



Experience Led Commissioning (end of life care) commissioning Insights Report

"I think that by and large the way the healthcare professionals handle death, I think in the main they have got it right. And I think in its simplest way it is the time to stop being a professional and to become a human being."

Background to this work

Georgina Craig Associates (GC Associates) works with the Health Experiences Research Group (HERG) at the Department of Primary Care in the University of Oxford to support commissioners to undertake robust, evidence based experience led commissioning (ELC) programmes.

After secondary analysis of the existing archive of health experience data on end of life care by the research team, GC Associates translates insights into people's experiences drawn from the data into commissioning challenges. This interpretation is then quality assured by the research team to ensure it accurately reflects the evidence and the conclusions that can be drawn from it. GC Associates then supports clinical commissioners to implement the commissioning cycle, including facilitating co design of commissioning solutions with local people.

This is the first step in the ELC commissioning process. It is different from a traditional needs assessment in that it is multi media and includes trigger films of people's care experience.

In addition, it combines 'traditional' needs assessment data (provided by partner CCGs) about the needs of the local 'community of interest' with insights into people's experiences of end of life care, drawn from a National data base.

A needs assessment is a living document that develops over time and includes an assets map of local work, services and resources that can be harnessed to help improve care.

As we come across new data and insights, we will include them in this report. The experiences of care described in this current paper are 'generic' and drawn from the National insights data set. They are common to most people's current experience of end of life care.

Through the ELC event programme, you will refine and test this data set with local insights drawn from undertaking focused commissioning co design events with local people so that we ensure we incorporate local people's views. A comparison of National and local work

undertaken¹ has highlighted key areas where local insights are needed – often around access. This will steer the focus of local discussions.

This work underpins the whole commissioning cycle and provides an evidence base for work to improve experience.

The key themes that matter to people are:

Analysis of a robust national experience insights data set², which we know to be a representative narrative and that has been analysed to identify the key issues that impact on people's experience of end of life care has identified key themes:

- Receiving the news
- Thinking about where to die
- Care co-ordination
- Responsiveness of community care and ease of access to benefits
- Responsiveness of in-patient care
- Good pain control and management
- Staff attitudes and empathy
- Shared decision making
- My emotional journey
- My end of life choice (including where I would like to die) versus the actual experience
- Carer's needs, health and well being

Receiving the news

People's experience of hearing their prognosis was pivotal to their experience of end of life care. Clinicians who communicate with patients and their family members clearly, sensitively and adjust their communication style depending on the needs of the patient and their family provide a high quality care experience. Experiences of hearing the bad news suggested that if there was anticipatory planning, this experience could be improved.

Several people said having a meeting with the consultant a week after the diagnosis of a terminal illness was good practice. This allows time for the diagnosis to sink in and for people to begin to think about the questions they want answers to.

You don't take it in, you don't know, when someone tells you have a terminal illness, you don't know what questions you want to ask, you don't know at that moment how you are going to cope with it. (MND28, Motor Neurone Disease)

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The data also revealed how people interpret both what is said and what is not said very carefully.

It's the little things you hold on to. I am not sure doctors always realise that some of their slightly throwaway lines may either help or hinder your progress really. (LD17, kidney cancer)

Well I've reached a stage in my ovarian cancer where I get knowing looks from MacMillan nurses and the doctor because they seem to know, or seem to think, that I am nearer to the dying stage. (LD37, ovarian cancer)

Fully informed and need to know basis

Many people wanted to be kept fully informed of the progress of their disease or health condition so that they could make informed decisions about treatment options and have some control over the organisation of their end of life. Others wanted information on a 'need to know' basis. However, what people understand by 'fully informed' and 'need to know' varies enormously. In relation providing information and discussing the future, there is no substitute for a thoughtful communication manner that adapts for the person.

So I did actually say to my consultant that, you know, "I know I think I've got MND. Please don't drip-feed it to me. Just tell me straight." And that's what he did, very gently but he was none of the drip-feeding that I saw the other lady having done. He just came in and said, "You, you're right unfortunately", you know, "It's MND and I really wish it wasn't". And, but he didn't, he did it very gently. (MND10, Motor Neurone Disease)

The way that the oncologist told me that I was about to die it was handled in such a sympathetic manner that I was actually sitting there watching the process, divorced on one level from the fact that he was talking about me and my imminent death, and I was sitting there thinking this guy is so good I must remember this technique so that if ever I have to fire somebody I can use this technique because it's so gentle. (LC02, lung cancer)

My GP sat down and explained everything to me in detail. And she said, "You'll have it for about six weeks. It'll get gradually less painful and go away. But it's nothing to worry about." And she's brilliant like that. She just takes the time to explain things to me. (MND28, Motor Neurone Disease)

Those people who wanted to be fully informed said that they liked to hear some "good facts as well as bad facts". Even if a person is terminally ill, being told that they are doing well was important.

Another chap I say, who was a stand in for the specialist, he was Irish and he was really upbeat and boosted me. So as much as you want to know the facts, nobody knows the facts because everybody's different. But if you do talk to someone who gives you a bit of a lift then it does help you. (MND25, Motor Neurone Disease)

People who wanted to be fully informed about their prognosis often understood that there was always uncertainty about the future but information enabled them to have some control over decision making and planning the rest of their life, even if this meant being given the worst case

scenario. Some felt they were kept in the dark too long about the possible prognosis and would have preferred some indication of what the problem could be as early as possible. Without this information, even if turned out to be inaccurate, opportunities could be reduced rapidly.

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)

I feel very strongly that there shouldn't be discussions in huddled corners and mumbles and murmuring. I want to know everything about myself and the contract that I have with my health care providers and the people that administer to me is that you can treat my body as long as you tell me everything. (LD09, testicular cancer)

Because at the end of the day, I believe it is better to know, even if it is upsetting. And I think sometimes they just say, well they don't really know what is going to happen when in fact they do know and for me, at least, I'd prefer to know. (MND18, Motor Neurone Disease)

I don't want it to creep up on me and tap me on the shoulder one night at three o'clock in the morning and say "Your turn now", you know, I want to know. (LD09, testicular cancer)

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)

Being informed can often involve hearing uncomfortable or distressing news but many people appeared to cope with this.

And the specialist was very consoling. Of course I don't suppose really they should, it obviously isn't always easy but as regards the mechanics of dying he was very consoling, he said, "You will probably die of pneumonia and it won't be too bad." (MND13, Motor Neurone Disease)

When the consultant neurologist told me of the diagnosis, he said "There is no easy way to tell you. The best advice I can give you is to go home and put your affairs in order." But personally I like the direct man-to-man touch. There was no beating about the bush. I knew exactly where I stood. (MND36, Motor Neurone Disease)

We buried our heads in the sand and didn't want to know

A few people said they did not want to know their prognosis at all, preferring to stick their 'head in the sand'. They either wanted to avoid thinking about death altogether or sometimes doubted the ability of doctors to make useful predictions about what would happen in the future. They felt people experienced illness differently and, as some argued, there was always the possibility of new treatments or medical breakthroughs which could transform their illness experience.

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)

I mean I don't mind that, I mean you work that out for yourself when they say it could be days it could be years, you think well you don't know and they don't, of course they don't because nobody does. I don't just try and, try not to sort of patronise I suppose. I mean most people can understand statistics if you explain it to them and understand I think and can understand that they're part of a distribution of possibilities. Whether, whether people want to be told that if you're, you know well I'm sure they don't, they only want to be told that they're the good ones and not the bad ones. I don't know what the answer is, I really don't. (LC01, lung cancer)

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, oesophagael cancer)

Carers' information needs

In some cases, partners or family members wanted different levels of information or acted as buffers between the patient and the doctor. This again calls for sensitive and flexible communication approaches by doctors.

I know my wife has very different conversations with them. The information she gets is more pointed than that I get. I'm grateful she can cope but it's just too, still too raw for me. (MND29, Motor Neurone Disease)

Room for improvement

Less positive experiences were often linked to clinicians using jargon so people did not fully understand what was being said or the doctor's manner being inappropriate.

There was one occasion where we had to complain to the consultant that one of her registrars, he spoke to us like he was an undertaker, not a doctor, so that's just not on. (LD14, secondary cancer)

When communication did not work so well it was often because the doctors were too tentative in providing information or giving bad news. The following extract, for example, illustrates how one person had read about what he could expect at the end of his life rather than being told about it.

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)

People felt doctors were trying to protect them or found delivering bad news too upsetting themselves to be open about prognoses. This could be frustrating for some people, particularly when they had come to terms with having a terminal illness.

They'll talk to you in an almost childlike simplicity but maybe this is a persona that the medical profession have taken on to treat all patients in the same simplistic way so that nothing gets misunderstood. (LD12, breast cancer)

Thinking about where people want to die

People with terminal illness often think about where they would prefer to die. Hospital is rarely the preferred option. A few said they would accept whatever was best for them and they understood that hospital might be necessary because of the medical implications of their condition.

"Unfortunately the illness that I have the end is very, the end stage is very messy and things stop working and there needs to be intervention. And I don't know yet, I'll have to talk to people nearer the time. I've got an open mind but I don't want, I don't, when I say I don't want to inconvenience people that isn't being blasé, it, it's being honest and practical. You know very much as I would love to be at home here with the things that surround me, the things that I love and are part of me, I recognise that that may not be possible." (LD09, testicular cancer)

A few said they did not want to think about their end of life.

"I recognise the time will come when somebody will be saying to me well we can't really do anything for you now and I'll have to start thinking about well am I going to stay at home or am I going to go into a hospice well when that time comes I, I'm pretty confident I can deal with that and cope with it okay but I guess what it comes down to is I don't want to talk in those terms until I've got to." (LD21, oesophageal cancer)

The most common preference is to die at home or in a hospice.

The decision about where to die was very much an individual one. It is strongly influenced by concern for their life partner or family members. People did not want to be a 'burden' on family members and wanted to leave good memories. One woman wanted to be remembered as 'dignified and peaceful' rather than 'worried and upset'. The data demonstrate how people draw on past experience or anecdotal evidence to inform their decision making.

"I don't want to be a burden to my family that is something that's definitely out of order as far I'm concerned. I've seen other families that endeavour to cope with situations of that type when they couldn't and it practically destroyed the family therefore I, well it's not for me." (LD31, non Hodgkins lymphoma)

Some people were not only concerned about the present, but also thought ahead to after their death. They did not want their homes associated with their death because this would be difficult for family members.

Other things also influenced people's preferences. A few people had personal experience of caring for people at their end of life. One woman, for example, did not want to die at home after the 'incredible strain' of nursing her mother at home;

"I mean everybody says don't want to be, that dreadful burden, I'm prepared, prefer to say goodbye in a much more loving, rational situation and when you've got more control over your bodily functions, or more or less your mind. (LD32, secondary cancer)

I think it would be very difficult for them [children] to come to the house if my husband was here on his own and they had seen me die here." (LD15, breast cancer)

A few women raised the difficult shift from the role of carer to being cared for. They were concerned that at the end, they would not allow people to do things for them at home and, instead, keep trying to do things themselves so the hospice was more suitable for them.

Decisions about place of death were also influenced by whether or not people lived alone, their perceptions and experience of other people's end of life decisions and care and their age. Some younger people, for example, felt that hospices catered largely for older people. They felt very out of place in the hospice setting. People who lived alone were less likely to choose to remain at home as they realised a greater need for external care and support.

Care co-ordination

Continuity of care was valued and rarely experienced. Joined up services and good communication between the different service providers were valued by people. Others said there was little communication or continuity and they bore the responsibility of trying to organise appropriate care. People did not understand why they had to keep repeating their story and why people did not know that they were on an end of life journey.

When services are not joined up and the responsibility falls to carers co-ordinate care, carers find it is difficult to access the right information and that it is time consuming and exhausting.

Based on experience insights, there were certain bits of information whose inclusion in patient and carer care plans and in core hand over information could greatly improve patient experience e.g. patient consent to the carer being told information about prognosis and treatment, simple instructions about how cleaning or washing was to be done

It's been just wonderful, the treatment you get, yeah

Many participants praised the organisation of their care and described how the different health professionals worked together to provide them with a joined up service. The service they received was appropriate, well organised and relevant professionals clearly communicated with each other.

I think the clinic I go to, which is sort of chaired by the consultant neurologist, is a multidisciplinary clinic, with a senior OT, a senior physio and speech, the MND clinical specialist, the neurologist herself - I'm trying to think who else would be there - the dietician, are all present. So there's obviously been a bit of work to get all these ladies together. And for the client to be able to ask any question from a group of specialists at one time I think is wonderful. (MND36, Motor Neurone Disease)

The person that coordinates it all is yourself

Several people felt their care was not coordinated at all and it was up to them, as a 'go between', to try and bring together the different professionals.

I know that the government has brought out this like glossy leaflet. I mean, I've even seen the leaflet which says that for long term neurological conditions people should have more joined up services and more coordinated care and they should pay attention to giving them things as soon as they possibly can and so on. But in reality it's just a leaflet. You know, it doesn't, in my experience, as far as wheelchair services goes anyway, it hasn't led to anything. (MND1, Motor Neurone Disease)

We had to handle it. That's what we found out. We have to handle it. People, different people give different amounts of advice. Some people are very helpful like the OT from the council, and some people appear to be very unhelpful like wheelchair services. But there's no plan whatever happens. You know, you're in charge of it basically. (MND18, Motor Neurone Disease)

Others described how their care was 'disjointed' or how 'parts of care' were coordinated. In a few cases, the care all came at the beginning but was too soon to be helpful. One person who arrived in the country with high support needs said it was difficult to organise care in advance which was stressful. Many participants were aware of the rhetoric of joined up services and continuity of care but did not experience it in practice.

It was a bit all too much to begin with, and now it's almost like, "Where are they?" I think I've kind of sent them away a bit too far. (MND11, Motor Neurone Disease)

Apart from that load of bumph, I thought I would see the speech, the OT in order, but they didn't connect up at all. I think that was because the coordinating person was on leave for two months. (MND24, Motor Neurone Disease)

I think I counted that in the first two months of being here I'd met twenty carers. And that is really dull, telling people how you want things all the time. And, "Not like that or like that" and, yeah, really quite tiring. When I have carers in, I just want to babble on and so that the fact that I'm being washed and dressed becomes irrelevant [...] because you were gassing on about something. (MND39, Motor Neurone Disease)

Other people had difficulty because of a lack of continuity with professionals familiar with their case.

I have six monthly checks and all the other checks have been by a different person every time. There's no continuity of care. Each person as they've come in to see me, until they read my notes have no idea what has happened to me. (LD15, breast cancer)

I know that they're trying for a seamless service and, but it doesn't always work so you're having to, you just still feel very much that you're on an individual one-to-one basis with all the healthcare professionals and perhaps they're not communicating as well as they could do. (MND10, Motor Neurone Disease)

Well, it comes down again to lack of communication and poor administration I think, those are [pause 2secs], you know, the basic faults everywhere between departments and between organisations and the patient. It's, it's just very bad communication. (LD02, breast cancer)

Several people suggested that it would be helpful if a key person oversaw or coordinated their care. The lack of coordinated care meant people had to be determined and prepared to fight for the care they needed.

Responsiveness of community care and access to benefits

People discussed the support they received or would have liked to have received in some detail. For some, a lack of support had an impact on the quality of their lives while others, particularly those with cancer, felt very well supported by particular health professionals, such as district or Macmillan nurses or GPs, or by the service they received at their local hospice.

Insight data showed that once they are on the end of life journey, people need services to be more flexible as their needs may be changing rapidly. This was especially true of community and personal care services that often came at the wrong time to help people. Community services sometimes seemed to be very inflexible.

A strong message from the research is that people wait too long for treatment and access to the resources they need – including disability badges, welfare benefits, wheel chairs as well as clinical care.

We don't have the palliative care we should be getting

Many people described a lack of support which they usually related to a lack of resources. Social service cutbacks, a lack of awareness about particular conditions, geographical variation in the quality and quantity of provision and poor comparisons with voluntary sector provision for cancer were all discussed by participants who felt they did not receive adequate support.

There was no one sort of to, to come along and say, "Well this is what you're entitled to". Really you have to sort of depend on the, the Citizens Advice rather than, some sort of trouble-shooter come to see you and say, "Well yes I can see what you're like and, and you should getting this and you could get that, and this is what you're, this is what you're allowed". It took a long time. (MND16, Motor Neurone Disease)

I had a fall earlier this year, where I broke my hip, and ended up in hospital. The understanding of MND at the hospital was nil. They didn't know what it was. The care was atrocious, and because of the shock to the system my voice went completely, and it was very frustrating. (MND26, Motor Neurone Disease)

But where with my disease and people with other diseases which aren't cancer, we don't have that. We don't have the palliative care, which we should be getting. Some health authorities will have a palliative care unit but it depends if you live in the right road, really. It's the old postcode lottery. A few miles down the road from where I live there is palliative care but because I live 5 miles away from that, I don't get it. (LD25, chronic obstructive pulmonary disease)

Some people felt that their GP's were not supportive enough and they would have liked more contact with them. One person even suggested her GP was "fairly disinterested somehow".

I mean I couldn't really fault anybody

Several people were very positive about the support they received. They felt very well supported by their care team who were accessible, responsive and reassuring.

My family don't want to think about me dying and sometimes I get depressed about it and they don't like me being depressed and particularly my husband, it will set off a row or words spoken. And I can say things there or to my Macmillan nurse and they understand and I can voice my feelings, and vent my feelings about this and there aren't any recriminations and I've been heard and I've listened to and that's the support you know. (LD08, secondary cancer)

In fact it has to be said that the, the district nurses have been a tower of strength when it comes to fighting our corner with problems with the agency for example or with the [um] local Social Services or whatever. They really have been very supportive. (MND09, Motor Neurone Disease)

Benefits help – if you know how to get them

The range of benefits and allowances and the bureaucracy surrounding these were daunting to many people. Some got help from the Citizens Advice Bureau or MacMillan nurses who had experience in form filling.

The other side of it, of course, is how you manage financially, and benefits and all those things. And that's a minefield for people. There's lots of basic information in terms of, "There's this allowance and that allowance and the other allowance." But some things are means-tested, some things aren't means-tested. There are things that are there that you don't know about. And there's, if you don't know about them you can't get them, but you might be entitled to them. And that's happened to us on a number of occasions, where just by word of mouth and talking to other people we've thought, "Well, you know, we can get that" you know. (MND28, Motor Neurone Disease)

Several people were entitled to mobility allowance and were able to get specially adapted car or scooter which helped them to remain mobile. Disabled parking permits were also useful.

And also it enables you to have a parking disc if you can't walk, well if you are disabled, and you need to get out of the car near to where you're going, whether you're driving or not that can be used. And then I discovered also that you can have a dentist come to your own home if there's some reason you can't go to a dentist's surgery. At least to do sort of patching up work and, and I have that. (LD04, leukaemia)

There were different financial implications for people depending on factors including pension provision, age, dependents, level of allowances given, nature of adaptations or equipment they needed and whether the benefits were means tested.

And we also had to pay for the through-floor lift, which was another sad expense, because we had to, we took the back of the garage and behind the kitchen, we, we built a, a kind of extra room behind the garage and we put the lift in that [...] And by 2000 I'd acquired enough money, my, my wife had worked part-time,

so we put all this into trust for her so that she would have a pension. Of course all of this counts against me. So we had to pay for the lift, the conversion of the house, the car, the portable hoist, various other things, which we would have got mainly free had we not had this money. And she's lost some of her money for her pension as well. It's unfortunate. (MND15, Motor Neurone Disease)

Many people talked about the practicalities of home adaptations, home care and the time and effort involved in arranging care.

That said, a huge amount of mental energy and emotional energy has been consumed at our end I think by making sure that we do get what we want. Things, it has to be said, have not worked very well in some respects, like the length of time it's taken to get particular care arrangements in place. Problems with the agency not always being able to provide staff, so you get a phone call perhaps rather late in the day saying, "We can't provide anybody tonight" something like that. And making sure you get the right kind of staff. (MND09, Motor Neurone Disease)

Time is precious to me

It often took a considerable time to organise equipment or adaptations. This was particularly important for MND patients who could not anticipate the speed at which they would deteriorate; equipment could be surplus or not available. Carers and patients said they wished someone would help them to anticipate their needs as they were often fire fighting to get the support they needed when it was almost too late – especially in relation to mobility aids.

You have to anticipate where you're going to be in a, in a few weeks' or months' time, rather than sort of asking for something now that you need now. In the case of setting up the care for example, what we found, and obviously this is just our experience, is it could, it can take six weeks before something arrives. And with a condition like this, you know, things could have changed by then, your needs could have changed by the time you get something. (MND09, Motor Neurone Disease)

I wait for the district nurse to come every day before my day starts

Many people felt well supported in terms of the amount of care they were given yet there were practical issues that arose around this care. For some, the inflexibility of care was problematic.

We did have help but they were coming in at all times and I have to get up when I feel like I want to get up you know but she was coming in eleven o'clock, twelve o'clock, well most days I like to get up about half past eight, nine o'clock and all she's doing is, [my wife] was you know giving her coffee, and she's sipping coffee and because I have a pension I had to pay for it and I think [my wife] didn't like the idea of paying someone just to come and sit down. (LD27, secondary progressive multiple sclerosis)

One woman talked about how the social services staff were no longer allowed to take her shopping which meant her 'normality' was taken away from her. An additional problem was the high turnover of staff.

I did find people who would supply meals and do cleaning and things but it didn't work out very well, because when you needed help they were not always there, and the people who came for cleaning did not come regularly, and you finish up showing them what to be done, and you might as well do it yourself. Offers were there but they did not work very well for me. (LD42, prostate cancer)

Others felt carers were not appropriately trained to deal with their needs.

I mean just because somebody's done a, a manual handling course, it doesn't mean that they're used to handling a patient who has breathing problems, who, who can't shift themselves around in the way that somebody who's more able can. (MND09, Motor Neurone Disease)

Some people opted to try to manage their own care for as long as possible.

We took the decision that rather than rely on nurses to come in and do feeds and all of that stuff, we've all along have said we'd prefer to be trained how to do these things because we wanted to sustain our own independence, so that we could still carry on doing the things that we want to do. (MND23, Motor Neurone Disease)

Responsiveness of in-patient care

People said that their experience of hospital care (especially if it was for non related conditions) was often poor. They expected to be treated differently because they were on the end of life journey; at least with dignity and respect and the reverse was often true. Not many people would choose to die in hospital; and this should impact on decisions about whether to hospitalise people on the end of life journey.

Good pain control and management

The key aim for most people was to have a pain free and peaceful death. The importance of commissioning high quality pain management across all settings is critical.

Pain is probably the worst aspect of any illness

Many people experienced pain as part of their condition and they described the pain as exhausting, debilitating, relentless and, in some cases, unbearable.

The excruciating pain I hadn't mentioned that before, but I am now at this moment in my life, I get excruciating pain, I, I can't really explain. It's as if all my muscles are being electrocuted, that's the best way to explain it and sometimes when I'm in bed, I lay down and I burn as if I'm burning from inside out and yet the feel of my body is cold. Other times I can be perspiring and my lower half of my body is, is burning. (LD27, secondary progressive multiple sclerosis)

Pain level increases all the time and my biggest, my biggest amount of time, my, largest part of my day is coping with what is going on inside my body. (LD07, breast cancer)

I'm never going to be frightened of pain because it can be controlled

Often the pain was managed effectively with medication albeit with side effects such as tiredness or constipation.

I have to take morphine because sometimes the pain can be severe but not frightening because you know that the pain is controlled, you can control the pain because I also have a very good pain consultant and they measure my pain and they adjust my pain treatment accordingly to how I am so I know when the pain gets very bad that something will be done. (LD27, secondary progressive multiple sclerosis)

Many people were taking morphine, either by injection or in liquid form, and found this an effective way of managing pain.

I haven't got any pain no because I'm on 80 milligrams of morphine a day and also on Diclofenac. (LD28, secondary cancer)

Pain management clinics had helped some to develop effective strategies. For one woman this boiled down to 'planning, pills and patience'. She learned to organise her days in a way that reduced pain, balanced side effects of medication- with the benefit of reducing pain - and remained patient about continuing to take medication. Pain clinics helped people with other strategies, for example;

And I agreed with the pain management doctor that I was allowed a worry time, I could worry about all my problems. I wanted three hours but she wasn't having that [laughs], she got me down to about three quarters in the end. (LD22, sub arachnoid haemorrhages)

A few people talked about how difficult it was to anticipate the pain they would experience.

And they talk to you in terms of pain score, of 1 to 10 or 0 to 10, 0 being no pain at all and 10 being the worst pain that you could ever, ever experience. And I've found that it is very, very subjective because what I thought six months ago was pain level 7 or 8 I now realise is only pain level 2 or 3[...] If I could have one wish to do with my condition I would like to experience for ten seconds the worst pain that I'm ever going to have to feel so that I know because at the moment I don't know. My pain levels get higher, I find it very hard and sometimes intolerable to cope with and I am tearful, I make no, I make no mistake about that. (LD07, breast cancer)

Others talked about not taking the level of pain medication they were prescribed because they wanted to monitor their illness;

Say I get a stabbing pain, they say I should take pain killers all the while to keep it under control but my message is that if I take pain killers all the while I don't know whether that's the pain killers stopping it or whether that's just the thingamabob. (LD23, breast cancer)

The benefits of seeing professional palliative care staff for pain relief were clear. Palliative care professionals were praised as knowledgeable. In contrast, GP's were less effective.

So she [hospice nurse] was always good on that, and pain, pain relief, control of pain and control of symptoms I think is one of the things that palliative care does concentrate on. (LD04, leukaemia)

But I can't control the pain effectively

Pain sometimes could not be controlled by painkillers or painkillers were contraindicated because of allergies or sensitivities.

They (MacMillan nurses) have helped me identify that I'm trying to cope with two different sorts of pain. One is the, what I call the background pain, but it isn't background pain any more, that is there all the time from both my kidneys and at the base of my spine and in my bladder and the other is the spasmodic pain where my kidneys go into spasm. [...]. And, I am no hero, I'm very much a coward in some respects and I can't cope adequately with the pain. (LD07, breast cancer)

A few people felt that they were not given adequate pain relief. One woman, for example, said her GP would only give her half of what she asked for.

One of main concerns has been to what extent am I going to be in pain.

People talked about thinking ahead to their death and reflected on how the pain would be managed at that point. Several were confident that they would be given adequate pain relief.

During the last stages when you know, there will discomfort and pain around, and I'm sure they'll give me enough morphine or whatever it is to control the pain. If I ask for it I'll get it, I like to think that and I do believe that will happen. I should say that if I find there is some resistance, I mean I'm not asking anybody to overdose me or anything, but if I find that they're not controlling the pain to my satisfaction, well then I will um be aggressive about it and push them. I'm not reluctant to do that. (LD21, oesophageal cancer)

I mean obviously a painful death has its own problems but then that's what the doctors are there for and I'm happy that the pain control people will look after that side of things and let me die with as much serenity as I can muster when the time comes. (LD38, bladder cancer)

Others were less optimistic and hoped that their pain would be management effectively.

Pain management was a major concern for many of those who wanted to be cared for at home. Being able to deliver good pain management at home and reassurance for some people that pain could be managed at home was important.

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 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. (LD16, prostate cancer)

Staff attitudes and empathy

Some people felt that health professionals did not seem to know how to behave towards them and treated them differently because they were terminally ill.

And my wife said [to a paid carer], "You're struggling, aren't you?" She said, "What do you mean?" She said, "I think you're afraid of death". And she said, "Yes, I am. Does it notice, do you notice it?" [...] And there's a tendency to think of a person as being something less than human, as if they haven't got feelings. Well, they're them. And they're the same as they've always been but they've just got a nasty illness or they're close to death. (LD16, prostate cancer)

I definitely needed more emotional support from the medical profession early on but sadly, probably due to time restraints, none was forthcoming. (MND21, Motor Neurone Disease)

We need, we need the oncologist nurse, or whatever, to help us, and we need that help, and they need to understand it's not textbook, it's human lives, it's human beings. It's individual. Detach yourselves away from the textbooks and live with the reality side. (LD01, brain tumour)

Poor communication between doctors and patients was sometimes resolved by finding information on the internet or from other health professionals

Well, I have not been hesitant to ask my doctors about things, and also I've found out quite a lot from the internet. But, even so, there would be times when I, I didn't feel I had enough information and then I would ask my hospice nurse and she would either know or suggest a way that I could find out or suggest how I could perhaps put a question to my doctors when I next saw them. (LD04, leukaemia)

My emotional journey

Accepting that you have a terminal illness and you may be reaching the end of your life can be very difficult for people to cope with. Many people described anger, fear, regret, sadness, panic and blame. Some said they were still in denial over the diagnosis and were reluctant to engage with the idea they might die in the near future.

I don't want to give up. I will try till to the end, or till I get rid of it, until I cure this thing. I will try to cure this thing.(MND33, Motor Neurone Disease)

Denial was seen as a stage in the grieving process.

Yeah so you, you, you grow to accept your diagnosis and as, as everyone will, as everyone says your GP will tell you, you'll go through a grieving process. But my GP was talking about the grieving process and she made me laugh because she said about these stages that you go through. But what she didn't say is everyone goes through these stages at a different lengths of time and also they don't go in a particular order. They can be all higgledy piggledy mixed up. (MND10, Motor Neurone Disease)

There's no hiding place really, so get used to the idea

Others discussed the importance of accepting they were going to die.

It hurts, it's, it's puzzling, it's scary. And at the end of the day, like everybody else, I'm scared of dying and I don't want to. And I'm sure everybody else don't want me to but the reality check on it is I am. (LD01, brain tumour)

Acceptance is a great thing. It heals the mind. You know, you didn't bring yourself, you didn't make yourself sick. It comes on. You don't know why. So, that's all I can say, because that's all I can go to it, I accept it. (LD11, lymphoma)

From an emotional front we're more accepting

Most people talked about the emotions they experienced over time. Many talked about feeling angry about the diagnosis and reflected on ‘why me?’ Becoming terminally ill after leading what they saw as healthy lives. But these emotions were sometimes recognised as futile or destructive.

I was angry, at first, because I wanted to know why it was there, what it was doing, what it had done, what I had done. They couldn't give me the answers for that. It's something there that's grown, for no reason, that nobody can give an answer for that. It's nobody's fault, it's happened. There's no point in beating yourself up about it, because it doesn't help. (LD01, brain tumour)

And I don't think about the other things that I can't do anymore. It's not worth dwelling on them because you get bitter and you get upset too. So you just don't. You just concentrate on the things you can do and ignore the rest. (MND10, Motor Neurone Disease)

Religious or spiritual faith helped some people while others highlighted counselling or their hospice staff as being pivotal in helping them to cope. Several people talked about the role of humour in their lives, and described being flippant about dying. Recognising that others were in a worse position helped some older participants who felt that they had lived their ‘three score and ten years’. Those people with experience of death, either through family members or work, were sometimes less worried about the prospect of their own death.

I think going to the hospice helped me, I think going to the hospice helped me to coming to, to come to terms with it you know. They talk to you and you see so many people in the same boat that and they've all got the same thing you know and we all help such a lot that I think that does help you, you know you're not alone you know, you know that there's some people off a lot worse than what you are. I mean there are some people a lot, you know a lot iller. (LD23, breast cancer)

When you're told that you've got an illness that you're dying from, you've got to make that decision in your mind to talk. It's easy to hide behind a pillow and cry on your own and not tell everybody you're frightened, it's hard to admit that you are. And I should think anybody who's just been told they are now terminal is terrified. The best way to deal with that fear is to talk. (LD25, chronic obstructive pulmonary disease)

Shared decision making

People discussed how they made decisions around treatments, the choices they faced, the way in which choices were communicated to them by health professionals and what factors influenced their choices. The analysis revealed a range of decision making models, illustrating the continuum from doctor centred to patient centred communication. Decisions were often not dyadic, but also involved partners and other family members. (This was illustrated by the use of ‘we’ in patient talk, for example LD32 below).

The choice will be yours

A few people emphasised *their* choice in making decisions about treatment and described (working in partnership with) doctors who provided the information to enable them to make informed choices.

And I'm working in partnership with a team rather than being passive patient if you like and feeling, feeling that you can only have things done to you, rather than being part of the decision making process and full, fully informed, which we did very much feel when I went and had the liver section. (LD32, breast cancer)

Effective decision making is dependent on patients being informed about treatment options, potential benefits, risks, burdens, side effects and alternative options and about the way in which these are communicated as discussed in the previous section.

I think you can 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 are talking to a fellow professional and things like that I think that goes a long way, yes. (LD24, chronic obstructive pulmonary disease)

Other people did not feel they were in partnership but, instead, described having to be careful managing their interactions with doctors;

If you go to a specialist or a surgeon or somebody like that and start suggesting things, and when you are doing it yourself, they think 'Oh cocky bugger', you know, so you've got to be very careful like that not to give the impression you think you know better and that you're running things, you know, so you've to be careful in that respect. (LD20, pancreatic cancer)

Had I known beforehand, I might have refused it

While some people felt very well informed of the potential benefits, risks and burdens of the various treatment options, several reported making treatment decisions without full information. One woman, for example, decided to have a PEG (percutaneous endoscopic gastrostomy) inserted early on in her illness because of weight loss. She was not told, however, that there would be a risk of infection, a long healing time or that it had a 'shelf life'.

It's the quality, not the quantity

In making decisions about treatment options some people weighed up the possible side effects and their quality of life.

I mean, the major decision is whether you go for a treatment that may prolong your life by two months [...]. And when I asked which two months it was - was it the two months when I was in Spain or was it going to be the two months when I was lying in bed - and they couldn't tell me, I decided not to bother. (MND28, Motor Neurone Disease)

Those people who decided against particular treatments often drew on the experiences of friends or people they had heard of, who had used treatments with negative effects. The anecdotal knowledge could be about a quite different condition or treatment.

Another friend of mine, living in Canada. He had cancer and he had treatment which knocked him out for the last year. He was a professor of English. And it just, you know, it was worse than being dead. (MND24, Motor Neurone Disease)

Another woman who decided against further chemotherapy, following her consultant's advice, said;

I was quite happy with that, in fact, because we have seen two friends die after struggling with chemotherapy, one for four years, her quality of life was very poor and she just had four years of illness and I was quite happy to accept that. (LD15, breast cancer)

One carer described how his wife decided to stop eating during the final stages of her life. The GP was supportive of this decision and was 'kind and practical and very human about it';

And the GP was, when, when June had decided to, we, we wondered what the GP's view would be when, when June decided that she was no longer going to eat and absolutely fine, you know. He came over, he wanted to hear from her herself that that is what she wanted. You know, and she kind of spelled it out and when he asked, she asked her to nod or shake her head. So that was good. So that you know, and, and he was very supportive of whatever decision that she wanted to make. (MND42, Motor Neurone Disease)

It did not feel like a choice

For a few people, the availability of a potentially life prolonging treatment meant there was no choice to be made and the consideration of risks or side effects were outweighed by the prospect of the extension of life. Participants with Motor Neurone Disease, for example, discussed the use of riluzole and, for some, a possible increase in life expectancy of three months was better than nothing. Another participant, talking about the decision to have chemotherapy said;

But I think it [not having chemotherapy] wasn't an option for me, or I didn't feel it was an option for me, I thought I was running out of time. (LD35, multiple myeloma and aml amyloidosis)

Decisions will be made for me

Other people did not want to make decisions and preferred to leave responsibility for their treatment to health professionals. One person said "They know best, they definitely know best, don't they?" while another reported; "the decisions will be made for me. I'm in their hands, am I not, as far as treatments and medications are concerned?" Despite this there was a suggestion that doctors did check that the patient agreed.

When I say we, it was not me but my consultant, and it was generally very nicely talked over with him. I say we but it was really his guidance and I agreed. (LD42, prostate cancer)

I do put myself in their hands, but they do, they do, do ask. I mean I'm not there to say this chemo or that chemo because I don't understand all the chemos anyway. (LD28, ovarian cancer)

I'm always sort of argy bargy with me consultant

There was some concern among a few participants about the treatment choices offered to them. One person, for example, expressed concern that he was not given chemotherapy while another wondered if he should have been offered a treatment.

But because the area is so large, they, they said that the chemotherapy, the suffering I'd have wasn't worth doing. So [pause 2 secs] I don't know. I think in myself I would rather have taken the chance and had it just to make sure they'd got everything because we've still got, you know, we still know that this is going to come back. (LD19, mesothelioma)

Yeah, when I think on reflection, I wonder [pause 2secs] did they choose not to give me that information which surely they must have had that information? And if they chose not to give it me, why was that, because they didn't think I was a suitable patient or because there was some sort of financial shift or, or did it just not occur to them in my case? (LD32, secondary cancer)

Other people were more active in their complaints and challenged the decisions or options presented to them.

I had made the decision that no matter what, I would override my surgeon if he decided not to do me operation but, and I had decided I was going, that's the route I was taking, that was my own personal decision but when we did managed to contact another professor who was really well thought of in the field like, and the co-operation between the two surgeons, they're linked you know, it seemed to get us to the point where well something's going to happen now like. (LD30, secondary cancer)

Some consultants raised the option of seeking a second opinion which some people did. Others used the internet to find relevant information which they used to request particular treatments or referrals.

He said "now the next three months of your life are probably the best you've got left in your life" he said "you'll feel fine, you're fit at the moment, very fit" he said "you're probably fitter with cancer than a lot of people without" he said "this is the time for you to go and make the most of it". He just said "Go and have a second opinion by all means I'll recommend you somebody who, one of my companions", he said, "or go to London if you want to go to London and see, whatever you want to I'll recommend or go and see who you want". (LD41, ovarian cancer)

People's choices and preferences (including where I would like to die)

Once people had accepted their prognosis, this allowed them to organise their lives. Getting their affairs in order, making decisions about funerals and overcoming problems such as being able to get travel insurance were all discussed by participants.

What becomes important is the quality of what you are doing

People often change their priorities and choose to spend their time with family and friends.

You have a different set of priorities. Things that were very, very important in the past became less important and things that were less important become important. It is very difficult for people that aren't completely involved in the centre of it to realise what is important to you and why it's important. (LD09, testicular cancer)

Got more time for things, more time, there is no need to rush to places and there is, you know, I mean a day like today when it starts to rain and people moan, I go 'no', you know, it's just a wonderful, every day is a wonderful day, (LD41, ovarian cancer)

Some people described feeling liberated by their acceptance of their prognosis and the re-evaluation of their lives, although this was often related to the person's age. Older people tended to reflect on their appreciation of happy and fulfilled lives.

So if, if you didn't have death, you didn't have disease, then you wouldn't quite see the richness of life either. And that helps me, yeah.(MND39, Motor Neurone Disease)

You see I got this disease when I was 55. And there are lots of people who are disabled for the whole of their lives. By the time I got this disease I'd had the bulk of my life, I'd enjoyed it, I'd had two children, I've had a very happy and lucky family life. So I didn't feel that it was unjust really or unjust that I should suffer. I felt that compared to many people I've had a very successful and happy life. (MND12, Motor Neurone Disease)

Younger people were less likely to embrace this position and, instead, talked about their sadness at not seeing their children grow up or do all the things they had planned to do as they grew older.

A long time ago - but I was a child too, you're kind of, you're invincible, aren't you? You'll go on for ever. [pause 8 secs] And that [sighs] - that really is one of the hardest parts of it. [pause 4 secs] Little things you know you'll never, you'll never do or you'll never see. It's not about regrets. Coo, blimey. It's really about coming to terms with the future you won't have. And that's hard. We have a great present, in spite of the things that aren't right with me. But it's knowing that ultimately there isn't much of a future. (MND29, Motor Neurone Disease)

Advance refusals

About a quarter of participants had had written advance refusals, or said they were going to. Others were either unaware of the process or did not want to engage with idea of dying. People who discussed their feelings about their end of life treatment used various terms, such as 'letter of wishes', 'living will', 'life will' and 'guidelines'. Some had planned advance refusals.

My solicitor kindly researched it on the web

There was no one route to drawing up an advance refusal. People described different sources of help. One person, for example, asked her consultant what to do and was told to ask the MacMillan nurse. The nurse found out for her but later said it was the first time she had been asked about it. Others were either helped by hospice staff, one person asked her solicitor, a few people got a pro forma via support groups or they found information on the internet. A few people said they would have liked advice and support in drawing up the document because the process was distressing.

They didn't have a pro forma [...] but the doctors found out from the internet and I made one up myself. (LD06, multiple system atrophy)

If I am unable to express myself then my desires are quite clear

The motivation, for people, to organise advance refusals included a desire to have their ‘wishes heard’, to maintain some control over their end of life treatment and have an ‘easy’, ‘pain free’ and ‘peaceful’ death. They didn’t want family members to be left uncertain what to do. As one person said; “I’m holding the reins here; I’m the one who’s got the disease, who is going to die”. Most people wanted to avoid resuscitation and other forms of invasive treatment and not to prolong their lives ‘when there was no point’. Several people said they did not want to remain in a vegetative state.

I don’t want to be a burden on other people, I don’t want to be totally dependent, I don’t want somebody changing me and cleaning me and spoon feeding me. (LD09, testicular cancer)

Yes, I don’t want a tracheotomy and I don’t want to be force-fed. I’ve seen that once when [name] had the traction and I cannot see the point of it. I don’t want my life to drag on when it’s not necessary. (LD34, Motor Neurone Disease)

R: If I go into cardiac arrest or anything like that, I don’t want to be resuscitated. Mainly because every time it happens the pain is worse. It is the pain at the end that I won’t be able to cope with the pain at the end. That terrifies me. I live with pain the whole time, I can cope with it the best as I can but it’s [pause 5 seconds] I don’t know how to put this, [pause 6 seconds], I think, I’m scared I haven’t tried hard enough when I die.

I: Tried hard enough for what?

R: Keeping alive. (LD25, chronic obstructive pulmonary disease)

A few people used their advance refusals flexibly, changing the content for particular operations or if their circumstances changed.

And I also know my living will isn’t written in stone. It can be changed at any time. And I’ve got a really excellent relationship with my GP and my neurologist who both would know, I think, would know me well enough to know that the time’s not yet. (MND22, Motor Neurone Disease)

People with advance refusals generally left a copy with their GP, sometimes with a solicitor, family members and at the hospice, as well as keeping a copy themselves. One participant had it put in the Emergency Services database.

Everybody wants you around that little bit longer

While some people with advance refusals described supportive partners or family members, a few said that their family were upset by their decision and thought they were being selfish to not try to extend their lives. In the following extract, the man describes how his family don’t understand his experience of his illness;

I’m not being selfish: I’m being practical. I just at the end of the day, you want the illness, the cancer, whatever it be, to be finished because you’re living with a time-bomb. And unless they’re living with that time-bomb they can’t understand the emotions, the feelings, the hurt, the pain that you’re going through because they don’t understand that side of it. (LD01, brain tumour)

We don't want to sit and be morbid

Some of the people without advance refusals (or plans to make one) said they didn't want to think about the future and they avoided discussing death. In some cases it was their partner who was reluctant to discuss death.

We do know about living wills and about, you know, right to die and all of this, this sort of stuff, but it's not something that we, we discuss. It's not something that we feel, I don't think, that we need to discuss because we don't, we're not even placing ourselves there, you know. At this moment in time we're just, I think the place where we're at is we're just trying to manage and be normal. And we don't want to even go there, do we? (MND23, Motor Neurone Disease)

These people talked about their faith in their doctors or their partners to keep them comfortable and know what was best for them.

I think the specialists know best, and they keep you comfortable, don't they? (MND25, Motor Neurone Disease)

I suppose, when you spend a lot of time, you know, many years with someone and gone through all the details, I feel, I feel that my husband would know, and I'd know with him, you know. (LD32, secondary cancer)

Is that to do with your disposal or your demise?

Some said they had never heard of living wills or advance refusals or they demonstrated a lack of understanding surrounding advance refusals.

I: What is your understanding of what it [living will] 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. So I haven't, I haven't. I've thought about it but I haven't. (LD15, breast cancer)

Hospice versus home

People who are terminally ill often think about where they want to die. Few people wanted to die in hospital. Few did not want to discuss the subject. Most want to die at home or in a hospice. Some people were very keen to die at home while others wanted to end their lives in a hospice.

Just because it's hospice care doesn't mean you are on your last legs

Many people were overwhelmingly positive about their experiences of hospice care. This was due to the level of attention they received, the understanding and sensitivity of the staff, the accessibility of palliative care doctors, the atmosphere and the services provided including massages and drinks before dinner. Some realised that staying at home might not be practical at the end and accepted the hospice as a 'fine second best' if necessary.

There were some psychological barriers to considering hospice care. As one man said, "you have to accept you ain't gonna get well" and some people were not ready to engage with the

idea of end of life care and decisions. Those who had been in and out of hospices for symptom control were better informed about provision offered by hospices and were more flexible.

And my GP said to me it was time to make a visit to the hospice which I strongly objected to but I did, I did go. And I can't wait to go back. [chuckles] (LD39, non small cell lung cancer)

My hospice nurse is the only person who comes regularly to see me whom I can ask any questions of, and she has such a wide experience and she's able to make suggestions and speak from her own experience and also make sort of wise comments, you know. (LD04, leukaemia)

The local Hospice has been marvellously supportive; within a matter of weeks after diagnosis I had a call from the specialist nurse for palliative care at the hospice. She described herself as a 'cage rattler'. She came to visit, and has done so every three weeks to give medical and moral support[...]It is NOT a place to die, as I had thought. It is a place where there is immense kindness and support for anyone with a life-threatening condition. They offer emotional support to the patient, their carer and families, and respite care and, ultimately, palliative nursing care. It was a revelation to me that they work in conjunction with the whole patient team, the specialists, the GP and community nurses. (MND31, Motor Neurone Disease)

A few people told less positive stories about their experiences with hospice care. One participant found the routine didn't agree with him while another described the care as too 'medicalised' and 'bound by bureaucracy'.

Not everyone has access to hospice care but those who had spent time at hospices said they felt that they would be given effective pain relief in that setting and receive appropriate, sensitive care and understanding. Some people talked about being 'spoilt' by visits to their hospice where they had enjoyed massages, counselling, specialist care and the company of others in a similar condition.

I said to one of the nurses yesterday that this man looks pale and she said, "But he always does". I said, "Yeah, I know he does but he's rather drawn" and I said, "He is special". And she said, "You're all special". So that was very nice to be told and there's a, a feeling of love. There's a lot of love there. Comes out of the walls I think. (LD16, prostate cancer)

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 where they control the pain for you, look after you. (LD15, breast cancer)

Home is the best place, you know, it's where you belong

For some people, home was where they wanted to spend the remainder of their lives. One person felt that hospice care was for those people without family or a support network. She felt there were too many restrictions in place in the hospice, such as visiting times, car park charges and so on, which would limit her family and friends visiting. A man who had stayed in a hospice briefly to give his partner respite said it did not work for him;

I found that the change of routine and the changing of sort of living conditions as it were really didn't suit me at all well. I came out a lot weaker than I went in. MND09, Motor Neurone Disease)

Sometimes it was the partners who wanted them to remain at home. Pain management was a major concern for many and reassurance for some people that pain could be managed at home was important.

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 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. (LD16, prostate cancer)

Getting affairs in order

The wellbeing and future life (financial and social) of their partners and family members was a frequently expressed concern and it was very important to most people to have their affairs in order.

People discussed legal considerations including registering deaths and applying for power of attorney.

And one of the things I hadn't realised was that to register a death you've got to be 18. So in the event of me dying before my children reached 18, I had to make sure I nominated another person to, to do that. (MND22, Motor Neurone Disease)

The getting of a power of attorney actually proved to be more problematic than one would have realised. (MND41, Motor Neurone Disease)

Knowing that their death was imminent gave people the opportunity to have all their 'affairs in order'. They discussed clearing out their belongings, 'clearing the air' after any rows with people, writing their wills, arranging what sort of funeral they wanted and making sure the future provision for their partners and family members was as organised as possible.

I think you want to leave on a good note with your relatives and that I mean, we've all been to funerals where they moan and groan about whose been left what. Yeah I think it's quite important from my own point of view you know, you've just got to accept the fact that you know that's going to happen and you, and you should make the most of what time you've got save any unnecessary problems for anybody afterwards if you possibly can. (LD20, pancreatic cancer)

And there are 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, mesothelioma)

I had the will before and I've put everything in order. I've started clearing out my clothes and so I'll get rid of them to a mate of mine. Sort through my gear but most of that's done. I've ear-marked things I want people to have, whatever, some daft things [...] I think that people should come up to you say, "Apart from medical things, have you got everything in order?" Like wills and all this sort of stuff. I think this is important so it's not - I don't want to use the wrong word - messy. (LD06, multiple system atrophy)

So I rang a funeral director up, who I knew, knew had done, done a funeral for a friend of mine, and kind of said, "I want to arrange my own funeral. Can I just leave it?" And he said, "Well, you can, but I would rather come out and see you." So he came out, and I was actually gobsmacked at how much information he actually - the time of the funeral, did I want flowers? Did I want a church? What sort of service did I want? I picked the music, and I picked the service. What to wear? Which was quite humorous, working out what I'm going to wear in the coffin. Hopefully I'll look good. [laughs] But also it takes the pressure off my immediate family. (MND22, Motor Neurone Disease)

The significance for many people of getting their lives organised before they die can be illustrated by this final extract;

R: I'm convinced in my mind I will know when it's time.

I: To just let go?

R: Yes. When I've done everything I need to do, when I've put my house in order. When I've got everything given to everybody I want to have; then it will be time to let go. (LD27, secondary progressive multiple sclerosis)

Travel insurance – no ticket to ride

The difficulty getting travel insurance raised problems for people who wanted to travel in their final months. Some had to relinquish their plans.

But this time I phoned them and I said "look I'm going on, going all round the world, I've got, I just want to check, I am covered for the cancer" and I said "I'm going abroad, the oncologist has told me I've got to go now, and I'm coming back in three months and possible have some more cancer" and she said "well if you've got anything following then we won't cover you". (OV26, ovarian cancer)

Going to the airport, hanging around the airport, getting into, being moved - because you have to be physically moved onto a special trolley to get onto the aircraft and so on and so forth. It's the hassle - and the cost is very difficult. The hassle is difficult, but the cost is prohibitive, because of course medical facilities are extremely expensive, so that any hotel, the price is about twice that of a normal price of a hotel room. And we'd have to take a carer, at least one of my carers with us. So the price is prohibitive. (MND38, Motor Neurone Disease)

Carer's needs, health and well being

Those people in relationships talked in detail about their concern for their partner both while they were alive and thinking about the future after their death. This concern was often related to the responsibility the partners took on as carers for them and the strain this could put on their health and well being.

The data suggest that people's end of life experience is made more stressful because of concerns about their carers well being. There are also data to suggest that caring can take its toll on carers' own health. There is a case for introduction of preventative carer support plans that cover: emotional and clinical needs (including primary prevention of illness); information needs; respite care; personal care and recognise financial concerns, and that these support

plans should continue after the death of the person being cared for. Such plans should recognise both adult and child carers.

Sometimes I think it's harder being the carer than it is being the patient.

Many people described how their partners had become their primary carer, a role that could involve significant responsibilities with little provision for respite.

I'm very much aware that it does pose a huge, huge strain on her. And one of the biggest decisions I think in terms of arranging the continuing care has been making sure that as far as possible some allowance is made for the fact that she can't do everything herself in looking after me. What we found was that at an earlier stage a huge burden was still left on her as far as the caring for me was concerned. (MND09, Motor Neurone Disease)

It was actually over a year before we realised that his health was suffering because of my illness, so that's something which has to be born in mind. (LD04, leukaemia)

The care provided by the partner was often 24 hours a day and some partners combined paid employment with their caring role. People worried about the impact of caring on the health of their partner and many talked about the lack of time they felt their partner now had to socialise or do activities other than caring.

She gets absolutely exhausted. She's my carer day and night. If I wake in the night, she's the person who has to get up and get me a bottle so I can go to the lavatory and this sort of thing. [...]She's always up, she's always running around, she's, you know, she's got to feed me, she's got to wash me, dress me. She hardly has any time for herself. (MND15, Motor Neurone Disease)

She leaves around 5 in the morning, she doesn't come back till about 2.30 in the afternoon. And then she's so tired that she needs to sleep for one hour. Then she is looking after me. I think it's too much for her at the moment. (MND32, Motor Neurone Disease)

My husband has been thrown into the caring role

Some people reflected on the shift in gender roles that occurred within relationships as an outcome of terminal illness. For some, this was a negative development and they described feeling concerned or uncomfortable about the changing dynamics within their relationship. Others were more positive about the shift.

He's, he's been with me all along, and he is my primary carer, which is, is testing him. He's, he's very willing, but it's been an awful job for him in many ways because I always have run the household and done all the shopping and all the cleaning [...]. So really to have me stop doing all those things put a big load on to him really. (MND12, Motor Neurone Disease)

The responsibility on her has changed dramatically. Where I would have been, if you like, in the old-fashioned term head of the household, now she's the head of the household and really is having to make, the decisions that we would have either made jointly or I would have made she now makes independently. (MND28, Motor Neurone Disease)

External carers for personal care could maintain the boundary between caring and caring for within their relationship.

I find that the, when the roles become very fuzzed and very furred, um, it becomes very difficult to have a complete loving relationship with someone who is also caring for you. And we decided at the very, very beginning that the role of carer and the role of fiancée or wife and partner have to be two separate roles.(LD09, testicular cancer)

For some, asking paid carers to do things for them was easier than asking their partners or other family members because they could be more assertive about the care they wanted. Other people did not want carers coming into their house because it was too intrusive and preferred their partner to care for them.

And my husband said he would never want anybody in to get me up in the mornings or put me to bed at night. He feels much happier doing that himself. He doesn't want people coming into the house really, to intrude.[...] So at the moment he's, he's quite ready to care for me in order to avoid that. (MND12, Motor Neurone Disease)

I'm quite happy to ask things of people that I'm paying, or that that is exactly what they're there for. It, it makes me, I feel like I'm much more independent, and that they really are an extension of my arms and I can tell them exactly how I want, want it. (MND39, Motor Neurone Disease)

A few people were cared for by their young children, which they found particularly difficult;

I think the hardest thing is that they've, from being my, their mother and their parent and being their carer and running around after them. It's turned and they're my carers now. And my son makes me food and he makes me hot drinks and my daughter helps me to the toilet and she has to do my clothing for me to go to the toilet and at 10 years of age it's quite heartbreaking to see. (MND10, Motor Neurone Disease)

I thought gosh he's not seen me naked for years

Terminal illness can have different effects on relationships; some had grown stronger and closer, others felt additional responsibilities, shift in the roles within the relationship, coming to terms with increasing dependency or death created strain and tensions. One woman, for example, described the thought of her husband assisting her with personal care 'horrendous' because she was so 'fiercely independent'. A few people said their partners had withdrawn from them because they were unable to cope with them being ill and dying.

And we have thought of, of going to a counsellor together and sort of, you know, to help us deal with the sort of feeling, because my wife's got very strong feelings about it, I've got strong feelings. Sometimes we can help each other and sometimes we, we, we don't help each other and we make each other worse. (MND18, Motor Neurone Disease)

Others described becoming closer as a result of the shift in their relationship;

He said, "I'll, I'll wash your hair and shower you." And it was quite funny because when you get old you don't really look at each other anymore in that way. And I thought, "Oh, gosh, he's not seen me naked for

years. I don't know whether I'll like that." But anyway he said, "Well, give me a try before you get, start getting other people in." I said, "Oh, all right then." So he's, he's doing very well. [laughs] He's learnt how to put shampoo and conditioner on because they don't know about these things, do they? And so he's, yes, we're a lot closer I suppose, because I've let him in. (MND25, Motor Neurone Disease)

Implications for commissioners

When the whole system understands how the individual person and their carer(s) define a good end of life experience, then the chances of the system focusing and working together to deliver it will be greatly increased.

When people are ready to discuss their preferences for their end of life experience, then they need to do so the system can start to support its delivery. The insights show that many people want to exercise control over their end of life experience and often had strong preferences about where they would like to die.

There was evidence that professionals found it difficult to talk about death and dying. Clearly there is also a need to ensure that someone has reached a stage where they are ready to talk about it. This issue may be conducive to development of a patient decision aid that the individual and their family could access directly.

There was evidence that some did not understand what the hospice care experience was like and had preconceived ideas about it. Commissioners need to provide easy to understand information that helps people to understand the different experiences available locally at the end of life (hospice, hospital, home; other) so they can make the right choice for themselves and their family.

Commissioning strategies need to focus explicitly on supporting and rewarding providers to work with people to define and deliver their good experience. Doing so acts as a key measure of commissioning strategy success.

Pain management is the overriding clinical issue on the end of life journey. Once they are on that journey, pain and symptom control are the priority issues from the patient's perspective. However, they still want to feel in control of their pain management so that it does not interfere with them achieving goals they have set themselves. People being cared for at home were especially concerned about pain management.

Data suggest many more people would like access to hospice care (especially non cancer patients); both short stay and at the end of their lives. Experience data suggest that short hospice stays increase people's ability to make an informed choice about their end of life experience. People also valued the alternative therapies e.g. massage and access to talking therapies and counselling (including couples counselling) in hospices.

In contrast to the current policy of 'no decision about me without me', people's wish to engage in shared decision making varies in end of life care. People have very individual preferences about the degree to which they want to be an active partner in their treatment and have all the options explained to them. Their information needs may vary significantly over time. In light of people's

very individual preferences, commissioning strategies also need to focus on how providers ensure clinicians tailor the amount of involvement to each individual's preference and ensure this is reviewed over time.

The ability of staff to empathise with a person's end of life journey and show kindness and humanity was a key factor in determining how good the person's experience of end of life care is. Pivotal to this was the point where the person received the news that their condition was terminal and then onwards right through the journey and afterwards for the carer. The importance of this attitude amongst staff extended beyond to clinicians (doctors, nurses and others). It extended to administrative staff and formal carers whose kindness made a big difference to peoples' experiences.

There is evidence from the insight data that there is huge variation in how well clinicians and non clinical staff currently treat people on the end of life journey. Creating greater consistency amongst staff to empathise and where necessary, enabling and welcoming clinicians' recognition they are not competent at telling people bad news well and then delegating this role to others e.g. the nurse tells the patient; the consultant is present to answer technical questions, could improve the consistency of patient experience – especially at key emotional touch points like hearing the news.

Another stress point for people on the end of life journey was financial (including welfare benefits) and legal preparations. They felt they and their carers needed support with this. Whilst it may not be a health service, for commissioners taking a holistic approach and wanting to improve patient experience, it is an area of great opportunity to improve patient experience.

It was very important to people on the end of life journey and their carers to have access to peer support and social networks. Hospices provided this in part. As people often had mobility problems. This often got in the way of forming social networks. There may be an opportunity to use web based social networking to create virtual networks of people with the same health experience.

This throws up a number of commissioning questions:

Commissioning questions

- How can you help people articulate their preferred end of life experience so the system, can deliver it?
- How can you measure whether the system delivers the end of life experience people and their cares choose?
- How can you prevent emergency admissions for people on the end of life journey?
- How can you provide patients/carers with choice about who should co-ordinate care? Is there a need to create a key worker/ care co-ordinator role? What role could third sector play in this? How can you empower people with information about what should happen to them?
- How can you create a **system wide, stigma free identifier** for E of L patients so everyone recognises their needs are different?

- How can you ensure community services are flexible for people on the end of life journey? How can you work with social care to make personal care services flexible as well?
- How can you assure quality/set standards/measure the degree to which care planning is consistently **anticipatory**? Insights data suggests this anticipatory approach should start before breaking the bad news (planning to break the news) and continue after the death of the person to ensure the carers needs are addressed, especially in the early days.
- How can you embed a simple 'fast track' for people on the end of life care pathway so they get easy access to the resources they need from the welfare system, health and social care quickly and easily?
- How can you ensure that the burden of worrying about their carers is lifted from people on the end of life journey? How can you ensure you commission adequate respite care? How can you prevent illness and keep carers as healthy as they can be?
- How can you work with benefits agencies and others to ensure patients and their carers have access to the help and support they need to deal efficiently with their financial and legal concerns?
- How can you assure systematically high quality palliative pain management services across all settings?
- How can you increase hospice capacity? How can you deliver a hospice led approach in other settings: hospice at home, hospice in hospital? How can you use existing hospice resources as centres of excellence and mentors to support non specialists to improve palliative care and continue to be involved? How can you make services that people value in a hospice setting e.g. alternative therapy, counselling more widely available to those not under hospice care?
- How can you ensure that hospitals improve the in-patient experience for people on the end of life journey? How can you ensure that hospitals preserve people's dignity, especially in relation to personal hygiene and toileting?
- How can you as commissioners support peer network and community development amongst those on the end of life journey?
- How can you ensure that all those providing front line care (and indeed service and commissioning managers who are responsible for acting as surrogate 'purchasers' for patients empathise with and understand the emotional journey?
- How can you ensure that clinicians are competent to deal with bad news and key conversations well? Would self assessment tools help? How do you ensure that the team focuses on the patient's experience and who is competent to make it good rather than who 'should' tell the patient the news?

Contract and performance management quality standards

The insight data suggest there is a need for quality standards in relation to:

- Breaking bad news (Unless they choose to be, the person is not alone, suitable physical environment, time provided to collect oneself/for discussion, communication and empathy, offering a follow up a week later)
- Quality of handover information (do I have to keep repeating my story?)

- Partnership approach to treatment (qualitative and quantitative e.g. choice, use of decision support aid)
- Pain management and symptom

Incentives and deterrents

The insight data suggest that service experience in end of life care could be improved by:

- Rewarding flexibility in service delivery
- Rewarding the system for achieving people's stated preference for their end of life experience
- Classifying the following as 'never events': failure to undertake a timely follow up post diagnosis that results in delayed treatment; death in hospital for someone who has a different preference.

Joint commissioning agenda

The insight data suggest that service experience in end of life care could be improved by working with social services to:

- Identify the role of joint personal care budgets for people at the end of life
- Improve commissioning of mobility aids (including a fast track system)
- Create flexibility in personal care commissioning (linked to activities of daily living)
- Improve co-ordination and joint care planning and delivery
- Improve care staff's empathy and communication skills (see below)

Communication skills and professional development

The insight data suggest that service experience in end of life care could be improved by:

- Enabling clinicians to self assess their personal competence in communicating bad news and where appropriate, delegate until they feel they are competent to do it well
- Providing CPD for non clinical staff and clinicians that helps them to: recognise the different aspects of grief; understand the end of life experience (increases speed of rapport building); improve their communication skills
- Increasing non specialist training in palliative care approaches especially pain management
- Providing CPD for managers (both providers and commissioners) to help them to understand the end of life experience and thus manage and commission sensitively.



For more details about this report, contact:

Georgina Craig Associates

Best contact number: 07879 480005

Email: georgina@gcraigassociates.co.uk



: [@GCAssoc](https://twitter.com/GCAssoc)

Learn more about our business at LinkedIn: [Georgina Craig](#)