

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: Low MR unit

*DATE:

*ID: Patient Patient53

*INTERVIEWER: DJW

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

Patient: I didn't know very much really because I've not had any involvement with anybody who's had breast cancer. Erm, I've got an aunt who had it 26 years ago but it's such a long time ago, technology's moved on so much, that really her experience I don't think's relevant to the situation now. So, I didn't really know much about it other than that there's so much greater success rate now than there used to be when my aunt had it. So I didn't really know a huge amount but things were definitely going in the right direction.

INT: SO YOUR AUNT, WHAT OPERATION DID SHE HAVE?

Patient: She would have had a mastectomy.

INT: RIGHT, MM. AND HAVE YOU HAD ANY FRIENDS AT ALL OR COLLEAGUES OR ANYTHING LIKE THAT?

Patient: No I've not had any friends or colleagues who've had breast cancer. I had a friend who had ovarian cancer and she died, erm, but no, I haven't got any friends who, or any connection with breast cancer whatsoever, so I knew nothing of it really.

INT: OK. ERM, SO CAN YOU TELL ME HOW YOU FOUND OUT THERE WAS SOMETHING WRONG?

Patient: Erm ... I wore an older bra one day that felt a bit uncomfortable and when I took it off I thought, it didn't quite feel right, so, I don't examine myself regularly - I hold my hands up, I don't - but because I felt uncomfortable I thought perhaps it had been digging in somewhere, so I felt it, I thought, 'I can feel something,' but I was on a period at the time and you know they say not to take much notice because you change around that time anyway, so I didn't take a lot of notice of it.

INT: SO WHEN WAS THIS, THEN?

Patient: Just after Easter. Er, at the time my father was in hospital, he was at Glenfield of all places, same place I went to, and I was running backwards and forwards every night to there and making sure my Mum got to visit him, take her home, sort things out for her, so I'd got a lot on my mind at the time. But around the time as I found it was around the time that Karen Keating died and there was a lot in the newspapers about ...

INT: OH YES, THAT'S RIGHT, YES.

Patient: ... her having fought it for seven years, and although I was busy at the time I mean I couldn't ignore it. So, when my Dad was on the mend, I made an appointment and went to the doctor.

INT: YOUR GP, YEAH?

Patient: Yeah.

INT: AND WHAT HAPPENED WHEN YOU WENT THERE?

Patient: Er, well, I made a point of seeing a lady doctor, erm, she was fantastic. She did an examination, said that there was something there that was palpable, I think her description was, she thought it was best to send me to Glenfield for some tests and that she was going to fax them that day and that I should hear something to get an appointment within two weeks. And that was on the Wednesday, on 5th May, and I got the letter come from Glenfield on the Saturday morning.

INT: OH RIGHT.

Patient: So she had literally got straight onto them.

INT: THAT'S RIGHT, YEAH. OH THAT'S GOOD.

Patient: So that she was first-class. I'd never met her before and I can't thank her enough for that.

INT: MM. AND THEN YOU GOT THE LETTER AND HOW SOON FROM GETTING THE LETTER DID YOU HAVE TO GO AND ATTEND THE CLINIC?

Patient: Erm, a week the following Wednesday, so it was exactly two weeks after I'd been to the doctors.

INT: MM. AND, ERM, I MEAN, OBVIOUSLY YOU MENTIONED KAREN KEATING AND SOMETHING BEING IN THE NEWS, I MEAN WHAT WAS GOING THROUGH YOUR MIND DURING ALL THIS TIME?

Patient: I was terrified to be honest. Erm, I didn't want to tell people about it 'cos I didn't want to worry people unnecessarily, so I didn't tell my parents ... told virtually nobody. Erm, my friend at work, she wanted to know what was wrong, she's one of these people that has to know everything - she could tell there was something not quite right, erm, and she insisted she wanted to go with me to the hospital, which meant I had to talk to the bosses to make sure that it was OK. I didn't think they'd let us both go out of the office together, but they were great. Erm, our manager, apparently his best friend is going through cancer at the moment and he's been very understanding, so those two knew and a couple of other people. Finally had to admit it to my brother just I went to the hospital because he was going through a hard time as well for some completely different issue, so there was only a handful of people knew really.

INT: RIGHT, OK.

Patient: But, it was a ... it's the not knowing, not knowing what you're gonna be facing and what, what the outcome's likely to be, you know, how bad is it, how far has it got, all these things to through your head and, especially when you've not really not anybody to talk to, you've got nobody to talk to who's been through it. And, er ... it was hell.

INT: AH, I KNOW, I CAN WELL IMAGINE IT. ERM, SO YOU, OBVIOUSLY THEN YOU HAD YOUR FIRST APP[OINTMENT AT THE CLINIC, CAN YOU TELL ME ABOUT THAT PLEASE?

Patient: Yeah, they were, I had the first appointment, it was quarter to nine, erm, I was in straight away. They, er, first of all they did the mammogram and they said, 'Yes we can see something ... there's definitely something there,' but not giving any hint at that point as to what they thought it was, just there was something there. Erm, went back and sat out, waited a bit, and then I had an ultrasound done. They again said, 'yes, we can see something,' erm, then the last thing they did, they did the core biopsy.

INT: YEAH.

Patient: Erm, I waited a bit longer and by half past ten my friend and I were called in, and they sat me down and didn't beat about the bush at all, they came in and says, 'Right, I have to tell you, Cheryl, it's not good news. You have got breast cancer,' ... just like that.

INT: YEAH, OK.

Patient: To which apparently I looked like a rabbit startled in the headlights, just ... stunned, like somebody had just shot me between the eyes. And then they went on to explain what it meant.

INT: YEAH.

Patient: Once I got over the shock.

INT: YEAH, IT IS, IT'S A MASSIVE SHOCK, ISN'T IT, REALLY? WHO WAS IN THE ROOM AT THIS TIME WITH YOU? THERE WAS YOUR FRIEND OBVIOUSLY ...

Patient: Erm, my friend from work ..

INT: YEAH. ERM, WAS THERE, WAS IT A CONSULTANT YOU SAW?

Patient: Erm, it wasn't the actual consultant. I don't know where Dr Denton fits into the hierarchy there, but she was, just one down from her or something. There was Dr Denton, erm, there was a breast care nurse in there. I think there might have been one other person in the room, I can't remember now to be honest.

INT: RIGHT, YEAH. SO IT WAS DOCTOR ELIZABETH DENTON YOU SAW?

Patient: That's right.

INT: SHE WAS THE ONE THAT BROKE THE NEWS TO YOU?

Patient: Yeah.

INT: YEAH. AND, ERM, AND THEN WHAT WERE YOU, YOU SAID YOU WERE STUNNED ...

Patient: Yes.

INT: WHAT'S, [???] YOU WERE FEELING AT THE TIME.

Patient: The next thing she did say, though, was, 'Let me start by saying you've done everything you could possibly have done.'

INT: RIGHT.

Patient: 'It's only small, it looks like we've found it early, plenty of people would have missed it, so you've got every chance of getting over this because you have done everything you could possibly have done.'

INT: AND HOW DID YOU FEEL WHEN SHE SAID THEN, THEN?

Patient: A lot better, [chuckles] a heck of a lot of better. Erm, knowing that she said it was a bit, it was small, she said about 2 cms, erm, said from the position of it, it shouldn't be a problem, I shouldn't, erm, be disfigured in any way by it. Erm, and generally made me feel quite a lot of better.

INT: RIGHT, YEAH, OK. AND THEN WHAT HAPPENED AFTER THAT THEN, WHEN YOU'D HAD YOUR DIAGNOSIS?

Patient: Erm, she was telling me obviously there's two different ways of treating it: either to do the wide local excision to just remove the lump and follow that up with taking the lymph nodes out to examine; or the mastectomy. Because of the position and where it was, she didn't feel it was gonna be necessary to do a mastectomy, not to worry that, erm, the lumpectomy and removing the lymph nodes, followed by radiotherapy, is equally as successful as having a mastectomy ...

INT: RIGHT.

Patient: ... there was no need to think that I was going to be in any less chance of recovering from it by having that than having a mastectomy ...

INT: RIGHT.

Patient: ... which was very reassuring.

INT: YEAH, AHA. AND, AND THEN, AFTER SHE DESCRIBED THE TREATMENT OPTIONS, WHAT HAPPENED AFTER THAT?

Patient: Erm, after she been through everything, she said it might be an idea to leave me alone for a few minutes, gather your thoughts and that, so, erm ... then I had a chat with the breast care nurse and she explained a bit more of what was going to be happening.

INT: RIGHT, WHAT DID SHE TALK ABOUT, DO YOU REMEMBER?

Patient: Erm ... basically went through, reassuring me as to what was gonna be happening and, erm, again saying about the wide local excision being a very good option and that, erm, you know, everything should be fine, but talked through in a bit more detail about everything, and very reassuring.

INT: YEAH, OK. [???] ERM, HOW DID YOU FEEL YOU GOT ON WITH DR ELIZABETH DENTON?

Patient: ... Well I didn't talk to her for very long, but ... how she put things was very good. Erm, I think straight to the point was probably better than beating about the bush: although it was a shock at the time, it probably was the best way to do it. But, as I say, following it up with the reassurance of 'You've done the right thing and everything should be fine,' erm, she was very nice. Erm, but me at ease, as I say, made me feel a lot better, and was very understanding.

INT: THAT'S GOOD. AND THE BREAST CARE NURSE - DO YOU REMEMBER WHO YOU SAW?

Patient: Her name was Sue.

INT: OH, SUE [???]... SHORTISH GIRL, DARK HAIR?

Patient; Yeah, yeah. Yeah, she was lovely, really was. Talked to you in not quite such a professional way as Dr Denton had, more, more familiar. Erm, and talked probably more in sort of layman's terms and more, more that I'd understand. Not that anything Dr Denton said was complicated at all, it was just the way Sue explained things made me feel a lot better. Erm, and she was very good and I saw her on a number of occasions, so ... I was very pleased with Sue.

INT: AND AFTER YOU HAD THAT CHAT WITH THE BREAST CARE NURSE, ERM, WHAT HAPPENED AFTER THAT? TAKE ME THROUGH THAT ... WHAT HAPPENED AFTER THAT.

Patient: Erm, she gave me a leaflet on the wide local excision and she asked did I want the leaflet on the mastectomy, and I said, 'Well I'll take it just in case they have to do anything later,' because they did say that, erm, if the results didn't come back as they hoped, that there's a possibility that they'd have to take me back in and do a mastectomy afterwards, but that they wouldn't, they wouldn't, erm, get me to sign a consent form and that I'd wake up and find it was gone, 'cos that was something that crossed my mind, if they find it's worse when they get in there, are they gonna go straight for that. And they said no, they don't do that.

INT: THEY USED TO DO IT YEARS AGO ...

Patient: Yes.

INT: [???

Patient: Yeah, they don't do that at all, 'cos I did ask about that. So, and she was very good at answering any questions I put to her. So she gave me the leaflet for that as well. Erm, basically spent as much time with us as we needed, erm, until we felt we were OK to leave and go and ponder.

INT: MM, YEAH. AND THEN WHEN WAS THE NEXT TIME YOU WENT BACK?

Patient: Erm, nine days later, and met the consultant.

INT: OH, THE CONSULTANT, YEAH.

Patient: Yeah, Miss [???

INT: OH RIGHT, YEAH, MISS [???, YEAH, GREEK LADY?

Patient: Yes.

INT: YES. AND SO TELL ME ABOUT THAT CONSULTATION, WHAT HAPPENED THEN?

Patient: Erm, she was very thorough, erm, she told me that there's three different types of tumour and from the results of the biopsy, erm, mine was the faster-growing variety, so that being the case and because I'm classed as young for breast cancer, that they would recommend that I had chemotherapy. Erm, which would probably only be as a precaution, but they felt that it was best to do that. So she explained all that. She drew some diagrams as to where the lump was in relation to my breast, and explained what would happen. I can't remember what else she said. She went through everything in quite a bit of detail.

INT: MM?

Patient: I've blanked now. [chuckles]

INT: OH, TAKE YOUR TIME, IT'S OK. SHE DREW YOU A DIAGRAM?

Patient; yeah.

INT: DID SHE, DID ...

Patient: [???

INT: DID SHE USE ANY OTHER VISUAL AIDS, LIKE, ERM, DID SHE SHOW YOU YOUR MAMMOGRAM? DID SHE SHOW YOU ANY PICTURES, ANYTHING ELSE?

Patient: No. She didn't show me anything like that.

INT: WHAT ABOUT, ERM, MISS DENTON, DID SHE USE ANY DIAGRAMS, PICTURES ...

Patient: No.

INT: DRAW ANYTHING?

Patient: No.

INT: NO?

Patient: No.

INT: OK. AND, ERM, THINKING ABOUT THE TIME YOU SPENT WITH MISS DENTON, IS THERE ANYTHING ABOUT THAT CONSULTATION THAT YOU DIDN'T UNDERSTAND WHAT YOU WERE BEING TOLD ABOUT YOUR CANCER OR YOUR TREATMENT OPTIONS?

Patient: No, because she was thorough in what she told me. And, as I say, it was put in a way that I could understand.

INT: RIGHT.

Patient: And then followed up by Sue in more general terms.

INT: MM.

Patient: So ...

INT: AND THE CONSULTATION YOU HAD WITH MISS [???], HOW ABOUT HER, WAS THERE ANY-, HOW MUCH DID YOU UNDERSTAND WHAT SHE WAS TALKING ABOUT?

Patient: ... Yes, she was, erm, very good in how she described things, as I say, and she backed it up with the little diagrams she drew, and she told me not to worry about it. Erm, it wasn't a very long consultation so there's not very much I can say about that. Erm, she told me that I could have it done in about 10 days time, but, erm, I'd got a trip to London booked that had been booked since January, so I put it to her, with it being fast-growing, was it going to make a difference to wait a week, 'cos they always have the surgery on a Tuesday, erm, and she said the fact that it was fast-growing meant that it had got to that size in a matter of months rather than years, so waiting a week wasn't going to make any difference ...

INT: RIGHT, OK.

Patient: So that she was quite happy for me to go and have a day out in London and enjoy myself, erm, and then come in for the surgery the following Tuesday, so it was like two and a half weeks' later she put me in for.

INT: RIGHT.

Patient: But she wasn't going to be there then because she was going on vacation.

INT: OH RIGHT, OK. AND DID YOU HAVE YOUR TRIP TO LONDON?

Patient: I did.

INT: AND DID YOU ENJOY IT?

Patient: It was wonderful.

INT: OK.

Patient: I went to see the Lion King.

INT: OH, RIGHT, OK. I'VE SEEN THAT.

Patient: Yeah, very good.

INT: YEAH. ERM, WELL I SAW, WHAT WAS IT, LAST [???] BEFORE LAST YEAR, I SAW IT. I'VE ONLY SEEN THAT AND PHANTOM OF THE OPERA.

Patient: That's the two I've been to.

INT: IS IT? AH RIGHT, OK. I WANTED PHANTOM OF THE OPERA BECAUSE I KIND OF, WELL I'VE GOT A, I'M A BIT OF A HORROR GEEK, TO BE HONEST, HORROR AND SCIENCE FICTION, [???] AND I TOOK MY MUM TO SEE THAT AND I THOUGHT TO MYSELF, YOU KNOW, THAT'S PROBABLY THE ONLY ONE I CAN REALLY SIT THROUGH, AND LION KING BECAUSE MY FRIEND'S GOT A LITTLE, TWO KIDS, AND I OFTEN GO ROUND TO HIS HOUSE, SORT OF THING, AND THEY'VE BOTH SEEN THE LION KING PERHAPS TOO MANY TIMES ON VIDEO, SO I THOUGHT, I WONDERED WHAT IT WAS LIKE ON THE STAGE REALLY. I WANTED TO COMPLETE THE WHOLE SCENARIO REALLY. ERM, BUT I REALLY ENJOYED IT.

Patient: Yeah, I did.

INT: YEAH, IT'S GOOD REALLY. AND I THINK WITH PHANTOM YOU SORT OF KNOW THE SONGS, DON'T YOU REALLY?

Patient: Yeah.

INT: SO IT'S QUITE FAMILIAR REALLY. THAT'S COMPLETELY BY THE BY ... ERM, YEAH, ERM, THE INFORMATION THAT THE BREAST CARE NURSE GAVE YOU, SUE, YOU SAID SHE GAVE YOU SOME LEAFLETS ...

Patient: Yeah.

INT: ... ABOUT MASTECTOMY AND WIDE LOCAL EXCISION.

Patient: Yeah.

INT: DID YOU READ THEM?

Patient: I did. Cover to cover.

INT: AND DID YOU FIND THEM USEFUL?

Patient; Yeah, yeah very useful. I mean it did go into details about the, erm, possible effects of having the lymph glands removed ...

INT: RIGHT, MM.

Patient: ... of the restriction of movement of the arm, that sort of thing, so I did read everything, so I sort of prepared me for what could happen, but I tried to focus on the positive side of it [chuckles] more than anything.

INT: THAT'S FAIR ENOUGH, I THINK. ERM, SO, YOU SAW MISS [???], DID YOU SEE THE BREAST CARE NURSE AFTERWARDS?

Patient: Yeah, yeah, Sue was there again.

INT: YEAH. AND DO YOU REMEMBER WHAT YOU SPOKE ABOUT THERE?

Patient: Erm ... I think we probably discussed, we did discuss chemotherapy actually 'cos I asked Sue what were the chances of me not losing my hair and she said, 'You're gonna hate but you will, it will go.' But, er, there's, 'Obviously, it's only because of your age that we're gonna be doing it, and it's like to make sure that it kills anything that might have escaped, so once you've had that you will be fine.' So ... and she also told me about something called the cold cap that they've been trying out on people so it might reduce the chance of losing my hair but ...

INT: I'VE HEARD THIS. I SPOKE TO A PREVIOUS PATIENT ABOUT THIS BECAUSE I'D NEVER HEARD IT BEFORE, AND SHE SAID, 'OH AND I PUT MY COLD CAP ON,' AND I SAID, 'YEAH, WHAT'S THE COLD CAP?' 'COS I'M NOT A SURGEON, YOU SEE, MY BACKGROUND'S PSYCHOLOGY. I SAID, 'COLD CAP? WHAT'S THAT?' SORT OF THING. AND APPARENTLY IT'S LIKE THIS COLD CAP WHICH THEY PUT OVER SOMETHING AND ...

Patient: Yeah, it's supposed to sort of like freeze your head so that it's not so affected by the chemotherapy.

INT: THAT'S RIGHT, YEAH. I'M NOT ...

Patient: [???]

INT: I DON'T KNOW THE TECHNOLOGY BEHIND IT.

Patient: I don't know how successful it. Apparently some people have tried and it's too cold and they don't try it again afterwards.

INT: OH RIGHT.

Patient: So, I might give it a go. I don't really want to lose my hair, [chuckles] so ...

INT: NO, I THINK THAT IS A BID CONSIDERATION WITH CHEMOTHERAPY.

Patient: Mm, it's taken me a long time to get my hair how I like it, and everybody likes my hair at the moment. It's like, 'Great, now I'm gonna lose it.'

INT: OH RIGHT. ERM, SO, DID YOU HAVE ANY CONTACT WITH BREAST CARE NURSES IN BETWEEN HEARING YOUR DIAGNOSIS FROM MISS DENTON, TO THE POINT WHEN YOU HAD YOUR SURGERY? AT ANY TIME DID YOU CALL THEM, DID THEY CALL YOU?

Patient: No.

INT: DID YOU DROP IN TO SEE THEM OR ANYTHING?

Patient: No. There really wasn't anything I was concerned about enough to need to contact them. Erm, and there was too many other things I was trying to get organised as well. [chuckles]

INT: OH YEAH, YEAH.

Patient: So the next time I saw Sue was the day I was admitted, the day before surgery she made a point of coming to see me and having a chat.

INT: SO WHAT HAPPENED ON THAT DAY WHEN YOU WENT FOR YOUR SURGERY?

Patient: The day of the surgery or the day I was admitted?

INT: WELL, SO THE DAY YOU WERE ADMITTED, YEAH.

Patient: Erm, Sue took me into a separate room, asked me how I was feeling, erm, and reassured me everything'd be fine, and she gave me a leaflet of exercises to do, erm, to strengthen my arm up and try and start them as soon as I felt comfortable to, and do as much as I could. Erm ... that was basically it. But a nice informal chat and, as I say, the leaflet was quite useful.

INT: MM, AND THEN HOW SOON AFTER THAT DID YOU HAVE YOUR SURGERY?

Patient: The following morning.

INT: OH RIGHT, OK. COULD YOU TELL ME ABOUT THAT?

Patient: Erm, well I suppose I must have gone down about nine o'clock, I think, and the next thing I remember was being wheeled back onto the ward at just after one.

INT: AND WHEN YOU WOKE UP, HOW WERE YOU? WERE YOU OK? WERE YOU SICK OR ANYTHING?

Patient; I wasn't sick when I got back onto the ward, erm, I was thirsty, was finding it hard to swallow [???] must have put a tube down my throat, but when I tried to drink some water - I mean this was sort of tea-time, must have been, by the time I was trying to drink some water, when I'd got my visitors there - and 'Oh dear, I'm going to be sick.' [chuckles] So I was sick a number of times, and then they decided they'd perhaps be best to give me an injection to stop that, [chuckles] so they gave me an injection in my arm and that got rid of that.

INT: OK. WHO WAS IT THAT DID YOUR SURGERY?

Patient: Miss Kenny.

INT: OH, FRANCES KENNY? RIGHT, OK. ERM, WHERE ARE WE ... WHAT, YOU KNOW, YOU MENTIONED THE CONSENT FORM, WHEN DID YOU SIGN THE CONSENT FORM TO SAY WHAT SURGERY YOU WERE GONNA HAVE? WHEN WAS THAT DONE?

Patient: ... I would imagine it was when I saw the consultant, I can't remember to be absolutely honest.

INT: WAS IT WITH MISS [??]? DO YOU THINK IT WAS THEN?

Patient: I would think it must have been then.

INT: AH RIGHT, OK. [??]

Patient: It's a bit of a blur that. [chuckles]

INT: RIGHT, YEAH, OK.

Patient: But I think it must have been then.

INT: MM. ERM, AND WHEN YOU WERE, ERM, TALKING TO MISS DENTON ABOUT WHAT OPERATIONS YOU COULD HAVE, WHO DO YOU THINK ASKED MOST OF THE QUESTIONS AND WHO DO YOU THINK DID MOST OF THE ACTUAL TALKING?

Patient: Erm ... I'd say probably Miss Denton did because I was in such a state of shock I really didn't know what to ask. I did ask some questions, I managed to get my head together to ask a few questions, but she sort of started the ball rolling and obviously said the main bulk of the information I needed, erm, and answered anything that I came up with afterwards.

INT: RIGHT, MM. AND WHEN YOU SAW MISS [???], A SIMILAR QUESTION, WHO DO YOU THINK ASKED MOST OF THE QUESTIONS, WHO DO YOU THINK DID MOST OF THE TALKING?

Patient: Well again she started off doing the talking and then asked me afterwards if there was anything I needed to know and, as I say, at that point I asked her whether it would hurt to wait a week and there were a few other questions I come up with at the time, so she basically told me all she needed to tell me first and then answered anything I needed afterwards.

INT: AND DID YOUR FRIEND GO WITH YOU TO THAT CONSULTATION?

Patient: Yeah.

INT: YEAH, OK. ERM ...

Patient: And she's very good at asking questions, so I knew if there was something that she thought of, you know, that I hadn't, she'd come out with it. So ...

INT: THINKING ABOUT YOUR TIME WITH MISS DENTON, DO YOU FEEL THAT SHE LISTENED TO YOU, THAT SHE UNDERSTOOD YOUR NEEDS AND ANY CONCERNS THAT YOU HAD?

Patient: I'd say so, yeah.

INT: AND WHAT ABOUT MISS [???], DO YOU THINK THAT SHE LISTENED TO YOU AND UNDERSTOOD YOUR NEEDS AND ANY CONCERNS THAT YOU HAD?

Patient: Yeah. Definitely.

INT: YEAH? DID EITHER ONE OF THOSE CONSULTANTS HAVE A, SEEM TO HAVE A PARTICULAR TREATMENT IN MIND?

Patient: ... I'd say they had in mind to do the wide local excision because they didn't, they didn't it feel it was necessary to do anything more invasive than that.

INT: YOU SAID THAT MISS DENTON ACTUALLY SAID THAT?

Patient: Yeah.

INT: YEAH, DID MISS [???] SAY ANYTHING THAT INDICATED THAT?

Patient: She didn't really discuss mastectomy because it rally wasn't necessary to do it.

INT: RIGHT, OK. AND WHEN YOU WERE WITH THE NURSE, SUE, ERM, YOU GOT ON QUITE WELL WITH HER BY THE SOUND OF THINGS ...

Patient: Yeah

INT: YEAH. ERM, DO YOU FEEL THAT SHE LISTENED TO YOU AND UNDERSTOOD YOUR NEEDS, YOUR CONCERNS THAT YOU HAD ...?

Patient: Definitely, yeah.

INT: OK. ERM ... LET ME SEE, WHERE ARE WE? HOW SOON AFTER HEARING YOUR DIAGNOSIS, THAT YOU HAD IT CONFIRMED THAT YOU HAD CANCER, HOW SOON AFTER THAT DO YOU THINK IT TOOK YOU TO MAKE UP YOUR MIND WHAT SURGERY TO HAVE?

Patient: ... I don't think it took me very long, to be honest. I mean I have no medical knowledge myself and they were so thorough at Glenfield with all the information they gave me that ...

[INTERRUPTION IN RECORDING]

INT: YEAH, SO ... YEAH, SO ... YEAH, WE WERE ASKING HOW LONG IT TOOK TO MAKE YOUR MIND UP WHAT SURGERY TO HAVE, THAT'S RIGHT.

Patient: I would probably say I decided within 24 hours.

INT: RIGHT, OK. AND WHEN DID YOU ACTUALLY GIVE THEM THAT DECISION? WHEN DID YOU TELL THEM THAT'S WHAT YOU WERE GONNA HAVE?

Patient: When I saw the consultant.

INT: MM, WAS THAT MISS [???]?

Patient: Mm.

INT: YEAH, OK. AND, ERM ... YOU WENT FOR THE WIDE LOCAL EXCISION?

Patient: Yeah.

INT: THAT'S RIGHT, YEAH. AND, ERM, DID YOU AT ANY POINT CHANGE YOUR MIND ABOUT WHAT DECISION YOU MADE?

Patient: No, I was happy with the decision.

INT: YOU WERE HAPPY WITH THAT, YEAH?

Patient: Yeah.

INT: OK. AND, YEAH, WHERE ARE WE, MAKING SURE I'VE GOT ALL THE INFORMATION [???]
OK ...

[???]

INT: IN BETWEEN YOUR, HEARING YOUR DIAGNOSIS AND YOUR SURGERY, DID YOU LOOK FOR ANY OTHER INFORMATION ANYWHERE ELSE, FROM BOOKS, MAGAZINES, VIDEOS, YOU'VE GOT A COMPUTER, IF YOU WERE ON THE INTERNET, ANYTHING LIKE THAT?

Patient: I'm afraid I didn't, no.

INT: NO, OK.

Patient: I probably should have done but no, I didn't.

INT: OH IT'S OK. DID ANY FRIENDS OR RELATIVES GIVE YOU INFORMATION OR ANYTHING LIKE THAT?

Patient: Erm ... as I say, I had an aunt who had surgery 26 years ago, erm, she told me to 'Keep a positive attitude and you'll be fine,' 'cos it's 26 years since she'd had it, so, erm, we tend to be quite positive in my family, so ... 'Just keep being positive and you'll be fine.' [chuckles]

INT: THAT'S [???] YEAH.

Patient: Erm, and there was also a lady at work who I didn't know has been going through it, she doesn't work in our department, but a friend in our department is a friend of hers and she went through the treatment with her, visited her in hospital and stuff, and it turned out she'd had exactly the same, the wide local excision, and she'd been through her chemotherapy, she'd just finished radiotherapy. Erm, and she'd come out the other side of it and she was fine. So, erm, she came and had a chat to me at work and I said to her, 'How's your arm? How can you move it?' and she went, 'Oh, it's fine.' So she put my mind at rest quite a lot. And she said, 'You know, if you need anything else, let me know, and I'll [???] too you.' So she offered to be there if I needed any other help.

INT: RIGHT.

Patient: So I did speak to her about it.

INT: ERM, AND DO YOU FEEL THAT YOU HAD THE AMOUNT OF CHOICE THAT YOU WANTED BETWEEN THE SURGERIES?

Patient: Yeah. I mean I didn't rule out having a mastectomy, erm, you know, if I particularly one then I could go for that, but when they said that it was going to be just as effective to not go that route, then I was happy to take their advice.

INT: MM, YEAH. AND, ERM, CAN YOU TELL ME NOW, YOU'VE HAD, YOU GOT TO THE POINT WHERE YOU'D HAD YOUR SURGERY, ERM, AND YOU'D COME ROUND FROM THE OPERATION, CAN YOU TELL ME WHAT HAPPENED AFTER THAT UNTIL ABOUT NOW [???] ?

Patient: Erm ... in what respect?

INT: JUST SORT OF FILL ME IN ON THE REST OF THE STORY SORT OF THING, BECAUSE YOU'VE OBVIOUSLY HAD YOUR SURGERY, HOW LONG WERE YOU IN HOSPITAL?

Patient: Erm, nine days altogether.

INT: OH RIGHT.

Patient: Erm, as I say, they did tell me that you have to stay in, erm, until the drain that presumably takes overflow from where the lymph glands are removed, I don't know exactly what that is but ...

INT: IT HAS TO BE AT A CERTAIN LEVEL OR SOMETHING, IS THAT RIGHT?

Patient: Yeah, it has to come down to a certain level, but that if it didn't come down to the level after a week they removed the drain anyway, it's not a good idea to leave it in for more than a week. So the longest I'd be in really would be the Tuesday after the surgery. Erm, and I just kept draining and draining for England - it was never anywhere near the level it needed to be come home.

INT: [???]

Patient: So ... I finally came out on the Tuesday.

INT: AHA.

Patient: By which time I'd been doing the exercises and was quite happy with how much movement I'd got in my arm and walking around the hospital and ... erm, was generally ready to come home by then.

INT: OH YEAH, ESPECIALLY IF [???] YOU WOULD BE.

Patient: Yeah.

INT: AND THEN DID YOU GO BACK AND SEE THE CONSULTANT TO GET BACK THE RESULTS OF THE HISTOLOGY OR SOMETHING?

Patient: That was yesterday.

INT: OH THAT WAS YESTERDAY. CAN YOU TELL ME ABOUT WHAT HAPPENED THERE, THEN?

Patient: Erm, well it started off with a discussion about, about what happened to me the night before, as it turned out, 'cos on the Tuesday night, erm, I went down with an infection.

INT: OH RIGHT.

Patient: I just put down the swelling in the area where I'd had the surgery, as just being post-operative swelling, but, erm, then I became very inflamed, felt very hot, shaking from head to foot and shivering, all at the same time. So I rang the breast care unit up and they said it sounded like an infection, because I hadn't a clue what was going on: I didn't know that was what it was. And they said if I was really worried, erm, I could call 999 and they could try and get me in to Glenfield or I'd end up going to the Royal Infirmary, erm, but they said, 'There is a bed on 23A,' but unfortunately this is where Glenfield didn't particularly cover themselves in glory because when the ambulance got here and tried to find out if there was a bed nobody knew anything about it. They couldn't confirm there was a bed and they ended up taking me to the royal Infirmary.

INT: BREAKDOWN OF COMMUNICATION?

Patient: Yes.

INT: [???] [CHUCKLES]

Patient: Yes. And then they confirmed at the Royal that, yes, it was an infection, so I was basically told off by the doctor for wasting ambulance resources and calling 999 for some, for 'a bit of breast inflammation'. So ... I wasn't happy about that.

INT: I DON'T THINK ANYONE WOULD. THAT'S TERRIBLE FOR THEM TO SAY THAT.

Patient: Mm. And so they gave me some antibiotics and I had to get a taxi home, erm, which cost quite a lot of money, and then headed off for my appointment yesterday morning, with no sleep whatsoever. [chuckles]

INT: OH DEAR. AND WHO DID YOU SEE YESTERDAY?

Patient: I saw Miss Kenny yesterday.

INT: OK.

Patient: And so she obviously read the notes, 'cos I gave her the letter they'd given me at the hospital, and said, 'Oh dear, what's been going on?' was very concerned and apologetic that there was a breakdown of communication and that I'd been treated in that way at the Royal and, erm, examined it, said, yeah, it was an infection, and that the antibiotics would get rid of that so not to worry about it. I'd done the right thing regardless of what anybody else had said. Erm, she then went on to check my stitches, said they were obviously healing well, erm, checked to see if there was any fluid build-up, because the Royal had said that there wasn't. She couldn't feel anything but thought she was best to perhaps try a syringe just in case anyway, and there was, so she aspirated an amount of liquid off, which eased it quite a bit. Erm, and then told me the results.

INT: RIGHT, AND ...?

Patient: Which were that the lymph nodes were clear.

INT: OH.

Patient: So ... good news.

INT: VERY GOOD NEWS. YES, THAT'S GOOD. HOW DID YOU FEEL WHEN YOU HEARD ABOUT THAT?

Patient: Wonderful.

INT: YEAH.

Patient: Erm, and she said because the tumour was so close to the skin there wasn't anywhere for it to spread to where it was and the lymph nodes being clear was an important thing. Again confirmed that because of my age and the type of tumour that I did have to have chemotherapy. I should get an appointment through in the next two weeks to see the oncologist, erm, and then obviously he'll tell me what I've got to go through and when it's gonna start.

INT: WILL YOU HAVE TO GO TO THE ROYAL FOR THAT, THOUGH?

Patient: Yes, unfortunately.

INT: OK. I'VE HEARD THAT BEFORE, [???

Patient: And [???

INT: SO YOU DON'T KNOW WHEN THAT'S GONNA START?

Patient: until I get the letter, no.

INT: UNTIL YOU GET THE APPOINTMENT WITH THE ONCOLOGIST.

Patient: No, so I've got to get the appointment first and then he'll tell me when it's gonna start. So it's going to be at least a couple of weeks I would think yet. They also said that they'll, erm, see me in six months' time, erm, and after that they'll see me every year and I can have a mammogram every two years separately from the appointments for the check-up every year. Erm, and they'll do that for at least five years, the check-up. So that was about it, I think.

INT: ERM, THINKING ABOUT YOUR DECISION ABOUT WHAT SURGERY TO HAVE, WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD OR THAT YOU READ OR THAT YOU HEARD THAT HELPED YOU MAKE YOUR DECISION TO HAVE THE WIDE LOCAL EXCISION?

Patient: That that was likely to be the most successful type of operation to have and that there was no need to have anything more drastic.

INT: AND THAT WAS FROM THE CONSULTANT?

Patient: Yeah.

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

Patient: First-class.

INT: MM. DO YOU THINK IT'S MET YOUR EXPECTATIONS?

Patient: Definitely.

INT: YEAH?

Patient: As I say, right from the doctor contacting them straight away, through to ...

INT: SHE WAS VERY GOOD THAT, VERY ACTIVE ABOUT THAT, WASN'T SHE?

Patient: Yeah, because I've heard some horror stories since then about other people at other practices, but, erm, but yeah, from going to Glenfield, I think being well informed was the most important thing really, giving you all the information and all the options, and, erm, reassurance that, you know, what they were suggesting would be successful. And they also did mention that, I think they've got something like a 76 per cent success rate, or survival rate, I'm not sure how they termed it, and they are one of the best places for treating breast cancer, so I'd no reason to not go along with their advice. As I said, they did inform me of everything.

INT: YEAH. WAS THERE ANY ASPECT OF THE TREATMENT, ERM, OR CARE, THAT DIDN'T MEET YOUR EXPECTATIONS?

Patient: No, I can't say that there was, no.

INT: AND IF YOU WERE TOLD THAT YOU HAD THE POWER AND THE MONEY TO CHANGE SOMETHING ABOUT THE SERVICE AT GLENFIELD, ABOUT THE SERVICE THAT YOU WENT THROUGH, WHAT WOULD IT BE, DO YOU THINK? WE ALWAYS KEEP THE HARD QUESTIONS TILL LAST.

Patient: Mm ... that one wasn't on the questionnaire you sent out. [chuckles]

INT: NO, A COLLEAGUE SUGGESTED THAT, WHEN WE WERE DESIGNING ALL THIS, IT CAME UP RIGHT AT THE VERY END AND WE THOUGHT IT'S SUCH A GOOD QUESTION WE'LL PUT IT IN ANYWAY AT THE END.

Patient: So what could I change about the service I've had.

INT: YEAH.

Patient: I mean the thing that I would change wouldn't be really on that side of things, it'd be for more people to get checked out at an earlier age, because if I hadn't have found it, I'm too young to be part of the mammogram scheme and, being fast-growing, if I hadn't found it I don't know what my chances could have been.

INT: MM.

Patient: So I think they should try and put more money into that so that there's early diagnosis, because the earlier you find it ...

INT: PREVENTION RATHER THAN CURE.

Patient: ... the better ... yeah ... the better chance you've got of ...

INT: ABSOLUTELY, YEAH.

Patient: ... of curing it.

INT: YEAH, I THINK, I MEAN I THOUGHT THAT WAS QUITE REASSURING FOR YOU WHAT ELIZABETH DENTON SAID TO YOU ...

Patient: Oh yes, definitely.

INT: YEAH, TO SAY, TO SAY YOU'D DONE EVERYTHING RIGHT.

Patient: Yes, yeah, because that was, that was the first thing she said after I'd, you know, been told the news. 'Let me start with saying you've done everything you could possibly have done.'

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

Patient: Being given the right information and being absolutely frank, I think. Erm, because I think what's it hit you, you've got that diagnosis, you need to know exactly what you're facing, because once you know then you can figure out how you're going to handle it. So I think being absolutely straight about it is very important.

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

Patient: Erm ... again I would say being informed of what the best outcome's gonna be according to what surgery you choose. Erm, I mean obviously in some families there's a history of breast cancer, then somebody might prefer to go for a mastectomy as a precaution anyway, so obviously the option's got to be there. So as long as the information you're given is right about the options that are there, then that's fine.

INT: ERM, A 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? ANYTHING THAT WE HAVEN'T COVERED, DO YOU THINK?

Patient: ... I think we've covered it pretty much from start to finish.
[chuckles]

INT: YEAH.

Patient: No, it's a very thorough questionnaire. Erm ... I don't know, I think the two most important things is early diagnosis and the right information.

INT: RIGHT. OK, IF YOU'VE FINISHED, I'LL SWITCH OFF.

[End of interview]