

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: Low MR unit

*DATE:

*ID: Patient52

INTERVIEWER: DJW

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

Patient: Erm, well I knew because my sister was diagnosed with breast cancer eight years ago ...

INT: RIGHT, OK.

Patient: ... when she was 42, so I'd really been through that with her all along the road. She had a mastectomy ... erm, you know it obviously frightened me and made me aware, but my aunt had had breast cancer when she was 45 and is now 47, 47 ... 87, and well, so I sort of always thought, well my sister, would, you know, probably follow the same pattern, but unfortunately she didn't. And she died two days before my routine mammogram.

INT: MM, OH DEAR.

Patient: So, I didn't have, I had nothing wrong with my breasts as far as I was concerned.

INT: RIGHT, OK. WAS YOUR SISTER, ERM, DID SHE GO TO THE SAME HOSPITAL AS YOU?

Patient: No, my sister was in Hertfordshire.

INT: OH, RIGHT OK. I USED TO LIVE THERE.

Patient: Did you?

INT: YEAH.

Patient: In Hemel Hempstead, and she discovered hers, erm, the summer before she was due to go on holiday to America, she discovered a lump in her armpits, which she went to the doctors with, who just said, 'Oh, we'll do a blood test,' erm, you know, 'You've got an infection.' She was then sent to the, after she went on holiday and then came back and said she'd got an appointment with a breast special-, er specialist. And she'd said to the consultant, 'Oh, what's wrong under my arms?' you know, 'Is it bad?' and he said, 'I'm more worried about the lump in your breast.' And she'd got quite a big lump in the under pat of her breast which she hadn't, didn't know about. The result was that, just before Christmas she had a mastectomy and, although there is a choice, I think in her case there was no choice.

INT: RIGHT, YEAH.

Patient: Had the mastectomy which was, er, followed by two years later she found a lump in her other breast and when she said, 'Could I have a mastectomy?' to the lady surgeon, was told, 'It's no use bolting the stable door ... closing the stable door after the horse has bolted,' so my sister was a bit ... taken aback. Erm, this consultant has since retired but not before my sister told her about her bedside manner, [chuckles] but she had spots on her spine following by this, and her liver, which she actually changed her diet, she went onto ... she went

to the homeopathic hospital in London, was referred to and was put on courses of treatment and changed to totally organic food, and we're quite religious, we went to Lourdes, but, you know, the shadows did go away and they, whatever happened. And then she had a hysterectomy, about three years ago because the cancer had spread to her ovaries, and then she was a bit unwell in March, she went to visit my son in Munich for five days, she continued, she'd started a new job at another secondary school and worked the week, until the week before Easter, broke up for holidays and said she didn't feel too well, and was, thought she had a water infection. And, erm, went to see the doctor the Tuesday after Easter, who said 'We'll do some water tests and we'll have a scan and bring your oncologist's appointment forward,' because she was still on routine oncology support then. So she had the scan and went to see her oncologist on the Monday after Easter, that would be about the 19th April, and the oncologist said, 'Erm, there's cancerous cells but don't worry we'll get the fluid,' because she was by this time, you know, gaining fluid, erm, 'Drain the fluid and give you some chemotherapy, and you'll be fine.' I spoke to her on the Thursday, they'd taken four and a half litres off, and then they clamped it because apparently it's too much to lose, you know, you don't want to lose too much. So on the Friday she was, they drained the rest off, which was another one and a half litres, and they were going to give her chemotherapy and she was going home at lunchtime. Her children had come home from university to see her. They did that and then my brother-in-law phoned me at five o'clock on the Friday to say they'd taken her back in because she was in such pain. She slept through the Saturday and Sunday. Sunday, the 25th, I was told, my brother-in-law phoned up in a state, they thought she'd got 12 hours to live, they thought she was just going to go to sleep. Erm, they thought it had gone to her brain: it hadn't in fact, and she actually lasted, erm, another week, she died on the Saturday morning. The cancer had spread, it was breast cancer but it had spread through the body. So her kidneys went into failure. She never really regained consciousness, you know. So ... I knew, obviously I knew quite a bit about ca-, no I won't say quite a bit, I knew a bit about cancer having sort of lived with it. And then I went for my routine mammogram on the - she died on Sunday, 2nd May, the next day was a bank holiday, and I'd got my routine mammogram. I wasn't going to go, I said, 'Oh I'll leave it, I'll book another appointment,' and my husband said, 'No, you must go.' So I went for my routine appointment, her funeral was the next week, and then the next week, because I was just so down, my GP said, 'I think you need some time, you know, time off,' so I had five days off school and on the Wednesday I got the letter about my second visit. So I went back for my second visit on the Monday and saw a wonderful radi- ... now would she be a radiologist?

INT: RADIOLOGIST, YEAH.

Patient: And I had an ultrasound and she explained everything very detailed to me, she said, 'We've found something very small that wasn't on your mammogram a few years ago,' and I had another mammogram and I had an examination by the Registrar, who said, 'I don't think I'm going to feel this but do you mind if I have a go?' Couldn't find it. So I went back the next day for a, do they call, core biopsy, and then went back like a week on the Monday because it was the next bank holiday, so I went back on, I suppose it would be about June 7th, and got my result, which was cancer. Had blood tests, chest x-ray, went back on the Thursday to check the bloods were all right, booked a date for the following Tuesday which was last week. Had the operation and that was it.

INT: MM. WHEN YOU, WHEN YOU GOT YOUR LETTER TO GO BACK FOR THE SECOND MAMMOGRAM, WHAT WENT THROUGH YOUR MIND AT THAT POINT?

Patient: I was terrified. I really did, I think to be honest that, that and the Monday was the worst time of my life, because all I could think of was my sister.

INT: YEAH.

Patient: And I can remember that, you know, there was a number, '[???' if you're worried phone this number,' and I did, I phoned the number and I spoke to a breast care nurse. I tried to get hold of my husband, he's a teacher and I couldn't get hold of him, so in the meantime I thought, 'I will phone them,' and I think I was crying. I was very anxious and agitated and, erm, I spoke to a very nice nurse who reassured me and said, 'It's not always serious, you know, there can be other causes.' But I'd just a funny feeling, you know, with my sister, I'd just got the strangest feeling. My worst of it was, I tried to put it out of my mind, I couldn't. I was worried about taking time off school to go back to the hospital again, but in the end I thought, 'That's not a worry,' ...

INT: NO.

Patient: On the Monday when we went to hospital, that was agony, sitting waiting, because I didn't know what I was going to be told. I could have been told I'd got six months to live, I'd got a huge cancer, I kept feeling myself, can I feel anything, can I ...? You know. And once I'd gone in and seen this radiologist and she was so calm and reassuring, I did feel, and I thought, 'well, I'm here now, I'll just have to go along with whatever's said.' And from that moment I settled. I don't think my husband did because I think he'd felt all along it was, hoping it was nothing. But that was the hardest for me, when the letter came and actually seeing them. Fortunately it wasn't long: the letter arrived on the Wednesday and I was seen on the Monday. So it was very quick.

INT: YEAH, WHICH WAS GOOD.

Patient: Erm, which I think is supposed to be the case in Leicestershire, that they are very, very quick, and I did appreciate that.

INT: I THINK SO, YEAH. I MEAN, YEAH, I THINK CERTAINLY WITHIN A COUPLE OF WEEKS OR SOMETHING THEY GET EVERYTHING TURNED ROUND, DON'T THEY NORMALLY?

Patient: Yeah. Because they did say to me it was going to be two, between two to three weeks. They said three weeks because they'd had some sort of problems, I don't know what, you know, but definitely I would hear within three weeks, and it was actually two weeks two days from my mammogram that I heard. Two weeks and one day, and then I was at the hospital the next Monday, so it was, it was quick, yeah.

INT: YEAH. I THINK IT IS CONSIDERING THEY SEE A LOT OF PATIENTS. THEY SEE SOMETHING LIKE, ON AN AVERAGE WEEK, 50 PATIENTS A WEEK - NOT ALL CANCER BUT ...

Patient: Well, I, yeah, I know, but that was another thing that amazed me when I went to the hospital and saw all these people sitting there and I thought, 'Oh ..' you know.

INT: YEAH, BECAUSE THEY'VE GOT A HUGE CATCHMENT AREA, IT'S MASSIVE.

Patient: Yeah, 'It's not just me.'

INT: YEAH, WELL I DIDN'T REALISE HOW MASSIVE LEICESTERSHIRE WAS. I ACTUALLY BOUGHT A MAP AND STARTED DRIVING ROUND IT AND, YOU KNOW, THEY COME FROM FAR AWAY. I MEAN, ERM, I MEAN IN THIS AREA I DIDN'T EVEN KNOW RUTLAND WAS A SEPARATE COUNTY, YEAH.

Patient: I was going to say, there's Rutland, there's, you know, you go from the north to the south.

INT: YEAH, IT'S A BIT AREA. SO ...

Patient: There's a big ... and something else it taught me, that there's no age, there's no age barrier. You know I saw people a lot younger than me and I saw people a lot older than me.

INT: I THINK 80 PER CENT OF FALL IN THE, IS IT 50-70 BRACKET, I THINK, SOMETHING LIKE THAT, YEAH.

Patient: Yeah, but, you know, the younger ones as well, and I thought ... so I mean, and then, you know, when they sort of ask you questions and there was questions, you know, that ... I'd said, 'No, I've never smoked, I was never on the contraceptive pill, and I breastfed all my children,' and they were the three key, you know, people ask. And, erm, it just happens.

INT: YEAH. ERM, SO YOU WENT AND GOT YOUR SECOND MAMMOGRAM AND SOME TESTS ...

Patient: The ultrasound and the core ...

INT: ... THE ULTRASOUND AND THAT, RIGHT, YEAH. AND THEN YOU, DID YOU WAIT A WEEK OR SOMETHING THEN TILL ... YOU SAW A REGISTRAR, DIDN'T YOU, ON THE 8TH?

Patient: Saw a Registrar.

INT: YEAH, HE EXAMINED YOU, DIDN'T HE?

Patient: Yeah, lovely man, lovely.

INT: AND THEN YOU, WHAT, DID YOU WAIT A WEEK FOR YOUR RESULTS OR SOMETHING?

Patient: No, I had the core biopsy on the Tuesday ...

INT: RIGHT.

Patient: And I had to wait till a week on the Monday because there was a bank holiday the next week.

INT: AH RIGHT. YEAH, OK. SO CAN YOU, I MEAN, THAT MUST HAVE BEEN A HELL OF A WAIT ...

Patient: Well, it was and it wasn't, because I'd ... my son was coming over from Germany to spend a long, this had been planned for, to spend a long weekend, so we were looking forward to that. I was terrified of the core biopsy but in actual fact it wasn't a problem, it didn't hurt, I had no reaction. And at that, by then, I felt so reassured by the people I'd met at Glenfield and that, whatever happened, I was in the right hands and the right decisions could be made, and I just felt much more positive. So I went along, I mean I was you know, what I was told, and then I went back on the Monday. Part of me, I think, I wasn't totally surprised, my husband was absolutely shattered but, devastated, but I think I had accepted it, or whether I'd built myself up to 'You must accept this,' [???

INT: MM, ERM, SO WHEN YOU WENT TO THE ACTUAL CONSULTATION TO HEAR, ERM, ABOUT YOUR RESULTS, CAN YOU JUST TELL ME WHAT ACTUALLY HAPPENED? YOU OBVIOUSLY WENT TO THE CLINIC, YOU'D HAVE WAITED FOR A WHILE AND THEN WENT IN THE ROOM?

Patient: Yeah, we didn't wait too long, probably 10, 15 minutes, and was called in. The first thing I was asked to do was to take - I'd never met this consultant before - was to have my blood pressure taken because this consultant

liked them to have a blood pressure taken. I must admit that I felt a bit unnerved by, because I thought, 'Why? It's bad news, it's bad news, I've got to have ...' you know, I thought it was going to be bloods but it wasn't, it was blood pressure. But then she said, no, she likes it done to all of her patients just as a matter of course.

INT: OH, OK.

Patient: I suppose it's to see, I don't know, don't really know, see how you are. And I went in and met my consultant. At first I thought she was a bit stern and foreboding but I really appreciated her directness.

INT: YEAH. WHO WAS IT?

Patient: Miss Stotter.

INT: MISS STOTTER.

Patient: She's very direct and very straight, and, erm, I said to, we walked in and she said to me, erm, 'Oh Mrs [???' and then she asked my first name and, erm, my husband came in, I said, 'Could my husband come in?' 'Yes, yes.' So he sat with us. And she said ...

INT: WAS ANYBODY, WAS THERE ANYBODY ELSE IN THE ROOM, WAS THERE?

Patient: There was a breast care nurse and another nurse.

INT: RIGHT.

Patient: And she said, erm, 'What have you been told?' so I told her exactly what I'd been told and what had happened to me. She said, 'And what did they tell you about the diagnosis?' I said, 'I was told it could be a very small cancer, it could be fibrous tissue.' And she said, 'Yes, quite right, it's cancer.' And I just went, 'Oh ...' and I turned to my husband and I said, 'Are you all right?' because I mean I could sense, you know, he's a very strong man, but I knew and he said, 'Yeah, are you?' and I said, 'Yeah.' Carried on talking to the consultant and she said to me, 'You're taking this very well,' I can remember her saying that. 'You seem to be taking this very well,' and I said, well, after all I'd gone through in the past few weeks, I didn't really expect ...

INT: BECAUSE SHE WAS AWARE OF YOUR SISTER?

Patient; Yeah, I'd told them about my sister, because the first visit I was nervous and I told them and people were so kind and I think a bit shocked and thought it was a bit, you know, bad timing ...

INT: YEAH-YEAH.

Patient: And she was saying, 'Oh, people tend to blame Glenfield, they think we've given them cancers but we haven't,' you know. And I said, 'No, I didn't mean I'll have it ...' I talked about my sister to her and she said, 'Well, this isn't the type of cancer your sister had,' and she explained, she was very reassuring, that it was a small cancer and she could, erm, what they could do. And then she said to me quite directly, erm, that there could be an operation. She said, 'We treat it in three ways,' 'We can treat it in three ways, there was tablets, erm radiotherapy, chemotherapy, you know, after surgery.' She said, 'Of course, if you want treatment you are entitled to refuse any treatment.' And I just said, 'No, I want treatment.' And she said, 'Good, now do you want a lumpectomy or a mastectomy?' And I am the most indecisive person on this world,

my husband will tell you, and I usually go, 'Ooh, what colour shall I have?' you know, dress, 'What shall we do?' And I just said, 'Lumpectomy' and I said to my husband 'That's, we've talked, haven't we?' and he said, 'Yes, that's fine.' And she said, 'Good, that's what I would have made,' she said, 'I'm not allowed to ...' or 'I'm not allowed' is probably the wrong word ... to sort of tell you what you must have, but it wasn't that ... it was what she ... what she said to me, the way she explained the cancer to me, made me feel that a mastectomy wasn't necessary for me.

INT: SO WHAT WAY DID SHE DESCRIBE IT?

Patient: That it was a very small cancer at the back, erm, hadn't grown, she said it was only a diddy one, that it hadn't grown very big and, erm, it had started to invade slightly but they hoped it wasn't in the lymph nodes, you know, but she didn't think so. They'd examined my lymph nodes and didn't think there was anything. Erm, and that was what made me, and it was when she'd said, you know, 'Good,' I knew I'd made the right choice and that she agreed with my choice. I also had felt with her that if she'd have felt a mastectomy was the choice that I would have been left in no doubt. Not that she would have said, 'You must have a mastectomy,' but I think the way she'd have described my cancer and it's implications would have made me, you know, aware that perhaps the mastectomy was the better choice. And especially the week before with the registrar as well, he'd sort of said it was only small and I was reassured by that. But I have utmost faith in her and I felt that, if, and talking to breast care nurses as well, who also said, you know, how good she was, that I do feel that, had she considered a mastectomy, I would have, I probably wouldn't have been given the choice, she probably wouldn't have said, you know, mastectomy or lumpectomy, she have said ... because apparently some people just say as soon as they have cancer, I want a mastectomy, I want to do away with it.

INT: YEAH, SOME THEY DO, THEY JUST WANT TO GET RID OF THE BREAST THEN THEY THINK IT CAN'T COME BACK.

Patient: That's right.

INT: WHICH IS NOT TRUE, OF COURSE, I MEAN SOME PEOPLE ...

Patient: No, it can still, yeah.

INT: ... SOME PEOPLE ARE REALLY RADICAL AND HAVE LIKE A BI-LATERAL MASTECTOMY AND THEY THINK THAT'S IT, BUT OF COURSE IT CAN COME BACK IN SCAR TISSUE AND ...

Patient: It's not ... so I said, you know, so that was mine, that was how I came to my decision. And also, erm, I can't remember whether that was the Monday or the Thursday ... yeah, because then we had to tell our children and I was determined to be open and honest with them, and, erm, because we'd had a couple of things before. I'd had one of these rodent ulcers, which I was supposed to be too young to have; and I hadn't told them about it till I'd had the biopsy and they were furious. So we decided, you know, they were gonna be told, especially because my niece and nephew were told all along about my sister. We told them, and my daughter immediately was on the internet and she said, 'When you go back ask her what sort of cancer?' I said, 'But I thought cancer was, you know ...' And she said, 'No, ask her, ask her if she can, knows the name.' So I said, 'All right,' and she was reading through, you know. So when I went back, I had my bloods taken that day and she said, erm, on the Monday, she'd said to me, erm, 'Right, when do you want to have the operation done?' and I said, 'As soon as possible.' And she said, 'Good.' You know, she appreciated that. She said, 'Good, I'm pleased, I'm pleased, that's, I'm glad you've said that.' And I said 'The only proviso is that my daughter's going to, she graduates on the 30th ...

[Interruption in recording]

... she graduates from Durham University on the 30th and,' I said, 'And I would like to be there,' And she said, 'Of course, of course. Brilliant, I think you should be.' So she said, 'Right, well, if I can op-, if I've got a slot on Tuesday I can operate on Tuesday, which is the 15th, and you'll be fine by the 30th.' So I said, 'Do you think so?' and she said, 'Yes, yes, you'll be fine.' So I said, '[???' So she said, 'Providing your bloods are all right, we'll look at that.' So I went back on the Thursday and she said, 'Your bloods are fine, your x-ray's are fine, [???' so again went through it and she said, 'Right ... Tuesday ... you'll come in Tuesday morning and I'll operate on Tuesday afternoon.' And I said, 'Fine.' And she said, and I said to her, 'Excuse me,' you know, 'Can you tell me what sort of cancer it is?' and she said, 'Yes.' I said, 'Do I have to wait for the operation? Can you tell me know?' She said, 'No, I can tell you ...' and she seemed to appreciate me asking, you know, questions like that and I said, she told me what it was, it was a lobular in situ, and she said, 'It's only little, blah-de-blah and it's low-grade.' I said, 'Fine, that's what I want to know,' and I'd explained my daughter wanted to know, and she said 'Oh, good,' you know. She was appreciate of the fact, I think, that we actually asked questions and, erm, although no medical [???' at least we took some sort of, you know, comfort from that.

INT: YEAH, OF COURSE.

Patient: And, erm, so I duly reported that to my daughter, then I went into, I had to go to hospital the next day for pre-operatives tests and then went in Tuesday morning. And, erm, that was the first time, Tuesday morning, when I was really, really worked up. But I think before that, because I was a schoolteacher, I'd got reports to finish and my husband kept saying, 'I don't know how you can get your reports done when you're thinking ...' I said, 'I think that's probably why I'm doing my reports to ...

INT: YEAH, FORGET ABOUT IT.

Patient: ... to forget everything else. And, erm, when I really panicked was when I got to the ward on the Tuesday morning, and I thought, 'My God, I've got cancer ...' you know, but we were put into a side ward and I said, you know, 'Can my husband stay?' 'Yes, yes, of course.' And I had to go down for the needle to be inserted so that could see where the cancer was,' you know, before, and he came with me there and he stayed with me, erm, when I went to theatre and they actually let him stay until ten at night, I think he could have stayed all, if he'd have wanted, but he stayed right through till ten, it was only exhaustion that I made him go home. And then the next day I was two timish to the big ward because they needed the side room for a man, which in actual fact by that time I think I was ready or more company. I think the day before it was lovely because I was so nervous and I don't think I'd have liked to have been around people who'd had the operation carrying their bags round, [chuckles] so that was brilliant form my point of view. And I can't fault the care and attention I received. Yeah. It went in a whirlwind and then they let me go.

INT: SO HOW LONG FROM ACTUALLY HAVING YOUR MAMMOGRAM TO ...

Patient: Well the first mammogram was May 4th and I had my surgery on June 15th.

INT: RIGHT, LIKE SO SIX WEEKS ...?

Patient: Five weeks, five-six weeks, yeah ...

INT: FIVE OR SIX WEEKS?

Patient: Six weeks, yeah. It was very quick, because in actual fact, once my hus-, we thought it was cancer, my husband said, 'Right, we're going privately,' and I said, 'We can't afford it,' and he said, 'Well, [???], I'm hanging round,' because I'm absolutely, in this instance, no [???]. I know it's not the same as other surgery and things, but for this, we can't fault it, we can't fault the care or, you know, anything.

INT: MM? ERM, AND YOU SAID THAT YOU WHEN YOU WENT TO THE ACTUAL CONSULTATION, YOU SAID YOU'D SPOKEN WITH THEM ABOUT WHAT YOU MIGHT DO ABOUT IT, IS THAT RIGHT?

Patient: Yes, before, in case there wasn't a cancer.

INT: RIGHT, OK. SO CAN YOU TELL ME A LITTLE BIT ABOUT THAT? [???]

Patient: Oh we just, you know, because my sister had had a mastectomy and, erm, I said, 'Do you think I'll need ...' you know, 'Will I need a mastectomy? Will I need, you know, a lumpectomy, or what?' and he said, he said, 'Well, we'll wait and see,' you know, 'What do you think?' and I said, 'Well, I don't want a mastectomy unless I really, really have to have a mastectomy,' erm, I said, 'If I can have a lumpectomy I would sooner do that,' although I realise now with the surgery it's basically the same surgery except they take the breast away, you know, recovery's [?] probably not much smaller, and I said, you know, that's what I would go for, I would go for a lumpectomy and he agreed. He said, 'Oh yeah, don't, you know, if you don't need a mastectomy then I don't think you should have it.' Not ... I don't even think from a cosmetic point of view, but I think he just thought that, if I didn't want to have my body sort of, you know, ravaged [?], if you like, there was no need for it. And so we never [???] there was not a lot of discussion, I just said, 'Well, unless I really have to, I'll go for the lumpectomy,' and that was it.

INT: SO YOU WERE SORT OF AWARE OF THE CHOICE BEFORE IT WAS ACTUALLY DESCRIBED TO YOU, IS THAT RIGHT?

Patient: Yes.

INT: YEAH?

Patient: I knew there was, it was either going to be lumpectomy or mastectomy.

INT: YEAH, YEAH

Patient: And, erm, I'd had, I knew several people that had had a mastectomy as well and, although the three of the people who'd had the mastectomy I knew, including, as well as my sister, there was no real choice because the cancer had invaded other tissues ...

INT: MM, YEAH, QUITE ADVANCED, YEAH.

Patient: Yeah, and when she ...

INT: THEY WERE FRIENDS, WERE THEY? LIKE FRIENDS OR ... WORK COLLEAGUES?

Patient: Well ... people I knew vaguely, yes, from other schools actually, teachers from other schools, and I know my aunt was a long, long time ago but she always said she had no choice, she had to have the ...

INT: YEAH, THAT'S, THAT WAS ...

Patient: It was just done and she didn't know ...

INT: THEY KIND OF TOLD YOU AND THAT WAS IT, AND IT WAS A VERY RADICAL OPERATION AS WELL, SO ...

Patient: Yeah, yeah, whereas, as she says, you know, today she might not have, you don't know, I think if they found a lump years ago they just took the whole breast off no matter what it was.

INT: AND HOW BIG AS WELL.

Patient: Yeah, yes, because she has got nothing there, you know, really.

INT: YEAH, YEAH, IT WAS A VERY, VERY RADICAL OPERATION YEARS AGO. ERM, WHEN THIS, WHEN MISS STOTTER WAS DESCRIBING THE DIAGNOSIS AND THE TREATMENT OPTIONS TO YOU, DID SHE USE ANY VISUAL AIDS SUCH AS DID SHE DRAW ANY DIAGRAMS ...

Patient: No.

INT: ... ANY PICTURES, MAMMOGRAMS, ANYTHING LIKE THAT?

Patient: No.

INT: NO?

Patient: She did say, 'Have you seen your pictures?' And I said, 'Yes,' because the radiologist, this Dr [???], had shown me. And I said, 'I have but my husband hasn't seen them,' and she said, 'Oh, would you like to see them?' and he said, 'Oh, yes, please, I'd love to,' and she put up them up for him and pointed out to him, showed him exactly what the problem was.

INT: AND DID YOU SEE IT AS WELL THEN?

Patient: Oh, yes, I'd already seen them, you see, [???] when I went for the ultrasound the radiologist pointed out to me, she said, 'That little tiny area there ...' and my husband asked her question, 'Is that ... which ones ...' you know, '... is that?' and she said, 'No, that's this year's and that's three years ago.' And he said that actually showed him exactly what, where the area was and what would be taken ...

INT: AROUND.

Patient: ... around, yeah. And she explained to us both about the needle being inserted so that basically ...

INT: IT CAN GUIDE THEM IN [???]

Patient: Guide them in and saves them time and probably more discomfort to me if they're, you know, rooting around trying to find something literally, from a crude point of view, she said, 'We can just go straight into the tumour and take it out.'

INT: RIGHT.

Patient: And when I'd had my diagnosis actually, because I'd said to her, 'Can you see the tumour? Can you ...' you know, 'Can you touch it?' you know, 'Can you tell it's cancerous?' and she said, 'No, because we have to be careful just to take the whole, you know, the whole block.' And, you know, they were very good, because when she said she'd, they'd take the two lymph nodes which I believe in future they might not have to - because it's the lymph nodes that are the problem, the breast's no problem at all, it's the lymph nodes that are sore.

And she said, erm, and I said, you know, 'What happens? Do you do this?' she said, 'No, no, we take the lump and then that goes down to Histology to make sure we've taken it, then we work on the lymph nodes, by which time the ... the, erm, result are back, and so we just carry on and if everything's OK we just basically sew you up, if not we, erm, take the rest of the tissue you.' But she said, 'No, it's straightforward.'

INT: RIGHT, OK. ERM ... WHEN YOU WERE OBVIOUSLY DISCUSSING TREATMENT OPTIONS AND DIAGNOSIS, HOW MUCH DID YOU UNDERSTAND ABOUT WHAT YOU WERE BEING TOLD?

Patient: About the cancer?

INT: ABOUT THE CANCER AND THE TREATMENT OPTIONS AND THINGS.

Patient: Well I think we understood pretty much, you know, all of it. But again, I don't know how much of that was due to because my sister had been through it. But she was, you know, she did explain that they would take the lump away, which would be sent for analysis basically, and then we would know as a result of the analysis how advanced the tumour was, what treatment ... and what they found was going to depend on my treatment follow-up. But she did stress, you know, several times, 'You don't have to have any treatment,' you know, 'Don't ...' and that whether I would need Tamoxafen or not, you know, I was made aware of that, you know, erm, yeah, I was made, I think we were made aware all along.

INT: WAS THERE ANYTHING YOU THINK YOU DIDN'T UNDERSTAND OR WAS DIFFICULT TO UNDERSTAND?

Patient: Well, if there was anything we didn't understand, you know, I asked her and she did explain ...

INT: YOU FEEL YOUR QUESTIONS WERE ANSWERED BY HER?

Patient: Yes, she did explain, erm, you know, she wasn't dismissive and, which I think it can be, and then, other things that I perhaps ... sort of cosmetic things, you know, like taking things into hospital and how will I feel afterwards, I did talk to the breast care nurse afterwards, which was great, because I didn't think Miss Stotter would want to, you know, bother with trivia like that. She probably would have been but, you know, will I be sore and the drains, and she explained about the drains. And when I said how, you know, my main question was how long am I gonna be in, and she said up to seven days, but we got varying days from the nurses, you know. In actual fact it was Miss Stotter who, erm, I went in on the Tuesday and on the Friday they were emptying, they were going to clean the walls so we were moving to a day ward but, erm, her registrar had come round and said, you know, 'If you feel ... like, if you can go home with one drain in ...' although I was still losing quite a bit, and then she came back and she said, erm, 'I hear you've been offered the option to go home and you're taking it?' and I said, 'Yeah,' I said, 'I don't really see the point in ... I don't mind being hospital,' I said, 'but I don't really see the point, you know, my family having to come across and I might as well sit at home.' She said, 'Good choice,' she said, 'You know, I think you'll recover better at home.' And, erm ...

INT: LESS CHANCE OF INFECTION.

Patient: Yeah ... well I ended up with an infection in hospital anyway, because after, [chuckles] it was funny because that was another ... I kept saying, what I was really worried about was the anaesthetic, I'd never had an anaesthetic [???] before and I was frightened, I was very frightened ... and when I'm frightened I just talk about it to anybody. 'I'm frightened of this anaesthetic ...' you know, and, erm, in fact that was the only thing in my stay in hospital,

when the anaesthetist came to see me in the room, he was friendly, but he sat down on the bed and he reeked of cigarettes, he'd obviously just had a cigarette.

INT: OH, RIGHT.

Patient: And ... I didn't like that particularly, you know, because I think if you don't smoke - I don't know whether you do - but, you know, and offensive is probably not the word, but it was very strong while he was talking. And then when I went to theatre he was joking, you know, because he knew, he said, 'Don't worry, don't worry,' and he was joking like, said 'I'm going to give you a gin and tonic,' I said, 'I don't like gin and tonic,' and while one doctor was working on my hand, I heard him say, 'Don't put the mask on.' I don't know whether they normally put a mask on in the waiting area, I don't know, but he said, 'Don't ...' and I can remember saying, 'No, I'll have some ...' and I remember just going, 'Well ...' but as he was leaning over me talking, again I could smell smoke, and I found that, that was the worst part in all this. I know it sounds stupid when you've had breast surgery, but I did find that, you know, I didn't like that bit, you know, but smell of the smoke. But the next day, I came round the anaesthetic quite well apart I got the shakes in theatre and they gave me some pethidine, but she said that was natural, I suppose it's your body sort of coming back again, I just started to shake, and she said 'It's normal.' [chuckles] And then, erm, the next morning, I didn't drink much, I didn't have much to drink, and then the next morning I had a bit of breakfast and then I got up, went to the toilet then got up and had a wash, then I sat in the chair and then I felt really peculiar and they got me back in bed. But then they found, they couldn't get my temperature down, they sent me for a chest x-ray but they found out it was a water infection, [???] in hospital. And I think that didn't help. [chuckles]

INT: WHEN YOU GOT YOUR DIAGNOSIS, WHEN IT WAS, YOU KNOW, WHEN IT WAS CONFIRMED THAT YOU DID HAVE A BREAST CANCER, WHAT WERE YOUR FEELINGS THEN? BECAUSE UP TO THIS POINT YOU HADN'T HAD IT CONFIRMED?

Patient: I think I was more concerned about my husband, I really was, my husband [???]. I never thought at that point - I don't know whether it hadn't really hit me - I think, I think I was on like a whirlwind. There was my sister's death, there was so many other things going on, and I think I thought, 'Oh, well, you know ...' and I was able to talk about it quite matter-of-factly. People at school, I went back to school and people were saying, 'OH, you know, it's terrible,' and I said, and I people were asking me and I was talking, and I do feel that talking helped. And somebody came and said to me, 'You don't need this, you don't need to be telling people.' I said, 'No, it's fine, I really don't mind.' But I think talking to people was like a therapy in itself: if people asked me ...

INT: MM, CATHARTIC REALLY.

Patient: Yeah, if people asked me I told them. We made the decision not to hide it because I knew people who'd hidden things, you know, before, and it's so much easier if you tell people. People are much more supportive and encouraging and I haven't found, well most people, I think my sister-in-law, the member of the family who's been the least supportive and encouraging, everyone else has been wonderful. And I did find it helped, but as I said I was more worried about my husband's reaction and the children, because I knew, I remember my sister always used to say, you know, 'I've got to go through it,' but her husband, Phil, she said, 'He's terrible, he can't do anything.' And I realised then how true it was, you know, my husband just watched ...

INT: MM THEY JUST [???]

Patient: They're just apart ... they're just on the sideline. And he was worried, you know, he was frightened.

INT: WE USED TO DO A SURVEY, A COUPLE OF YEARS AGO WHEN I FIRST STARTED WITH BREAST CANCER PATIENT, LUNG AND COLORECTAL PATIENTS AS WELL, AND WE USED TO LEAVE THEM A QUESTIONNAIRE TO FILL IN AFTER THE INTERVIEW, AND SOME OF THE SPOUSES WOULD PICK UP THE QUESTIONNAIRE AND START READING IT AND IT WAS ASKING ALL ABOUT SORT OF, ER, PHYSICAL FUNCTIONING AND, YOU KNOW, ALL THIS KIND OF STUFF, AND THEY WOULD LOOK AT THEM AND THEN THEY'D SAID, 'OH, I DIDN'T REALISE IT WAS ALL AS COMPLICATED AS THIS, YOU KNOW, SO IS THIS SOME OF THE THINGS THAT YOU'RE GOING THROUGH?' BECAUSE OBVIOUSLY THE PERSON WAS FILLING IT IN, OR THEY DID IT TOGETHER, THEY FILLED IT IN TOGETHER OR SOMETHING, AND THERE'S ALL THESE QUESTIONS AND THEY SAID, 'NO, I DIDN'T REALISE YOU WERE GOING THROUGH ANY OF THIS,' ...

Patient: No, I don't think you, and I think things go through your mind that life's precious and that, I mean I do think mine's precious, always have done, but it comes home to you very hard and you suddenly think, I certainly felt, I'm never gonna take people or any thing for granted again, you know. You tend to think everybody's got a right to this and a right to that when in actual fact we haven't really, we just, erm, you know ... you don't appreciate, you don't appreciate what you've got until you think it might be taken away from you. And, you know, things like, I want something trivial like winning the lottery, and I said to my, you know, we were told, we often joked, 'Oh, if we won the lottery this ...' and, you know, and I said to Michael at the time, 'But if we won the lottery it wouldn't take this away. All the money in the world wouldn't take this away.' And you realise then how things that you thought were important aren't really important.

INT: YEAH, YEAH.

Patient: You know, things that you've taken for granted are probably much more important.

INT: YOU SAID YOU SPENT SOME TIME WITH THE BREAST CARE NURSE AFTER YOU SAW MISS STOTTER?

Patient: Yeah.

INT: IS THAT RIGHT? YEAH. CAN YOU TELL ME A BIT ABOUT THAT PLEASE?

Patient: Yeah, she just sat, that was the first time I actually cried, sitting in the waiting room, and I just, not much, only a bit, and, erm, and she came in and she was lovely, and she was very calm, very reassuring, very friendly, and she was explaining what would happen, physical things about going to hospital, going on the ward, and she was saying what a lovely ward it is and the staff were lovely, erm, things I wanted to hear, and which in actual fact were true, they weren't just a placebo they were actually very true. And that, you know, husband's would be welcome and she told us visiting times and what to take in and she things like take baggy, sort of baggy nightshirts, which I had to go out and buy, you know, because of the drains, and she said, erm, she told me about the drain and just general things like that and, you know, 'You might be uncomfortable, you might not.' 'You might not have to spend seven days in,' she said, 'You know, you might find it's five, and if you're really well we can let you out three or four ... we will let you out with one drain,' and just reassuring and, you know, 'Don't think of it as the end of the world' and [???

INT: DID SHE GO THROUGH THE TREATMENT OPTIONS WITH YOU AT ALL?

Patient: Erm, no, not really. I just said, 'Oh I'm sure I've made the right decision.' And she was reassuring, she said, 'Yes, you have, because Miss Stotter would have made sure you did,' you know, 'That if you made a treatment and she thought it was wrong, she would have ... you know'

INT: YEAH.

Patient: And so I had every conf- ... I knew I had because of the way Miss Stotter had reacted, but it was also, it was also reassuring to hear that, you know.

INT: YEAH. AND DID YOU HAVE ANY FURTHER CONTACT WITH THE BREAST CARE NURSES IN BETWEEN THAT MEETING AND THE ACTUAL SURGERY?

Patient: Well, they kept giving me their number and I was told 'You must phone up, you must phone up,' then I went to the pre-operative clinic and there was supposed to be a breast care nurse but I think somebody's been sick so I spoke to another nurse who used to work in breast care and she showed me the drain, which I was absolutely flabbergasted by at the time [chuckles] at the size of it, you know, I didn't realise they'd be bottles like that. And, erm, but again I was reassured and, erm, I actually saw Miss Stotter that day, she was just passing and she said, hello, you know, but everybody always said how, oh, you know, she was difficult, not difficult to work with, she's wonderful to her patients, knows her job ...

INT: WHO SAID THIS?

Patient: The nurses, you know, some of the nurses, but could be quite demanding, you know, because she had a professional code and a code of etiquette.

INT: MM, IT'S A BIG UNIT WELL.

Patient: It is a big unit.

INT: SHE'S GOT, 70-ODD PROFESSIONALS [???

Patient: That's right. But the breast care nurses that work with her said she was lovely, because you know where you are with her. And that's something to be said for that, you know, and, erm, and because they respected her and admired her which I do, you know, which makes, it's a big, erm, you know, you trust her.

INT: AND YOU GOT ON WELL WITH HER BY THE SOUNDS OF IT?

Patient: I did. Well, I did in the end, you know, I respected her, erm, I mean she came onto the ward on the last day and she said, erm, and I was there when she was doing her round before surgery in the afternoon, and she said, 'Anne, this is the first time I've seen you without your minder,' and I said, 'Yes, he's a work,' and she ... we laughed, and then when I went back for my results last week, erm, I went in and she says, 'Come on in, come in ...' she was very smiley, and I thought, 'Ooh ...' and then my husband opens, put his head round the door, because the nurses, at the clinic, [???] , they'd just gone in, you see, which you have to wait and 'I'll just see if she's ready,' you know. And, erm, and my husband poked his head round the door and they said, 'Her minder's with her, can he come in?' and she said, 'I didn't expect she'd be on her own,' you know, so there was that sort of joke and then she said, she just sat down and said, 'I've got excellent news, lovely news,' and she said, 'And I think you should have a bottle of champagne tonight,' that the tumour hadn't invaded and they'd managed to get it and I wouldn't need chemotherapy and [???] And she said, 'Why am I so surprised that you're happy?' you know, about the chemo?

INT: HOW MANY LYMPH NODES DID THEY TAKE? WAS IT TWO, DID YOU SAY?

Patient: sorry?

INT: TWO ... TWO LYMPH NODES, DID YOU SAY?

[? Something missing]

Patient: And then she said, you know, she just said, erm, asked me how I was feeling, and I said, 'Fine, just a bit uncomfortable,' and she said, well that would, you know, would wear away, and, erm, she explained the next treatment I was going to have ...

INT: WHICH WOULD BE?

Patient: Radiotherapy and she exp- ...

INT: AND HOW LONG WILL THAT BE FOR?

Patient: She said as soon as the ... how long would it be for?

INT: YEAH.

Patient: Five weeks for fi- ...

INT: FIVE DAYS ...?

Patient: Five days a week for five weeks.

INT: YEAH, SO IT'LL BE AT THE ROYAL, WILL IT?

Patient: The Royal. And she told me the name of the doctor I'll be seeing and I'll be seeing the doctor at Glenfield, and, erm, and she explained what would happen on the first visit and she said, 'Have you any questions?' and I said, 'Yeah,' I said, 'We have a family holiday booked ... well, it's not, my son has taken a house in France for two weeks with his wife and four children and my four daughters and I, and husbands and boyfriends, and the dogs were all going over for some of the time,' and she just said, 'Splendid, you must go.' And I said, 'Well, there's the radiotherapy treatment.' She said, 'Well, forget about that, we'll work round it,' either ... I think they like to do in the five-week block.

INT: BLOCK. THEY DO, YEAH.

Patient: So she said, 'Well we'll do it ...' you know, 'have it afterwards.' And I think possibly because, maybe because my, I've had the surgery and it's fine, probably there's not the urgency of somebody who's got to start, [???] chemotherapy, you know.

INT: YEAH.

Patient: And then she said, erm, she asked me to go in the other room and she wanted to look at the wound and she was pleased with it, very pleased with it. And then we talked about, I said, 'Because I'd had such a positive feeling about this experience, what could have been a very un-positive ...' I said, 'Not just, and I'm not talking about just because of the result, the result was lovely and obviously it was the best news we could hope for, and, erm, but because of the care I'd received,' I said, you know, 'my husband would like to do ...' and I said, my husband said, 'We have a charity each year, you know, at the school we

work for, and I'd like to make the breast care unit one of the charities,' and she was absolutely delighted, you know, and he asked her how could he, could we do, she's given us a contact name, the breast care nurse that was there, and then I said I would like my class to do something. So I said, 'It wouldn't be a lot of money, probably £100,' she said, 'Whatever you can, it's brilliant,' you know. So she was very, very pleased about that, you know.

INT: MM, YEAH, ABSOLUTELY. DO YOU THINK, I MEAN DO YOU FEEL THAT SHE LISTENED TO YOU, UNDERSTOOD YOUR NEEDS AND CONCERNS?

Patient: Yes, I do, I do.

INT: SOUND LIKE IT, YEAH.

Patient: In a very professional way, you know, I mean she wasn't sort of smarmy and ... she was really how I'd expect a professional, a consultant to be. Erm, I ... as a surgeon I would have the utmost faith in her and I think in a sense that's the important ... I means she wasn't, she wasn't, she hasn't got a warm manner, she was direct, but I think in the end that's better because I think if somebody starts sort of smoothing the path and saying, 'Well, you know, I've got something not very nice to tell you ...' I would start bells ringing and, you know, which she could have done. She could have said, '[???' we've found a little cancer ...' and I don't think, I would much prefer saying, 'It' a cancer but ...' you know, the way she said it, 'It's not a big one.' But, yeah, I do, I just feel very positive about the treatment I've had from them.

INT: AND, YOU KNOW WHEN YOU WERE TALKING TO THE BREAST CARE NURSE, DO YOU FEEL THEY LISTENED TO YOU AND UNDERSTOOD YOUR NEEDS AND CONCERNS?

Patient: Oh yes.

INT: YEAH?

Patient: Yeah. The breast care nurses were, you know, were brilliant.

INT: AT ANY TIME DID YOU GET THE IMPRESSION FROM EITHER MISS STOTTER OR THE BREAST CARE NURSES OR ANY PROFESSIONALS THERE THAT THEY SEEMED TO HAVE A PARTICULAR TREATMENT IN MIND?

Patient: No. I think, I think it was all individual, what an individual needed or what they found - even to discussing pain relief, you know, afterwards, you know, she said, 'The nurses will sort you out with pain relief,' and she said, 'Whatever you ...' you know, 'what you need,' and whatever I asked her, like the blood thingy, that was great, I got, you know, the time I asked, I used to ask what this is for, what's that for, and, erm, when it came to the pain relief they gave me paracetamol with dihydrocodeine and at first I kept saying, 'I've got a terrible headache,' just like that, I said, 'I don't know whether it's because it's hot' because it was a particularly hot week that week, and one of the nurses said, who actually, it's strange, because one of the staff nurses I, my eldest daughter was at school with her and I taught her, so I knew her, so that was another bonus. And she said, 'No, I think, Anne, it's the dihydrocodeine that's giving you headache.' She said, 'We'll leave it off and see what happens.' And the headache went, and then one of them said, 'Perhaps you need a stronger painkiller.' I said, 'No, I'm really OK on paracetamol.' She said, 'Well we can give you this other one,' and I said, 'Well ...' she said, 'Is there anything you can't take?' and I said, 'Well the only one I'm not very keen is Voltarol,' I said, 'I took it once and it just sent, everything went sort of ...' you know, the settee was sort of like that ...' and she said, 'Ah, that's the other painkiller we give.' IO said, 'Well I'd rather not.' [chuckles] So I didn't, so I just, I've just been on paracetamol which I've found have been

adequate, you know.

INT: AND DID YOU GET ANY, ERM, SORRY, DID ANY OF THE PROFESSIONALS HAVE A PARTICULAR PREFERENCE FOR ANY KIND OF SURGERY DO YOU THINK?

Patient: No.

INT: NO?

Patient: No, I don't ...

INT: [???

Patient: No, I really feel ... you mean any other cons-, what I picked up on the ward, talking to other people?

INT: ANY PROFESSIONAL YOU SPOKE TO, FROM MISS STOTTER, THE BREAST CARE NURSES, ANYBODY?

Patient: No, no.

INT: NO-ONE SHOWED A PREFERENCE OR ...

Patient: No.

INT: NO.

Patient: And I never really, I was never in the position where I said to them, 'Do you think I've chosen the right ...?' I never felt, I never felt I had to ask anybody that, which is, you know, my husband's just telling people, 'It's very unusual for Anne because she ...' I do, I am indecisive, I'm terrible, erm, but this time for some reason I just made up my mind and stuck to it, and I've never, ever felt it was the wrong decision even when I was [???] you know. I mean the people in the hospital ward, there was, erm, there was six in the hospital ward, two had got ... when I went in there was only two other ladies, one had had a mastectomy and it was actually her second, she was in her early 70s, she'd had a recurrence after 10 years; the other lady, I don't know what she'd had, she'd only ever had one drain so she had to have lymph nodes done. But then two other ladies came in and they both, were both going for mastectomies. But because, having talked to them, it was the nature of their disease ...

INT: RIGHT, OK.

Patient: ... and they said they'd had, you know, they'd had to have it done. One was a very sad case, you know, I did say to Miss Stotter I found it very humbling in hospital as well.

INT: MM. DID YOU GET ANY CANCER OR TREATMENT SUPPORT INFORMATION, LIKE A PACK OR LEAFLETS OR ANYTHING LIKE THAT?

Patient: I got a booklet about cancer support [???

INT: OK, AND DID YOU READ THAT?

Patient: I read it though, yeah.

INT: WAS IT USEFUL OR ANYTHING?

Patient: Yes, it was useful, but at the stage where I got it I didn't think at

the time that I, I probably needed it, because I went, it was basically when she said you had cancer and then the breast care nurse came and gave me the leaflets on cancer, and, erm, and looking at them, and I thought, there again, I think mine was coloured by my sister because I'd spent so much time with my sister and, you know, she talked about her cancer, that I was probably more aware than a lot of people are. But, having aid that, if I hadn't been aware, they were very informative, everything was really, you know, very good. And the leaflets they gave actually explaining what the various surgery was useful.

INT: AND IN BETWEEN THE SORT OF DIAGNOSIS AND YOUR ACTUAL SURGERY, DID YOU LOOK FOR ANY FURTHER INFORMATION ABOUT BREAST CANCER AND ITS SURGICAL TREATMENTS OR ANY, ANYTHING THAT FRIENDS, NEIGHBOURS, SENT YOU ANY BOOKS, MAGAZINES, ANYTHING ...

Patient: No, the only thing was my daughter went, was on the internet.

INT: RIGHT.

Patient: And she just found out this information and she printed it off for me.

INT: IS SHE DOING A MEDICAL DEGREE OR SOMETHING OR ...?

Patient: No, she works in the House of Lords actually. [chuckles]

INT: OH RIGHT.

Patient: But she was just happening to look on the site and she just happened, and this site told her about the different types of cancer, and so I think she was probably very worried which cancer it was, and of course when I told her what it was she was, well, delighted as much as, you know, you can be. So she found comfort from that she'd read up about it, you know. And she's the one that's actually said, 'Ooh, they might give you Tamoxafen,' she said, 'It's very good,' that she'd read the report on it. there must have been something come up in her job and she said, you know, 'It tends to be what, what they have,' you know. I know my sister was on it for a while but then she went on to something else because it wasn't suited to hers.

INT: IRIMADDEX [?]

Patient: Mm, yeah.

INT: WAS IT? YEAH.

Patient: But then, when my GP came last night he was telling me about Tamoxafen, about the oestrogen receptors and, but I suppose I haven't rally thought a lot about it at the minute because I don't know that I'll be having it, they're waiting for the, she hadn't got the hormone test back but she said it would be back when Dr [???] sees me.

INT: OH RIGHT, OK.

Patient: So, and then we'll discuss, you know. And they were very good when I asked how, you know, what about going to school, you know, and Miss Stotter said, 'It's going to be three weeks at least, you're not going to feel like it,' you know, 'You must get well.' That was fine, so I'm not going back this term.

INT: CONSIDERING THE SURGICAL SIDE OF THINGS, DO YOU THINK THAT YOU HAD THE AMOUNT OF CHOICE THAT YOU WANTED?

Patient: Yes.

INT: YEAH. AND WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD, THAT YOU HEARD, YOU READ, THAT HELPED YOU MAKE YOUR DECISION WHAT TREATMENT TO HAVE?

Patient: Well, it was listening to the consultant and the people in charge of me from, I was reassured from the first minute I went in that, whatever they found, was very small and unlikely to be invasive. That was the term they used, 'unlikely', but, I knew although they say it's [???] there could be a chance that it was, so I was basing my choice on the fact that it was unlikely to be, you know, invasive, or to have gone, or it could have started to invade, but it probably hadn't, or if it had they could, you know, and that if that was the case then my choice was going to be a lumpectomy. But if, you know, I wouldn't have been afraid to have said, 'Would a mastectomy have been better?' but I knew that, well I felt in my heart of hearts that the lumpectomy was the best for me and was what the people dealing with me agreed with as well.

INT: YEAH. ERM, AND YOU, YOU'VE GOT TO START YOUR RADIOTHERAPY YET, HAVEN'T YOU?

Patient: Yeah.

INT: THAT'S RIGHT, OK. ERM, NOW, LOOKING BACK FROM WHEN YOU FIRST DIAGNOSED UNTIL NOW, HOW DO YOU FEEL ABOUT THE CARE YOU'VE RECEIVED?

Patient: I think it's excellent.

INT: YOU THINK IT MET YOUR EXPECTATIONS?

Patient: Sorry? Oh, yes. Probably more because, as I said, when my sister talked about her first consultant, this lady ...

INT: MM, SHE SOUNDED VERY ...

Patient: She was very abrupt.

INT: YEAH.

Patient: And very matter-of-fact. Which Miss Stotter was, but in a different type of way, you know, I felt I could have, I'm sure if I'd have said to Miss Stotter, you know, [???] I can't believe he'd have come out like that.

INT: NO, NO.

Patient; You know.

INT: IS THERE ANY WAY THE TREATMENT, YOUR CARE, DIDN'T MEET YOUR EXPECTATIONS?

Patient: No.

INT: NO.

Patient: Not at all.

INT: APART FROM THE MAN WITH THE SMELLY BREATH.

Patient: Yeah. That was, I mean, I know it sounds stupid, but it really was ...

INT: YEAH, BUT THESE THINGS STICK IN THE MIND, DON'T THEY? THAT'S THE THING.

Patient: Yeah, that's really what I think, and my husband remarked on it because

he doesn't smoke, and he remarked on it. You know, he came into our hospital, the side room, and he'd also brought a coffee cup which he hadn't finished and he left the plastic cup down on my [??] which was one of these tall, slim things, and he sat down and then left it there, went out and left it there. But it was that, it was just the smell of the smoke which, you know, if you've been eating garlic or curry the night before, you've have said, 'Oh I've got to clean my teach, I'll stink all over my patients,' and yet to me the tobacco is ...

INT: YEAH, IT'S OFFENSIVE, ISN'T IT TO SOME PEOPLE? YEAH.

Patient: Very, mm. Especially if you're, you know, a bit panicky. The only thing, as I say, I went into hospital feeling well, came out feeling very sore. [chuckles] And then, I tell you when it did hit me, when I came home from hospital, I came, and I said to my, I got in the car and I was fine, and I said to my husband, 'I feel funny,' and on the Saturday morning I cried a bit because I think the enormity then had hit me, 'I've had cancer,' you know. 'I've got cancer ...' and then, and we said, 'No, no, I've had cancer.' But now I feel fine.

INT: IF YOU WERE, APART FROM THE MAN WITH THE SMELLY BREATH [CHUCKLES] IF YOU WERE TOLD YOU COULD CHANGE ONE THING ABOUT THE SERVICE AT GLENFIELD, WHAT DO YOU THINK IT WOULD BE? IF YOU HAD THE POWER AND MONEY TO CHANGE ONE THING?

Patient: I really don't know, because everyone was so kind and ... very caring, and I felt I got the best care. Like I said, we considered doing privately and there would have been absolutely no need at all.

INT: RIGHT.

Patient: No, I can't really see because I think I was dealt with very quickly from, you know, from the 4th May ...

INT: TO THE OPERATION, YEAH.

Patient: Mm.

INT: AND NOW 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?

Patient: Well I think they need to be told what it is and what the prog-, my reaction is the prognosis as well, 'What can I expect? What is going to happen to me? Am I going to die?' I think these are the questions because the word cancer, immediately people think death.

INT: YEAH, IT'S GOT A BIG CONNOTATION THAT WORD, HASN'T IT?

Patient: Whereas it probably, you know, it hasn't, I mean, my, you know, now, I, you know, my expec-, life expectance is probably just the same as the next person who hasn't had a breast cancer. But, erm, you know, you automatically assume that it', death, it's a word. So I think a lot, people need to be told, you know, you have to be straight with people and tell them what it is and to be reassuring as much as you can be, depending on what the cancer is.

INT: YEAH. AND WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THE OPERATIONS THAT THEY CAN HAVE?

Patient: Well I think basically what I was, you know, you should be told what operations are available and what treatment is available and that if you don't want the treatment you don't have to accept the treatment either, which is a big

shock when, you know, when she says, 'You don't have to have the treatment,' but I think, I would have thought 99 people out of 100 would say, 'I'm gonna have the treatment.' There's very few, although some people refuse treatment, don't they? Some people say, 'No, I'm not going to have the treatment.' Erm, I don't know how they can do that. But maybe people are frightened, maybe people are frightened of the surgery. As I said, it wasn't the surgery that frightened me, it was the anaesthetic, [chuckles] you know, and 'What am I gonna feel like?'

INT: YEAH.

Patient: Erm, and I think possibly the knowing that something's happening to you you know nothing about, you know, part of your life has gone, it's not like being asleep even, is it, you know?

INT: YEAH, I USED TO GET ANAESTHETIC WHEN I WENT TO THE DENTIST.

Patient: did you?

INT: YEAH, YEARS AGO, A COUPLE OF TIMES, I HAD AN ANAESTHETIC, THEY DON'T DO IT SO MUCH NOW.

Patient: No, they don't.

INT: ERM, BUT, YEAH, [CHUCKLES] IT'S STRANGE COMING ROUND AS WELL [???

Patient: Yeah, I can remember this face coming in and out when I was coming round, you know. I could hear the people talking and I was talking back, but, you know, it was like somebody else.

INT: YEAH. 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, ANY IMPORTANT POINTS WE HAVEN'T COVERED?

Patient: No, I don't think so. I mean it's just made me realise, I'd like to do something to help people, you know. I don't mean just fundraising, you know, either talking to people or perhaps my experience will help other people, because I certainly know that what I knew concerning my sister helped me an awful lot with going through this. And I just think sometimes you need, you know, don't get me the wrong, the breast care nurses were wonderful and so was the doctor, but sometimes I think you need to talk to people who've actually had a breast cancer or gone through similar things. You know, that's the ... and what, what else, because, as I said, when I said it was humbling in hospital, there was a woman there who'd found a lump in October, had been to a doctor's, lady GP, was told it was nothing, and she went back three times and then she ended up in Glenfield on Christmas Eve seeing Miss Stotter having an ultrasound and mammogram and they told her she'd got an advanced cancer. And I can't believe things, today, that goes on. And she'd had to have the chemotherapy to shrink the tumour before, [???, and then she had a mastectomy while I was in. And that sort of experience makes me feel humble, you know, mine's only a diddly little thing and ... and people like are, you know, experiencing things like that, which I think is ...

INT: YEAH, I HEAR [???,] STORIES ANYWAY DOING THIS KIND OF JOB.

Patient: Shocking.

INT: YEAH, AND SORT OF, I THINK THE QUICKEST I'VE EVER HEARD WAS SOMEONE FOUND A LUMP AND GOT OPERATED ON SIX DAYS LATER, YOU KNOW, JUST THE WAY IT ALL KIND OF WORKED OUT WAS VERY, VERY QUICK, ERM, AND THEN, YOU KNOW, YOU HEAR SOMEBODY, ONE LADY WHO HAD IT FOR A YEAR, YOU KNOW, IT WAS A LITANY OF MISTAKES THAT WERE

MADE, YOU KNOW, LIKE GP DIDN'T KNOW WHAT IT WAS, DIDN'T REFER HER, YOU KNOW, KEPT GIVING HER ANTIBIOTIC FOR MONTHS ON END.

Patient: You'd think they'd refer, wouldn't you, just because ...

INT: YEAH, WELL YEAH, I MEAN THE MOMENT HE SAID HE DIDN'T KNOW WAS THE MOMENT HE SHOULD HAVE REFERRED.

Patient: Exactly.

INT: THEN SHE MOVED TO A DIFFERENT AREA, THIS GUY, THEY LOST HER NOTES IN TRANSIT AND SO IT WENT ON.

Patient: It's frightening, isn't it?

INT: YEAH.

Patient: I mean the only thing I would say is, you know, people say, self-examination, examine yourself, it's important. But talking to Miss Stotter and everybody else, I wouldn't have found this till two years later perhaps.

INT: EXACTLY, YEAH.

Patient: And by that time it would have spread, and so I could have ended up with a mastectomy anyway.

INT: YEAH.

Patient: You know.

INT: AND YOU SAID THAT YOUR GP WAS A SURGEON, MR [???] IS THAT RIGHT?

Patient: [???], Dr [???]

INT: DR [???] WAS A SURGEON AT NOTTINGHAM, IS THAT RIGHT?

Patient: Nottingham City Hospital, yeah.

INT: RIGHT, OK. A BREAST SURGEON?

Patient: Breast surgeon, yeah.

INT: WHAT, HOW HAS HE BEEN WITH YOU THEN?

Patient: Brilliant.

INT: YEAH.

Patient: He actually, when my sister was diagnosed eight years ago he was quite new to the practice, but I went to see him for something routine, maybe a cough/cold or something, and, erm, I told him about my sister, we were just chatting, he's very, very friendly. And he said, 'Right, I'm gonna send you for a mammogram,' so I had my f-, and I said, 'No, I just want to check, you know,' and I went for my first mammogram, I would have been about 44, 45, and I had two maybe or three there, I went for three, they took me every year. And then they stopped because they'd said they'd, I'd had, it must have been two or three, and they'd said they'd been doing some studies and they didn't think that it was, well not genetic, but they didn't think there was any need for me to keep going annually because they didn't think she was close enough even though it was my sister. And then I said about my aunt, and they said my aunt wasn't, but, er, so

I didn't, and then I went back for my routine one three years ago, which was normal again, and then this was my second one once I've been 50. So, erm, you know, he was very much on the ball then.

INT: YEAH.

Patient: But of course, you know, studies change, don't they? They find genetic links, they find non-genetic links and, I mean this one, you know, Miss Stotter said wasn't, isn't genetic. I mean I think there's particular types of cancer that are genetic, aren't there? You know - from what I gather - I don't know. I'm not talking about breast cancer I'm thinking of other cancers, but it's very hard, I'm not very sure.

INT: I'M NOT A DOCTOR, MY BACKGROUND'S A PSYCHOLOGIST, I'M NOT ENTIRELY SURE ABOUT THAT, BUT IT SOUND ABOUT RIGHT I THINK.

Patient: Yeah, you know, so I was, so we stopped that, but he's always, you know, you can go and talk to him and when you have, or should I say, a smear test, I've been for that, and he's then said, oh, you know, he's examined breasts of people, you know ... and I would have been clear and never found anything, so I mean as he said, if I'd have, when I had the smear test, he wouldn't have found anything. And nobody would, so I just think I was lucky.

INT: IF THAT'S IT I'LL SWITCH OFF.

Patient: Yeah, that's fine.