

COMPASSION IN DYING

SUPPORTING YOUR CHOICES
AT THE END OF LIFE

How do people approach decision making at end of life? A secondary analysis of narrative interviews with patients about experiences of living with terminal illness

Part A

Summary

This secondary analysis of patient interview data held by the University of Oxford's *Health Experiences Research Group* was commissioned by Compassion in Dying with the generous support of Lord Joffe CBE. Lord Joffe's donation was in memory of Dr Ann McPherson, co-founder (with Dr Andrew Herxheimer) of the patient information website www.healthtalkonline.org for which the patient interviews were initially gathered.

The 'Healthtalkonline' module Living with Dying was the starting point for this review and was re-analysed in detail. It comprises a total of 42 narrative interviews with participants who identified themselves as having a condition considered terminal. Carried out in 2004, it should be noted that these interviews were conducted prior to implementation of the Mental Capacity Act 2005. That Act formalised provision for Advance Decisions and introduced new Lasting Powers of Attorney for healthcare matters.

A further ten 'Healthtalkonline' modules where patients were interviewed about conditions that could lead to expectations of reduced life span were computer searched by relevant keywords (e.g. death, dying, terminal, 'advance decision', 'living will' etc). This second dataset included some 400 further interviews. Identified data were then reviewed where appropriate. This extended search did not yield significant additional variant data, but further reinforced earlier findings.

There is further discussion of method in Part B of this report. Part C sets out the detailed discussion of findings grounded in all of the data sources identified above.

The secondary analysis focused on patients' orientation towards, understanding of and expectations around decision-making at end of life. It was thought prior to starting the secondary analysis that the data might yield insight into the following questions (among others)

- How consonant with principles of medical ethics and law are patients' and families' experiences of decision making at end of life, advance decisions, and decision making on behalf of others?
- What are patients' and families' perceived barriers to advance care planning?
- What are patients' and families' perceived barriers to shared care and shared decision making where these are desired?
- What are patients' and families' perspectives on taking responsibility for 'difficult decisions'?

The data supply some indicative answers to these questions. They also raise important questions about the implications of the recently published (2012) National Bereavement Survey.

Seven themes emerged and are discussed in brief in the summary below. The full report explores the first six of the seven themes in depth. Research is continuing on the final theme, iatrogenic harm, and this is not discussed further in the full report.

1. Avoiding, resisting, recognising and accepting the curtailment of life
2. Information seeking and information provision about end of life
3. Expectations of the dying process and what it might entail
4. Anticipating decisions and getting advice
5. The importance of familial practices and processes to patients at end of life
6. Knowledge and use of preference tools
7. Incidental data concerning patient perception and experience of iatrogenic harm

Theme One: Avoiding, resisting, recognising and accepting the curtailment of life.

Although all of the participants had volunteered to be interviewed about their experience of having a 'terminal' condition the majority of interviewees evidenced strong psychological aversion to such a label. Determined optimism, refusal to entertain negative thoughts or emotions, and living day to day without thinking about the future, were frequently cited as key coping mechanisms. Several interviewees discussed a point at which they had had to face up to their prognosis, for example when applying for benefits for those terminally ill.

- These data illustrate the well-known difficulties that surround promoting advance planning for care and decision making at end of life. They are also suggestive of where targeted information about end of life rights and decisions might have most (and least) impact.

Theme Two: Information seeking and treatment decisions

There was marked variation in patients' desire for information about prognosis, and their information seeking behaviour. Some sought to avoid negative information while others were frustrated that clinicians avoided giving them the 'bottom line'. Some were critical of professionals for initiating information-giving while others were critical that information was not freely volunteered. Some had sought information about their condition on the internet, but none spoke of using the web to locate information about their rights or the dying process.

- These strongly divergent data are indicative of the difficulties of tailoring appropriate information for this audience, both for health providers and advisory organisations. What some patients welcome, others resent. It should be noted that while internet use for health advice has greatly increased, there remains very little sensitively written and balanced information about the physiological and social processes around dying.

Theme Three: Expectations of the dying process and what it might entail

Interviewees' understanding of the dying process and thus what decisions or choices might arise was derived from three main sources: advice from health professionals,

discussions with friends, and experience of the death of family members, friends or other patients. Interviewees' recall of the information supplied by health professionals suggests that they either receive or choose to remember a comforting account of pain-free 'fading away'. Expectations based in the experience of the death of another were more divergent, so that some interviewees anticipated a dignified exit with well-managed pain whilst others feared inevitable indignity and/or pain at the end of life.

- These data supply an informative qualitative commentary on and counterpoint to quantitative data created in the National Bereavement Survey published in 2012.

Theme Four: Anticipating decisions and getting advice

Interviewees were prompted to describe the sorts of decisions they thought might need to be made as their illness progressed. Reflecting the themes above, few identified medical decisions. Many referred to making provision for family and had consulted legal or financial advisors. None of the advisors were reported to have raised end of life decisions, and by and large were reported to be ignorant of the scope for making advance decisions at that time.

- The frequency with which legal and financial advice was sought, and the limited knowledge of these advisors about end of life rights, suggests that considerable progress in vindicating decisional rights could be made if they were better informed.

Theme Five: The importance of familial practices and processes

From the perspective of medical law and ethics one of the most notable features of the data is interviewees' concern for familial practices, relationships and responsibilities. Family and familial practices entered participant narratives generally without prompting, and in many interviews were a main pre-occupation. Protecting intimates from distress constituted a major source of anxiety, and the data are revealing in how interviewees construed the notion of becoming a 'burden' on family and others close to them.

These data point to how concerns for significant others are a core part of the experience of terminal illness, but are a neglected part of the discussion in medical law and ethics. Published research in this field tends to focus on the legitimacy and capability of family members as decision makers on behalf of incapacitated patients. Our data illustrate how thin a conception of carer involvement in the life of dying persons this represents. They pose questions about how patients' decisional processes should be understood, theorised, and supported.

- Greater consideration should be given to carer involvement in shared decision processes. Concern for family and friends could supply a valuable focus for information and campaign work. Information aimed at family members might also be a means of enhancing the current provision of information by advisory services.

Theme Six: Knowledge and use of preference tools

It has already been noted that the core data set was created prior to the Mental Capacity Act 2005 and the introduction of new decision instruments. A prompt to talk about 'living wills' was however included in all interviews. As might be expected, there was widespread ignorance and misunderstanding about their aims and legal validity. Refusal of CPR tended to be conflated with refusal of all life sustaining procedures. Among those who regarded advance decisions as valuable, the most frequently cited reason for not having made one was that it was 'too early' in the

course of their terminal illness, even though being in receipt of benefits (Disability Living Allowance or Attendance Allowance) meant many had a prognosis of less than six months to live. This attitude towards advance decisions strongly echoes Theme One. Some data also suggested that for participants, simply not knowing what their preferences were was an inhibiting factor, particularly when seeking to make plans independently of medical advice.

- These data powerfully reinforce existing understanding of impediments to using preference tools. They also serve as a commentary on the National Bereavement Survey findings relating to patient preferences. It is clear from our data that many patients will not have considered their preferences in detail or discussed them with family, so data in the National Bereavement Survey relating to care organizations' compliance with patient preferences may be unreliable.

Theme Seven: Incidental data concerning perception and experience of iatrogenic harm

The secondary analysis yielded an unexpected finding, which was a strikingly high rate of perceived medical harm among those interviewed. Interviewees identified misdiagnosis, delayed referral, and serious medication side-effects in nearly half of the interviews. Some also ascribed their illness to iatrogenic harm, although these ascriptions might be misleading (e.g. referring to the coil as a source of breast cancer, which might apply to the Mirena but not non-hormonal contraceptive coils). In biomedical research terms these data are of limited evidentiary status because they are retrospective reports. However, they are of ethical and psycho-social significance.

- These data are undergoing further analysis.

Part B

Methods

This report is based on a secondary analysis of interviews collected by researchers based in the Health Experiences Research Group, University of Oxford. These data were created as part of an award-winning patient information project published to the web as www.healthtalkonline.org

Data about patients experiences or health and illness are collected in accordance with a highly regarded qualitative research protocol. The methods used have been described by the National Institute of Health Research as the 'gold standard' for qualitative research in health experience. The research has been approved by a National Research Ethics Service Committee, and all data gathering and data processing is carried out in compliance with the terms of this approval. Data are copyrighted to the University of Oxford for use in broadcasting, teaching, research and publication.

The sample

Each research project focuses on a different condition or health issue – for example, cancer, heart disease, motor neurone disease, caring, and bereavement – and includes interviews with 40-50 participants from a range of social and geographical backgrounds. A diverse purposive sample is recruited via the following routes: GPs; other primary care staff such as community nurses and midwives; hospital

consultants and specialist nurses; expert advisory panel members; local and national support groups; advertising online and in local newspapers; and snowballing through personal contacts.

This analysis was based primarily on interviews drawn from the Living with Dying section of the site. In addition the following sections were appraised by either a keyword computer search or through review of the thematic analyses already published to the web on www.healthtalkonline.org:*

Breast cancer
Colorectal cancer
Heart failure
Leukaemia
Lung cancer
Lymphoma
Motor Neurone Disease
Ovarian cancer
Pancreatic cancer
Parkinsons Disease
Caring for someone with a terminal illness

Participants in the Living with Dying section identified themselves as having a condition considered terminal. In some cases, participants were close to the end of their life and were anticipating death in the near future (within a matter of weeks). Other participants anticipated living longer.

As the Living with Dying topic was the core data set for secondary analysis, most quotations below have been drawn from it. Each interviewee has been assigned a code number for ease of identification.

The interviews

The interviews are a combination of narrative and semi-structured method. In the first part of the interview participants are encouraged to start telling their story in their own words. This narrative is not constrained by the researcher's questions. Whilst participants probably shape their narrative so as to manage impressions and put themselves in a positive light, they are free to choose what to divulge. These data thus afford opportunity to extrapolate theoretical or thematic constructs from patient accounts of lived experience.

Later sections of the interviews are semi-structured. Here the interviewer has invited comment on specific issues identified in the literature; or issues which have become apparent in interviews conducted earlier in the project and which merit further exploration.

Analysis

The transcripts have been reviewed using analytic expansion and retrospective interpretation. The full transcripts were re-analysed with a focus on how participants conceptualised the decisional context and decisional challenges that faced them at end of life. Once preliminary re-analysis had been completed, and notable features of the participants' experience coded, the data were reviewed and grouped into the first six conceptual themes above. The seventh theme – referring to incidental findings of

* Original research for Living with Dying was carried out by Alison Chapple and Audrey Chamberlain. For full research credits please see the end of the document

medical harm – has not yet been analysed in detail, and is not a separate conceptual category as such. Those findings are not reported here.

Part C

Findings

Interviews for 'Healthtalkonline' modules characteristically commence with the interviewee outlining initial awareness of ill health and the path towards diagnosis of a condition. There is therefore a considerable volume of interview material that addresses diagnosis, and consequently the theme of 'breaking bad news' about a condition that is potentially life-limiting. I have not included that material here, for two reasons. The first is that there is nothing significant to add to the plentiful material already in circulation, including on the www.healthtalkonline.org site. The second reason is that for most of the interviews reviewed for this report, diagnosis of the specific condition had come years or months before the illness finally came to be acknowledged as likely to cause death within the near future. I therefore pick up the 'story' at a later point.

Theme One: Avoiding, resisting, recognising and accepting the curtailment of life.

Although all of the participants had volunteered to be interviewed about their experience of having a 'terminal' condition some objected strongly to the use of this term. One indeed withdrew permission for her interview to appear on the 'Living with Dying' part of the website because she did not want to be publicly identified as having a "terminal illness". By way of contrast, others made it a point to press on the interviewer that they were truly at end of life, and described the impact this uncomfortable truth had on others. Accepting the notion of "terminal" illness was not a matter of proximity to death. Some interviewees with a longer prognosis were more accepting of the term 'terminal' than others apparently much closer to death.

So one interviewee, chair of a local group supporting an organisation that supplies end of life care, commented:

When I got the letter [a circular invitation and patient information leaflet] I was very angry, more than upset, by the word terminal which I think must be taken out of this research. Because no illness is really terminal or people who have an illness, don't always think they'll get better, I think the majority of us think we'll get better. And where there's life there's hope and I think to be named as somebody with a terminal illness is absol... is quite wrong, because I think we must all be positive and think that we can cure this illness and think of it as just something we can cope with and it'll go and we will live, I don't want to know how long I've got. (LD 26 colorectal cancer)

On the other hand, this COPD patient was clear that her disease was end stage and sought to bring that home to the interviewer:

... since I've gone end stage people feel uncomfortable, friends who were here all the time, you truly discover who your friends are now. Your true friends are still here but a lot

of them can't cope with it. People can't cope with the fact that you're, you know your illness is going to make you die and they don't know what to say, they feel uncomfortable...It means it's gone to the point of no return, it means the lungs have got that damaged there's nothing that can help them now. It also means that I have to think seriously about how my quality of life, how it will be now. But really it's so...so it's not brilliant, I'm a prisoner in the house most of the time. (LD25 - COPD)

Several interviewees reiterated at points during the interview that they were not dying but living. For example

I didn't tell [my children] I was dying, because I'm not. As far as I'm concerned, I'm not - I'm living. And this thing isn't going to kill me just yet. It's going to help me, them two are going to help me get through. And that's the only thing you can tell them. You tell them that you are ill, very ill, and no matter what happens, I'm always here; so. (LD01, brain tumour)

Seeming to anticipate - and wishing to avoid - a form of 'nocebo effect', many interviewees assiduously avoided negative labelling of any kind. References to using positive thinking to get through the illness – indeed overcome it – were also a common feature.

We talked to [the surgeon], about, you know, the cure and he said, "Oh, it's not a cure". And that was a big shock to us, knowing that I was going to have this [um] radical surgery but still not be cured. [ah] And he told me then that without the operation I may live six months to a year - with the operation it may give me another year and that was a big shock. But we decided, that's myself and my wife, that it was our best chance of survival, you know. Rather than go away knowing I was going to die within six months to a year. We would go away and give it our best shot and our plan is that I'm going to be the first survivor. So that, that's our plan. (LD19, lung cancer)

Interviewees frequently echoed the title of Charmaz's definitive study of chronic illness (Charmaz, 1991) commenting that they had good days and bad days, had learned to take one day at a time, and would not look too far into the future. Indeed, this was what professionals had advised them to do, as in the following example:

... my hospice nurse is...able to make suggestions and speak from her own experience and also make sort of wise comments, you know. Such as to take one day at a time, which seems a very, it might seem to some people a trite thing to say, but in fact, I came to see that as very important, particularly sort of on bad days, because you can have bad days and better days. And it, it's, it's a very useful idea if you really take it on board, that you take, take one day at a time. (LD 04, leukaemia)

Determined optimism, refusal to entertain negative thoughts or emotions, and not thinking about the future, were frequently apparent as key coping mechanisms.

I: Do you ever think about how, how the immediate future might go?

R: Not really I think you've got to take each day as it comes. I can't do, you can't plan your future can you, you know, you just, you just say well that's that and when the time come I can't look after myself then I'll have to you know go somewhere where I, you know where I will. (LD23, breast cancer)

Several interviewees described a point at which they had been brought face to face with their prognosis, for example when making an application for benefits available only to those terminally ill. (Those under retirement age with a prognosis of less than six months to live are entitled to Disability Living Allowance, which is not means-tested. For those over retirement age, the equivalent benefit is Attendance Allowance.)

A benefits application was often initiated by the Macmillan Nurse, as in the interview below.

No, you see [the nurse] has asked me that [the prognosis]. I didn't ask [the doctor], there again I didn't ask, but perhaps, did I ought to, do you think?...Going back a little while when she got me the extra £55 or £56 per week which made one hell of a difference to us, believe you me...

(Gets upset at this point)

...on the form that I saw, it was that I was terminally ill. But that - no one had really told me that - not actually said, you know, and terminally ill could mean as little as 6 months. (LD03, colorectal cancer)

One interviewee became aware of her terminal prognosis through her financial advisor's efforts. Having consented to a GP's assessment for actuarial purposes, it became clear to her quite how limited her future life-span would be.

And the gentleman who was arranging [my late husband's] estate he put it to me that if I really was - and that's what everybody does say - "Are you really at least eighty percent disabled?" - He said, "If you really are I'm pretty sure that there's a new company who are doing something for people who are terminally ill and that they expect to live no longer than ten years". So I said, "Well what's involved?" He said, "Well we put a lump sum in and," he said, "there are perimeters within which they will consider," and he said, "I think, I'm almost sure I can arrange that but in order to know whether or not you qualify they will ask your GP to give you [um] a check-up". (LD22 sub-arachnoid haemorrhages, epilepsy)

Because of the association between cancer and terminal illness, the following interviewee, who had been very unwell and on dialysis for several years, had found a diagnosis of breast cancer more shocking than the prospect of kidney failure:

But I think that upset me more than the kidneys, in a lot of ways, because you talk about “terminal cancer”, but people don’t talk about “terminal kidney failure”, which is actually quite likely to happen. (LD36 renal failure and breast cancer)

Some interviewees were aware that they had been given a prognosis, and had clearly chosen to avoid thinking about it. Others believed that their prognosis had not been explained to them. As these were retrospective interviews, exactly what patients had been told by care staff remains unknown.

Theme Two: Information seeking and treatment decisions

This theme reflects interviewees’ thoughts on seeking information about their condition and its medical management.

In the past few decades healthcare law, ethics and policy have come to place particular value on informed treatment decisions and patient autonomy. With informed consent at its core, medical law casts capacitous patients into the role of critical appraisers of medical information. Ethics has supplied a richer account of the demands of autonomy, emphasising that it requires more than information to support true patient self-determination (social norms, adequate resources, and decisional support for example). Health policies in turn promote shared decision making for a range of instrumental, political and moral values. So there is a widespread consensus that shared decision making is a social good. But shared decision making in the wake of a diagnosis of terminal illness can be particularly challenging for both patients and care staff.

Even fully capacitous patients may struggle with the role of critical appraiser and collaborative decision maker when unwell, vulnerable, or coming to terms with the prospect of life-limiting illness. In the *HERG* data, there is a marked diversity in patients’ desire for information about the terminal stages of illness, their information-seeking behaviour, and their readiness to make shared decisions. While some interviewees viewed knowledge as power - and the more the better - some interviewees actively sought to avoid negative information, regarding it as prejudicial to their health and well-being.

It should be noted that interviewees spoke at considerable length about practical aspects of managing their illness and its treatment. There are extensive interview data on the role of care staff in instigating and co-ordinating social care and support, providing information about self-care, disability aids, welfare benefits, and so on. For many, Macmillan Nurses and community providers such as District Nurses provided an invaluable lifeline, and they were key to integrating what was often an unco-ordinated patchwork of different services. However, consistent with the underlying purpose of this secondary analysis, I have focused here on interviewees’ interest in getting information about *their illness* and about the *treatment decisions* this necessitated.

(i) Expectations of shared decision making

First, we should be clear that many interviewees normatively expected to participate in collaborative decision making. By ‘normatively expected’ I mean to convey that they regarded it as a moral right, anticipated participating in shared decisions, and experienced a sense of moral outrage when they imagined or experienced things

turning out otherwise. This interviewee articulated a view shared – as will be seen in later extracts - by many others. It was not always expressed as strongly:

When it concerns you and your body you cannot make a wrong decision because whatever decision that you make is the right decision for you...I, I feel very strongly that there shouldn't be discussions in huddled corners and mumbles and murmurings. I want to know everything about myself and the contract that I have with my health care providers and the people that treat me and the people that administer to me is that you can treat my body as long as you tell me everything. The minute you start holding information back from me or not telling me anything then you lose the license to treat me. (LD09, kidney disease)

(ii) Finding the right language for shared decision making

One of the difficulties both patients and care staff encountered was finding the right language with which to approach collaborative decisions. Interviewees commonly emphasised their need to maintain a positive outlook, and expressed an aversion to terms such as 'terminal' or 'fatal' which carried negative connotations.

Interviewees' desire to protect themselves and others from too blunt a description of their situation should not be viewed as simple avoidance behaviour. It was more a recognition of the 'fateful' nature of language and how, in defining reality, language affects how individuals feel and how others behave towards them. Interviewees resisted definitions of reality that might place them in social, psychological, or physiological jeopardy. The interviewee below, who had 'set his affairs in order' soon after diagnosis, reflected how the label 'terminal' affected his thinking so that he now avoided it.

Both my wife and I as I mentioned just now, we've been very positive in our approach and my wife objected to the term terminal illness more than I did probably and I think her feeling was that when you talk about a terminal illness it implies that you're going to die within the next twelve months or something, death is imminent. And neither of us really feel that. ... Of course if you include the terminal description it does bring a different focus to it - once you start talking about terminal illness and death you start thinking in a totally different way than if you've got a chronic illness where you know you're going to struggle on for the next twenty years or so... (LD21 cancer of oesophagus)

But interviewees also described finding professionals' euphemistic terms, false optimism and avoidance of plain speaking either frustrating or patronising.

Maybe they assess people as to their ability to cope... I don't know. I'm quite sure they do it differently for different people...I can't understand why they thought I couldn't cope...I kept asking whether - there'd been lots of meetings - I kept asking for them to tell me the whole route of what they thought it was going to take, what was going to happen to me.

But it was always “Next, next, later”, or “Everybody’s different”. But I’m quite sure they knew certain characteristics were going to happen. (LD06 Multiple Systems Atrophy)

...if other people are out there and just found out they've got a terminal illness or a life shortening illness, don't be frightened to talk, don't be frightened to ask questions. And to medical people out there, please, we don't break easily, talk to us. (LD25, end stage COPD)

One of the interviewees who objected to the use of the word ‘terminal illness’ reported instructing care staff on the matter of language:

...with a student nurse, when I told her what the problem was she said, “Well that’s fatal isn’t it?” Which I thought was really rather funny so I put her right and told her she really mustn’t say this to people.
I: What did you say to her exactly?
R: I can’t remember exactly but I burst out laughing and said, “Don’t ever say that again to a patient”.
I: Did she understand what point you were making?
R: Well I hope so, I hope so. You mustn’t say anything’s fatal. Because as you can gather from the rest of the interview I don’t think things are fatal. So long as there’s life, there’s always hope. (LD26 colorectal cancer)

Not a few interviewees struggled to convey how important it was not to be badged and labelled as ‘terminal’ – with all the attendant disadvantages – and yet equally how important it was to hear clear description and plain speaking. The next interviewee was emphatic that labelling patients was unhelpful, and equally emphatic that patients were capable of and wanted to be involved in shared decision making:

I think with any serious illness, life threatening or terminal, there shouldn't be labels. You should be treated and looked at as an individual. What's going on inside you doesn't – you, it does sometimes, it will affect your thinking and, and your brain and perhaps in time - but normally, a lot of people still can think, can talk for themselves, explain what's happening for themselves, you know.
- - -
I think you make informed decisions for yourself if what people are saying to you is made perfectly clear and not jargonised, you know sort of thing, or as if they're talking to a fellow professional and things like that.

(iii) Initiating information exchange

Following on from some of the views already cited, interviewees were divided over whether information should be volunteered by care staff or whether they should wait for patients to initiate a request for information. The following examples give a flavour of the views expressed.

One interviewee’s wife, who was present during the interview, commented:

Even the surgeon at the [hospital] wanted to tell [my husband] certain things: “yes they had got the tumour out but, no he wasn’t fully clear of it” But I think that there’s only certain times people can take that on board, you don’t destroy somebody after they’ve been through the operation by telling them “we’ve only got 80% of it out and you’re still living with 20% of it”. There are times when they can be very very harsh; but that’s their perception of the way they have to conduct themselves as you know, professional people. (LD30, Wife of man with bowel cancer)

Her husband added

I think that it's, in some ways its ridiculous to tell something that's not necessary - which could have a counter productive effect, especially on a person who is very ill at that particular time like. I find that an astounding stance to take, really like, you know. (LD30, bowel cancer)

A patient activist who was living with ovarian cancer compared her own experience, and her appreciation that the conversation had been opened, with the views of fellow patients:

...that's already been discussed, whether I want to go to hospital or the hospice or whether I want to stay at home. But that's only because the Macmillan nurse knows me so well. Having said that, I've got people who've got ovarian cancer where their Macmillan nurse has gone round and discussed things like that too early and upset the patients...then they're sort of 'don't give me another Macmillan nurse, don't send anymore to me'. (LD37, ovarian cancer)

And other interviewees noted with approval those instances in which clinicians presented a frank picture of the course of their illness in an appropriate way.

...I am deteriorating and I - the word that was used to me - that I was, because I was. Because I like being spoken to frankly and I ask to be spoken to frankly. And the doctor said, “Well [his name] you’re on a slippery slope, your health in three years...” and it measured by the way I’d deteriorated. He said I’ve come down from nineteen and a half stone to under eleven, and I’m no longer able to swim, I can’t walk at all now, I’m totally dependant on my wheelchair and - But they did prepare me for this. (LD27 MS)

Common to both groups were comments that information needed to be presented the right way. Even those who expressed a strong preference for direct and frank information also offered stories of how information had caused distress by being offered unkindly or thoughtlessly.

(iv) Seeking a prognosis

Interviewees were divided on how far they wanted to know the course of their illness and how long they had to live. As we have seen, some sought to avoid negative

information. Some appreciated plain speaking. Many commented that they did not believe that a doctor could give them a definitive prediction of their life span. Others sought greater clarity than they were offered. An example of each of these follows.

Not 'needing to know'

I haven't asked them specifically how many years I could expect and I'm not ducking that question but I do believe in adopting a very positive approach to the whole thing and I don't need to be told it's one or two years. I don't think I would welcome that. (LD21, oesophageal cancer)

'Needing to know'

I think they [doctors] should be aware that somebody like myself wants to be in charge and therefore wants to know all the possibilities of the illness, all the side effects, all the possible symptoms. (LD15, breast cancer)

Expecting doctors to prognosticate

I'm not putting it all on doctors to turn round and, say, got a magic crystal ball, and say this is going to happen and this isn't going to happen because that is silly. But they can give you percentages. I'm quite sure that it is well within their powers of assessment to be able to do this. (LD06, multiple system atrophy)

Exempting doctors from prognostication

I never pressed any of them to give any kind of prognosis because one knows how very difficult it is and the disadvantage of taking a figure rather out of the air, which might or might not prove to be correct in the event. So I'd much rather not think of it in those terms and just cope with problems as they arise. (LD38, bladder cancer)

(v) Finding the right balance

In the next example, the interviewee describes how wise guidance and clear information should not be viewed as alternatives but are, rather, complementary to one another. Feeling that he needed both expert counsel *and* frank information, the lack of information about what to expect in future was a source of significant anxiety. In common with many other interviewees, he viewed nurses – who he thought had more time to spend with patients – the natural source of the information he sought.

...I think that most people, doctors and consultants, are there because they have a lot more experience than the patient has, and you ought to talk to them and respect their judgement, especially when you are discussing things and deciding things, what you are going to do. In nine cases out of ten they have a lot better judgement than you have.

I: And at the moment do you have any particular worries or fears or anxieties? What are your biggest worries at the minute?

R: Things happen in a sort of step change, and I would like to know what's going to happen next. Yes, I am anxious all the time.

I: Have you ever asked anybody what's going to happen next?

R: I've tried to broach the subject with people, but I don't get a clear answer. I'm sure people who talk to different people - this is how nurses can help. They see so many patients and they have a very good idea of what's going to happen next. I wish they would guide us a bit more in that direction. (LD42, prostate cancer)

Several interviewees did however recount with gratitude how grim news had been clearly presented to them, in ways that gave them something to 'hold on to' in the way of optimism or hope. The following example gives a flavour of how interviewees experienced an appropriate balance.

The person who cared for me throughout the illness was absolutely brilliant and he was completely straight forward with the grim statistics. And when we went into the chemotherapy he said to me, and the words ring in my ear, "If you survive the first cycle of chemotherapy you'll have a better chance of surviving the second". So we all knew that you know it was touch and go and that helped me because I sorted out my will you know, I thought about lots of things that I needed to think about if the children were going to be left without either parent and - I would have resented not knowing. (LD35 multiple myeloma)

Theme Three: Expectations of the dying process and what it might entail

Understanding of the dying process appeared to be extremely patchy, even among those whose illness was very advanced. Interviewees based their expectations on what they read in books or the internet, on what health professionals told them, and perhaps most commonly, on deaths they had witnessed among friends and family. Interviewees' limited understanding of what was involved in dying inevitably led to scant understanding of the sorts of medical decisions which might be required, and about opportunities to express preferences in advance. (These are discussed under Themes Four & Six)

Many interviewees had sought information about their *condition* on the internet or in material produced by support groups. However, far fewer referred to having looked specifically for information about the *dying* process or about end of life care. The following extract is therefore slightly unusual, from an interviewee who made clear throughout that he had taken steps to get as much information as he could about how his condition would lead to his death:

I: So, it's not the illness that's going to lead to dying, it's an infection you might get in the chest?

X: Yes - it is. I am losing control of my throat so liquid or food can go down the wrong hole. It seems I've lost the ability to cough, that I can only do spasmodically and so once some stuff goes down there, that's when the infection will start.
I: I understand, yeah.
X: That's what I understand: nobody's actually told me that.
I: Nobody's told you: how did you find that out then?
X: I read it in a book. (LD06, multiple system atrophy)

And this extract is rather more typical of the position of the majority of interviewees at the time at which they were interviewed:

R: I don't actually fear dying, I fear that, I fear the what leads up to the dying I think as I said to you before. To me dying is just like going to sleep and that's it, you don't know that you're not going to wake up. But I certainly fear the pain and illness that might go before it.
I: Have you been told by anyone what that might entail or have you asked?
R: No I haven't no. [laugh] I just know that cancer can be very painful.
I: Do you think you might ask some time?
R: I think if the sarcoma rears its ugly head again yes I might.
I: But not till then?
R: Not till then no, there's no need for me to know, there's no need to put myself through that situation, not at the moment no, no. (LD15 breast cancer)

A handful of interviewees mentioned that they had pressed care staff to describe what would be likely to happen to them in the final stages of life. Interviewees' recall of the information supplied by health professionals indicates that *either* they receive a comforting account of 'fading away' with managed pain, *or* that this is what they choose to remember.

Well they say, with luck, I shall just get weaker and weaker and gently fade away, which would be ideal. (LD07 breast cancer, metastases in liver, lung and bones)

...but I have asked "What do, what must I expect? What is going to happen? How will it, you know, end?" And they have explained it very well. They have said "you will gradually, as it gets, may get tummy gripes," she said "we must keep the bowel going, which we will keep with the Movicol, whatever. If necessary you'll have to have a colostomy. Um we'll keep that going and we'll keep you going as long as possible. If there's pains we'll give you stuff for it, and gradually as it takes over it'll eat into organs and it'll stop going and you'll just get, you'll find you're getting tired and you'll be sleeping more and eventually you'll just sort of go to sleep, you know, you'll go into a coma" she said "you won't feel much about it" which is nice to know. I feel I needed to know. I'm probably being morbid with people because I really feel I want to know...(LD41 ovarian cancer)

I don't know. I, again I, I don't know from the doctors what is likely to happen apart from they say I will just get weaker and weaker and as more pain occurs in the bones then I will be given more painkiller. Eventually that painkiller I suspect will be Diamorphine and from 2 milligrams, you get to 4 milligrams, to 8 milligrams and whatever it is to take, keep me out of pain. (LD14 prostate cancer with metastases)

These received or remembered accounts of what to expect at the end stage of life are interesting when read in the context of quantitative survey data on pain management in the last three months of life, reported in the 2011 National Bereavement Survey. Those data will be discussed at the end of this section.

Expectations based in the experience of the death of another were more divergent than expectations derived from information from professionals. Some interviewees anticipated a dignified exit with well-managed pain whilst others feared that indignity and/or pain would accompany their death. The following two extracts are typical of these contrasting expectations. The first interviewee is confident that pain can be managed and looks upon the dying process with a degree of equanimity; the second, having seen friends dying in pain in the hospice he attends for day care, is more apprehensive.

I think palliative care nowadays is so extremely developed that it, people, the professionals have assured me that it needn't be a painful experience. And [uh] I've even had, you know, you need to dot the I's, cross the T's, and so, there were things that were bothering me when, I had a MacMillan Nurse come and, a young man, and he didn't mince his words. He said, "Do you want to die at home or do you want to go into hospital?" And I said, "I, I'd prefer to be at home". He said, "That all right, We, we can do that for you so don't worry about, and we can control the pain as well". Well, if he says that that's good enough for me... .. My father died with cancer, my wife did, my mother-in-law, her, my sister-in-law so I'd seen the effects of cancer and so I, I felt that I know the progress in, in the illness in many respects and I know how competent people are in dealing with the pain and the symptoms and that's quite comforting to know that [uh] that can be cared for, catered for, yeah. (LD16 Prostate cancer)

But one of my major concerns all along is pain, I'm not particularly sensitive to pain but that aspect of it always has worried me and therefore I guess it set me thinking how am I going to die...On the one hand it's helped me to speak to people who've got very serious illnesses like myself and how they cope with it, on the other hand to some extent it has depressed me in that I've come across a few people who have reached a very advanced stage of their illness...One poor guy covered in bedsores now that has, that brings me down. And because I've seen people like that I have also given some thought to how I want to approach the end. I've thought about that and it's certainly not fighting to the bitter end like these people. (LD21 cancer of oesophagus)

So how do these expectations, expressed in interviews carried out some eight years ago, measure up when compared with recent quantitative data from the National Bereavement Survey?^{*} According to these survey data, the anxieties of interviewees who feared a painful or undignified exit would appear to have been well founded.

Informants reported in the NBS that during the final months of life pain was very rarely completely controlled. This was so even in the best possible circumstances, which was care in a hospice. Even when a person died in hospice, only 62% reportedly had their pain completely controlled, all of the time. Moving down the scale, some 45% of carers for those who died in a care home reported that the deceased's pain had been completely controlled all the time. Those in hospital fared worse, with 36% reportedly having their pain completely controlled all of the time. Strikingly, given that home is the place most of us would prefer to die, a mere 18% of those who reported on the death of someone at home, reported that pain was completely controlled all of the time.

Looking at these figures the other way around, it means that more than a third of hospice patients, more than half of care home residents, some two thirds of hospital patients, and more than three quarters of people who died at home, experienced pain that was not or could not be controlled in the last three months of life.

As we have seen, our interviewees feared indignity as well as pain. The NBS can only offer a partial insight on this aspect of dying, because it asks whether the patient was treated with dignity and respect, *not* whether the death was dignified. (The notion of *treating* a person 'with dignity' is a linguistic peculiarity. It would be possible of course to be treated with respect, with attentiveness to one's dignity, and still leave this life in a very undignified fashion.) But being treated with respect must surely help. So it is disturbing to see again that, even in the *best* possible setting of hospice, 20% of informants reported that patients were NOT always treated with 'dignity and respect' by nurses. In the *worst* possible setting, hospital, more than half of informants reported that in the last three months of life patients were sometimes treated *without* 'dignity and respect'.

Theme Four: Anticipating decisions and getting advice

In the 'Living with Dying' project, Health Experiences Research Group interviewees were prompted to describe the sorts of decisions they thought might need to be made as their illness progressed. This appears to have struck many interviewees as an odd question, and more than a few sought guidance on what was meant. Whether they needed further prompting or not, most chose to talk about financial, legal and other domestic decisions.

Reflecting the data reported in previous themes, few had anticipated the range of medical decisions they might be called upon to make. Those who had consulted legal or financial advisors reported that, if asked about advance decision instruments, legal

* The National Bereavement Survey (VOICES) is commissioned by the Department of Health, administered by the Office for National Statistics (ONS), and based on the more extended 'Views of Informal Carers – Evaluation of Services' questionnaire developed by Addington-Hall and colleagues and now widely used. In 2011 a sample of 1 in 6 was drawn from the ONS database of deaths registered between 1st November 2010 & 30th June 2011. A questionnaire was sent to the name and address of the person who registered the death. The bereaved person was contacted between four and eleven months following the death, and just over 22,000 completed responses were received (a response rate of about 46%).

advisors had known little about them. (I discuss awareness and use of advance decisions below in Theme Six.)

The following two examples are typical of how this part of the interview tended to proceed:

Yes. I think - say we're, we're positive about the future, about survival, but we must make plans in case, you know things don't turn out as we expect because all these, the plans, certainly with the house, the alterations we're having to the house and things like wills and things like that. We need to do them while I'm still able to play an active part in it. And there's things like, changing things over to my wife's name. It's sort of seems irrelevant when, when I say I'm going to survive but it just means that if something happens to me then all these little things, are already, already in place. (LD19 lung cancer)

I think in many ways it just simply helps you to arrange your affairs for want of another word. I now live here in a bungalow but I have already bought a flat in town knowing that if I can't cope with a bungalow, either financially or physically then I shall be in the town where it'll be easier to just go to the shops and things like that. I always want to be prepared rather than caught out.

I: ...so you've thought about making a will?

R: Oh it's made yes, oh yes.

I: And some people talk about making a living will, have you heard of that term?

R: I have heard of it, yes. But I think I've got all my, my affairs in order from that point of view. I have actually got the address of the organisation but when I got to the point of getting in contact I felt that I'd already achieved it. I don't know whether I'm right in thinking that or not. (LD22 sub-arachnoid haemorrhages)

The importance of interviewees' responses to this question is that by and large they suggest interviewees did make practical plans for the future, anticipating a worsening of their illness; *and* they took steps to secure legal rights that they had some knowledge of, thought necessary, and, in particular, which secured the interests of loved ones.

It may be therefore that if preference tools for treatment decisions were presented as practical (rather, than, perhaps, moral instruments) and were believed to be of benefit for family members, they might be treated in the more matter-of-fact way that people seem to approach financial instruments such as trusts and wills.

I include one further extract in this section to illustrate how care institutions focus patients' perceptions of the future through providing certain services. The next interviewee wryly reflected that she had herself organised a solicitor to visit her in hospital, to discuss securing her family's financial future after her death, whilst the hospital had arranged a visit from a wig maker. As she reflects, the difference is that one offers a glimpse of a future with life, whilst the other reinforces the message of

impending death. Should offering to arrange a visit from a rights advisor be as much part of holistic care as a visit from a wig maker; or would this jeopardise the fragile foundation of hope that patients construct for themselves?

... I found myself in hospital shortly after diagnosis one day, dealing with making a will. Because I was desperate that I should make the best possible provision for my children and make sure that they could get through full time education. So I had a solicitor coming to see me. And in popped a wig man. He said, "You're about to have chemotherapy so they've asked me to come and see you, because you're going to lose your hair". So I seemed to be dealing with a future with the wig, and no future with the will, and I was terribly confused! (LD35 multiple myeloma)

Theme Five: The importance of familial practices and processes

From the perspective of medical law and ethics one of the most notable features of these data is interviewees' concern for familial practices, relationships and responsibilities. Family and familial practices entered participant narratives generally without prompting, and in many interviews were a main pre-occupation. Protecting intimates from distress constituted a major source of anxiety, and the data are revealing in how interviewees construed the notion of becoming a 'burden' on family and others close to them.

Notions of responsibility to intimates, altruism and burden occupy an important but under-theorised place in discourses around end of life care. These data point to how concerns for significant others are a core part of the experience of terminal illness, and deserve greater recognition and analysis in the literature.

(i) Responsibilities towards intimates

This first extract is typical of many in which interviewees found that their first thought on hearing a bleak diagnosis or prognosis was how they would share this news with intimates.

The kidney consultant came to me and said, "I think you're very ill, its not a kidney problem as such, although your kidneys are not functioning very well at all, but I'm going to hand you over to the haematology team because I think you've got multiple myeloma"...The thing that concerned me the most was not so much that I was ill with an incurable cancer but how on earth was I going to tell my children? I had an 18 year old daughter, sorry 17 at the time and a 20 year old son who only a few months earlier had lost their father and were facing the prospect of losing their mother fairly rapidly too because my understanding at that time was that I was very, very ill. I, there was family christening coming up...and I thought I can't possibly ruin the christening and have a black cloud over it all. So I wanted to keep the information to myself and I wanted my friend to help me through those few days till the christening was over...(LD35 multiple myeloma)

Many interviewees spoke about how they had discussed distressing information with those close to them. It is easy to anticipate that talking about end of life with children would be particularly difficult, and the *healthtalkonline* site presents a number of interview clips where interviewees describe the difficulties of telling young children and also adult offspring. But interviewees' concerns were not only intergenerational. Some of the most moving interviews are those in which interviewees describe the difficulties of sharing diagnosis and prognosis with partners. One reason for this was wanting to protect a partner from the news; another was needing space to manage their own emotions before they would have to take on board a partner's distress.

For one interviewee, then in her early seventies and suffering bowel cancer, her first priority was protecting her husband of fifty three years:

...They did tell my son, they didn't tell my husband because he is over 80 and he - as you met him now - he is in a rather nervous disposition and I did tell them not to worry [my husband] too much because you know that that would have worried me more, knowing that [my husband] was too worried about me - - - He comes in and he says, 'are you alright?' you know and I say 'yeh I'm all right love', you know I mean I, I can't - I try not to show it to them. I hope [my husband] understands that I'm probably going to go downhill...I am going to ask [the nurse] if she'll have [my husband] just to talk to him really to make it to let him really understand that I'm going to go downhill ... (LD3, bowel cancer)

The following interviewee, who had undergone chemotherapy for colon cancer, describes arranging to receive a prognosis in the absence of his wife:

The last time, she had to go down to Exeter to go to the library or something, so I, I asked the quack, I said, "You know, realistically how much longer do you think I've got?" He said, "Well I gave you six months and you've had eighteen, so you've seen us off for a year." (LD05 colon cancer)

And a female interviewee with breast cancer employed similar subterfuge, wanting to be able to compose herself before having to deal with her husband's feelings:

I managed to have the news without my husband in with me, he's always come in to the consultant's with me, he's always been very, very supportive but I managed to dodge him on that occasion because I had a feeling that the news was going to be very unpleasant. I could tell from the consultant's face and the way that he had talked when we were there together. So with the help of the nurse, the dedicated nurse I managed to leave him sitting in the, in the waiting room when I went in to see the consultant. So I actually heard the news about the two years on my own, which is what I wanted. I told my husband in the car coming home because obviously we were talking about it, he was a bit upset because I didn't want him to come in with me and he was obviously asking me why and I told him why. Because I said, "I wanted to cope with it

myself first even if it was only going to be for a short time," as it was. (LD15 breast cancer)

A different dimension of solicitude for loved ones was evident in interviewees' reflections on what they were leaving behind. For example, many were anxious to leave good memories, as the next participant explained:

So with this regime of morphine comes a lot of mental pictures because people immediately think 'right, you're on morphine you must be getting nearer to the end' ... But the only way I can treat it is by saying 'okay I'll let the morphine do the job that it's got to do, but my job is different, my job is trying to leave memories for the rest of the family'. We had ... a pre-funeral party that we could all enjoy and all enjoy each other's company, so when the time does come for me to have a funeral, people will know each other and be able to talk to each other, and they will be able to have that memory. So that to me will be lovely that they have got that memory. And the other thing that I am trying to do is build memories in the garden ... and ... go to places with different people in the family, go away and have special weekends, buy little bits to bring back to remind people of really, really nice times. So this summer it's a building memories summer...(LD37 ovarian cancer)

Rather differently, some were concerned about the legacy of potential illness they were leaving to children, as was this interviewee with breast cancer:

I felt very guilty for the implications that [breast cancer] made for my daughters. It was very difficult because I knew I'd got to tell them and I'd got to warn them to be careful and to be aware of what could happen to them although as far as I'm aware my breast cancer was not genetic. So that I felt very guilty about.
- - -
I How could you blame yourself when you hadn't done anything?
R I blame myself for what might happen to them I think. Rather than blaming myself for what happened, I blame myself for what the possibilities - of what might happen to them, that they might get breast cancer as well. (LD15)

Whilst interviewees frequently reported distress at having to tell loved ones about their prognoses, and having to deal with loved ones' emotions as well as their own, it also cut the other way. Familial relationships provided an important source of advocacy and, of course, practical and emotional care. One interviewee and his wife discussed how it had been the determination of his wife and her sister that had secured him the best treatment, when he had been too unwell to pursue the matter himself. Believing that he had been misdiagnosed for several years, they took up cudgels on his behalf:

[Interviewee's wife] When [my sister] picked the phone up ... she said "don't take no for an answer, "push" and [my sister] has a very good rapport...[She would ask] "Could you just

listen and explain [my husband's] history and the fact that this has been missed". And I think as soon as the medical professional pick up on somebody who has been missed and it, it could go down the horrible track of you know, we could put this in the paper which is not something they want you to do - they don't want you to start talking lawyers, papers - people sit up and listen.

- - -

[Interviewee] Sometimes they were frightened of [wife] actually, like, you know. [laughs] She used to go in and lay the law down what had to be down like you know because, when you're visiting the hospital and you're gleaning information over maybe a year period, you know, you pick up on things like, you learn to stand your ground.

(ii) 'Being a burden'

The HERG data are also very suggestive of what patients mean when they talk of not wishing to 'be a burden' on loved ones. This is important because 'burden' is an increasingly contested notion in the practice and theory of care at end of life. There remain relatively few studies of patients' meanings when they talk about 'burden', despite recognition that the area is under-researched (McPherson et al., 2007).

Some commentators and professionals argue that patients *ought* not to be anxious about becoming burdensome or dependent, but should be willing to become 'receivers' rather than 'givers' of care. One *healthtalkonline* interviewee who suffered advanced motor neurone disease reported hearing this apothegm from hospice staff, and had found it to be comforting:

Something that I've really struggled with through the illness is receiving help, constantly, and never giving back, or feeling like you don't give back, anyway. That's been something really huge for me to get over. I was always the sort of person that, I liked doing things for other people. I got a lot of satisfaction out of that and I didn't like to be in deficit, if you know what I mean. I didn't like to be at the receiving end all the time. So now that I am, I find that really, really hard. But somebody at the hospice ... they said, "You know, as much as you liked giving, you know, in your past, then there are lots of people that get a lot of satisfaction from giving, and that's their human nature. But unless there are people to receive, then they can't give. And so that's your role now, [tearful] is to be, is to be, someone to receive." And that really helped me, because you know, when I'm ordering people around and asking them to help me to get a glass of wine, I'm actually helping them. [laughs] (MND39)

Although care staff offer these crumbs of comfort to terminally ill patients, in truth it is precisely the notion of 'caregiver burden' that has long been the dominant concern in both research and public policy on informal care. Furthermore, emotional 'burden' remains a common justification for withholding discussion of end of life treatment decisions from family members when the patient is incapacitous; it is held that doing so 'relieves the burden' on them. On the other hand, if caregivers or family *do* voice a sense of burden they run the risk of incurring negative moral judgements by care

staff on their willingness to care and their relationship with the dying person. And finally, patients who cite 'not wanting to be a burden' as an argument for withdrawal of treatment or assisted death are said to be placing themselves and future patients in jeopardy, sliding down a slippery slope to involuntary euthanasia at the hands of abusive families.

Our data cannot refute any of those justifications or normative expectations. However, they do invite reflection on the nature of the discourse around care burden. Johnson et al noted that US patients feared four kinds of burden on family: emotional, physical, social, and financial (Johnson et al., 2007). Whilst some of our interviewees experienced financial worries, free NHS care reduced the nature of this burden by comparison with terminally ill patients in the US. Our interviewees were most preoccupied with emotional burden, the loss of reciprocity in caring relationships, and becoming a physical burden.

The next interviewee spoke eloquently of different kinds of burden: the general burden of ill health on a marital relationship; the sense that her children would feel obligated to her; the unremitting hard labour of physically caring for a seriously ill person at home. While the marital burden would seem to her to have been what she 'signed up for', she was determined to avoid the other two. We pick up the story as she talks about becoming a carer for her husband during his terminal illness, after she had been unwell for several years.

I was still limited in what I could do but at least I could look after [my husband]. He, poor darling, had been looking after me for seven years but when the roles were reversed I think each of us was rather conscious of what burden we'd been to the other one, you know, whichever way it was going...I don't want to go and live near my children. My friends wouldn't be their friends and they would feel a duty of care towards me, which at the moment on a day-to-day basis is not needed. And they lead their own busy lives. It's like going away and booking up for Christmas, I never want that expression between the two of them "Oh it's your turn to have her"...I know one lady who's determined to go on looking after her husband and in the eleven years since he was diagnosed with Alzheimer's he got to the stage where he was blind, dumb, and she thought deaf and she was still pushing food in one end and collecting it the other. He wasn't alive, he was existing. God forbid that I ever got to that. And I can see no point in anyone being, she was having the first break of one night away from him in eleven years. I don't want to lumber myself on anyone or any institution for that matter. (LD22, sub arachnoid haemorrhages/epilepsy)

Interviewees' anxieties about emotional and practical burdens were often coterminous. We heard earlier from an interviewee above how her 'job' had become leaving good memories to her family. Conversely, she was eager to avoid becoming dependent on others, and anxious that if she did the family home would be 'contaminated' by bad memories:

...as you're getting older you begin to think what's going to happen, who's going to be left on their own, my husband and I are very close but we've got, its an old fashioned marriage in

that I do certain things and he does certain things....[Um] So I feel very guilty about saying this but when I first had the prognosis I thought hooray I'm not going to get old and decrepit and be a pain. I'm not going to be dependent on anybody, I'm going to die before I get to that stage. And that was quite a, quite a plus. ...My husband is not terribly practical when it comes to looking after someone who is very ill and I think that I would like, if it came to it, to be in a hospice... I don't think I would want to come home to die. I think I would like to stay where I am because I think it would be very difficult for my family to come to my home, or for my husband to visualise what had happened...(LD15 breast cancer)

Knowing that someone could and would cope with one's growing dependence did not answer the problem, as this gentleman hints:

My feeling at the present time, and it is only a feeling because it's something I have to discuss with my family, and I haven't done as yet, my feeling at the present time is that I would like to go into a hospice because I would have all the support to hand and really I don't want to put that burden on my wife...I will be very much influenced by what she tells me. I know she would be very capable of looking after me at home. But I'm not too sure that it's the best way of dealing with it. I need to discuss that further. (LD21, cancer of the oesophagus)

Neither is it always question of whether the other person would *perceive* caring for the interviewee as a burden. In her comments the next interviewee differentiates between burdening her daughter, someone who would be willing to care for her; and burdening her social circle, of whom it would be 'too much to ask':

The one thing I do not want to have to do is to burden my daughter. Not that she would look at it with as a burden, I know, but she's got her life and her family...I have a very good friend neighbour who comes in and helps me now and does a lot of work for me but again she's older than I am and there'll be a time when she won't be able to do it either. And ok I've got church people but you can only put onto them, or not put onto them... people are willing to help but when it becomes sort of day in day out it's really too much to ask them to do it (LD24 end stage COPD)

Theme Six: Knowledge and use of preference tools

It has already been observed that the core data set was created prior to the Mental Capacity Act 2005, so that interviewees would not have been able to avail themselves of healthcare powers of attorney. However, advance decisions were in principle effective in common law, providing they were valid and applicable to the situation in hand. A prompt to talk about 'living wills' was included in all interviews. As might be expected, there was widespread ignorance and misunderstanding about their aims and legal validity.

It might be thought that following implementation of the End of Life Care Strategy, tools such as the Liverpool Care Pathway and Advance Care Plans would be more widely used than they were at the time of many of the HERG interviews. We should be careful though not to *over-estimate* the spread and impact of advance care planning and use of the Mental Capacity Act instruments.

The National Bereavement Survey (see earlier footnote) makes apparent that a considerable proportion of those dying in the UK today seem unaware that they are at the end of life; and neither have they expressed any preference for where they wish to die. The Survey records that even among those who had been ill for between six months and a year or more before they died, only about a third seemed to relatives to have been aware that they were dying. And in the NBS sample as a whole, more than half of those who died in the UK in 2011 had *never* expressed a preference, to their carers' knowledge, about where they wished to die.

Extrapolating from those figures, therefore, our 2004 purposive sample of people living with dying was no less knowledgeable about choices at end of life than we might expect a representative sample of patients with life-curtailling conditions to be today. Indeed, our sample may have been unusually well-informed even by today's standards. Our interviewees were clearly aware that they had a terminal illness, having volunteered to be involved in the study. (Given how many resolutely declared that they did not see themselves as dying, it does though beg a question about what their bereaved carers might have reported on the NBS about awareness of impending death.) Many of our respondents had discussed their preference for place of death with their partners and, as we have seen, had 'put their affairs in order'.

But their use and understanding of the then available preference tools was patchy.

Interviewees' attitudes towards advance decisions strongly echoes Theme One: a determined stance of optimism, and a sense that making prior medical decisions might generate a form of placebo effect. In addition, the data also suggest that for participants, simply not knowing what their preferences were was an inhibiting factor. Far more had *heard* of 'living wills' than knew what they were, several confusing them with instructions for some form of assisted dying or advance refusal of resuscitation (DNAR). And many more knew what they were for than had entered into one.

Typically, those who had long term illnesses such as MS and MND and had engaged with active 'condition charities' were those most aware of preference tools. For example, this interviewee with MND had a clear 'letter of wishes' that had been discussed with all her care providers:

...my family know I've got a...letter of wishes... A living will, that's the same...I've made all the decisions that I want. I'm not interested whether my family like it or my friends like it. That's for me to decide...I don't want a tracheotomy and I don't want to be force-fed...I don't want my life to drag on when it's not necessary and they're fully aware at the hospice, they're brilliant.

Intriguingly one interviewee with MS reported how her advance decision had been implemented:

... the first thing of course we make a living will, so that, as I explained to you, I've a bad heart so if, and I've, this is done and the hospitals and the hospice I attend are all aware of this and it's in writing, that if I collapse and have a heart attack, I am not to be resuscitated at all, that's done. They won't, they won't kill me, they won't let me commit suicide or they won't, they will do what they can without trying to resuscitate me. That's happened to me once and I - I'm not quite sure now what they resuscitated but I'm glad they did because I kept my brain but - after that I seemed to have gone to pieces in many other ways. But that's one way of doing it. (LD27 MS)

Among those who regarded advance decisions as valuable, the most frequently cited reason for not having made one was that it was 'too early' in the course of their terminal illness. This was so even in those cases where the interviewee was in receipt of benefits (Disability Living Allowance or Attendance Allowance) for which the test of eligibility was whether they had a prognosis of less than six months to live. And as with the next interviewee, there was some confusion whether any 'living will' would anyway have been legally binding.

Actually when I went to remake my will shortly after having my diagnosis, I asked the solicitor how to go about making that and he wasn't all that sure but he kindly researched it on the web and gave me some print forms which to be honest I haven't filled in though it is my intention to. Because, as I was thinking last night in the concert ooooh you know, I want to be here in this lovely world as long as I can be. That's with the proviso that once my quality of life becomes so poor that I am in pain and I can't do anything or whatever. I certainly don't want to be kept alive just for the sake of it. So I must get on and do the form. As I understand it at the moment, making a living will doesn't have any legal force but my GP suggested putting one everywhere that I could think of: with the solicitor, with her, with my children - so that if I am taken into hospital at any time or unconscious or whatever, they are likely to know. (LD 17, kidney cancer)

The following extract is indicative of the confusion about what 'living wills' were for, with several interviewees confusing them with making provision for assisted dying (and evidencing further confusion about the difference between voluntary euthanasia and assisted dying).

R I've thought about [a living will] but I'm not really sure I want to go down that road because again its putting control into somebody else's hands.
I What's your understanding of what it means?
R That if you're incapable of dealing with it yourself you can be taken off to Switzerland and it's done for you. I'm losing control, I'm putting it in somebody else's hands and that's not for me...
I Do you understand anything more about what it would entail, like setting criteria for different stages?

R Not really...No I know basically what it is and I haven't really wanted to go any further with it.

The notion of a 'living will', which could be used to refuse a wide range of potential interventions, also tended to be conflated with instructions not to attempt resuscitation (DNAR). This was so even among those who were otherwise quite knowledgeable about medical decision making, as the next interviewee was. He had taken steps to ensure that all relevant parties were aware of his wishes, and they were recorded in his hospital notes.

I feel strongly that I don't want to be kept alive artificially. I'm now eighty-five and I've had a very good life and I don't want to be a burden in a sort of inanimate way. And so I would rather just die cleanly as it were and - we've arranged this with our solicitor, our GP, and the director of the hospice, and we've signed the documents to say that I don't want to be resuscitated and I'm very happy with those arrangements. (LD38 bladder cancer)

As the extract above hints, among those who had discussed DNARs with legal advisors or their care team, there was a sense that 'Do Not Attempt Resuscitation' either meant, or would be treated by care staff to mean, 'Do Not Actively Treat'. For example,

...when I was taken in with my stroke - one of the doctors, female actually who was covering that ward she came to me one day and she said "[patient's name] I've got to ask this question - but I don't like having to do it but I've got to do it - if you have a cardiac arrest do you want to be resuscitated?" And I said, "If it would mean that my life would be as a vegetable you do not resuscitate me". So she said, "Well if I put in your notes no resuscitation in the event of cardiac arrest are you happy with that?" I said, "Yes". But then when I got better and they started giving me chemotherapy I said to the oncologist I said, "I think we'd better take that out now or else it could jeopardise treatment". And he said, "No problem". And he drew a line through it. (LD31 lymphoma)

The interviewee above may have been confused as to the effect of a DNAR order; or, rather, he may have been quite insightful into how they work on the ground. Other data sources indicate both (a) that patients and families may wrongly believe that a DNAR instruction means that no treatment beyond comfort care will be given; but also (b) that care staff are, without justification, inclined to treat patients less actively in general once a DNAR instruction has been recorded.

Finally, our interviews clearly raise questions about the extent to which patients know their own preferences and concomitantly, how knowledgeable carers can be about patients' preferences.

The National Bereavement Survey asks carers (Q48) 'Looking back over the last three months of his/her life, was he/she involved in decisions about his/her care as much as he/she would have wanted?' There is a reassuringly high rate of affirmative answers to this question – some 85%. Involvement in decisions is perhaps

something that carers are well able to judge, basing their view upon the dying person's reactions at the time. But Q50 asks 'Were any decisions made about his/her care that he/she would not have wanted?' Nearly 20% answered that they did not know, a figure that will be unsurprising to the reader given the data discussed in this report. But in respect of the 17% who answered that decisions *had* been made that the dying person would not have wanted, and the 63% who reported that decisions *had not*, our data would beg the question of how those carers would have known.

Research Credits

Conducted by Suzanne Shale

We are grateful to those researchers who conducted the original interviews. They were:

Living with Dying: Alison Chapple and Audrey Chamberlain
Caring for someone with a terminal illness: Fiona Barlow and Julie Evans
Breast cancer: Suman Prinjha and Julie Evans
Colorectal cancer: Linda Rozmovits
Heart failure: Kate Field
Leukaemia: Julie Evans
Lung cancer: Alison Chapple
Lymphoma: Julie Evans
MND: Louise Locock and Carol Dumelow (principal researchers)
Ovarian cancer: Julie Evans
Pancreatic cancer: Julie Evans
Parkinsons Disease Rachel Miller and Carol Dumelow

References

Charmaz K (1991) *Good days, bad days: The self in chronic illness and time* New Brunswick, Rutgers University Press

Johnson JO, Sulmasy DP, Nolan MT (2007) Patients' experiences of being a burden on family in terminal illness *Journal of Hospice and Palliative Nursing* 9: 264-269

McPherson CJ, Wilson KG, Murray MA (2007) Feeling like a burden to others: a systematic review focussing on the end of life *Palliative Medicine* 21: 115-128