

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)
*VENUE: Medium MR unit
*DATE: 18/11/2004
*ID: Patient15
*INTERVIEWER: DJW

INT: FIRST OF ALL, THANK YOU FOR AGREEING TO BE INTERVIEWED. I'D LIKE TO START WITH QUESTION ONE. CAN YOU TELL ME A LITTLE BIT ABOUT WHAT YOU KNEW OR UNDERSTOOD ABOUT BREAST CANCER BEFORE YOU REALISED THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: Erm, the only thing that I knew was my Grandma had breast cancer and that she'd had a mastectomy, because I actually lived with her when I was, when I was little, I was about 13, and I know what she sort of went through really. So that, I mean, that was the only thing I knew, I knew that it was possible to have sort of different types of surgery but, you know, I didn't really know a lot or understand a lot about it.

INT: RIGHT, OK.

Patient: Really.

INT: RIGHT, SO JUST YOUR GRANDMOTHER THAT YOU HAD?

Patient: Yes, yes.

INT: HAS ANYBODY ELSE YOUR FAMILY HAD BREAST CANCER?

Patient: No, nobody at all, no. Just my Grandma.

INT: AND YOUR GRANDMUM HAD, SHE HAD A MASTECTOMY, IS THAT RIGHT, YOU SAID?

Patient: She did, yes, yes. Yes, she, erm, she had that and then she lived for I think it was about five years and then she developed lung cancer and died of that, so ...

INT: OH RIGHT.

Patient: ... so she sort of ...

INT: WAS HER LUNG a PRIMARY, WAS IT, DO YOU KNOW?

Patient: Erm, I'm not ...

INT: [???

Patient: I'm not sure.

INT: YOU'RE NOT SURE.

Patient: I'm not sure about that, but I just know that she had the breast cancer and then she was really well and then all of a sudden developed problems with her chest and, as I say, that's what they said it was when they did the post mortem and things, so ...

INT: OK. HAVE YOU ANY FRIENDS, FAMILY FRIENDS OR WORK COLLEAGUES, ANYTHING LIKE THAT THAT HAVE HAD BREAST CANCER BEFORE?

Patient: Erm, I have a friend who lives up the road, erm, who I went to see last July, erm, and she'd a mastectomy and I just went to visit her because I spoke to her husband and he said she wasn't too well, so I said, 'Would you mind if I

popped to see her?' and she was feeling a bit down in the dumps so I went to see her and she was, she told me quite a lot more, so I was sort of more aware then.

INT: WHEN WAS THIS, WAS THIS LAST ...?

Patient: This was last year.

INT: LAST YEAR.

Patient: Last July time. Erm, and she was telling me all about what she'd gone through, and losing her hair and all the bits and pieces, that her cancer was more serious than mine.

INT: RIGHT, OK.

Patient: She had to have ...

INT: THE CHEMO ...

Patient: ... quite a lot of surgery and she's still having, having

INT: CHEMO.

Patient: ... treatment, yes, yeah. Yes, she's having, she's having an American trial.

INT: OH RIGHT.

Patient: Erm, I believe she has all her treatment at Weston Park ...

INT: OH YEAH, YEAH.

Patient: ... it had branch-, the cancer had branched out or something and had gone into her glands.

INT: RIGHT, OK. OH THE LYMPH GLANDS?

Patient: Yes, yes. So it was, er, quite, quite a, you know, big surgery I think that she had to have done and they're giving her everything that they can give her to make sure it's, you know, goes away basically.

INT: HAVE YOU SEEN HER RECENTLY AND ...?

Patient: Yes, she's doing, she's doing really well. Her hair's grown back now and she's, she's still having treatment. She's had, I think 18, 18 lots of treatment up to now, so she's, she's had a really rough time of it.

INT: YEAH, YEAH, IT'S A LONG, BIG LONG JOURNEY, ISN'T IT THAT FOR HER?

Patient: Yeah, yeah, but I think, as I say, she's going through as much as she can 'cos she's got two little children and, you know, she just really wants to make sure it's gone.

INT: ABSOLUTELY, YEAH.

Patient: So, yeah, she's doing, she's doing very well really.

INT: OK. SO CAN YOU JUST BRIEFLY TELL ME HOW YOU CAME TO FIND OUT YOU HAD BREAST CANCER?

Patient: Well, I was on holiday ... on holiday in May, erm, and I usually examine my breasts you know sort of when I have a shower and things, probably once a month or whatever, erm, and I was on a period and I noticed this lump and just thought it was nothing to worry about and sort of left it really, carried on on the holiday, came back and it was still there. It didn't hurt, it wasn't painful or anything, erm, but just I knew it wasn't right, so I left it another week, erm, and then I thought, 'Well maybe I ought to do something about this,' and so I went to the GP and he of course examined me and said, 'We'll refer you to the hospital and get this checked out.' erm, you know, 'It's the best thing to do really,' and so that's sort of, you know, went away and waited for my appointment at the hospital.

INT: RIGHT, OK. SO WHEN YOU FIRST FOUND THE LUMP, I MEAN, WHAT WENT THROUGH YOUR MIND AT THAT POINT?

Patient: Erm, I think at first I just thought, erm, it's probably a cyst and it's nothing to worry about and ... maybe it's something to worry about but in the back of my mind, I think I was pushing it to the back of my mind thinking, you know, it's probably something and nothing and it'll just go away, or it's a fatty lump or something, erm, because I did breast feed and I thought, well maybe, you know, maybe it's something to do with that.

INT: RIGHT, OK.

Patient: You know, so I wasn't too concerned at that stage, but obviously concerned enough to sort of, with my Grandma having problems, I just thought, you know, it'd be silly to leave it, you know, and not have it investigated really.

INT: RIGHT, AND THEN, YOU KNOW, ERM, AS YOU WENT TO SEE YOUR GP AND HE REFERRED YOU, WHAT HAPPENED, WHAT WERE YOU THINKING THEN AT THAT POINT?

Patient: Erm ...

INT: DO YOU REMEMBER?

Patient: ... I think I got, I got more concerned 'cos I thought, 'Well, obviously he's concerned about it enough to refer me to the hospital,' and I'm thinking, 'Well, you know, hopefully it won't be anything serious' but, because of my Grandma's history, I was, I was quite worried by then, yeah. Yeah, I was getting myself in a bit of a state really I think, 'cos, you know, you get yourself all worked up about these things and at first I just thought, 'Oh, it's something and nothing,' and then I was starting to think, 'Oh well, you know, maybe this could be something that I need to, you know, put in my mind and realise that maybe there is a problem, you know, and I might need something doing or I might need this lump removing,' and having to have surgery, I was worried about surgery really because I've never been put to sleep and I was worried about having to be put to sleep. So, er, I was more frightened of that, having to be put to sleep than, and not waking up, you know what I mean, it's, when you've not had surgery, that was one of my fears and thinking, 'Oh, my kids' and stuff so, you know ... so I was sort of, you start worrying about them and think about them as well really. 'cos you think, if it is something serious, you know, then they're without a Mum aren't they if it is something that can't be treated and things, if it is, you know, if it had gone somewhere else or ... 'cos I have had problems with my stomach for quite a long time and I thought, 'Well maybe, you know, should I have gone back to the doctors with that?' and everything goes through your mind really, you do sort of worry about it really.

INT: YEAH. I MEAN, I WAS GOING TO ASK YOU EARLIER ON, I MEAN, ARE YOU A GENERALLY FIT AND WELL PERSON OR ...?

Patient: Yes normally.

INT: YOUR MEDICAL HISTORY AND THAT.

Patient: Erm, the only thing I do suffer with is this irritable bowel syndrome which is sort of bloating and things and, you know, certain foods irritate my stomach and things like that, so I do have tablets to take and, you know, I try and avoid taking those really but generally I don't get many colds, I don't suffer with anything really, so I've been very healthy, very lucky really, you know, so ...

INT: SO, ER, THE GP REFERRED YOU?

Patient: That's right, yes.

INT: TO THE HOSPITAL. CAN YOU TELL ME WHAT HAPPENED WHEN YOU WENT ON THE FIRST VISIT TO THE HOSPITAL? JUST WALK ME THROUGH THAT.

Patient: Yeah, erm, I think the first, went off for the mammogram, erm, and had that done, had the x-ray done, erm, I can't remember whether I saw the doctor first or not ... it seems such a long time ago. Erm, we went, as I say, had the mammogram done, erm, and then I had an ultrasound scan ... yes, I did see the doctor first, that's right, and he ...

INT: THIS WAS THE CONSULTANT, WAS IT?

Patient: Yes, it was Mr Chadwick I saw first, and he sent me off for the mammogram and the ultrasound scan, that's right. Erm, and then, once I'd had those done, I had to have a biopsy done, erm, which they took a cutting of the lump, and then I then went back and see Mr Chadwick again, erm, and he said that it was a little bit worrying, they'd have to send off this sample, erm, to have, have it assessed or whatever to see whether, you know, what was, whether it was anything to worry about, erm, and they'd look at that and then they'd see me again, erm, I think it was in ten days or something like that, erm, just to find out the results of those. But at that stage I think I knew there was something wrong ...

INT: RIGHT.

Patient: ... erm, ... just ...

INT: WHAT MADE YOU THINK THAT THEN?

Patient: Erm, because, because I used to work as a nurse, auxiliary nurse ...

INT: RIGHT, OK.

Patient: ... erm, I think a little bit of knowledge is probably worse than nothing, and I just sensed, I sensed that he was concerned and he was, he drew a picture and everything and showed me what, how big this lump was and said the same, how big it was, and when he said how big it was and things I just thought, [??] 'Obviously he needs to see me again, there's something not quite right,' and I came away thinking, you know, erm, that it is, it is something, there is something wrong sort of thing. And he did say at that time, I said, he said, 'Whatever the results are, you will need to have surgery ...

INT: RIGHT, OK.

Patient: ... and so I'm thinking, like, 'Oh gosh, I've got to have surgery' like, you know, so I did come away a bit, a bit concerned but, you know, not too

bad, I just thought, well, you know, obviously I've got to wait and ... the waiting was the worst dread, I had to wait that for the results and things, so ... but then I saw the breast nurse, er ...

INT: ON THE SAME DAY?

Patient: Yes, yes, she, erm, I went into the room next door and she gave me some leaflets and I asked her if there was any information on breast cancer, erm, and you know anything she could give me information on and so she gave me these leaflets and things and I came, and then I came out, came away, and sort of, you know, came home and sort of sat and read these leaflets and thought, 'Oh dear,' kind of, but, erm ...

INT: WHO WAS THE BREAST CARE NURSE, DO YOU REMEMBER?

Patient: It was Mary.

INT: MARY.

Patient: Yeah, she was lovely, she was really nice.

INT: DO YOU REMEMBER HOW LONG ... HOW LONG, HOW LARGE SIZE THE TUMOUR, HOW LARGE HE SAID IT WAS?

Patient: Erm, I think it was 7 ... he said it was the size of my thumb ...

INT: RIGHT.

Patient: Erm, I think he said 10, 10 cms or 10 ...

INT: TEN MILLIMETRES.

Patient: Ten millimetres, something like that. So, as I say, it wasn't a huge lump and he said he was amazed I'd actually found it.

INT: REALLY?

Patient: He said, he said, 'Well done, because,' he said, 'You're very lucky to find it, erm, just ...,' as I say, he was amazed that I'd actually found the lump myself because he said a lot of ladies don't, you know, they come when it's a lot bigger than that, so, you know, it was very good that I found it at that sort of stage really.

INT: RIGHT, ERM, AND DID YOU GO ON A VISIT, DID YOU GO BY YOURSELF OR WAS SOMEONE WITH YOU OR ...?

Patient: Erm, my neighbour actually took me. My husband was busy that day so my neighbour came with me, so I'd got my neighbour with me who is a very close friend as well really, we're good friends, so ...

INT: YEAH, OK.

Patient: ... so she came and brought me to the hospital and things, so that was nice to have another lady with me as well, 'cos it's, you know, just somebody to chat to and things. As I say, she was there as support for me, so ... yeah, it was good.

INT: ESPECIALLY WHEN YOU'RE GOING FOR THE TESTS AND YOU'RE HAVING TO WAIT FOR THIS AND THAT [???] ...

Patient: Well that's it, when you're waiting around it was just nice to have somebody there to talk to and it was nice in the, you know, the waiting room, they'd got the coffee, so you could have a coffee, and there was lots of nice magazines and things and stuff so, and there was a lady making coffee for everybody, which I thought was nice, you know, while you were waiting, that was very good. Erm, 'cos I say, you're sort of at there and it's warm and, you know, you don't want to go off in case you miss being called for something, so it was nice to be able to sit there and have a drink while you were waiting to be seen and things. So that was good. Mm.

INT: ERM, AT ANY POINT UP TO THIS STAGE WHAT WE'RE TALKING ABOUT, DID YOU HAVE ANY THOUGHT IN YOUR MIND ABOUT WHAT YOU MIGHT DO IN TERMS, IF IT IS, IF IT COMES TO AN OPERATION OR ANY KIND OF TREATMENT, HAD YOU ANY THOUGHT ABOUT WHAT YOU MIGHT DO ABOUT IT?

Patient: Not really, no. Erm, they just said that the lump would have to come out, erm, so I was sort of hoping that that's what they would do, they would just be able to take the lump out, to remove the lump, so that's, I think that's what I'd got in my mind, when I went, you know, when he told me that it was, you know, I'd need surgery anyway, erm, as I say, I wasn't thinking of, like, mastectomy or anything like that at that stage. So that wasn't a concern at that time, so ... and he hadn't mentioned that so ...

INT: OK. AND YOU HAD THE RESULTS, WHAT, TEN DAYS LATER?

Patient: Yes, yes. I went back and I saw Mr Holt that time.

INT: RIGHT.

Patient: Erm, and he, he said that, erm, it was definitely cancer and that it needed to be taken out as soon as possible and just asked if I'd got holiday and things and I said no. Erm, and he said can you come in on Monday and I said, 'Yes, as soon as ...' 'cos once I knew it was cancer, I just said yes, you know, 'I'll come in whenever,' you know, 'tomorrow or whenever you want to do it,' just, I just wanted to get it removed basically when I knew it was sort of cancerous, you sort of think, 'Ooh, just want to get it out of the way and gone,' so it's, it's not doing any more damage or, you know, spreading somewhere else really. So I just wanted to get, get it done really. So ... and he just said to me at that stage that, erm, they would take the lump out, erm, but I might need further surgery, but they did say to me at the time did I, if I wanted to have a mastectomy then I could have that done, they did give me the option. He said, 'You can have the lump taken out,' and they would take the glands from under my arm, erm, but if I preferred to have a mastectomy then I could have that done, as because, because once they sort of get inside, it can, the lump can be bigger obviously they can't always see how it big it is or, I suppose, whether it's, you know, moved somewhere else or whatever, erm, so he said, you know, 'You might need to, if you have the lump removed and then you might need to have to come back for further surgery. Are you happy to do that?' and I said, 'Look,' you know, asked his advice and he said, 'Well, I believe that you don't need to have a mastectomy,' he said, he said, 'If we just take the glands, erm, and the lump and the tissue from around the lump then hopefully that should sort that out.' And I was, I was very happy with that really because I didn't want to lose my breast if, you know, if he'd have said to me 'You need a mastectomy,' then I would have gone ahead with that ...

INT: YEAH, SURE.

Patient: ... but, but because he sort of advised me that that was, that was fine, and, and I suppose if, you know, at the end of the day, if you can get away with less surgery then it's better for you, erm, and also being quite young I wanted to keep my breast if possible, you know.

INT: ABSOLUTELY, YEAH.

Patient: 'cos it's quite important for a woman to feel like normal really, I suppose, you know, [???] normal really.

INT: AND, ERM, THE WEEK PRIOR TO THAT, IN BETWEEN YOUR FIRST VISIT AND THE DIAGNOSIS WITH MR HOLT, ERM, I MEAN WHAT WAS GOING THROUGH YOUR MIND DURING THAT WEEK WHILE YOU WERE WAITING TO GO BACK?

Patient: Er, it was, I think it was probably the longest week of my life really, erm, it seemed to drag so, you know, so long, erm, but, yeah, I was, I was worried, erm, I was worried that I'd got, I was going to have to have surgery, erm, but, erm, I was just hoping that it would come back and they'd just say it was, you know, a fatty lump or a cyst and, you know, it wasn't a problem. But, erm, as I say, I knew, I knew it had got to come out. So I was sort of prepared for surgery but I wasn't prepared for the cancer bit ...

INT: RIGHT, OF COURSE.

Patient: ... you know, that was a bit of a, when he said that I'm thinking, 'Oh gosh,' you know, and sort of thinking of my Grandma, how, the sort of, first, at first, I thought, 'God, you know, I'm gonna lose my breast,' and, you know, 'Has it gone anywhere else?' and you sort of start panicking a bit, but, as I say, all sorts of things go through your mind. You think all sorts of silly things, I suppose. But, erm, I was just relieved that, you know, that I'd found it and that, you know, I was actually having something done about it, which, you know, they were going to do something, so I'd just got to wait for a few days, but it did seem like a long time. [chuckles] You know, it's a long week.

INT: DID YOU SPEAK TO ANYONE ABOUT YOUR FEELINGS OR ANYTHING LIKE THAT, OR WHAT YOUR THOUGHTS MIGHT BE?

Patient: Erm, I didn't, I didn't really speak to family because I didn't want to, [???], I say, I spoke to my husband, but I didn't to my, my sort of family live in Buxton, erm, I didn't speak to my Mum or anybody really, I didn't, erm, I didn't sort of talk to them because I was, I just said I'd been for this appointment and I'd got to go back for some results, erm, because I didn't want to worry them. Erm, and I thought if it's nothing to worry about, if it's just, you know, a lump and things, then they don't really need to know, do they? You know, it's sort of ... but, er, I must admit I did speak to my friend, erm, up the road, Fran, she ... obviously she'd been through it and I knew, you know, er, what she'd been through, and I spoke to her and she just sort of said, said to me, 'Oh you'll be fine, Marilyn, it'll be something and nothing,' and, you know, sort of thing. She was sort of very supportive. Then my neighbour, as I say, we're very close so I went round to Val's, had a cup of coffee and had a chat and, you know, had a little, little weep and ... [chuckles] you know, sort of thing. But, erm, you know, you sort of, you just sort of get through that week the best you can until you can find out the results really.

INT: YEAH.

Patient: Yeah, it was glum week really.

INT: YEAH. ER, AND WHO WENT WITH YOU? DID ANYONE GO WITH YOU ON THE SECOND VISIT TO MR HOLT?

Patient: Yes, yes, my husband came with me that day.

INT: AND WAS HE IN THE CONSULTANT WHEN YOU WERE GIVEN THE DIAGNOSIS?

Patient: He was, yes, he was, yes, yeah.

INT: WAS ANYBODY ELSE IN THE ROOM AT THE TIME, DO YOU REMEMBER?

Patient: Erm, there was, erm, the breast nurse and I think there was another, I think there was another doctor in there and another nurse, so there was about four ...

INT: RIGHT, OK.

Patient: I think there were about four people in there as well as myself, so.

INT: WHICH BREAST NURSE WAS IT? DO YOU REMEMBER?

Patient: Erm, I think that time it was, erm, ...

INT: DONNA?

Patient: Donna, yes. Yeah, Donna was in there, yeah, yeah.

INT: AND WHEN MR HOLT WAS, ERM, I KNOW MR CHADWICK, HE DREW A DIAGRAM, DIDN'T HE?

Patient: Yes, he did, yes.

INT: ... THE FIRST VISIT.

Patient: Yes.

INT: WHEN MR HOLT WAS TELLING YOU ABOUT YOUR DIAGNOSIS AND YOUR TREATMENT OPTIONS AND THINGS, DID HE USE ANY VISUAL AIDS SUCH AS DIAGRAMS, PICTURES, DID HE PUT ANY MAMMOGRAMS UP OR ANYTHING LIKE THAT?

Patient: Erm, yes, I think he did, he did show me the mammograms on the screen where, showing me the size of the lump, erm, and he'd actually shown me Mr Chadwick's drawing again that was in the notes, erm, and he was saying that this area needed to be removed and that the glands would be removed from under my arm, and he explained about, erm, the surgery and things and just, erm, he was hoping that I would be in, you know, only for a short time, overnight possibly but maybe longer, erm, and just said that I'd need to have drains and things in, erm, so I was prepared for that. Erm, but, yeah, he explained things really well, but I don't think I took a lot of it in, erm, which was why I was glad my husband was there, because he was talking about the cells and, you know, how they evolve and, you know, what they do and things, and I was just sort of sat there thinking, you know, 'I've got cancer,' you know.

INT: YEAH, IT STOPS PEOPLE IN THEIR TRACKS ...

Patient: Yeah.

INT: [???

Patient: Yeah, I think the shock was, yeah, I think the shock was, erm, you know, but as I say, because I'd got somebody else with me, when we came home my husband said, 'Well did you understand what they said?' and obviously he explained it again to me. So it is good to have somebody there with you.

INT: ABSOLUTELY YEAH.

Patient: Yeah, you know, so that if you don't, like, understand it or you don't, don't hear what they're saying really, 'cos sometimes you switch off, don't you, when you've just heard that word? It's ...

INT: EXACTLY YEAH, YEAH A LOT OF PATIENTS SAY THAT, IT'S VERY COMMON. YEAH.

Patient: So, er, but, yes, he explained really thoroughly to me and, you know, just said, 'We'll get you in Monday and get on with the surgery, you know, it's not a huge lump and it's lucky you found it when you did' and, you know, just basically 'We'll get on with it and get rid of it for you.' So, you know, but he was very ... he was lovely, you know, he was really ... I think, I mean some doctors I've met and their bedside manner's not very good, but he was just really, really nice and just, I mean, they've all been lovely, you know, all the breast nurses, everybody, you know, they've been, couldn't have done, done any more really, I don't think, you know, they was really, really nice, and they give you time as well which is nice. They didn't, you didn't feel rushed. You know sometimes you go to your GP and you feel you've only that sort of 10 minute slot, and you just, you just felt that you'd, you know, if you'd got any questions you could have asked them, erm, and my husband asked a few questions but I just sort of, as I say, I just sort of sat and listened to what they'd got to say really. And, but, yes, it was, he explained it all really well and just said that, you know, I would might, maybe need surgery and that was, you know, something to consider, but he thought that this was the best way forward as long as I was happy to do that. And with that I said, 'Yeah,' you know, 'if that's how you, what you think is the best is the best surgery, then, you know, I'm happy to go along with that.'

INT: AND AFTER YOU SAW MR HOLT, DID YOU SPEND ANY TIME WITH THE BREAST CARE NURSE?

Patient: Erm, I didn't, no, not on that day, no. Erm, I just, I think we just came out and we went home that day, I don't think actually I was shattered with the ... I think she came outside and said, 'Is there any more questions you want to ask?' erm, but, but she didn't sort of take me to the room or anything 'cos I was fine, I wasn't sort of upset or anything so she just said, 'Is there any more questions or is there anything you didn't understand?' er, and I said, 'No, that's fine.' And she said, 'Well, you know, erm, you have to come to such-and-such a ward and all that sort of thing, it'll be sent in the post. And so she just explained that and then, as I said, we came home and waited to go in on the Monday morning for the operation.

INT: DID YOU GET THE DIAGNOSIS WHEN, WAS IT THE THURSDAY? DID YOU SAY TUESDAY?

Patient: Erm, it was 13th July, I think it was, yes, it was a Tuesday, yes it was, yes.

INT: OK, AND THEN SO YOU WENT IN THE FOLLOWING MONDAY, SO A WEEK LATER?

Patient: Yes, yeah.

INT: OK. ERM, AND HOW WERE YOU DURING THAT WEEK IN BETWEEN THE DIAGNOSIS AND THE OPERATION?

Patient: Erm, not too bad really. I expected to be sort of, I was, I was obviously upset but, erm, I think I was more worried about being put to sleep, erm, and not waking up, [chuckles] that was my fear. Er, but, erm, no, I was, as I say, I was worried, but, erm, you know I just felt that I was lucky that I'd, I'd found, found a lump, and it wasn't big and he sounded, he sounded really positive about it, erm, so it made me feel sort of more positive that it was, you know, it wasn't going to be a big, such a big deal and that it was going to be sorted and, you know, I'd be fine. So, you know, it was, erm, it was just

take the lump out and, er, and I'd be OK, sort of thing, you know, which, which I was really relieved about. I think I was just more frightened of the surgery and, erm, one of the things I did ask him was, erm, because they'd said about the mastectomy, erm, I said to him, 'If you find that the lump is bigger than what you think, you won't just take my breast off while I'm asleep?' because at one time I think that's what, what they used to do sometimes. If it was ...

INT: THAT'S RIGHT, YEAH, THEY DID.

Patient: And that's what happened to my Grandma ...

INT: OH I SEE, RIGHT.

Patient: ... erm, and I said to him, I said, 'You wouldn't do that?' and he said, 'No, we wouldn't, Marilyn,' he said, 'There's, we would wake you up first and then we WOULD go ahead.' He said, 'We just can't do that now, we have to have ...

INT: [???

Patient: ... consent and everything.

INT: YEAH, CONSENT FORM.

Patient: He said, so 'Don't,' you know, 'don't be worried about that. It's just something that will not happen.' So, erm, as I say, that was on my mind a bit and, once he'd sort of confirmed that that wouldn't happen, then I was sort of OK, you know, just relieved I wasn't going to have to have a mastectomy really I think.

INT: RIGHT, OK.

Patient: At that stage anyway. So, you know, so ...

INT: ERM, YOU'VE PROBABLY TOUCHED ON THIS A LITTLE BIT BUT I'M GOING TO ASK YOU ANYHOW, HOW MUCH DID YOU UNDERSTAND ABOUT WHAT YOU WERE BEING TOLD ABOUT THE CANCER AND ITS TREATMENT?

Patient: Erm, I think it was explained so that I could understand it and, you know, they try and explain it as well as they can, erm, and I did, I did explain what was, you know, understand what was happening, erm, and the surgery and everything. Erm, but, erm, as I say, I think possibly because I know a little bit of, sort of because I worked in the medical professional, erm, I think I sort of knew probably a little bit more than probably the normal person would know, erm, about the cells and things like that, and I did actually come home and get one of my books out and read, read up on what the cells do when ...

INT: OH, A BIT OF REVISION?

Patient: ... you know, so that I ... yeah, so I just, er, so I understood it more, er, when I got home, so, you know, erm, so you know exactly what's happening in your body and so you're not, I don't think you're as frightened when you realise that it's, you know, the cells are there and, you know, they don't, once it's not, if it's not moved anywhere else then, you know, you're pretty OK sort of thing. So ... so, as I say, I think that put my mind at rest. And my husband's saying, 'Well, you know, it's only that big and, you know, it's like the end of your thumb and things, and it's only tiny and, you know ...' so, so I think I was sort of quite relieved that I'd found it and, erm, and I did sort of chat with my Mum and things and she'd had, erm, she's had some like cysts and things but nothing, nothing sort of desperate, so, so she was sort of

just saying, 'Oh, you'll be fine,' you know and everybody was saying the same thing, 'Of course you'll be OK,' you know, ...

INT: THIS IS AFTER THE DIAGNOSIS?

Patient: Yes.

INT: YEAH, YOU TOLD THEM THE DIAGNOSIS, DIDN'T YOU?

Patient: Yeah, yeah, yeah, yeah, 'cos I was sort of, then rang my Mum and said, you know, 'This is what's happened and I've got to go in to hospital' and things, so that they knew, and everybody was really supportive and just said, you know, 'I'm sure you'll be fine, Marilyn,' and [???] you know, 'Once it's gone, you'll be OK,' sort of thing. So, so I just sort of looked forward to going in, erm ... I know one, one day I did sort of feel that, erm - whether anybody else does, but - I just felt as though I wanted to rip it out.

INT: RIGHT, OK.

Patient: I just wanted to be able to get, get rid of it, and I just felt I wanted to rip it out my chest, which sounds strange, but that's how I felt. I just wanted the lump gone, you know, once I knew it was cancerous, I'm like thinking, 'I just want to get rid of this thing,' you know.

INT: YES, ABSOLUTELY.

Patient: And that was one of my feelings, I just, as I say, I just woke up one morning and thought, 'God, this thing's got to come out,' you know, 'it's got to go.' Erm, but, other than that, as I say, I think I was, you know, OK really, you just have the odd day when you feel a bit, you know, more stressed about it than, than others. But, er, you just sort of get on with it and, you know, hope everything's gonna be OK.

INT: MM. ERM, SO, ER, CAN YOU TELL ME A BIT ABOUT WHAT HAPPENED ON THE DAY OF THE OPERATION, YOU KNOW, WHAT THE PROCEDURE WAS AND THINGS?

Patient: Er, we went to the ward and the nurses, erm, nurses sort of showed me to my bed and everything and then they said that they needed to take me down to x-ray to mark up the spot, erm, they needed to do an ultrasound scan, sorry, and they needed to mark the area. So I went down to the x-ray department and they marked, marked it up for me and they made sure it was the right area that Mr Holt needed to operate on. And then they brought me back to the ward and then I just sort of waited till, till they took me down to the operating theatre, you know, on the trolley sort of thing, so ...

INT: RIGHT.

Patient: Yeah.

INT: AND, ER, IT WAS MR HOLT THAT ACTUALLY PERFORMED THE OPERATION, WAS IT?

Patient: Yes, it was, yes.

INT: YEAH. AND SO HOW WERE YOU WHEN YOU, YOU CAME ROUND? OBVIOUSLY RELIEVED THAT YOU DID COME ROUND ... [CHUCKLES]

Patient: Yes, exactly. Erm, I felt, actually felt quite good really, you know, sort of you wake up and you think, 'God, this is gonna hurt,' you know, 'I'm gonna be in so much pain,' and, and I woke up and was fine, I wasn't really sick or anything like that. Erm, and I was sort of sat up and had a drink of water, very dry, but just relieved it was all over I think. [chuckles]

INT: YEAH.

Patient: You know. Erm ... as I say, the nurses gave me sort of painkillers and stuff obviously, you know, to make sure I wasn't in discomfort, erm, and I just sort of stayed, stayed overnight, erm, and the other ladies that I was in with, they'd all had mastectomies, erm, and so I'm like, because I used to be a nurse, I'm there, one of the ladies was, was being quite sick, erm, so I'm, I got out of bed because I hadn't got anything attached to me and I'm going, getting her the, you know, the bowl so she could be sick, bless her.

INT: OLD HABITS DIE HARD.

Patient: Yeah, exactly. [chuckles] Yes, she couldn't get to it so I helped her out, but, erm, but, no, I felt really good, erm, you know, erm, I got up in the morning and felt, as I say, you felt, you feel a bit groggy and a bit tired but the following day I sort of got up and they said I could go home because I'd not got my drain in, so I was like biting at the bit to come home, [chuckles] had lunch and I came back, back home, which, yeah, it was, it was quite a good experience really 'cos I wasn't in too long, you know, it's ...

INT: DID YOU HAVE ANY VISITORS IN THAT TIME AT ALL? DID ANYONE COME AND SEE YOU?

Patient: Erm, my husband came, came in the evening, erm, but, as I say, because I was only in overnight, sort of everybody came here really once I'd got home, so, you know, 'cos I wasn't in that long. So, which was good I was say. It was nice just to go in, have it done and come home really, you know, and get back to my, to my children really, 'cos I'd not really left them and that was, that was one of my concerns because of sort of, you know, not being at home and things. Erm, but they were with their Dad, so they fine, you know, they were, they weren't too worried, but ...

INT: OH, THAT'S GOOD THEN. ERM, LET ME SEE, WHERE ARE WE? WE'VE GONE QUITE A WAY HERE. ERM, AND THEN HOW SOON AFTER THAT DID YOU GO BACK TO HEAR ABOUT THE RESULTS OF YOUR, THE OPERATION?

Patient: Erm, I went back, erm ... trying to think when it was ... erm, [???] erm, oh I went back to have my stitches out, erm, was it the following ... I think it was the following week, no, the ... I think it might have been the following week I went back after the ... 'cos I went back to see Mr Holt and they, they sort of looked at the wound and everything and checked that was OK. I think it was probably the following week I went back, erm, and just checked, he checked everything over and everything and said, you know, that that was fine and I was doing really well, and, erm, they were quite happy they'd got all the tissue from around the lump and they'd only taken, I think it was 16 lymph nodes, they hadn't had to take anything, erm, any more than that, and also the fact that it hadn't spread to my lymph nodes, which was a big relief. Erm, and just basically then that I was going to go on and see the oncologist, Mr [???] and I'd got an appointment to see him on 12th August, erm, and that he would organise the radiotherapy, that I would just need radiotherapy at that stage. Erm, so, erm, and he said that, erm, you know he was quite happy with the surgery and hopefully that I wouldn't need any further surgery, the radiotherapy would, erm, sort that out. I would also need to take the Tamoxafen for five years, which, erm, would also make sure that the cancer didn't come back. Erm, but, yes, he was very pleased with me and, er, you know, they'd done the right thing by just removing the lump and, you know, how was I doing and I said, 'Yes, I'm doing fine,' and so he just said, you know, 'So you need to see Mr [???],' and then I went off and, you know, had to wait for the appointment to see Mr [???] after that.

INT: OK. AND, ER, HOW ... OBVIOUSLY ... YOU SAW MR [???], IS THAT RIGHT?

Patient: Yes, yes.

INT: AND, ERM, SO HOW WAS THAT THEN? [???

Patient: Erm, when we went on the morning I was, I was quite worried, erm, I don't know why, I just sensed something wasn't quite, quite right, erm, and we got there and he said to me, erm, that, basically that they'd all got together and the grade, the stage I'd seen Mr Holt, the cancer had been graded as a grade two, erm, and they'd all got together that particular morning and had a chat about the results and, and the gentlemen in the lab and everything, and basically they'd upped the cancer to a grade three ...

INT: OH RIGHT.

Patient ... erm, so that he, he suggested that, erm, I had the chemotherapy which he said I really do need, because if I don't have that done there's a 35 per cent chance that the cancer could return. Erm, so that, I think that was a bit of a shock really, that, erm, because I just expected the radiotherapy, erm, but one of the results hadn't come back when I went to see Mr Holt and this was the result that we were waiting for ...

INT: OH, RIGHT, OK.

Patient: ... and I was, I don't know, I just sensed, because this result hadn't come back, my husband was saying, he says, 'You're fine,' you know, 'You've had your surgery and everything and everything's OK ...' and whatever, and I said, I said, 'Yeah, just hang on a minute, Pete,' I said, 'we've still got one result,' erm, and that was at the back of my mind sort of thing when I went in. And he said to me, he said, Mr [???] said, 'You knew, didn't you?' And I said, 'No ... well, I was worried about this result, and I'm sort of thinking well, until I know that's, that's OK, erm, and, er ...' but he just, he sat and said, 'You knew, didn't you, Marilyn, that you'd have to have ... you know, the results wasn't gonna be good.' And I said, 'Well I just hadn't put it out my mind totally that things were gonna be OK.' Erm, and he said, 'Well,' he said, 'if you were my wife, I suggest you have the chemotherapy,' he said, 'It's not gonna be pleasant,' he said, 'but it's gonna make sure that we get rid of the cancer and that's the important thing.' Erm, and he told me I was gonna lose my hair and things and that was, that was quite upsetting, erm, so, er, as I say, he just gave me time to sort of pull myself back together again and, you know, erm, and he gave me sort of a prescription for the wig and all the bits and pieces and explained all about that and, and he was lovely, he was just so nice. Erm ... so we had, we did that, and then he just said, 'Well, you know, we'll organise you coming in to have, start to have the chemotherapy,' and that I'd need four, four sessions of chemotherapy, plus the radiotherapy as well. Erm, and I was sort of, I wasn't too worried about the chemotherapy, I don't think that had really, I didn't realise what that involved to a certain extent ...

INT: RIGHT, OK.

Patient: ... erm, but I was more upset about losing my hair when I came out, I was like ...

INT: THAT'S REALLY, REALLY COMMON.

Patient: That was ... it was, it was like the end of, the end of my world really. It sounds silly but it was just, you know, afterwards you sort of think, 'Oh, why was I being so silly?' you know, but, but it is, it's the, I think it's the hardest bit of the cancer, is, you know, losing your hair, 'cos it's, it's part of you really, part of your personality, you know, and I've always been one

that's sort of looked after my hair and had it cut regular, and it's always, always ... you know ...

INT: IT'S AN OUTWARD SIGN AS WELL, THAT'S THE THING.

Patient: Yeah. I think ...

INT: YEAH, IT'S AN OUTWARD SIGN THAT SORT OF SOMETHING'S ...

Patient: Something's ... something's not quite right.

INT: NOT QUITE RIGHT, YEAH, EXACTLY.

Patient: And so that was, that was one of my biggest concerns I think. As I said, I was worried about having to have, have the chemotherapy but, erm, as I say, at the forefront of my mind was this, like my losing my hair.

INT: YEAH, A LOT OF WOMEN SAY THE SAME THING IN THEIR INTERVIEWS, A LOT OF THEM.

Patient: Yeah, yeah, yeah, it was, it was, er, pretty horrific, I think, the thought of it coming out was not good. Erm, but at the end of the day, you know, you have to have it done and it's part of the treatment and, you know, they said, even if I used the, you know, the caps that they've got ...

INT: OH, THE COLD CAP?

Patient: Yeah, the cold cap, even if we tried that, he said, 'It just wouldn't work, Marilyn,' he said, 'There's just no point,' he said, 'It's just gonna come out, so there's no point telling you any different,' because that's more upsetting if you think you can stop it coming out and then it does come out.

INT: YEAH.

Patient; Erm, so, as I say, then, then it was just sort of wait until the, the first sort of chemotherapy started. So that was ...

INT: SO HOW SOON AFTER THE APPOINTMENT WAS THAT?

Patient: Erm, that was, I think that was, erm ... the 2nd September, erm, when I actually went back because we went to, my husband arranged for us to go to Wales for a week, so I went on a holiday for a week before the treatment started, so I spent sort of like a week with the kids and things ...

INT: WHERE DID YOU GO?

Patient: We went to a place called [???

INT: OH RIGHT.

Patient: And it's beautiful, there's ...

INT: WE WENT TO WALES THIS YEAR, WE WENT TO ANGLESEY.

Patient: Yeah. Oh right.

INT: WENT THERE AGES AGO AND I REALLY ENJOYED IT, AND WE WENT WALKING.

Patient: Yes, we did.

INT: SO WE THOUGHT, 'OH WELL, [???] WE'LL GO TO ANGLESEY AND HAVE A BIT WALK ROUND ANGLESEY,' WHICH WAS VERY NICE, WE GOT A DECENT WEEK FOR IT, STOPPED AT A FARM, IT WAS REALLY NICE.

Patient: Yeah.

INT: I LIKE WALES.

Patient: Yeah, we stay on a, we stay on a farm, there's a farm little, like little cottage that used to be a pig farm [chuckles] basically. And, er, we've been going for a long, long time, my husband used to go as a child and, er, there's just the river and the, you know, the children like playing in the river and we go for walks and things, so we had a lovely week ...

INT: THAT WAS NICE THEN.

Patient: ... it was really nice and we had a nice break and ... and then sort of knew I was gonna come back for the chemo, but, as I say, it was just nice to have that, that week and just, you were away from the telephones, 'cos everybody seemed to be ringing and everybody's sort of saying, 'How are you doing?' and you just, as I say, by the end of it you just, you just don't want to answer the phone any more, [chuckles] you know.

INT: YEAH.

Patient: I mean it's nice that people care and things but it does get a bit much sometimes. So it was just nice to have a week away, and we had picnics by the river and ... we just ...

INT: YEAH, IT SOUNDS GREAT.

Patient: ... we had a quality week really, it was lovely.

INT: YEAH.

Patient: So, it was really nice ... yes. So, and then I came back to the, sort of started the chemotherapy then and I was absolutely terrified the first morning when I went, I was absolutely dreading it.

INT: DID YOU GO TO WESTON PARK FOR IT, DID YOU?

Patient: No, no, I went to the Cavendish Suite in Chesterfield.

INT: OH RIGHT, YEAH.

Patient: Erm, and I think, the not knowing what they were going to do to me was the worry, erm, I would think I was more frightened what they were gonna do, because you don't, you don't really know what's gonna happen. And I hadn't had chance to talk to my friend, erm, and, er, so, as I say, we, it was, I would say I was really nervous, but once they'd got the needle in and everything that was sort of fine. I calmed myself down and was OK. Erm, but, erm, but as I say, it wasn't too bad: the first one wasn't too bad at all, I felt, I felt reasonably well, erm, I felt a bit tired and a bit sickly and things but, er, but not too bad at all really.

INT: RIGHT, AND HOW LONG DID THAT, DID THAT GO ON FOR THEN, THE CHEMO?

Patient: Erm, I've had to have four, four sessions of that.

INT: FOUR SESSIONS, RIGHT.

Patient: Erm, and I think as it builds up over the sort of treatments I felt more and more, more and more poorly really.

INT: YEAH.

Patient; Erm, it's, all the, just the different side effects and the sickliness and, as I say, after the, after the first one I was just due to go to, back for my, erm, next one, and that was when my hair started to fall out.

INT: RIGHT, OK.

Patient: Erm, and, er, I felt pretty, pretty dreadful at that stage, but, erm, but, you know, you've been measured up for your wig and I had my hair cut really short so that when it did come out that it wasn't as traumatic, erm ... it was still traumatic I suppose, but, erm, at the end of the day, you know it's gonna happen and I just then, once, once it got to the stage where it was irritating me, I just got the razor out and just shaved it all off, the rest of it that was left, so, 'cos it was like hurting. My head was hurting from the chemo ...

INT: YEAH.

Patient: It was like really, really sore and tender, and, as I say, once I'd sort of shaved the rest of my hair off it stopped hurting, so, erm, and then sort of started to wear my wig and things, you know, trying to get used to that and things, but, er, as I say, it's still, still not the best thing in the world but, you know, I've got scarves and different hats and things so you sort of try and get along without, you know, you get through it, don't you, until it sort of comes back again? But, er, as I say, I think that, out of the whole procedure, I think that has been the hardest, hardest bit to bear really. Erm, and just feeling, feeling rotten, feeling sickly, feeling tired all the time, you feel as though you've no energy to do things and, er, it's frustrating, 'cos you think, 'cos normally, you know, I'm quite a fit, healthy person and, you know, I'm always running round doing things and, and I just had to, you know, say, 'Right, my body's telling me I can't do this so I've got to just give in to it basically and do,' you know, 'go to bed if I need to go to bed, or whatever,' but, erm, friends have been really good and helpful and taken the kids to school and things, so that's, you know, that helps so you don't have to get up first thing in the morning and you, friends have had the, a friend had the children overnight when I've gone for my treatment so that she's taken them early to school in the morning so I've just been able to go off and not have to worry about taking the kids to school and things. So, so everybody's been really good and supportive, you know, family and friends and, you know, so, er, that all helps, doesn't it? All helps you get through it all. So, you know ...

INT: SO WILL YOU JUST TELL ME NOW, SO WHERE ARE YOU NOW IN TERMS OF THINGS LIKE TREATMENT AND WHAT'S FOR THE FUTURE AND ...

Patient: Right. Erm, I actually start my radiotherapy on the 7th December, erm, I've got to have a break in between: erm, I start my Tamoxafen, I have to start taking them next week, erm, and, as I say, I start my radiotherapy on the 7th December, so I've got to have ...

INT: AND HOW LONG WITH THAT BE FOR?

Patient: Erm, five weeks for, erm, I've got to have 25 sessions basically of that.

INT: RIGHT, EVERY DAY FOR FIVE WEEKS?

Patient: Yeah, yeah. So that, that's gonna be sort of getting to Weston Park's gonna be a bit of a nightmare I suppose ...

INT: YEAH, EXACTLY.

Patient: ... but, er, because the parking I think is not so good round there, there's not a lot of parking space and things and ...

INT: WHAT HAPPENS OVER CHRISTMAS THEN?

Patient: Erm, I believe that, erm, they're open, they're open other than Bank Holidays, I think, they'll be actually doing them, doing the treatments, so, er, I think they're sort of Monday to Friday, they'll still be doing and I suppose, you know, they'll fit me in, you know, where they can. As I say, my treatment actually starts on the 9th, but I actually go on the 7th to have the, do they call it mapping out ...?

INT: YEAH.

Patient: ... and they have to put the dye under your skin and things, so I've got to have that and they said I'll probably be there for an hour on that day, erm, so I've got to there on the 7th and then, as I say, start my treatment on the 9th, which is Thursday or something, and, erm, and then I presume sort of like the weekend I'll be free and then like it'll follow on the next week, so ... but they've said that's not anything like the chemotherapy, basically it just makes you feel tired and your skin feels a bit sore and tender. But, erm, yeah ...

INT: MM, MOST PEOPLE REPORT, SORT OF YOU GET MORE TIRED AS YOU GO THROUGH IT REALLY.

Patient: Right, right.

INT: TOWARDS THE END OF IT ESPECIALLY.

Patient: Yes, yeah.

INT: YEAH, IT IS QUITE TIRING.

Patient: Because it's sort of, the other thing was I was a bit concerned about having to drive, drive down there. I said, they've said, erm ...

INT: SHEFFIELD IS A NIGHTMARE.

Patient: ... I should, you know, that I should be able to drive but, erm, I don't know, because, as I say, 'cos of the tiredness and also with the chemotherapy, it makes you feel very, erm, it makes it hard for you to concentrate, erm, ..

INT: YEAH.

Patient:... and I think, you know, sort of a city, you need to have your wits about you.

INT: WELL, YEAH, I MEAN, SHEFFIELD'S NOT EXACTLY THE NICEST CITY IN THE WORLD TO DRIVE THROUGH, IS IT, REALLY?

Patient: No, no. So, er ...

INT: [???) JUST THIS MORNING [???)

Patient: Yeah, yeah. So, I'm, er, I'm sort of, as I say, I've got friends, and like my husband works, he's self-employed so it's sort of, the worry of getting

down there and getting back again and, you know, in between sort of school trips and things like that. So ... but I'm sure we'll get round it, we'll work round it, sort of thing. I've had, I have asked if I could have one of the Medicar taxi service, I don't know, I've got to see Mr [???] and ask him about that when I go on the 7th. Just, I just thought if it was, you know, if I can have something like that then I'm not gonna have to worry about asking neighbours and friends ...

INT: MM, EXACTLY.

Patient: ... because my family aren't close by, they live at Buxton and so it's, erm, it's a long way for them to come every morning to take me.

INT: I DON'T KNOW WHAT THE PUBLIC TRANSPORT'S LIKE, [???]

Patient: I don't know, as I say, there is the train ...

INT: YEAH, EXACTLY, BUT YOU'RE QUITE A WAY FROM WESTON PARK, AREN'T YOU REALLY?

Patient: That's right, that's right, so ...

INT: IT'S A GOOD 20 MINUTES ON THE BUS PROBABLY.

Patient: Yeah, yeah, so I mean, you know, they've sort of said, unless you've got a medical condition, er, they might not allow me to have it, but I've got to ask Mr [???] so I'm hoping that he might say yes, you know, that would be OK, but I've got to wait and see what he says sort of thing. So ... it would just make life easier to get there and things so ... you know.

INT: OK THEN. I'LL RECAP OVER SOME BITS AND PIECES, ERM, GOING BACK NOW, ERM, THINKING ABOUT, ER, YOUR TIMES YOU WERE TALKING WITH MR HOLT, OK ...

Patient: Yes.

INT: ... HOW DO YOU FEEL YOU GOT ON WITH MR HOLT?

Patient: He was lovely. He was, he was very, very nice: I think he's the nicest man, well the nicest doctor I've ever met really. He was just really, really ... easy to talk to, er, approachable, not, erm, you weren't frightened of asking questions and he was very relaxed, he was, he was just, appeared a very nice person. Erm, and, er, I wouldn't ever be worried about seeing him again. Erm, I just think he came across as having a really nice bedside manner, er, just very polite, very, he was very nice really.

INT: MM.

Patient: You know, he was lovely.

INT: DO YOU FEEL HE WAS LISTENING TO YOU AND HE UNDERSTOOD YOUR NEEDS AND YOUR CONCERNS AND THINGS?

Patient: Yes, yeah. As I say, he was, he was just very ... easy to talk to, erm, and, as I say, you didn't feel rushed, you know, you had plenty of time to ask him questions and, er, he did, he did listen to what you'd got to say. And, as I say, my husband asked sort of questions more than me really, erm, and he was, you know, happy to answer those and, you know, erm, and he did say to me a couple of times, he said, 'Marilyn, is there any, you know, you'd like to ask?' and I said, 'No, I'm, you know, that's fine.' sort of thing, but, er, you know, he was, as I say, he was lovely, he was really, really nice.

INT: MM. ERM, AND THINKING ABOUT THE TIMES YOU SPOKE WITH THE BREAST CARE NURSES, HOW DID YOU GET ON WITH THE BREAST CARE NURSES, MARY AND DONNA?

Patient: Yeah, lovely. I mean they couldn't have been more helpful, I mean I asked for the forms, Mary was really, really nice and Donna was helpful. Erm, you know, nothing, nothing was too much trouble really ...

INT: RIGHT, OK.

Patient: ... which is, which is nice, and I suppose how it should be. But they were, you know, they were [???

INT: AND DID YOU FEEL THEY WERE LISTENING TO YOU AND UNDERSTOOD YOUR NEEDS AND YOUR CONCERNS AND THINGS?

Patient: Yeah, yeah, yeah. But, as I say, they were just all very, very good, erm, I was very impressed really. Yeah, I was very impressed with the service. So ...

INT: MM. AND, ERM, DID THEY? YOU MENTIONED THAT I THINK MARY GAVE YOU SOME LEAFLETS AND THINGS ...

Patient: Yes, yes she did.

INT: WHAT WERE THEY ABOUT, DO YOU REMEMBER?

Patient: Erm, it was, erm, Breast Cancer ... I can't remember, there was, as I say, a selection of different, erm, different leaflets. Erm ... I honestly can't remember what they were, but she just gave me a few, a few of these leaflets, she picked a few up and just handed them to me and said, you know, 'These might help if you just,' you know, 'have a read of these,' sort of thing.

INT: AND DID YOU READ THROUGH THEM?

Patient: I did, yes, yes.

INT: AND WERE THEY USEFUL IN ANY WAY?

Patient: They were, they were, erm, as I say, once I'd sort of, I got home and I'd read them and that was probably because I sensed that things weren't quite right, erm, and that's why I sort of asked, asked for the forms, but, erm, yeah, I think, as I say, because you, you actually, if you read about these things you sort of get a, more of an idea of what's, what's happening to your body and what it's all gonna entail and how it affects everybody and family members and things like that. I mean I've got leaflets galore in the kitchen, you know, I've got, erm, that many, as soon as I've seen something I've just thought, 'Right, OK, let's have this and let's read it,' because it just, you know, erm, if you don't know what it entails I think, you know, any, anything, any information helps you, erm, to look at it, you know, if, erm, it gives you a bit of, more of an insight to what's happening. You're not quite as frightened when, then when you go back to the doctors, erm, you know, you've got an idea of what, what questions you want to ask as well, you know. They did say to me if there was anything that I wanted to ask, just to write it down, because you get into the, you know, into the doctor and you forgot what you, forget what you want to ask.

INT: YEAH, YEAH.

Patient: Erm, so, you know, they were very helpful really. Yeah, yeah, very good.

INT: AND, ERM, DID THEY GIVE YOU ANY KIND OF CONTACT CARD OR NUMBER TO RING OR ANYTHING LIKE THAT?

Patient: Yes, Mary .. yeah, Mary gave me one of her cards and she said, you know, 'Any problems at all don't hesitate to phone, we're always here and if you can't get hold of us there's always somebody on hand that you can either leave a message and we'll get back to you as soon as we can,' so, you know, she said, 'Don't ever be at home and worry about things,' she said, 'You must ring,' you know. So I thought that was really good as well, so ...

INT: AND THINKING ABOUT THE CONSULTATION WITH MR HOLT WHERE YOU HEARD YOUR DIAGNOSIS ...

Patient: Yes.

INT: ERM, ONCE HE DESCRIBED THE TREATMENT OPTIONS AND THINGS AND YOU'D HAD A CHAT WITH HIM, ERM, HOW SOON DO YOU THINK IT TOOK YOU TO MAKE UP YOUR MIND WHAT SURGERY YOU WERE GONNA HAVE? AFTER YOU HAD THE DIAGNOSIS AND STUFF ...

Patient: Er ... I think, because of his, erm, because he was so positive about the lumpectomy, erm, and he said that lots of ladies go ahead and have the mastectomy because they're frightened that, erm, if they don't they're gonna have to have further surgery, erm, but I didn't want to lose my breast, which was one of my main concerns, erm, and if I could get away with the lumpectomy and the glands removed, then that was, you know, that was, that'd be fantastic. But I was also open to the fact that I might need further surgery, so it was just, erm, a relief that I didn't need a mastectomy and I was quite happy because he was positive and he felt that was the way forward for me, erm, and I sort of, you know, just felt that he knew what was best, really, you know. He's, erm, he seemed really sure. Mr Chadwick had been really positive about the lumpectomy and said that, you know, this is one of the things that they do more often these days. At one time they used to just take the breast off, erm, just to make sure that, you know, that it was dealt with, erm, but this was something they were, you know, doing a lot more of and had been very, very, good [???], you know, good surgery really. Erm, so, you know, I was just happy that, erm, 'cos he seemed, as I say, positive that this was the way forward and he was sure that that's would do it, you know, it would get rid of the cancer and, you know, deal with the problem sort of thing. So ...

INT: AND WHEN YOU'D MADE YOUR MIND UP ABOUT WHAT SURGERY YOU WERE GONNA HAVE, DID YOU AT ALL CHANGE YOUR MIND OR HAVE SECOND THOUGHTS?

Patient: No, no.

INT: IN BETWEEN THAT AND THE OPERATION?

Patient: No. No, I was positive that's what I wanted to do, erm, you know, because of how confident he was, erm, with the surgery and things land, you know, I thought, well at least if I have had a lumpectomy and then there is, is a chance that I might need further surgery, but, you know, at the end of the day, I've not lost my breast but, you know, erm, if I need to have the surgery then I'm prepared for that, but I was quite happy to go along with the lumpectomy and see how that worked and, you know, take my chance I suppose, but, erm, he seemed positive about it and I was happy to have that done really.

INT: YEAH, MM. DO YOU FEEL, THINKING ABOUT THE SURGERY, THE TREATMENTS ON OFFER, DO YOU THINK YOU HAD THE AMOUNT OF CHOICE THAT YOU WANTED?

Patient: Yes.

INT: IN TERMS OF SURGERY.

Patient: Yeah. Yeah, the, I mean they gave me a choice, I mean he didn't say that I had to have the lumpectomy or anything, he just sort of said, 'Well,' you know, 'this is the options, this is what we can do,' erm, he just said, 'Some, some ladies feel that they don't want to have to go through further surgery and that's why they go ahead and have the mastectomy done,' and he said because I was young and healthy and, you know, hopefully that wouldn't, you know, wouldn't be necessary and I was just quite happy that I wouldn't need to have that done really. So, you know, I was just relieved that the lumpectomy would do it and, erm, and that, you know, that was the way forward and I was happy with that really.

INT: MM. AND THINKING ABOUT THE TIME AFTER YOUR DIAGNOSIS AND LEADING UP TO YOUR OPERATION, ERM, DID YOU - I KNOW YOU DID BUT I'M GONNA ASK IN A MORE BROADER SENSE - DID YOU LOOK FOR OR WERE GIVEN ANY OTHER INFORMATION ABOUT BREAST CANCER AND ITS TREATMENT? I KNOW YOU LOOKED IN YOUR BOOK, DIDN'T YOU ...?

Patient: Yes, yeah.

INT: YES. DID YOU VISIT YOUR GP? DID RELATIVES GIVES YOU OR FRIENDS AND NEIGHBOURS GIVE YOU ANYTHING? DID YOU CALL A SUPPORT GROUP, READ ANY BOOKS, MAGAZINES, VIDEOS, ANYTHING, ANYTHING LIKE THAT?

Patient: Er, no, I didn't, I didn't go on the internet because at the stage when I was, before I had my surgery, Mr Chadwick had said to me, he said, he said, erm, that some people go on, looking on the internet and it frightens them to death because some of the, some of the information is not quite right or accurate and he said, 'It's not a good idea to do that,' erm, but they did give me some more leaflets and I've got leaflets through my breast nurse, so I'd got those, erm, and I did buy, I think I bought a couple of magazines that had got stories about breast cancer and things like that from, you know, when I went to the shop. But really I didn't, I didn't want to frighten myself so I don't think I, as I say, he advised me not to go on the internet. He said, well maybe till after you've had your surgery and then, but he said there's different support groups and things like that, erm, and I have actually been on since, since I've been at home, I have looked on the internet ...

INT: OH RIGHT.

Patient: ... erm, but, erm, I haven't, I haven't rung any support groups or anything like that, I've just sort of, you know, tried to cope, erm, you know, with sort of support from friends and family and things, and, you know, managed to get through it without too much difficulty, thank goodness, really.

INT: RIGHT. ERM, THINKING ABOUT YOUR DECISION ABOUT WHAT SURGERY YOU WERE GOING TO HAVE, WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD, THAT YOU READ, THAT YOU HEARD, OR ANYTHING LIKE THAT, THAT HELPED YOU MAKE A DECISION TO HAVE THE SURGERY YOU DID?

Patient: Erm, I think the fact that, erm, the lump was only small, erm, and because, erm, Mr Chadwick said, the first time I went to see him, that, you know, that the surgery was very good, very good and they'd ha lots of, you know, really good results with this type of surgery, and that lots of ladies had their breast off and they didn't really need to have that done. Erm, and then I went again to see Mr Holt and he, you know, he just, erm, he just said the same things really.

INT: YEAH.

Patient: Erm, which, erm, made me sort of make the decision really because I, you know, obviously they're both, erm, consultants and things, and they know

exactly what the surgery is, how the things have improved, and he, they know what's best for you really. Erm, but basically because the lump was small. I think if he'd said it was a big lump, erm, and that, you know, maybe breast, mastectomy was better, then I might have sort of swayed toward the mastectomy but, because the lump was small, erm, I was sort of hopeful that that would do it, you know, and they were confident and so like they gave me confidence in them and, you know, that's why I went ahead with that really.

INT: MM, RIGHT, OK. ER, LAST COUPLE OF QUESTIONS. LOOKING BACK FROM WHEN YOU WERE FIRST DIAGNOSED UNTIL NOW, HOW DO YOU FEEL ABOUT THE CARE YOU RECEIVED?

Patient: It was fantastic.

INT: YEAH?

Patient: Absolutely fantastic.

INT: DO YOU THINK IT MET YOUR EXPECTATIONS? DID YOU HAVE ANY EXPECTATIONS?

Patient: Erm, I don't think I had any expectations but I think, erm, I was very impressed, erm, I just think the whole, the whole set-up, erm, at Chesterfield's really, really good. Erm, they're just, everybody's sort of, you know, everybody's there for you, they give you as much help and support as they can, erm, and I was just really impressed with how the doctors were with you, how the nurses were with you, erm, you know, sort of from when they, you were being examined you were, the curtains were drawn and you were covered up, you weren't sort of left on a trolley for ages, you were, you know, you were, you were looked at and you were treated like a person. And, erm, as I say, it's a sensitive thing you're going through and you need to be treated sensitively, don't you? And I just think they were very, very good, very good, you know, yeah, as I say, they were, as I said, everything was really fantastic. There was, you know, I couldn't have wished for a better service really, you know. I mean I've worked in the Health Service and I was very, very impressed ... very much so.

INT: AND, IF YOU WERE TOLD YOU HAD THE POWER AND MONEY TO CHANGE ONE THING ABOUT THE SERVICE, THE BREAST SERVICE AT CHESTERFIELD, WHAT DO YOU THINK IT WOULD BE?

Patient: Erm ... I would, erm, hopefully, erm, build an area where the radiotherapy could be so that patients don't have to go to Weston Park, 'cos I think Weston Park is, the hospital is very, very old-fashio-, seems very old-fashioned, erm, and, erm, I mean I've been a couple of times and I just think that, if the whole, the whole sort of service could be done at Chesterfield, then that would be much better for the patient. I know sometimes that's not possible because the treatment's different for other people, but, but just to be able to have everything done in one place and not have to go ... it's the travelling and the worry of getting there and things like that, because, you know, when you've got children you've got to go, I mean I'd had a temperature a things and you have to go there and then, you can't sort of leave it, because they say it's important, you know, you've got to get down to Weston Park. Erm, and I just feel that it'd be nice to be able to have that ...

INT: SOMETHING MORE LOCAL, YEAH.

Patient: Yeah, more service in Chesterfield. I mean the Cavendish Suite is wonderful, all the staff were lovely, you know, I can't praise them enough, they were fantastic, erm, but just to be able to have that in Chesterfield, 'cos I think that's probably worried me more than anything, having to go down there every day, erm, but, as I say, I need to have it done and, you know, that's, I've got to, got to do that. But that's what I'd spend the money on. Yeah. But

I've been told that that's not possible because of the radiotherapy and it has to be underground and things like that. So ...

INT: RIGHT, OK. MM.

Patient: But, er, I don't know. Maybe, I might start and raise some money, [chuckles] see if we can do that, you know.

INT: WELL, THE QUESTION WAS, IF YOU HAD THE POWER AND MONEY, SO IF THAT'S WHERE YOU WANT TO SPEND IT, THAT'S FINE. [CHUCKLES]

Patient: Yeah, so that's, that's probably what I'd do.

INT: NOW THAT YOU'VE BEEN THROUGH THIS EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW FIRSTLY ABOUT THEIR DIAGNOSIS? WHEN THEY'RE RECEIVING THEIR DIAGNOSIS, WHAT DO THEY NEED TO KNOW?

Patient: ... I think, er, basically the fact that it does affect the whole of your family. It's not just you, the cancer affects everybody, and I think at first you just think it's you, you know, it's just you as a person that it's affecting, but it affects lots and lots of people, 'cos people, all people, erm, deal with it differently. And some of my sisters, erm, can't even talk to me about it ...

INT: YEAH.

Patient: ... you know, and you don't sort of, you don't realise that that is gonna affect, you know, how people treat you or, erm, you know, like when some-, like when somebody's died or whatever, people avoid you, and that is the same thing when you've got cancer, which is a bit of a hard thing to sort of cope with. You think, well, you know, I've not, I've not got anything nasty or whatever that's catching or whatever, but I don't know why, why people, you know, deal with it like that, but everybody does deal with it differently. But I think it affects you as a family and I think, as I say, you need to know, and you need to have the support, erm, and just basically, as I say, being able to talk, having the phone, the phone numbers and, erm, the breast nurses, as I say, you know, the information, all the information you can get really I think. Erm, and just sort of having that back-up system and, and just being explained to like Mr Holt did to me, you know, explaining everything as well as they can, erm, and putting you in the picture and, you know, 'cos I think at one time they didn't used to sort of tell you, did they? They used to sort of, erm, it was sort of done, years ago it was probably told to your husband and you didn't know about it and, you know ...

INT: YEAH, YEAH, THE COMMUNICATION WASN'T AS GOOD REALLY ...

Patient: No, no.

INT: ... YEAH, YEARS AGO. WELL EVEN THE SURGERY WAS MUCH MORE RADICAL.

Patient: That's right, that's right.

INT: YEAH, THAT SORT OF THING.

Patient: So I suppose things have, things have changed a check of a lot and, er, as I say, it's, it's just coping with it all really. I mean it's, it's not an easy thing to cope with, but, erm, just having, having the service that they've got at Chesterfield I think is really, really important, because then you don't have to Weston Park, and the Cavendish Suite is wonderful. And, I mean, you don't want to go but, you know, the treatment there's fantastic. Mr [???] I

think is the nicest man I've ever met, he was lovely, you know, he was really, really nice and, just everybody's been really, really good. So, you know, that helps you get through it all, you know, they way they re with you and that, erm, you can ask any questions, you're not, you don't feel as though you're being a nuisance or, you know, if you ring up it's, 'What can we do?' you know, erm, and 'We'll get back to you as soon as we can,' sort of thing. Any queries or ... you know. And the nurses on the wards, you know, sort of helped answering questions and they said to you, 'Have you got any problems and is there anything we can do to help you,' and things like that, and that, erm, and just the atmosphere when you go is really nice and, you know, everybody seems to get on well and they're really positive for you and that, you know. And it's nice, the patients even in the waiting, erm, I noticed that, 'cos you go into the doctor's surgery and everybody's sat there and nobody talks to anybody, but all, all the patients all talk to each other, and that was really nice, because I was, there was, er, patients coming back for like 10-year check-ups ...

INT: YEAH.

Patient: And you're thinking, 'Wow, you know, they've been through it, they've got, they're like 10 years away from having this,' you know ...

INT: IT'S QUITE ENCOURAGING REALLY.

Patient: Yeah, that's right, that's right. So, I mean, you have the horror stories and things that ...

INT: YEAH, OF COURSE.

Patient: ... but, erm, but, you know, I mean that was, that was really good as well. So ... but yeah, I've had really, I mean, no, everything's been really, really good, really positive and everything that I've been through I think has been helped by the service that they provide really, you know.

INT: AND A SIMILAR SORT OF QUESTION IS, NOW YOU'VE BEEN THROUGH THE EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THE OPERATIONS THAT THEY CAN HAVE?

Patient: I think you need to have the option to know whether you can have either the lumpectomy or the mastectomy or whatever, that you need to have done. Because my friend, she, she had the mastectomy because she was frightened of having further surgery, who was in at the same time as myself, erm, and I think it probably depends on the age of the person. I think if it's an elderly person they're not, not that worried about losing a breast, they just want the cancer gone and things, whereas if it's a young person, I think you need to be given the option to have, if you can have the lumpectomy that's gonna sort the problem out, to be given a chance to have that and not just go ahead with a mastectomy when there's, it's not always necessary. Erm, which, you know, I mean, I didn't realise that they could do like lumpectomies and get rid of the cancer, but I think that is, you know, for what I've had to have done, I think that's fantastic, 'cos the surgery was not, not horrendous, it didn't, it wasn't really painful, erm, my arm, I think my arm and getting that moving was the worst, worst sort of bit of it really.

INT: RIGHT, OK.

Patient: Erm, 'cos your arm gets stiff and things, erm, and feels a bit numb and a bit funny, but, erm, no, I think, as I say, the options of the surgery, I think you need to be aware of what you can have done, erm, but I think you sort of follow the consultants, erm, you know, what they say or their advice to a certain extent anyway.

INT: RIGHT.

Patient: Well, I would, with my personality I would. Maybe some people are strong-willed and would just, you know, decide what they want to do, but I go by what, what they think is best for me really, 'cos they know the job and they've been doing it for a long longer than I've, I know.

INT: YEAH, SURE.

Patient: You know, so you sort of go with their speciality and what they advise really, you know, what's best for you.

INT: YOU SAID YOU WERE AN AUXILIARY NURSE, IS THAT RIGHT?

Patient: Yes, yeah.

INT: WAS THAT AT CHESTERFIELD, WAS IT?

Patient: Yes, it was. Yeah, I worked in the orthopaedic clinic for 11 years. So ...

INT: OK. ERM, FINAL QUESTION, IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANYTHING YOU THINK WE'VE MISSED OR ANY IMPORTANT POINTS WE HAVEN'T COVERED?

Patient: No, no I don't think so. Just, I was just very, very happy with my, my treatment by everybody that I came across in the department, erm, and just, you know appreciate, everything they've done for me really.

INT: MM. THERE WAS ONE THING, I JUST SUDDENLY REMEMBERED ... ERM, BEFORE YOUR OPERATION, YOU SIGNED THE CONSENT FORM ... IS THAT RIGHT?

Patient: I did, yes. Yes, I did.

INT: AND WHEN DID YOU DO THAT, DO YOU REMEMBER, WHEN DID YOU ACTUALLY SIGN THE CONSENT FORM?

Patient: Erm ... I did, I did it when, er ... let's see, I did it when I saw Mr Holt

INT: WAS THEN WHEN AT DIAG ...

Patient: It was ...

INT: AT DIAGNOSIS OR ... ON THE MORNING OF THE OPERATION? PRE-ASSESSMENT?

Patient: Pre-assessment clinic, yes, that's when I did it, at pre-assessment clinic when I went to see him before, before I had the operation. Yeah, that's right.

INT: OK. JUST I WANTED TO GET THAT ...

Patient: Yeah, yeah, sure.

INT: RIGHT THEN, THAT'S IT THEN.