HELP THE HOSPICES COMMISSION
into the future of hospice care

International Observatory on End of Life Care

LANCASTER UNIVERSITY

Supporting family carers:

report on the evidence of how to work with and support family carers to inform the work of the Commission into the Future of Hospice Care

A report for the Commission into the Future of Hospice Care

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hospice UK

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Help the Hospices has changed its name to Hospice UK

This resource was published prior to the change and so still refers to the old name

In 2010 the think tank Demos published a report entitled 'Dying for Change' which highlighted some of the challenges facing hospices in the future. Help the Hospices responded to this by setting up the Commission into the Future of Hospice Care to provide guidance, information and options for hospices to inform their strategic position and offerings in the next 10 to 20 years. Opportunities exist across the UK to improve the experience of people who are approaching the end of their life, and that of their families and carers. The Commission is considering how hospices need to develop over the next three to five years to be prepared for the challenges facing them in the future.

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Foreword

How carers are best supported and engaged in the care of individuals who are approaching the end of their life is a key issue being considered by The Commission into the Future of Hospice Care. The Commission has been exploring what hospice care could look like in 10-15 years time. In so doing it has been giving thought to the most appropriate models of care to be provided by hospices and others who are committed to providing the very best care to those who are dying, as well as their families, friends and carers.

The need for a specific piece of work around carers of people with a life threatening condition was identified by hospices and other stakeholders of hospice care at an event held by the Commission in January 2013 at which future needs for hospice care were explored. Participants were encouraged to identify areas in which they thought particular investment was required in terms of knowledge, skills or future resources. Support for carers was identified as one such area given some significant changes anticipated in the future:

- The condition(s) from which someone is likely to die in the next decade is likely to be different to that which hospices have addressed previously. These are likely to be chronic and multiple in nature and they could include dementia. These shifts will have major implications for carers.
- Where informal carers exist, they are likely to be engaged in the business of caring for a prolonged period and may well face significant challenges in this role as a result of the complex and multiple nature of needs experienced by the individual for whom they are caring. They may well be elderly and have health care needs themselves.
- Carers are likely to be experts in their role and in their care of the person living with a life threatening condition.
- Carers will know a great detail about what the individual needs and how best to meet these needs. They may also wish to have a central role in caring for this person, even when he/she is receiving care from others.

It was recognized that there is real room for improvement in the way that hospices and others work with carers. They often fail to see carers as partners in care and are uncertain about how to support them in this central role. There is lack of awareness about the challenges and stress of this role and how best to help carers continue in this work. Paradoxically, they may also fail to recognise how important it is for carers to be able to continue to offer this support, regardless of its challenges and subsequent impact on their well being.

This publication by the University of Lancaster helps redress the lack of knowledge about what carers experience in this role, their needs and how professional carers can support them to do it well. The Commission welcomes it and is very grateful to Professor Sheila Payne and her team for their work in producing it.

As a commissioner, and as an academic with a particular interest in the role of informal carers and how they are best supported by professionals in this role, I urge all who are engaged in planning and providing hospice care to read the report and to reflect on local and national developments that could help ensure carers are enabled to fulfill their vital role.

Professor Jayne Seymour ,
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Executive summary

This report has been commissioned by the Commission for the Future of Hospice Care in relation to support offered to family carers undertaken by/in/related to hospice care.

The aims of the study were to:

1. **Primary aim:** to draw together existing knowledge related to hospice care about how best to work with, and for, family carers of those facing the end of life.
2. **Secondary aim:** to provide recommendations that address important gaps in service provision for family carers to inform the work of the Commission into the Future of Hospice Care.

Sources of information used to produce the report:

The report draws on published and 'grey' literature and evidence from empirical research. It predominantly draws upon studies investigating family carers' support services in hospices in the United Kingdom, Australia and Canada.

The following statements and recommendations have been developed from the synthesis of the above evidence. Our intention is to provide clear information to stakeholders charged with considering the future role of hospices in supporting family carers.

Key messages

We summarise here the key messages about what is already known from the published evidence and, from these, we propose a limited number of implications and recommendations. These points are likely to be of relevance to the majority of carers whether they are looking after children, young people or adults. The key messages are grouped into three categories relating to:

Family carers:

Evidence:

- The dual experience for **carers as care providers and care receivers** is marked by competing demands to attend to their own health while at the same time supporting the cared-for person.
- An ageing carer population has significant health needs that may soon need carer services and support. Carers and their family members can often have multiple morbidity and **mutual, fluctuating care giving/receiving** relationships.
- People living into late old age, including those **over 100 years old, are the fastest growing demographic group**, with a doubling in population size every decade. Yet only 0.2% of those over 100 years old die in hospices. Many of these older people will be cared for by equally old carers.
- Carers may experience considerable **physical, psychological, social and financial challenges** which they are largely unprepared for.
- There is evidence that carers perceive that they have **little choice in decision making** about their role and the nature of care provision.
- Little is known about the **full economic cost** for individuals in providing end of life care. Analysis of economic costs tends to focus on the perspectives of statutory and Third Sector service providers.
- Little is known about how the control of **personal, social and health care budgets** will affect carers of those near the end of life.
- Changes to employment patterns with more female workers, delayed pension entitlement, and more part-time working, are likely to mean that more **people will be required to combine paid employment with care provision**.

- **Altering family constellations** involve complex family care arrangements for divorced, step and single carers. Multi-generational caring roles are becoming more commonplace, with a 'sandwich generation' providing care for both parents and children or grandchildren.

Implications and recommendations:

- Family carers require respectful and compassionate care.
- Family carers are experts in relation to their cared-for person.
- Family carers require information and access to up-dated knowledge about how to provide care.
- Family carers should be offered regular assessment of their needs.
- Family carers should be offered a menu of support services which are timely, accessible, affordable and appropriate.
- Little is known about the specific needs of older carers using hospice services, especially those who are in late old age. It is recommended that research is commissioned to address this knowledge deficit.

Health and social care professionals and others associated with hospices

Evidence:

- Despite the rhetoric about personalised learning and well-being, professional work is often still organised in ways which fail to be centred upon human beings. Many health **professionals often feel unprepared** for supporting and understanding the experience of carers.
- There is a lack of understanding of **the needs of people with dementia** and preparation for the rise in patients **and** carers with cognitive impairment or dementia within hospice care.
- **Changes to workforce configurations** with fewer qualified nurses may mean that hospices will need to seek alternative workers, both paid and unpaid.
- There is evidence that the **transitions into and out of hospices and other care settings in the final year of life are poorly managed** and considerably increase the demands placed upon carers.
- Most hospice staff are intrinsically motivated to help family carers but **systems and patterns of working may consistently place barriers** in how carers are recognised and supported.
- Most evidence is gained from retrospective accounts of carers and relies on their recall of interpersonal communication and events associated with hospice care some time previously. More effort needs to be focused on **obtaining their feedback during the process of caring**.

Implications and recommendations:

- Hospices should explore the opportunities and challenges of greater involvement of volunteers in direct support to family carers, in their homes, communities, and in hospices.
- Hospices should explore how best to support internationally qualified medical and nursing staff to understand the cultures, norms and expectations of end of life care in Britain, especially when staff and patients and families do not share common languages.
- Training in cultural sensitivity may be required for all hospice staff in raising awareness of their own cultural assumptions and how they affect interactions with family carers.

- Planning and development of services which are appropriate to supporting carers of family members with dementia, for end of life care delivered in their homes, communities and hospices. Training at all levels of hospice care and workforce (paid and unpaid) in the specific needs of support for carers of those with dementia.
- The regular assessment of family carers needs should be embedded in routine hospice care, and it should not require a 'crisis' or 'problem' to precipitate its introduction.
- Greater attention needs to be placed on managing transitions across care settings including hospice care, to reduce disruptions to patients and distress for carers.
- Quality leadership in hospices is needed to boost and value carer support.
- Little is known about what types of support are most effective, how they should be delivered by hospices, and how they link to other forms of support, for carers of patients with dementia approaching the end of life. Further research in this area is warranted.

National organisations associated with hospice care and society

Evidence:

- New and innovative services for family carers may appear to be 'successful'. However, **lack of rigorous evaluation and publication** means that other hospices do not have access to the benefits and outcomes. Important **lessons are lost and knowledge is not transferred**.
- Recognition of changing roles and family relationships may mean that **neighbour and friendship networks** become increasingly important to sustain caregiving, especially in the home.
- Current end of life care policy that emphasises dying at home is based on the **assumption that there are family carers able and willing to provide care**. This potentially marginalises certain groups of people without access to these resources and networks.

Implications and recommendations:

- If caregiving is extended beyond kinship networks, this raises implications for hospices and staff in sharing confidential patient-related information. However, access to this information is vital for those providing care to ensure safely and continuity.
- New methods are needed to map, quantify and thereby recognise the 'hidden' networks of actual and virtual care provided. This is likely to reveal the contribution made by these people, but also identify their support needs.
- Many best practice tools, models and processes have been established to support family carers by hospices, but they are not always used effectively, resulting in patchy provision and 'gaps' across hospices. This may mean that individual carers' experiences are not optimal. A recommended minimum provision of support should be agreed across all hospices.
- Rigorous evaluation of the diversity of hospice carer support services is required; what works best, for whom and when, and what is most cost effective.
- Greater attention is required to ensure integrated procedures and practices across health and social care, and associated Third Sector organisations, that recognise carers' relationship with dying patients. This is needed to facilitate navigation and access to appropriate supportive services for both parties.
- Little is known about the complex networks of actual and virtual (information technology mediated) care provision that sustain patients approaching the end of life.

- Imaginative use of health and communication technologies may offer hospices ways to support family carers that are less labour intensive. These should be investigated and tested for acceptability and feasibility.

Conclusions

There is a wealth of research **evidence on the demands upon carers and their needs**. There has been a history of policy changes designed to benefit carers but sadly the experiences of family carers of those approaching the end of life appear to be largely unchanged and continue to be unnecessarily challenging. The question is why. In our view, the culture of hospice care needs to shift to truly include family carers as central in their relationship with patients and as worthy beneficiaries of support both during and after the death of the patient.

Report background

Aims

The primary aim of this report is to draw together existing knowledge related to hospice care about how best to work with, and for, family carers of those facing the end of life.

The secondary aim is to provide recommendations that address important gaps in service provision for family carers to inform the work of the Commission into the Future of Hospice Care.

Note: This report focuses on adult carers of 18 years and over. While children and adolescent carers face common experiences in the function and tasks of caring, their needs and the issues facing them are specific and require careful, special considerations, which are beyond the scope of this report.

Methods

This report draws on existing published and 'grey' literature and evidence from empirical work undertaken by the International Observatory on End of Life Care, the European Association for Palliative Care Task Force on Family Carers and the International Palliative Care Family Care Research Collaboration. It draws predominantly upon studies investigating family carers' support services in hospices in the United Kingdom, Australia and Canada. We are aware of commonalities and differences in the evidence base of family carer research in other fields such as caring for those with dementia, stroke, severe and enduring mental health problems, frailty, physical and learning disability. However, it is out of the scope of this report to review this more extensive literature.

A scoping approach identified studies on family carers associated with hospice care since 1992. Relevant data has been synthesised into a narrative report which clarifies what can be considered as 'good practice', gaps in knowledge, and opportunities for further development. Summary findings are outlined with recommendations and priorities to inform the Commission into the Future of Hospice Care.

Anticipated Outcomes

The outcomes of this study will:

- Enhance understanding of new models to conceptualise the role of family carers and identify how best to meet their needs, and clarify where evidence is weak or not available.
- Provide information for the Commission into the Future of Hospice Care which will help to inform the integration of family carers' assessment and support services within hospice care clinical and organisational practice.
- Contribute to the design and development of more effective family carers' support in hospice care and provide models for implementing services.
- Contribute recommendations for appropriate and feasible family carers' support services, and prioritisation of further research and evaluation in hospice care.

Defining carers, families and roles

Definitions with a policy focus tend to emphasise the tasks and functions of caring, as evident in such documents as Carers at the Heart of 21st Century Families and Communities (DOH, 2008:19), whereby carers are identified as 'spend[ing] a significant proportion of their life providing unpaid support to family and / or friends.' Other definitions of family carers recognise broader social and emotional bonds, not just those related by kinship or marriage, and extend the responsibilities and experiences of the status. In this report we utilise National Institute of Health and Clinical Excellence (2004) definitions that promote wider, self-defined and less formalised relationships and that accommodate the dynamic nature of social and familial connections:

Carers – 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.

Family – include[s] those related through committed heterosexual or same sex partnerships, birth and adoption, and others who have strong emotional and social bonds with a patient.

Hereafter in this report 'family carers' are referred to. The term 'caring' is used when referring to tasks and actions involved in providing care. Our report considers evidence of the role of family carers across the life cycle.

The caring scene to 2025: Future demographic considerations for the carer/caring end of life context

The Government's Next Steps for the Carers Strategy, for England: (DOH, 2010) maintains the vision over the next decade that:

> ... carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring ... p5

This assertion can be viewed as a national imperative as the well-rehearsed demographic changes see people living longer with increasingly complex and multiple health and social care needs. This is alongside policy drivers for increased community care, and other influences such as advances in clinical technology that enable more people with life long disabling conditions to live longer. By 2037 it is estimated that over 9 million individuals will have caring roles (Carers UK, 2012). Within the specific context of palliative care the World Health Organisation calls for health provision to be extended to families, ensuring their quality of life, ability to cope and bereavement phase are addressed alongside the health and wider needs of patients receiving end of life health services (Hudson and Payne, 2011). Alongside the management of conditions, symptoms and provision of information for people approaching the end of life, Quality Standards issued by National Institute for Health and Care Excellence (NICE) also acknowledge problems faced by carers at this time:

> Families, including children, close friends and informal carers, also experience a range of problems at this time. They play a crucial role and have needs of their own before, during and after the person's death: these too must be addressed.

Health care costs in the last year of life are known to be high, and account for about 12% to 25% of heath care spending (Hughes-Hallett et al, 2011). Costs are known to be greater when patients spend more time in hospitals or other institutional care settings. Despite these high costs, many patients do not have adequate symptom relief or access to high quality end of life care. One option that has been emphasised in recent end of life care policy initiatives is to promote an increased proportion of people dying at home (DOH, 2008). However, this policy is based on the assumption that there are family carers able and willing to provide care for the dying person.

Within Europe there are estimated to be 100 million family 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. While the important work that carers contribute is recognised, there is increasing evidence that they are often unprepared for the many demands they might face and that they experience considerable physical, psychological, social and financial challenges (Hudson and Payne, 2008). Despite more recent focused policy initiatives to address these caring demands and needs, Hanratty's (2013) report which follows a large study on transitions in end of life care, shows that little has changed to affect carer experiences. Indeed, it argues that despite what is now an embedded rhetoric in policy and practice initiatives, choice was not recognised by carers and strategies promoting choice were selectively initiated, with approximately 25% of carers in the Hanratty study reporting that they were '... involved a little, or not at all, in decisions about care.' (p8).

Overlying these demands is the dual, and what can be competing, position for many carers of being both the providers of care, and also the recipients of services and support (Payne, 2010; Payne and Grande, 2013). So much so that the circumstances of family carers and households that are the site of end of life care are complex locations of personal

and emotional distress, familial and social support, and advanced health care provision. Ultimately this dual experience for carers as care providers and receivers is marked by the competing demands to attend to their own health while supporting another with theirs.

In the context of at least 49,000 children and young people living with life-limiting and life-threatening conditions, care providers include parents, grandparents, siblings and the wider family network. The STEPP project examined the health transition of young people with life-limiting and life-threatening conditions between paediatric and adult health care services (Beresford 2012). The authors highlighted a number of important recommendations about the involvement of parents in decision making and improving support to them following bereavement.

Financial and economic costs of care provided by family carers can be ascertained (Andersson et al, 2004; Chai et al, 2013). It is more difficult to establish the effects on individual carers of the more nebulous emotional strains of being there for a family member, not being able to leave them alone for even short periods of time, sitting up awake at night or frequent disturbances through the night. While the stresses and strains of such circumstances are widely acknowledged, so too is the potential to gain from the rewards and positive outcomes of the experience (Hudson and Payne, 2011; NICE, 2004; Whittingham et al, 2013). However, the possibilities of a more affirmative experience of family caring is based on carers being able to access a greater number of resources and possessing personal resilience characteristics that support their coping mechanisms (Hudson and Payne, 2011).

Recent systematic reviews (eg Candy et al, 2011) and a growing body of empirical research suggest that there is some evidence about the effectiveness of interventions to support family carers. However, new models of working with, and offering support to, family carers of those near the end of life are not readily accessible to people designing and developing services in hospices, with the result that service providers are often disappointed with the up-take of specific services, or fail to design support that is acceptable, appropriately timed or flexible enough to meet the diverse needs of family carers (O'Brien et al, 2010). Moreover, even when new services appear to be 'successful', the lack of rigorous evaluation and publication means that other hospices do not have access to the lessons and important knowledge is not transferred. This potentially wastes limited resources in hospices and disadvantages family carers. Recent research has highlighted that despite the implementation of a range of policies, little impact or improvement in the experiences of carers has come about (Hanratty, 2013). There is therefore an urgent need to draw together existing knowledge to inform the work of the Commission into the Future of Hospice Care about how best to work with, and for, family carers of those facing the end of life.

Who will be caring?

Of the 6.5 million people in the UK fulfilling an unpaid caring role for a family member, for approximately half a million of these people the caring relationship will exist within the context of an end of life phase (NCPC, 2012). If, as can often be the case, more than one person provides care to such a family member, and if also those who have been recently bereaved are included, the numbers of those involved in caring or transitioning from an end of life care role are significantly higher than the above estimated figure.

Approximately half a million people die annually in the UK, with most dying from chronic conditions and two thirds aged over 75. Therefore even a modest estimate of one carer per person, allowing that some people will die suddenly or have no carers, will be almost half a million carers involved in some type of end of life care provision each year. Unfortunately unlike some other European countries such as Denmark, the UK lacks data systems that readily identify carers

unless they are nominated by patients. A population based study in Australia has revealed the extensive but largely hidden network of care provided by people who are probably not known to health and social care services and may not attribute the title 'carers' to themselves (Burns et al, 2013).

With population projections and demographic forecasts, together with health and social care policy influences, public wishes (NCPC, 2012), and significant mortality trends (Calanzani et al, 2013a), a further increase in the numbers of people caring for those approaching the end of life will be seen in the future to 2025. By 2030 projected numbers of older people will rise from 14.1 to 19.9 million, constituting 28% of the UK population (NCPC, 2012). This profile signifies how:

> Death is now an event of older age, and needs for care and support have become more complex. Frailty, multiple co-morbidities and reduced family size are some of the challenges that current systems will need to anticipate and accommodate. (Hanratty, 2013:11)

With these shifts in ageing populations is a marked and concomitant increase in ageing carer numbers. Age UK (2010) identifying two distinct groups of older carers, those having had a life-time caring role for a child (and we could add to this siblings or other family members, eg children of siblings see Morbey et al, 2013) and those who become older carers in later life. While these trajectories to a caring role are notable, there is an important range and diversity of carer characteristics in end of life caring within the headline figures that is of central importance in order to plan future carer needs for special and specific support and services.

It is noteworthy that a significant number of people classified as carers do not identify with this formal status and title (DOH, 2010) resulting in invisible numbers of carers with hidden needs. Indeed, in the context of end of life some writers have described these overlooked carers and family members as 'hidden patients' (Aoun et al, 2005:319; Burns et al, 2013). Unlike some other European countries, such as Denmark, the UK lacks data systems that readily identify carers.

Caring roles and relationships sit within cultural, societal and relational contexts such that people identify themselves as spouses, partners, or family and other social relations. Within these relationships they fulfil caring functions and support, through commonly held social and family expectations, and not always through freely determined choice (Hudson and Payne, 2008). Further, caring may develop over time, with the result that carers can accrue substantial caring responsibilities sometimes over many years, and therefore assimilate the role without necessarily identifying with a distinct carer status (DOH, 2010). Empirical studies show these factors to be relevant for agencies aiming to target user groups for service design and provision, when take-up can be affected by non-identification with a caring role (Morbey et al, 2013; Milligan and Morbey, 2013).

Age profile of carers:

While the peak age of caring is between 50 and 59 years, the number of carers over 65 years is set to increase. A rise of 35% shows this to be the fastest growing age carer group (Carers UK, 2012 and 2013). In essence, as the UK population ages the overarching trend will be that the people classified as family carers are older themselves; increasingly it will be the case of 'older people caring for other older people.' (Age UK, 2010:3).

A further significance of age is in the proportion of weekly hours given to caring, with an incremental rise by age cohort to over 50 hours per week (higher intensity caring) mostly provided by people 85 to 90+ years (DOH, 2008). People aged over 85 are most likely to be those in need of care. For those with life limiting illnesses and conditions, and those for whom enduring or degenerative health conditions such as cancer, dementia or

cognitive impairment predominate, a quarter of their carers are themselves over 75 years (Age UK, 2010; van der Steen et al, 2013). As Calanzani et al, (2013a) point out, for the above conditions it is not always possible to describe when sickness moves on to become a dying trajectory.

A study of older people dying in institutions in Ireland proposed a model of understanding the transitions between living and dying as fluctuating and non-linear (Payne et al, 2009). With the combination of complex co-morbidity in frail older dying patients integrated, multi- professional support will be needed alongside hospice care, eg geriatric, rehabilitation and mental health services, in order to meet the end of life care needs of older patients fully, and support their caring families.

The most common location of caring for the increasing older patient populations is within their own household and this is most likely to be provided by a married or cohabiting partner (NHS Information Centre for health and Social Care, 2010). These caring relations will often be lifelong partnerships imbued with care and commitment expectations that carers feel bound to honour:

> "And we sat in the garden this day and he says 'and when I get erm near the end' he said 'you send me to the hospital'. And I can remember looking at him and I said 'after nearly 40 years' I said 'you expect me to let strangers be there when you...', I said 'I don't think so' and he sort of smiled as if 'oh thanks'. I don't think he wanted to go but he was always thinking of me. And I says 'you can get that out of your head, you're going nowhere' I says 'you know, 40 years, you'll stay here' and he sort of gave me this smile, the smile I knew as if mmm. And that was it really, I would have always have done it, I didn't care about myself what I'd got to go through."

(Wife aged 60 caring for husband aged 65). Payne et al, (2013) 'Unpacking the home': family carers' reflections on dying at home.

Summary of trends:

- High intensity end of life care increasingly provided by older carers for a spouse or partner in the same household.
- End of life care provided for frail family members in later old age with one or more significantly debilitating, chronic diseases.

Gender profile of carers:

While life expectancy trends show narrowing age differentials between women and men, it will remain the case that becoming a carer is gender determined, with women more likely to assume such roles than their male counterparts, in all age categories. In England, 60% of all carers are women. When care is provided for people living in the same household, 56% are women, and a greater percentage still are caring for people who live elsewhere, 65% of women compared to 35% male carers (NHS Information Centre for Health and Social Care, 2010). Carers UK highlight that women have a 50:50 chance of caring by the age of 59 years, while for men the respective age is 75 years (Carers UK, 2012).

Consideration of the gender breakdown of carers is relevant when considering equality and those most likely to be disadvantaged as carers through reduced or loss of income, and the impact of caring on health. Over half of high intensity care (of over 20 hours a week) is provided by women, 62% compared to 38% by male carers (NHS Information Centre for Health and Social Care, 2010).

While the above carer profile is widely reported, gender as a determinant of caring is complex, and in respect of older carers research has highlighted the significance of marital status

and intensity of support as factors that should be accounted for. When doing so we see that older men are more likely to be married, and as married status increases the likelihood of becoming a carer, there is a corresponding increase in caring by married older men of 65 years and above. In turn, it has been shown that never married or widowed older women are more likely than older men to be carers for someone living outside their household (Del Bono et al, 2008). With trends of increased life expectancy for older men, and therefore more total married years, changing role expectations and economic factors influencing men's availability to care, increases in older male carer cohorts will become more evident. Of particular note is the growth in men caring for a family member with dementia, with one source reporting the numbers of these male carers to have almost doubled in the past 15 years (Alzheimer's disease facts and figures 2013).

Changes will also be seen for older female carers of those outside their households, as increased divorce rates create an additional group of lone older women joining those of never married and widowed status. We are reminded that women more readily self-define as carers than men (Del Bono et al, 2008), and it is common for older men who identify with a carer status to do so much later in their caring journey when they are providing significant levels of support to a spouse (Milligan and Morbey, 2013).

Summary of trends:

- Women will provide the majority of high intensity, palliative and end of life care, for family members in their own and in other households.
- Increase in the number of men 70+ years caring for spouses and partners at the end of life.

Black, Asian and Minority Ethnic (BAME) profile of carers:

The 2009/10 National Carers Survey classifies 92% of carers in England as white. However, there is significant regional variance in proportions of ethnic groups providing care within and outside family households (NHS Information Centre for Health and Social Care, 2010). For example, white carers provide almost the same levels of care as Pakistani carers in Wales and the North East, but much less than in the other survey regions (Young et al, 2006). Higher proportions of BAME carers provide high intensity support, (20 or more hours per week), for people in their own households (NHS Information Centre for Health and Social Care, 2010:30). Allowing for age and gender, Bangladeshi and Pakistani people are more likely than any other ethnic groups to provide care. They are twice more likely to be a family caregiver than white carers when socioeconomic status and other factors were controlled (Young et al, 2006). Within households where 20 or more hours of care are provided, women across all ethnic groups fulfil caring roles more than men, the highest being Bangladeshis and Pakistanis. Women from these particular ethnic groups are twice as likely to provide care as men from the same group (DOH, 2008). Other writers add black Caribbean younger women to these higher represented groups (Evans, 2012).

Comparative data for 2000 and 2010 show a doubling in the proportion of BAME carers providing high intensity support over this 10 year period, compared to a relatively small reduction in numbers of white carers giving the same levels of care (NHS Information Centre for Health and Social Care, 2010). 2011 census data shows a near 20% increase in BAME carers, revealing this category as having the fastest growing groups of carers (Carers UK, 2013b).

While BAME groups provide these levels of care to family members, it is significant that patients from these groups have some of the highest levels of unmet end of life needs, reflected in figures that highlight that just 4% of such patients died in independent hospices in 2006-7 (Audit Commission, 2008). It follows that absence of support for the carers of family members at end of life from BAME groups is likely. A recent systematic review of end of life care for minority ethnic groups signals just this:

> The review revealed a paucity of research regarding patient and caregiver experiences and opinions. HCPs [health care professionals] were, by far, the most frequent subjects of research and few studies actually attempted to explore how patients and carers feel about their own cultural needs. (Evans et al, 2012:281)

Cultural perceptions, experiences of death and dying, and caring roles in families differ (Calanzani et al, 2013b; Audit Commission, 2008). We cannot assume shared understandings of what it means to care for a family member who is at the end of life. There are differences between and within ethnic communities, as well as individual family variance. Indeed, with this in mind it is of interest that a direct translation for the word carer has not been possible in Gujarati, Urdu, Punjabi or Bengali languages (DOH, 2008). However, cultural-only explanations for higher levels of care given in some BAME populations should be avoided as socioeconomic and demographic factors may be equally applicable and relevant (Evans et al, 2012). For example, where more care is provided by older BAME carers this may be due to their lower employment status and opportunities; some younger women traditionally marry older husbands and will therefore assume earlier and longer caring roles; and the impact of household composition on intergenerational caring (Young et al, 2006) shows that decreasing BAME family size, lessening importance of extended family living, as well as higher numbers of employed women, are also influencing shifts in patterns of caring in Asian families (Evans et al, 2012).

Summary of trends:

- Increasing levels of high intensity support provided by BAME carers.
- Greater likelihood of caregiving to fall to BAME women.
- Socioeconomic, demographic and cultural influences on patterns of caregiving within BAME families.
- Absence of research focusing on BAME carer experiences and needs.

Carer health needs and reciprocal caring:

With a significantly ageing carer population, health care needs are at the forefront of anticipating carer services and support. Carers UK (2013a) report a 10% increase in the past 10 years, to 84% of surveyed carers describing a negative impact of caring on their health.

Patient morbidity trends are indicative of ill-health scenarios for many older family members providing care. This is because older carers fall into the age categories which have the highest prevalence of disease conditions. As Calanzani et al highlight:

> Older age is closely linked with the development of cancer, dementia and cognitive impairment. The longer people live, the more likely they are to suffer from these conditions ... three quarters of cancer cases were diagnosed in people aged 60 and over ... Age is the strongest risk factor for dementia ...[and furthermore] older patients are also usually frailer and many have painful conditions such as arthritis and osteoporosis ... (2013a:11)

Gunn et al, (2006) note that older patients with a cancer specific diagnosis are less likely to receive palliative care than younger age patients. Their study of hospice at home services reveals that carer age may be a greater influence than patient age in access to such services.

Family carers over the age of 75 years provide higher levels of support of over 50 hours a week or more than younger age cohorts. Twice as many of these older carers will have poorer health than the general population and experience the strains of tiredness, sleep disturbance, stress and feelings of depression in addition to their own health condition's symptoms (DOH, 2008 and 2010).

Wadhwa et al, (2013) highlight greater levels of mental rather than physical strain for carers of patients with specific cancers, and also a correlation between the quality of life of carers and that of a cared-for family member with advanced disease. These strains have greater health related impact for carers with multiple caring responsibilities.

With the numbers of carers who have their own health needs increasing, it can be argued that the use of fixed terms to describe those who care (care givers) and those who don't (care receivers), becomes increasingly unhelpful. Further to the older carer/older family member situation Barnes (2012) highlights that as children with learning and life-long physical disabilities live longer, traditionally those viewed as care receivers will provide vital care giving roles for their longer living parents.

Research (Gott et al, 2007; Morbey and Payne, 2013) shows how carer roles can be mutual in their giving and receiving dimensions through fluctuations in the health needs of individuals in a relationship (see case illustrations below). Consequently it is more helpful to move beyond individual role defined perspectives of caring to a more relational focus (Barnes, 2012; Payne, 2007), or 'whole family approach' (DOH, 2010). This is particularly appropriate when considering the increasing health needs of the largest growing section of older, spousal carers of those at the end of life. These are likely to have their own health needs, and may be supported in some way by the people they are classified as caring for.

The following case examples (Morbey et al, 2013) illuminate the mutual, shifting nature of the giving and receiving dimensions of care through fluctuating health needs of both carers and their family members:

Case study 1

Mrs D has cared for her husband Mr E who has dementia, for approximately two years. Prior to this Mrs D was cared for by Mr E following a stroke. Mrs D was recently diagnosed with cancer and requires hospital inpatient treatment. Mr E has a planned care home respite stay arranged for the duration of her hospital admission and her recuperation afterwards.

Case study 2

Two brothers living together, the younger brother Mr C has a primary caring role for his older brother Mr D of 73 years of age. The older brother has a diagnosis of cancer and attends the local hospice regularly. The carer brother has diabetes, a chronic organ disease requiring surgery, and joint problems causing considerable pain, with imminent planned joint replacement surgery. Mr C is prescribed specialised treatment that cannot be obtained from his GP or local hospital and he travels by taxi to another hospital at some distance to obtain this. Mr C experiences sleep problems and feelings of being unable to cope as his own and his brother's health deteriorates. He has been asked to complete an employment assessment form to evaluate how his illness will affect his ability to work, which is also causing him further stress and worry. Mr D takes a caring role for Mr C during periods of his health improvement.

Case study 3

Mr B is 73 years and is the primary carer for his wife who is also 73 years of age. Mr B is awaiting heart surgery and struggles with mobility because of his heart condition. Mrs B has terminal cancer and symptoms of dementia. She is in hospital awaiting discharge to their new home. The pressures of caring have added to Mr B's own health concerns leaving him feeling very stressed, which compounds his health issues.

A final case example illustrates how older carers' own health needs may develop to a level of seriousness that prevents them from fulfilling their caring role. The example portrays the complex circumstances of multiple need for some older carers who maintain the 'carer' title and status for a family member, while this role may be suspended by virtue of their own health or treatment requirements:

Case study 4

Mrs A, 85 years, is a long-term carer for her partner of 87 years of age. He suffers from depression and mobility difficulties. Mrs A has visual impairment and a diagnosis of lung cancer for which she received a course of chemotherapy. Mr A had respite care during her treatment period. This was a source of great distress for Mrs A. Mr A died within a few months of Mrs A's own health declining, when she was in receipt of hospice care.

Summary of trends:

- High health needs in ageing carer populations.
- Impact of caregiving strains on existing or developing health conditions of carers.
- Intensity of strain for carers of those with advanced diseases.
- Mutual and fluctuating care giving/ receiving relationships.

Changing family, household and employment trends:

Changes in family and household make-up have been significant over the past 50 years, and contemporary family relationships and roles create potentially complex caring arrangements and scenarios. More geographically dispersed families, and work patterns, reconfigured households through divorce, remarriage, step and single parenting and cohabitation, family size leading to fewer adult children, together with standard of living expectations, affect who cares, where and for whom (DOH, 2010; Payne, 2007). Taken-for-granted reciprocal spousal expectations of care (Egdell, 2013) disappear on divorce and remarriage, and adults may find themselves caring for their divorced parents in different households and locations. They may also encounter complicated dynamics in negotiating adult carer roles and expectations of care involving step, half or estranged siblings. These challenges are heightened by the demands on carers of family members with advanced disease and who are at the end of life.

Reference is increasingly being made to the particular circumstances of a 'sandwich' generation who still have dependent children, or are looking after grandchildren, also taking responsibility for the care of their elderly parents (Carers UK, 2012). They may also still be working in paid employment. At the point of retirement they may have health problems related to stresses of caring. As with other carer scenarios, women are more likely to provide this form of dual care.

Almost half of all carers support family members while also undertaking paid employment outside the home. Most of these have either needed to take holiday leave or work overtime to meet the demands of their caring role. Others have found it necessary to leave their employment altogether in order to care (Carers UK, 2013a). Impact on pension contributions and complicated welfare benefit claims can result in adding further stress and complications to already difficult circumstances for carers (Payne, 2010). As they constitute the majority of carers, women are more likely to feel the impact of immediate financial hardship brought about by giving up paid work to care, and potentially life long disadvantage through inadequate pension provision (DOH, 2010). Those supporting male spouses and partners in caring households may take on additional work hours to help fill shortfalls where household income is affected in this way.

Fulfilling both, and in some cases multiple and cross generational, caring and employed roles, brings with it additional strains and specific support needs. There are implications for particular groups of carers in this area with changing employment and immigration trends. Asian women, for example, are increasingly employed outside the home (Evans, 2012), and as a proportionally higher intensity carer group, greater impact may be felt by this group through being in paid employment and fulfilling a caring role. Economic migration and asylum protection result in people and families leaving their homelands and communities. Their social situations are likely to result in limited or non-existent family, kinship or community support networks to call on when family members need care (Monroe et al, 2011).

Growth in the numbers of people affected by these dual circumstances is inevitable. Retirement will extend, as the age of retirement will rise to 66 years for both men and women by 2020 in the UK. With peak caring age between 50-59 years, and a growth in carers over 65 years, increasing numbers of people in these age groups will experience their final working years or early retirement years providing end of life care for spouses and partners, and elderly parents (Carers UK, 2013b).

Summary of trends:

- Increasing dual caring roles for middle age- range carers.
- Divorce and remarriage patterns creating complex family and household constellations.
- Managing joint paid employment and caregiving responsibilities for longer.
- Impact of caregiving during last working years or early retirement years.

What care will carers provide?

The spectrum of physical, social and psychological dimensions of caring for an ill family member at the end of life is extensive and deep (see Figure 1 on page 20). The many elements of support which carers provide are, at differing times, of equal importance, from maintaining morale, providing company and personal care, shopping, cooking, lifting and giving medicines, through to fitting aids, attending appointments, and being the conduit of information and contact between family members often across households or at distance.

Carers have high expectations in their ability and extent to which they attend to their family member's end of life needs:

> "Her bowels were troublesome and I couldn't manage getting her out of bed onto the commode. I was finding it difficult and because of her heart condition also she kept sliding down in the bed, and she's got a double bed that she kind of slept on one side, and what happened it used to be that I would climb on the bed, get behind her and lift her up, pull her up like that, put my hands under her arms and grab her arms across and pull her up. And I was doing that several times a night..."

(Daughter aged 57 caring for mum aged 77). Payne et al, (2013) 'Unpacking the home': family carers' reflections on dying at home.

In respect of older carers, at one and the same time they may experience support or health needs in similar domains to their cared-for family member. Older carers will increasingly need to provide support in a combination of caring tasks, shown in the table on page 20, while also contending with their own life limiting, long term health issues, which may include painful, restrictive conditions such as osteoarthritis. Indeed, they may have health needs similar to or greater than those of the identified patient (Higginson et al, 1990; Hudson et al, 2012). Of concern in this context is that many carers are reluctant to express these needs, and may have greater levels of unmet need than the family member they care for (Candy et al, 2009).

With competing demands of their own and family members' health needs many carers can be faced with conflict and choice about which to prioritise. Carers' health needs can be extensive, diminished and difficult to attend to, as this older carer found:

> "I've got a dickey hip now [...]and everybody was saying to me 'well why don't you go and get it seen to?', and I said 'well I've got enough on my plate', because in the last three months of last year I had a sigmoidoscopy, followed by a barium enema, followed by a coronary angiogram in [hospital], followed by a colonoscopy back here again in [hospital]. I said 'I'm sick and tired of hospitals and people prodding about', I said 'I'll live with my hip for now'."

(Husband aged 75 caring for wife aged 71). Payne et al, (2013) 'Unpacking the home': family carers' reflections on dying at home.

Future end of life and palliative care health policies will continue an emphasis and direction towards home and family care as a preferred place for the majority of people to receive care (NCPC, 2012), and as a means of tackling acute in-patient care for end of life when care costs are substantial (Aoun et al, 2005; Grande et al, 2009). With homes and communities necessarily promoted as the site of treatment and medical care, family carers will increasingly undertake their role and execute caring tasks in these settings for protracted periods, possibly over years, while requiring different dimensions of support to meet their family member's and their own needs.

Spheres of caring can be categorised around identified areas of support required by family members in the final months and weeks of life (Ewing and Grande, 2011; Grant et al, 2013; Moorman and Macdonald, 2013; Payne, 2007 & 2010) (see Figure 1).

Figure 1: Spheres and tasks of caring

Spheres of caring in end of life care	May include support in:
Emotional and Psychological	emotional labour of reassurance, comfort, stress-relief when relatives experience pain and discomfort; anxiety; depression and uncertainty.
Familial and social	family mediation; maintaining social and community relationships; access to social events/opportunities; leisure activities.
Financial	multiple finance needs: transport costs to attend healthcare appointments; welfare benefit claims; costs of special diets, additional heating and washing; employment /sick leave arrangements; pension and insurance payments; charitable funding.
Information and communication	arranging and managing health professional visits; obtaining disease-specific, care-specific, and treatment-specific information; cognitive and memory needs; patient advocacy; symptom reporting; family communicator; hospital or emergency admission; legal information eg power of attorney, will making; personal paperwork and bills.
Physical and personal care	symptom and pain management; complex care tasks; medication; handling and lifting; feeding and drinking; shopping, cooking, DIY, gardening, pet care; mobility and exercise; equipment and aids; washing / dressing; household cleaning; wound/infection treatments; disposal of body waste and fluids; night time supervision/care; sitters or respite care; dying process.
Spiritual/existential	comfort and reassurance; anticipating dying and death; access to spiritual practitioners; maintain faith practices; observing religious practices.

Advancing complexity and 'specialist' end of life caring:

The range and complexity of tasks undertaken by carers is expanding as more advanced and sophisticated medical treatments permeate the delivery of care in home settings. Once the sole domain of professionally trained nursing or ancillary staff, family carers are increasingly involved in medically complex procedures, including the operation of 'high tec' equipment, diagnostic judgements, managing multiple or titrated medications, and instigating high risk procedures (Moorman and Macdonald, 2013; Whittingham et al, 2013). Specific disease conditions bring challenges particular to them, and may confront the carer with uncertainty and unpredictability, which further exacerbate the strains upon them (Whittingham et al, 2013).

Physical and practical components of caring for a family member with advanced illness are relative to the psycho-emotional demands of end of life care. We are minded that the scale of the above responsibilities for managing, organising and decision making are all undertaken while under the emotional duress of loss and grief (Hudson et al, 2010a) with these becoming more intensified nearer to the family member's death (Chai et al, 2013). In their recent study Grant et al (2013) report high levels of caregiver burden in carers of people with lung cancer. There was a decline in carers' sense of skill preparedness and quality of life over time, with notable increases in psychological distress the longer care was provided.

Advances in medicine that extend life in turn result in lengthier periods of time that carers meet the needs of family members wishing to spend their final weeks and months of life, or to die, at home

(Payne, 2010). End of life suggests an intense, relatively short phase to care (Ewing and Grande, 2013). However, burgeoning incidence of long term conditions in ageing populations (Calanzani et al, 2013a) will see people living for more years with poor health (NCPC, 2012). Care needs differ for those with an identifiable condition and disease progression, from those facing a less predictable and protracted decline in health. The latter will necessitate care spanning across more years of a '...prolonged slow trajectory of dying found in late old age ...' (Payne, 2007:10). Although carers may provide support for relatively fewer years for those with cancers, continuing improvement trends over the coming decades in cancer survival rates also indicate that carers can undertake support for a growing number of years (Kim et al, 2012).

Family carers will experience the combined physical and emotional load for longer, for people with co-morbidities and for older, frailer family members (Grande et al, 2009). Essentially both carers and patients will live longer with an awareness of proximity to death (Payne, 2010).

Added to prevailing physical diseases carers will face Alzheimer's disease and other dementias as a likely primary or secondary condition affecting older family members' health needs. With one in five people over the age of 80 years, and one in 20 people over 65 years having a dementia, projected rises are inevitably high (Calanzani, 2013a). Currently one in three older people die with dementia (NCPC, 2012). Increasingly, dementia specific care will form a component of support provided by family carers, bringing with it distinct challenges for those living in the same household, in close proximity, or for those supporting family members from a distance, including hospices and hospice at home services.

In turn, cognitive impairment and dementia needs should be anticipated in older carer cohorts. With the growing age profile of family carers this area of health need will present particular challenges and implications for carers, their family members, and the health and social care practitioners and organisations providing services. The demands and complexities such scenarios potentially raise are illustrated by the circumstances of this carer whose mother, with dementia, had been the primary carer for her father:

> "Well my mum and dad moved in to live with us in millennium year, because my dad had peripheral neuropathy, and he was going gradually downhill and obviously my mum was getting older and finding it harder to look after him."

(Daughter aged 64 and her husband aged 66 caring for her dad aged 90; mum with dementia still being cared for). Payne et al, (2013) 'Unpacking the home': family carers' reflections on dying at home.

In the context of challenging end of life circumstances, carers are required to navigate a complicated path to statutory providers in order to access treatment and services for their family member and, in many cases, for themselves. This involves becoming familiar with organisational areas of responsibility, designated and specialist professionals and practitioners, together with their locations and areas of provision. Multiple providers from health, social care and third sector agencies such as hospices may be involved, all with their own service protocols. An additional future element to health care provision for long term conditions will be the implementation of personal health budgets (DOH PHB/EOL, 2010). End of life care planning is set to increasingly incorporate the use of this form of individualised budget for those with chronic health conditions. This will therefore become an additional area of involvement with which carers will need to become familiar.

Through a position in the household of locus of care, family carers also fulfil an on site expert role for visiting practitioners. This facilitative dimension to the carer role will be increasingly central if home and household locations are to be the site of end of life

care. Hanratty's (2013) study showed many carers to be the coordinators and providers of care in the home. However, their research revealed that often deficits in support and information prevented carers from undertaking this crucial role with confidence and in the way they wished. Communication and relationships between multi-disciplinary professionals were identified as especially important when transitions in care were experienced by patients. These relationships affected carers who described feeling unheard and unsupported, and professionals were shown to have little shared understanding about the carer role, experiences or expectations.

Summary of trends:

- Advanced medical procedures and treatments increasingly delivered in homes and communities.
- Longer end of life trajectories and caregiving years.
- Frailer family members with long term co-morbidities, cared for by older family carers with health needs.
- Dementia as an increasing component of care needs.
- Importance of collaborative working relationships between carers and professionals.

How will we know what carers need?

Assessment of needs:

It has been recommended that family carers are offered regular assessment to identify their needs. One recent systematic review of assessment instruments identified 62 tools that had been administered in palliative care settings (Hudson et al, 2010b). However, within these a number of studies did not directly measure carer needs and presented indicative areas of support largely through primary examination of the demands of caring (Ewing and Grande, 2012).

Identifying caring tasks and the impact on family carers of fulfilling this role have been a focus of research, often with an emphasis on 'burden' and longer term caring (Grande et al, 2009; DOH, 2010). Less reported are interventions and approaches that can be utilised in home settings to support carers by identifying needs and preventing negative outcomes (Grande et al, 2009; Hudson et al, 2010b). Factors which could influence carer stress include their family member's disease condition, psychosocial characteristics, and longevity of caring. As discussed earlier, some of these factors and determinants may occur over months or years, where disease or chronic conditions can be more successfully treated and managed.

Recent work by Ewing and Grande (2012) aims to address suitability and usability issues identified in the above reviews. Through the development of a standardised assessment tool that can be utilised in home settings, an evidence based means of identifying the needs of carers supporting family members through giving end of life care has been designed. Importantly the tool addresses a key issue raised earlier in this report, through ensuring that carers' own health and support needs are identified alongside those necessary to care for a family member.

Research with bereaved carers enables aspects of caring to be identified from which Ewing and Grande designed a 14 item (domains) psychometric testing tool. Crucially, a simple design is based around the overarching question: Do you need support with ....? From this each of the 14 areas is explored. The limited number of distinct areas and the uncomplicated, carer-accessible question format provides manageable administration in informal care. This is a crucial factor for the successful implementation in practice settings.

The intention of the tool is for areas of need to be highlighted, in order that practitioners can then identify forms of support in each of the areas through subsequent discussion with carers. Essentially the Carer Support Needs Assessment Tool (CSNAT) acts as a starting point for carer and practitioner to explore a full range of the areas that affect the carer's more personal needs and on their caring needs.

The CSNAT creators highlight an important benefit of the dual purpose function of the tool. Carer needs are not lost because of a priority emphasis on caring support, which is the likely consequence of single focus intervention and assessment strategies (Grande et al, 2009). CSNAT ensures attention is drawn equally both to an important intent for informal end of life care, that positions carers as co-workers with health practitioners (as promoted in The End of Life Strategy), and also to the complex, multi-role and task nature of end of life care is visible to practitioners and carers, policy makers and researchers alike.

What interventions will be needed to support carers?

A wide research literature base exists, including systematic reviews, reporting on study outcomes of carer support interventions and their effectiveness (Candy et al, 2009; Evans, 2012; Gomes and Higginson, 2006; Harding et al, 2012; Hudson et al, 2011; Hudson et al, 2010a and b). A selected bibliography of studies and systematic reviews related to interventions supporting family carers is provided on page 33 at the end of this report. For example, Hudson et al (2013) in Australia have demonstrated the impact of a relatively short term intervention on carers' sense of preparedness and competency to provide palliative care for patients in their homes. Increased levels in both these areas resulted from between one and two visits (significant for intervention of two visits), by a family caregiver support nurse who provided individual information and resources, devised a care plan, and provided additional support to that given by the palliative care team. The authors suggest that there could be related benefits for wider carer psychological well-being associated with the preparedness and competency outcome in this study, although further research is recommend in the area.

It is beyond the scope of this report to review all the interventions described in the literature. Instead we offer a typology of supportive interventions, which are categorised in terms of 'complexity' of therapeutic intent from least to greatest (see Figure 2). Information, training and education are likely to benefit virtually all carers and they can be provided in a range of formats including leaflets, websites, downloads, apps, etc. Supportive activities refer to all those elements that hospices can deliver with volunteer contributions such as 'drop-in' opportunities, via in-home befriending, or practical tasks such as gardening, or via virtual means. Finally, we have grouped activities with a specific 'therapeutic' intent together which have specific outcomes, perhaps led by a therapist or expert (paid or unpaid). These may be time-limited activities. Our examples are indicative rather than comprehensive and clearly may function to offer benefits across the three categories. We recommend that hospices have a clear rationale when developing carer support activities and that a menu of options across the three domains is available. It should be recognised that carers may find it difficult to leave the cared for person and that suitable respite should be offered. More research is required on how best to tailor support to carers in the context of an often rapidly fluctuating condition of the patient. The window of opportunity for carers to access appropriate information and support is often brief.

Figure 2: Types of hospice support for adult family carers

Information, training and education	Supportive activities	Therapeutic activities
■ Strategies for safe moving and handling of the patient. ■ Information resources on disease process, trajectory and prognosis. ■ Information on how to provide specific care tasks, equipment and medication. ■ Information about the dying process and symptom management in a timely way. ■ Access to welfare or benefits advice.	■ 'Drop in' centre/coffee mornings/ lunch clubs. ■ Self-help groups, virtual or face-to-face. ■ Walking, exercise or activity groups. ■ Volunteers visiting or befriending. ■ Art making or creative groups.	■ One-to-one or group counselling. ■ Therapeutic support groups. ■ Drama, music or art therapy. ■ Relaxation, meditation, mindfulness or yoga classes. ■ Complementary therapies. ■ Psychotherapy.

Recommendations

The challenges carers face have solutions in the support that hospices and other service providers can put in place by anticipating opportunities to address gaps in services. Identifying what works and sharing this is crucial for successful medium term provision, and to address future planning for longer term informal caring demands.

Recommendations to meet these challenges and to find solutions and opportunities are outlined below in respect of individual family carers giving care; hospice practitioners and organisations working at the interface of care with family carers; and at the level of policy developments that shape future end of life support for carers.

There is an overarching need to address the dearth of systematic evaluation and research evidence in this area. With the exception of a limited number of systematic research reviews, little priority has been placed on substantiating robust and effective carer support interventions. Establishing the means to disseminate and share evidence of successful interventions that address carer experiences and needs cuts across all recommendation areas.

Family carers

Recommendations:

- Family carers require **respectful** and **compassionate care**.
- Family **carers are experts** in relation to their cared-for person.
- Family carers require **information** and access to **up-dated knowledge** about how to provide care.
- Family carers should be offered **regular assessment** of their needs.
- Family carers should be offered a menu of **support services** which are **timely, accessible, affordable and appropriate**.
- Little is known about the specific needs of **older carers** using hospice services, especially those who are in **late old age, male carers, and those from socially marginalised** groups. It is recommended that research is commissioned to address this knowledge deficit.

Health and social care professionals and others associated with hospices

Recommendations:

- Hospices should explore the opportunities and challenges of **greater involvement of volunteers** in direct support to family carers, in their homes, communities, and in hospices.
- Hospices should explore how best to support internationally qualified medical and nursing **staff to understand the cultures, norms and expectations of end of life care in Britain**, especially when staff, patients and families do not share common languages.
- Training in **cultural sensitivity** may be required for all hospice staff in raising awareness of their own cultural assumptions and how they affect interactions with family carers.
- Planning and development of services appropriate to **supporting carers of family members with dementia**, for end of life care delivered in their homes, communities and hospices. Training at all levels of hospice care and workforce (paid and unpaid) in the specific needs of support for carers of those with dementia.
- The **regular assessment** of family carer needs should be embedded in routine hospice care, and it should not require a 'crisis' or 'problem' to precipitate its introduction.
- Greater attention needs to be placed on **managing transitions** across care settings, including hospice care to reduce the disruptions to patients and distress for carers.

- **Quality leadership** in hospices is needed to boost and value carer support.
- Little is known about what types of support are most effective, and how they should be delivered by hospices, and how they link to other forms of **support for carers of patients with dementia** approaching the end of life. **Further research** in this area is warranted.

National organisations associated with hospice care and society

Recommendations:

- If caregiving is extended beyond kinship networks, this raises implications for hospices and staff in **sharing confidential patient-related information**. However, access to this information is vital for those providing care to ensure safely and continuity.
- New methods are to map, quantify and thereby recognise the **'hidden' networks of actual and virtual care** provided. This is likely to both reveal the contribution made by these people and identify their support needs.
- Many best practice tools, models and processes have been established to support family carers by hospices, but they are not always used effectively, resulting patchy provision and 'gaps' across hospices. This may mean that individual carers' experiences are not optimal. **Recommended minimum provision of support should be agreed across all hospices**.
- **Rigorous evaluation** is required of the diversity of hospice carer support services about what works best, for whom and when, and what is most cost effective.
- Greater attention to integrated policies and practices across health and social care, and associated Third Sector organisations to ensure carers relationship with dying patients are **acknowledged and respected to facilitative navigation and access** to appropriate supportive services.
- Little is known about the complex networks of actual and virtual **(information technology mediated) care provision** that sustain patients approaching the end of life.
- Imaginative use of **health and communication technologies** may offer hospices ways to support family carers that are less labour intensive. These should be investigated and tested for acceptability and feasibility.

Conclusions

There is a wealth of research evidence on the demands upon carers and their needs. There has been a history of policy changes designed to benefit carers but sadly the experiences of family carers of those approaching the end of life appears to be largely unchanged and continues to be unnecessarily challenging. The question is why. In our view, the culture of hospice care needs to shift to truly include family carers as central in their relationship with patients and as worthy beneficiaries of support both during and after the death of the patient.

Acknowledgements

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International Observatory on End of Life Care, Lancaster University

Lancaster University is approaching its 50th anniversary with a world-class reputation as a centre for excellence in teaching, scholarship and research. Established in 2008, the Faculty of Health and Medicine brings together a critical mass of expertise in teaching, research and outreach from four established departments and their associated centres: Biomedical and Life Sciences; Centre for Training and Development (CETAD); Health Research; and Lancaster Medical School. Situated within the Division for Health Research, the International Observatory on End of Life Care (IOELC) aims to undertake high quality research, evaluation, education, advocacy and consultancy to improve palliative and end of life care for patients and their family carers. Established in 2003, the IOELC is a globally recognised centre of excellence for research in palliative and end of life care. Since the early days the range of work undertaken at the Observatory has expanded dramatically and the numbers of staff, students, honorary members and associates have increased commensurately. The IOELC works closely with the local health and social care community in the North West, as well as nationally and internationally. They offer a range of methodological and theoretical expertise drawn from clinical and social science perspectives. Their aims are to improve palliative and end of life care for patients and carers, and they include: to provide research-based evidence on end of life care provision - locally, nationally and internationally - through primary research studies and reviews; to disseminate results in order to make a practical and academic impact; to provide appropriate programmes of education and training, as well as consultancy services; to work in partnership with key organisations and individuals as a 'community of effort' for the global improvement of end of life care.

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Spheres and tasks of caring

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Types of hospice support for adult family carers

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Notes

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