



Committed to Scotland's carers

Supporting carers of people at the end of life

www.mariecurie.org.uk



A report by the Marie Curie Cancer Care Policy and Public Affairs team, based on qualitative research funded by Marie Curie Cancer Care and undertaken by the Health Experiences Research Group in the Department of Primary Health Care Sciences at the University of Oxford.

March 2012

Contents

Foreword	Stephen Mangan.....	3
Chapter 1	Marie Curie Cancer Care is committed to carers.....	4
Chapter 2	The impact of caring for someone at the end of life.....	6
Chapter 3	Access to information and support.....	10
Chapter 4	Place of care and place of death.....	14
Chapter 5	Bereavement.....	18
Chapter 6	Conclusion	20
Chapter 7	Summary of recommendations	21

Foreword

Stephen Mangan

My mother was diagnosed with cancer in 1991, just as I graduated from university. Watching her become increasingly ill was exhausting and enormously emotional. It was a huge relief when, at the end of her life, my family and I were helped by Marie Curie Nurses. When my father died six years later from a brain tumour, Marie Curie Nurses were there to give him the care he needed.

It made a difference. Both mum and dad were able to die at home in familiar and relaxed surroundings. Having Marie Curie Nurses there to look after them meant that we could be the family we are without having to worry about anything.

So many people at the end of life and the people that care for them have a drastically different experience. At a time of stress and high anxiety, things are made much more difficult by the absence of high quality support and information.

This needs to change. *Committed to Carers* draws on the direct experiences of people caring for someone at the end of life and on Marie Curie Cancer Care's years of expertise of caring for carers. Its recommendations set out how we can improve the situation both for people at the end of their lives and for their carers, based on the first-hand experience of people who have been through this experience.

I hope that the report is widely read and fosters a better understanding of the experiences both of people with a terminal illness and of those that care for them.

Stephen Mangan



Photo: Piers Allardyce

Chapter 1

Marie Curie Cancer Care is committed to carers

Marie Curie Cancer Care is one of the UK's largest charities. Our nurses work to ensure that more people are able to be cared for and die at home, surrounded by friends, family, and other loved ones. Our hospices provide specialist in-patient and outpatient care, together with day services, complementary therapies and services specifically designed to support carers and families.

The charity employs more than 2,700 nurses, doctors and other healthcare professionals. In the last year, the charity delivered care to more than 31,000 terminally ill patients both in their own homes and our hospices. In 2010/11 the charity spent approximately £12 million providing care to 3,480 patients in Scotland, in their own homes through our nursing service and in our two hospices in Edinburgh and Glasgow.

Marie Curie provides care to carers and families, as well as patients at the end of their lives. As well as the carer and family focused services offered by our hospices, the charity also runs the Marie Curie Helper programme. Marie Curie Helpers are trained volunteers who provide a listening ear and emotional support to patients, carers and families caring for someone at the end of life. They also help carers and families to take short breaks from their caring roles and provide information on relevant local services that would be of benefit to carers, families, and the people they are caring for. Support for carers from a Marie Curie Helper continues into the bereavement period.

The charity is dedicated to improving knowledge about carers who look after people who are terminally ill. The next Dimpleby Marie Curie Cancer Care Research Fund grant programme has invited research proposals within two carer-related themes:

- The demographic characteristics and personal circumstances of those who provide unpaid care for people at the end of their lives.
- Educational interventions to assist those who provide unpaid care for people at the end of their lives.

Marie Curie campaigns to ensure that more people are able to be cared for and die at home. We do so because we know that most people would choose to die at home if they were terminally ill (65 per cent¹) and because it makes good economic sense. Our estimates suggest that reducing hospital stays for 30,000 patients by just four days could potentially save the NHS £34 million per year².

However, we also know from our patients and their families that caring for someone who is terminally ill at home places a huge amount of stress on carers. If carers are unsupported, that stress can frequently become too much, leading to a breakdown in carer health. This can lead to emergency admissions to hospital for both the carer and the patient. This is costly for the NHS, and can mean that the patient does not achieve their preferred place of death.

The reality in the UK is that just 21 per cent³ of people die at home, while the majority die in hospital (53 per cent), the place they say they would least want to be. We know from our experience as a provider of palliative and end of life care that it is not enough just to get people home from hospital. The support structures, particularly for carers, must be in place to ensure that people who are terminally ill can stay home and die there.

This report is based on qualitative research, funded by Marie Curie Cancer Care, undertaken by the Health Experiences Research Group in the Department of Primary

¹ YouGov (2008). *Dying at Home*.

² Marie Curie Cancer Care (2012). *We know about end of life care: understanding the cost of end of life care in different settings*.

³ Department of Health (2011). *End of Life Care Strategy: Third Annual Report*.

Health Care Sciences at the University of Oxford. They interviewed 40 carers about their experiences of caring for someone at the end of life. Some were currently caring for a sick friend or relative; others had been bereaved.

The research was designed to explore how people experience caring for someone with a terminal illness in the context of their family, work and social lives. The research team sought to interview carers and patients with a range of experiences. Some of the patients used hospice or hospital in-patient care, others remained at home. The research provided the basis for content on the award-winning website www.healthtalkonline.org that is designed to improve public and professional understanding of people's experiences of health and illness.

This report makes recommendations based on this research, on Marie Curie Cancer Care's own findings, and on examples and case studies drawn from carers of patients cared for by the charity. The recommendations are designed to ensure that more carers of someone at the end of life receive the support they need to keep caring. Marie Curie is committed to ensuring that more people who are terminally ill are able to be cared for and die at home, and to support the carers who make this possible.



Chapter 2

The impact of caring for someone at the end of life

Identifying carers

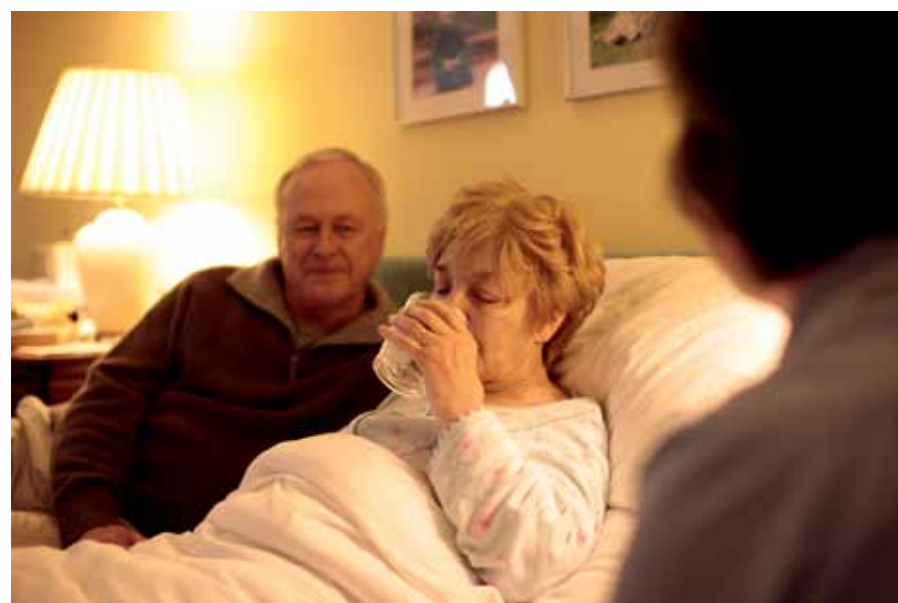
Most people in the UK will be a carer at some point in their lives. Seven out of 10 women will be carers, and nearly six out of 10 men. Carers are most likely to be caring for their spouse or partner followed by another relative living in the same household⁴ and 70 per cent of carers will have been caring for over five years⁵.

Data from the Health and Social Care Information Centre *Survey of Carers in Households*, 2009-10⁶, show that of 2,200 carers who responded to the survey, 4 per cent claimed to be caring for someone with a terminal illness. In addition to this, a further 10 per cent cared for someone with dementia, 37 per cent for someone with a long-term illness and 17 per cent cared for someone with "problems connected to ageing" (respondents could choose more than one option). It could be argued that many of these people are also likely to be caring for someone approaching the end of life and the proportion may be much higher than 4 per cent.

It is estimated that there are around 6.4 million unpaid carers in the UK with around 517,000 in Scotland or 10 per cent of the population, of whom over 115,000 care for 50 or more hours per week⁷. They are estimated to save the Scottish economy over £10 million, which equates to around £18,000 per carer per year⁸. Various sources^{9,10} estimate that 500,000 of UK carers care for someone with a terminal illness. If such carers are similar to carers in general, this suggests that they save the UK approximately £9 billion per year.

However, many of these people may not define themselves as a carer – they would simply call themselves a wife, a son, a friend, or other loved one. This often presents a barrier to the carer seeking out formal support to undertake their role.

Similarly, it is often difficult to distinguish between carers of people at the end of life and carers in general. This is because it can be very difficult to define when an individual is at the end of life. There is evidence to suggest that identifying when a patient is nearing the end of life is more straightforward for diseases with a more predictable decline, such as many cancers, rather than diseases with peaks and troughs, such as heart failure, or very gradual decline, such as dementia¹¹.



⁴ Carers UK (2001). *It could be you – a report on the chances of becoming a carer*.

⁵ Scottish Government (2010). *The Carers Strategy for Scotland 2010 – 2015*.

⁶ The NHS Health and Social Care Information Centre (2010). *Survey of Carers in Households, 2009/10*.

⁷ The Princess Royal Trust for Carers (2010). *Key facts about carers*.

⁸ Carers UK and the University of Leeds (2011). *Valuing Carers*.

⁹ Grande, Stajduhar, Aoun, Toye, Funk, Addington-Hall, Payne and Todd (2009). *Supporting lay carers in end of life care: current gaps and future priorities*. *Palliative Medicine*. June 2009, Vol. 23 Issue 4 p339.

¹⁰ Seale C, Cartwright A (1994). *The year before death*. Aldershot: Avebury.

¹¹ The King's Fund (2011). *Issues facing commissioners of end-of-life care*.

Through the *Carers Strategy for Scotland 2010–2015*, Scottish Government policy is now aimed at identifying carers at the earliest opportunity and ensuring they are given adequate human rights through a Carers' Rights Charter. The Scottish Government working with Convention of Scottish Local Authorities (COSLA) stressed determination for carers to be supported to manage their caring responsibilities 'with confidence and in good health', and to 'have a life of their own outside caring'. The strategy emphasised the importance of recognising carers as 'equal partners in the planning and delivery of care in Scotland' and the need to 'acknowledge carers' expertise, knowledge and the quality of care they give'.

Many of the carers interviewed for Healthtalkonline raised issues with the support and advice they received from clinicians. These included feelings that the GP was not honest about the severity of the patient's condition; that professionals gave test results and did not take the time to explain them in detail; and that professionals needed more training to understand the support needs of people at the end of life.

The sentiment of these comments was reflected in Marie Curie's own case studies of carers, with one carer saying about her experience of being a carer: "It felt like I was on a treadmill and I had to find out everything as I went along."

“ *I know everybody's different and I know everybody maybe can't take a diagnosis of terminal illness but in some cases when the people actually ask 'How long have I got?' and, 'What's going to happen next?' 'Am I going to be left gasping for breath?' I think it would be a good idea to tell them the truth as they know it.* **”**

Victoria thinks that professionals should be more upfront about a diagnosis of terminal illness and what is likely to happen.

Recommendations:

- Carers of people at the end of life need to be supported to identify themselves as carers. Health and social care professionals should have conversations with carers about what a patient's diagnosis will mean for the carer at the point of diagnosis, and be prepared to revisit these conversations as the patient's condition progresses.
- Health and social care professionals need additional support and training to help them identify carers of people at the end of life.
- Health and social care professionals should ensure that carers are included in conversations with the patient about their condition so that they feel as though they are part of an expert care team.

The impact of caring for someone at the end of life

Research into the experiences of people caring for someone at the end of life has consistently found that carers report that their experience involves "intense, conflicting, negative and/or difficult emotions"¹². Carers' own health can often be negatively affected, particularly where they are older¹³. This was the case for many of the carers interviewed for Healthtalkonline.

¹² Funk et al. (2010) *Home-based family caregiving at the end of life: a comprehensive review of published qualitative research* (1998-2008). *Palliative Medicine* 24(6):594–607.

¹³ The Princess Royal Trust for Carers (2011). *Always on Call, Always Concerned*.

Some of the carers interviewed found joy in their caring role, although they acknowledged that the caring role remained physically taxing and that knowing the person they were caring for was going to die made the situation difficult.

“ We got very close. A friend actually asked Di, she said to her in the last few weeks: ‘It must have been a terrible year’. And Di said: ‘No it wasn’t, it was actually a wonderful year’. The comment she made, she said: ‘In the last year I’ve actually learned to accept love fully for the first time and it’s just been really wonderful’. And it was the same for me, it was, it was painful – very. It was difficult. It was exhausting, utterly, utterly exhausting. I’ve used the word exhaustion in my life before but I never really knew the meaning of it until then. ”

Dick describes caring for his wife as a ‘labour of love’. It was a wonderful experience, even though it left him utterly exhausted at times.

Many of the carers had individual coping strategies for dealing with the pressures of being a carer. These ranged from having a strong beer to communing with nature or doing some physical exercise. Some of the carers had accessed formal counselling – usually after the death of the person they were caring for – and had mixed views about its effectiveness.

As far back as 2005 when *The Future of Unpaid Care in Scotland Report* was published, it was recommended that the Scottish Executive, local authorities and NHS agencies along with partner agencies focus strongly on the health and well-being of unpaid carers. It was also advised that increased access to counselling and emotional support services made available to unpaid carers.

For some who were interviewed for Healthtalkonline, working provided a sense of normality and gave them a break from their caring responsibilities, though tiredness could have an impact on work performance. Other carers had retired before becoming a carer.

Caring Together – The Carers Strategy for Scotland 2010-2015 sets out the government’s commitment to ensuring that carers are able to take breaks from caring in order to sustain their role as a carer and, where possible, to enable them to continue working where that is their desire. By July 2012, the Scottish Government have pledged to reassess the timescale for delivery of the manifesto commitment to a guaranteed annual entitlement to breaks from caring for those in greatest need.

Living and Dying Well, Building on Progress goes one step further for people who are caring for someone with a terminal illness, indicating that a care plan should be developed for the carer, taking account of their needs and ability to cope with the caring role. Holistic assessment of physical, emotional, social, and other relevant life circumstances with both carer and patient should be prevalent. NHS Scotland is also moving towards anticipatory care planning aimed at providing more continuous care and more support closer to home.

Carers do have a legal right to an assessment of their own needs, as distinct from the needs of the patient. Carer Support Plans are designed to reinforce a participatory and collaborative approach. The carer's assessment presents carers with an opportunity to discuss, with the social services department of their local authority, the support they need with caring and maintaining a balance between their caring role and other commitments, such as work and family.

Most local authorities offer emergency services that allow carers to register a contingency plan if they become too ill to cope or need urgent respite, which can help reduce carers' anxiety about getting sick or taking a break from their caring role.

Recommendations:

- Local authorities should do more to promote the support and emergency services that they offer which are designed to prevent carer breakdown.
 - When patients are placed on Palliative Care Registers, their carers should be automatically be offered a carer's assessment.
 - Carers can feel guilt and anxiety about being away from the person they are caring for, particularly in the last few weeks, where carer breakdown can lead to an emergency admission to hospital. This should be considered by health and social care professionals when planning respite breaks with carers.
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Chapter 3

Access to information and support

Getting the right information

The End of Life Care Strategy recognises that carers need access to high quality information about the illness that the person they are caring for has and what to look out for if they are going to carry ongoing responsibility for care. Indeed the *Carers Strategy for Scotland 2010–2015* emphasises the need for support by way of information provision and training opportunities as well as identifying a need for respite and will look at continued promotion of the awareness and understanding of unpaid carers across a range of services. This information is needed to help them plan their lives and to be prepared for the practical eventualities of caring for a person with a terminal illness.

Different carers will have different information needs. Some people interviewed in the research for Healthtalkonline felt that they had been given sufficient information by healthcare professionals, while others felt that they needed all the information they could get and sought it out from various sources.

The amount of information available at the point of diagnosis varied across the carers interviewed for Healthtalkonline. Some received leaflets about the condition the person they were caring for was diagnosed with and others had not. Some reported not understanding the terminology the doctor had used, and so looked up words on the internet. It was noted that using the internet in this way could be daunting, as there was so much information, not all of it reliable, and some frightening for both the carer and the patient.

Carers also wanted information about the practical and financial support available to them as a carer or someone approaching the end of life. Again, provision of this type of information was patchy: some carers felt that they had received enough from health and social care workers while others felt that they had received nothing useful.

The researchers found in some of the interviews that there was a clear mismatch between what the patient wanted to know and what it was important for the carer to know. One carer wanted only the minimum information about his wife's illness in order to avoid thinking of her as a patient. In some cases, the patient wanted little or no information, and this meant the carer putting their own information needs to one side.



While every patient and every carer will have different information needs, the experience of the carers interviewed for Healthtalkonline was that in some cases people are not getting access to basic information about diagnosis or being directed to further sources of information which they could then choose to investigate.

“ *It's difficult to know where to find out anything more about it. The leaflets or the booklets don't tell you an awful lot, even the mesothelioma site doesn't tell you an awful lot and they're all telling you about treatment and drugs and chemotherapy and radiotherapy. Nobody tells you what to expect if you're not having any treatment. So that's why the support from the Marie Curie Nurse is very helpful and I do think if I ask they may tell me, you know, what to expect next.* ”

Victoria couldn't find any information about how her husband would be affected by his rare cancer as it progressed, so she asked a Marie Curie Nurse.

Recommendations:

- Health and social care professionals should recognise that carers have varied information needs that are distinct from the people for whom they are caring.
 - Where carers want more information than patients about the process of dying and death, health and social care professionals should sensitively direct them to reliable sources of additional information.
 - Carers also need information about the practical support and financial benefits that are available to them. Carers should be presented with this information during an assessment of their support needs.
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Accessing financial support

When someone is diagnosed with a terminal illness, there are likely to be financial implications for the patient, as well as for carers and families. Carers might give up work to care for their friend or relative and may need to pay for care at home or in a care home. Research conducted by Carers UK in 2008 found that many carers were struggling to pay basic bills, with 52 per cent cutting back on buying food, 65 per cent in fuel poverty and 74 per cent struggling to pay essential utility bills; 55 per cent were in debt as a result of undertaking a caring role.

“ When you’ve got someone unwell at home, you’re spending all your time in the house. You’ve got the heating on. You’re running out buying x, y, z that they fancy for tea or x, y and z that they need for, you know, for personal care or, so yeah, it was a very expensive time actually. ”

Caring for her sister-in-law and her young niece was expensive. Katie was grateful that her husband earned enough to make it financially possible.

Carers of people at the end of life encounter similar financial pressures. Many of the carers who were interviewed felt fortunate to have savings, pensions, and critical illness cover so that they were able to take time off from work at full pay while undertaking their caring role. Without these funds, many felt they would not have coped financially.

There are several state benefits available to people who are terminally ill, including Disability Living Allowance and Attendance Allowance (for those over 65). Carers of people at the end of life may be eligible for Carer’s Allowance, Employment and Support Allowance (if they are also in ill health and unable to work), or Jobseeker’s Allowance (if looking for work while undertaking a caring role).

Many carers do not apply for the benefits to which they are entitled. The recent Ipsos MORI/Macmillan Cancer Support report¹⁴ on carers found that only one in 20 carers in the UK have had a carer’s assessment or receive Carer’s Allowance (5 per cent in both cases). Carers UK estimates that there are 300,000 people in the UK who are



¹⁴ Macmillan Cancer Support (2011). *More than a million: Understanding the UK’s carers of people with cancer – a report by Ipsos MORI for Macmillan Cancer Support.*

missing out on the financial support they are entitled to, amounting to £843 million in unclaimed Carer's Allowance every year.

For carers of people at the end of life, as well as the people they care for, the process of applying for benefits can often be too slow. The carers interviewed for Healthtalkonline described situations in which they received financial support late in a patient's illness, or even after the patient's death. Because a person at the end of life can deteriorate quickly, timely access to benefits and support is critical.

“ It came back as the middle rate, and I knew at the point at which it came back at the middle rate, that actually, he was no longer, his circumstances had changed and, actually, he was eligible for higher rate. So I then had to, not appeal, but then I had to do a change of circumstance form and we got the decision about the high rate DLA on the Saturday and he died on the Monday. ”

Jane's husband's Motor Neurone Disease progressed fast, and so he was entitled to a higher rate of Disability Living Allowance than they had initially applied for. He died two days after she received the correct decision about the funding.

Carers' financial difficulties often continue after the death of the person they care for, particularly where the carer used up savings or pension funds in order to undertake a caring role. Carers are able to claim Carer's Allowance for up to eight weeks after the death of the person they are caring for, but many will need financial advice on how to make ends meet over the longer term.

Recommendations:

- Many carers are not claiming the benefits and support they are entitled to due to lack of knowledge about which benefits they are eligible for. When a patient is registered on the end of life care register, information on the range of benefits available should be provided to the carer.
- Many carers find the claims process for benefits is too slow or confusing. Applications for benefits for people at the end of their life and their carers should be dealt with as quickly as possible.
- Support from social care workers makes a huge difference to carers of people at the end of life. Carers need access to personal care for the person they are caring for quickly. Local authorities should do their best to ensure that these applications are processed as swiftly as possible.

Chapter 4

Place of care and place of death

Home

Research on people's preferred place of death shows that most people say that they would prefer to die at home if they had a terminal illness. A sizeable minority would opt for hospice care if they had a terminal illness. The reality is that, in the UK, more than half of deaths still occur in hospital, the place people say they would least want to be.

Many of the carers interviewed for Healthtalkonline reported that the person that they were caring for had achieved their wish to die at home and many were comforted by the fact that they had helped the person they were caring for to die in the place of their choice. However, the carers acknowledged that the experience of caring for someone at home was hard, exhausting, and emotional.

“ You could feel it in her and it was the remarkable increase, again, in her spirits and that's all I can say. So, no, I had no hesitancy in agreeing, well, it wasn't agreeing, in saying: 'Yeah, you come home.' And, as it turned out, it was a wonderful development. ”

When Pat said she wanted to come home Keith didn't hesitate. Pat was a home bird and coming home raised her spirits.

The carers interviewed also presented a varied picture of the quality of care and support they received from external sources. The work of District Nurses provided by the NHS, in particular, received a mixed reaction, with some carers being very happy and others disappointed and even appalled. The carers pointed out that District Nurses were often limited to treating the medical needs of the patient, and could be abrupt or impatient because they were short of time. Other carers felt that their District Nurse provided a great deal of emotional support.



Marie Curie and Macmillan Nurses were highly valued by carers, who appreciated their ability to provide wide-ranging advice and support. While Marie Curie Nurses care for people in the last few weeks of their lives, regardless of their diagnosis, Macmillan Nurses care for people with cancer from when they are diagnosed. Macmillan Nurses spend up to an hour in a person's home providing advice on pain management and symptom control together with emotional support. Marie Curie Nurses spend several hours providing practical nursing care and emotional support, often overnight. Many of the carers said that Marie Curie and Macmillan Nurses cared as much for the carer as the person at the end of their life.

“ *At times like that, you stop being able to function properly and make decisions. So it helped to have someone around who could help me do what I wanted to do. Our nurse made the whole process more straightforward. The whole thing would've been much more stressful without her.* ”

When her mother died, Fiona was relieved that a Marie Curie Nurse was there to help her make decisions.

Where carers brought professional social care workers into the home, either through the local authority social services or through private care agencies, there was variability in the quality of care. Some reported being happy with the standard of care they and the person they were caring for received, while others struggled to find a social care worker who was reliable. A frequent complaint was that professional care workers were often late, which made it difficult for carers and families to plan respite time together.

Where carers were unable to cope with providing care at home, hospice was seen by some as the next best option. Admission to hospital was usually resisted by those carers presented with this choice. For some people at the end of life, home was also not their preferred place of death. They usually opted instead for care in a hospice. Whether or not a patient has the choice to die in a hospice varies greatly across the UK. In the 20 per cent of English local authorities with the lowest hospice death rate, between 0 per cent and 3 per cent of people die in a hospice. In the 20 per cent with the highest hospice death rate, between 7 per cent and 13 per cent of people die in a hospice¹⁵.

Hospice

Hospices were frequently used by carers and the people they were caring for to provide respite for the carer. Following this experience, some made the decision to move care of the patient to the hospice indefinitely.

Hospices are often viewed as a place to die, but many hospices offer a range of services for patients, carers, and families, ranging from complementary therapies, respite, financial advice, and practical support.

Hospices were held in high regard by the carers interviewed for Healthtalkonline, who were usually impressed by the attentiveness of staff, the environment, the relaxed atmosphere and the range of activities and therapies available. However, there were reported disadvantages, including extensive travelling and patients becoming upset by the deaths of others around them.

¹⁵ www.endoflifecare-intelligence.org.uk/profiles/2/Place_of_Death/atlas.html

“ My mother said to me: ‘You know, I want to go to the hospice’. I felt relieved and I felt that she felt relieved - like she felt like she was going home. I think she knew at that stage that the amount of care that she was going to get, she would get it from the hospice. ”

Saba’s mother chose to go to a hospice where she had received good care before. Saba was relieved and thinks her mother would have felt it was like “she was going home”.

Hospital

Some carers interviewed for Healthtalkonline felt that care in hospital at the end of life was often focused on prolonging and enhancing life rather than understanding terminal illness and respecting people's wishes to let death take its natural course.

Emergency admissions can lead to the patient dying in hospital rather than at home or in a hospice as planned. Emergency admissions were sometimes traumatic, especially if carers and patients encountered long waiting times, as well as poor treatment and personal care. Carers also reported heightened levels of anxiety if they were aware the person they were caring for could die while admitted to hospital. For others the news that the death was likely to be soon came as a shock.

On the whole, carers reported negative experiences of deaths in hospital. They highlighted that staff at hospitals were often focused on treatment, rather than controlling symptoms or pain management, and that they had a poor understanding of the needs of carers of someone with a terminal illness. Inflexible visiting hours were cited as an example of this, though some carers managed to negotiate visits outside approved times.

“ She was then put in touch with the staff at the other hospital and again, she didn’t have an issue with the care but she felt that it was a little bit too focused on, ‘We want to make you better come what may’. Or, ‘We want to treat you the best way we know how regardless of how you may be reacting to it.’ ”

Janet felt the hospital care was too focused on achieving a good medical outcome rather than controlling Chris’s symptoms.

Achieving preferred place of death

What is striking about the issues raised by carers interviewed for Healthtalkonline about place of death is that while achieving the patient's preference for place of death was important, so was the quality of care received. No setting was without challenges for both carers and the person they were caring for.

While most people would prefer to die at home, most of the carers pointed out that the

experience was hard, emotional and exhausting for them. Many had difficulty accessing support from District Nurses, palliative care nurses and professional care workers. When they did, there were concerns about the quality of care they received, particularly from District Nurses and professional care workers. Supporting more people to die at home necessarily involves making sure that the people who care for them are able to access the right kind of support.

In hospital, carers found that staff were frequently focussed on treatment of a patient's condition rather than controlling symptoms or providing pain management. The Liverpool Care Pathway is designed to transfer the best quality of care for patients at the end of life from the hospice movement into other clinical areas, such as hospitals¹⁶. One carer interviewed for Healthtalkonline reported that hospital staff were urging her husband to continue with radiotherapy and that he had to decline treatment twice. It was agreed that he could be moved to a hospice, but his condition deteriorated to the point that he was too ill to move. The carer was relieved when, after a team meeting, her husband was put onto the Liverpool Care Pathway.

Recommendations:

- The majority of people in the UK would like to be cared for and die at home, but it should be recognised that home death is often hard on carers. Health and social care workers should sensitively help carers understand the degree of commitment required to care for someone at home.
 - Many people in the UK still die in hospital. Hospital staff should be sensitive to patient and carer wishes around treatment and pain and symptom control and respond to these quickly. Hospital staff should be prepared to initiate discussions with carers and patients about putting the patient onto the Liverpool Care Pathway, where appropriate.
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¹⁶ <http://www.mcpcil.org.uk/liverpool-care-pathway/>

Chapter 5

Bereavement

Practical things after death

Memories of the actual moment of death can stay with carers forever, particularly if it was not as they had hoped, and many do not have any practical idea of what to expect in that moment. Some find comfort in the fact that they were able to be with the patient when they died, although for some it was the first time they had seen a dead body.

After death, many decisions and arrangements must be made, which can be difficult for carers in a time of grief. These include registering the death, settling the deceased's estate and making arrangements for a funeral. Financial worries for carers during this period can be acute.

“ Everything to do with death is about money, whether there's money in the pot for you to have a carer, whether you've got money to pay for the funeral, whether you've got money to do this and yeah, it all revolves around money I'm afraid. The only people that seem to get rich are the funeral directors. ”

Lynne was angry that the funeral directors expected payment so quickly after her mother's funeral and was delaying burying the ashes because of the costs involved.

Carers interviewed for Healthtalkonline reported that their experiences after the death of the patient were very emotional and sometimes unsettling. Some had difficulty covering funeral costs, but others were happy to be able to plan the funeral the person they were caring for wanted.



Bereavement support

People express grief differently and the amount of time it lasts can vary enormously. For patients who were ill for a long time, often much of the grieving is done while the patient is still alive. One carer interviewed said that end of life care was more like a series of 'mini bereavements'.

Many carers of people at the end of life experience loneliness after the death of the person they were caring for. Carers build a daily routine around their caring role, and when it stops they often find they have extra time. Visits from nurses and others who provided support stop. One carer interviewed for Healthtalkonline even commented on the sudden absence of noise from medical machines.

“ I missed them. I really missed them because I just didn't see them. I see one of them up at the pool and we, you know, we have a chat now and again. But you're a patient. You're the wife of a patient and they've got loads of other patients so obviously, they move on to the next person but it was so quiet when Bill had died and my son had gone. Nobody dashing in at nine o'clock and half past to wash him and see to him. No care manager ringing. No Macmillan Nurse coming in and I really missed them all. It was just very, very strange I think that's quite a common thing. ”

Heather found the house seemed very quiet after her husband died. Not only did she miss the nurses calling in but also the regular phone calls from the care manager.

Carers also reported varied responses to bereavement counselling. Some found it helpful, while others found it did not work for them. One carer reported that she was unable to attend counselling sessions because they were only offered during working hours. For some carers, bereavement counselling prior to the death of the patient may be useful. Marie Curie Hospices offer this to carers and families, with access to bereavement counselling available up to a year after the death of the patient.

Recommendations:

- Carers of people with a terminal illness experience grief differently, sometimes before the death of the patient. Services for helping people with their bereavement should be flexible and allow carers of people with a terminal illness to use these services when they are needed by the carer, both before and after the death of the patient.
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Chapter 6

Conclusion

All of the carers interviewed by Healthtalkonline and those who have come into contact with Marie Curie Cancer Care have had unique journeys in their caring role. They have different requirements for information and practical support, and their relationships with the person they are caring for are individual and diverse.

What we do know from our experience as a provider of high quality palliative and end of life care is that the needs of carers of people at the end of life are best met when they are supported by health and social care workers to understand that they are undertaking a caring role. We think that when carers understand themselves as carers then they are best able to articulate their needs and preferences.

We know that caring for someone at the end of life is hard for carers and frequently exhausting. We know many of these carers will face breakdowns in their mental and physical wellbeing and will have to confront negative emotions. But we also know that with the proper support carers can have the best possible experience of caring and work through their bereavement. We think that for many carers undertaking a caring role can have positive outcomes.

Chapter 7

Summary of recommendations

- Carers of people at the end of life need to be supported to identify themselves as carers. Health and social care professionals should have conversations with carers about what a patient's diagnosis will mean for the carer at the point of diagnosis, and be prepared to revisit these conversations as the patient's condition progresses.
- Health and social care professionals need additional support and training to help them identify carers of people at the end of life.
- Health and social care professionals should ensure that carers are included in conversations with the patient about their condition so that they feel as though they are part of an expert care team.
- Local authorities should do more to promote the support and emergency services that they offer which are designed to prevent carer breakdown.
- When patients are placed on Palliative Care Registers, their carers should be automatically be offered a carer's assessment.
- Carers can feel guilt and anxiety about being away from the person they are caring for, particularly in the last few weeks, where carer breakdown can lead to an emergency admission to hospital. This should be considered by health and social care professionals when planning respite breaks with carers.
- Health and social care professionals should recognise that carers have varied information needs that are distinct from the people for whom they are caring.
- Where carers want more information than patients about the process of dying and death, health and social care professionals should sensitively direct them to reliable sources of additional information.
- Carers also need information about the practical support and financial benefits that are available to them. Carers should be presented with this information during an assessment of their support needs.
- Many carers are not claiming the benefits and support they are entitled to due to lack of knowledge about which benefits they are eligible for. When a patient is registered on the end of life care register, information on the range of benefits available should be provided to the carer.
- Many carers find the claims process for benefits is too slow or confusing. Applications for benefits for people at the end of their life and their carers should be dealt with as quickly as possible.
- Support from social care workers makes a huge difference to carers of people at the end of life. Carers need access to personal care for the person they are caring for quickly. Local authorities should do their best to ensure that these applications are processed as swiftly as possible.

- The majority of people in the UK would like to be cared for and die at home, but it should be recognised that home death is often hard on carers. Health and social care workers should sensitively help carers understand the degree of commitment required to care for someone at home.
- Many people in the UK still die in hospital. Hospital staff should be sensitive to patient and carer wishes around treatment and pain and symptom control and respond to these quickly. Hospital staff should be prepared to initiate discussions with carers and patients about putting the patient onto the Liverpool Care Pathway, where appropriate.
- Carers of people with a terminal illness experience grief differently, sometimes before the death of the patient. Services for helping people with their bereavement should be flexible and allow carers of people with a terminal illness to use these services when they are needed by the carer, both before and after the death of the patient.

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Marie Curie Cancer Care provides high quality nursing, totally free, to give people with terminal cancer and other illnesses the choice of dying at home, supported by their families.

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