

Right, I've been asked to discuss my journey of cancer which was four years ago and had both good and bad experiences with this. I think it's important to remember that when you're first diagnosed with cancer, that in my case, I was a happy, fit person and this was a complete shock to me and to my family. I did have to have surgery; I had to have chemotherapy, radiotherapy. So and I think it's worth mentioning that throughout all of those three stages, everybody was so kind, so professional, treat me with respect and dignity the whole, everybody there.

When I became ill with some of the chemotherapy drugs which was life threatening and I was in hospital for three weeks; that's when I think everything sort of went wrong. And I think it was the nursing staff that didn't really give the care that I should have been having. Medical professionals were excellent, the other ancillary staff they were very good, physiotherapist was very good, she was there when I needed her, she helped me to get on my feet, she helped me to work my way up some stairs so I could get home. But the care itself on the ward I think was absolutely dreadful. I don't think nurses looked at the person in the bed as a person. I was looked on as somebody with cancer, who was ill, and given, task orientated care was given but not person-centred care. And I do think nowadays that students are being taught to look at people as people not as an illness and to centre the care round the person and the family, not the disease. And I don't think that happened with me.

I think I was ill, I was in a side ward. I was left on my own for most of the time unless my family or friends were there. I was actually not given, as far as I can remember, I know I was ill and I don't remember all of it; but my family do and my friends do and they tell me how appalling it was. They would have to come in and wash me, clean my teeth, change my nightie, do the basic, basic nursing skills. And I don't think that is right in this day and age. Other nurses would come and they'd change syringe drivers, change drips, change catheters, change other bits and bobs that I had all over the place. But nobody would actually ever really actually talk to me. They wouldn't know, they knew I was married but I doubt that they knew anything else about me. And I think you need to look at patients as people, people who've got their own, they're all individual, we've all got our own unique life history and we all have expectations of good care. And I don't think it's always there, it certainly wasn't on that ward.

Yeah, when I was diagnosed, as I said before, I didn't think, I wasn't really unduly worried. I had had a history of lumps that weren't malignant so it didn't really bother me too much or my husband. But I was actually told on my own and he was in the waiting room. And that really upset him quite badly and he still today, thinks it's totally wrong and there should always be two people, you know, a family member there when you're given the news. But other than that, all the treatment from that end was fine.

I did know that when I started chemotherapy, that my hair, I would lose my hair. And I wasn't too bothered about it, I thought 'oh well, you know, I'll lose it but it will come back'. But I wasn't prepared for the devastation I felt when you know, I'd go in the shower and my hair would fall out and you know wake up in the morning and it's all in the bed. And it's really, really upsetting and it doesn't come out nicely, it comes out in clumps so you're left with bald patches over your head. I had to go and be fitted for a wig, which I found (while I still had my hair) and I found that quite upsetting as well. The fact that they put like a rubber thing on your head so you look bald before you start trying on wigs and that really upset me. I don't think I'm a vain person but I didn't like the thought of not having any hair. The, with the treatment I think I coped fairly well with the IV chemotherapy. But when I started the oral chemotherapy that's when things went wrong. That's when you know the side effects

were horrendous. The good thing about the hospital I was attending was they did have open access to the ward, anytime, 24 hours a day and if had a problem I didn't need to go through the GP or outpatients or casualty. I could just immediately go to the ward and I'd be attended to. Which I needed to do on several occasions and was always pleased that that service was there. There was always a doctor on hand, my notes were there, they dealt with the problem and I went home. Until the last episode when I was in for the three weeks. Now I know there were nurses on the ward who were caring but were leaving, actually leaving the job because they weren't able to do hands-on care. And I think that's a sad reflection of that ward. You know, nurses go into nursing because they want to care for people, they want to look after them. Or, I believe that's what nurses should do but that really wasn't happening. Anything else?

Can you give some examples?

Well, as I said before, my family, friends used to come in and wash me, clean my teeth, change my nightie, change the bed or whatever. They would help me. I had a problem getting in and out of the bed. There were other things, little things and you know people don't listen to you. I like to sleep with the window open all the time and I had to, it was a battle to have the window open. Why? You know I can't understand the logic in that. I was in a side ward, I couldn't get to the toilet in the bathroom. So I demanded I had a commode by the side of the bed because I needed a commode because of my problem. And then it was commode is at the side where all my drips and everything was because it had to be - but the alarm was at the other side. So I would try and get myself out onto the commode, then I couldn't ring anybody to get me back into bed because I just couldn't, I couldn't do it myself. The effort of getting out was enough but I had to do that or I'd have, you know, it would have been a disaster really. So it's things like that and I think listening to what you want and I just ... for me it didn't happen. And I think that's a sad reflection of the ward but I do think that possibly comes from the person who runs the ward rather than the nurses. You know they've got to follow what the ward sister or ward matron or whatever, says.

So how did that make you feel?

I just felt totally neglected. And my family felt as though I was neglected as well. And there's lots and lots of anxieties around, when somebody's ill, you know with your family, and as a person and a person who always been in control of my life, I suddenly wasn't in control, I was totally out of control. I had to rely on other people and that's not me. You know I'm always the one who does everything, so ... and my family, my grandchildren, they all had their worries about it, you know the little ones didn't like to see me with no hair. The older granddaughter worried that you know this could be hereditary and you know that it could be her in a few years' time and you know you've got all those things to think about and help them with and try and make it easier for them and sometimes you know, inside you just want to curl up really sometimes

And did anybody try and help you with those issues?

Just my family. Just my family really. Except that I also used to go to, for some alternative therapies and I used to have Reiki which used to help me. Sort of made me feel better, gave me a bit more, I don't know, energy I think and that was after this episode in hospital. The consultant realised probably that I needed a bit, something extra to prepare me for radiotherapy which I still needed to have. It was suggested that I go and have some

alternative treatment and Reiki was chosen which I was grateful for. And still, even to this day I still enjoy it

That's good

Yeah, yeah it still does me good

Did you have a MacMillan nurse?

No I didn't

At all?

No I didn't

Oh that was your choice was it?

That was my choice, yeah. And that wasn't because I don't agree with MacMillan nurses because I do. Professionally I was a MacMillan nurse - but I know some of my friends are all, well most of my friends are MacMillan nurses so I had a little gang of them around me so I didn't need one professionally because I had them there to help and support me and actually in a few instances, actually pave the way for me a little bit, especially the day that I was discharged

So what happened on the day that you were discharged?

Well I decided and the consultant decided that probably it would be better if I went home for the weekend that I was off all my drips and I was starting to take a little bit of fluid and a little bit of breakfast I could have. So we decided it possibly would be better for me to get home for a few days. So, and I was to go. So it was explained that there was, you know this discharge lounge that I could go to and be there until I could be collected. They were told that my husband couldn't come until six o'clock in the evening but I was out of that room by 11 o'clock - with Venflon still in, they hadn't even taken them out - and was transported to the discharge lounge and for somebody who hadn't been out of bed really very much in three weeks, to expect me to sit up for seven hours was you know, not right. Fortunately my colleague, ex colleague who worked as a MacMillan nurse in the hospital, she came to see me and saw to that - they did actually get me a bed. So that made it a bit easier until he could come and collect me and I did actually sleep for most of the day. I needed the bed but you know it was just like 'well you're going', we'll push you there, here's your bags and left. And I don't think that was good either.

No, whose responsibility do you think that was?

What the way

Sending you to the discharge lounge without

Well I think they needed my bed. I think instead of letting me stay on the ward until I could be, you know he could come and pick me up, they definitely needed the bed - because as I was being pushed out of the ward, there were chairs lined up, you know people waiting for beds. So I think they needed the bed. So, you know, and the discharge lounge was very nice,

you know like a posh airport lounge - but no facilities to lie down. And there were a lot of poorly people in there as well, really poorly people waiting to be collected. I mean if I was being collected in an hour, that would have been ok. But you know when it was going to be six o'clock it was a long time to have to sit

And did you, you didn't come back after that weekend?

No I didn't come back. And I think everybody knew I wouldn't come back. I think even the consultant, 'You know' she said 'I knew you wouldn't come back and you'd improve at home' and really you know, I just took it easy and had, my husband was fantastic, my friends were fantastic and they really got me through that stage until I got stronger and then had to start again with radiotherapy

Yes, so did you have nursing at home during that period?

No, no, family, friends

But I suppose because you were a nurse, you were confident enough to do that weren't you?

Yeah, yeah. But I'm a bit stubborn as well so. No I was fine. I mean I knew my limitations, I knew what I could do and what I couldn't do and everybody else did as well. So they just let me go at my own pace and you know, and we got there. And here we are four years on, I'm still here to tell the tale so you know it was worth it in the end really even though it was so horrible at the time

So after you convalesced at home then you had another therapy didn't you?

I had to have radiotherapy and that was 15 treatments of radiotherapy and the radiotherapy staff were excellent. You know they met you, they greeted you properly, they took you through to the department, they stayed with you, they asked how you were, dealt with, if there was a problem it was dealt with straight away and you had the same person throughout so I thought that was excellent as well.

On the ward, did you have a named nurse?

As far as I remember I didn't have a named nurse. I did make a complaint one day when I was particularly, really, really upset about the lack of care. And the person in charge came to see me and asked about a named nurse and I, by then I was a bit more alert so I knew that people weren't coming on a morning and saying 'hi, I'm your named nurse' so no it didn't happen. The only time a named nurse, I did have a named nurse was the day I was being discharged when she came about 8 o'clock and said 'I'm your named nurse' and came with all my drugs and left them and said 'I'll see you later' and I never saw her again, so no

So that didn't work

So it didn't work in my case. No, you know it may work with other people but it just didn't work for me

And you say you made a complaint? Did things get better?

No, not really (laughter) no, it just continued. That's why I think I needed to get home

Yes, yes.

And my consultant knew I needed to get home as well and I think she was aware of some of the, you know the lack of nursing care on the ward, didn't actually say in words but you could tell she was aware of that so ... But some nurses were good, I don't say they were excellent but some were good but others it was just straight in, do the drip, in, change the catheter, in, do this, whatever and not really talk to you either and I think that's - as a nurse who talks to people - I found that quite upsetting really

Yes. Cos you're lying there for long periods of time aren't you? Worrying I suppose about you know the results and how you're recovering.....

Yeah, yeah I was yes. Well I think everybody didn't expect me to come out of hospital and even now lots of my friends still say 'God, I remember coming in and thinking I'm never going to see her again'. Or not even recognising me because you know I was so ill. Looked so different and no hair on my head and you know, said 'God, we didn't think it was you' and ... but so you know, I can't remember all they can remember and I think maybe that's just as well really. But I still think it wasn't good and I do think nurses really should think about the person as a person and not an illness and talk to them and try and find out a little bit about them and you know, just don't rush in and rush out. I know it's easy for me to say that because I know the wards are busy but there's still got to be some personal touch there. Yeah? You know some contact really, not 'are you in pain? Here, I'll give you this' or 'I've come to change your drip'. I mean that isn't enough, not enough at all

So the good nurses were the ones that tried to help you emotionally really?

I don't think any of them tried to help me emotionally to be honest. Not really, nobody really, not on the ward at all. And I had been on a clinical trial. And both my husband and I decided that enough was enough that I couldn't take any more of that drug and fortunately the consultant agreed as well. But nobody's ever asked me how I feel about that clinical trial being stopped. And I do think it's a big issue for people. You know you're taking these wonder drugs to try and cure you then suddenly, you know, you've got to stop it and it's not replaced by another drug. It's stopped. So it is a big, big issue and you know I think people should be sitting down and saying 'well, how do you feel about this? Is there anything we can do or is there anything you'd like to ask or do you want to know how the trial's progressing?'

You've never heard about what

I'm still on the trial, they're still, I still have to fill in the questionnaires, they still ask me questions every time I go to the hospital but nobody is actually even now saying 'oh well, how do you feel?' you know? And I still would love to know the results of the trial when it's complete but I'm not sure whether that actually does happen or not. You know if it was, if I was just one out of, I think I was, it wasn't expected and I think I was unlucky really.

Did you know other people on the trial?

No, not on the trial I was on, no. I'd known other people in my professional life, who'd actually been on this drug and I wasn't very happy about taking it because I knew one or two

of them had had some quite serious side effects so I was a bit, you know, oh I'm not, I don't really fancy this but I think I was unlucky to get the severity of the side effects that I did.

So what made you go on the trial then?

Well I think it's trying to help other people, you know? I mean I, you know, treatments have come so far in a short time really and all that's through clinical trials and research isn't it? So if you can help, and if you can be part of a trial and try and help for other people then I think it's well worth doing. I think if I became ill again and there was another clinical trial going and they said, I think I would possibly even do it again - but you know, touch wood. But you have no choice, I mean with the drugs, I mean at the time I said 'oh I don't really fancy this one.' There are four arms to the trial and I would have chosen the other three rather than this one but it's the computer picks you out - so you can't do anything about it - so I wasn't happy with it but, you know and it was proven to be true as well really.

So did you, you knew which arm of the trial you were on?

Yes, oh yes you're told right from the beginning. You get all the information, you're given a load of information and every time I went to the clinic then you're seen by the clinical trial staff who ask, you know ask a lot of questions and you do a quality of life questionnaire every, I think it's every year now. And I think I'm on that for like five years so, but I still think you know, there could be a little bit more thought for people

Yes, yes and have you managed to discuss coming off the trial with the clinical trial staff?

Well they knew I was coming off it because the consultant had told them that I was coming off it. I say I still see them but they're not asking the question and I'm not going to ask them to ask it, am I? They should ask it!

Yes, yes

But I think I'm, I mean I'm not so bad about it really but I think there could be other people you know, with less knowledge than I have, who could be devastated by it.

By coming off the trial? In case...?

Yeah in case 'oh this is going to start all over again'. I mean I just thought 'well I've had the IV ones, I'm half way through this one but maybe that's enough, you know that will help' so, but I just think for other people they should be aware of that. I think of how people might feel about it.

So, we've talked about the effects on yourself and your family haven't we? And you were saying that even your grandchildren found it really hard?

Hard, they did yes, yeah, yeah. They used to look at me and think, you know, like 'have you got any hair Nana?' (laugh) 'No, do you want to have a look?' 'No, no, no' you know they'd pull at the wig or the scarf but they would never ever, never wanted to see me until I was in hospital and then they came in and then that was it, I was there and that was it. So they had no choice. But they were fine after that, they were ok once they got used to it. But even now, they're always sort of stroking my hair and saying 'oh isn't your hair lovely' although it's totally different, colour, different everything to what it was. Yeah (laugh)

And how did you get on with the wigs?

Hated it, I absolutely hated it. It was very, very nice, it was very like my own hairstyle, same colour. I felt I had a wig on. I felt cold, 'cos it was winter time. And I just felt cold when I had it on. I didn't like it. I tended to wear the scarves or you know the fancy bonnets and hats and things rather than the wig. But no I didn't, I wasn't happy with it and I was really pleased when my hair started to grow back. Though I was Judy Dench for a while. I like that

Very modern

I like that, yeah

No that's good. So you said some of the staff on the ward were good nurses, were good caring nurses? What made them different?

Well because they would spend a little bit more time. When they were actually changing drips, doing the task that they came in to do, you know they might have a little word like to *me*. I never really got to know any of them very, very well but you know one would say like 'I'm leaving because I can't do hands-on care' and she was going to a hospital where it was definitely hands-on care, although she liked the work, she liked the subject matter. But she wasn't satisfied in her role. There was a couple of them actually in the three weeks I was there, left to go to other places for the same reason. Others would come in, do what they had to do - go, ask the question, you know 'are you in pain? Do you need anything?' - go. (inaudible) 'how many times you've been to the toilet' - go - that kind of thing. Some of the care assistants who did, came in and changed the beds, were a bit more communicative but tended to talk about what they did the night before or you know about their boyfriends or talk over me in the bed - which I don't think it good either. And I think you know they need to be taught to speak to the person; not about their lives - unless - there are - maybe some patients like that but I didn't like it

I wouldn't think most people do, would they?

I didn't want to know what they'd had for supper last night! I couldn't eat, I didn't want to hear what other people could eat!

Oh yes, wasn't that another thing you said

Yes, when I was actually allowed to have a warm drink, after, you know sips of water, I asked for warm milk and I actually couldn't have it you know because of health and safety. And the microwave was about ten steps away from where I was, but they wouldn't. You know that was another issue - I could not have warm milk. So my husband would bring warm milk in, in a flask from home, but that day when I really, really wanted it, he had to go downstairs to one of the canteens and bring it up. Now I think that's more a health and safety issue, carrying milk halfway round, hot milk round a hospital, than ten steps away. But again I think it's not listening to what people need or want. I was desperate just for some hot milk. I don't drink tea and I couldn't fancy coffee and, but no.

And the other thing that was really quite annoying was outside the door was barrier nursed, nil by mouth and every morning they would ask one of the ladies who did the breakfast, 'do you want a cup of tea love?' you know and there's me

Oh dear and she didn't read the notice?

She obviously hadn't read the notice, yeah. So again it's lack of thought isn't it?

It is, yes

You know, when you can't have something, you want it

Especially it's sort of tempting you to have something you can't have, isn't it?

Yes, yeah

You know, you were in hospital three weeks and you said you didn't really didn't get to know any of them; was that because of staff changes and staff leaving?

I don't really know, I think

You were so ill I suppose, most of the time

Most of the time, yes

Did your husband get to know any of them?

No, no he didn't

It's quite surprising isn't it that?

I couldn't tell you the name of one of the nurses and I think that's, me being a nurse would expect I would, you know. No, I couldn't tell you one name of one of them. I do see people now, I do recognise them as being on the ward. Some care assistants I've seen out and about and a couple of, in fact one of the nurses, I met, I saw a few weeks ago who'd actually left the ward but, because she wasn't getting any hands-on, but she's now back to the ward

Oh, the same ward?

Same ward, well I think it's the same ward. But yeah she's gone back 'cos I think she enjoyed the subject.

Has she gone back because the ward's improved do you think?

I don't know, she never said. I hope it's improved. You know I'd like to think it's improved because I know there's been quite a lot of people have complained

Have they?

of the wards, so it has to be taken on board, hopefully!

Yes, yes, did you make any more, you complained and saw the matron while you were on the ward; did you take that any further or not?

Not officially, I think when I came home I was so poorly that you just can't think 'ah I'm out, just thank God I'm out of there' that was the main thing. 'I'm out'. But I've tried in other ways to try and make a difference so hopefully.....

You are doing this

It will, yeah hopefully.