

Difficult conversations with dying people and their families

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Introduction

Marie Curie Cancer Care is a leading provider of care and support for terminally ill people and their families, and reaches more than 38,000 people each year. This care is provided through the Marie Curie Nursing Service and our nine hospices across the UK. We also campaign to improve the quality of end of life care for all, regardless of diagnosis, location or other factors.

We believe the type of care available should be based on what individuals and their families need, rather than what works best – or is easiest – for the health and social care system to provide. For this reason, we have worked with Oxford Strategic Management (an independent research organisation) to talk to terminally ill people, their carers and their families about the type of services they and their loved ones used in the last few weeks and months of life, and what gaps exist in the care they received. In some instances we spoke directly to people who were dying, while in others, to bereaved family members and carers. The nature of these 'difficult conversations' meant the research had to be handled with care, and with support provided to those who needed additional assistance.

The overriding goal of all who contributed to this project was the desire to improve care and support for other terminally ill people and their families. They wanted the good and bad experiences of care they experienced to help shape the care available to others in a similar position in the future. The clear wish was to see the quality of care available to terminally ill people improve across all care settings.

Our ageing population, together with ongoing, long-term financial constraints across the health and social care sectors, mean we must face up to the challenge of providing care for more people over the coming decades, with less money. It is often overlooked that an aging society means more deaths and an increased need for the services that terminally ill people require.

It is essential that, as we face the twin challenge of demographic and financial pressures, we configure and deliver services in a way that works for terminally people, their families and their carers. Now is the right moment to take stock to enable us to prepare for the major changes which will take place over coming decades. It is vital that we learn from terminally ill people, their families and carers about what currently works and what does not. By speaking directly to those who have received or witnessed care in different settings (in their own homes, care homes, hospices and hospitals), we will gain a better understanding of what services are like and how they impact upon those who use them. This will help ensure that the care we deliver in future is genuinely built around the needs and wants of terminally ill people, and those around them.

The research approach

Research objectives and purpose

We placed terminally ill people and their families at the heart of the development and design of our research in order to:

- gain a deeper insight into the needs of terminally ill people and their non-professional carers, including their practical, physical, emotional and spiritual needs, and the extent to which they are met
- understand experiences across the journey from diagnosis to death
- consider (retrospectively via carers) how the needs of the terminally person (and their own needs) changed over time, and understand the experiences and needs of carers in the immediate period following the death of their loved one

Insights from this qualitative research provide a very human dimension to help:

- develop a 'journey map' of end of life experiences which focuses on needs both met and unmet
- identify services, products and information terminally ill people and their families have found or might find helpful at different stages post-diagnosis, and whether these differ by disease types
- identify powerful individual stories and anecdotes which give a deeper understanding of the experience and what might be done to make it a more positive one for all concerned

Method and sample

The research adopted an ethnographic approach which places a strong emphasis on gathering qualitative data in order to initiate the telling of personal stories in the form of a conversation. These conversations have then been used to form a narrative which is driven by the subjects covered, points of view expressed by interviewees and built around their own words. At the heart of these conversations were a series of face-to-face and telephone interviews. The length of interviews varied depending on the preferences of the interviewee and the type of interview used.

Interviews lasted between 75 minutes for phone interviews to over three hours in a small number of cases for face-to-face interviews. Face-to-face interviews were recorded (with permission) and transcribed, whilst extensive notes were taken for telephone interviews to aid the report-writing process. In total, 26 conversations were held with people who were terminally ill, and with current and bereaved carers.

The aim at the beginning of the project was to recruit terminally ill people, and current carers of people with a terminal diagnosis. Initially, for the purposes of the study we sought to focus on those with a terminal diagnosis who were 'not expected to live beyond the next 12 months'. However, whilst recruitment of those with a 'terminal diagnosis' was relatively straightforward, the difficulties in putting a time frame on diagnosis, and unexpected events, meant that identifying those who were 'not expected to live beyond 12 months' was difficult to achieve in practice. For example, a person with chronic obstructive pulmonary disease (COPD) had been given the news that she was at 'end stage' (meaning 'nothing more can be done medically, with palliative treatments only') seven years ago, whilst a person with cancer had been told that they had exhausted all available treatments, including new, experimental options, leaving her to estimate the likely timeframe.

Thus, the sample achieved was based on the following:

- Terminally ill people had all been given a terminal diagnosis – meaning that the only treatment available was palliative care.
- Current carers interviewed were all looking after a relative or partner who had been given a terminal diagnosis (as above).
- Bereaved carers had all looked after a partner or close relative who had died within the past year or so.
- The terminally ill people had a range of different terminal conditions and in some instances multiple conditions. The majority were people with cancer.

The sample was as follows:

Terminally ill people	8
Current carers	4
Bereaved carers	14
Total	26

In total, 13 interviewees were recruited through external organisations, personal contacts, and/or by asking those contacts to suggest other potential participants; the remainder were recruited through Marie Curie Cancer Care and the National Council for Palliative Care (NCPC).

Each participant is identified throughout this report by their status (terminally ill person/carer/ bereaved carer and the disease/condition. Further anonymised details of the participants are set out in Appendix 1.

The ideal: a good death

Overview

A 'good death' is a term frequently used in policy documents and by professionals involved in end of life care. However, in this research, it was an expression only used or recognised by a few participants who were actively engaged with NCPC, the Dying Matters coalition, or who were aware of debates about the use of the Liverpool Care Pathway. Nevertheless, there is an implicit understanding of what a 'good death' could mean.

A good death is usually associated with:

- being pain-free – pain control on tap, administered by experts
- being peaceful and calm, with those chosen by the terminally ill person present and not alone
- having the role and emotional needs of carers (and wider family) recognised and respected.
- a feeling of control over the process (for the terminally ill person and family)
- a private space for family being available
- being in a hospice (for some)
- being at home (for some)
- knowing what to expect, and who does what
- being able to summon help 24/7
- an appropriate level of physical and personal care that respects dignity
- individuals accepting their diagnosis and being at peace

Conversely, a 'bad death' is associated with:

- poor or inadequate pain relief, administered by healthcare professionals not used to dealing with death
- chaos
- being alone
- carers being excluded from decisions, family kept in the dark, procedures not explained
- lack of feeling of control
- lack of private space / privacy and dignity
- being in hospital (and at worst A&E)
- a confusing and changing cast of healthcare professionals sweeping in and out of the process,

- with nights a particular source of concern
- inadequate physical and personal care that reduces dignity
- person still in denial – or other negative state

Awareness of what is meant by a 'good death'

Not surprisingly, the idea of planning a 'good death', or even planning one's own or a close relative's death was not a concept familiar to most of our participants. This level of acceptance of the reality of death by the individual was seen as the exception, rather than the rule:

"My mother-in-law, after the diagnosis in hospital, decided she didn't want to have any chemotherapy. She didn't want to go into a hospital, to see anybody at [the hospital]. She wanted to come home and take her chances and that was her choice. ... My mother-in-law took it to the extreme. She closed her bank accounts down and narrowed it down to one. She got rid of all her credit cards and things. She'd labelled ornaments, given me letters to post. She'd put everything in one place for me. She'd made all her own funeral arrangements... after a period of being really upset in hospital, just a couple of weeks, (she) decided to deal with it."

(Current carer – mother with pulmonary fibrosis)

The concept was really only understood and accepted by those involved with Dying Matters and NCPC, a minority in our sample. Even those who see planning a 'good death' as an important thing to do find it very difficult to talk about their death to their family:

"It must have been after the last time I was resuscitated – I'd had a bad night and my cousin had died recently, and so the next day I had a talk with M about it. I discussed it with him and said it wasn't fair on the family to have to make the decision, so then we sat down as a family and I explained to D and A what I wanted... It's the worst thing I've ever had to do – it was terrible and I felt terrible. I told my mum and dad too, that was before their dementia really kicked in and they were very upset, especially my dad."
(Terminally ill person with COPD)

For some, support for the notion of a good death has been prompted or reinforced by anecdotes or experiences of 'a bad death', and many respondents had an anecdote where the final hours were undignified, painful or chaotic. Any experience or awareness of what a 'bad death' might involve helped define the conditions of a 'good death' and prompted people towards a more proactive approach to management of their own death.

For most of our participants, plans around death tended to be vague. Individuals (those interviewed and those discussed by current and bereaved carers) usually want to focus on and just talk about life, and avoid any specific reference to their own death, making it quite clear in body language and tone of voice that this topic crossed a line. This was particularly apparent amongst those with a very positive attitude, and determined to hang on to life.

"I'm never a patient unless I'm in the hospital. I never feel like a patient and I don't want to be treated like one either. I dread being physically disabled in some way and everybody going, 'Oh the poor thing'. But in the meantime I just try and be as normal and carry on, that's being positive. I haven't got my head in the sand."
(Person with cancer)

Carers described a general idea of what they hoped would happen, sometimes having established a relationship with a hospice with the vague idea that this would be the ideal for the individual, but had not discussed a specific plan as such with their loved one. There was also a feeling that nature should be allowed to take its course, with the idea of 'planning' (where introduced by healthcare professionals) somehow imposing an unnatural control over the process, 'playing God', interfering with destiny.

The principles of a good death

Although there was little conscious awareness of the concept of a 'good death', there was an implicit understanding of what it would involve in the general ideal of a calm, peaceful, pain-free death in pleasant and private surroundings – with care from a team who were already familiar to the individual and their family.

Although dying at home was often the preference for some individuals and carers, for many we talked to, this ideal was exemplified by the local hospice. Several individuals and carers had started to build a relationship with the local hospice from an earlier stage (post-diagnosis), using it as a resource for various kinds of advice and support, as well as equipment. This was done to ensure continuity of care, and ultimately an experience that could be described as a 'good death' (although this phrase was rarely used by participants).

The holistic approach of the hospice was especially commented on and appreciated in the context of the complexity of emotional, spiritual, physical and medical needs. In our conversations there was frequent reference to the consideration (and inclusion) of the needs of the whole family group (eg counselling and other support for carers), willingness to become involved early on in the process post-diagnosis (and not just being there for the last few days), and the offer of what seemed to be an ideal combination of empathy and practical help throughout (advice, counselling, complementary therapies, day care, respite care, equipment, medication).

"I always said when I die I don't want to die at home, I want to die, if possible, in a hospice. I don't want to put on anybody the burden of having to look after me at home, and I think if I can go to a hospice if there is a place then... I'd be much happier."
(Person with cancer)

In some instances this support extended into bereavement.

"I'm very lucky, I have bereavement counselling once a week and I found that a huge, huge support, that is amazing. I've been having that now nearly six months... the hospice provides a group for us bereaved. There's a group of people who have lost their husbands and partners, and we meet once a month at the hospice just for chats and practical stuff because we're all in this together and we've all had different practical issues – and then we try and go out once a month as a social group, to do something fun."
(Bereaved carer – husband with cancer)

Some had achieved their ideal, either dying at home with appropriate levels of pain relief, surrounded by their family – or at the local hospice, with the individual in a peaceful or accepting frame of mind:

"We carried her from the bedroom downstairs to the family room where we had a hospital bed in the daytime but when she was not conscious. Even so we were all just around there with her. ... We had our daughter here, she was in that living room which is where we watch TV and make our meals and read our newspapers all the time, every morning you brought her down here, we carried her there and when she was sitting in chairs, we made her as comfortable as possible and eventually we had the hospital bed in there because we felt, and I'm sure this was right, that she just wanted that towards the end. I'm not sure she was conscious yet but maybe

she just wants to hear mum having a tiff with my brother about something or mum and dad having a laugh about something. The TV is on. Those noises I think are comforting noises of family around all the time."
(Bereaved carer – daughter with cancer)

Achieving a good death can be thwarted by unforeseen developments

In some instances, the ideal was not achieved (or will not be) because circumstances had taken over, with no beds available in the hospice, individuals deteriorating more quickly than expected, or finding themselves in hospital for acute infections or other procedures:

"We had a lot of equipment delivered to the house but unfortunately he was too sick. And then they offered to bring him to the hospice here on the Tuesday, they said there was a bed ready for him, and they said sorry he's too ill to move and he was dead the next day. So it all went a bit wrong if you know what I mean."
(Bereaved carer – husband with cancer)

This idea of someone being too sick to move is a common one, with individuals having to stay where they are, regardless of previously stated preferences or planning, because of a rapid deterioration in their condition:

"So he was admitted to [the hospital] and had his radiotherapy because he needed it. But after the third day of radiotherapy they said, 'He's just going, we're losing him. There's no point in having any radiotherapy, it's too late for him to go to the hospice as well.' They just couldn't move him and he died shortly after."
(Bereaved carer – partner with cancer)

This underlines the reality of dealing with death and dying – that no matter what an individual or their family wants or plans, there are never any guarantees.

The journey

Overview

When faced with a terminal diagnosis, every individual and family begins their own journey towards the end of life. This journey varies according to the conditions, circumstances and the people involved. The journey is a physical, emotional and practical one, encompassing diverse needs which change over time, often in unexpected ways or at short notice. However, these different journeys tend to converge at the very end of life, with common experiences shared by people regardless of condition or settings. Not meeting important needs can make this journey and the period that follows more distressing than it needs to be.

There is no single journey

Our conversations with terminally ill people, carers and bereaved families reveal many types of journey, depending on type of illness, age, level of family support, financial circumstances, geography and –equally importantly – personality and individual coping strategies. This concept of the journey is important because it indicates the changing nature of experiences and needs between diagnosis and death. While journeys may differ, a number of common themes emerge:

- The needs of individuals and carers change as they progress through their journey.
- There are perceived differences between people with cancer and non-cancer diagnoses in terms of the pattern and flow of practical, physical and medical needs.
- The ability to cope with the diagnosis and the journey involves a set of changing emotional needs that may or may not be met, depending on personality, circumstance and beliefs.
- The ability to cope with the journey can depend on getting the right level of physical support, both medical and non-medical, as physical needs change and pain increases.
- Changes are not always anticipated, and plans need to be able to adapt as the illness progresses.
- The continuing needs of carers after death.

We now explore these issues in greater detail.

Differences in the journeys towards end of life – cancer and non-cancer diagnoses

For people with cancer and their carers, the journey is perceived to be very up and down, with periods of debilitating and exhausting treatment (such as chemotherapy) requiring fairly extensive physical and practical care from relatives. This includes accompanying him or her on trips to hospital, and support as they recover from the effects of their treatment. There are alternating periods of optimism, hope and relative 'wellness' where the individual can resume a fairly normal, independent and active day-to-day existence, and in many instances look after their own physical needs. During these 'normal' interludes, the role of carer may be reduced to emotional support for visits to the oncologist. Availability of new and experimental treatments for some forms of cancer means that the cycle of ups and downs can be repeated and prolonged, encouraging bouts of optimism among individuals and carers:

"He was really poorly to start with. As soon as he had some chemotherapy it was amazing. He really started to feel well apart from the side effects of course. But the treatments were incredible... he was very ill for about four weeks and then slowly he started to recover..."

(Bereaved carer – partner with cancer)

The final stage requiring high levels of physical and medical care, with special beds, other equipment and regular visits from healthcare professionals etc, is often relatively short – possibly a matter of a few months, weeks, or even days before death. At this point, there is a much heavier and more intense burden on family carers in terms of nursing care, management and administration of drugs and medical procedures, taking over personal care and hygiene, ensuring comfort, and possibly helping with feeding and drinking:

"The intense period didn't last that long... In December and January (two months before she died) she was then saying, 'I don't want to be looked after', but she then had symptoms. She started having difficulty walking and things like that but she didn't need care, she was still able to shower and dress herself and things like that. I would say therefore that period when we really... when she could no longer quite take care of her own hygiene was mainly six or eight weeks, probably eight weeks – not more."

(Bereaved carer – daughter with cancer)

The up and down nature of cancer is illustrated by a bereaved carer:

"Cancer is like playing snakes and ladders. There's the snake when you find out, then you go up and down and then the biggest snake of all when you find out the options have run out."

(Bereaved carer – daughter with cancer)

For people with degenerative conditions like COPD, Motor Neurone Disease (MND), Multiple Sclerosis (MS) and dementia, the journey may be longer, with the ups and downs of the condition leading to uncertainties. These conditions may start with what seem to be minor but niggling physical symptoms, and may take a long time to diagnose, with months or possibly years of tests. A person with MS reported a period of 14 years from experience of the very first symptoms to eventual diagnosis, with more defined and debilitating symptoms and tests lasting over a period of 10 years to reach a final diagnosis. Recall of chronology for some is more 'fuzzy', but the general pattern is gradual decline as symptoms get worse until another milestone is reached – a step down marked by a further loss of function.

Families report a very drawn-out period (several years) of increasing physical disability, with escalating physical and practical needs eg specialist equipment and aids to mobility, a daily rota of professional carers to help with personal care, lifting in and out of bed, dressing, and, in some instances, with feeding and drinking

– in addition to whatever level of physical and practical care family carers feel able to provide. Opportunistic infections, including pressure sores, urinary tract infections (UTIs) and similar conditions become an increasingly common and life-threatening occurrence, adding to everyday medical needs.

One person with MS was formally diagnosed in 1994-95; having first noticed the symptoms a decade earlier, they chart the progression of the condition:

"Then I would say slowly over time I noticed... it was mainly in my legs and not on my arms and hands, at that point. Then really I would say from there it's just progressed quite aggressively to the point of affecting my hands. I'm unable to feed myself or drink and then problems with urinary tract infections and things like that. The need for catheterisation... so unfortunately it's definitely progressed quite aggressively in the last 10 years. I've just had eight days in hospital in February with a UTI and I must say the time I spent in the hospital was very difficult and it's always, 'Is this the one that's going to get me?' ie the infection."

(Terminally ill person with MS)

This gradual decline in physical ability is echoed in respect of COPD:

"I've had lung problems all my life. I've got bronchiectasis as well as severe chronic asthma. As a child I was very chesty.. I was told I was end stage 15 years ago... I'm finding it hard, very hard, even to the extent if I prepare a meal I haven't got the energy to eat it when I've prepared it. I'm just too tired. I'm tending to live on soups now anyway because I'm finding it harder and harder to swallow. It gets stuck in my throat and I choke and I get worn out eating..."

(Terminally ill person with COPD)

Whilst the journeys towards the end of life differ,

this research suggests that they are likely to converge in the very final stage of life in which round-the-clock care, nursing, personal care and symptom/pain relief are likely to be necessary. We explore what this means for end of life care at a later point in this report.

Coming to terms with a terminal diagnosis

One of the most marked differences between terminally ill people interviewed was the quality of their emotional outlook, level of engagement with the life they still had (irrespective of levels of disability/mobility), and the extent to which this was reflected in acknowledgement of the reality of their illness. This could be summed up as learning to live with a terminal diagnosis (ultimately acceptance), versus battling against the inevitable (depression and denial). Some individuals had managed to find their own way of creating a more positive emotional journey, and a way of coping through dint of personality and sheer determination:

"He was OK with it. He was a very practical person. He accepted it. Even before he was diagnosed in the beginning he said, 'I know there's something very wrong' and when it was diagnosed the first time he was very, very practical about it. I'd have been upset... but he wasn't; he was very practical and he said, 'I've had a good life' and that's how he was. He just accepted it."

(Bereaved carer – husband with cancer)

For others, however, it had only been achieved through some kind of process, eg self or group reflection through counselling (professional counsellors provided in hospices and local centres or via GPs, religious advisors, spiritual healing or religious guidance). Proactive involvement with locally organised groups around specific diseases (eg local multiple myeloma group, or MS Society group), or National Council for Palliative Care (NCPC), had also provided inspiration or support for radical reappraisal of perspective on prognosis – and indeed on life:

"I think the people, the individuals, the organisation, what it stands for is a real arm around my shoulder to walk me

through at my pace, the different and the difficult issues, from basic stuff in terms of funeral wishes and Will-writing to the emotional stuff. We're talking about how you're feeling – which is constantly changing anyway, but I think they've been the anchor, the NCPC, Dying Matters coalition, and have been and still are a very, very strong anchor for me. They helped me enter that area of my being that was comfortable to talk about these issues. I felt safe that these people kind of get where I'm coming from and will let me explore things that I haven't worked out for myself."

(Terminally ill person with MS)

However, taking this step to seek emotional support was not always easy, and did not necessarily come naturally to those who had done so:

"So I went to that (patient information day run by Myeloma UK) and I met the person who runs the local group. Like everybody I thought, 'Groups ... that's not exactly my type of thing. Do I really want to sit around talking about cancer?' But actually we sit and have a glass of wine... Hadn't crossed my mind. I think when I first heard about this particular support group I was still in remission and there was nothing really to worry about. Of course there was, but you know what I mean. It wasn't something I needed to go and get off my chest."

(Terminally ill person with cancer)

Joining groups of people with a shared condition, whilst helpful to some, also had the downside of coming face to face with more advanced stages, confronting the future, or being negatively affected by others in the group, making it difficult to sustain involvement or to feel that it was of benefit:

"I didn't belong in terms of what I felt like age-wise, disability-wise, because I was still walking – and so what I saw was lots of people in wheelchairs, lots of people over the age of 50 or 60 and I was twenty

something. And also I didn't see anybody from a different ethnicity, so it was predominantly white, predominantly male, 50s and 60s and I just couldn't... in some ways I left feeling more isolated, more kind of confused is probably the word."
(Terminally ill person with MS)

"My fears [are] for what's going to happen to me when the disease progresses and I'm terrified of losing my dignity and I'm absolutely terrified of that. But I felt then I need to get going and be positive and I started to again do things in the garden. I thought I'd never see the garden again and I've always loved my garden ... so I then started to feel more positive...".
(Terminally ill person with cancer)

For others, support came through other local groups and support networks:

"Initially I didn't want to get out of the house, that was really after my husband died as well, and I just sat here and they dragged me out and started to take me to wonderful little church groups and art and craft groups and we go now, four of us, to a flower demonstration thing once a month. Tonight I'm going with one of my neighbours to the cinema here, the local cinema and everybody they've all rallied round me. There came that time where, with the help of people around, I started to go out more and to just generally be positive because I felt better in myself, I started to go swimming again which is very good for my back. So I started going out, go round walking a bit if I can... Everything is a bit of an effort for me but it doesn't worry me so much anymore. In myself, I'm doing alright and I feel now I have just accepted my situation. I have accepted that I have got terminal cancer that can't be cured."
(Terminally ill person with cancer)

By adopting a more positive and accepting approach, some of the terminally people we interviewed (especially amongst those with cancer) perceived themselves to be continuing to lead relatively full, 'normal', independent and active lives, determined to hold on to and enjoy the life they currently had for as long as they could, accepting that it might be a different life from the one they used to have. They were equally aware of the need to avoid negative emotions.

Those with degenerative conditions such as MS or COPD who had good emotional support and physical care also remained positively engaged in life in whatever way they could, including volunteering to help others, despite (often) high levels of physical disability. Being active, continuing to work, remaining part of society was seen as an affirmation of self-worth as well as life:

"My work keeps me going ... and I think that's what quite honestly keeps me alive... On a Friday I go over and look after my parents as they both have dementia. They've both got advanced vascular dementia so I go to the home where they are and spend the afternoon and look after them, feed them and do things with them and I also do a craft group over there once a month as well for the other dementia patients. Because while I'm doing it with Mum and Dad, I might as well be doing it with everybody else and help them, really just to help stimulate the brain. Two times a month I read a story to them and I end up usually with four or five people who I end up in a room looking after but that's OK, I don't mind that because I still feel I'm of some use. That's important to me and that's what bobs me along."
(Person with COPD)

Bereaved carers sometimes turned to counselling post-bereavement, having found it difficult to cope with grief and the emotional after-effects of caring. This process sometimes leads carers to look back and think that counselling might have been beneficial at an earlier stage to help achieve an emotionally healthier approach to their role, and understanding of its toll on their mental and

physical health. However, as some commented, the priority and focus during this period is looking after the terminally ill person, and some carers find it difficult to find the time to go to counselling themselves:

"Frankly, I'm not sure I had time for it. It was an express train... However now... I do think it is useful to be able to pick up the phone and talk to someone who has been through it – it might only be a quick chat. You haven't got time to leave the house or for long conversations."

(Bereaved carer – wife with cancer)

When is the 'end of life'?

Most people who talked to us wanted to talk about support for 'end of life' in its broadest sense of living with a terminal disease, and quality of life through this stage – rather than the moment of death and final stages of dying (although the recently bereaved also felt it important that their loved one died in the place and the manner that they wished, free from pain). Although current carers were more obviously thinking ahead to how they would cope at later stages, and about death, the subject of care and support tended to focus on more immediate needs around making the best of their remaining time with their families rather than issues relating to the end of life.

There was need for some kind of continuity in care and support from terminal diagnosis to the final few days. For some, developing a relationship with the local hospice post-diagnosis is one way to do this. For those choosing to die at home, it is a little more challenging to achieve. However, one of the unsettling features of current end of life care for carers and family members is the dramatic change in the care team at the point when death is imminent. Even if this has been planned and negotiated with the individuals and family, the moment when a new team with unfamiliar faces sweeps in, takes over and sets up specialist equipment is a shock.

Denial

A striking factor in many of our conversations was the extent of denial, either for the person or family. Unlike those who discussed their condition, others had remained in denial until the very end, creating an additional emotional burden for themselves as well as their carers (and family) both before and after death:

"He refused to accept he had this (pancreatic cancer). He refused to acknowledge it. He was never going to die, hence the situation we're in now. He was in complete denial, complete denial. He thought they'd find a cure and he'd planned that's what would happen – something he found in America. He'd sold shares. He thought he'd go there and be cured and we would live our lives and that would be it."

(Bereaved carer – husband with cancer)

Clearly, awareness of, and receptivity to, the idea that there is a parallel emotional path to the more obvious medical and physical journey is an important first step for some people in seeking psychological and emotional (and non-medical) interventions. An equally important second step is a belief that professional counselling or other types of non-medical support can make a significant impact on the trajectory of the emotional element of the journey.

Some of those we talked to (both terminally ill people and carers) dismissed or down-played emotional support, other than what they might expect from the family. Even with family members, they would remain 'closed' or 'proud', stoical, or unwilling to discuss feelings and emotions. This was usually explained as a function of their personality, combined with personal beliefs and upbringing: it is simply 'not for them', not their thing. The result was a more single-minded focus on physical symptoms and medical prognosis as the only dimension of disease that matters:

"It's difficult when you're first diagnosed with cancer. My mum particularly didn't really want to speak to anyone. She wouldn't seek any counselling and she wouldn't go to any support groups, she

wouldn't have a prognosis, she wouldn't do any of that... She wouldn't face the prognosis. It takes a while for my mum to know anybody. If services are more willing to come out here, had she been able to build a relationship with somebody who came out and did her feet or came out and did her nails and she'd built up that sort of thing, but it took her a long time to be willing to walk through those doors (to have the therapeutic massages). She's not that sort of person. It's fear of not knowing what it's like, what will happen. Proud lady – doesn't take anybody's help. My mum's gone to hospital in extreme pain and she's totally colour co-ordinated, her make up's on, she's extremely proud."
(Current carer – mother with cancer)

The emotional response to terminal diagnosis is a parallel journey

The emotional dimensions of the journey were recognised by some terminally ill people, family members and carers more than others. There was a tendency for descriptions of the journey to focus on the physical and medical path, with the parallel emotional, psychological and in some cases spiritual path underplayed and seen as of secondary importance, other than in terms of support from immediate family members. However, whether this was recognised or not, it was clear that the emotional response that accompanied each stage or set-back in the medical/physical process played a very significant role in the journey for individuals and carers.

A terminal diagnosis usually comes as a great shock to the individual and their family. Many cite that the shock is followed by the emotions triggered by contemplation of how the disease is likely to progress, how life will change, what will be lost, fears for the future, fear about pain, concerns about the feelings and reactions of family and how the surviving family will cope. Carers report similar anxieties. From both terminally ill people and carers we heard examples of the transition through the different stages of dealing with an impending death (Kübler-Ross), including anger,

bargaining, depression, acceptance, and, most frequent of all, denial.

The nature of the emotional journey is influenced by a variety of inter-related and interacting factors, including:

- the nature of the disease (degree of physical disability and patterns of progression)
- style, tone and content of medical conversations with healthcare professionals – including delivery of bad news. Medical professionals' skills (or lack of them) in communication clearly play a major role in the individual and carer journey
- personality and personal beliefs as the source of individual coping mechanisms. Established personality traits such as being 'closed' vs. 'open', pride, dislike of sympathy, 'a fighter', down to earth, no-nonsense, practical, spiritual, in touch with feelings and emotions (and many other traits) all came into play in responses to disease and prognosis
- quality of emotional support from immediate family and whether they accepted the prognosis or were themselves in denial
- individual understanding of the importance of emotions and emotional support (both person and carer) – including willingness to recognise and access professional emotional support, other non-medical interventions such as complementary therapies or counselling, and for some people, spiritual guidance
- engagement with, and influence and support of disease-specific charities such as the Motor Neurone Disease Association, Parkinson's UK, MS Society and organisations such as the National Council for Palliative Care (NCPCC)

How some of these factors interact is discussed in more detail in the following section.

Differences in emotional journey pattern between cancer and non-cancer

The range of emotional response experienced along the emotional journey appears to be similar for people with cancer and non-cancer diagnoses, but there appears to be a difference in the patterns of these experiences. The ups and downs of cancer and cancer treatment, optimistic encouragement

to go for further treatment from oncologists, or possibly the promise of a new miracle treatment may lead to periods of hope and positivity (often manifesting as denial), alternating with more negative states of mind, with the emotional journey mirroring the physical path:

"So if it had been now I think we would have all probably reached the conclusion that look, things are not good. But then I don't know if he still would because he was having that radiotherapy and because of the radiotherapy he needed to be in the hospital because they still thought, stupid doctor at [the hospital], was saying to P, 'Well I wouldn't rule out another stem cell transplant'. He told him that two weeks before he died... And I think P wanted to hear that and it was giving him the wrong signals because he was desperately thinking he was going to live anyway and then for them to come out with this rubbish, he was clutching at straws then which was really terribly sad, tragic."

(Bereaved carer – partner with cancer)

Some people with degenerative diseases may experience some sense of denial during the early stages when symptoms are at a very low level. However, a gradual increase in the level and extent of immobility and loss of function brings home the reality of a diagnosis, with a long time to contemplate what this means for themselves and their families. This is the point at which some of those involved had proactively sought emotional help.

"I had a mini-stroke and lost the use of this arm, probably due to my very high cholesterol. That's what alerted me to noting things down. I thought they were due to that. I didn't realise at the time. I started getting lost... I just used to devise ways to hide it so that's how it started... I set up systems to recognise my patients... My finest moment came when chairing a committee meeting and I asked them who they were and why they were there! I couldn't understand it because they were

my colleagues. I thought, 'well there's something the matter with me'... I certainly wasn't going to tell anyone about it and then it got worse... A second neurologist did investigations, scans and said yes there was something but he couldn't give a definite diagnosis. I knew I had dementia by that time and didn't admit it and struggled on... it got worse and eventually I stopped recognising my husband, and then we knew we would have to do something about it, and that's when we came here."

(Terminally ill person with dementia)

Accessing emotional and spiritual support

Terminally ill people and their families cited a range of non-medical interventions and support that they felt to be beneficial including:

- organised religion (including chats with priests/ministers) for those with religious faith (individuals and carers)
- specialist professional counselling (offered by some hospices and charitable services)
- spiritual healing
- complementary therapies, especially touching/sensory therapies such as aromatherapy, Reiki, reflexology
- personal care sessions such as hairdressing, make up, manicures etc. (offered by specialist centres in some hospitals). These restored a sense of 'normality', made recipients feel spoiled and enhanced feelings of self-worth
- carers' groups offered by some hospitals. These provided a welcome source of support and information, as well as a channel for expressing frustrations, concerns and fears

With complementary therapies in particular, the benefits were instantly visible in face-to-face interviews. Respondents' faces immediately lit up when discussing their value in promoting relaxation, as well as feelings of emotional and physical wellbeing. These were offered by specialist centres in some hospitals, and were a feature of hospices and centres run by charities. However, a key issue is the availability and accessibility of such support.

The family

Overview

Understanding the dynamics of the family context and the emotional needs of all involved in caring for the terminally ill person is important for those providing support through care at the end of life. Too often, the wider family context is ignored or overlooked by healthcare and social care professionals who focus exclusively on the immediate needs of the individual and ignore the needs of carers and other family members. Such an approach is crucial to development of a holistic approach to care and support for terminally ill people.

Changing roles and unspoken needs

A terminal diagnosis can significantly change family dynamics, often reversing traditional roles, for example with offspring looking after parents. Initial shock is often followed by the emotional challenges of coming to terms with a terminal diagnosis for both the individual and those around them. All of this often happens alongside the physical effort of day-to-day care for someone who is terminally ill.

The emotional intensity of the situation and distress about the imminent loss of a close family member is sometimes made more complex by:

- an unstated complicity between individual and carer, with each instinctively wanting to 'protect' the other, especially when the relationship is parent-child, where established roles conflict with 'new' roles (eg child caring for parent)
- terminally ill people often want to avoid worrying or inconveniencing their partner/parent/child/sibling. The prospect of dependency on family members for care, especially personal care, can create considerable anxiety and dread (about personal privacy, reversal of roles, burden, inconvenience, embarrassment for family members)

Carers often have a strong sense of duty, 'ought' and wanting to 'do their best' for their partner/

parent/child/sibling. Thus, both parties can seek to tread carefully around each other, rather than engage in completely open and honest conversations.

For some, relying on others can result in a sense of guilt:

"They help me, yes they certainly do and I do get shouted at in a nice way because I try and do it before they come here and end up in a mess, upside down in the bathroom sometimes, but it's so strange because you feel alright, your mind is still like it was... I don't have any outside people as such to come and do things. But I feel guilty that the family have got to take time out of their lives with their children and do things for me."

(Terminally ill person with Parkinson's)

Caring can become all-consuming at the expense of carers' own well-being

The tendency of carers to develop a 'be strong' attitude drives a need to establish control over the caring process, and/or feel bound by a sense of what they 'should' do, all often at the expense of their own health, wellbeing, and ability to cope with other responsibilities (eg to their immediate family, job etc).

"You can't make definite plans or decisions. There's no spare time. You just build your life around it (caring)... You live your life through another person whose needs are paramount... We put off things for oneself and our health – self comes last. It can take a toll on the carer – medical, stress, guilt – especially if it was not a good death."

(Bereaved carer – mother with cancer)

The huge emotional burden can have a devastating impact on the carer that can last for several years after death:

"It cost me five if not 10 years of my life."
(Bereaved carer – mother with cancer)

There may be past emotional history that adds to the sensitivity of the relationship between the person with the illness and their carer (eg some kind of playing out of previous problems with relationships – adding to the emotional burden of the carer, as well as driving an emotionally unhealthy determination to do more than they can really manage).

"I was just so busy working, two children. My mum was so angry so she wasn't always easy to be around, so she could be quite aggressive, she was forever picking at me and she wanted things done a certain way. There just wasn't anybody really at that time coming in that would ask me, 'What sort of personality is your mum? How's best to approach your mum?', because everybody wants to include her which is great but this is a very young woman who is very angry and she wasn't telling the truth about her pain, wasn't telling the truth and it put me in a really difficult position. I was feeling really stressed and sick. She was shouting at me, falling out with me. We were arguing in front of people, it was just stressful."
(Current carer – mother with cancer)

Sharing the family home with a dying relative can also put a strain on family dynamics, and place a heavy emotional burden on other family members, especially knowing what to tell the children or if there has been some disruption to normal family life to accommodate the terminally ill person (eg grandmother has moved in to daughter's family home):

"We're getting used to it. The boys were arguing a lot because those first few weeks after she first moved in we didn't know her diagnosis. They kept saying the cancer hadn't spread. I felt it had spread, she was in terrific pain. The children were frightened because of the screaming and crying that they could hear and we

couldn't get anybody to listen to us. It was a terrible time. We were at the GP, we were at the emergencies, we were on to the [unit] where she was being treated and in the end I just took her, and I said, 'She's staying here, you've got to admit her'. We got to breaking point with it all. But that was the time my youngest was sitting his exams and we hadn't got the beds yet so one of them was sleeping on the floor and one was sleeping in the other bed."

(Current carer – mother with cancer)

There can also be friction between family members sharing the care, or from those watching from the side lines, that adds extra tension and another layer of complexity to communication with the individual, as well as with healthcare professionals.

"My brother was pretty much in denial – and he said, 'When Dad is better...' and I'm just looking at him thinking, 'But you were there in that appointment, you have all the documents if you want to read them'. I felt very much like my brothers left it to me to deal with all the doctor stuff, all the dealing with all the nurses, doctors, carers, social workers, all of that was mostly me."
(Bereaved carer – father with cancer)

Caring can also be a uniquely fulfilling experience. There is also a sense of pride associated with what they were able to do for a family member:

"I was very grateful for that three months... I feel very proud of myself. Proud I did that for Mum."
(Bereaved carer – mother with cancer)

A number of people reflected upon the impact of caring and emphasised that it essentially brought the family closer together:

"It was a precious, special time for us – I know it sounds strange, but we became closer than ever."
(Bereaved carer – wife with cancer)

Others report that this period of caring helped them to prepare for the death of a partner or family member:

"It was our 'special time' and, in retrospect, an important part of her preparing us (and herself) for her death. It was an experience that was bizarrely wonderful... part of her looking after us as well as her... It allowed us to be the people we were to her and not her carers."

(Bereaved carer – partner with cancer)

The system

Overview

The journey towards and at end of life involves a bewildering situation with a changing cast of different sources of care, support and advice, with further variation according to postcode and condition type. Terminally ill people and carers are often required to navigate a complex and unfamiliar system, providing a source of additional stress and distress. There are often perceived to be many 'fingers in the pie'. It is not only difficult to decipher who does what, but also to know what is available, relevant or what questions to ask.

'Fog of confusion' – who does what?

A strong and consistent theme across all of our conversations was a sense of 'fog' and confusion about what support is available, who provides it and how/when it can be accessed following diagnosis and throughout the terminal period. This was particularly strong amongst carers, including those who had worked within a hospice or other medical settings, social work or NHS services.

A number of carers stated that they wanted to 'take control' following the terminal diagnosis. They report wanting to maintain their loved one's state of mental, emotional and physical comfort throughout the last few months of their lives. However, the fragmented and labyrinthine nature of the care and support available is a source of real frustration, bewilderment and distress. It takes considerable effort, time and knowledge to navigate. Carers often feel in the dark, with a sense of being out of control and unable to ensure the comfort of the terminally ill person. This adds considerable stress to the overall situation.

The perceived complexity of the care/support system is further complicated by variations in policy between different areas and individual hospitals. Where an individual has more than one medical condition (co-morbidity), they may be dealing with more than one consultant and/or

more than one hospital – often with no apparent communication between the different treatment centres. This may be further complicated if they move in with a family member who lives in a different area. At this stage they may be required to establish new relationships with GPs and local hospital teams.

In addition to this there are predictable differences in personality, communication skills and approach by individual GPs, consultants and nurses, with some having a naturally more empathetic and congenial approach, and others appearing more abrupt, or dismissive, or seemingly uncaring.

Lack of advice, information and coordination

As well as not knowing who does what and when, there can be a lack of any central coordination of information about available services:

"I know I'll need things because it suddenly hits you when you go to do something and you find you can't do it and you need that thing that would help but I don't know what thing. Nobody's giving me any advice, they don't give you a list to say that you might need this or you might need that. I suppose that's sensible because some people might think I'll get them anyway or I don't know how... I'll do without things as long as I can. It's just total bewilderment to me... I don't know what help you need to ask for. I don't know what to expect with it... how to go about getting these things. Nobody comes forward with anything for you to do. Each time I go to an appointment I think they're going to tell me something that will show me the way. It's just bewildering... I can't get to the bottom of it... No answers proffered properly to me and I don't know how to ask... what way to go about asking for things and whether

I'm being a mad case or a needy case, I just don't know."

(Person with Parkinson's)

There is a clear sense that families feel alone throughout this process and it falls to them to make their way, often unaided, through the system:

"It was chasing up and stuff and trying to get stuff done, and I felt like if I hadn't done all of that he wouldn't have had the care he was supposed to have. And at the time... I did get frustrated about it and ranted about it to my friends and [was] annoyed, but partly I just got on with it because it had to be done... I forget which because there was a lot of discussions and lots of things I used to have to chase, that I would have to ring up the relevant person to get something done. I wouldn't rely on a GP's letter to get anywhere, I would chase it up. I would always ask for copies of letters and ring up the people who were meant to be referred because otherwise I found that things didn't get done."

(Bereaved carer – father with cancer)

Where one lives can also have an impact upon what help is available.

"My overwhelming impression is that there's lack of consistency. It all depends where you live. It really is a postcode lottery... the support we got when looking after M at the end was excellent, but you wouldn't believe some of the stories I've heard from others since I became involved in different groups... Having all the information helps you feel that bit more in control."

(Bereaved carer – daughter with cancer)

The complex set of arrangements and number of different individuals involved undermines the effectiveness of the system:

"There are so many fingers in the pie, it only needs one to fall down for the whole thing to fall down... It's not seamless at all – no one can say who the single point of

contact is... there's a real opportunity for a one-stop shop."

(Bereaved carer – wife with cancer)

There is no one to help navigate the system

Families repeatedly referred to the need for some to help them navigate this complex health and social care system. There is a huge unmet need for someone trusted to help terminally people and carers navigate this complexity – to provide a human touch, rather than another leaflet. The ideal is a 'case worker' with whom individuals and carers can build a relationship, and turn to for general advice and answers to specific questions about needs. This might include medical, emotional or physical needs, as well as advice about how to access particular services. Equally, individuals want a confidante to listen to their fears and anxieties. The sense is that such advice and support would help individuals keep everything else ticking over:

"The challenges are... keeping things on track, keeping on living, the need to constantly talk to people, the fact that there's not one co-ordinator so you have to deal with a range of different people, there's not a coordinated care package. You're not told 'This is the person to speak to'. I wish there was someone you could go to who says, 'This is how it all works'. The ideal is coordination without being rigid... a key worker who can consider everything and gear it to the individual."

(Bereaved carer – father with cancer)

The role of local hospices

Against this backdrop of confusion and complexity, for many of those we spoke to the local hospice had become something of a lighthouse in the fog. Having established a relationship with their local hospice (as a way of planning for the future), in the absence of any other central source of information or advice, some carers began to rely on the hospice as a valuable resource for a variety of immediate needs – eg specialist equipment, respite care, nursing support, counselling, or just a friendly source of general advice.

The difficult conversations

Overview

A terminal diagnosis and any discussion around death involves difficult conversations between individuals and carers, and also between healthcare professionals, individuals and their families. It is often said that our society continues to shy away from taking about death and dying – with the result that *not* initiating conversations about what people want, expect and understand can create problems for all involved. Lack of conversations and poor communication mean that terminally ill people are not involved in key decision making, professionals are left unsure about what services to provide and bereaved families are left asking whether their loved one wanted something different.

Talking about death and dying: denial

Conversations between terminally ill people and family carers can be difficult because of the sensitivities for both parties. The individual themselves may want to avoid discussions of progression, prognosis and dying, and rather focus on life, especially when life is continuing more or less as normal (with little obvious change in day-to-day existence) which is often the case with some conditions.

"I try when I get together with friends, well they ask me at first... how I am but I always then try not to talk about it. We'll talk about different things going on..."
(Terminally ill person with cancer)

This can create frustration for other family members:

"When I go to Germany I make that very clear... 'Please the one thing when I come don't talk about my illness all the time', so my sister said, 'It's just because we care and we just wonder'."
(Terminally ill person with cancer)

For some terminally ill people, they simply want to defer such questions and conversations and to focus on the time they have left:

"That's fine, we can do that when I first come, you can just check with me, but then I think we should just leave it and let us enjoy our time together."
(Terminally ill person with cancer)

Whilst this might be frustrating for carers and family members, they can see its positive side in the earlier stages:

"I think it was helpful he was in denial in a way because otherwise it would go the other way if you feel like you're going to die and then you kind of give up hope."
(Bereaved carer – father with cancer)

Difficulties for some carers emerge at much more advanced stages of the disease when some terminally ill people go into denial or shut themselves off from all discussions about emotional support, what's going to happen, and decision making about treatments and about where they want to die.

"He wasn't stupid. The doctors were very clear it was terminal and straight after he was told, he wanted to have a conversation with me about his pension, getting things in order, so I know he understood he was dying. But I was too upset to discuss things like that then, and after that he never wanted to talk about it even when I tried to open a conversation... He said silly things... When he first came home and could still get in the garden, he said, 'I must get myself better and fix that shed roof'. It wasn't like *Beaches* where you walk hand-in-hand and tell each other how much you love each other. All we had was small talk."
(Bereaved carer – husband with cancer)

It is important to acknowledge that the reluctance to talk can work both ways, with families and carers similarly reluctant:

"In fact that whole period I think what we found the hardest was to know how to talk to our daughter about death and whether we should be acknowledging with our daughter... and if I'm really honest I think I wasn't that keen to talk to her about it because I thought by talking to her about the fact that she's dying would upset her but at the same time we always felt through the two years and nine months we were always wondering, 'What does she know? What does she understand?' At the early stages particularly, 'Does she know that she's terminal, does she know that she's not operable, does she understand she is going to die?'"

(Bereaved carer – daughter with cancer)

Being unable to have such conversations, and the unanswered questions which can result, can leave bereaved carers in a state of anxiety and guilt long after the bereavement, with questions about 'should I have done more?'

For some people, it can be the failure to deal with financial, practical and legal matters that poses difficulties (or possibly devastating consequences) for those left behind.

"It's a very difficult situation. He was determined he wasn't going to die so he left a rubbish Will that he made and never went back and changed it but it will sort eventually... I've got a massive legal case coming up. And also I'm moving out of my home, our home, and that's another thing, someone's died but I've now got to move. I've never bought a house before in my life."

(Bereaved carer – husband with cancer)

Talking about death and dying: Conversations with health and social care professionals

Conversations between terminally ill people and their families and health and social care professionals can play a pivotal role in shaping the type of care an individual wants and ultimately receives. For some, conversations with the right professionals at the right time helped to approach such conversations and decision making with greater confidence:

"If people give you some confidence you feel better to deal with it and they gave you a lot of positives... the consultant, Mr F, he was a lovely, lovely man and he gave you so much confidence..."

(Bereaved carer – husband with cancer)

Conversely, other people report more negative experiences relating to conversations with healthcare professionals. These highlight three key gaps.

First, how to deliver bad news. There were several examples of poor and/or insensitive communication about prognosis from hospital staff, including consultants. In the worst instance, one person received a terminal diagnosis by phone:

"I had a phone call, 'Oh by the way just to let you know you've got end stage COPD. We've written a letter to your social services so we sent you a copy so you'll find out, so we thought we'd better let you know by phone call.' Not once was I asked, 'Is anybody there?' I wasn't asked to go into the hospital to be told by my consultant when he found out. Somebody rang me up to tell me, and he (the doctor) was livid because he'd actually just got the results back from the hospital and wanted to break the news to me gently. And to be told over the phone that actually you've got an end stage problem. I went into meltdown. M went into meltdown. D was traumatised because I was on my own when I got the message and I just sat in the sun lounge with the cats and cried

my eyes out because end stage, I thought that was it, I was going to die tomorrow. Nobody had explained what actual end stage means."

(Person with COPD)

There were also reports of instances of healthcare professionals insisting on giving bad news to individuals even when carers requested that this should not happen, and the individual did not wish this to happen:

"It would have destroyed her. After 30 years, I knew her well enough to know she wouldn't want to know or discuss this. I told my son and daughter and discussed it with the GP and they all agreed it was right decision – GP said it was 'usual practice'."

(Bereaved carer – wife with cancer)

Second, discussions about how and when to move from treatment to palliative care. At later stages, health professionals, including consultants who are trained to maintain life, appeared to several interviewees to see the admission that there is nothing more to be done as a failure. They still talked about treatment, prolonging life and giving hope, even when the person is clearly at end of life or has no prospect of quality of life:

"The culture in the medical professional is that they know best. If they talked to her, they never talked about her dying. They offered her a trial drug. They continued to offer her treatments... but D had had enough. To the medical profession living was the important thing... not how she was living."

(Bereaved carer – partner with cancer)

Third, involving individuals and their families in conversations about very end of life care. As discussed, it is essential that families don't feel left out of discussions or insufficiently informed as to what is involved. This has been witnessed in recent debates about the use of the Liverpool Care Pathway or 'Do Not Attempt Resuscitation' notices.

Planning requires talking about death and dying

An important trigger for other decision making is a conversation about what a terminally person and their families want. Taboos around talking about death made this a difficult topic in our conversations with terminally ill people and current carers – with any detailed discussion of death scenarios largely limited to bereaved carers. It is obviously an awkward and emotionally charged topic for conversations between terminally ill people and their families, and often one that many would prefer to avoid. Equally, it is awkward also for less-experienced healthcare professionals. Our sample represented the spectrum of attitudes, ranging from those who wanted the unvarnished truth, to those who wanted to know nothing and refused to acknowledge any aspect of what was happening. A further complication arises when family and carers wish to keep the prognosis from the individual, posing difficult practical and ethical dilemmas for the professionals caring for that person.

"The thing is no one is interested in or wants to talk about death, until it affects them. They're happy to put money into the tin (daffodil appeal) as they know it's important, but they want to run away as quickly as they can – they don't want to talk about it."

(Bereaved carer – wife with cancer)

The 'death conversation' is clearly a challenging communication problem for healthcare professionals. For some it is difficult to achieve the right tone and balance between reality and sensitivity.

Conversations around death with healthcare professionals seem to involve either:

- At one extreme, some kind of avoidance and false optimism, eg from people who are trained to maintain life still talking about treatment and maintaining life, even when the person is clearly at end of life (even within the final day or two), or has no prospect of quality of life. Consultants appear reluctant to put a time-scale on prognosis – especially with cancer which has an unpredictable path.

- At the other extreme, insensitive treatment of families and family carers in the breaking of bad news.

For some, heavy-handed communications from hospital-based healthcare professionals who excluded relatives and carers meant the end of life experience was far from ideal, sometimes chaotic, and, in some instances, highly traumatic for families who were left feeling helpless, in the dark and with no say at all in the process. Teams of unfamiliar people sweeping in and taking over added to a feeling of loss of control, leaving an unhappy reminder of the last hours of the individual with their family, with no opportunity to put things right.

“Medical practitioners in the hospitals were making their own decisions about having those conversations with her because to them she’s the patient – not us... I felt it wasn’t the right decision. She is their patient, but telling her wasn’t going to make a difference to the outcome. It made a difference to her because she was very frightened at the end and she said she didn’t want to be left alone, she was frightened of the nights in hospital. It made it hard for her... One doctor said to her when he was talking about resuscitation and we’d said, ‘Why have you put don’t resuscitate?’ and he said, ‘I’ve had that conversation with your mother’. I said, ‘She’s not told us that’ and he said, ‘I said to her, would you like to die peacefully or not?’ Well what kind of question is that? Who is going to say no to that? And he said, ‘She needs to know what resuscitation involves for someone who’s as ill as she is.’ And I think he did graphically tell her what resuscitation could mean for her. That she could have broken ribs, that it’s quite a violent thing being resuscitated and that she would probably survive to take ill again days later and that her illness would mean she would feel like she was drowning. He didn’t do it in a good way really I don’t think.”

(Current carer – mother with pulmonary fibrosis)

There is a clear need for training in communications for all care professionals providing end of life care.

Adapting conversations to reflect different conditions

Interviews with those affected by dementia indicated there is a particular problem with conversations and communication among carers, families and healthcare professionals. The nature of dementia means that the conversations have to be very different for people with these conditions.

Those involved in care (including family carers) currently remain unaware of advances in research and clinical evidence vis-à-vis the possibility and benefits of learning to communicate effectively with people with dementia – through a system of exercises and workbooks that encourage individuals to regain some memory pathways, and some ability to communicate. This relieves their frustration, limits difficult and challenging behaviour (disinhibition, anger) and can make for a much happier relationship between individuals and carers.

The unmet needs

Overview

In talking about their experiences of care, those terminally ill people and current and bereaved carers we spoke to identify a range of different needs that they feel are currently not being met. These needs cover all aspects of end of life care and support.

Unmet needs:

1. The absence of a 'road map'

Families cite as a major concern the absence of a coherent 'road map' that explains who does what and when at different stages of their journey. Terminally ill people and families perceive that services are too often not joined-up, and that this can lead to expectations of support not being met. Carers report having to spend a lot of time on the phone trying to sort out different aspects of support, often being passed from one person to another.

Some carers perceive that the health and social care system is essentially set up to respond to specific events or crises, whereas families and carers want to think and plan ahead, or anticipate the next set of needs as a way of feeling in control. The perceived lack of forward planning may leave some families feeling left in the dark, out of control, bewildered and frustrated by delays as specific needs arise.

2. The lack of sign-posting and coordination

In addition to a road map, people want an individual or individuals to help them navigate the health and social care system. The ideal would be to have one person who stays with them and the wider family unit throughout, although with different levels of presence and input at different stages. For some people this role is already filled by a local hospice; however other people feel that they are on their own. One respondent referred to the notion of a 'lighthouse' – someone to show the way and to explain the what, where, and how. This

signposting includes practical help in accessing equipment such as grab handles and wheelchairs, providing condition specific information and explaining the condition; its progression and treatments. It also includes having someone to confide in about concerns and fears, and to advise or facilitate difficult conversations with families and professionals.

3. Lack of consistency of contact

For some families, there is a lack of consistency in the contact they experience throughout their journey. From diagnosis, through to being told that they are terminally ill and onto the end of life, they come into contact with a succession of different organisations and people. Consistency builds trust – which, given the difficulties over communication in this area, is obviously an important principle. A lack of consistency of contact can undermine trust and leave individuals and families feeling confused.

4. Adopting a whole family approach

A number of terminally ill people and their families said that they want health and social care professionals to more actively consider the needs of the wider family and carers, as well as those of the terminally ill person. They feel that this could make a huge difference to the emotional experience of terminal illness and death itself, for all involved. Again, for some people, this need was being met by a hospice, for those in hospital, it was perceived to be less apparent:

"There appears to be a tendency for some healthcare professionals, particularly those involved in hospital care, to exclude or downplay the importance of the carer's involvement in the process. Not only does this add to a tendency to feel out of control, but can also create very high levels of emotional distress for the carer that may extend into the bereavement process, and persist for months, or potentially years, after the death (with feelings of guilt, inadequacy, of not having

done enough etc). Carers (and close family members) need to be included in important conversations about, for example, what will happen regarding end of life care."

(Bereaved carer – wife with cancer)

Without such involvement, family and carers can feel marginalised:

"I explained that I didn't want W to know (the) seriousness but [the professional] was adamant she wouldn't talk to me on my own. I felt very annoyed after the visit as if she wasn't interested in listening to me."

(Bereaved carer – wife with cancer)

5. Supporting better communication

As discussed, many people find talking about death very difficult. Terminally ill people and carers tell us that they would welcome more support to enable conversations, particularly where an individual remains in denial about the progression of their condition or where existing family relationships inhibit open conversation. Although some healthcare professionals communicate very well, it is perceived that many would benefit from additional training, particularly around communicating bad news and in ensuring the whole family are engaged in and understand discussions around the planning for care at the very end of life.

6. Greater access to hospice care and services

For some people, hospices are a preferred place of death. Some people see hospices as both comfortable places to die and as a source of advice and support in the 'fog of confusion'. A number of people referred to the valuable role of hospice day services in both providing support and in establishing a relationship with a local hospice. However, the availability of hospice care and services varies by location and some participants had been unable to access hospice beds (especially at short notice) or day services when they needed them.

7. Better access to support for people with non-cancer diagnoses

On the whole, people with cancer and their families felt that they were well-served in terms of their practical/physical needs, with high perceived

levels of access to support and advice. Unmet practical needs could largely be resolved by providing easy access to sources of advice and equipment.

For those with degenerative conditions, there was a perception that there was less available or that access to support was more difficult. This is illustrated by one respondent who had both Parkinson's and breast cancer and who had personal experience of different levels of support available:

"Completely and absolutely different. Everything was offered to you (with cancer), even a Blue Badge. I suddenly got this disabled driving badge delivered, and I rang up and said, 'I think you've made a mistake.' Counsellors, therapists, wonderful they were, absolutely wonderful. If you needed something you could tell them and they'd get it. Even if you needed a washing machine and stuff like that, they ask you... they did actually ask me did I need any implements, gadgets or anything. But nothing for this (Parkinson's). Not as I've been offered. Maybe in other parts of the country there are, I don't know."

(Person with Parkinson's and cancer)

For people with long-term degenerative diseases, it was perceived that very little is provided as a matter of course, with very little direct interaction with Social Services.

"I would say that from the very basic social care and very basic grab rail, everything's had to be justified and almost feels like a sword battle almost... it's been exhausting and it still is exhausting. At the same time I'm very grateful for what I've ended up with, however on the same point, the most emotionally exhausting, some of this can a lot of times be quite degrading, having to justify every little element of why you need this, why you need that."

(Terminally ill person with MS)

Where these needs were being met, it was felt that this was either because:

- the person had the will, tenacity, energy and personality to fight for the physical and practical care they needed – with the language of battle being very much in evidence; or
- the local representative of their condition-related charity had applied and possibly fought for this care on their behalf.

For some, there is a sense that such support is being rationed:

"Well you know it's kind of 'Do you want to swap places? Do you think I'm enjoying this? Do you think I really want this?' Because you're dealing with people, I understand they've got targets, they've got processes, they've got guidelines but you're dealing with a human being who's unwell, and severely unwell, that sometimes a bit more flexible approach and to say to people, and I use that generically because everyone's different... thankfully up until now I've been able to fight those battles."
(Person with MS)

There are also concerns that issues relating to the inadequate provision of physical care and support for degenerative diseases are likely to increase as the result of funding cuts. For those who have managed to achieve an appropriate level of care, there are concerns about the impact:

"I'm very scared because a big part of my social care is funded by the Independent Living Fund. I don't know if you know about it? That is going within 18 months. The government have closed that which means that the local authorities will have that pot of money but it hasn't been ring fenced for social care. There's been a lot of rhetoric and no major commitment so a large part of social care will... I don't know what's going to happen to it, so I'm very anxious, very scared for the future."
(Person with MS)

A clear message that emerges from those with non-cancer diagnoses and those caring for them is that there needs to be parity of access to

assistance and support for people with different diagnoses.

8. Pain management

As Marie Curie argued in *Death and Dying: Understanding the Data*, there is a need for a more coherent and joined-up system for administering pain relief for people at home. This appears to be both during the last few weeks, as well as the last few days, particularly where the terminally ill person deteriorates quicker than expected.

Families report witnessing a convoluted process, with a doctor required to be present to prescribe, but not administer pain relief. Carers report having to chase prescriptions, nurses waiting around in the middle of the night for prescriptions to arrive and concerns that some locums cannot issue prescriptions, which delays access to pain relief:

"You're forever running out of liquid or running out of this tablet and then you've got to ring the doctor, get the doctor to raise a prescription and then you've got to get it picked up, take to the chemist and the chemist doesn't have the morphine in because it's an expensive mixture and you've got to wait and you've got a family and you're working."
(Current carer – mother with cancer)

9. 24/7 services

Families also identified the absence of efficient and empathetic out-of-hours access to medical advice – particularly in the middle of the night, when untrained family carers had to make decisions about worrying changes in symptoms or the overall condition. In the middle of the night, carers felt exhausted and completely alone:

"Obviously when it happened in the middle of the night it was terrifying because it's dark, it's cold when we leave and you've only got a skeleton staff on and they wake up somebody and you know he's really ill. I did feel a bit abandoned and a bit scared because I was thinking, 'Oh God, what do I do, what do I do?' ... I think I would say a lack of support there because the middle of the night is a very terrifying place to be

in when you're not sure what to do... because obviously you don't have all the main doctors and nurses on that know you that well. I just coped with it in the end... but I used to find that I didn't sleep then because I was worried in case he died and I would watch. I would watch his stomach to see if it was going up and down and keep checking on him to make sure he was OK and then just pray for the morning to come."

(Bereaved carer – husband with cancer)

10. Emotional support

Terminally ill people and carers who were able to access and take up some form of psychological, emotional or spiritual support say they found it helpful and comforting. However, people report often finding it difficult to recognise or express their emotional needs compared to practical or physical needs.

Respondents cite an increasingly secular society, together with medicalised attitudes to death as possible reasons why emotional and spiritual support for terminally ill people and their carers is perceived as an optional 'add on' in coping with disease and the prospect of death, and not really an integral part of the discussion/language surrounding end of life. Even those with religious faith may use this to pray for a cure or for extra time than as a way of coming to terms with a poor prognosis.

Whilst the emotional support of family, neighbours and friends was understood and valued by individuals and carers, the value of emotional, psychological and spiritual support was often underestimated. More particularly, the need for more professional emotional support (counselling) and/or non-medical therapeutic interventions (complementary therapies) tended to be downplayed in our interviews, or take second place to discussion of 'official' sources of support or medical interventions. However, any kind of psychological/emotional/spiritual support that helps individuals and carers adopt a positive, or at least accepting, attitude to diagnosis and prognosis was viewed as beneficial.

11. Better support for carers

In addition to greater recognition and involvement, there is also a need to provide greater support for families and carers who, through a sense of duty and determination, provide care and support, often to the detriment of their own health and wellbeing. This support might include respite breaks at weekends or overnight, as well as practical support such as support with cooking meals:

"Sometimes maybe you could have done with somebody who could have come for a couple of hours so you could just go out and have a cup of tea with somebody or chat to a friend, just get out of your situation that you were in. Not to forget but some kind of respite."

(Bereaved carer – husband with cancer)

There appears to be a lack of awareness of how to access sources of respite care.

There is also a specific need for support for children of carers. Children may be confused and distressed by having a dying relative in their home and/or their parent being distracted from providing normal parenting duties. Helping them to understand what it is happening would help the wider family to deal with the situation more effectively.

12. Bereavement support

Bereavement support helps families to adjust to their loss and to address new challenges. People who have spent weeks, months and in many cases years caring for their loved one suddenly find that their realities and daily routines change. Their central role as a carer has gone, as are the banks of professionals who have provided support:

"What is quite alarming for some is the sudden silence that follows death... All those who helped prior to death, including professionals, stop contacting you and, [and] from a social point of view, invitations stop arriving; no-one knows what to say, or what to do."

(Bereaved carer – husband with cancer)

Some continuity of contact from those involved in care prior to death would be appreciated – even if this is just a phone call to check if the person is OK:

"Even an odd phone call because you feel very alone... I think if someone could have just rung up... Just that closure of things to make you think well they've not forgotten."
(Bereaved carer – husband with cancer)

For those who have lost a partner, there are specific challenges to be faced:

"Well maybe events, parties or weddings, something that I'm invited to, I think I'll have to go but I don't really want to go because I feel I'm on my own. Because other people have got partners and even though we've been friends for years maybe you just feel different and I think well you've got to make yourself go because if you don't they won't want to keep knocking on the door asking you to do things, so I'm pushing myself really to do it."
(Bereaved carer – husband with cancer)

Bereavement counselling is a service that was appreciated by those who felt the need to access it:

"I had a letter come saying would I like some counselling and I said, 'Yes please', so I started straight away. For me that was the right thing. It really was the right thing for me to have... We have quite an interesting relationship. She knows me well and I know her and she knows I can talk to her about anything and we have done in the past, talked about awful stuff. She's a great support."
(Bereaved carer – husband with cancer)

However, it is clear that bereavement support is not offered to everyone, yet it should be.

Conclusion

The voices of terminally ill people and current and bereaved carers are often missing from discussions about experiences of end of life care, but the reality is that it is only through understanding their experiences that we can begin to improve experiences for other terminally ill people and their families.

Those involved in this project identify a broad range of experiences, both positive and negative. From their accounts, a number of key themes and messages emerge.

Death is a journey, not a moment in time

It is clear that death is a journey and not a single event. Changes happen, often punctuated by specific events, until it is clear that the very final stage has been reached. Most people do not understand the process of death and are not necessarily prepared for it. Helping people understand, anticipate the changes, plan for them, and access what they need as things change, would be valuable.

Putting people at the centre

The care and support available to terminally ill people and their families must be built around their needs and wishes and not simply delivered in a way that works for the health and social care system and those who provide services. People want care and support at the time they need it. They want advice, home visits and pain management at whatever time of the day or night. The fact that we talk about out-of-hours services is very telling – people deteriorate and need care support at different times of the day and services need to be able to respond faster. From communicating bad news to access to services, and from care planning to bereavement support, we need to place terminally ill people and their families at the centre.

Talking is beneficial

Giving people the opportunity to talk is important, particularly when they can tell their stories at their own pace and relive the experiences that they choose. All those taking part in this qualitative research study found it a positive experience. Even those who broke down many times while telling their story chose to go on and felt it had been helpful to them. This went beyond a sense of public spirit in helping others who might be in a similar situation. It allowed them to make a little more sense of their experiences. It appears to be important to both terminally ill people and carers to have the opportunity to talk. It is part of the process of coming to terms with death. Indeed, many described the stress of denial if either the person themselves or relative or the carer could not admit to what was happening.

There are many unmet needs

The previous chapter details many unmet needs and, in particular, the complexity of 'the system' that prevents many needs being met. Virtually every respondent described trying to find a path through 'the fog'. They spoke of the need for a 'road map', more continuity of contact with professionals and services, a whole family approach and support for better communication about dying/death for families and professionals. There is also an unmet need for greater availability of hospice care (both in-patient and day services), for palliative and specialist end of life care for people with non-cancer diagnoses, for more effective pain relief at home, and for a more empathetic out-of-hours service. What people want is practical support, not another set of leaflets and yet more websites to add to 'the fog'.

There are many organisations that already provide some help and support. However, it is perceived that there is currently no one-stop shop for such support. In order to meet this need, the service would need to meet the following criteria:

- Awareness – the service should be known to people who might need it and they should know how to make contact.
- Accessibility – the service should be available, comprehensive and with sufficient resources to meet all needs.
- Simplicity – the service should ideally be a 'one-stop shop' and should not add to the 'fog'.
- Personalised – the service should fit with individual needs at the stage of the journey they have reached, and their individual situation.

Any service passing such a test would make a significant contribution towards enabling more people to experience a 'good death'.

Appendix 1: Details of participants

People with cancer

M/F	Age (approx.)	Type of cancer	Other conditions
M	82	Prostate	Emphysema, Osteoarthritis
F	72	Breast, metastasised to spine	
F	62	Multiple myeloma	

Current carers

M/F	Age (approx.)	Relation to person
F	40	Daughter caring for mother
F	25	Daughter caring for mother
F	65	Wife caring for husband

Bereaved carers – cancer

M/F	Age (approx.)	Relation to person
M/F	60	Mother and father caring for daughter
F	50	Wife caring for husband
F	74	Wife caring for husband
F	55	Partner caring for partner (M)
M	-	Father caring for daughter
F	-	Partner caring for partner (F)
F	-	Daughter caring for mother
M	-	Son caring for mother – also currently caring for wife
F	-	Daughter caring for father
F	-	Wife caring for husband
M	-	Husband caring for wife
M	-	Husband caring for wife
F	-	Daughter caring for father and mother
F	-	Daughter caring for mother, father and others

Terminally ill people – non-cancer

M/F	Age (approx.)	Primary disease	Other conditions
M	-	Multiple sclerosis	Frequent UTIs and other infections
F	51	COPD	Psoriasis, psoriatic arthritis, osteoarthritis, angina, frequent infections
F	70	Parkinson's	Breast cancer
F	65	Dementia	
F	-	Motor neurone disease	

Current carers

M/F	Age (approx.)	Relation to person
F	50	Daughter caring for mother (pulmonary fibrosis)

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