

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: Low MR unit

*DATE: 12/10/2004

*ID: patient65

*INTERVIEWER: DJW

INT: THANK YOU FOR AGREEING TO BE INTERVIEWED. I'D LIKE TO START WITH QUESTION ONE, WHICH IS 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: I think the main thing is I'm really, there was a lump there was, the ... was the main thing that you were looking for. I hadn't really panicked about mine. Looked at a bit of, my home-, did a bit of homework on mine, thought it was nothing really, and just sort of ignored it, 'cos I had like a puckering at the side.

INT: RIGHT, OK.

Patient: And because I could feel a lump I didn't really panic.

INT: MM. RIGHT. SO WAS IT VISIBLE, WAS IT NOTICEABLE?

Patient: Yeah.

INT: YEAH.

Patient: Yeah.

INT: AND YOU FOUND IT YOURSELF, YEAH?

Patient: Yeah.

INT: AND, WHEN YOU SAID YOU DID A BIT OF HOMEWORK, WHAT DO YOU MEAN BY THAT, DID YOU ...?

Patient: Looked in a couple of medical books and there was couple of things I sort of read said, well it's probably blocked glands and things so ...

INT: RIGHT, OK.

Patient: ... just ignored it.

INT: RIGHT, AND SO HOW LONG AGO WAS THAT THEN?

Patient: Just after Christmas, round Christmas-time.

INT: RIGHT, OK.

Patient: Well I ignored it first, [chuckles] but it didn't go away.

INT: RIGHT.

Patient: Obviously.

INT: AND HAVE YOU YOURSELF, HAVE YOU HAD ANY PREVIOUS HISTORY OF BREAST CANCER OR ANYTHING LIKE THAT BEFORE?

Patient: In the family?

INT: YEAH.

Patient: I have an aunt who had it.

INT: RIGHT, OK. YEAH.

Patient: She's dead now though.

INT: RIGHT, AND SHE, WAS SHE IN LEICESTER, WAS SHE?

Patient: No.

INT: RIGHT, OK. AND, ERM, DID SHE HAVE SURGERY FOR THAT ALL OR ...?

Patient: Yes.

INT: WHAT DID SHE HAVE, DO YOU REMEMBER?

Patient: I know she had a mastectomy, but I mean she was a lot older than me anyway.

INT: MM, AND YOU YOURSELF, YOU PERSONAL MEDICAL HISTORY, ARE YOU A GENERALLY FIT AND WELL PERSON?

Patient: Generally, yeah.

INT: MM, OK.

Patient: I thought, 'I'm too young for this,' [chuckles] [???] I'm not, but there you go.

INT: SO, ERM, WHEN YOU INITIALLY SAW THIS LUMP, YOU DID A BIT OF HOMEWORK, AS YOU SAID, A BIT OF RESEARCH, YOU DISMISSED IT AS PROBABLY NOTHING SERIOUS, YEAH?

Patient: Mm.

INT: AND THEN CAN YOU JUST TELL ME WHAT HAPPENED AFTER THAT THEN?

Patient: It started to bother me and I'd gone to the doctor for something else.

INT: TO THE GP, YEAH?

Patient: Well actually I'd gone to the, yeah, I'd actually gone to the doctor, made an appointment for the doctor, and gone for a routine smear with a nurse, and she said, she just went through all the general sort of lifestyle quest-, she started go through the, and handed me a breast aware leaflet. And I said, '[???' not interested, don't want to know,' sort of thing, then told her why, told I'd obviously got my appointment, but she had a look and said, 'I think we'll go and see if there's a doctor in the building,' but there wasn't one available and she changed my appointment to the next day. So obviously I thought, 'Aha, something a bit more here, then.'

INT: RIGHT, OK.

Patient: I first of thought about really. And then saw a GP the following day, who did the fast-track referral system, and went into a two-week, guaranteed to be seen in two weeks, so they faxed it off. She didn't seem over-worried really.

INT: YOUR GP?

Patient: No, because she couldn't feel a lump or she, you know, but she said, 'It's not right, it's not gone away,' with ignoring it and all the rest of it, so, 'Yes it needs sorting.'

INT: AND ABOUT HOW LONG WAS THIS AFTER YOU'D FIRST NOTICED?

Patient: Well, this was August.

INT: MM, OK. AND SO WHAT WENT THROUGH YOUR MIND AT THIS POINT WHEN YOU HAD LIKE YOUR APPOINTMENT BROUGHT FORWARD AND YOUR GP ...?

Patient: I still didn't press the real panic button.

INT: RIGHT, OK.

Patient: I think it's, well, partly probably, on reflection is ignore it, stick your head in the sand and ... everything'll be OK.

INT: RIGHT, OK. ERM, AND SO YOU WERE, WERE YOU SEEN WITHIN TWO WEEKS, WERE YOU?

Patient: Yes.

INT: SO CAN YOU JUST TELL ME ABOUT WHAT HAPPENED WHEN YOU WENT TO YOUR FIRST VISIT TO GLENFIELD?

Patient: Erm, my GP had been very good in describing what it was like and saying exactly what would happen and everything that they would do, so I was sort of prepared for that. But what I wasn't prepared for was I think quite the bluntness from the initial consultation with the doctor as soon as you're seen, who immediately said, 'It doesn't look good' from her point of view. She described what's going to happen during the morning,

that I'd have a mastecto-, er, [chuckles] a mastectomy [???] erm, mammogram, biopsies and then she'd see me again ... oh and a scan. Erm, and by the end of the morning she just said they were 99.9 per cent sure. Then sent me for a chest x-ray and bloods, and brief introduction to a breast care nurse. And made an appointment for the following week for the results. Erm, the most annoying thing at that point was the attitude of the reception staff.

INT: OH RIGHT.

Patient: Because the clinic was overbooked for the following week and in front of myself and the breast care nurse, the reception staff were saying, 'Well we're fully booked, we're pushed as it is,' and the nurse was saying, 'We're sorry, but we've got to have this lady in next week.' And, after everybody had been really nice and you're actually really upset, you know, because I mean you go into the [???] so as soon as you go in there anyway and two people come in, you know what they're going to tell you, and all the rest, and so you know you try and get yourself together to get back out to the reception area and, there's little receptionist saying, 'You can't come in ...' [chuckles] so it's a bit annoying, that little bit, at that point.

INT: YEAH, IT'S SPANNERS IN THE WORKS THAT DON'T NEED TO THROWN IN REALLY.

Patient: Yeah.

INT: YEAH, OK. SO YOU WENT THERE. DO YOU REMEMBER WHO YOU SAW, THE DOCTOR WHO YOU SAW?

Patient: Yeah, Dr Denham. Denim, Denham?

INT: DENTON.

Patient: Denton.

INT: YEAH, LIZ DENTON, YEAH. ERM, YOU SAW HER FIRST, IS THAT RIGHT?

Patient: Yeah.

INT: AND SHE TOLD YOU WHAT WAS GONNA HAPPEN, OK. AND THEN, ERM, YOU WENT ...

Patient: I think it might be worth mentioning as well that in the room I saw her, I could hear her talking outside.

INT: YOU COULD ...?

Patient: Hear her talking to the nurse outside.

INT: RIGHT, OK, SO ...

Patient: About myself.

INT: ABOUT YOU?

Patient: Yes.

INT: OH, RIGHT, OK. OH ... AND WAS THAT ABOUT YOUR PARTICULAR CASE AND THAT THEN?

Patient: Yes. And, I mean, obviously when she told me I was obviously very upset and they sort of offered me cups of tea, I said, ' No, let's just get on with it, 'cos I want to get it over.' Erm, and I could hear her reiterating the conversation to the nurse outside.

INT: WAS IT THE BREAST CARE NURSE SHE WAS TALKING TO?

Patient: I don't know whether it was the breast care nurse or the staff nurse on the unit.

INT: RIGHT, OK.

Patient: But the sound system is ...

INT: YEAH, IT'S NOT VERY, NOT VERY PRIVATE, IS IT NOT? RIGHT, OK.

Patient: I don't know whether that's been mentioned before.

INT: MM, IT HASN'T ACTUALLY, THAT'S SOMETHING NEW AS FAR AS I CAN GATHER. ERM, AND SO WERE YOU IN HER CONSULTING ROOM, WERE YOU?

Patient: Mm, and she'd shut the door but I could still hear.

INT: RIGHT, OK.

Patient: Yeah.

INT: AND, ERM, SO YOU SAW LIZ, LIZ DENTON, AND YOU SAW THE, YOU SAW A BREAST CARE NURSE AT THE SAME, JUST AFTER THAT, AT THE END OF THE DAY [???

Patient: At the end of the day I saw her, yeah.

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

Patient: That was Maureen.

INT: MAUREEN. RIGHT, OK. I MEAN, AT THIS POINT, WHAT'S GOING THROUGH YOUR MIND REGARDING, YOU KNOW, WHAT'S HAPPENING TO YOU AND ... ANYTHING, WHEN YOU WERE GETTING YOUR TESTS AND STUFF, WHAT WERE YOU THINKING OF AT THE TIME?

Patient: Scared stiff really, because suddenly this was real. Up to then it hadn't been real, er, it was just like something was gonna happen but, it wasn't you going through it, but suddenly sat in that room it was me, and that was frightening.

INT: MM, AND DID ANYONE, ON THAT PARTICULAR VISIT, DID THEY GIVE YOU, ERM, ANY INDICATION THAT IT COULD BE CANCER?

Patient: Yes. Right from the word go, at every stage, they were very ...

INT: [???

Patient: ... it was a bit hard to take but I think it was very good, it was right, erm, and the doctor was very, very good, bedside manner, is how I'd put it in, in the way she spoke to me, and obviously it's not what you want to hear but, as I say, she said that she was sort of 99.9 per cent sure.

INT: OK, IT WAS GONNA BE CANCER?

Patient: Yeah.

INT: ERM, AND DID YOU GO ALONG WITH ANYBODY ON THAT VISIT?

Patient: Because I'd been told to expect to be in the for three hours, I'd told a friend, 'Don't bother coming for the first hour and a half ...

INT: RIGHT, OK.

Patient: ... erm, in retrospect it was wrong.

INT: RIGHT, OK. HOW LONG WERE YOU THERE, THEN?

Patient: They did very good, I was one of the first appointments and all the stuff initially in the breast care clinic was for about an hour and a half.

INT: REALLY [???] THAT'S WAS QUICK.

Patient: They really did push me through.

INT: RIGHT, OK.

Patient: Partly perhaps it was because I was, you know, so they needed to take me in hand, I was very upset.

INT: YEAH, OF COURSE, ABSOLUTELY. ERM, AT THAT POINT, WHEN YOU HEARD THAT IT WAS 99 PER CENT SURE IT COULD BE CANCER, DID YOU HAVE ANY THOUGHTS ABOUT WHAT YOU MIGHT DO ABOUT IT IN TERMS OF ANY KIND OF TREATMENT? DID YOU HAVE ANYTHING IN MIND?

Patient: No, she said normal-, because they found two areas, one a lump and one they just called an area, on the mammogram, and took a biopsy of the lump and tissue samples, cell samples or [??] the other, and she just sort of say, 'Normally they recommend a mastectomy under these circumstances,' erm, and my mind didn't concentrate on that, my mind concentrated on, 'What the hell do I tell the children?' 'How do I tell the children?' erm, 'How do I tell everybody else?' 'Who's gonna look after them when I go in hospital?' You know, my mind went, not on the mastectomy as on the practical side of all the rest of it. And, erm, yeah, it just sort of sends your mind going whirring in silly directions. Your thoughts just don't, well the thoughts weren't connected necessarily, they were out of order in [??] erm, order of where things, perhaps I should have asked about things, I don't know, because to me that hadn't been a real possibility and, even when I said, spoke to my GP about it, she sort of said, 'Well, they just don't often do full mastectomies these days anyway.'

INT: RIGHT.

Patient: So I mean at the back of my mind ...

INT: WAS THAT BEFORE YOU WENT?

Patient: Yes ... was, that was not a real possibility, a full mastectomy, you know, so that wasn't really there, if you know what I mean.

INT: MM, YEAH, IT DOES HIT YOU, THOUGH, DOESN'T IT? I INTERVIEW A LOT OF PEOPLE AND THEY SAY THAT THEY OFTEN COME OUT AND THEY DON'T EVEN KNOW WHAT THE PERSON'S SAID TO THEM ...

Patient: Yeah.

INT: YEAH, BECAUSE THEIR MIND'S KING OF IN A BIT OF A TURMOIL.

Patient: Yeah, your mind suddenly sets off at 90 miles an hour and it just, not in any real sensible sequence either, it's hard.

INT: WAS ANYBODY ELSE IN THE ROOM AT ALL APART FROM YOU AND DR DENTON?

Patient: Initially, no. Oh the breast care nurse.

INT: THE BREAST CARE NURSE, YEAH, MAUREEN, AND DID YOU SPEND SOME TIME WITH HER AFTERWARDS, DID YOU?

Patient: Yes.

INT: AND DO YOU REMEMBER WHAT YOU TALKED ABOUT?

Patient: Didn't spend long with her afterwards, erm, went and got my friend. I can't really remember then whether she was there, whether it was just Maureen on her own, with just two and Maureen or whether Dr Denton was still there. Erm, then they packed me off to

x-ray and for bloods, and that's when we went out to reception to book the appointment for the next week. And that's when I felt, that's, the worst bit was 'more than my job's worth' sat there on the reception desk [chuckles]

INT: YEAH, RIGHT, OK. ERM, SO THEY MADE AN APPOINTMENT, WHAT, A WEEK LATER? IS THAT RIGHT? ERM, BECAUSE SHE FINALLY GAVE IN, DID SHE?

Patient: Yes [chuckles]

INT: SHE FINALLY GAVE IN AND SAID, 'OH WELL, WE'LL LET YOU IN ...' ?

Patient: The nurse said, 'There is no ...' I can't remember her words, she said, 'There is no messing about with this, this lady has to come in.'

INT: OK, SO YOU GOT IN, THAT'S THE MAIN THING. ERM, HOW WAS THAT WEEK LEADING UP TO THAT, THAT NEXT CONSULTATION? WHAT WERE YOU, WHAT WERE YOUR THOUGHTS, WHAT WERE YOUR FEELINGS DURING THAT WEEK?

Patient: They varied really from, I told the children in, the day I came home, and somehow, I don't know, I just knew it was, well I mean 99.9 per cent sure you've got to take it that it's gonna be right, so I'd spoken to the children, spoken to the school. I wasn't at work either, I did go in just for one day, erm, but your mind goes really because, if you talk to people, everybody keeps saying, 'Be positive, when you go there it's probably going to be nothing,' and it's other people that build you up, ready for that knock-down when you get there again, in a way.[chuckles] Yeah, your mind goes up and down thinking different things. I did go and see my GP ... no I didn't, no I didn't, not that time, it was the time after I went to see her afterwards. Er, in retrospect ... I don't know, just a phone call maybe just from the breast care nurses halfway through the week might have been a bit more supportive.

INT: SEE YOU WERE SORT OF THING?

Patient: Yeah. Because they give you so much information, well not so much, but quite a few pamphlets and booklets to read and I came home, put them in my wonderful filing system under the settee, and didn't look at them until several days later, and you just think, 'This is just ...' yeah, it starts to hit you a bit that this is for real, then there's that little naggle, niggles of doubt that crept in, creeps into your mind to thinking, 'Well it might not be ...' and it's like you want to sort things out and know what to do, you want something practical to do, but there's nothing you can do until you know for sure, you know, so it's more on edge really, just waiting.

INT: YEAH, MM. SO THEY GAVE YOU PAMPHLETS THE FIRST TIME YOU WENT, IS THAT RIGHT?

Patient: Yeah.

INT: IS THAT THE BREAST CARE NURSE GAVE YOU THEM, YEAH?

Patient: Yeah.

INT: DO YOU REMEMBER WHAT THE PAMPHLETS WERE ABOUT?

Patient: Coping with Cancer, erm, there was question, not questions and answers, there was something about ... mastectomy and breast care, there was Younger Women with Breast Cancer, which my daughter said I should be complimented on, [chuckles] she said, 'Well you'd be a bit insulted if you had The Older Woman with Breast Cancer one, wouldn't you? and Talking to your Teenagers about Breast Cancer. And Cancer Services in Leicester and Leicestershire.

INT: RIGHT.

Patient: And that was it, about four or five.

INT: SO HOW OLD ARE YOUR CHILDREN THEN?

Patient: Seventeen and 13.

INT: AND HOW DID THEY TAKE THIS THEN?

Patient: ... Erm, a bit shocked. The 17-year-old, well they kept being very clingy first of all, both of them, and it was like I couldn't move, you know, because one behind me all the time, 'Did I want this?' 'Did I want that?' 'Let [???] mother hens ...

INT: OH, THAT'S SWEET OF THEM.

Patient: Mm, I couldn't go anywhere without finding one there. [chuckles] It was awful, you couldn't even go to the loo without, 'Are you all right?' Erm, the younger one I think is more embarrassed by the nature of what it is and is really struggling to talk about it to me, or mention it. The older one, it's obvious that it's preying on her mind an awful lot. I mean obviously she's older, she understands a bit more and [??]

INT: ARE THEY BOTH GIRLS OR A GIRL AND A BOY?

Patient: Both girls.

INT: OK.

Patient: Yeah, she probably looks up more stuff as well. Erm, the schools have both been very good as well, and I know that they're sort of looking out for them at the moment, which is good, it's just, it's a rough year for the older one, because it's her final 'A' level year.

INT: RIGHT, OK. ERM, SO CAN YOU TELL ME NOW A LITTLE BIT ABOUT WHAT HAPPENED WHEN YOU WENT BACK TO HEAR YOUR RESULTS? CAN YOU JUST TALK ME THROUGH THAT DAY?

Patient: I was sat waiting for well over an hour until the nurse came and said they were still waiting for confirmation of the result, which was a bit nerve-racking really. Erm, I saw

Consultant [???] and a different breast care nurse, this is Pat. they went through what they'd found and what they recommended, but that's when they threw me because that's when they gave me a choice of I could have a partial or a full mastectomy.

INT: OH RIGHT.

Patient: Erm, having not expected to have a choice, that really did throw me. She said, if I had a partial I would definitely need radiotherapy afterwards: if I had a full they didn't know. Erm, if I also went for the partial there was a one in three chance I would need a full, so like an idiot I said, 'Well are we talking months or years?' and she said, 'No, two weeks,' 'cos I hadn't sort of clicked that, that ...

INT: [???]

Patient: ... and that's been the worst thing really, is trying to decide and make a choice.

INT: RIGHT, OK. ERM, SO YU SAW MISS [???] ... YEAH, POPPY, SHE LIKES BEING CALLED POPPY, ERM, SAW MISS [???] AND PAT, THE BREAST CARE NURSE, SHE WAS IN THE ROOM, YOU SAY. DID ANYONE ELSE GO WITH YOU?

Patient: My friend went, yeah, and then ...

INT: DID SHE COME IN THE CONSULTATION AS WELL?

Patient: Yeah, they went through it again. The nurse went through again with my friend there, 'cos I said, 'Could I go and get my friend now?'

INT: BUT SHE WASN'T ACTUALLY IN WITH MISS [???]?

Patient: No.

INT: OK.

Patient: Erm, and I sort of said to Pat, 'Can I go through what I think I understand from this and will you fill in the gaps, just so that I can hear it before we go out, you know, if I've got any other questions really?' and then meanwhile Poppy had gone to find the diary to find out when I'd go. And I was told I didn't have to make my decision the day I had the operation, so that was about two and a half weeks' time.

INT: RIGHT, AND IT WAS THE CONSULTANT WHO ACTUALLY SAID, 'IT IS BREAST CANCER.'

Patient: Yeah.

INT: YEAH. AND HOW, WHAT WERE YOUR FEELINGS AT THAT POINT, WHEN IT HAD BEEN FINALLY CONFIRMED?

Patient: Suddenly the brick wall had gone up, just how the hell do you get over this? And then, as I say, it's bit like the first time really, practical things pop in your head, erm, you

know, looking after the kids and just, just ... because we all like to think that we're indispensable, don't we? And that nobody else can do it, and ... so I just ... just got very, well afterwards was upset obviously, but ... I think they were waiting for a reaction from me there and then, I felt they would have, but I'm not that sort of person to do my emotional displays in public usually. [??] said, 'Well ...?' [??] 'Well, what?' You know, 'What do you say after that?' 'Well thank you very much.' you know. I don't know, I don't know whether, I mean presumably some people do get very emotional at that time immediately, some, we're all different, aren't we [??] ?

INT: AND THEN AFTER THEY SAID THAT, THAT'S WHEN THEY TOLD YOU ABOUT YOU HAD A CHOICE OF TREATMENTS, IS THAT RIGHT? ER, ONE WAS THE MASTECTOMY, WHAT WAS THE OTHER ONE?

Patient: She just said a partial.

INT: A PARTIAL MASTECTOMY?

Patient: Mm.

INT: YEAH, OK. AND, ERM, AND YOU SAID YOU WERE SURPRISED YOU HAD A CHOICE, IS THAT RIGHT?

Patient: Mm, because previously Dr Denton had said usually they recommend a full mastectomy.

INT: RIGHT, OK. AND DID YOU MENTION THIS TO THE ...

Patient: No.

INT: OK, RIGHT.

Patient: No, I mean, she was probably just going on what they'd seen at the day, on that day, you know.

INT: YEAH, SURE. OK. AND, ERM, DID YOU HAVE ANY INITIAL THOUGHTS ABOUT WHICH SURGERY YOU WOULD CHOOSE?

Patient: Yes, because I asked Poppy what she would choose.

INT: OH RIGHT, OK. AND WHAT DID

Patient: She said if it was her or her family she would recommend the full mastectomy.

INT: RIGHT, OK. AND, ERM, AND DID YOU MAKE A CHOICE THERE AND THEN THEN? DID YOU TELL HER WHAT YOU WANTED THEN OR DID YOU DECIDE TO WAIT?

Patient: No, she told me I could wait until the day I came in.

INT: OK. ERM, AND, ER, THEN AFTER YOU SPOKE TO MISS [???] DID YOU HAVE ANY TIME WITH THE BREAST CARE NURSE AFTER, DID YOU SAY, WITH PAT? IS THAT RIGHT?

Patient: Yeah.

INT: AND THAT'S WHEN YOUR FRIEND CAME IN?

Patient: Yeah.

INT: YEAH. SO COULD YOU JUST TALK ME THROUGH A LITTLE BIT ABOUT WHAT YOU ACTUALLY SAID WITH THE BREAST CARE NURSE, TALKED ABOUT WITH THE BREAST CARE NURSE THEN?

Patient: Well I asked if I could just reiterate what they'd said so that it was clear in my head and that somebody else could hear it at the same time as well. Erm, again, sort of how long will I be in hospital for, erm ... er, I can't really remember. I can't really remember.

INT: MM, OK. AND WHEN YOU WERE TALKING TO MISS [???], ERM, IN THE CONSULTATION, DID SHE USE ANY VISUAL AIDS OR TOOLS SUCH AS DIAGRAMS, DID SHE SHOW YOU YOUR MAMMOGRAM, ANY PICTURES, ANYTHING LIKE THAT?

Patient: No.

INT: RIGHT, OK. AND DID THE BREAST CARE NURSE USE ANYTHING LIKE THAT?

Patient: No.

INT: OK. ERM, AND WHEN YOU WERE TALKING TO THE DOCTORS, LIZ DENTON AND POPPY [???], AND THE BREAST CARE NURSES, HOW MUCH DID YOU FEEL YOU UNDERSTOOD ABOUT WHAT YOU WERE BEING TOLD ABOUT THE CANCER AND ITS TREATMENTS?

Patient: It was limited information but I know, again, I don't think I could have taken much more in anyway. Erm, I did actually ask if they did a one-to-one with somebody who's been there and done that.

INT: OH RIGHT, OK.

Patient: And she said, no, they didn't, but some people have previously asked about this and said that there's a group, self-help group, and I said I wasn't ready for a group.

INT: RIGHT, OK.

Patient: But I'd like to see somebody on a one-to-one who's been there. And later in the time waiting for hospital, a breast care nurse did ring up and said did I still want to see somebody, but I assume that was, time had gone for that because I'd spoken to my GP about it.

INT: RIGHT, OK.

Patient: But that's what I would have appreciated at that point.

INT: RIGHT.

Patient: Literally somebody who's been through it.

INT: WAS THERE ANY INFORMATION YOU GOT, YOU SAID IT WAS LIMITED BUT WAS THERE ANYTHING YOU DIDN'T UNDERSTAND, LOOKING BACK?

Patient: No. What I would have liked to have had further clarification on, and it would have been too much at the time, and this is where I think in that period to have had a visit or to have an appointment with a breast care nurse when you've got your head round things, to have seen pictures what a mastectomy site looks like.

INT: OH YEAH, THE AFTER THE OPERATION, YEAH.

Patient: Yeah. To have actually seen that beforehand, see the picture. To have had further clarification on, or the chance to have gone through that on exactly how much would have been removed and how much distortion there would be, because once it's gone into your head and you start to churn, you know, my mind swung from one to the other, and by the time I went in couldn't remember really how much she said would be removed. I'm thinking, 'Well if it's totally distorted, I don't want to know, I'd rather nothing,' and I think that, in retrospect, if there could have been some form of consultation in between whiles, not, doesn't have to be the consultant, but with perhaps the breast care nurse with pictures or something I think would have benefited me.

INT: RIGHT, OK. MM. WHEN YOU MENTIONED PICTURES, I MEAN, OF ONE OR TWO PATIENTS I'VE INTERVIEWED IN THE PAST HAVE TALKED ABOUT USING PICTURES, BUT IT'S NOT SOMETHING THEY TEND TO USE AN AWFUL LOT, OCCASIONALLY THEY DO BUT VERY RARELY. ERM, WHAT KIND OF PICTURES DO YOU THINK YOU WOULD LIKE TO SEE? WOULD YOU LIKE TO SEE REAL LIFE PHOTOGRAPHS OF SOMEBODY WHO'S, YOU KNOW, AGREED TO HAVE THAT, WHEN THEY'VE HAD THE OPERATION FINISHED, TO TAKE PHOTOGRAPHS? WOULD YOU THINK PHOTOGRAPHS IN BLACK AND WHITE OR COLOUR? WOULD YOU THINK DIAGRAMS OR ALMOST LIKE, YOU KNOW, SKETCHES OF THE OPERATION? WHAT DO YOU THINK?

Patient: Well I was given a leaflet that had a sketch of a mastectomy, but no I'd have like to have seen a real life colour photograph.

INT: RIGHT, OK.

Patient: Something real.

INT: ERM, YOU SPENT TIME WITH THE BREAST CARE NURSE AFTERWARDS AND THEN DID YOU HAVE ANY TESTS OR DID YOU COME HOME?

Patient: I came home.

INT: CAME HOME? YEAH. AND HOW SOON AFTER SEEING THE, MISS [???] FOR YOUR DIAGNOSIS, HOW SOON AFTER THAT DID YOU HAVE YOUR OPERATION?

Patient: About two and a half weeks.

INT: RIGHT, OK. AND WAS IT MISS [???] THAT DID THE OPERATION, WAS IT?

Patient: I assume so [chuckles].

INT: RIGHT, OK.

Patient: I wasn't awake. [chuckles]

INT: RIGHT, OK. DID SHE COME ROUND ON THE MORNING AT ALL ?

Patient: Yes, she did.

INT: OK. IT WOULD HAVE BEEN HER THEN, SURE. ERM, SO JUST TALK ME JUST BRIEFLY THROUGH THOSE TWO WEEKS, TWO AND A HALF WEEKS. HOW WERE THOSE?

Patient: I'd gone from, I was fairly adamant it was going to be a full mastectomy and then for some reason it dropped into my head, because somebody said, 'Whatever you decide, you're always gonna wonder the other way,' and I started to go the other way, thinking, 'Well, partial' and then that was only brief really and then swung back the other way to a full mastectomy, yeah. And it was pure hell going backwards and forwards and backwards and forwards, which is why I think I would have appreciated just somebody later on, just to have gone through that again and ... and at that point perhaps showed pictures of partial mastectomies, of a real mastectomy site, so that you know what you'd be facing. Erm, and it was, it did me, it re-, you know, it's such a long time because you go backwards and forwards and your mind is just constantly on it, churning and churning. Or my mind was.

INT: AND DID YOU SAY YOU SAW YOUR GP IN THAT TIME?

Patient: Yeah.

INT: DID YOU GO TO THE GP? IS THIS TO DO WITH THE CHOICE THAT YOU HAD?

Patient: Erm, no I needed another sick note, on a practical level. [chuckles] On a practical level I needed a sick note. Erm, but, yes, but unfortunately I'd gone before she'd had the information from Poppy anyway, so I was telling her more than she already knew, which was a bit weird.

INT: RIGHT, OK THEN. AND ...

Patient: That was the time I did get very upset talking to her.

INT: AND SO WHAT DID YOU TALK ABOUT AND WHAT DID SHE SAY?

Patient: Erm, just sort of the shock, how it wasn't expected, just sort of ... how two or three weeks makes a difference in your life, and just ... just the whole thing that you're just not expecting it and it wasn't what I wanted to hear obviously, and ... also sort of thank you to her really as well.

INT: YEAH, FOR REFERRING YOU.

Patient: Yeah.

INT: AND DID YOU MENTION THE OPERATION AT ALL TO HER THAT YOU WERE HAVING?

Patient: Yes.

INT: DID SHE HAVE ANY OPINIONS ON IT AT ALL?

Patient: No. She was very good. She didn't express an opinion at all. Again, she was very down the line.

INT: OK.

Patient: I did go and see, call in on the, erm, practice nurse, because I didn't know whether she knew or not, and just to let her know what it was and why because in case it ever came up for her again, and she had a very strong opinion what it, what I should do.

INT: AND WHAT WAS THAT THEN, IF YOU DON'T MIND ME ASKING?

Patient: She said, 'You're going for the full, aren't you?'

INT: MM, AND YOU SAID ...?

Patient: Yeah.

INT: AND DID SHE SAY THAT WAS ...

Patient: She said, 'I think that's the right thing to do.'

INT: RIGHT, OK. ERM, OK, SO YOU KNOW, I MEAN WE'RE TALKING PRACTICAL LEVELS HERE, SO HOW DID YOU GET SOMEONE TO LOOK AFTER THE KIDS AND STUFF LIKE THAT THEN?

Patient: Yeah, my Mum got prepared to move in for a week.

INT: RIGHT, OK.

Patient: Erm, ... and they dropped everything obviously to move in here, er ... how I'd have managed if they didn't live locally I don't know. You know, friends can only help so far, can't they?

INT: MM. AND, ERM, DID YOU AT ANY TIME BEFORE YOUR OPERATION AFTER HEARING YOUR DIAGNOSIS, DID YOU CONTACT THE BREAST CARE NURSES FOR ANYTHING?

Patient: Yes, she rang me, as I say, regarding this request for a one-to-one, by which time I'd, you know, I'd spoken to my GP, I said, that what I felt I could do with. My GP also offered to refer me to the Macmillan nurse, and then she said that she'd actually had a patient in who has finished her treatment and ... she has actually said if anybody was ever in the same situation and wanted to talk things through that she was quite willing to do that.

INT: OH YES.

Patient: So obviously she couldn't give me her name or number because she said, 'Confidentiality, I will contact her first, but can I give her your number?' and that's why I went, I mean this lady came round and she was lovely. Unfortunately she was another good 20-30 years older than myself, but she was very young outlook, very sprightly, and she'd had one mastectomy then closely followed by another, and she did show me her scars, and when I saw mind, to be honest, that helped having seen hers, that's why I say photographs or something ...

INT: RIGHT, OK.

Patient: ... might help, because it certainly helped me having seen somebody for real. And the fact that she was so front, 'Ask me anything, and I'll tell you,' 'If you ask me something that I'm not comfortable with ...' erm, and, you know, she was just so normal. When she rang up, she said, 'Would you like me to come to you? Would you like to come to me? Do you want to meet somewhere totally different?' And she was, you know, that sort of person who's been there and done that and is a bouncing, living proof at the end of is ...

INT: IT'S QUITE A POWERFUL TESTAMENT, ISN'T IT, REALLY?

Patient: Yeah, yeah.

INT: YEAH.

Patient: That meant so much more than, than a lot of other things.

INT: MM, YEAH. ERM, [??] WHEN YOU WERE TALKING WITH MISS [??] ABOUT YOUR DIAGNOSIS, WHO DO YOU FEEL DID MOST OF THE TALKING AND WHO DO YOU THINK ASKED MOST OF THE QUESTIONS?

Patient: Well she would always start with the talking and I think I probably asked questions. The first time in the breast care clinic I'd actually gone with a list of questions.

INT: WAS THIS WHEN YOU SAW MISS [???]?

Patient: Yeah, yeah. Erm, but they more or less answered all the questions on there anyway.

INT: OK. AND CAN YOU JUST TELL ME A LITTLE BIT ABOUT THE DAY OF THE OPERATION? DID YOU GO TO A PRE-ASSESSMENT CLINIC AS WELL?

Patient: Mm.

INT: TELL ME ABOUT THAT PLEASE [???]

Patient: I had a lovely nurse, very caring, very understanding, and I asked if I could go up to the ward and she took me up there.

INT: THIS IS THE BREAST CARE NURSE OR ...?

Patient: No.

INT: ... CLINIC NURSE, YEAH.

Patient: This is the clinic nurse and she did take me up there, showed me round, erm, apparently people don't normally, this isn't routine, but if you ask they'll take you, but they don't usually say. Little things like, say, and I discovered there's hairdryers and the baths are [???] just female comfort items, if you like.

INT: YEAH, FAMILIARISING YOURSELF WITH THINGS.

Patient: Yeah, it was nice to know they're there. Erm, she also showed me a prosthesis and things like that, erm, which I hadn't seen before. Erm, it was more or less, one thing I remember that did strike it was more or less assumed by that point that I was having a mastectomy by the way she was talking. Er ... don't think much else happened really. I mean all the obvious bits and bobs. Erm, didn't think much to the house officer I saw because she sort of starts to examine me, etc, she'd got notes in front of me and then said, 'Well, which one is it?' [chuckles] Doesn't inspire a lot of confidence.

INT: SOMETHING YOU'D EXPECT IT FROM A DENTIST. [CHUCKLES]

Patient: Well, exactly.

INT: BUT, ERM ...

Patient: You know, I thought, well, actually I thought it was patently obviously, but then again, unless she was trying to make sure I knew which one it was.

INT: RIGHT, EXACTLY. BUT YOU'RE RIGHT, IT DOESN'T ... OK. ERM, YOU SAID THAT THEY ASSUMED IT WAS A MASTECTOMY, HAD YOU MADE A DECISION AT THAT POINT ... OK. HAD YOU SIGNED ANY CONSENT FORMS OR ANYTHING?

Patient: No.

INT: NO, OK, RIGHT. ERM, AND THEN SORT OF HOW SOON AFTER PRE-ASSESSMENT CLINIC DID YOU HAVE THE OPERATION?

Patient: A week.

INT: A WEEK. SO IF YOU CAN JUST TALK ME THROUGH THE DAY OF THE OPERATION?

Patient: How about the day before when they nearly did me in?

INT: OH, YEAH? THAT'LL BE FUN.

Patient: Got there for whatever it said on the Monday and the, I mean obviously all through that time I'd been going through hell and back trying to decide which one, got it quite firmly in my mind that I was going for the full mastectomy, so you get clerked in by the nurse on the word and she asked if I'd decided and I said, 'Yes.' She said, 'Are you aware of the other options?' and I said something like, 'Don't put doubt in my mind now,' and so she started talking about it.

INT: AND THIS IS THE CLINIC NURSE OR THE BREAST CARE NURSE?

Patient: This is a nurse on the ward.

INT: RIGHT, OK.

Patient: And she says, she sat with the ... 'cos I said to her, 'Well, OK,' I said, 'Look, I'm ... I know where I'm going with this and that's a full mastectomy,' sort of thing and she kept saying, 'Well, Poppy's also mentioned she would do a wi-, she could do a wide local excision' or something,' I said, 'I presume by that you mean a partial?' and she said yes. So then I said, 'Well how much would be removed? Is it gonna look fully distort-, really distorted?' She said, 'Yes.' I said, 'Well that's it then,' I said, 'No problem, I'll go for the full.' And she, but she started to put doubts in my mind ... but then she showed me the notes that said, erm, full mastectomy recommended because of reconstruction point of view and the likelihood of the cancer coming back.

INT: RIGHT, OK.

Patient: So I said, 'Well there we go, if it says it in the notes, that's what I'm going for. Fine.' And then, blow me, two or three hours later one of the breast care nurses came up and started going through the same thing again. And I really started to get a bit wound up because I thought, 'What do you think I've spent the last two weeks deciding? I've had this this morning and now you're starting?' or I felt ... I know they've got to be sure.

INT: YEAH, ABSOLUTELY.

Patient: But ... and then on the Tuesday morning a house officer came up [chuckles] starts off again. I thought, 'Oh God, no!' And Poppy again just to ... I mean, and then again within theatre, and it's too much too late, if you know what I mean.

INT: YEAH, IT'S A LOT OF PEOPLE SORT OF ...

Patient: Yeah, because it's an emotional time anyway and it's too much too late if, that's why I say again, to have had somebody in between-whiles and then to reduce the number of people at that final time.

INT: YEAH, SURE. DO YOU REMEMBER WHICH BREAST CARE NURSE CAME TO SEE YOU? CAN YOU REMEMBER?

Patient: No. I saw another two at different times on the ward. And that's another thing that I think really lets the system down, is that in total I've seen five I think now, and only one of those twice.

INT: DID YOU FEEL THERE WAS LIKE A LACK OF CONTINUITY ...

Patient: yeah.

INT: ... BETWEEN THE BREAST CARE NURSES?

Patient: No, not so much continuity because obviously things are written down, it's ... something that you, well I think you'd like to build a relationship with one person rather than constantly seeing different people.

INT: RIGHT, YEAH.

Patient: Would help.

INT: MM, ABSOLUTELY, YEAH.

Patient: I don't know whether that's come out before, has it?

INT: ERM, WELL, I CAN'T REMEMBER, I THINK THERE'S SOME PEOPLE MENTION THAT THEY DON'T SEE THE SAME PERSON, BUT SOME PEOPLE THAT'S FINE, THEY'RE ALL RIGHT, YOU KNOW, THEY ACCEPT THAT THE OTHER PERSON'S NOT ON THE SHIFT OR SOMETHING OR OTHER. ERM, I THINK SOME PEOPLE FEEL THAT THEY DO, THEY WOULD LIKE TO SEE THE SAME FACE. AND SOME PEOPLE DO, SOME PEOPLE DO SEE THE SAME PEOPLE. AND IT VARIES, BECAUSE WE'RE DOING THREE DIFFERENT UNITS, AND THEY ALL HAVE SLIGHTLY DIFFERENT PRACTICES AND THINGS LIKE THAT. BUT THAT'S A PERFECTLY VALID COMMENT IF THAT'S HOW YOU FEEL, YOU KNOW, IT'LL BE NOTED AND [???

Patient: I mean it's just something ... you feel, as a lay person if you like, you've got silly questions to ask, and if you're seeing a new face each time you don't feel as though you can ask that silly question, but it might actually be fairly important to you.

INT: EXACTLY, YEAH, MM.

Patient: Whereas if you've built up a relationship with somebody it's far easier just to say, 'Look, this is a really stupid question, but ...' or 'Can you repeat that again?' you know, you don't feel as silly when you've got to know somebody.

INT: RIGHT, YEAH.

Patient: Or that's me anyway.

INT: YEAH, SURE.

Patient: Perhaps think I'm stupid anyway. [chuckles]

INT: ERM, WHERE ARE WE? SO WE GOT TO THE MORNING OF THE OPERATION NOW, CAN YOU TELL ME JUST WHAT HAPPENED ON THE MORNING AND ...

Patient: As I say, this house officer came in. I don't know why they leave it so late but he came in to just go through it, and the consent form, and then silly little things like having to go out to find a marker pen, you know, you just want to get yourself sorted really, never mind them faffing about, and then he came he, he sort of sat down and he went, 'Oh now I need an escort' And I said, 'Oh give it here, I'll mark it.' Poor lad didn't even know what to do. So in the end he found somebody else to come in [chuckles] and escort while he marked, he just did a nice neat little star. But, yeah, it's just, just things like that should have been done, 'cos I was first one down, I think should have been done the night before.

INT: RIGHT, OK.

Patient: You know.

INT: YEAH.

Patient: Less intrusive, less ... because all the while you're thinking, 'Well, hang on, I haven't signed the consent form, I haven't had the mark, you know, time's ticking on and I want to know that I've got time to go to the loo and I've got to sort or sort myself out first,' so it's made worse because I knew I was going down first. Just silly little things like that.

INT: OK. YEAH. AND SO WHEN, YOU SIGNED THE CONSENT FORM ON THAT MORNING, IS THAT RIGHT?

Patient: Yeah.

INT: YEAH, OK. ERM, AND THEN YOU WENT DOWN FOR THE OPERATION. HOW WERE YOU WHEN YOU CAME ROUND.

Patient: I wasn't very well. [chuckles]

INT: OH RIGHT. WERE YOU SICK AND STUFF?

Patient: Yeah.

INT: WAS THAT WITH THE ANAESTHETIC?

Patient: I don't know, I think I had a terrific migraine actually because the lights, erm, fluorescent lights were really, by the time I got back to the ward, really were doing me in. And then I started throwing up. Erm, then I got told off because I wasn't drink, but every time I drank I was throwing up. So then I got told off because I didn't something for, to stop me, making me be sick. And I thought, 'Well really that shouldn't be up to you to ask for, it should be offered.' [chuckles] You know, you don't know, do you? You know ...

INT: WELL YEAH. I WOULD THINK IT'D E OFFERED, I MEAN ...

Patient: Well, yeah.

INT: I MEAN YOU'RE BEING SICK, AND THEY GIVE YOU, 'WE CAN GIVE YOU SOMETHING FOR IT, DO YOU WANT IT?'

Patient: Well, yeah. One of the doctors said, 'Well you're written up for it, you haven't had it.' Well I didn't know I was written up for it. Er, it's, and previous to that, the day before I'd had an anti-coagulant injection but she'd come along with trolley, just sort of stopped and I said, 'Oh I'm not on anything.' And she said, 'Oh yes you are,' and she got this needle out. And I said, 'Well what's that for?' so she said, 'It's an anti-coagulant.' But I mean it was thrown because I asked what it was for. Nobody said, 'You're having this and you'll be having it for the next three days,' or whatever. Just to be informed would be nice.

INT: YEAH.

Patient: Why you're having something injected in you. It doesn't matter but it'd just be nice to know.

INT: YEAH, SURE. AND, ERM, HOW LONG WERE YOU IN HOSPITAL?

Patient: I was out on the Friday.

INT: AND YOU WENT IN WHEN?

Patient: Monday, operation Tuesday.

INT: FOUR OR FIVE DAYS. MM. OK. AND, ERM, HOW SOON AFTER THAT DID YOU GO BACK TO GET YOUR RESULTS FROM YOUR OPERATION?

Patient: That was this Wedn-, last Wednesday.

INT: SO IS THAT A WEEK?

Patient: Ten days.

INT: TEN DAYS, OK, RIGHT. AND WAS IT MISS [???] YOU SAW?

Patient: Yes.

INT: OK. SO CAN YOU JUST TELL ME A LITTLE BIT ABOUT WHAT HAPPENED THEN WHEN YOU WENT TO SEE HER?

Patient: ... Sat in my dressing gown for 40 minutes or so, swinging my legs in this little room waiting.

[Interruption when telephone rings]

INT: OK, SO YOU WENT THERE AND THEN YOU WERE SITTING IN YOUR GOWN AND STUFF ...

Patient: Yeah, I mean you just feel vulnerable sat there in this clinical room for such a long time. And then Miss [???] came past and said she was waiting for a breast care nurse and then eventually they got themselves together and came in together. And again, because there's two of them you guess, 'Right, it's not good news,' and it certainly was not what I was expecting.

INT: RIGHT, OK.

Patient: Erm, she went through that they'd removed two lumps and I was going to have to have six months' chemotherapy because the, it was found in the nodes, and then followed by radiotherapy. Er ... yeah, and it was just a hell of a shock. So I probably asked some really stupid questions and then she went, Miss [???] went out and Pat said that she'd go through it again, with my friend - I'd got my poor old long-suffering friend, she came along - and we were back in another comfy room, so of course, my friend, you could see her face drop again, thinking, 'Oh, God, here we go again.' And it was really just to reiterate again what they'd said. Erm ... and then I realised when I came out that I hadn't asked things like Tamoxafen, does that, you know, will I be on that, when does that kick in ... just little things that you think afterwards you should have asked. I mean I'd got my little list again but it just wasn't what I was expecting.

INT: RIGHT, OK. DID THEY SAY ANYTHING ABOUT THE CANCER THAT THEY TOOK OUT?

Patient: I asked should I know what it was and she said, 'Will it make any difference?' and I said, 'Well, no, I don't suppose it will, but ...' it was just that this one particular woman on the ward knew, seemed to know everything about her specific type of cancer and I thought, well, you feel a bit stupid not know [chuckles] what I've got really.

INT: RIGHT, YEAH.

Patient: So she said, 'Well,' she said, 'I can go and look it up for you if you want.' This was the breast care nurse. I said, 'No it doesn't really matter then,' and she said, 'Well you can always ask at oncology when you go.'

INT: RIGHT.

Patient: And I also had my letter from the oncology clinic on the morning before I went, so of course that sort of gave an indication that things weren't ...

INT: THE MORNING BEFORE YOU WENT TO THE ONCOLOGY CLINIC?

Patient: No, for the appointment at the, for the results.

INT: OH, RIGHT, OK.

Patient: Yeah. Looking on the positive side, at least Miss [???] moved very quickly.

INT: RIGHT THEN.

Patient: It was just bad timing for that to have happened. [chuckles]

INT: OH RIGHT, OK. ERM, AND HAVE YOU HAD YOUR ONCOLOGY APPOINTMENT, HAVE YOU?

Patient: No, that's next week.

INT: RIGHT, OK. ERM, AND SO AS FAR AS YOU'RE AWARE NOW IT'S GOING TO BE CHEMOTHERAPY AND RADIOTHERAPY? AND YOU'RE STILL NOT SURE ABOUT THE TAMOXAFEN.

Patient: Yeah, I went to the GP yesterday and asked her and she said, yes, it's actually written, she'd actually got the letter, she said, 'It's actually written down it wasn't discussed, but yes it will be. and it'll be discussed at oncology.'

INT: OK. ERM, SO, LOOKING BACK NOW SORT OF OVER THE WHOLE TIME REALLY, CAN YOU, YOU KNOW, THINKING ABOUT THE TIMES YOU SPOKE WITH MISS [???] ... WELL LET'S JUST SPEAK, THINKING ABOUT THE TIME YOU, THE ONE TIME YOU SPOKE WITH MISS, LIZ DENTON, HOW DO YOU FEEL YOU GOT ON WITH LIZ, LIZ DENTON? DID YOU THINK SHE ...

Patient: I thought she was brilliant.

INT: YEAH. DO YOU THINK SHE LISTENED TO YOU AND UNDERSTOOD YOUR NEEDS AND CONCERNS AND THINGS?

Patient: She was normal.

INT: YEAH, OK.

Patient: Very normal.

INT: RIGHT. AND SHE SEEMED TO THINK THAT IT WOULD PROBABLY BE A FULL MASTECTOMY GIVEN THE INFORMATION SHE HAD AT THE TIME?

Patient: Yeah.

INT: OK. AND THINKING ABOUT THE TIMES YOU SPOKE WITH MISS [???] HOW DID YOU GET ON WITH HER?

Patient: ... Her manner's different, totally different. I mean she's ... comes over as very good, very competent, very professional, but just not quite got that same ... level of interaction.

INT: RIGHT, OK.

Patient: ... as [???]

INT: AS LIZ DENTON?

Patient: Yeah.

INT: [???]

Patient: Yeah. Just slightly different, they're different in their approaches, erm, I've since found out that Dr Denton's actually a GP as well, and I just wonder if that's perhaps a difference, that she interacts with patients on different levels all the time ...

INT: IT MIGHT BE.

Patient: ... I don't know.

INT: MIGHT BE.

Patient: It's just ... I don't know, but there is a difference. Erm, I think because Dr Denton just said, you know, ... I just don't know. She ... she brought it down to my level, said, 'I'm the same age as you and I just don't know how I would feel,' and just ... brought it to be a little bit more ... human. Bit more feeling in it? I don't know. Yeah, probably feeling, I think that's probably the right word.

INT: RIGHT, YEAH. OK. AND WHEN YOU WERE TALKING WITH MISS [???] DO YOU THINK THAT SHE LISTENED TO YOU AND UNDERSTOOD YOUR NEEDS AND YOUR CONCERNS AND THINGS?

Patient: Yeah.

INT: YEAH?

Patient: Yeah.

INT: AND DID YOU FEEL THAT SHE HAD A PARTICULAR TREATMENT IN MIND? - WELL YOU ASKED HER, DIDN'T YOU, YOU SAID, AND SHE RECOMMENDED, WELL SHE SAID, 'IF IT WAS ME OR MY FAMILY YOU'D HAVE THE [???] FULL MASTECTOMY'?

Patient: Mm.

INT: THINKING ABOUT THE TIMES YOU SPOKE TO THE BREAST CARE NURSES, AND I APPRECIATE YOU SAW DIFFERENT ONES, HOW DO YOU FEEL THAT YOU GOT ON WITH THOSE?

Patient: Erm, different ones in different ways. Erm, it would have been nice to have stayed with Maureen, having had that first initial contact with her as well, but she was going off sick for whatever reason, and my initial reaction with Pat wasn't brilliant but after the second visit I felt much happier with her. The two that came to the ward also came accompanied with a student, which I found awkward. Erm, and one that came to the ward to ask or discuss the bras I'd brought in to be fitted up with the softies, asked to have a look and everything I'd brought in was wrong. And then she went on to describe what I should have brought in, and then gave me a leaflet about it. Well if that leaflet had been given to me prior to going in I'd have brought in the right sort of bras.

INT: YOU'D HAVE [??]

Patient: Previous to that, I mean, I'd gone to Fenwicks [?] and asked their advice and been fitted out at Fenwicks.

INT: RIGHT, OK.

Patient: Erm, then she turned and said, 'Well we recommend you go to Marks and Sparks at Foss Park,' or [??] really - well if they'd said that before ... it's a little thing, but you've some-, you know, you've brought that you think is right, you've gone specifically to buy what you think is right, and it's wrong. You know, it's just sort of, doesn't help.

INT: YEAH, SURE.

Patient: Erm, and, as I say, the fact that she had a student with, both of them had a student with her each time, doesn't help for what's sort of quite an distressing and intimate-type contact, because you're trying to look at two people instead of one, and you, it's very hard to hold a three-way ...

INT: CONVERSATION.

Patient: ... yeah.

INT: YEAH.

Patient: Yeah, so, whilst I know it's difficult with students, I appreciate it's hard for students and they do need to learn, erm, ...

INT: DID THEY MENTION IN ADVANCE THAT THE STUDENT WAS GOING TO BE THERE?

Patient: No, no.

INT: DO YOU THINK THAT MIGHT HAVE HELPED? IF THEY'D SAID, 'CAN WE BRING A STUDENT ALONG?' OR ...?

Patient: Yeah, I think it would actually. No objection on the whole to students being there, but ... and again you didn't know when they were going to turn up, they just turn up and ...

INT: MM, YEAH, OF COURSE.

Patient: Which is, yeah, I know they're, they have other things to do but, erm, if you knew they were coming then you've got anything you want to ask already sorted in your mind as well, which would have helped.

INT: RIGHT, OK.

Patient: You know, if you think, oh the breast care nurse comes on about two o'clock, you know, if you've got anything you want to ask about, if you want to see them. It just would have, would have helped I think.

INT: RIGHT, OK. ERM, DID ANY OF THE BREAST CARE NURSES THAT YOU SPOKE TO, DID ANY OF THEM SEEM TO HAVE A PARTICULAR TREATMENT IN MIND THAT THEY THOUGHT WOULD BE THE BEST ONE, OR ...?

Patient: I didn't ask.

INT: OK. ERM, AND THEY GAVE YOU SUPPORTING INFORMATION, WRITTEN SUPPORT INFORMATION, DIDN'T THEY? ERM, I KNOW YOU READ IT, YOU SAID YOU READ AND THAT, DID YOU FIND IT USEFUL AT ALL?

Patient: Yeah, when I could get my head round it.

INT: RIGHT, YEAH, MM. WAS THERE ANYTHING IN PARTICULAR YOU FOUND USEFUL? ANY ONE OF THE LEAFLETS OR ANY INFORMATION THAT YOU FOUND USEFUL?

Patient: Yeah, I think it was the Breast Care for Younger Woman, erm, Breast Cancer for Younger Women leaflet that had quotes, pictures and statements from other women in it that you could actually relate to and sort of, sort of questions and answers type thing. Very simply written, because I mean that's all you can take in anyway really, but that was very good.

INT: RIGHT, OK. AND, ERM, FROM HEARING YOUR DIAGNOSIS TO THE OPERATION, HOW LONG DID IT TAKE YOU TO MAKE UP WHAT, YOUR MIND WHAT SURGERY YOU WERE GOING TO HAVE?

Patient: As I say, immediately it was going to be a full mastectomy then it had a brief swing to a partial but it went back fairly quickly.

INT: AND DID YOU CHANGE YOUR MIND AT ALL ONCE YOU'D SETTLED ON THAT, THEN?

Patient: No.

INT: NO. RIGHT, OK.

Patient: I mean you're always gonna wonder did you make the right decision?

INT: YEAH.

Patient: Always.

INT: YEAH.

Patient: And I suppose it would have been nice if she'd been able to say [chuckles] well, it wouldn't work really, but if she'd been able to say, 'Yes that was right because we'd have had to have you back in,' that was the saving grace when I went for the final results, at least I've not got to go back in again and have the breast removed. But, yeah, that would have been nice, the icing on the cake if she'd just been able to say, 'Good thing you decided that.'

INT: RIGHT, OK. LIKE SOME KIND OF CONFIRMATION?

Patient: Yeah, yeah.

INT: YEAH, SUPPORTING YOUR DECISION WAS RIGHT. YEAH.

Patient: Yeah. You obviously wouldn't want to hear it the other way [chuckles] would you? That's why I say, that's a difficult one because ... you wouldn't want that one, but, yeah, that would have been just, you know ... because as I say you do have doubts and whatever, and probably you'll always think back every so often, should you or shouldn't you.

INT: ERM, THINKING ABOUT THE TIME BETWEEN DIAGNOSIS AND YOUR OPERATION, I KNOW YOU SPOKE TO THIS LADY THAT HAD THE MASTECTOMY, BUT DID YOU LOOK FOR ANY OTHER INFORMATION? YOU WENT TO YOUR GP, WHAT ABOUT RELATIVES, FRIENDS AND NEIGHBOURS, DID THEY GIVE YOU ANY BOOKS, MAGAZINES, VIDEOS? DID YOU LOOK ON THE INTERNET? DID YOU GO ... YOU DIDN'T DO SUPPORT GROUPS. ANYTHING ELSE THAT YOU CAN THINK OF ...?

Patient: I was initially told by Maureen that if I went on the internet to be very careful where I went site-wise. Erm, no, I purposely avoided reading anything else, and it's been quite hard because it's been Breast Care Awareness, hasn't it?

INT: YEAH.

Patient: Everywhere you go it's ... it's everywhere. But, no, purposely ...

INT: YOU DIDN'T LOOK ON THE INTERNET? NO?

Patient: I went on one site briefly, erm, that was before I went to the GP actually ...

INT: THE FIRST TIME?

Patient: Yeah, and then after that I haven't been since. Well, before that, I have been since now on the BACUP site, mainly regarding sort of the next stage [???

INT: IS THAT CANCER BACUP? YEAH?

Patient: Yeah. Er, and this lady that came to see me had been, been there, done that, she'd got a couple of clothing catalogues and gave them to me and said, 'You might be interested in these.' They, one of them does, not, it's not a lifestyle magazine twice a year, but they do a magazine with issues related to breast cancer so I've rung them to put my name on the mailing list and that's been very useful, it's been very good. And there's stuff on the ward in a letter rack [???] you know, it's not particularly nicely arrayed, and I think it would have been more useful to have a pack to take home and look at at your own leisure rather than expect you to pick it up, because at the time you just really don't want to ... well, I didn't want to.

INT: LOOKING BACK ABOUT THE ACTUAL SURGERY, DO YOU FEEL THAT YOU HAD THE AMOUNT OF CHOICE THAT YOU WANTED?

Patient: I wouldn't have wanted a choice. I wanted that made for me.

INT: RIGHT, OK.

Patient: And that's something I did ask Poppy, 'Can they not, can you not take me down there and decide under the anaesthetic?' and she said no.

INT: ERM, AND THINKING ABOUT THE DECISION THAT YOU MADE WHAT SURGERY TO HAVE, WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD, THAT YOU HEARD, THAT YOU READ, OR WHATEVER, THAT HELPED YOU MAKE THAT DECISION TO HAVE THE MASTECTOMY?

Patient: ... Her advice.

INT: MM? JUST, MISS [???], YEAH?

Patient: Yeah.

INT: MM?

Patient: Yeah. She's the specialist, she should know.

INT: MM. ERM, AND LOOKING BACK NOW FROM WHEN YOU WERE FIRST DIAGNOSED UNTIL NOW, HOW DO YOU FEEL ABOUT THE CARE YOU'VE RECEIVED?

Patient: ... As I say, just really, what I've already said really, it would have been nice to have had that bit of contact halfway through that time [???] going into hospital, and the decision to make. Even if it was just a courtesy call from the breast care nurse to say did I

want to pop in?, well, I don't know, somebody come out, I don't know, just to churn things through again. Because suddenly you're back out there on your own and for me to make that call to them, it's like ringing the doctors, you don't do it unless you're really ill.

INT: RIGHT, YEAH.

Patient: So for me it would have been easier to come from them rather than the other way round.

INT: RIGHT. DO YOU THINK THE CARE THAT YOU RECEIVED IN TOTAL, DO YOU THINK IT MET YOUR EXPECTATIONS? DID YOU HAVE ANY EXPECTATIONS?

Patient: Just odd things, like since I've been out, I would have assumed somebody - even from the GP side - would have come out.

INT: WOULD HAVE VISITED YOU AT HOME?

Patient: Yeah. Because once you're out ...

INT: LIKE A DISTRICT NURSE OR SOMETHING?

Patient: Yeah, [???] you know, you'd have thought there'd be some, at least some sort of courtesy call, or I thought there would have been, but, no.

INT: OK. ERM, IF YOU WERE TOLD THAT YOU COULD CHANGE, YOU HAD THE POWER AND MONEY TO CHANGE ONE THING ABOUT THE BREAST SERVICE AT THE GLENFIELD THAT YOU WENT THROUGH, WHAT DO YOU THINK THAT WOULD BE?

Patient: To have a designated breast care nurse per patient.

INT: MM, AND YOU'D SEE THE SAME FACE EVERY TIME?

Patient: Yeah.

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

Patient: Don't stick your head in the sand. [chuckles] Don't ignore it because it doesn't go away.

INT: RIGHT, OK.

Patient: Not just pretending that you've got an infection and getting antibiotics from your GP that don't work. Yeah, it's just, yeah, it's just to keep, I think it is obviously getting better, keep publicising it, erm, and I think the fact that people, it's becoming, are more aware is going to help.

INT: MM.

Patient: Because I've not no [??] the embarrassment of it will go, and it just becomes a fact, doesn't it? Once you talk about it to one person, or to another person, it's amazing how many people know somebody who knows somebody ...

INT: A COMMON PHRASE IS, 'THEY ALL COME OUT OF THE WOODWORK.'

Patient: Yeah, exactly. But where are they when you need them, you know? Yeah. Or that, you know, as I say, the facility to do one-to-one in somewhere, you know, if that was available it would be good. But I think it's got to be from somebody that's been there and done that. And, I don't know, if you can ... could there be a scheme set up where people who've been there, done that, are willing to be trained as counsellors, whatever ... that's going long-term, isn't it, into fairyland really? But they've been there, you know.

INT: I'M SURE THERE ARE SCHEME, YOU KNOW, PEOPLE DO THAT, BUT I DON'T THINK IT'S A NATIONALLY, NATIONAL THING, YOU KNOW, I THINK IT'LL PROBABLY BE MORE OF A LOCAL INITIATIVE. SOMEBODY THINKS, 'THIS IS A GOOD IDEA, WE'LL DO THIS.'

Patient: Mm.

INT: MM. ERM, AND NOW YOU'VE BEEN THROUGH THIS 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: The drains. [chuckles]

INT: OH RIGHT, YEAH.

Patient: Nobody tells you about the horror of the drain removal.

INT: OH RIGHT, OK. I NORMALLY ASK ABOUT THAT AS WELL, SORRY, I DIDN'T ASK ABOUT THAT. YEAH. YOU DIDN'T LIKE THE DRAINS, WAS IT NOT VERY COMFORTABLE AND ...?

Patient: No. [chuckles] And to take in button-through pyjamas.

INT: OH RIGHT.

Patient: Because nobody said what sort of pyjamas to take.

INT: NOBODY TOLD YOU WHAT BRA TO GET AND NOBODY TOLD YOU ...

Patient: No, button-through, getting yourself dressed is far easier than trying to put a t-shirt-type pyjama top on.

INT: OH RIGHT.

Patient: Silly practical things like that would have been useful.

INT: REALLY, YEAH, MM.

Patient: And to know that you can't use antiperspirant and you're gonna smell. And to take in some unperfumed soap 'cos then at least you can wash with that. Again they don't tell you that. But otherwise everything is as per normal really.

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

Patient: No, it's really just, as I say, the ... the pictures bit, erm, regularity of the same nurse and the bra information before you go, erm ... I mean generally the wards and everything else was very relaxed, a bit too relaxed at times. Erm, it was just nice [???] at Glenfield that you could go off, off the ward, go wandering, there's no one. [chuckles] It would have been useful to know at what time roughly the doctors were coming because I was missed. [chuckles]

INT: JUST YOU AND YOUR DRAINS JUST WANDERING AROUND, YES?

Patient: Yeah, I did.

INT: OH RIGHT, OK. WELL MY DAD HAD AN OPERATION YEARS AGO, PASSED AWAY NOW UNFORTUNATELY, BUT YOU KNOW HE WAS IN FOR A BOWEL OPERATION, BOWEL CANCER, AND, ERM, THE FIRST DAY AFTER HIS OPERATION, ON THE MORNING, THEY COME IN, THE NURSES, SORT OF SAYING, 'OH, HE'S UP AND ABOUT,' AND HE SAID, 'OH I'VE BEEN EVERYWHERE,' SORT OF THING. AND I'M THINKING 'OH THERE'S BOUND TO BE SOME ANAESTHETIC STILL LEFT IN HIS SYSTEM, IT'S GOT TO BE, YOU KNOW, IT HASN'T BEEN THAT LONG AFTER THE OPERATION,' AND THE NEXT DAY I WENT TO SEE HIM HE WAS [???] [???] AND ALL THIS KIND OF STUFF, BECAUSE HE JUST, HE WAS EVERYWHERE, HE WAS DOWN THE CAR PARK AND EVERYTHING. AND HE'D JUST HAD A BOWEL OPERATION AND I SAID, 'WELL YOU CAN'T BE DOING THINGS LIKE THAT, MAN.' HE WOULDN'T SIT STILL, BUT I LOVED MY DAD, [???]

Patient: Well I think it aids me to get out because I ...

INT: THERE'S A CHAP WALKING DOWN YOUR DRIVE ... [CHUCKLES] IS THAT THE END OF THE INTERVIEW, NOTHING ELSE YOU WANT TO SAY?

Patient: No, I don't think so.

INT: OK, WE'LL SWITCH OFF AND LEAVE YOU IN ...