on the tasks and responsibilities of caring but resist being labelled 'carers'.²⁴ Carers may not see their contribution as 'care', which is often equated with purely physical tasks, such as lifting, personal care and help with mobility²⁵ – although it is argued here that the carer's role encompasses far more than that.

Healthcare 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 an extended way, to include friends and other people in supportive relationships but not necessarily related to the patient through kinship. In addition, not all members of the caring network may live with the patient.¹⁵ It is important, therefore, that healthcare professionals are proactive in identifying who is providing what type of care to the patient, so that all carers can be offered the type of support that they may need. However, this has major implications in terms of workforce, resources and training. The appointment of a key worker to co-ordinate the various helpers, both formal and informal, may be necessary.

5. Place of care and death

The place of death differs considerably within and between European countries, depending largely on the availability and resources of health- and social care services and on family patterns. Research shows that many people would prefer to be cared for at home, if high-quality care can be ensured and as long as they do not place too great a burden on their families and carers.²⁶ Home death can be both the best and worst experience.²⁷

Currently, there is an 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.²⁸

Whether end-of-life care and death can take place at home is heavily dependent on the availability of carers,²¹ as patients spend most of their last year of life at home. Death at home can place considerable burdens on the family and friends of the patient, yet few studies have considered the preferences of carers regarding the place of death.⁷ 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 home death.²⁹ However, carers' preferences are often not ascertained, or there may have been pressures on carers to agree with the patients' wishes.³⁰ This reinforces the challenges faced by health- and social care professionals, as they attempt to meet the needs of both patients and families.

An increase in the number of patients dying at home, rather than in hospital, may well prove to decrease costs for healthcare services. However, the hidden costs of home deaths arising from the involvement of carers are largely unrecognised and unreported. The limited, and often inconsistent, availability of practical assistance has a considerable impact on carers' experience of caring. It is argued that the current imperative to enable people to die at home may place undue moral pressure on families to provide care, whatever the cost to them.¹¹ The move, in some countries, to formalise advance care planning may increase the pressure on carers.³¹

Despite the fact that people are living longer, as 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 than in the past. Many people will not have had to deal with a close family member or friend dying until they are in their mid-life years, and some will never have seen a dead body. While family carers may be anxious to comply with the patient's wishes, few will be prepared for the physical practicalities of death.³²

6. Impact of caring on carers

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.¹⁵ Many carers are older and may consequently have their own health problems. More than one-third of carers experience psychological distress, including feelings of powerlessness and helplessness, and this can be long-lasting.³³ A large Italian study found that one-quarter of carers experienced emotional suffering when caring for a dying relative. In that study, powerlessness, anger, remorse, guilt, fear and a feeling of emptiness after the patient's death were all reported by family carers.³⁴

Impact on family communication

There is a large body of evidence from psychiatry that focuses on communication patterns and conflicts within families, and how these patterns and conflicts can affect family members during caring and in bereavement.³⁵⁻³⁸ Family carers will need to develop communication and negotiation skills to interact with a range of people, including other family members and healthcare professionals, so that they are able to obtain the help they need and advocate for the patient. They are often the ones who have to communicate information, including breaking bad news, to other members of the family. This can be stressful and demanding.

Social impact

Monroe and Oliviere²² highlight the social implications of assuming a carer role and acknowledge that family structures may be strained both before and during the care of a dying family member. They caution against the simplistic notion that the family as a social entity is always mutually sustaining and supportive. Moreover, Exley and Allen highlight the notion that 'home' is not merely a physical space, but that the social and emotional relationships therein are crucial.³⁹

Impact on work and finances

Caring has an impact on carers' work and financial situation. For younger carers, education may be interrupted. Being tied to the home and kept away from normal employment affects carers' social and working life.⁴⁰ Negotiating leave from work or a reduction in working hours can be difficult, and future employment prospects, including promotion, may be jeopardised. People involved in activities such as running a small business or a farm may find it virtually impossible to

reconcile the demands of caring with those of their work, despite the fact that their activities might seem to offer greater flexibility.

The resulting financial issues compound the difficulties faced by the carer. Pensions may be affected, and the complicated rules of many national benefit systems can become even more daunting to a person who is already burdened by caring. Some financial support may be discretionary and families may find themselves dependent on assistance from charitable funds to bear the cost of caring.

A Korean study found that carers' unmet needs negatively affect both the quality of the end-of-life care they deliver and their workplace performance.⁴¹ Flexible working practices, extended leave and back-to-work training would be helpful.¹⁵

Caring at home is expensive and there may be the extra costs of travelling to attend hospital appointments, of special diets and equipment, or of doing alterations to the home.¹² Currently, across Europe, many carers receive insufficient financial support.

Impact on social identity

There are reported to be changes to the social identity of carers.⁴² Caring may be an isolating experience, leaving the carer little opportunity to engage in recreational and social activities.

Positive impacts

In spite of the difficulties outlined above, caring can also be fulfilling.⁴³ A carer's ability to cope is a reflection of their individual circumstances and resources, and may change throughout the patient's illness.¹¹ The resilience and adaptability of families mean that the role of carer may be taken up by different family members at different times; sometimes carer and patient might even swap roles.

It has been argued that personal characteristics such as hardiness, positivity and the ability to laugh are factors that predict better outcomes for carers.⁴⁴ The attitude with which the carer approaches the tasks of caring may show how well they will cope. Some people are naturally pessimistic, others optimistic. Some have more inherent resilience.

If a carer gains enhanced self-esteem from caring, experiences social approval and believes they are in control, then they will benefit from the role. Love and the satisfaction of fulfilling a moral duty also play a role in a carer's well-being. An Australian study reported that some carers felt

A carer's ability to cope is a reflection of their individual circumstances and resources, and may change throughout the patient's illness

a sense of reward and were able to think positively about what caring meant for them, which helped them come to terms with the loss of their relative.⁴⁵ Personal growth and improved family relationships were identified as positive aspects of caring by an Italian study.³⁴ A Canadian study found that the following were all important factors contributing to carers' ability to cope: the carers' approach to life, their relationship with the patient and their sense of security; the patient's illness experience and their recognition of the carer's contribution.⁴⁶

7. Carers' support needs

Caring in the final phase of life raises some specific issues and carers have specific needs, which are outlined below.

Psychological and emotional support

Caring for a person knowing that they will die has an emotional cost. The psychological support provided by carers has been referred to as 'emotional labour'.¹¹ The experience of caring for a dying person is likely to be perceived as stressful, and most carers will feel anxiety.⁴⁷ The closer the relationship, the greater the impact may be.¹⁵ Carers need to deal with their own sorrow and sense of impending loss.⁴⁸ For all these reasons, carers need to receive psychological and emotional support.

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.⁴⁹ This includes information about practical care and support to the patient and hospital discharge planning. Carers also need to know how to minimise the burden placed on them and how to survive the experience.

When a patient is nearing the end of life, the carer also needs information about disease progression and prognosis, and how to deal with the dying process. However, information must be given taking into account the needs of both carer and patient, which may not be the same. After death, carers may require information about the practical arrangements 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'.⁵⁰ This means that carers need access to the same

information as patients, but also additional information about care provision and bereavement support.

Help with personal, nursing and medical care of the patient

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 or special diets add to the daily chores and the carer might struggle to get them all done. Advances in medical treatment can increase survival times for patients of all ages, and caring for the patient can become unexpectedly protracted. If a person wishes to die at home, a major task is to co-ordinate the different providers of support, and carers may need a key worker to take on that organising role. All this means that support and 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 and any time normal healthcare services are not available. Strategies to deal with queries, and forward planning, may help to avoid crisis situations and unnecessary transfers to hospital.⁵¹ This means that services should design mechanisms to provide support day and night; for example, dedicated telephone helplines.

Respite

Carers 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. Carers may not want to leave a patient who may die while they are away from them.⁵² This means that respite should take the form of 'sitters' coming to the home, at night or in the day, as well as inpatient admissions.

Financial help

In some countries, carers are entitled to receive state-funded allowances to enable them to temporarily relinquish paid employment. There may also be additional funds available from charities, or through state welfare provision, to assist with additional household expenditures (such as heating, laundry and special foods) and transport costs (journeys to and from hospital or

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hospice for patients and carers). Carers may need advice and assistance in understanding what benefits they are entitled to and support in preparing the claim forms.

Part 2 of this White Paper, to be published in the European Journal of Palliative Care 17.6, will consider existing interventions and services developed to address carers' needs, make recommendations for improving support and services to carers, and outline areas where further research is needed.

For more on the EAPC Task Force on Family Carers, read the article by Sheila Payne and Peter Hudson, EAPC Task Force on Family Carers: aims and objectives, published in 2009 in the European Journal of Palliative Care 16.2.

Acknowledgements

The authors are grateful to the UK Cancer Experiences Collaborative for partially funding the preparation of this White Paper.

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White Paper on improving support for family carers in palliative care: part 2

Recommendations from the European Association for Palliative Care (EAPC) Task Force on Family Carers

In part 2 of this official position paper of the European Association for Palliative Care (EAPC), **Sheila Payne** and her colleagues from the **EAPC Task Force on Family Carers** outline different types of support offered to family carers, and highlight future challenges in the areas of service provision, research and policy development

... continued from the European Journal of Palliative Care (EJPC) 17.5

This is the second part of a two-part paper. In part 1, we considered the definitions and roles of family carers in Europe. In particular, we explored the context of providing care at home, the places of care and death, and the impact of caring on family carers. In part 2, we will consider some of the types of interventions or services that seek to address carers' support needs, and we will make recommendations for future service provision, research and policy development.

8. What support is available to carers?

While there is more and more literature on the types of practical support, education and information services that may improve the well-being of carers,¹ few interventions are supported by rigorous research. Harding and Higginson's systematic review of such interventions and their effectiveness found only six that had been evaluated and the authors called for more rigorous evaluations of services for carers. They 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.²

A search of recent examples of interventions for carers published in peer-reviewed journals found only two from the UK 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 carers have the opportunity to share concerns; bereavement support; specialist palliative care; educational programmes; and advance care planning.³

The following subsections highlight examples of the types of support that may be offered to carers. It should be noted that many palliative care providers seek to encompass, within their remit, several of these types of support. While a lot of interventions fit into everyday palliative care provision, there remains the challenge to raise the profile of carers' needs, as carers themselves are often reluctant to request support for fear of diverting resources from patient care.

Studies have shown that carers need:

- Psychological support – emotional, social, bereavement and spiritual
- Information
- Help with personal, nursing and medical care for the patient
- Out-of-hours and night support
- Respite care
- Financial help.

The unpredictability of caring for a person at the end of life is an important factor when determining what carers need. 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 their illness trajectory. Carers may be in this role for a relatively short time and, therefore, require a rapid response to their needs.⁴ Because the focus of care is primarily on the patient, carers may be reluctant to express their own needs.

Previous research has focused on repairing problems such as stress rather than preventing them.^{5,6} Most of the existing research focuses on primary family carers in general and lacks information on the experiences of certain groups of carers, including male carers, children, new immigrants and non-host country language speakers. There is also little information about carers of non-cancer patients.⁷

It has to be recognised that many palliative care services (for example, hospice at home [HAH]) provide a combination of the types of support listed below. Further evaluation may be needed to establish whether these different types of support are best provided in separation or as an integrated service.

Psychological support – emotional, social, bereavement and spiritual

Carers may benefit from help to prepare for loss and grief, and from bereavement support after the patient's death.⁸ This means that psychological support should be provided to carers throughout the illness trajectory.

Psychological support can be delivered to carers in individual counselling sessions or in a group where members can interact and support each other. Psychological support sessions are often also used to give carers information about services available to them.

Evaluated examples include a psycho-educational programme (group sessions three times a week) to prepare carers for the role of supporting a relative with advanced cancer at home;⁹ 'Friday afternoon tea', a support group for carers of patients in a palliative care unit;¹⁰ and an eight-week bereavement support group in a hospital setting.¹¹

Many cancer support centres offer stress reduction and relaxation to both patients and carers, generally through complementary

therapies classes. St Christopher's Hospice in London gives free access to complementary therapies (aromatherapy, hypnotherapy, reflexology and relaxation) provided in the community by dually trained specialist palliative care nurses. Butterwick Hospice in County Durham 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, but little evidence of research in this area. It should also be noted that support that takes carers out of the home may sometimes be problematic for them.

There is little evidence of interventions designed to offer spiritual support to carers.

Information

Information can include education (individual or group) and communication with healthcare professionals and institutions. It is often part of the services offered by carer support groups. Examples include a short question prompt sheet to encourage US family carers to discuss concerns.¹² Another example is a coping and communication support intervention for patients with advanced cancer and their families, which also provides psychological support.¹³

Help with personal, nursing and medical care for the patient

Help with personal, nursing and medical care for the patient is usually provided in the home and is aimed at supporting carers, but few services offer 24-hour help. This may be described as community care, home nursing, outreach, domiciliary or ambulatory care – or, in the UK, as HAH – and it may be provided by specialist palliative care services or general healthcare services.

Examples of evaluated services include a domiciliary occupational therapy service, for patients in the palliative stage of cancer, that supplied equipment and made adaptations to the home for patients and their carers.¹⁴ Another example is an HAH service providing 'hospice-style' care at home for people in the last days of life, enabling them to die at home;¹⁵ a project leader co-ordinated the day-to-day running of the service, which involved one clinical nurse specialist and a number of staff nurses.

Carers may be in this role for a relatively short time and, therefore, require a rapid response to their needs

The question of carers' reluctance to leave a person who is near to death has rarely been discussed in the literature

Out-of-hours and night support

Out-of-hours advice and support is provided by HAH, special night services and helplines, which are usually based in hospices.

King *et al* report on carer's views of an out-of-hours support service that provides night-sitters, crisis contact numbers, access to drugs and equipment, and 24-hour support from district nurses in the UK.¹⁶ Another service is a dedicated telephone line, 'Palcall', which is used by hospice nurses to provide out-of-hours support and advice to palliative care patients, carers, GPs and healthcare professionals;¹⁷ the majority of calls come from carers.

Respite care

Respite care is provided by hospices, hospitals and care homes, and sitting services. The question of carers' reluctance to leave a person who is near to death has rarely been discussed in the literature.¹

One example of an evaluated service is inpatient respite care in a hospice.¹⁸ Out of the 33 inpatient beds, eight are used specifically for planned respite. Referrals are from GPs and other healthcare professionals. Patients and their carers are offered planned inpatient respite care for a two-week period once a year. Some emergency respite is also available.

Another service, also in a hospice, offers, at no cost, respite to children with life-limiting conditions and their families.¹⁹ There are ten children and eight family rooms; respite is planned in advance, for three to four days at a time. This is supplemented by a respite care at home service.

Financial help

Carers can access information about financial support on government websites and through cancer support services. There appears to be little research in this area.

St Christopher's Hospice in London evaluated a service that teaches carers how to address their financial concerns.²⁰

9. Goals and challenges for service provision to carers

Future challenges include identifying gaps in services to carers. Below, we make suggestions for improvement in specific areas.

Information

Carers need practical, but also financial, information (for example, on welfare benefits,

charities, modifications to the home, grants). They also need more substantial and accessible clinical information, to help them take part, as proxies, in the decision-making process throughout the course of the disease.

Psychological support

Counselling, stress management, relaxation and other techniques are needed to promote well-being and reduce anxiety and depression. Carers need help, during the period of caring and afterwards, to prepare themselves to manage grief, loss and bereavement.

Education

Carers should be given: education on the nature of the disease and disease progression; practical education, such as how to lift the patient; medical education, including on medication, nutrition and symptom control; and education on how to offer emotional support to the patient.²¹ Such interventions have to be timely and there is still debate about the best time to provide them.

Out-of-hours support

Out-of-hours support is vital to carers.¹⁷ Continuity of care can help to prevent unnecessary hospital admissions.

Crisis prevention

Palliative care professionals should work towards crisis prevention for carers and patients, rather than react to crisis situations once they have occurred.²²

Respite care

It has to be recognised that carers often do not want to leave the dying person, so a diversity of types of respite care (in the home and in institutions) needs to be available.^{1,23}

Assessment of carers' needs

There is need for robust, short and acceptable assessment tools for assessing carers' needs that are available to palliative care professionals for use in daily practice.^{5,8,24}

10. Goals and challenges for research into carers needs

Characteristics of carers

More research is required into the personal characteristics of carers – such as age, gender, health, education, resources, life experience and relationship with the patient – as these are

all likely to have an impact upon carers' willingness to take on that role and the quality of their caring. In addition, more needs to be known about the nature of caring and the demands on carers who deal with specific challenges, such as incontinence.

Demographics and information systems on carers

One of the major challenges, if one wants to undertake systematic research, is the lack of information about family carers in healthcare records. A better recording of the demographics and preferences of carers will help research. Currently, as carers are predominantly viewed – by healthcare professionals and ethical review boards – in relation to the patient, it is difficult to identify them in their own right. Patients and healthcare professionals both tend to function as 'gatekeepers', blocking the recruitment of carers into research studies.

Understanding the processes of caring

To understand the longer-term processes of care, there is a need to recruit carers earlier, to conduct longitudinal studies, and to compare different contexts of care, including between countries.

Under-researched groups

Under-researched groups include: older carers, carers of non-cancer patients, carers from ethnic minorities, male carers,²⁵ employed carers, carers who are migrants, carers of people who have disabilities, carers of people with dementia, and carers of patients dying in acute hospitals. How to access some of these under-researched groups may need to be given particular consideration.

Under-researched disease areas

There is limited research on caring for people with certain diseases, including respiratory disease and heart failure.²⁶ Carers of people with rare cancers are often overlooked as well.

Assessment tools

There is a lack of tools to assess carers' needs and theoretical models to guide their use.⁵

Evaluation

There is a need to evaluate interventions and services offered to carers in terms of their efficacy, effectiveness and cost-effectiveness.

A life course perspective on caring

Carers may move from caring for a dying parent (or other relative) in middle age to caring for a spouse/partner later in life. We need to establish what the different experiences of, and demands on, carers are in different age cohorts. There is a need to focus research on exploring the needs of older carers, as more and more people in Europe die in older age and are increasingly supported by older spouses and family members.

11. Goals and challenges for policy development

Awareness raising

We need to raise awareness of carers' needs in the wider community and ensure that they are recognised by the governments.²⁷

Caring and paid employment

There needs to be a greater recognition of the problems faced by carers when they are trying to combine caring and paid employment, with legislation to protect their employment and pension rights, and access to further education and retraining on re-entry into the workforce.

Benefits and financial support

Benefits and financial support for carers of dying patients (such as those implemented by the Canadian government in 2004)²² are required to ease the financial burden on family carers. In Europe, the right for carers to take palliative care leave only exists in Austria and France. Similar rights should be put in place in other European countries.

Lack of resources

There needs to be a greater awareness of the lack of material and financial resources available to carers, because of inadequate levels of investment, bureaucratic government systems or political instability.

Complex households

When providing support for carers, healthcare professionals must take into account the complexity of modern families (see part 1).

Part 1 of this White Paper was published in the *European Journal of Palliative Care* 17.5 (September/October 2010).

Acknowledgements

The authors are grateful to the UK Cancer Experiences Collaborative for partially funding the preparation of this *White Paper*.

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