

would understand that I'd just come out of recovery. I'd just really stopped the heavy medication that I was on and

So it was a sensitive time?

It was a very sensitive time but I when I did have the meeting with the sister and the junior doctor she did say to me 'well the time that you can spend with your mam, looking at the sort of pain and distress she has; that's going to be vital and it's going to be an enormous help to us in monitoring'. And looking back, I think that placed quite a burden on me because I did feel as if I should be there all the time, 24 hours. I just had no way of knowing when she was going to come round and that I was going to have to shoot away and try and get some injection or. She was on a syringe driver at that time as well and there were perhaps times when you weren't sure whether to run and get help or just wait until she lost consciousness again. And I felt I could have done with a little bit more help and information on that because the question in my mind was 'do I ask the nurse to give her an injection which might disturb her further or do I just let her go back into a sleep?' Because nine times out of ten, by the time you'd rang for that injection...

Is the difficulty about the responsibility that you had? That you felt that you'd been given?

Yes I mean I did have that responsibility because I'd been a carer so long anyway and it was hard to let go of that role. But I did feel they'd put a little, a little bit of pressure on. They offered me a bed there, I can remember that but I ended up booking into so that I had a base. I was ringing home to friends and family but I was completely alone. The snow was thick, it was icy, the hospital was about 20 miles away and I was completely on my own at that point. But I do remember contacting my own specialist. I might have even had an appointment, a routine monitoring appointment so I did see him at this time. And I said, 'I've got no background of this at all, I don't know what to do? Should I be staying 24 hours?' and he said 'no, you can't do that'. He said 'the only way a family can manage that is if there's siblings of four

Ye, if there's more than one of you

And you take a six hour slot, and you can cover the 24 hours. But because me mum was so frail, I did think the end would be quick. I did miss out one thing, we did have our 'I am dying' moment which I don't think everybody has and in some cases perhaps the patient doesn't know. But there was one point where my mother did say 'I think I'm dying'. And I had to kind of give her some hope although deep down I knew there wasn't. There was part of her that grieved for herself and there didn't seem to be any way of tackling that. You know I really didn't know whether that came under the umbrella of depression or what it was but there didn't seem to be any kind of support in that

For your mam you mean? For you mam realising it was the end? You didn't feel that that was handled or kind of, you didn't see what you expected to see to help her deal with it?

No, I still don't know what the answer is for that and I do raise it in some of the patient circles I work in now. So that's still something that I do think about

So in a way she had the fear and all the feelings and it was you to confide in?

Yeah but she also had the fear of leaving me on me own. Anyway, that's how the palliative care spanned out and it went on, in my mind it went on a long time. It was nine days. And every day you went in you kept thinking 'this will be it' and it just kept being prolonged really

I think that's the difficult part isn't it? Of that, the end of that journey is that you can't say exactly what day it's going to be? And that is a difficult one.

No. I did need spiritual support as well and with it being Christmas, the hospital chaplain, you know the priest, vicar, there was no one there. And people did say to me 'oh your mum will wait 'til the vicar comes'. Eventually he did arrive and he was a great support he was.

So that, do you think that his role was about that containment - and about your mum's fears and feelings?

Well, I felt that was more the counselling side of things and I didn't know who took that role and I still don't. I don't know whether a good Macmillan nurse might you know? I don't know

Yeah, do you think the priest offered that, in the end?

To me, but me mum was unconscious at that point, she never got

Oh right. So she never got that comfort?

No she didn't she didn't but he was a comfort to me and he also started me in the planning stage

Yeah

So

The planning?

Yeah the funeral, yeah, yeah. By the time I left that hospital I knew the readings I was going to have for me mam and the hymns which, I knew what she wanted. I did have a really good idea what she wanted. But it seems awful to be planning that while she was still alive but I had to focus on something and he did give me that focus. Afterwards, I went through the practicalities and to friends and family it looked as if I was fine. I went to the GP and I started asking one or two questions about the misdiagnosis and I had suspected it was all about masking of symptoms, that the pain from the arthritis had masked the cancer pain. And I was perhaps naive in that I'd always thought there were safety nets in place that if, you know if doctors were collaborating, you know discussing a case that there would perhaps be a call for immediate referral when somebody was in really severe pain. So I didn't really get any reassurances there. The GP said it was very unusual to contract that particular cancer at my mother's age and that she'd been very unlucky. He then said 'oh this might be a case we can talk about at our team meeting'.

Right

And I felt that was said with a little bit of flippancy, you know, as if 'oh well we can make a study of this in the hope that we don't do it next time' but I was left with feelings that I'd let

me mum down. In that I'd never pressed for a scan when she was initially ill and I should have done. And that the other guilt was that I hadn't been there all the time when, you know when it did get into end of life, I wasn't there all the time because I didn't feel I could sit with her. So there was guilt associated with that. And the memories are as vivid today as they were then and I can perhaps recall most of the detail of it and I'm trying to do that, something about that, to give something to other patients in whatever way I can from a patient safety perspective and it's led me into the world of patient involvement.