

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)
*VENUE: High MR unit
*DATE:
*ID: Patient32
*INTERVIEWER: DJW

INT: THANK YOU VERY MUCH FOR BEING INTERVIEWED. I WANT TO START WITH QUESTION ONE WHICH IS, CAN YOU TELL ME A LITTLE BIT ABOUT WHAT YOU KNEW OR UNDERSTOOD ABOUT BREAST CANCER BEFORE YOU REALISED SOMETHING WAS ACTUALLY WRONG WITH YOUR BREAST?

Patient: Well I didn't know anything about breast cancer first of all only what you read in the magazines and what people talk about, that's all. I did have a scare about 15 years ago, erm, I did actually feel a lump. I went to the doctor and he sent me to a specialist and I was told that it was just my breast maturing nicely, so that was it, and it did actually go down, so they were right. But other than that, you know, you just examine yourself and that's it. I didn't really, I didn't really think of anything happening to me, like having breast cancer, it was just ... not on, just didn't think about it. Because I didn't even, well I didn't even know anybody who had breast cancer at all.

INT: OH THAT WAS MY NEXT QUESTION, DID YOU HAVE ANY FRIENDS OR FAMILY ...

Patient: No, no, nobody.

INT: NOBODY?

Patient: No, you just read about these things happening and, no I didn't have any contact with anybody who had actually had breast cancer.

INT: OK.

Patient: I mean I used to go for the mammograms every three years I think it is and I just expected the letter to come through that says everything's all right, which it did every year, every time I went. And, but it didn't do this time.

INT: RIGHT. SO DID THEY FIND SOMETHING ON THE SCREENING?

Patient: They did, yeah.

INT: OH, OK.

Patient: Erm, I didn't feel a lump at all, there was nothing, nobody, even the specialist didn't feel anything, it was a very, very tiny thing, it came up on the breast screening. One of the girls from work went, erm, I was the first one to go, and they all had their results to say everything's fine, you know, and I didn't have my results and they kept me asking me and I'd say, 'No, I haven't got anything,' and I just knew then there was something wrong. I just felt there was something wrong, [???] there was. And then I had a letter from the hospital to say come and have another x-ray, er mammogram, and it showed up there, that tiny little lump.

INT: RIGHT, OK. AND CAN YOU TELL ME ABOUT THAT TIME THEN FROM WHEN YOU REALISED THERE WAS SOMETHING WRONG AND YOU HAD THIS LETTER UP TO THE POINT WHEN YOU WENT TO HEAR ABOUT YOUR RESULTS? WHAT HAPPENED DURING THAT TIME?

Patient: My whole life turned upside down, absolutely. Erm, from having, because I am a very fit person. I mean I swim twice a week, we go walking at the weekends, and you just think you're invincible, I think that's what it is. And

having something, breast cancer, I mean, it's not as bad as it was years ago but it's not a thing that you, you can't talk about these days, but, it just turned my whole world upside down. I just couldn't think about anything else. I've a very supportive husband, and my kids, I just didn't want to tell the kids until I knew something definite. And that, I think that three weeks of my life, were the worst three weeks of my whole, of all of my life. I never want to go through that again. It was terrible.

INT: YEAH. SO FROM WHEN YOU GOT THE LETTER TO SAY TO GO BACK FOR A SECOND MAMMOGRAM, TO THE ACTUAL TIME WHEN YOU WENT TO HEAR ABOUT YOUR DIAGNOSIS, HOW LONG WAS THAT?

Patient: It was about four weeks.

INT: ABOUT FOUR WEEKS, YEAH.

Patient: Yes, because they gave me, I went in for the mammogram, the second one, and I had a biopsy taken, and they told me to come back in a fortnight, and the day before I was supposed to go back they rang me at work to say that the pathologist needed another week to, erm, for another test on some shading or screening or [???] and well, after gearing yourself up to going the next day, and you know you're put back for another week, well, oh, well I was wanted, I couldn't cope with that. I can manage, I can accept everything as long as I know what it is, you know, you can adjust, I think you can adjust to anything, but not knowing. The day after I rang this lovely, they're love people these people, I rang this breast care nurse and I said to her, I explained how I felt, that I can't wait another week, I really can't wait another week, I need to know what's happening. So she said to me, 'Well, I'll have a word with the pathologist and I'll ring you this afternoon,' which she did pathologist just needed two days and I had an appointment in the afternoon of the morning that he would have completed his tests. So that was brilliant, so I went on the Thursday afternoon.

INT: YEAH, THEY'RE VERY HELPFUL THERE [???]

Patient: Ah, they bend over backwards to help you. I think it's because they realise, they do know what's happening, you know, you're just on the edge of a cliff all the time, just, you know, are you going to jump or what? It's a terrible, terrible thing, you can't explain it to anybody really.

INT: SO CAN YOU TRY AND EXPLAIN IN A LITTLE BIT, IN SORT OF A BIT MORE DETAIL ABOUT WHAT WAS ACTUALLY GOING THROUGH YOUR MIND AT THIS POINT?

Patient: Well, I think you're fighting to keep away this thought of, er, there's something really wrong here. You know there's something wrong because you've got a lump, you know you've got a lump because that's why they've sent, that's why they've sent you, well asked for you to go back. And you're thinking to yourself, 'Well, maybe it'll be all right, maybe it'll be OK,' these, your friends are telling you, 'Oh, there's nothing to it, I went and they found a lump and it was nothing at all, and it was just left,' and you just think to yourself, 'Well maybe that's it.' But something in the back of my mind it isn't, it isn't, there is something wrong. And I knew there was something wrong. I can't say how I knew but I just did know.

INT: AND DID YOU ACTUALLY THINK IT WAS A BREAST CANCER?

Patient: Yeah, because, this may sound silly, I'm a Roman Catholic and, erm, well I don't know what your views are on religion, but I have a special relationship with God, and I talk to him now and again, you know. And it's happened to me before, you just, I ask him questions and I have, and it goes to me. And I just knew that there was something wrong, but even so you're just

hoping that you might be wrong. So, er, and people are telling you all the time, 'Don't worry about it, you'll be fine, you'll be fine.' Phew, I know I'll be fine but I know there's something wrong.

INT: BUT THEN THEY'RE TRYING TO BE SUPPORTIVE.

Patient: Ah they are trying to be supportive, of course they are, that's what, you know, I've got so many wonderful friends, and you really do find out who your friends are, and I've found out who mine are and I've got so many wonderful ones, and I'm so grateful for that. But, erm, it's just, it is the worst period of your life. Terrible thing.

INT: MM. AND DID YOU TALK ABOUT YOUR INITIAL THOUGHTS AND FEARS AND THAT TO ANYONE?

Patient: I did, to my husband. And to my daughter, my sister, who then, you know, the more you talk to people, erm, the more you find out 'That's just what happened to So-and-So, and she had a breast cancer, I think it was ten years ago, and she's had the all-clear,' and then somebody else says, 'Ah, that's just what happened to Auntie So-and-So, and she's fine, you know, that was ten years ago ...' so the feeling of 'it could be breast cancer' sort of is a little bit not so terrifying because you know it's happened to other people that people who are close to you knew or know - in spite of the fact that you don't know anybody who's had breast cancer. It still didn't help very much.

INT: NO, NO.

Patient: I did a lot of crying and a lot of ...

INT: YEAH, I CAN IMAGINE.

Patient: ... you know, and I think that's a necessary part of it. I think you've got to, you've got to show people how you feel as well so they can be supportive to you. I don't think you can take it inside, all of it, you know, I try to be very strong for the kids. I wanted to wait until I knew something was really wrong until I told my daughter, who I'm very close to. But I couldn't wait, I just had to tell her that, you know, I'd got to go.

INT: SO YOU TOLD HER BEFORE YOU WENT?

Patient: Yeah.

INT: AND HOW DID SHE TAKE IT?

Patient: She was very, very, very positive about everything. Then she told me about friend whose mother had had the same thing and ... you know, it sort of makes you realise that other people out there have had this lump inside and it's not as devastating as you think it is. But then it's happening to you and, you know, this hasn't happened to you before.

INT: NO, OF COURSE. DID ANY OF THE DOCTORS OR NURSES GIVE YOU A CLUE OR A HINT ABOUT WHAT THE DIAGNOSIS MIGHT BE BEFORE YOU WENT?

Patient: Well the radio-, this lovely radio-, what is it, radio-?

INT: THERAPIST.

Patient: No.

INT: RADIOGRAPHER.

Patient: Radiographer, erm, when I went back for the second mammogram, she showed me the little lump, I had a look at the x-rays, and she said it was a shading round the, there was shading round the edges that they were concerned about. And nobody actually said anything about it being breast cancer, it was a lump there that needed looking at, and then I went and had the biopsy, and they were all telling me about what was gonna be happening but nobody actually said - well they couldn't really tell me anything until the results came through anyway, could they? So, erm, no. It was just, waiting, waiting to hear the actual results of the biopsy and then everything was going to be taken from there.

INT: AND DID YOU AT THIS POINT, IF YOU THOUGHT IT WAS CANCER, DID YOU HAVE ANY THOUGHTS ABOUT WHAT YOU MIGHT DO ABOUT IT IN TERMS OF YOUR TREATMENT, SURGERY OR ANYTHING LIKE THAT?

Patient: No, because I didn't know what was open to me at that time until I'd actually seen the specialist.

INT: OK. WELL, SO THEN WHAT HAPPENED WHEN YOU WENT TO THE CLINIC TO HEAR YOUR DIAGNOSIS AND YOU WERE TOLD THAT IT WAS A CANCER? WHAT HAPPENED THAT DAY THEN?

Patient: Right. Erm, well we had a nice old wait, as you usually do, let's face it, and you sit there and you're full of thoughts, you know, you try to make polite conversation with everybody sitting round, you know, and you're thinking to yourself, 'She's got the same problem,' and you're trying to make light of everything because ... and then there's a lull in the conversation and you just sort of go back into it. 'Oh God, I wish I could not be here,' you know, not be here, or get on with it; I've got to be here so let's get on with it.

INT: HOW DID YOU ACTUALLY FIND THE CLINIC ITSELF, YOUR ENVIRONMENT THERE, WHAT DID YOU THINK?

Patient: Erm,, the staff were wonderful, I couldn't fault the staff in any way whatsoever. It is the waiting that's the worst part about it. It's always so crowded, there's so many people there. That's just the NHS, isn't it? It's so ... I feel so sorry for them because they are so busy. And then I went to see the specialist and he was very - I couldn't get over how frank he was, he was a great big fellow, ever such a nice face and very polite, shook hands with me and sat me down and 'Right, Mrs L-, ...' and he went straight to the point. He said, 'Right, OK, you have a very small breast cancer,' and he just carried on and I thought it might be a shock to have actually have heard it, but it wasn't, I just was so glad that it had actually been confirmed what I was thinking and that I knew where I was, and that I needed to be very positive about everything, everything was gonna be fine, and I was just trying to listen very carefully to everything he was saying and take it all in, because I know that when you hear something like that, I was told, you can't hear anything, you don't listen to everything.

INT: WHO SAID ALL THIS? WHO TOLD YOU ALL THIS?

Patient: Well people you talk to, it's amazing how many people say diff-, different things about this [???

INT: MAYBE IT'S TRUE, THAT'S EXACTLY WHAT THEY, THEY'VE TOLD HAS BEEN PERFECT.

Patient: Well, exactly.

INT: EVERY CANCER PATIENT INTERVIEWED SAYS THAT WHEN THEY HEAR THE WORD CANCER THEY DON'T REMEMBER A THING AFTER, WHAT THEY'RE TOLD AFTERWARDS.

Patient: That's right, yeah, that's what I'd been told, because it's such a big shock, it's such a major, such a major thing. So I was ready for it, I needed to hear everything, I needed to get through it all, and do everything I was told and that was it. So this chap [chuckles] just sat there and looked at me and I said, 'Oh, right. Erm, so where do we go from here?' and he told me, which I was, this was a shock, he told me I'd got two options. I could either have a lumpectomy or a mastectomy, and I thought to myself ...

INT: WERE YOU FAMILIAR WITH THOSE TERMS?

Patient: Yes, yeah, because I'd been reading all the bump that came through with everything, you know, and, erm, he said to me that, oh well I thought he was the, he's the expert obviously so he's the one that should say to me, 'Right, you're going to have a lumpectomy' or 'You're going to have a mastectomy,' not 'Which would you prefer?' And I said to him, 'Well, which do you think I should have because you know what's happening inside?' So he said, 'Well, it's entirely up to you. We can remove the lump that everything nasty that's around the area ...' which would mean that I would have to have radiotherapy for five weeks, 'Or you could have a mastectomy which will take everything away anyway ...' - that doesn't sound right just [???] 'but you wouldn't have to have radiotherapy.' So, well, you obviously can't decide that there and then, well I couldn't.

INT: NO, I DON'T THINK THEY EXPECT YOU TO.

Patient: But, having thought about it, to me there was no need to have thought about it any further than if you can get rid of everything with just having a lumpectomy then why go to the extremes of having a mastectomy - if they are sure that they can get rid of everything. I mean they're the experts, they should, they know what they're doing. So we took, we came home - well we then saw this lovely breast care nurse ...

INT: CAN I JUST BACKTRACK ON SOMETHING?

Patient: Yeah, sorry.

INT: WHEN YOU ACTUALLY WENT TO THE CLINIC AND THAT, I MEAN YOU WENT IN THE ROOM, WAS THERE ANYONE ELSE WITH YOU APART FROM YOU AND THE CONSULTANT?

Patient: Not first of all, my husband was there with me, he was there with me all the time, and then there was just Mr Sibbering, the three of us; and halfway through this lady came in, the breast care nurse.

INT: RIGHT, OK. AND DID YOU HAVE ANY EXPECTATIONS ABOUT WHAT YOU MIGHT BE TOLD OR WHAT WAS GONNA HAPPEN NEXT?

Patient: No, erm, no, because I didn't know, I just didn't know what was gonna happen next. I did actually wonder what she was coming in for, I thought, 'Flipping heck, what's happening now?' you know, it's just sort of a ... a shock when you see somebody else walking in. But then of course I realised, well, he's the specialist, he's a very busy chap, he needs to tell you what's wrong with you, and this nice breast care nurse goes into it in length when you need to ask all the question and, you know, that maybe you feel you can't ask the specialist, you can sort of open up to a lady who, erm, is obviously there for the job. And they are handpicked these ladies, I'll tell you that, they're wonderful.

INT: WHEN MR SIBBERING TOLD YOU THE NEWS ABOUT YOUR DIAGNOSIS THAT IT WAS CANCER, DID HE USE ANYTHING, ANY AIDS OR TOOLS SUCH AS DIAGRAMS, PICTURES ...

Patient: Mm, he drew a little ... when he told me about the lumpectomy he said, 'What we would do it ...' and he drew this little diagram of the lump, he said, 'That's your lump, it's a very tiny lump, and we would take out, cut out the area surrounding it, erm, and then we would take out a little bit of lymph nodes,' to see if they were affected or whatever. [???] So that was, he explained it very well, I understood everything. I think I was trying to listen too hard, you know, I was watching him, you know, sort of glaring at him. I thought, 'Phew, got to explain this properly.' So, yeah, he explained it very well indeed, I understood it.

INT: IT SOUNDS AS IF, IT SOUNDS LIKE ACTUALLY, WITH TALKING TO YOUR FRIENDS AND STUFF, YOU WERE ATUALLY VERY WELL PREPARED WHEN YOU WENT?

Patient: I think, yeah, that's, yeah. Do you know, all the way, all the way through this I was, to everybody else I was so calm and positive about everything, took it just ... but at home here I absolutely fell apart, with my husband. Oh, he took all of it, he was amazing. You go to work and you have to be, everybody's saying, 'How are you?' you know, 'Are you all right?' as if to say, you know, 'There's something really wrong with you.' And I thought, 'There isn't, and I know I'm gonna be OK.' So, but the real you comes out when you're at home.

INT: MM, OF COURSE, MM. SO THERE WAS YOURSELF IN THE ROOM, THERE WAS THE CONSULTANT, THE BREAST CARE NURSE CAME IN, AND THEN THERE WAS YOUR HUSBAND AS WELL, YEAH?

Patient: Yeah, and then ...

INT: SO HOW DID YOU GET ON WITH THE CONSULTANT IN THERE?

Patient: Very well, very well indeed, yeah. Yeah, he was very friendly, very down to earth and very frank, which I appreciated very much indeed. I don't, I don't want, I just wanted to know what was wrong and no pussy-footing about. And then ...

INT: WAS THERE ANYTHING YOU FOUND DIFFICULT TO UNDERSTAND OR TAKE IN WHEN HE WAS TELLING YOU STUFF ABOUT ...?

Patient: No, understood it all, took it all in.

INT: THAT'S ALL RIGHT.

Patient: And my husband asked a few, quite a few questions and he was very patient with us and understanding and was very good, I understood it all.

INT: AND WHEN YOU'D HEARD ABOUT THE TWO TREATMENTS, ERM, JUST YOU HEARD THEM DESCRIBED, DID YOU HAVE ANAY THOUGHTS ABOUT WHAT TREATMENT YOU MIGHT HAVE AT THAT STAGE?

Patient: Not at that particular time because I was, I was shocked that I'd been given a choice. And I wanted to talk to my husband about it because I didn't know how he felt about if I decided to have a mastectomy or why should we have a mastectomy if they could take all the cancer away with just a lumpectomy. So I needed to talk to him on his own at home here, which we did.

INT: AND DID YOU GET, DID YOU GET THE IMPRESSION THAT IT MIGHT BE, ONE TREATMENT BETTER THAN ANOTHER?

Patient: Erm, well, not really because, if they'd given me the choice, then they must have been, erm, very sure or quite happy about the fact that they could remove everything with having a lumpectomy, so, otherwise they wouldn't have given me the choice, it would have been a mastectomy and that's it. So, it's quite a responsibility to put on your shoulders, actually [chuckles] that's what I thought. 'God, how can you do leave [?] to me?'

INT: YEAH. A LOT OF PEOPLE [???] CHOICE, THEY DON'T, YOU KNOW, THEY EXPECT THE CONSULTANT'S GOING TO TELL THEM.

Patient: Well that's right.

INT: BUT THAT, THEM DAYS ARE LONG-GONE NOW.

Patient: Yeah, yeah you see, I've never had an operation before, I haven't had anything like this. I've just been and had a smear test, you know, the usual things. Oh I did have some cancer cells many, many years ago that I had cut out, but I didn't, I've never had, I've never been put out with a general anaesthetic. And I think that probably one of the worst things because I'd never had anything like that before, and I was, I was absolutely petrified ... absolutely petrified.

INT: WELL, WE'LL COME TO THAT IN A MOMENT.

Patient: Oh sorry, yes, [???]

INT: WELL. SO, YOU'VE HAD YOUR DIAGNOSIS AND YOUR TREATMENT OPTIONS DESCRIBED, AND THEN THE BREAST CARE NURSE SO YOU, DID YOU SPEND SOME TIME ALONE WITH THE BREAST CARE NURSE AFTERWARDS?

Patient: certainly did, yeah.

INT: COULD YOU TELL ME ABOUT THAT THEN?

Patient: Yeah, we were taken to this little room and she was chatting to me all the time to sort of take my mind off things, you know, and that. Oh she was such a wonderful person, she was. And we sat down and she was talking to me about is there anything I wanted to ask or did I understand everything, and I think because I did understand everything, erm, I didn't need to ask her anything but ... I think because she was so nice - I find this, when people are very sympathetic towards me, it's the worst thing that can possibly happen, you know, it just makes me cry, which I did, I cried. And she was, she was actually on her knees, holding my hands, saying to me, 'Mrs L-, it's quite all right to cry, you know, because, you know, it's never happened to you before ...' this, that and the other ... but she was so nice. And she gave me all this literature and she was telling me about everything that was gonna happen and ... and I was, I was then a little concerned about when do I have to make my mind up about this mastectomy or lumpectomy, and she said to me that you didn't have to make it up, you don't have to make your mind up until the very last minute. So, which is another thing I wasn't quite sure about [chuckles] because if you don't make your mind up 'til the last minute, how do you, how does the specialist know what to do, you know, things like this just come into your mind, 'Well if it's not written down, how does he know what he's gonna be doing?' because I like everything written down.

INT: AND DID YOU HAVE ANY FURTHER CONTACT WITH THE BREAST CARE NURSE FROM THEN TO YOU ACTUALLY HAD YOUR OPERATION?

Patient: Yeah.

INT: CAN YOU TELL ME ABOUT THAT, WHERE IT WAS, WHAT YOU TALKED ABOUT?

Patient: Er, I went to see the physiotherapist, yeah, because, before I had my operation, that's right, and she was telling me that, what I had, all the exercises I've got to do, [???] and then the breast care nurse was there as well, and she gave me some information about, about the, erm, oh exercises and about the radiotherapy treatment, because I asked her all about that as well, so was giving me, I took home, I must have taken a great load of stuff home with me, weighed a ton, and I read it all. It was just ...

INT: WAS IT VERY USEFUL THEN, THE INFORMATION?

Patient: Oh, God, yes. I think the more information you can have about this kind of thing, is very helpful because, as I say, I didn't know, I'd no idea about breast cancer. And everything, everything you get is so informative, you know, all this literature is so informative, it's brilliant, wonderful. And they're always saying to you, 'If you've got any questions, give me a ring,' Veronica and, erm, who was the other one? Virginia, oh ... so lovely. So I did, I rang up a couple of times. What did I ring them for? About creams and this, that and the other and, yeah, very friendly and always put themselves out for you, they were always there. And it's so nice to know that there are people there that are looking after you because you're in a circle of people that, my wonderful husband, as wonderful as he is and he knows how upset I'd been and .. he doesn't know what's happening in here, you know, as the physical side of things, and it's nice to know that there are people that are supportive to you, they know what they're doing.

INT: YEAH, MM. AND WHILE, JUST GOING BACK A LITTLE, WHEN YOU WERE TALKING TO THE BREAST CARE NURSE AFTER YOU SAW THE DOCTOR THE FIRST TIME, AFTER YOU SAW THE CONSULTANT I SHOULD SAY, DID THE BREAST CARE NURSE USE ANY AIDS OR TOOLS, MAMMOGRAMS, PICTURES, DIAGRAMS?

Patient, No, no, I don't think so.

INT: OK. AND SO THROUGHOUT THE WHOLE CONSULTATION ON THAT DAY FROM WHEN YOU WENT TO SEE THE CONSULTANT THROUGH TO WHEN YOU LEFT THE BREAST CARE NURSE, WHO DO YOU THINK ASKED MOST OF THE QUESTIONS AND WHO DID SORT OF MOST OF THE TALKING?

Patient: Well I think we all did our fair share of it. The specialist first of all, of course, he was telling me everything that was happening. Then I was asking him questions about, well, why should I have a choice sort of thing, and this, that and the other, and he was going on about that. Erm, then my husband was asking a few questions and he was talking to my husband, explaining things as well. Erm, and then we went off with the breast care nurse and she was sitting down talking to us, asking us if we - well I have told you that - we understood everything, and we did. And it was ... and then just I was asking just sort of questions about going into hospital because I'd never been into hospital to have an operation, as I say, and I just wanted to know, because I was frightened, I was worried, I was petrified, absolutely, as I said before. So we all did our fair share of talking.

INT: OK. AND WHILE YOU WERE TALKING TO MR SIBBERING, DO YOU FEEL THAT HE WAS LISTENING TO YOU, THAT HE UNDERSTOOD YOUR NEEDS AND CONCERNS?

Patient: Yeah, yes, yeah. Yeah, he was very, he said to me, 'Do you need to ask any questions? Do you understand everything? and 'Are you sure you don't need to ask any ...?' he was very, he wanted to make sure that I had understood everything that was happening.

INT: AND THE NURSE, DO YOU THINK THAT SHE LISTENED TO YOU AND UNDERSTOOD YOUR NEEDS AND CONCERNS?

Patient: Yeah, yeah. [???

INT: DID YOU EVER GET AN IMPRESSION THAT EITHER ONE OF THEM HAD A PARTICULAR TREATMENT IN MIND [???

Patient: No, no. No, I did say to the breast care nurse, 'I don't understand why I've been given the option.' And she said because they feel that they can treat it either way so they can get rid of everything by having a lumpectomy or it's choice if you want a mastectomy. So I said, 'Well I can't understand why I'm given the choice ...' because, as I say, I always thought you have a lumpectomy or you have a mastectomy, you don't have a choice of what operation you have. So ...

INT: AND YOU MENTIONED YOU GOT SOME SUPPORT INFORMATION, YOU FOUND THAT HELPFUL.

Patient: Yeah.

INT: SO NOW YOUR ACTUAL SORT OF DECISION. YOU LEFT THE BREAST CARE NURSE AFTER YOU'D SEEN THE CONSULTANT, HOW LONG WAS IT BETWEEN THEN AND YOU ACTUALLY HAVING THE OPERATION? HOW LONG TIMEWISE, HOW LONG ...?

Patient: How long was it?

INT: ME [???

Patient: It was a fortnight.

INT: ABOUT A FORTNIGHT, YEAH.

Patient: 27th February, that's right.

INT: AND WHEN, AND WHEN YOU ACTUALLY HEARD ABOUT THE TWO DECISIONS, THE TWO TREATMENTS YOU COULD HAVE, WHEN YOU WERE TOLD YOU HAD A CHOICE, FROM THAT POINT TO WHEN YOU ACTUALLY MADE A DECISION, HOW LONG DO YOU THINK THAT WAS?

Patient: Er, the night I came home and talked about it to my husband I decided, erm ... no it wasn't, it was the night after, because my sister rang me. We talked, Brian and myself talked at home and he said to me, 'It doesn't matter to me, it's how you feel, if you want, whatever way you want to go I'm behind you anyway, it doesn't make any difference to me, you're still Anne and I love you ...' you know, blah, blah, blah. And my sister rang and her friend had breast cancer and I told her I'd been given a choice and we'd more or less decided what we were going to do. And she said that her friend had had the same, had a lumpectomy, which was ten years and she was clear, and that it was not as bad as you think it is. So I had more or less decided then I was just gonna have a lumpectomy.

INT: DID YOU AT ANY POINT CHANGE YOUR MIND OR HAVE ANY SECOND THOUGHTS?

Patient: No, no, not at all. Because I couldn't - I think I've said this before - I couldn't see the point in having a mastectomy if they could get rid of everything that was nasty without, with just having a lumpectomy.

INT: OK. I'D LIKE TO JUST MOVE ON A LITTLE BIT. ERM ... SO YOU CHOSE A LUMPECTOMY, CAN YOU TELL ME ABOUT WHEN YOU ACTUALLY WENT IN TO HAVE THE OPERATION?

Patient: Well I didn't ... oh dear ... yes, we went in to, what time we were there, I think it was 8 o'clock in the morning and they were, this was a real shock, there were five of us, five ladies with their partners waiting in this waiting room and that for two hours we didn't know whether we were going to be having our operation or not. We all had to come in at that time and we just, they didn't have any beds for us. We rang up first of all and, as you were told to do so, we did ring, and they said, 'Well we don't have one at the moment, but yes, come in. We don't like to keep ladies waiting anyway, so ...' I didn't realise there was gonna be anybody else in and I don't think the other ladies did either, there were five of us and none of us had a bed. Now I don't, you can't understand this, I know you can't, but after being geared up to going to have an operation on that particular day, and you've never had an operation in your life, erm, you are sitting waiting, you don't even know whether you're gonna have your operation on that day ... it was just awful.

INT: YEAH, HOW DID YOU FEEL ABOUT THAT?A

Patient: It was terrible. Inside you [chuckles] you're just so churned up and you're trying to talk to everybody, everybody's making like polite conversation, you know, they're all in for the same type of thing. One lady was having a mastectomy and reconstruction, and I thought, 'Phew, she's having a big job,' and she doesn't even know whether she's got a bed, and she might have to come back next week. Oh, that was horrible, it really was horrible.

INT: DID YOU TELL WHAT THAT WOULD INVOLVE, THE RECONSTRUCTION? BECAUSE I DIDN'T KNOW THIS UNTIL THE OTHER WEEK.

Patient: No. You actually have your breast off and there's, it's reconstructed there and then, isn't it?

INT: THERE'S TWO WAYS TO DO IT, I THINK YOU CAN GET IT DONE LATER ON I THINK. THE WOMAN I SPOKE TO WAS ACTUALLY UNDERGOING IMMEDIATE RECONSTRUCTION AND APPARENTLY THEY PUT SOME KIND OF A DEVICE THEY PUT INTO THE SKIN. WHAT THEY DO IS, IT'S ALMOST LIKE THEY SORT OF LIKE CUT AROUND AND I THINK THEY OLLOW OUT SOMETHING AND LEAVE SOME OF THE SKIN LEFT AND THEY PUT THIS DEVICE IN WHICH APPARENTLY STRETCHES THE SKIN. AND APPARENTLY WHAT THEY DO IS THEY STRETCH THE SKIN SO IT'S ONE AND A HALF TIMES THE SIZE OF WHAT IT USED TO BE ...

Patient: God, that sounds painful.

INT: I'M NOT SURE IF IT'S FULLY PAINFUL, I THINK IT'S UNCOMFORTABLE, THAT'S THE WAY SHE DESCRIBED IT. IT MIGHT BE DIFFERENT FOR DIFFERENT PEOPLE. AND THEY KEEP ADDING SALINE INTO IT ...

Patient: Oh, is that right?

INT: SO YOU NEED TO KEEP GOING BACK EVERY COUPLE OF MONTHS TO GET IT PUMPED UP. AND SHE WAS SORT OF ... I WAS SITTING ABSOLUTELY FASCTINATED, I HAVE TO SAY. ERM, AND THEN OF COURSE [???

Patient: It's marvellous what they can do, isn't it?

INT: YEAH, IT'S AMAZING. SO, ERM, YOU GOT A BED THAT DAY, DID YOU, OR NOT?

Patient: Oh we all got a bed.

INT: OH, YOU ALL GOT A BED, THAT'S GOOD.

Patient: But not in the wards that they said we were going to be in, but that wasn't a problem, it was nice that you had a bed. Yeah, so we all ... but, it

was an awful thing. The nurse would come in and she would call somebody and one of us would trundle out there, you know, leaving all the other four, and I'm thinking, 'Oh, I hope it's me next, I hope it's me next,' and then somebody, the nurse would come and you'd think, 'Oh, is it going to be me?' and then somebody else was called and you were left there sitting. Oh, it was terrible, and I felt, when I was, when I was called out I felt sorry for the other two that were left and I thought, 'Oh I do hope they get a bed,' but they did, everybody got placed, but you just didn't know. It was very upsetting at the time, because you can do without that kind of thing really. But, erm, they were just so busy. I can't believe how busy they were.

INT: AND THEN SO FROM WHEN YOU ACTUALLY GOT INTO THE HOSPITAL AND THEN YOU GOT A BED, WHEN DID YOU HAVE THE OPERATION?

Patient: It wasn't 'til the afternoon but I had to go ...

INT: WAS IT MR SIBBERING THAT DID THE OPERATION, WAS IT?

Patient: Yes, it was, yeah. I saw him first of all, yeah. And, er, I had what they called a needle marker put in, which wasn't very, it was not very pleasant, but it's a needle. Because the thing was so small, it had to be marked inside so a needle was put inside. Oh, I cringe at the thought of it now.

INT: NO, I DON'T LIKE NEEDLES.

Patient: It wasn't very pleasant. But I was left like that for, oh, quite a few hours, I didn't have any, I didn't have a drink or anything from 12 o'clock that, well, about 9 o'clock the night before, but they gave me a drink of water because I didn't have my operation 'til I think it was 2 o'clock. So I had to sit very still all the time from when it was put in, it was put in about half past 10 time. And I just had to sit there, it was terribly, it was horrible. And then they came for me for the operation.

INT: AND WHEN YOU CAME ROUND FROM THE OPERATION HOW DID YOU FEEL?

Patient: I felt fine. My whole body was shaking when I went down for that operation. But they were so, they were reassuring me, it was gonna be fine, you know. But you can't, it's very difficult to reassure somebody who just won't be reassured, because it's me, not them [chuckles] it's so difficult. I felt like a wimp, I really did, I felt like a [???] wimp.

INT: AND ERM, YOU'RE GOING, YOU'VE GOT TO RADIOTHERAPY NOW, IS THAT RIGHT?

Patient: Yeah.

INT: DID YOU KNOW YOU WERE GOING TO HAVE TO HAVE RADIOTHERAPY [???] ?

Patient: I knew I was going to have that, yeah, I knew that from the word go, yeah.

INT: RIGHT, OK. AND YOU SAID ALSO, YOU SAID YOU'D BEEN READING A LOT BEFORE YOU WENT IN FOR THE OPERATION. SO YOU SPOKE TO FRIENDS AND YOU OBVIOUSLY SPOKE TO YOUR HUSBAND ABOUT THE OPERATION ...

Patient: Oh gosh, yeah.

INT: ... AND YOUR FAMILY, AND YOU READ A LOT. DID YOU GET ANY INFORMATION ... WHERE DID YOU GET YOUR INFORMATION FROM THAT YOU READ?

Patient: From the hospital, from the breast care nurses and from, I just picked leaflets wherever I was in the waiting room about radiotherapy. I think perhaps I've got two or three of those. And just, it's amazing though how many people you talk to and ... now ... and they've had it all.

INT: DID YOU GET ANY INFORMATION FROM FRIENDS? DID THEY GIVE YOU MAGZINES OR BOOKS, LEAFLETS THAT THEY HAD THEMSELVES?

Patient: No, no.

INT: DID YOU LOOK ON THE INTERNET AT ALL FOR ANY [???]?

Patient: No, no I didn't go onto the internet, no. I had people ringing me up ... no, not people ringing me up, people saying to friends of mine who had had the same thing, give her my telephone number and tell her to give me a ring. And I did that, I talked to a lot of people who I'd never spoken to before, about the whole thing, they'd had, they'd had the same operation.

INT: OH RIGHT, OK.

Patient: And it did help to know how they, how it affected them and how they'd pulled through, everything was all right.

INT: THESE ARE ALL PEOPLE WHO HAD A LUMPECTOMY?

Patient: Lumpectomies, yeah, yeah, the same thing. There's loads of them. I spoke to about three of them.

INT: ON THE TELEPHONE?

Patient: Yeah, on the telephone. Mm.

INT: WHAT DO YOU THINK, LOOKING BACK NOW, WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD OR THAT YOU READ THAT HELPED YOU MAKE YOUR DECISION TO HAVE THE KIND OF OPERATION YOU DID?

Patient: Well, to me it was, for me personally it was just, it was just common-sense; it was, for my circumstances, erm, that was what right for me.

INT: RIGHT, YEAH.

Patient: I didn't need to read anything, I just felt that a lumpectomy would be sufficient for me, because I'm quite happy with going to radiotherapy, erm, whereas with a mastectomy you wouldn't have to go there, which I suppose could sway people an awful lot as well. Having said that, it's only the second time I've been, so I might feel differently at the end of five weeks.

INT: MM, IS IT EVERY DAY, EVERY WEEK DAY FOR FIVE ...?

Patient: Every day for five weeks.

INT: IS IT THE SAME TIME OR DIFFERENT TIMES?

Patient: Same time, oh twice I've got to the see the doctor and it's 9 o'clock. So, mm, and then you go to work it's, it is a bit difficult.

INT: AND LOOKING BACK ... SO YOU'RE STILL AT WORK ARE YOU?

Patient: Yeah.

INT: YOU'RE STILL GOING TO WORK, YEAH?

Patient: Yeah, full-time as well, ridiculous, isn't it? Mm.

INT: SO LOOKING BACK FROM WHEN YOU WERE FIRST DIAGNOSED UNTIL NOW, HOW DO YOU FEEL ABOUT THE CARE YOU'VE RECEIVED ON THE WHOLE?

Patient: Abs-, 100 per cent perfect.

INT: YEAH?

Patient: Wonderful.

INT: THAT'S BRILLIANT.

Patient: Everybody, the nurses, the little ladies who clean the place, they're wonderful people, absolutely ...

INT: AND HAS IT SORT OF MET YOUR EXPECTATIONS DO YOU THINK?

Patient: Ah, gosh, more, more, if it's possible. I've listened to a lot of people say what a dreadful National Health Service we've got, but if anybody says it to me again I shall stick up for them because I think they're wonderful people, they really are.

INT: THINKING ABOUT THE UNIT AT DERBY, DERBY CITY GENERAL, IF YOU WERE TOLD YOU COULD CHANGE ONE THING ABOUT THE SERVICE THERE, WHAT DO YOU THINK IT MIGHT BE?

Patient: Erm ... well there were two things really. It's that initial waiting, the 8 o'clock, arriving at 8 o'clock and sitting there for about two hours, that was terrible, that really was, and I think that should be, if there was a way to change that, that would be the one, number one. And number two I'd get rid of one of those nurses that was there - because I didn't like her.

INT: ONE OF THE BREAST CARE NURSES?

Patient: No.

INT: OH ONE OF THE CLINIC ...

Patient: One of the, I think she was a sister on the ward.

INT: OH ON THE WARD.

Patient: On the ward.

INT: OH, RIGHT, YEAH.

Patient: I was only in for three days, erm, and I had all this, because I've got a bit cut under here which has healed beautifully, but I had all padding and drains out of here, which was very sore. I had no pain whatsoever, there was no pain, never at any time did I have any pain, it was just a little bit sore that's all and uncomfortable. But there was a load of tape and padding under here, you know. And I'd had that on for two days and it was getting a bit sore so I thought I'd ask one of these sisters if she could just have a look to see if everything was all right. And [chuckles] she got hold of this plaster and she started to rip the damn thing off and I said, 'Oh, gosh, that's a little bit sore,' she said, 'Well it should be that sore ...' and I just wanted to turn round to her and say, 'Hang on a minute, it is sore: I've had this operation, not you, it's, I know it's sore,' and she just, she said, 'You take it off

yourself,' great big ... ethnic nurse, she wasn't very nice, didn't like that one so I'd change that one, I'd get rid of that one. But all the others were perfect, absolutely perfect, very caring and understanding.

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

Patient: All the information that they can have. They need all that. Well, that's what I needed, I needed all the information, and it needs to be there quickly, as quick as, as quickly as possible, because I think that's the worst part about it, all the waiting round not knowing.

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

Patient: Well there again, information. And I think thy need to know all the side effects and, er, well just information from the people that know what they're talking about really.

INT: ERM, I THINK WE'VE PRETTY MUCH COVERED EVERYTHING ACTUALLY, I'M TRYING TO THINK IF THERE'S ANYTHING WE'VE MISSED OUT. I DON'T THINKK SO. ERM ...

Patient: I think I've been waffling on enough now, don't you?

INT: YEAH, I THINK YOU'VE COVERED EVERYTHING, I THINK, YEAH. THE LAST QUESTION: IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY, ANYTHING YOU THINK WE'VE MISSED, ANYTHING YOU THINK MIGHT BE IMPORTANT, ANYTHING AT ALL YOU MIGHT WANT TO ADD?

Patient: No, I don't think so. I could do with the car parking fees being lowered a bit [chuckles]

INT: YOU ACTUALLY GOT A CAR PARKAING SPACE THEN?

Patient: Yeah, I had to queue up for them.

INT: IS THAT THE DRI OR AT ...?

Patient: The DRI actually, yeah, which is quite, which is better really from here. But it's still expensive, but ... it's just one of those things, isn't it? No I think that's generally it. I would like to say again how the staff are so wonderful, everybody that I've met, they've been so caring. I think they're special people, they really are ... absolutely ... I know I couldn't do it.

INT: OK.

[End of interview]