

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)
*VENUE: Low MR unit
*DATE:
*ID: Patient60
INTERVIEWER: DJW

INT: 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 LITTLE BIT ABOUT WHAT YOU KNEW OR UNDERSTOOD ABOUT BREAST CANCER BEFORE YOU REALISED THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: Absolutely nothing.

INT: OK, NOTHING AT ALL, NO?

Patient: No, it was never an issue.

INT: RIGHT, OK. DID YOU HAVE ANY FRIENDS OR FAMILY THAT HAVE HAD BREAST CANCER AT ALL?

Patient: No.

INT: NEVER? OK.

Husband: Only Mary years ago.

Patient: Oh, well, years ago.

Husband: Thirty years ago we had a friend, my partner who I worked with, she lost one breast, and about six months later she had the other one and about six months later she died, didn't she? But that's 35 years, I don't think they'd got the ...

INT: NO, OK. [???

Patient: Nobody I'm really close to has had breast cancer, it's never been in the family.

Husband: No.

INT: RIGHT, OK. THAT'S ALL RIGHT. AND YOURSELF, YOUR OWN SORT OF MEDICAL HISTORY? HOW HAVE YOU BEEN OVER THE LAST ...

Patient: Oh, all right, that's why I'm so ...

INT: YEAH?

Patient: ... shocked, because I didn't even feel ill.

INT: RIGHT.

Patient: I very rarely have an headache, do I?

Husband: No.

INT: YEAH.

Patient: I had a touch of colitis some years ago and had to go in hospital for a couple of days, but usually I'm not ... I never take pills or anything.

INT: RIGHT, OK. AND SO CAN YOU JUST TELL ME FROM, YOU KNOW, HOW YOU ACTUALLY FIRST FOUND OUT THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: Well I was just having a wash one morning and I just thought, 'Ooh, that's a bit strange,' it just, tiny little lump, and I thought it was going to develop into a pimple or something. A few days later it hadn't sort of developed into anything, it was under the skin. So I nipped to the doctors and she didn't think it was anything to worry about and said, 'Erm, come back in three weeks if it's still there,' you know, 'and we'll take it further.' Well she actually was on holiday that week so I went, it was a month later when I went back. And she just said, 'Oh, something's definitely happening inside there, so we'll get you looked at.' And then I got my appointment two weeks later.

INT: TO THE ... GLENFIELD?

Patient: Glenfield, yeah.

INT: YEAH, OK. RIGHT. AND CAN YOU TELL ME WHAT HAPPENED WHEN YOU WENT ON THAT FIRST VISIT TO GLENFIELD?

Patient: Scary, that was, wasn't it? Well I went in the room and she examined me, the consultant, and she said, 'Oh, I think your GP was right, you should be here though it isn't very big,' and she said, erm, 'We'll send you down for a mammogram,' and she said, 'And then we might to do a biopsy.' And I thought, 'Oh, my God.' And so, went down and had the mammogram and fetched me back for a scan.

INT: MM, ULTRASCAN, YEAH.

Patient: Yeah, and he did awful biopsy, which was awful.

INT; RIGHT OK.

Patient: Deep core biopsy, something like that.

INT: YEAH. I'VE NEVER SEEN IT PERFORMED BUT I'VE HEARD ABOUT THEM, THEY'RE UNCOMFORTABLE AREN'T THEY?

Patient: Afterwards, yes. Terribly, everything just went black. But I knew then something wasn't right.

INT: MM, OK. SO WHEN YOUR GP SAID COME BACK IN A FEW WEEKS AND IT HADN'T CHANGED, WHAT WAS KIND OF GOING THROUGH YOUR MIND AT THIS POINT?

Patient: I still, I wasn't unduly worried because it's not in my family, you see, so I thought, 'Oh, blocked milk duct, you know,' I think, nothing to worry about, never told the kids. And I, when I went to Glenfield I was going to go on my own, wasn't I? I was gonna walk [???] and it was pouring with rain that morning so he gave me a lift and he said, 'Oh, I'll stay with you for a while if you like.' So he came in with me and we were there three hours, [???]

INT: RIGHT, OK. SO DO YOU REMEMBER THE NAME OF THE CONSULTANT WHO YOU SAW?

Husband: Yeah, [???]

Patient: No, she was on holidays, she was the surgeon ...

Husband: Oh Denton, Dr Denton.

Patient: Yeah, Dr Denton, yeah.

INT: OH YEAH, LIZ DENTON, MM.

Patient: And, erm, then of course I had to go back for the results, erm, that's when she said, 'well you'll have to come in,' didn't she?

INT: MM. WAS THAT THE SAME DAY, WAS IT?

Patient: No, it's ...

INT: OH RIGHT, SO YOU HAD YOUR TESTS ...

Patient: Yeah. Then I think it was ...

INT: DID YOU SEE THE CONSULTANT BEFORE YOU LEFT OR ...

Patient: Well she had me back ... no ... oh I can't remember.

Husband: No, you told Denton again when she told you it was definitely a cancer.

Patient: That was two weeks later, was it?

Husband: When you went back for your results.

Patient; Yeah.

INT: OH, OK.

Patient: And she said Dr [???] was on holiday but she'd want to see me before the operation.

Husband: She was back the following Friday.

Patient: Ooh, that first day I went as well I had a chest x-ray, didn't I?

Husband: Oh yeah.

Patient: And I had blood tests well.

Husband: And ECG.

Patient: And ECG, that was all on the that ...

Husband: The first day.

Patient: ... the day we went, yeah, when we were there three hours. Yeah.

INT: SO YOU SAW DR DENTON, THEN YOU WENT AND HAD YOUR TESTS, [???] AND THEN WHAT HAPPENED AFTER THE TESTS WERE FINISHED?

Patient: I just came home, didn't I?

INT: DID YOU SEE A BREAST CARE NURSE OR ANY THING LIKE THAT, OR ANY OF THE NURSES?

Patient: Yeah, one of the breast care nurses did come in, didn't she?

Husband: Maureen, I don't know what her surname was.

Patient: Yeah. Maureen came in.

Husband: She was one of Dr Denton's [???

Patient: Yeah, she saw with her, and they gave me some leaflets or something which I didn't want to read, because I didn't want to know about it. [chuckles] I ...

Husband: Well it's a complete booklet about what might happen, different things, and she says, 'Only read the bit that concerns you, which is the lumpectomy: don't go reading about the chemotherapy and this, that and the other. At the moment you're not bothered with that, just read the ...'

Patient: Yeah, I did go back in on that last day because she said to me, didn't she, erm ... or was that the day ... I can't remember now. No, we didn't go back in, did I, because I took the ECG in myself, didn't I?

Husband: Yeah.

Patient: Yeah, I took my ECG paper ...

Husband: And gave it to the receptionist.

Patient: ... and gave it to the receptionist, yeah.

INT: OH RIGHT, OK.

Patient; And then they gave me an appointment to go back in two weeks for the results.

INT: SO ON THAT FIRST VISIT, DID ANYONE AT ALL SORT OF MENTION ABOUT WHAT IT MIGHT ...

Patient: Cancer.

INT: THEY MENTIONED CANCER AT THE TIME, YEAH?

Patient: Yeah.

INT: RIGHT, OK. AND SO, I MEAN, AT THIS POINT WHAT WAS GOING THROUGH YOUR MIND THEN?

Patient: Well I couldn't believe, could I? I just couldn't believe it. I was really upset.

Husband: She was hoping that, she kept saying that when the results came back from the biopsy it might just be what-do-you-call them ...

Patient: Cyst.

Husband: ... cyst or something. She still [???

Patient: I just kept saying to you, didn't I, 'Look all these people are going in and I'm still here,' [chuckles] 'I know there's something ...' And I was really upset when we left and I still don't, I weren't gonna tell the kids, I said, 'I shan't tell the kids till we get the results,' and it was nightmare, it really was.

INT: AND YOU GOT THE RESULTS A WEEK LATER, IS THAT RIGHT?

Patient: Two weeks, wasn't it?

INT: FROM THE FIRST

Husband: About ten days from the first visit.

Patient: Yeah, because we went, er, yeah, some friends came round, didn't they, they were going to Norfolk at the weekend and, well, they were going to Norfolk for the week and they asked us to join them for a long weekend so we went off for a long weekend to Norfolk while I was waiting for the results to come back. It was about 10 days I think.

Husband: Yeah.

INT: THEN YOU SAW, WAS IT LIZ DENTON AGAIN? WAS IT DOCTOR DENTON AGAIN?

Patient: Yeah, yeah. And then, erm, she said, erm, yes, it was cancerous and, erm, that, erm, she'd make an appointment to see Dr [???] because she was on holiday. What no, before we went for the x-rays, she did say to me, didn't she, because we went back in and she says to me, 'We don't know how you found it, it's so small,' and I said then, 'Well it's only because it was near to the surface really that I found it,' ...

Husband: She also said they'd have a job to pick that up on the mammogram, didn't she?

Patient: But it did show up. It did show up, because I'd had a mammogram about 16 month earlier, but it showed up on the one they took.

INT: RIGHT, OK.

Patient: And then she said, [???] Dr [???] she'll want to take it out.

Husband: Right, nice to meet you.

Patient; Yeah, see you in a bit.

Husband: I'm off.

INT: OK. BYE-BYE.

Husband: Bye-bye.

Patient: So, erm, then when I went back she said it would be this, a lumpectomy she thought, but she didn't know for certain until she saw Dr [???] and then she said, 'Then you'll go on to have radiotherapy,' and then she said, 'There are other treatments which is hormone based or chemotherapy.' And when she mentioned chemo I just didn't want to know any more, I just [chuckles] ...

INT: YEAH, I KNOW.

Patient; I just blanked it, I didn't want to know any more.

INT: MM. SO, JUST GO BACK A LITTLE BIT TO, YOU'VE BEEN FOR YOUR FIRST VISIT AND YOU HAD TO WAIT ABOUT TEN DAYS ...

Patient: Yeah, I think it was something like. It seemed like forever.

INT: I KNOW, I WAS GOING TO SAY, WHAT'S THAT TEN DAYS HAVE BEEN LIKE FOR YOU, I MEAN, WHAT WAS GOING THROUGH YOUR MIND, WHAT WERE YOU THINKING?

Patient: Well, half the time I kept thinking, 'It won't be anything,' and then on other time's I was sort of like hysterical thinking 'It can't be, I just haven't got time for this, I don't need this,' you know, 'I'm gonna be a grandma for the first time,' and all these plans that I've got in my head, and not even feeling ill, couldn't ... couldn't take it in. And I still kept thinking, 'Oh, I'm sure, when I get back, it won't be anything.' So we went away for a long weekend, and I worked, I work three days a week and I worked and, but it's, it's always there, it's always, it's never out of your head really.

INT: YEAH, I CAN IMAGINE.

Patient: But the nurse had said that half the battles, these aren't one on your breast, it's the one up here, but ... when I went back for the results I didn't hadn't that well at all.

INT: OH, OK. SO WHEN YOU WENT BACK FOR YOUR RESULTS, WHO WENT WITH YOU?

Patient: Rog.

INT: YEAH. ANYBODY ELSE?

Patient: No.

INT: OK. SO YOU WENT, YOU OBVIOUSLY HAD TO WAIT AND THEN YOU WENT IN THE ROOM TO SEE MISS DENTON AGAIN?

Patient; No, went to see Dr [???

INT: THE SECOND ...

Patient: Erm ...

INT: THIS WAS THE SECOND ...

Patient: The second time, yeah, I went to see, Denton, yeah, and that's when she told me.

INT: CAN YOU JUST KIND OF, TRY AND WALK ME THROUGH WHAT HAPPENED FROM WHEN YOU WENT IN THE ROOM AND ...?

Patient: Yeah. Well we sat down and she'd got the results and she did say it was, it was cancerous and that, erm, all the other results were fine, the x-ray and the blood tests and everything, they were fine, and that, erm, she, she wanted, she couldn't sort of say when the operation, she'd book me in provisionally for, I can't remember what day it was ... I got to see Dr [???] on the Friday and then she'd book me in for the following Monday, the first Monday that the doctor, that she was back for the operation. And I thought, 'Oh, my God, that's quick.' And, erm, and that's when I said to her, 'I didn't want to come back, I didn't want to know the results,' and that's when Maureen, the nurse, said, 'Well, we know where you live, we would have fetched you.' And I said, 'well, what happens if I just leave it? IF I just leave it and just don't do anything at all with it, if I just leave it?' Because I said to her I couldn't bear to look at my breast even, it was, after that biopsy, it was absolutely black, and, erm, Maureen said to me, 'Well if you can't look at your breast now you won't like if the cancer decides to start to grow on the outside,' and she said she'd seen a lady who'd left it and she wasn't about her end results as she was mine.

INT: MM, RIGHT.

Patient: And, you know, they were quite supportive, because I was, I was quite happy to have walked out and just ignored it, I think. But she says, 'You haven't really that happy to ignore else you'd never have gone to your doctor in the first place,' [chuckles] you know, but at the time I didn't want, I wanted to blank it out really, I didn't ... didn't want to know.

INT: AND DID, AND DID DR DENTON, DID SHE TALK ABOUT WHAT TREATMENTS ...

Patient: Yeah, that's when she said, obviously if, an I'd, you have the lump out and then your chemo, radio, automatically goes with it, and that's when she mentioned the other therapies, you know, as well, the chemo.

INT: MM, AND WHEN SHE WAS DESCRIBING THE OPTIONS, HOW DID SHE, CAN YOU TELL ME HOW SHE DESCRIBED THEM?

Patient: Well, she said it seemed very small, because I said, 'Well what happens if I just have the whole breast off,' and she said, 'Well that's something you'll have to discuss with your surgeon, you know, I can't, I can't tell you, tell you that.' But in the meantime I've got a friend - well she's not a friend really, she's an acquaintance, they've got a boat near where we've got our narrow boat, and she's a month in front of me, and she actually came in the, I think it was the Wednesday when I was actually first went there to be examined, she came in for the results of her, results of her operation. And she phoned me up a couple of days later and she's got to have a chemo and everything, you know. I think I started to live her nightmare with her really, thinking more of what Jan was going through than thinking of myself. I kept thinking, 'I can't bear that, I can't bear the thought of that, my daughter's not gonna come over ... oh, it was awful, awful.

INT: AND WHAT DID THIS LADY HAVE THEN IN THE END?

Patient: Erm, she's had the chemotherapy.

INT: WHAT OPERATION?

Patient: Oh, she had, she just had the lumpectomy, but she'd had cancer a few years earlier or something.

INT: OK. AND WAS THAT AT GLENFIELD AS WELL, WAS IT?

Patient: Yeah, yeah. Yeah, Jan, so ...

INT: SO THEY SAID IT WAS VERY SMALL AND THAT YOU WOULD HAVE TO DISCUSS YOUR SURGERY WITH ...

Patient: Yeah.

INT: YEAH.

Patient: Yeah. So then I had an appointment to see Dr [??] on the Friday.

INT; AND AFTER YOU SAW DR DENTON, DID YOU SEE A BREAST CARE NURSE AFTER THAT?

Patient: Erm, no, she was in there with her.

INT: OH, SHE WAS IN THERE, RIGHT, OK.

Patient: Yeah, she was in there with her, Maureen, and I did phone Maureen up the next morning because I was in quite a bad state.

INT: SO DID YOU JUST GO, DID YOU JUST GO HOME AFTER YOU SAW DR DENTON?

Patient: Yeah, yeah. Came home, then I went to work the next day and really was in a bit of a state [???] sort of get my head round it.

INT: MM. SO WHAT DO YOU WORK AS EXACTLY?

Patient: I'm manageress of [???] Charity Shop in [???] which is the hospice.

INT: AH, IS THAT IN THE VILLAGE [???]

Patient: Yes, just down here, you know, yeah, [???] hospice. Course, I thought, I'd visions of being a patient in there and all sorts, it was awful.

INT: OH DEAR.

Patient: The things that go through your heard are just untrue.

INT: YEAH, OH, I CAN IMAGINE. YEAH.

Patient: And of course it's not just you, is it, you know, Rog as well, and I think I saw Dr [???] on the Friday and that's, didn't' tell my son till the Saturday, that's when I told him.

INT: SO YOU SAW, YOU SAW MISS [???] A WEEK LATER, IS THAT RIGHT?

Patient: No, I don't think it was a week. I can' really member. It was the following week, yeah, it was ever so quick

INT: RIGHT, OK, THEN. MM.

Patient; It seemed, I can't remember, I wished I'd have put the dates down, I can't remember now.

INT: AH, IT'S OK.

Patient: I saw her on the Friday and I was in on the following, on the next Monday.

INT: CAN YOU JUST SORT OF, KIND OF WALK ME THROUGH THAT?

Patient: Oh that was ... yeah, well I went in and she introduced herself, you know, and she sat down and she'd got the papers. She said, erm, what they wanted to do, did this operation and take it away and some of the tissue and the glands, and that it was a moderate to fast-acting, from the biopsy, she said, which that upset me because I thought if it was slow-growing, I wouldn't worry so much. And, erm, I just said to her, 'Well why don't you just take the whole lot off, you know, I'm not bothered at my age, I don't care and ... just do it, just take the whole lot off,' and she said, 'Well I don't really think there's any need for that,' you know. I said, 'Well I just ...' she said, 'Why? Is it the radiotherapy that's bothering you?' I said, 'No, I just don't want a bit now and a bit later, and a bit more taken away, you know, just take the lot off.' Anyway, she said, 'Well, go and have a cup of coffee with your husband and sit and discuss it, you know, don't make the decision now off,' and as I came out a nurse, the nurse came out with us, Sue, Susan, and I just said, 'Oh, can I have a word?' and we went into this room and we sat in the room with a couple of settees and I just told her all what I was really worried about. And she was really, you know, she was really nice and she said, 'Look, don't worry about anything, you know, just pigeonhole, don't worry about anything only, you know,

what, what the doctor worrying about things that might, you might never need the treatment that you're worrying about,' you know, she just said, and, erm, and then we went off for a coffee and we went back about an hour later, and went back to Miss [???] and I just said, 'Well I'll leave it to you then, obviously, you know, you know, well, if you decide it's, it's ... you know, what you decide's obviously, you know, the best thing to do because you're the person who knows.' So I put complete trust in her really.

INT: RIGHT, YEAH, MM. HOW DID YOU GET ON WITH MISS [???] ?

Patient: Oh she's lovely, isn't she?

INT: I'VE INTERVIEWED HER, SHE'S A VERY NICE WOMAN, YEAH.

Patient: Yeah, yeah. Yeah, well she seemed, and the young, when I went in on the Sunday to go and signed in the young nurses all like her because she's young [???] I think, all her ideas are young with it, so she scores a big [???] with the young nurses. And it was still awful that, because I had to come in and tell the family, that was awful on my son, it was awful.

INT: YEAH, I CAN IMAGINE. IT'S NOT EASY, IS IT?

Patient: No, not when his mother-in-law had phoned me up earlier in the week and aid, 'Oh, they've just popped in. Oh, they're so happy,' and I thought, 'Oh ...' and we went to see his new unit and this machine he's bought, this printing machine.

INT: OH, HE'S A PRINTER, IS HE?

Patient: Yeah, he's just starting on his own.

INT: OH RIGHT, OK.

Patient: So they've gone into a lot of debt for this machine and I'm ... oh dear. I had to tell him and he was virtually [???] but once I'd told him I felt a lot better, I slept better than night, but in the meantime I had, I did have to go to the doctors for some sleeping tablets, I got in a right state at night, waking up. Well, I couldn't sleep, you know, wake up at two, four ... awful. The ... crying, scared ...

INT: AND HOW'S ROG BEEN THEN?

Patient: He's been brilliant actually because he's, he's got a history of manic depression so he's been really good, he's really had somebody else to think about instead of himself. But he's been more or less, he just said, 'Ooh, it's, you know, as far as I'm concerned it's a lump and you're having it out,' and he's, that's all he's seemed to think about. He didn't think of any consequences, that it would spread or anything like I did, you know.

INT: YEAH, OF COURSE.

Patient: I was, Oh my God, you know, where's it gonna end?

INT: YEAH, OK. ERM, OK THEN, SO YOU'VE BEEN TO SEE MISS [???] AT THIS POINT, AND, ERM, YOU SAID THAT YOU'D CALLED THE BREAST CARE NURSE, MAUREEN, WAS IT?

Patient: Yeah, I did one morning, yeah.

INT: ERM, WHEN MISS [???] WAS, SORRY [???] WHEN DR DENTON WAS DESCRIBING YOUR DIAGNOSIS AND WHATEVER TREATMENT OPTIONS SHE SPOKE ABOUT, DID SHE USE ANY VISUAL AIDS SUCH AS ...

Patient: No.

INT: ... DIAGRAMS ...

Patient: No.

INT: PICTURES AND

Patient: No.

INT: WHAT ABOUT MISS [???]?

Patient: No.

INT@ DID SHE DRAW ANY DIAGRAMS?

Patient: No.

INT: NOTHING, PICTURES, NO?

Patient: No.

INT: THE BREAST CARE NURSES, DID THEY USE ANY?

Patient: No.

INT: NOTHING LIKE THAT. OK. SOMETIMES THEY DO, SOMETIMES THEY DON'T.

Patient: Yeah, I mean I was warned obviously that my breast wouldn't be the same shape as, as it was before.

INT: YEAH. AND, ERM, LET ME SEE, WHAT ELSE WAS THERE, ACTUALLY WE'VE GOT ON QUITE HERE YOU SEE, [???] QUESTIONS. ERM, WHEN YOU WERE BEING TOLD YOUR DIAGNOSIS AND WHEN YOU WERE BEING TOLD ABOUT YOUR TREATMENT OPTIONS, THE SURGERY AND RADIOTHERAPY AND THINGS LIKE THAT, HOW MUCH DID YOU UNDERSTAND ABOUT WHAT YOU WERE BEING TOLD THEN?

Patient: not a lot I don't think. That's why it's best to take somebody else with me, you know, I mean, erm ... like Sue said, when we went in that room, 'Don't worry about it, it is small, and they haven't found, felt anything under your arm, so just think about the positive things, you know, that they've found. Don't go worrying about what might happen if this and that's found.' But no, I don't think you take it all in, no, that's, that's why it is best to have someone with you 'cos they can understand more than I can. But I did understand that it, radiotherapy, I thought she said there's 20 sessions but, as I say, I don't know till I go next week.

INT: RIGHT, OK. AND, ERM ... YOU SAID YOU SPENT SOME TIME, AFTER DR [???], MISS [???] WITH THE BREAST CARE NURSE?

Patient: Mm, yeah.

INT: AND CAN YOU JUST TELL ME A BIT OF WHAT YOU SPOKE ABOUT AT THAT TIME?

Patient: Well, just that, that I was really upset and frightened, and, erm, terrified of (a) having chemotherapy because I've heard such terrible stories

about it, and, erm, and my own, you know, I didn't want, well I told her, 'I didn't want to die.'

INT: YEAH OF COURSE, THAT'S RIGHT, YEAH. AND DID SHE GO THROUGH ANYTHING ELSE SUCH AS, DID SHE TALK ABOUT THE TREATMENT OPTIONS OR ...?

Patient: No, she just said that, you know, she said, 'We see a lot of patients in this hospital and [???' and if you've got, you know, if you're gonna have cancer anywhere your breast is probably the best place [chuckles] to have it, you know.

INT: YES, IT'S VERY TREATABLE THERE APPARENTLY, YEAH, THAT'S WHAT I'VE HEARD.

Patient: And I mean the speed with it all, I mean, I mean to be quite honest I couldn't have gone to the doctor any earlier than I did and, erm, you know, it all happened then, all happened that quick. It is quick when you look on paper, but up here it seems for ever.

INT: YEAH, YEAH, OF COURSE. YEAH, WHEN YOU BOIL IT DOWN IT'S PROBABLY A COUPLE OF WEEKS OR A MONTH OR I MEAN SIX WEEKS IN TOTAL FROM START TO FINISH BUT, YOU'RE RIGHT, PSYCHOLOGICALLY IT WOULD PROBABLY DRAG ON QUITE A BIT I THINK.

Patient: Yeah ... so on the Friday after, when you hear the results of the biopsy, and I'd got to go in, I, erm, I was quite positive actually. I remember taking the dog a long walk and thinking, 'Oh I can afford to lose a bit of my bust, it doesn't matter, you know, it could be worse, it could be a kidney, it could be your liver, it could ... be anywhere,' and then I'd come back and really all right, and then just wake up in the night and I'd just be a mess.

INT: MM, YEAH, YEAH. AND, ERM, SO, HOW SOON AFTER SEEING MISS [???] DID YOU HAVE YOUR OPERATION?

Patient: Erm, saw her on the Friday, went in on the Sunday ... Friday, Saturday, Sunday ... Monday, four days, yeah. I saw her on the Friday and had my operation on the Monday.

INT: YEAH?

Patient: Yeah.

INT: AND DID YOU HAVE ANY CONTACT WITH THE BREAST CARE NURSES IN BETWEEN THAT TIME?

Patient: No, no really. I went in on the Sunday and the other patients in the ward, when I saw them all dressed and they'd all had their operations and they were all dressed and looked really well, [chuckles] it made me feel a hell of a lot of better. That ward is a brilliant ward.

INT: IS THAT FOR YOUR PRE-ASSESSMENT OR SOMETHING?

Patient: That was, yeah, 23A the ward, it's brilliant, yeah, yeah.

INT: AND, ERM ...

Patient: The nurses on the ward were really nice, I mean, they come and sit with you and ...

INT: YEAH, OF COURSE.

Patient: I did have one young junior doctor, I can't remember her name, and she came just to check the glands and everything, she says, 'Oh you do know what's wrong with you, don't you?' so I said, 'Well, yes, I've spoke to with the doctor ' 'Oh well, you do know it's cancer?' I thought, [chuckles] 'Yes, well, yes, obviously'

INT: TACTFUL. [?]

Patient: She was a bit abrupt.

INT: AH, TACTFULLY PUT, YES, WELL SHE'S YOUNG, SHE GOT A WAY TO GO. [CHUCKLES]

Patient: They all look young to me.

INT: AND WHEN YOU WERE TALKING TO MISS [???], ERM, DO YOU FEEL THAT SHE WAS LISTENING TO YOU, THAT SHE UNDERSTOOD YOUR NEED AND YOUR CONCERNS AND THINGS?

Patient: Yes, I think, but I don't think I said a lot to be quite honest.

INT: RIGHT, OK.

Patient: I was sort of in shock I think. I mean there's so much you want to ask but she hasn't got the answers, has she, you know? I've got, you can't say, 'Well what happens if you find traces in my lymph nodes?' when they don't know whether there's any in there yet. Do you know what I mean? There's just so much going through your head, you know.

INT: AND WHEN YOU WERE TALKING WITH THE BREAST CARE NURSES, DID YOU FEEL THAT THEY WERE LISTENING TO YOU AND UNDERSTANDING YOUR NEEDS AND YOUR CONCERNS?

Patient: Yeah, I think they were, yeah, yeah. I think it's, it's very difficult, you know, they can tell, they can say what, what they like really, all you want, all I really wanted was somebody to say to me, 'It's gonna be all right, definitely gonna be all right.' Well, nobody can say that, can they? Nobody can actually say that to you, and that's what you want. You want some sort of ... well, some sort of insight, some tarot cards or whatever, but you just want somebody to say, 'It's gonna be all right,' you know.

INT: AND WHEN YOU WERE TALKING ABOUT WHAT SURGERY YOU COULD HAVE, DID YOU FEEL THAT EITHER MISS [???] OR DR DENTON OR THE BREAST CARE NURSES, DID ANY OF THOSE HAVE A PARTICULAR TREATMENT IN MIND THAT YOU THINK ...?

Patient: No, as I say ...

INT: ANY PREFER ...

Patient: I just, said at the time, just take it off, but, because that's my way of ... I didn't want any bother, but, no, they were good 'cos she was saying just, there was just no need for, you know, there was just no need to take it off. That's why we went for coffee and had a chat with Sue and decided to let her do what she wanted to do. [chuckles]

INT: AND THE BREAST TEAM, YOU SAY THAT YOU GOT SOME INFORMATION FROM THEM ON THE FIRST VISIT, I THINK. IS THAT RIGHT?

Patient: Mm.

INT: DID YOU GET ANY MORE INFORMATION? WRITTEN INFORMATION?

Patient: No, but in fairness I didn't ask.

INT: NO, OK, THAT'S FINE. AND THE INFORMATION YOU DID GET, DID YOU READ IT?

Patient: Mm, some of it.

INT: YEAH?

Patient: No, I just couldn't, because I couldn't believe it was happening to me I must admit I didn't sit and study it, no.

INT: DID YOU FIND ANY OF THAT INFORMATION USEFUL AT ALL?

Patient: No, I don't think I did really.

INT: OK. ERM ... NOW, WHERE ARE WE, A BIT FURTHER DOWN HERE. I HAVEN'T DONE THIS INTERVIEW FOR LIKE A COUPLE OF WEEKS NOW, I'VE FORGOT THE QUESTIONS. ERM, HOW, WHEN YOU FIRST HEARD ABOUT YOUR DIAGNOSIS TILL THE POINT WHEN YOU MADE YOUR MIND UP WHAT CHOICE, WHICH SURGERY YOU WERE GONNA HAVE, HOW LONG DO YOU THINK IT TOOK TO REACH THAT DECISION FROM HEARING YOUR DIAGNOSIS TILL WHEN?

Patient: Well, we only went for a cup of coffee for an hour, so I had more or less made my mind up to have my whole breast off, but, as I say, she said she didn't think there was any need whatsoever to go to those extremes, and so I sat with Sue for half an hour then we went off and, ourselves, and of course Roger heard more than I did so [???] so, you know, they see it everyday, you know, they're not like us, this is all new to us.

INT: YEAH, OF COURSE.

Patient: You, know, they know what they're talk-, you know, they know what they're talking about.

INT: YEAH MM.

Patient: You know, I mean they're not gonna want to do two operations if one's enough. [chuckles]

INT: YEAH. AND ONCE YOU'D BEEN BACK TO SEE MISS [???] AND YOU'D DECIDED THAT YOU WERE GONNA GO FOR THE WIDE LOCAL, JUST THE LUMPECTOMY, ERM, BETWEEN THEN AND HAVING THE OPERATION DID YOU AT ANY POINT CHANGE YOUR MIND OR ...

Patient: No.

INT: ... HAVE ANY SECOND THOUGHTS?

Patient: No, I didn't have really much chance because I went, I went to work on the Saturday and I was in on the Sunday.

INT: OH RIGHT, OK. ERM ... SO, THE OPERATION, CAN YOU TELL ME WHAT HAPPENED ON THE DAY OF THE OPERATION?

Patient: Yeah, I was the second one down so, erm, [???] the morning, went for a walk round the wards with one of the, a young girl who was already dressed just to pass a bit of time, just had a walk round. And, erm, I can't really remember owt about it ... they just came and said, 'Right, Mrs Smith, it's your turn now,' and I was all in my gear, you know. And, erm, I remember going down. It's a strange feeling 'cos you're not in pain, do you know what I mean, so ... if you'd got like appendicitis or something really wrong with you that you just want to get it over and done with, 'Let's get down there and get it out,' you know, I was laying on the trolley thinking, 'What am I doing here?' you know,

'What am I doing here?' you know, 'I don't really want to be here,' and, you know - you don't feel ill.

INT: YEAH, OF COURSE, MM.

Patient: So, you know, and of course then you go in the room and it's all scary but then you don't know anything till you wake up really, do you?

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

Patient: Yeah, yeah. She came to see me just before we went in, yeah.

INT: CAN YOU REMEMBER, WHEN DID YOU SIGN THE CONSENT FORM FOR THE OPERATION, DO YOU REMEMBER, WHEN DID YOU DO THAT?

Patient: Must have been on the Sunday.

INT: ON THE SUNDAY WHEN YOU WENT FOR THE PRE-, ASSESSMENT, PRE-CLERKING THING.

Patient: Yeah.

INT: OK.

Patient: Or it might have been Monday, Monday morning when the, erm, when the what's he called, puts you to sleep ...

INT: ANAESTHETIST.

Patient: Anaesthetist, yeah, yeah, it might have been when he came, I can't remember.

INT: OK.

Patient: I can't remember.

INT: AND, ERM, WHAT HAPPENED WHEN YOU WOKE UP? HOW WERE YOU? HOW DID YOU FEEL?

Patient: All right, well, I remember having an oxygen mask on and wanting to take it off and the nurse said, 'No, you must leave it on,' and then ripping that off.

INT: YEAH, LOTS OF PEOPLE SAY THAT.

Patient: I know. I know I saw them [chuckles] ... yeah, because when, the girl across the room, she came back the following day, she was doing the same. And, erm, I remember telling Rog I didn't particularly want him to visit me, and I remember telling my son I didn't want him to come, but of course they did. And you drift in, in and out really, erm, asleep all day, you know. And I remember going on the Tuesday, Monday night, thinking, 'Oh well, that's it, it's gone now.' Some sort of relief in that, I think. But, erm, then Dr [???] came and said, 'Ooh ...' on Monday night, 'Well you can go home tomorrow,' Tuesday, I could go home on Tuesday. But I didn't want to, I didn't feel, on Tuesday, when Tuesday came I didn't want to go home, I didn't feel well enough.

INT: HOW LONG WERE YOU IN HOSPITAL THEN?

Patient: Erm, I had the operation Monday, could have come home Tuesday but I didn't, I came home Wednesday.

INT: RIGHT, OK. AND THEN WHEN DID YOU GO BACK ...?

Patient: Ten days.

INT: DID YOU HAVE DRAINS IN THAT, DID YOU?

Patient: Yeah.

INT: NO, YOU DIDN'T HAVE DRAINS

Patient: No.

INT: OK.

Patient: No, some do, don't they?

INT: YEAH, SOME DO, YEAH.

Patient: Mm, no.

INT: THAT'S WHY I WAS ASKING HOW LONG YOU WERE IN HOSPITAL FOR BECAUSE USUALLY THEY DON'T LET YOU GO UNTIL IT'S DRAINING A CERTAIN AMOUNT.

Patient: Mm, no, I don't believe Miss [???] believes in drains, so the nurses said. No, I could have gone home, she said Tuesday, she came to see me Tuesday morning, she said, 'You can go home if you want to,' but ... there was still a lot of padding on and I hadn't seen the cuts or anything and, erm, she'd said, 'Oh ...' the nurses said that the district nurse'd come but if I stayed in the extra day then, erm, they'd see to it there at the hospital so that I didn't have to have the nurse. I mean when I first woke up I thought, 'I'm going home, I want to go home,' but as the day wore on I didn't, I didn't feel well enough to go home.

INT: MM, AND HOW WERE THE OTHER WOMEN ON THE WARD?

Patient: Well there was one at the side of me, Janet, she was really poorly, poor lady, and the other lady at the side of me, Jean, she'd had her operation just before me, but the others were all, two that had had their ops and then one who'd come in on Monday to have the op on Tuesday so ... oh, they were brilliant. I mean the nurses were brilliant on that ward, brilliant. If you've got to be in hospital it was the best ward I've ever been in, you know. They were lovely.

INT: AND YOU WENT BACK TEN DAY AFTER, IS THAT RIGHT?

Patient: Mm.

INT: AND WAS IT SEEING MISS [???] AGAIN?

Patient: Yeah.

INT: YEAH. AND JUST TELL ME WHAT HAPPENED THEN.

Patient: Well, God, what a day that was! One of my sons said he was coming, so he came as well and I didn't want him to come either, but [???] 'What if the results are bad?' and he says, 'Well, we'll sort that out when it ... [???]' and we were an hour. My appointment was at quarter to one, quarter to one I think, or quarter to twelve, and we didn't go in till quarter to one. Oh God, I shall have no nails left by the time I went in. And she came in, she just said that it was as expected, it was very small, about the size of a pea; that all the

surrounding tissue was clear and that it hadn't gone into any of the lymph glands. So ...

INT: AND HOW DID YOU FEEL WHEN YOU HEARD THAT?

Patient: Oh ... God ... relieved ... and that, I didn't hear anything else. I mean it's a good job that Rog and Stef [?] were there, I didn't hear anything else really. And I remember crying and turned round to Sue who was there, one of the breast care nurses, just said, 'Oh ...' She says, 'There you are ...' you know. I said, 'Well, I can't believe it,' you know. So ... And then she says that, you know, they'll get in touch with me [???] I haven't got an appointment for another 12 months before I see Miss [???] again.

INT: MM, THAT'LL BE YOUR FOLLOW-UP.

Patient: So ... that seems a long time. I think I'd have been happier with six months.

INT: WELL, I SUPPOSE YOU COULD ALWAYS [???]

Patient: Yeah, I know. I mean what they don't prepare you, well I haven't, what I wasn't told was, like, one of the reasons I'm going back to see my doctor today is that round the scarring, where they've taken the lump out, it's still ever so lumpy and there's a bigger lump there than there was before ...

INT: RIGHT, YEAH.

Patient: ... I started and you just think, 'Oh God, have they got it all?' You know, and I think to myself, 'God, they only took it out three weeks ago,' [chuckles] you know, they're not bloody stupid. But in my mind ...

INT: YEAH, OF COURSE.

Patient: ... you know, 'cos when I start to relax and think, 'Oh, it's gone,' and then the next minute I think, 'Oh my God, but it can come back.' I am on Tamoxafen as well.

INT: RIGHT, OK.

Patient: So ... I've been on that since ...

INT: IF YOU EVERY WORRIED JUST GIVE THEM A CALL, YOU KNOW, THEY'LL BE GLAD TO HEAR FROM YOU.

Patient: Will they?

INT: YEAH, YEAH. THEY'LL BE GLAD TO HEAR FROM YOU. THEY'D RATHER THAT YOU CALLED THEM RATHER THAN SIT AND WORRY UNDULY.

Patient: Mm. I haven't really examined my scars a lot until yesterday and I thought, 'God, that's a bit lumpy.' 'Cos I know they give you a leaflet 'cos you can get fluid your arm, seroma or something.

INT: MM, YEAH.

Patient: And, erm, I've got a number there if that came up, you just ring up and make an appointment and they see to it for you, you know.

INT: DO YOU HAVE ANY EXERCISE?

Patient: Yeah, yeah, I've been doing them quite religiously, yeah, four times a day. In fact they were doing them in the wards, I mean, they were really good and you sort of ...

INT: AND YOU ALL DO THEM TOGETHER?

Patient: Yeah, and they were making their own up, you know, some of them. Some of them that we wrote down and we were doing the ones we liked best. But I mean I have been, to be quite honest, I've been using my arm and my shoulder as normally as I can, without obviously lifting anything too heavy. But I mean I walk the dog a lot, I'm a big walker, I love walking, but he's not the best dog on the lead I've ever had, in fact he's a [??] on the lead ... a Springer ... so what Roger's doing, he's dropping me off whereas I'd walk him to the fields, he drops me off near the fields so he's off the lead more or less all the while we're out. This is the first time this morning I've actually walked him back. I had about 20 minutes with him on the lead and he was quite good actually, as if he knew. So, erm, but I haven't let him pull me. I mean we've got a little narrow boat and I always do the lock gates, well obviously I daren't, daren't be doing them yet.

INT: NOT FOR A WHILE, YEAH.

Patient: So that's not ...

INT: SMALL STEPS I THINK, JUST DOING WHAT YOU CAN, WHAT YOU [??]

Patient: Yeah. Well, I nipped in to work yesterday, not to work but just to see the girls and I had a cup of tea up there and it was so hot up there and ... that's the trouble with my job is that all the donations come in downstairs and everything has to go upstairs. And people bring boxes of books, you know, bags of clothes that ... that's gonna be the bugger, carrying.

INT: MM. I THINK YOU'VE GOT TO LET YOUR BODY BE THE GUIDE THERE. YOU KNOW. YOU DO WHAT YOU CAN WHEN YOU FEEL YOU CAN. ERM ... IN BETWEEN FROM HEARING YOUR DIAGNOSIS UP TO YOUR OPERATION, I KNOW THE BREAST CARE NURSES GAVE YOU SOME INFORMATION, DID YOU LOOK FOR INFORMATION ANYWHERE ELSE?

Patient: No.

INT: BOOKS, MAGAZINES ...?

Patient: No. No

INT: NO. DID YOUR FRIENDS OR RELATIVES GIVE YOU ANY INFORMATION,

Patient: No, I didn't ask. [chuckles] I mean one of the ladies, Joyce, who was in the ward, she'd got all these brochures. She'd sent, now she was the opposite, she wanted to know everything, and I didn't want to know anything, 'cos I just know that I could lay there at night and my imagination would run wild.

INT: YEAH, [??]

Patient: Because everybody's different, you know, Joyce wanted to know everything, and, erm, I said I just really want to know just my particular case, you know, I don't particularly want to read about anybody else 'cos I shall, I know what I'd done with Jan, I know that every time Jan phoned me and she was upset or worried, I was thinking, 'Oh, my God, what if I'm like that? What if I get this? What if I get that?' and I, I think it's the kind of person you are, isn't it? You know, it's how you accept these things yourself.

INT: MM, WELL THAT'S WHAT SOME OF THE QUESTIONS IN THE QUESTIONNAIRE ASK ABOUT, ABOUT, YOU KNOW, THE INFORMATION [???] I JUST WONDERED IF YOU'D ACTUALLY FOUND ANYTHING YOURSELF I COULD ASK YOU ABOUT.

Patient: No.

INT: ERM ... THINKING ABOUT THE SURGERIES THAT WERE AVAILABLE, YOU KNOW, THE MASTECTOMY AND THERE WAS, THE WIDE WAS WHAT YOU HAD, ERM, DO YOU FEEL YOU HAD THE AMOUNT OF CHOICE YOU WANTED BETWEEN THOSE SURGERIES?

Patient: Yeah, I mean, if I, I think if I'd have said, I'd gone back and said I wanted a mastectomy I would have had one, I wouldn't have been turned down I don't think. But, you know, I mean I'm saying now I'm glad I listened to her because I've not really lost that much but if I have to go back and some more away in a couple of years time I won't be very happy. [chuckles]

INT: OH, OK. AND THINKING ABOUT THE DECISION THAT YOU MADE EVENTUALLY TO HAVE THE WIDE LOCAL EXCISION, WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD, THAT YOU HEARD, THAT YOU READ, WHATEVER, THAT HELPED YOU MAKE THAT DECISION?

Patient: Well I think it was just, erm, the doctors really, because, erm, at the end of the day, you know, you can read into books, in any literature you can read into that literature what you want ...

INT: MM, YEAH, OF COURSE.

Patient: ... to read, in any kind of information. People will take it in different - it's like trying to describe something, isn't it? You could, two people could describe the same plant and other people'll envisage it different in their minds, so I think what information you get ...

INT: RIGHT, YEAH.

Patient: ... it's my husband said to me, 'You only, you're only picking up on certain things, you are, when you're listening to things. You're only, you're not listen to the whole,' but it's what goes, what goes in. So, no, I didn't, I didn't really ask a lot and when, you know, there's your surgeon who's really, well he's the specialist, isn't it? If they tell you that this is the best thing to go with, then you trust that person like you trust your dentist and, you know, your optician. I mean they, they're the people who know, aren't they, really?

INT: RIGHT, YEAH. AND, LAST COUPLE OF QUESTIONS NOW, ERM, LOOKING BACK FROM WHEN YOU WERE FIRST DIAGNOSED UNTIL NOW, HOW DO YOU FEEL ABOUT THE CARE YOU'VE RECEIVED?

Patient: Oh, I can't fault that.

INT: YEAH?

Patient: No, I can't fault it.

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

Patient: Er, it was above really I think. I didn't expect to be treated so quickly and ... 10 days to get the full diagnosis doesn't seem long, I suppose, to some people but when you're going through it it's a long time. Yeah, but I

don't think that's as bad, I think waiting for the biopsy results was probably the worst.

INT: RIGHT, YEAH.

Patient: You know, because at least you know when you're going in that something's being done. Mm.

INT: WAS THERE ANY PART OF THE CARE THAT DIDN'T MEET YOUR EXPECTATIONS?

Patient: No, not really. I think probably now, if, you know, when I left, if they'd have described that there'd be a few lumps and bumps here and there, then I wouldn't worry so much, but then I suppose that's hard to know because everybody heals different, don't they?

INT: YEAH.

Patient: You know, but then again I've got, I've got the phone number of the breast care nurse, like you say, I mean, it's up to me really if I'm that worried I should ring her.

INT: YEAH.

Patient: So, I mean I have got the number there and they did, I mean the only time I have rang someone did answer, so it's not as if I was left with an answering machine or something. So ... but I can't fault the care, no, not really.

INT: IF YOU WERE TOLD YOU COULD CHANGE ONE THING ABOUT THE BREAST SERVICE THAT YOU WENT THROUGH AT THE GLENFIELD, WHAT DO YOU THINK IT WOULD BE?

Patient: Oh, if you could have your results the next day. [laughs] That is impossible, isn't it, because I know they've got to go away to be tested. I mean the nurses on the ward were brilliant because one of the nurses, on the Tuesday as I was gonna go out, was reading a magazine and in this magazine it didn't start off about this chappy, but the father of the girl who the story was about, he suddenly had, erm, he had cancer, lymph cancer or something. And one of the, one of his, erm, one of the things that was happening to him was he was waking up at night really sweating - well I do anyway, you know, with my age. And of course when my husband came I was convinced I'd got lymph cancer and it had gone into my breast. And one of the nurses saw obviously that I was bit agitated with Rog and she came and said, 'What's the matter?' and Rog says, 'Ooh, she's just read this ...' and she just said, 'Ooh, don't read anything,' you know, she just said, 'It doesn't work like that, you know, it starts in your breast and [???' and that's one of the reasons I didn't go home Tuesday because during that, you have an injection when you're in there to stop your blood from clotting, and when she took the thing out and the drip was on she couldn't stop my hand from bleeding.

INT: OH RIGHT.

Patient: And I, so she just said to my husband, 'She's not going anywhere yet.' [chuckles] So I just said, 'Oh can ...' I just felt happier staying in hospital that extra day, because Wednesday, Wednesday morning I woke up and I felt entirely different, you know, I was ready to go home. But I didn't want to go home Tuesday, and they didn't throw me out.

INT: NO, NO.

Patient: They did let me stay. But, no, I can't fault them there, they were brilliant, absolutely brilliant.

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, FIRST OF ALL, THEIR DIAGNOSIS?

Patient: Before their diagnosis?

INT: NO, AT THEIR DIAGNOSIS, WHEN THEY'RE RECEIVING THEIR DIAGNOSIS, WHAT DO YOU THINK THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THEIR DIAGNOSIS?

Patient: ... I don't, it's very hard to say because I didn't want to know anything. I just wanted to know is it gonna kill me, I think and, you know, what are the chances but, and will it spread, but of course these are all questions that nobody really knows, do they? Not then anyway.

INT: UNTIL THEY GET ...

Patient: Until they get all the results, yeah. You know, you really want to hear it's benign and it's nothing to worry about, that's what we all want, but, erm, one of, like, when I was talking to Joyce on the ward, one of the things that really ... oh, I shouldn't say ... well, we got on us a bit, was everybody saying, 'Think positive, just think positive.' She says, 'You've just been given this devastating news and everybody's telling you to think ... how can you think positive, you know, when you've just heard you've got cancer, you know, a malignant cancer, how can you think positive?' And I think that's ... that is hard to think, it is hard. Now, it isn't for everybody because you know Nicky who was in there, I mean she'd got a young family, she'd got to have chemo, she'd had her breast off, she was just so ... she wasn't as upset, upset as we were.

INT: YEAH, IT HITS PEOPLE DIFFERENTLY.

Patient: You know, everybody's ... everybody's different.

INT: [???] YEAH, ABSOLUTELY

Patient: Yeah, everybody's different. As I say, a lot of people go on the internet, they want to know everything - I don't want to know. And it's like this Tamoxafen, we got a little, got a leaflet and as you read that about possible side-effects, but the big one you get with the tablets I've just not read because I just think, 'Well, what's the point?' you know, it might never happen, why look for something that's not gonna ... you know, if I start to feel bad or something happens I'll look on the paper then and see if that's one of the side effects but don't look for trouble before it comes, that's how, that's how I see it. But, you see, other people aren't like that, are they? They want all the information at had.

INT: YEAH, CROSS BRIDGES AS THEY COME TO THEM, YEAH?

Patient: Yeah, yeah. If they arise, you know.

INT: IF THEY ARISE, YEAH.

Patient: You know, and I spoke to a lady the other day and she's, ten years ago she had a lumpectomy, and she had radiotherapy and she had Tamoxafen for six years, and she said, you know ... and then you hear stories like that, you know, your face comes, you start to feel a bit ... I mean some days I forget I've even

had it done, and I'm getting back [??] and then of course when you have a shower or a wash and you think, 'Oh my God, it is real.'

INT: MM. SO WHEN IS IT YOU'RE GOING BACK TO WORK THEN?

Patient: I don't know. I'm waiting to see how long the radiotherapy'll be. I mean some people work while they're having radiotherapy I understand but I'm just gonna wait and see how I go. I mean ... I'll have had a month off next week, so that's not long, is it, really? I might wait till the end of my radiotherapy. I mean I'm not one, I won't milk it, there's no way. I'll go back when I feel I can ...

INT: YEAH, OF COURSE.

Patient: ... can do it. I only work three days, I'm a job-share, so ... and I love my job. [??] it's just the lifting.

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 THE OPERATIONS THAT YOU CAN HAVE?

Patient: Er ... well really, just how quickly people get over them. You go in with this awful dread. I mean even, even the ladies who'd had their breast off, they were doing their exercises the next day and lifting their arms quite well. And you go in thinking you're not gonna be able to move your arm, you know, really. And that, that was, yeah, how quickly you do get over it, you know, because once you've got that awful anaesthetic out of your system the next day people are walking around. I mean one of the ladies, one of then nurses came in to me on the Wednesday morning and she said, 'Have you ... are you just come in ... have you just come in today to get ready?' I went, 'No, I had my operation on Tuesday.' She said, 'Oh, you look too well.' You know. [chuckles]

INT: AH WELL.

Patient: Well, that's I got a bit ... I said to one of my friends, [chuckles] 'If anybody else tells me I look well, I'm gonna hit them, because I don't feel blood well.' But, it's just, you're just not ill. And I think 'cos it's not in the family, it's never anything, it's never, ever been an issue as far as I'm concerned. Of course I've got a daughter, you see, so I was worried about her.

INT: YEAH, OF COURSE. AND HOW'S SHE?

Patient: Well I just worried that she might get it, you know, but apparently this, it has to be so many generations down the line before, they're not unduly worried about my daughter, they've said, [??] so. As I say, I couldn't have gone any earlier than I did and they whipped it out early so, hopefully, it should all be all right.

INT: ERM, FINAL QUESTION, IS THERE ANYTHING ELSE THAT YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANYTHING YOU THINK WE'VE MISSED, ANY IMPORTANT POINTS WE HAVEN'T COVERED, DO YOU THINK? ANYTHING [??]

Patient: No, I think, probably more information about your lymph glands, but I mean I didn't ask because it didn't affect me, but now I begin to wonder what happens if they do find it in your lymph, but then, [chuckles] as it doesn't really affect me actually, it's not a question I would have asked at the time, you know, but, erm, you know, that's, there's just so much really that goes through your head. I mean really you should write everything down as you think about it to ask that question, but I did ... I did want, I wondered why they did a biopsy and then they still had to take it out, do you know what I mean? I

wanted to, I wanted to know the results more or less, I wanted to know everything from the biopsy results, I thought they'd, I thought that they'd be able to tell me more from that instead of waiting till, erm ... and I was really worried that, it might sound silly because I mean I don't, [???], when I had this biopsy the first time- and it's such a thud and they cut right into you - I was worried that they'd probably, 'Oh my God, have they woke it up now? Have they woken it up with giving it such a shock?' you know, like, a shock, and as it, as I'm bleeding inside, is it spreading all around. And I did ask, erm, I did ask the consultant that and she said, Miss Denton, and she aid, 'Oh you mean seeding?' so I says, 'Yeah, is that what you call it?' She says, 'Oh no, that won't happen, but that was something I thought of.

INT: RIGHT.

Patient: You know. I think, erm, but most of the ladies I spoke to in the ward, they said that the operation wasn't as bad as having the biopsy done.

INT: [chuckles] OH RIGHT. WELL I'VE NEVER HAD ONE, SO ...

Patient: Mm, it's, it's scary that, it's not after, it's afterwards when it's so painful, not when they actually do it.

INT: I DON'T EVEN LIKE NEEDLES ME, SO ...

Patient: Oh, yeah, my daughter's like. [chuckles] She's terrible.

INT: WHEN I GO FOR BLOOD TESTS I DON'T LIKE [???]

Patient: She's not so bad having an injection where you have in, but she doesn't like anything coming out of her body. [chuckles]

INT: IF IT WAS ME, JUST THE THOUGHT OF A, SOMETHING METAL BEING IN MY BODY, I HATE IT. SO ...

Patient: Mm.

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

[End of interview]