

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: Low MR unit

*DATE:

*ID: Patient46

*INTERVIEWER: DJW

INT: THANK YOU FOR AGREEING TO BE INTERVIEWED. I'D LIKE TO START OFF 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 WAS WRONG WITH YOUR BREAST?

Patient: Right. My initial knowledge of breast cancer came from mother, about 15 years she had breast cancer and I was the one that had to put most support in. Very advanced state when I found about it, she was, and went straight into hospital, had a complete mastectomy followed by radiotherapy treatment, and basically it's just been breast awareness from any sort of advertising, promotions or anything like that have been going on around me over the years. I've had three previous lumps which had all been benign, and this one I didn't find at all, so my awareness has just been from gen-, as every other woman's, I think, is just from what's been going on in the community and countrywide, etc, etc.

INT: SO HOW LONG AGO WAS IT SINCE YOUR MOM ...?

Patient: 15 years.

INT: FIFTEEN YEARS, RIGHT. AND ANY OTHER FAMILY MEMBERS WITH BREAST CANCER?

Patient: My mother-in-law had found a lump just over three years ago, went to the doctors, had it checked, it was benign. I came back and a week later she said to me, 'I think I've got a lump,' and I said, 'Oh,' I said, 'Have you, how long have you been checking, or how long did you know?' She said, 'I've just found it because I've never checked before,' and she went in and had a mastectomy. So ...

INT: WAS THIS ALL, THIS WAS ALL AT DERBY OR ...?

Patient: No this, my mother's was in Coventry ...

INT: OH, OK.

Patient: ... and my mother-in-law lives with us here, so it was in Leicestershire. So, yeah, she's got it as well, but she isn't blood relative, she's just ...

INT: NO, OF COURSE, YEAH. ANY FRIENDS OR ANY RELATIVES?

Patient: No, none at all.

INT: SO YOU FOUND THE LUMP YOURSELF, IS THAT RIGHT?

Patient: No ...

INT: OH RIGHT.

Patient: ... it was picked up on a routine mammogram.

INT: OH, SO IT WAS PICKED UP ON THE SCREENING PROGRAMME.

Patient: Yeah. Normally, as I say, I've found three previous lumps so I'm quite strict about self-examination, but I went along for the routine mammogram in February and they picked it up. The doctor couldn't find it at the hospital either, [???] you know, was just one of those things, one of those lucky things that they found it on a mammogram.

INT: COULD YOU JUST TELL ME A LITTLE BIT ABOUT WHAT HAPPENED WHEN YOU WENT TO GET YOUR MAMMOGRAM, WHAT HAPPENED THAT DAY?

Patient: Erm, when I actually went for the mammogram, not at the hospital, at the screening place, and they park a caravan-type contraption down in the local car park of the hospice ...

INT: AH, RIGHT.

Patient: ... erm, and we're called in to go in, make us welcome, you're usually in there on your own, you're sort of in and out, you pass someone going in and out. The ladies are charming, erm, very helpful, tell you when the results are likely to come through and then if you, they send, two or three weeks, and then you know one way or the other.

INT: OK.

Patient: They're usually [???]

INT: WAS IT THE STAFF FROM THE HOSPITAL? BREAST CARE NURSES ...

Patient: Yes, I think it must be because the lady that actually did the mammogram this time was actually at the hospital doing the mammogram when I went back.

INT: AH RIGHT, OK.

Patient: So yes, they would be breast care staff from Glenfield, I would imagine. I presume that's where the van comes from as well, the local health authority.

INT: SO THEN, WHAT HAPPENED AFTER THAT, YOU HAD YOUR MAMMOGRAM, YOU CAME HOME ...

Patient: About two and a half weeks later I had a letter telling me the good news that they wanted me to go back and see them, and then how long ... let's think ... a matter of a week was the appointment and I went in and saw the consultant and she had more tests done, more mammograms done and various other blood tests and things, and then ...

INT: WAS IT LIKE A ONE-STOP CLINIC YOU WENT TO, WAS IT? DID THEY DO EVERYTHING ON THE SAME DAY OR ...?

Patient: Yeah, they do actually, yeah ...

INT: MM, THAT'S A FAIRLY RECENT THING I THINK.

Patient: I think they're very up to date, I think they're very, the procedures are very modern in Glenfield, and everything was taken care of. And they said, you know, I went back in to see her after the tests were done, which I found amazing because normally when you see consultants in any sort of occup-, sort of occupation at the hospital you don't usually get to see the consultant, you see one of their men or ladies or whatever ...

INT: SpRs YES.

Patient: Yeah [chuckles] whatever the modern term is for them.

INT: SPECIALIST REGISTRARS.

Patient: That's what it is, yeah, OK. But I have sent the consultant four times. I haven't seen anybody else except the consultant. And she said, 'Well, you know, this is what we've got to do, we'll have you in.' So I said, 'OK, when do you want me in?' This was on the Thursday and I was in on the Tuesday. I cannot fault them at all.

INT: SO WHEN YOU HAD YOUR FIRST MAMMOGRAM IN THE MOBILE UNIT AND YOU GOT THE LETTER TO SAY THEY WANTED TO SEE YOU AGAIN, WHAT SORT OF WENT THROUGH YOUR MIND THEN, THEN, WHEN YOU RECEIVED THAT LETTER?

Patient: I actually, this sounds ridiculous, but I actually knew before I opened the letter.

INT: WHY'S THAT?

Patient: I don't know. Now this is perhaps purely feminine premonition, because I'm not the only one that felt this. I've had three lumps before, never had any problem when the letters have come back, and I stood in the hall and I looked at this envelope and I thought, 'I don't want to open you.' Once I'd opened it I thought, 'OK, let's get on with,' you know, 'There's nothing I can do about it, I've just got to get on with it.' I think I was quite badly shocked and I think it hit me more when my husband came home and I had to tell him. But ... yeah I think I'd anticipated it. It was a very bizarre reaction to receiving the letter.

INT: RIGHT, OK.

Patient: But that's purely I think psychological on my part. But, yeah, certainly shocked but not devastated because of ...

INT: AND THE NEXT TIME YOU WENT, IT WOULD BE TO GLENFIELD, WAS IT? AND THAT WAS THE ONE-STOP CLINIC YOU WENT TO, IS THAT RIGHT?

Patient: Yeah.

INT: SO CAN YOU TELL ME A LITTLE BIT ABOUT WHAT HAPPENED THAT DAY AS YOU REMEMBER IT?

Patient: A lot of waiting about [chuckles] and a husband that was getting agitated. Erm, you arrive at the clinic, one of the biggest bugbears of going there is the parking, like most hospitals.

INT: YEAH, DID YOU HAVE TO SORT OF STALK SOMEBODY TO GET A CAR PARKING SPACE?

Patient: Not quite that day but you do at the Granby, at the Infirmary, at the Royal, you do there.

INT: AH, YEAH, I'VE DONE IT AT GLENFIELD A COUPLE OF TIMES, IT REALLY FREAKS PEOPLE OUT WHEN THEY SEE THIS PERSON JUST FOLLOWING AROUND.

Patient: Watching them round ...

INT: I'VE GOT TO THE POINT NOW WHERE I JUST WAIT FOR SOMEONE COMING NOW AND JUST SAY, 'EXCUSE ME, ARE YOU LEAVING? CAN I HAVE YOUR CAR PARKING SPACE?' BECAUSE IT'S JUST ...

Patient: Yeah, I park over the far side more ...

INT: AND, SORRY, I INTERRUPTED YOU THEN ...

Patient: Yeah. Went in, everybody was sort of very chatty and kind and the ladies sitting in the waiting room were very sort of buoyant, which I think is artificial with a lot of them, you can see a lot of them are really, really frightened, particularly the more elderly ladies - she says reaching nearly 60 herself -

INT: [???] WHEN I'M SIXTY I'M NOT GOING TO BE ELDERLY.

Patient: No, I'm not elderly. So, yeah, it's a very good atmosphere in there. As I say, it was a lot of sitting around waiting, nothing seems to be going, which is, you think in most hospitals I think. But ... this is before you actually go down and see your consultant and she has a chat with you and tells you what's going to happen. And then she sends you off for mammograms and I think had three sets of mammograms that day because they took another one to confirm the initial one, see if it was still there; then they took another one on the other side which she said, 'We just wanted the comparison to see if there was anything else on the other side,' then I went and sat down again and they fetched me back again for some mammograms, and I sat down again and they fetched me back for some more mammograms. So why they needed three sets of mammograms I'm not quite sure, because I didn't ask, but they did. Erm ... did I have blood tests? I had a consultant with one of the breast care nurses who explained the procedures. I'm finding this a little bit difficult to remember actually because it's all gone so quickly, and you sort of go so many times ... erm, and then I went in to see Miss Stotter and ...

INT: WAS IT, IS IT MISS STOTTER THAT ...

Patient: Miss Stotter is my consultant.

INT: ... YOU'VE SEEN ALL THE TIME, YEAH?

Patient: Yeah, lovely lady, very nice lady, got a great sense of humour. And she was very kind when she gave me the information, and sort of looked at me to see how, whether I was going to burst into tears or have a, you know, histrionics or anything.

INT: DID YOU HAVE A, DID YOU SAY YOU HAD A BIOPSY THAT DAY AS WELL?

Patient: Yes, yeah.

INT: OK, SO YOU GOT EVERYTHING DONE THE SAME DAY?

Patient: Everything was done the same day.

INT: AND YOU GOT TO KNOW ON THE SAME DAY?

Patient: Yeah. Got to know everything on the same day. No, I didn't, I tell a lie. See I told you I was having difficulty remembering. They sent the biopsy away and I went back the following week and had the result of the biopsy.

INT: RIGHT, OK. SO, AND THAT, ON THAT FIRST VISIT, YOU GOT ALL YOUR BIOPSY DONE, YOUR THREE MAMMOGRAMS, THEN DID YOU SEE MISS STOTTER, DID YOU?

Patient: Yes.

INT: SO WHAT DID SHE SAY THEN?

Patient: Erm, what did she say? She said ... do you know I can't remember ... this is ridiculous, isn't it? Erm, ... I think she ... I'm trying to picture it, she gave me the information of what would happen if it was positive and what would happen if it was benign and she said 'We'll call you back as ... 'Come back in next week,' and I thought to myself, 'I think she knows from the mammogram what it is because she seemed very positive, but she's going to be positive anyway because, you know, that's her sort of thing, but she seemed to me positive. And, yeah, she sent me away and off I went and went back the following week and it was positive.

INT: AND IS THAT, AT THAT CONSULTATION WE'VE JUST BEEN TALKING ABOUT, DID SHE AT ALL MENTION TREATMENT OPTIONS?

Patient: Not at that consultation, it was at the second, it was at the other one ...

INT: RIGHT, YEAH.

Patient: ...yeah, it was at the other one.

INT: SO IN BETWEEN, IT WAS A WEEK LATER, WASN'T IT?

Patient: It was a week later.

INT: SO IN BETWEEN, THAT WEEK, IN BETWEEN THE FIRST CONSULTATION WHEN YOU SAW MISS STOTTER AND THE SECOND ONE, CAN YOU REMEMBER, YOU KNOW, WHAT WAS GOING THROUGH YOUR MIND AT THAT POINT, WHAT YOUR FEELINGS WERE AND ...?

Patient: To be quite honest, I don't think I accepted it at all. I think I have been in permanent denial and that's how I've dealt with it. And to be quite honest I think I'm still in denial, or I'm looking at it and saying, 'Right, I had it, it's gone, they've chopped it out, I'm having the treatment.' Erm, and it reflects back on when my father had lung cancer, I think because I was the only one of the family and because, no, I was trained as a medical secretary, and I, [???] a lot of terminology although it was a long, many years ago, and it's changed a lot, and they told me that, we were told he had a neoplasm, and because they didn't actually tell me he had cancer I denied it right to the end that he had cancer. My father didn't die of cancer. And ... sorry ...

INT: JUST TAKE YOUR TIME, IT'S OK. THESE THINGS NEVER GO AWAY. I STILL GET PROBLEMS WITH MY DAD, JUST TALKING ABOUT CERTAIN THINGS.

Patient: Erm, and I think, I think I'm treating my illness in the same way. And I went to work and I went to school, and I had to warn my boss that something might be happening and, well he knew obviously I was going for the appointments, and I think everybody else thought about it more than I did. I just got on with my work and put it to the back of my mind. I can't honestly say that it caused me particular problems or anything, or remember anything about [???] at that time. And I think that's what's happened all the way through. Erm ... I think when I told my daughter, that was quite upsetting because, having my mother as well, I had a feeling that she may fall into line for it, so obviously we went to make a few enquiries.

INT: HOW OLD IS YOUR DAUGHTER?

Patient: She's 23, this year.

INT: I SEE. AND YOU'VE MADE ENQUIRIES ABOUT ...

Patient: We've made enquiries and it appears that, because of the age groups, when my mother had it she was in her late 70s through to her early 80s, and me being rising 60, that it's not likely to be hereditary, so they haven't offered her any tests or anything.

INT: RIGHT, OK.

Patient: But I think it's seeing her more upset. I mean the boys don't show it quite so much, but she was desperately upset, so I think I finished up supporting her rather than her supporting me.
[chuckles]

INT: OH THAT QUITE OFTEN HAPPENS, A FEW PEOPLE I'VE INTERVIEWED HAVE SAID [???] SO YOU, IN BETWEEN THIS TIME, SORRY, CAN YOU TELL ME WHEN YOU WENT BACK TO SEE MISS STOTTER, WHEN YOU ACTUALLY SORT OF WENT TO THE CLINIC AND HEARD THAT YOU'D, YOUR DIAGNOSIS? CAN YOU TELL ME ABOUT THAT PLEASE?

Patient: Erm, went with my sister, who's been very helpful, and we went in and she said to me, 'It's good news in one respect,' she said, 'Because it is a grade A and it's very small and it's the least aggressive you can get.' So I said, 'Right, thank you, that's all I need to know.' Erm, and I think looking back on it, I must have been quite artificial because I think I was quite buoyant at that particular time. My sister was in tears and I was basically just sitting there talking to Miss Stotter and chatting about different, different things, not necessarily about even about the cancer, I don't think. I think I

was trying to avoid the actual topic. And once I knew that it was of such a low, erm, grade and that it was the least aggressive, I was quite happy. I, you know, some of the girls I was in with have had really quite horrendous ones so my comparison I'm very, very fortunate, and that's what I carry through on, I think.

INT: MM, YEAH. DO YOU THINK THAT PERHAPS THE SORT OF, THE SCREENING CAME ALMOST AT THE RIGHT TIME - WELL NOT EXACTLY AT THE RIGHT TIME, BUT [???] ...?

Patient: I think it did actually, yes, because the last lump I found brought my mammogram forward a year - this is going back three years now - brought it back a year, so I would have been on my, past my 60th birthday and may have missed that, because it stops at 60, doesn't it, the screening on the mammograms?

INT: I THINK IT DOES, YEAH.

Patient: I would have missed this mammogram because it would have been next year when I would have been 60. So, yeah, very fortunate, I feel extremely fortunate that they picked it up in that respect.

INT: SO MISS STOTTER, SORRY, JUST TO GET BACK TO THIS CONSULTATION, THERE WAS YOURSELF, THERE WAS MISS STOTTER AND THERE WAS YOUR SISTER - WAS THERE ANYBODY ELSE IN THE ROOM?

Patient: Yes, there was a breast care nurse as well.

INT: RIGHT, OK THEN.

Patient: She was sort of sitting ...

INT: AND ANYBODY ELSE IN THE ROOM?

Patient: No, she was sitting sort of slightly behind Miss Stotter and she was sort of smiling and, you know, the sort of very comforting [chuckles] that these lovely ladies do for you. Very supportive.

INT: THEY'RE A NICE, THEY'RE A NICE BUNCH OF PEOPLE DOWN THERE.

Patient: Yes, they are.

INT: I'VE INTERVIEWED NEARLY ALL OF THEM NOW. AND, ERM ... SO MISS STOTTER TOLD YOU THAT THIS WAS OBVIOUSLY A CANCER, YEAH? AND AT THAT POINT, DID YOU DISCUSS TREATMENT OPTIONS ABOUT WHAT YOU WERE GOING TO DO ABOUT IT?

Patient: She said, 'You have ...' I have two, 'You have two options: you can either have a mastectomy or you can have a lump- ...' I call it a lumpectomy, that's not quite, they call it a wide excision.

INT: WIDE LOCAL EXCISION.

Patient: Yeah. Erm, so I said 'Well you're telling me that it's least aggressive, what do you think I should do?' and she said, 'I can't make that decision for you, I can only tell you what you have.' I said, 'Well do I need a mastectomy?' and I was a bit, I wouldn't say I was annoyed, I was a bit upset I think

that she wouldn't say to me that I didn't have to have the mastectomy, that I would be quite safe the lumpectomy. Erm, and I said, 'Well is it, do I have to have the mastectomy?' and she said, 'It's your decision,' she said, 'because some ladies feel they just want to get rid of everything,' she said, 'and some ladies are quite happy to go on and do it the other way.' And whatever I sort of tried to ask her, she wouldn't give me a definite answer on, so I said, 'Oh, well, I'll have the wide excision,' I said, 'because if it comes back I'll just have the mastectomy afterwards,' you know, that was my attitude in the end. But, yes, she told me the details; she told me what would happen [???] go in, [???] glands ...

INT: DID SHE DESCRIBE THE TWO OPERATIONS? DID SHE DESCRIBE THE TWO OPERATIONS?

Patient: No, I don't think she did actually, no, she didn't give me any details of the actual operations themselves. She told me about the lymph glands and said [???] probably take a few lymph glands out, and I said, 'Well how many?' not knowing at the time how many possibly there were, so, erm, she said, 'Oh usually about four, perhaps five,' when I came round they'd taken all 19 [laughs] so I wasn't too chuffed about that and I did tell her that at the time, the next time I saw her. But they didn't, obviously they take away what they think they need to take away, but there was nothing in the glands anyway, so they most probably took it away for precautionary measures, I would think.

INT: AND WHEN MISS STOTTER WAS TALKING ABOUT YOUR DIAGNOSIS AND YOUR TREATMENT OPTIONS, DID SHE USE ANYTHING LIKE ANY AIDS OR TOOLS SUCH AS MAMMOGRAMS OR DIAGRAMS, PICTURES, DID SHE DRAW ANY DIAGRAMS, ANYTHING LIKE, DO YOU REMEMBER ANYTHING LIKE THAT?

Patient: I was shown the mammogram, erm, but not for that, that was the previous visit, and she'd just got a drawing, two little smiley type faces, and showed me, you know, just with a star where it was. And she said that it was on the chest, close to the chest wall but not on the chest wall. But no, no models, no, nothing like that at all ... nothing like that at all.

INT: OVERALL, HOW DO YOU FEEL YOU GOT ON WITH MISS STOTTER?

Patient: I think I got on, I was told I got on pretty well with her, because [chuckles] ...

INT: YOU WERE TOLD YOU GOT ON WELL WITH HER BY WHOM?

Patient: By a couple of her nurses. Erm, she's a ... how would you describe Miss Stotter? Very, very straight, erm, no nonsense, erm, and I don't think she likes wimpish ladies, [chuckles] but that's all I'm saying. And I think I gave as good as I got from her, so we got on quite well I think.

INT: RESPECT ...

Patient: I think she's excellent. I'm, having seen the other - this is, I shouldn't perhaps say this - but having seen the general oncologist in the hospital, I'm glad I had Miss Stotter. I think I had, I don't know for certain that I had better, had more better treatment, but I felt more secure with her than with some of the others that I saw come into the hospital.

INT: OK. SO, YOU'VE NOW OBVIOUSLY HAD YOUR DIAGNOSIS AND YOU'VE BEEN TOLD YOUR TREATMENT, WHAT WERE YOUR FEELINGS AT THAT POINT, THEN, HAVING IT CONFIRMED? I MEAN YOU SAID THAT TO A CERTAIN EXTENT YOU WERE, NOT HAPPY, BUT SORT OF PLEASED

THAT IT WAS A LOW GRADE CANCER AND THIS KIND OF THING, BUT DO YOU REMEMBER ANY OF THE FEELINGS YOU HAD AT THE TIME?

Patient: Erm ... I think I just wanted to get on with it and get it over, to be quite honest. I don't think I fear the cancer as much as the treatment for the cancer. That, I think, along with a lot of other people, it's the actual fear of the treatment more than, you know, what treatment you're actually going to have - whether you're going to have the full works, whether you're going to have the operation, the chemo and radiotherapy, etc. No, I think I was reasonably sort of laid back about it at that time. Erm ... in fact I think I came out of the hospital almost bouncing because it was, I was told that it was such a low grade one, and thinking, 'Well,' you know, 'this is about the best chance you can get. If you've got cancer this is, you know, you've got about the best chance you can have.' Just got on with my everyday things after that, waiting to go into hospital.

INT: AND DID YOU UNDERSTAND EVERYTHING THAT WAS, MISS STOTTER WAS TALKING TO YOU ABOUT IN TERMS ...

Patient: I think so, yes, I think so.

INT: ... TERMS OF TREATMENT AND THE ...

Patient: Yeah.

INT: YEAH? DID YOU UNDERSTAND WHAT THE TWO TREATMENTS WOULD ACTUALLY INVOLVE, THE MASTECTOMY AND THE WIDE LOCAL EXCISION?

Patient: Mm, no, because once I'd made the decision to have the wide, whatever, excision, I wasn't interested in the mastectomy, because she said, 'You've got this or this,' and she didn't really go into detail, she just gave me a brief overview of what would happen. And I wasn't interested in the mastectomy: if I'm not having it, I'm one of these people if I'm not doing it, if I'm not interested in it, or it doesn't, I don't know need to store the information, I don't store it, I don't take it into consideration. So I was quite happy with what she was going to do to me, I thought at the time, till I came round from the anaesthetic. [chuckles] And then they told me all the sort of side effects, seroma and that sort of thing. The only thing I think that did bother me was my mother had lymphoedema very badly, erm, and I think that bothered me quite a lot, in fact I know that bothered me quite a lot because she was in a lot of pain when she had it. Yeah, and I thought perhaps a seroma would lead to lymphoedema, which it doesn't, I don't think. So, yeah.

INT: OK. AND DID YOU EVER GET AN IMPRESSION FROM MISS STOTTER THAT THERE MIGHT BE ONE TREATMENT THAT SHE PREFERRED?

Patient: No, this was one, this was one of the things that I was bit cross with her about ...

INT: YES, YOU SAID, YEAH ...

Patient: ... is that she didn't, she wouldn't ...

INT: ... JUST WANT TO DOUBLE-CHECK THAT.

Patient: Yeah. No, she wouldn't sort of say one way or the other which she thought quite would be better, or whether I was equally safe having the wide excision or mastectomy. I wanted her to quantify it for me and she didn't, or she wouldn't. Yeah.

INT: AND DID YOU SPEND ANY TIME AFTERWARDS WITH THE BREAST CARE NURSE, AFTER YOU SAW MISS STOTTER THAT TIME?

Patient: Yes, she took, we went off into one of the little side rooms that they have, erm, and she went over the same sort of things. She told me the seroma; she told me about treatment in hospital; how long I would be in for; erm, what other effects I would have - drains, things like that; my general health care, erm, what else did she talk about ...? Basically I think making sure that I was all right after the consultation, which I was. I had to sign a consent form [???

INT: FOR THE SURGERY?

Patient: Yeah. In fact I think I signed two lots of consent forms, because I picked her up on one, picked Miss Stotter up on one of them.

INT: WHAT WAS [???

Patient: I'm just trying to think what it was about now ... there was little question, there was one little thing at the top that I ... I'm sure it was to do with the lymph glands ... no, can't remember, but she sort of laughed at me and said, 'You're being pernickety,' I said, 'I'm a librarian, I am pernickety.' [chuckles] But no, it was nothing major, it was just some terminology. I can't remember what it was now. A lot of it I think I've shut out.

INT: YEAH, OF COURSE. AND THEN, AFTER YOU'D SEEN THE BREAST CARE NURSE, DID YOU FEEL THAT THE BREAST CARE NURSE IN ANY WAY HAD A PREFERRED SORT OF TREATMENT BETWEEN THE TWO?

Patient: No, none at all.

INT: DID YOU HAVE ANY FURTHER CONTACT WITH THE BREAST CARE NURSES ...?

Patient: I was, no, I was offered it but I didn't sort of ring them up or ask them anything.

INT: DID THEY GIVE YOU SOME, DID THEY GIVE YOU ANY INFORMATION?

Patient: They gave you booklets and things and piece of paper ...

INT: DID YOU READ THEM?

Patient: Yeah, yeah.

INT: AND WERE THEY USEFUL IN ANY SORT OF WAY?

Patient: Yes, just for general information and sort of backing up what you'd been told and if you tend to put things out of your mind or you forget, and you think, 'Oh I'll just go back and have a look at the

paperwork and see what it says,' and that sort of thing. Yeah, yeah, that's, that was excellent [???] in that respect that was excellent.

INT: AND, LET ME SEE, THROUGHOUT THE WHOLE CONSULTATION PROCESS WITH MISS STOTTER AND WITH THE BREAST CARE NURSES, WHO DO YOU THINK ASKED THE MOST QUESTIONS AND WHO DO YOU THINK DID MOST OF THE TALKING?

Patient: Miss Stotter.

INT: DID THE MOST TALKING?

Patient: Yeah.

INT: YEAH. AND DID YOU HAVE ANY QUESTIONS AT ALL, CAN YOU THINK OF?

Patient: I don't think I did at the time, no. And when I came home and went through the paperwork I kept thinking, I know I thought to myself, 'Well this is fairly straightforward, it's fairly obviously what's gonna happen.' I can't think of anything because I didn't ring the breast nurses to ask them anything, so I think what I'd been told sort of clarified everything that I needed to know.

INT: AND DID YOU FEEL THAT MISS STOTTER UNDERSTOOD YOUR NEEDS, YOUR CONCERNS AND THINGS LIKE THAT?

Patient: Yeah.

INT: DID SHE LISTEN TO YOU?

Patient: Yeah, she did.

INT: AND THE NURSES, DO YOU THINK THAT THEY, YOU KNOW, UNDERSTOOD YOUR NEEDS, YOUR CONCERNS, AND LISTEN TO YOU?

Patient: They were all excellent, I can't praise them enough. My sister is absolutely totally impressed with them, she said, 'If I ever get it, I'm going there.' [chuckles]

INT: OK. FAIR ENOUGH. DID YOU AT ANY, YOU SAID YOU CHOSE THE WIDE LOCAL EXCISION IN THE ACTUAL CONSULTATION, DID YOU EVER CHANGE YOUR MIND AT ALL OR, ABOUT WHAT KIND OF TREATMENT YOU WERE GOING TO HAVE ...

Patient: No.

INT: ... BETWEEN THAT ACTUALLY HAVING THE TREATMENT?

Patient: No, no.

INT: OK, SO YOU'VE REACHED THE POINT WHERE YOU'VE SEEN THE BREAST CARE NURSES, YOU'VE COME HOME, HOW LONG AFTER THAT CONSULTATION WAS IT TILL YOU GOT YOUR SURGERY?

Patient: That was on the Thursday and I was in on the Tuesday.

INT: RIGHT, SO IT'S, LESS THAN A WEEK?

Patient: Five days, yeah, because she said to me, 'Right, now we'll give you an appointment to get you in for the surgery,' and I said, 'OK ...,' and I'd been told by my nurse at school about two weeks, so I was thinking, 'Oh, yes, I'll get things done at school, I can tie ends up etc, etc.' And she said, 'Right, next Tuesday.' And I said, 'No ...' and she said, 'We are talking about cancer, you know.' [chuckles] I said, 'Oh, yeah, OK then, all right, I can ... yeah, I think I can make it for next Tuesday.' So, yes, it was very, very quick sort of process, that's, you know, very very quick.

INT: AND SO WHEN YOU CAME HOME AND OBVOIUSLY YOU'D GOT TO DISCUSS THINGS WITH YOUR FAMILY AND THAT, HOW WAS THAT THEN?

Patient: Erm, that was quite difficult, erm, my sister was here with me when my husband came in and he had, and still has, he's been a lot better now, but considerable difficulty dealing with it. He cannot, erm, discuss it, shall we say? Bless him. My sister was totally disgusted with him because he came in and we were having a conservatory built and he was more concerned about what the men had been doing with the conservatory than what my result was at the hospital. [chuckles] And it's purely because he couldn't deal with it, which ... I think a couple of days later sank in and I realised that, erm, much as we have a very good relationship, he wasn't going to be much good to me in the way of support, and I think at that point I know I broke slightly and I had a ... I had a rant and a rave and a cry, and then put it all away again. Yeah, it was, that was, the biggest problem was dealing with my husband: my daughter was very good, and telling people, facing people I found quite difficult. I didn't want people, I didn't want to tell people, and when I got back to school and told my boss my diagnosis he said, 'What do you want me to do?' I said, 'I would rather you didn't tell people,' and as it happened we had school insp-, we had the inspectors in the following ... we'd had the inspectors and they were in, they were finishing on the Thursday as I went to the hospital on the Thursday. And he said, 'Well obviously we need to tell the head, etc,' which he did. And I left the school on the ... I went back into school on the Thursday and did a couple of things and then went home and that was it, it was finished, because I don't go in on a Friday anyway. So no-one knew until the following week where I was. And life just sort of went 'chunk' and disappeared, it just sort of went, I went, it appeared, I felt as if I'd gone straight from work into hospital, and I don't know what happened to the three or four days in between time. I still don't know what happened to the three or four days in between time. I think I was just busy trying to get things sorted out. Erm, but facing people I found quite difficult, and I'm quite happy that I didn't have to face the staff at school until I went back in after my operation, because I'm not very good on things like that. I'm in control. [chuckles] Oh dear. And I can't, I have problems when friends give me hugs and things and they're crying and saying, 'Ooooh,' you know. I can do it for them but I'm not very good at doing it for myself.

INT: AND AFTER THE OPERATION, WHEN YOU CAME ROUND, HOW WAS THAT?

Patient: Mmmm ...

INT: BECAUSE THIS IS ABOUT THE LOT, YOU SAID THAT THEY'D TOOK MORE LYMPH GLANDS THAN YOU WERE EXPECTING, IS THAT RIGHT?

Patient: They did, Miss Stotter told me four or five and when ...

INT: DID SHE DO THE OPERATION?

Patient: As far as I'm aware she did, yes, yes, as far as I'm aware she did. Erm ... I felt quite good actually, once I came out of it. I can remember being in the recovery room and I can remember shaking from head to foot, which I couldn't control, and I can remember somebody sitting there saying, 'It's OK, it's the shock, don't worry, you're OK.' Then I must have gone back to sleep. Erm ... and I was just glad it was over. I was more frightened of the anaesthetic than of the actual, other parts of the operation. I think a lot of people are frightened of anaesthetics. Erm, and ... the pain was not very great, it wasn't as bad as I expected. The results, they said when they told me the result was, everything was clear and they'd taken it out and they couldn't see any thing else, blah-de-blah-de-blah. And it was just basically going, getting back on my feet on the day to day basis and dealing with whatever cropped up, like the exercising. Breast nurse came round a couple of times, also very supportive, because it's still the same girls obviously that were in the unit. Yeah, I was quite positive when I came out of surgery, I think. I felt a lot better than I anticipated I would feel. And I think everybody feels pain, no matter how brave you think you are, you feel, you don't like having to suffer pain, do you? Particularly when you're not in control of the painkillers, you know, [chuckles] and yeah, I think I was quite bright when I came, when I [???

INT: AND DID YOU SEE MISS STOTTER AFTER ...?

Patient: Yes.

INT: ... AFTER THAT THEN?

Patient: Yeah.

INT: HOW WAS THAT, THEN?

Patient: She came round twice, three times, onto the ward. A couple of her staff came round who were also excellent, these girls came round, the registrars, whatever they're called. Erm, and she popped in two or three times to see me and said everything seemed to be going fine. One thing that did bother me was that they didn't seem to check the wounds, and that I found a little bit negative. Erm ... simply I think because one of the ladies in the ward who was next to me was an Asian lady, couldn't speak, very little English, erm, and I was having to try and sort of interpret - she sort of latched on to me - trying to interpret what she was telling me and passing it onto the nurses and to her family when they came in at night-time. And she was bothered about her wound, and I mentioned this a couple of times, and they just said, 'Oh, that's fine, that's normal, you know, don't worry about it.' And there never seemed to be any medical check, physically, of the wound. All right, yes, when ... if your dressing came off or the drain came out or something like that, then it was checked, but other than that it was just left, and I think for my, I know some people don't like things messed about with when they're stuck behind plasters, but for my peace of mind I like to know that everything is still all right, erm, infection-wise, I have this thing about infections in hospital [???]. And, yes, they came round and they your temperature and they took your blood pressure and ... a couple of things, checked your drains, but they never checked the wound, which I thought was a little bit off. But then it might just be modern nursing, I don't know.

INT: MM. AND THEN YOU SAW MISS STOTTER AFTERWARDS, DID YOU?

Patient: Yeah.

INT: DID YOU SEE HER?

Patient: Yes, erm ...

INT: DID SHE EXPLAIN WHY THEY TOOK MORE?

Patient: No, she didn't actually. No, she didn't. That was only on the ward, I've not actually had another appointment with her at Glenfield.

INT: OH RIGHT, OK.

Patient: I've got an appointment with her in September. The next person that gave me any information was Dr Peat ...

INT: IS THAT THE ONCOLOGIST?

Patient: Yes, the oncologist at the Infirmary.

INT: I'VE NEVER MET HIM, WHAT'S HE LIKE?

Patient: ... I don't really know that I formed an opinion because she was so quick.

INT: OH RIGHT. OH, SHE IS IT?

Patient: Yeah, I thought it was a male, but it isn't ...

INT: I THOUGHT YOU'D SAID HE BEFORE, SO ...

Patient: No, she; no, she, Dr Peat. She's also white-haired, bit more smiley, smilier than Miss Stotter, but very, you know, down to earth, 'This is this, this is this, this is this. This is what we're going to do to you. Do you have any questions? Here's your paperwork.' Not dispassionately, you know, just sort of doing the job, and I like that people that do their job and don't sort of faff around the bushes[?] what-have-you, so, yeah.

INT: THINKING ABOUT YOUR EXPERIENCE FROM WHEN YOU FIRST WENT TO THE, WHEN YOU FIRST GOT YOUR LETTER TO SAY THEY WANT YOU BACK AT THE HOSPITAL, TO YOUR SURGERY, ERM, DID YOU LOOK FOR ANY OTHER INFORMATION? I MEAN YOU WERE GIVEN INFORMATION FROM THE HOSPITAL, BUT DID YOU LOOK AT ANY BOOKS, MAGAZINES? YOU SAID YOU LOOKED ON THE INTERNET I THINK AT ONE POINT ...

Patient: No, that's for, that was for this other trial thing they wanted of me.

INT: OH RIGHT, OK. ANY FRIENDS AND NEIGHBOURS GIVE YOU ANY KIND OF INFORMATION, REALTIVES, YOUR GP, ANYTHING LIKE THAT?

Patient: She didn't know, I didn't see the GP until I went for my prescription for my Tamoxafen. I did go on the internet and I went on to look at the effects of the radiotherapy, but basically what I was seeing on the internet, I didn't want to know all the technical information, erm, and you also get all the

sides, that it's not good for you, etc, etc, so I think at that point I was thinking, 'Well, this is going to put me in a negative attitude, I don't want to know.' But I know I did check the radiotherapy, but nothing else. I tend to, as I say, compartmentalise and deal with things as they crop up.

INT: AND THINKING ABOUT THE TREATMENT OPTIONS, DO YOU FEEL YOU HAD ENOUGH, DO YOU FEEL YOU HAD THE AMOUNT OF CHOICE YOU WANTED?

Patient: Yes. Yeah, I think so, year.

INT: CAN YOU TELL ME WHAT DO YOU THINK IS THE MOST IMPORTANT THING YOU WERE TOLD OR HEARD OR READ OR WHATEVER THAT HELPED YOU MAKE YOUR DECISION TO HAVE A WIDE LOCAL EXCISION?

Patient: I can't say that anything made me do it because it had to be a fairly quick decision, I wasn't allowed to go away and think about it. I could go back the next week, you know, and say 'I want to change my mind' if I want to, but I basically, I made the decision there and then when she told me. And this I think, again, goes back to why I got so cross with her because she wouldn't sort of tell me which I could get away with, which was the, which was the most effective but the least drastic. I don't think anything, no I don't think anything affected the decision at all once ... no, I can't think of anything. Once that decision was made it was made. I'd made the decision and that was it. If she wanted me to have something else she would have to tell me, you know, she would, there was something else different to that, which she wasn't going to do.
But ... yeah.

INT: AND AFTER YOUR INITIAL SURGERY, WHAT'S HAPPENED SUBSEQUENTLY IN TERMS OF TREATMENT THERE?

Patient: Erm, I was in hospital for seven days; the drain wasn't completely clear so I, I had to come out, you have to come out after seven days. Mine was still leaking, typical, so I had to go back to the hospital, I had to go back to Glenfield five times to have the seroma drained. Er ... and then once I got over that, everything was going fairly fine, felt pretty good, recovered from the operation, and then within the month, exactly the month after my operation, I started on my radiotherapy [???] which I'm just coming to the end of now. Erm, all been very slick, very professional. Yeah, it's just gone, you know, very, very easily I think. Not ... perhaps I'm a little bit hard, I don't know, I'm not, I haven't felt too much trauma at it all, the people have been very, very good.

INT: AND LOOKING BACK TO WHEN YOU WERE FIRST DIAGNOSED UNTIL NOW, HOW DO YOU FEEL ABOUT THE CARE THAT YOU'VE RECEIVED?

Patient: It's been excellent. I cannot fault it.

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

Patient: It's more than met my expectations. After knowing, not that my mother did not have care or my mother-in-law didn't have care, my mother-in-law went into George Elliot, but my expectations would not, my own expectations on the first initial diagnosis certainly would not have known of the level of care that I was given. It's of a very, very high standard. No problem, no query with that at all. [???] Glenfield ... [chuckles]

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

Patient: The size of parking. Erm ... change anything ... no, I don't think I would. I think the only thing that I can say that may have been a little bit frustrating was waiting to see Miss Stotter for the first time and have everything sort of co-relate each other[?]

INT: WHEN YOU WERE AT THE ONE-STOP CLINIC?

Patient: Yeah. Because it was a long time waiting.

INT: HOW LONG WERE YOU THERE, DO YOU KNOW, ROUGHLY?

Patient: About five hours.

INT: OH!

Patient: [chuckles] And my husband is not the most patient of men. And, yeah, I think perhaps staffing levels, but they compensate with their capabilities. And I know that ... it isn't always their fault because on one occasion when I went in to see Miss Stotter, that was on, she apologised and said she was sorry to keep me waiting but two or three patients hadn't turned up earlier on in the afternoon and then they'd got behind. And I'd been sitting there for three and a half hours that afternoon, and I think, obviously, that is over their estimated waiting. I don't know whether they have specific times that they're supposed to see people, but she seemed quite upset that we'd had to wait that long. But, yeah, five hours easily the first time I went with my husband. And you're just sort of sitting there and you know people are doing things, and if you're listening like I do, you know why they're doing it and where they've gone and what they're doing. But some people who perhaps aren't quite as aware of what goes on around them, the older people, things like that, they might find it quite upsetting, the length of time they'd be sitting there not knowing what's happening or where people have gone with their bits of paper or their tests or ... you know. Yeah, a few more staff I think might be, might be helpful.

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

Patient: ... I think I needed to know at what level it was and how advanced it was. Erm ... that was my, that was my main concern was just how aggressive it was; what type it was, what particular type it was; whether it was ductal, whether it was something else; whether it was ... whatever, because I needed to rationalise that in my own brain so that I could sort of deal with it and say, 'Right, this is the type of cancer I've got, this is what is going to, I'm going to, this is what's going to happen, this is what I can do, etc, etc.' Erm ... yeah, that would be the most important thing to me, knowing what type and how long or what progression it might have.

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

Patient: ... Initially I thought, I thought about this some time ago, I thought to myself, I would like to have known what was going to happen in more detail when I came round and what the after-, some more, you know, sort of more, some of the simpler things that happen that you're not aware, not

expecting. And I know everyone is different, but I think I perhaps have liked a little more detail about the after-effects of the operation.

INT: RIGHT, OK.

Patient: Whereas some people like to stay ignorant, I think I might have liked to know just a little bit more, just for my own peace of mind - not peace of mind but what I was going to be, what was going to happen and I need to be able to deal with it before it happened, whereas some people might be frightened by that. Erm ... yeah, that's what I would say, I think.

INT: 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 OR ANY IMPORTANT INFORMATION WE HAVEN'T TALKED ABOUT YET, ANYTHING LIKE THAT?

Patient: I think the only other thing I would be con-, would consider, and it's perhaps something I didn't have to look at, but might have had to look at, was that I was referred to Leicester, which didn't bother me at all, is transportation and it's things like that, I don't know whether this comes under your remit ...

INT: MM, WELL YOU CAN TELL ME [???

Patient: I mean I didn't know how well or how poorly I was going to feel when I was going through radiotherapy. Now I drive, obviously, erm, I couldn't drive initially, the nurses warned us that if we had an accident and they know you, the insurance company found out you'd been in hospital, it negated your insurance basically. Erm, so you're relying on other people to get you backwards and forwards to hospital. My husband works, he's away, he comes home every day but he works some distances at times, and I was relying on my sister, who is 75, to transport me backwards and forwards at times. I think if they could make a package that sort of gave you all the sorts of telephone numbers and things like that, a more complete sort of customer awareness package, if you like - like you would get in industry, in commerce - that would be quite helpful. Yeah, that's just something, you know, transport, because I had great difficulty find- ... because I didn't think, I didn't know whether I was going to be able to drive when I was having radiotherapy and I was thinking, 'My God, who can I commit to five weeks' driving backwards and forwards to Leicester every day and sitting around Leicester?' you know. And that was quite, erm, a stressful thing for me. I mean I do it myself, it doesn't bother me in the least, it's, once I got used to driving into Leicester. But, yeah, I think that caused a lot of ...

INT: BECAUSE THE INFIRMARY'S IN THE CENTRE, IS THAT RIGHT?

Patient: Yeah, yeah.

INT: GLENFIELD'S JUST ON THE OUTSKIRTS.

Patient: Glenfield is easy-peasy.

INT: YEAH, IT'S EASY-PEASY THAT ONE.

Patient: Yeah, I mean I've driven in with my husband to the Infirmary before and he goes a different way to the way I go now: he goes right through the centre of Leicester and comes slightly back out again; I go M69 and then onto the 560 into Leicester, on the outer ring road, which is much easier. But

to commit someone, particularly a lady who doesn't drive, and she's got to commit someone - even at my age - to take them into Leicester every day, or to arrange a transport ... there was nothing there, you could see the odd notice on the noticeboards, in the corridors of the hospital, and I suppose if I'd have needed to and I'd have asked, people would have told me, erm, it's just it would help to reassure so that you haven't got to worry about something like that, if that sort of package was available, and all-round, sort of comprehensive package - not just a medical package, the more comprehensive package, which they have all the information about, I'm sure they have somewhere. You know, bus services or train services or things like that. And then of course ...

INT: I DON'T KNOW HOW WELL, ANYTHING ABOUT THIS AREA IN TERMS OF PUBLIC TRANSPORT.

Patient: Well they took the trains off actually from Hinckley to Leicester the first three weeks that I was going to Leicester [chuckles] and they were doing track work and they closed it, so they were bussing people in, but, yeah, it's ... it was just one of those things. I mean it's not difficult if you've got somebody who can do it for you or if you can do it yourself. But, no, otherwise the service was excellent, I cannot fault them. Fantastic bunch of ladies.

INT: OK, I THINK THAT'S IT THEN.

Patient: Right-ho. I hope I've answered your questions.

INT: NO YOU'VE DONE VERY, VERY WELL, THANK YOU VERY MUCH.