

It was perhaps a little bit before the days of formal care plans so there wasn't much communication and to this day I'm not really sure exactly what my mother was told because she never used the word 'cancer'. I think she knew she was seriously ill. There was some mental health problems as well with hallucinations and delusions and we couldn't work out what was happening there. Was it suddenly that she'd got Alzheimer's or senility or something on top of her illness? So there was a lot of questions there as to what was happening. But she did go downhill really, really quickly. You could see every day she was losing her appetite and having trouble sleeping and

So was she still in hospital at that point?

Yes. Yes, she never, ever came home after that. I think it was the third hospital, there was a fourth one to talk about a little bit later on, but the main treatment was at the third hospital and the oncology. She spoke extremely well of the palliative care specialist. I never got to meet him but I can only say that she did really bond with this man and she trusted him and there didn't seem to be any problem. And the clinical nursing was excellent. She was kept clean and supervised and you know I didn't have any problem. My big hurdle was communication. I just couldn't get any answers at all as to what the real diagnosis was and what the prognosis was. You know were we to expect the worst? I just really didn't know and the more I tried to speak to someone, it just seemed to completely elude me. And I knew there would be a Macmillan nurse attached to the ward, you know, a big cancer ward, but it was so busy it just seemed to be working flat out. It was Christmas time and that might be another factor that just, things that perhaps should have been in place, weren't. So I did speak to the Macmillan nurse on one occasion, but I have to say that was prompted by my own Macmillan nurse at one appointment I turned up very, very distressed and she stepped in and she said 'look, I'll ring this other hospital, I will try and speak direct with the Macmillan nurse and I'll try and get you an appointment'. So eventually that happened. But she did not really know an awful lot of history about me mam; I'd never met her before obviously and I felt she didn't quite grasp the seriousness of our situation. But she listened and I still kept beavering away, trying to get answers. I think it was,

What kind of answers did you want? What kind of information?

I just wanted to know exactly what was happening; why was my mother having stomach and bowel problems when it was a tumour in the spinal cord. I didn't understand that. I didn't understand what was going on in her head with the mental health side, with hallucinations that could be delusional as well and it was quite distressing

So some explanation would have helped?

Yeah, yeah. And I didn't know either what treatment options, if any, you know. And my mum did mention chemotherapy. She said 'well I think I'm going to have chemotherapy' but again it was very difficult to try and get the information

So it sounds like the information that was going to your mother wasn't getting to you and because of what was happening to her, psychologically, you know you in a way, by rights, possibly should have been given that information?

I think I definitely should have because you couldn't rely on what my mother was saying. You know the confusion. At times, I was asking other patients at the bed next door, and, you know 'what's happening?'

Just trying to seek information, yeah

And it was distressing. She had to have a hoist you know to take her from bed to toilet. It was very distressing the whole experience of it. One day, I mean the thing I was expecting was the specialist to call me in, and that never happened! I just thought well you know me mum seems to be getting more and more ill, surely he'll ask to see me

Yeah, eventually

But it just wasn't that way at all. It was me pushing. And they arranged a meeting with the sister and a doctor and myself. So we went into this room. I did know the sister by that time quite well and there was a junior doctor, very young, junior doctor but one I hadn't met before. And she started to explain that the cancer hadn't spread but the general health of my mother, she did have a lot of other complex problems with kidney and hypertension, diabetes, there was a whole host of you know, illnesses there. What she said was 'well no the cancer hasn't spread, but you must realise that what's going on in your mother's body – the effects are as if the cancer had spread'. So as I understood, blood supplies weren't getting to bowel and

Quite low

Yes. So, they weren't sure how long. They thought perhaps weeks. But then, just out of the blue there was a suggestion that my mother go to the community hospital which was very local to where I lived and at the time I did think 'well, yeah, that might be a solution'. So this was the run up to Christmas and, when we got to the community hospital, our own GP was there so he welcomed us. That was fine. There were a lot of local staff as well who we knew so it was much more personal and it was very, very caring. But the nursing provided in the community hospital just wasn't geared up for dealing with the very acute symptoms like me mother had. And on Boxing Day you could see there were real problems there. They managed to get her into a bath to make her a bit more comfortable. She was still having visitors at this point. Still sitting up and chatting but poorly. And I would go and I would find medication in the blankets, you know in the bed. I think that medication would be for pain relief. But I think as well it coincided exactly with my return to work. I'd been off for nine months but there was a little bit of pressure from my occupational health to get me back to work on a phased return. Just two or three days, so I was actually at work between Christmas and New Year when I got a call to say that the community hospital just couldn't manage, she would have to go back to the oncology department of the bigger town hospital. And yes, they did that straight away but it was quite distressing, yet another move when her pain was increasing all the time. We got back and I have to say initially she was relieved, she did say 'ah, I'm back, I'm pleased to see those nurses'. Whether those nurses were in fact pleased to see her I'm not sure - because I did feel with it being Christmas there was sort of an impetus to get beds empty and you know, whoever could go home, even for a weekend or whatever, you know to leave the hospital so and that's when things really started to go wrong. I mean they'd already gone wrong with the misdiagnosis in the first place, but they really went wrong in palliative care. From a clinical point of view, I have to say it was efficient and everything was above board, everything, I could see they were writing down the treatment of the pain relief and my mother had always resisted taking morphine, I think at one point when she was at home I'd perhaps said to the GP or ... 'is this not a time now' and me mother jumped down me throat, she really, I think there were a lot of myths from her old nursing days about the treatment of morphine. But at this stage when we did get

into palliative care, that's what the treatment was and it was difficult to know when she was in pain, when she was agitated and when she was distressed and you couldn't really differentiate. I do recall her coming round at one point and saying 'Mum are you in pain?' and she did manage to nod. But I think that was the only time that she was able to give me any signal as to whether it was pain or the other symptoms; breathlessness as well. And one of the worst things that happened was when my mother was put in a side room, right next to the nurse's station. And as I passed one day, they probably didn't even know I was there, they were all busy, but it was just before my mother sort of went into that semi-conscious state so there were incontinence problems, she was having to you know bleep them for support and I overheard one of the male nurses say 'oh it's again' and it was if he was complaining about her, you know that he was sick of her, you know, sick of her calling and I did think 'well, yes I've heard that' but it could have been me mam, me mum could have heard it just the same and it was an unnecessary, careless, throwaway remark, possibly the way nurses do talk amongst themselves but absolutely essential that they don't do it within earshot of patients and families. I never said anything, I don't think I could have really, I just was sort of operating on a day to day basis and to have tackled that issue and said 'look, that was wrong, please don't react like that or make any remarks' it would have helped someone else further down the line, who might, you know might happen to and he was quite judgemental this one nurse, I remember him commenting on the time I was spending there and it was a really difficult time. I just hoped that everybody